Growing up, ill:

Uncovering the experiences of young people living with chronic illness

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Statement of originality

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Imogen Harper
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Publication (1) is substantially similar to Chapter Eight, and contains material from Chapters Two and Three. Publication (2) is substantially similar to Chapter Six, and contains material from Chapters Two and Three. Publication (3) contains material from Chapter Two.

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As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Alex Broom
10 March, 2025

Abstract

Chronic illness in young people is routinely underacknowledged and underreported. In general, pain and illness are represented as the exception rather than the rule for young people, however experiencing chronic illness when young is not rare. Rather, it is misunderstood, unrecognised, and hidden. This speaks to how the experience of chronic illness when young is entwined with social expectations, long histories of discrimination and silencing, and current institutional and political failures. I examine this complexity in order to interrogate the ways in which current understandings of illness fall short, and consider what social, cultural, and healthcare changes are needed going forward.

This thesis is based on 33 in-depth interviews with adults aged 19-29 years-old who live with a range of diagnosed and un-diagnosed physical health conditions. The breadth of this participant criteria is an attempt to decentre institutional categorisations of disease and instead focus closely on how people construct and negotiate chronic illness in their lives. With reference to explicitly emancipatory sociological theory and critical disability studies, I seek to explore how individuals' experiences of chronic illness interact with the social and institutional judgement and neglect they face.

I argue that the marginalisation experienced by my participants is often caused by persistent failures to listen to young people, the enduring stigmatisation of chronic illness, and a socio-cultural environment that does not accommodate uncertainty, complexity, and vulnerability. I further argue for an understanding of chronic living while young that better incorporates the shifting meanings and expectations of youth, the multivalent tensions around visibility and recognition, the ambivalences and potentials of online worlds, and the fluctuating salience of diagnosis. This provides new and adapted conceptual frameworks to better understand the complex experiences of young people living with chronic illness.

Abbreviations

CFS/ME	chronic fatigue syndrome / myalgic encephalomyelitis
CSF	cerebrospinal fluid
ED	emergency department
GP	general practitioner
HBSC	Health Behaviour in School-Aged Children
hEDS	hypermobile Ehlers-Danlos syndrome
HSC	Higher School Certificate
IBD	inflammatory bowel disease
IUD	intrauterine contraceptive device
MCAS	mast cell activation syndrome
MRI	magnetic resonance imaging
MUS	medically unexplained symptoms
NDIS	National Disability Insurance Scheme
PCOS	polycystic ovary syndrome
PDHPE	Personal Development, Health and Physical Education
POI	premature ovarian insufficiency
POTS	postural orthostatic tachycardia syndrome
TBI	traumatic brain injury

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CHAPTER ONE | *introduction*

This thesis explores the experiences of young people who live with chronic illnesses – experiences which are often sidelined in social, healthcare, and political discussions. Drawing on 33 in-depth interviews with 19–29 year-olds living with chronic physical illness, I argue that the challenges young people face not just from living with illness or pain, but also from preparing for a life where it continues, offer insights into where current assumptions and understandings of illness fall short, as well as a guide to ideas and vocabularies that could help fill those spaces.

Many people are socialised to see illness and pain as exceptions to the norm of a functioning and reliable body, but a significant number of people, including young people, live with prolonged or chronic illnesses. There have been considerable gains in life expectancy (concentrated in the Global North) in the 20th and 21st Centuries, in part because previously life-ending events and conditions – including many cancers, serious injuries and infections, and progressive autoimmune disorders – can now be prevented, treated, or managed (Greco & Graber, 2022). These stretched lifespans are part of the reason we are now grappling with the rise of "chronic living" (Manderson & Wahlberg, 2020). This is not the only reason more people are living with chronic illness: persistent alarm bells are ringing about the role of environmental toxins, changing diets, widening inequalities and life chances, and disrupted lifestyles in our increasing rates of chronic (and acute) inflammatory diseases (Marya & Patel, 2021).

Chronic illness has serious and varied impacts on everyday life, and a sociological examination of chronic illness seeks to understand these individual experiences in conversation with one's social position or broader societal structure (Anderson & Bury, 1988; Nettleton, 2021). The symptoms and risks associated with chronic illness cause real bodily pain, distress, and discomfort. These embodied experiences combine with medical, political, and social isolation in a way which can fundamentally shift how individuals experience the world.

Despite its increased prevalence, the spectre of chronic illness still seems to threaten our social and medical ideas about what a good life is, and the role that biomedicine ought to play in that (Clarke et al., 2003; Williams, 2010). For young people living with chronic illness, two common normative assumptions about illness can obscure and even hide their experiences: assumptions about the life-span chronology of deteriorating health, and framings of illness that rely on an acute and curative model of disease. I argue that while experiencing illness as a child, adolescent, or young adult can make one's illness experience more difficult to see and explain, it also can mean that illness incorporates itself into one's identity and expected future in a way that helps us imagine different relationships with bodies and illness.

In listening to, documenting, and interpreting the experiences of young adults living with chronic illness, this thesis holds space for experiences that are consistently minimised and misunderstood by healthcare professionals, peers, institutional provisions systems, and loved ones. The unseen emotional and administrative work of managing the persistent challenges presented by chronic illness was frequently described by participants as lonely and exhausting, and one contribution of this thesis is to synthesise and articulate this shared struggle. The complex nature of young adults' experiences and needs is part of what keeps their lives hidden from view, and so this thesis is in part a work that models what it can look like to hold space for what appears to be in contradiction: joy and grief; relief and frustration; hopelessness and perseverance. It is by holding space for these stories that this thesis can then look more structurally at the shortcomings of the education systems, healthcare institutions, and social interactions that surround participants, and imagine how there can be better accommodations for, and a better understanding of, those who live with chronic illness.

Background

The vocabulary of illness and youth

There are a variety of descriptive words and categories which have been used to think about bodies and health. Someone can be sick, or unwell, or ill, or diseased, or experiencing a health condition. I primarily use the terminology of (chronic) illness, and most frequently describe my research as exploring the experiences of young people who live with chronic illness.

I use the terminology of illness to describe the experience of someone who is in some way managing or living with something that something feels, to them, 'not right'. This is in contrast to disease, which, while having a promising etymology in its literal meaning of 'dis-ease', now refers more explicitly to something which is causing dysfunction. As Leon Eisenberg explained:

> "To state it flatly, patients suffer 'illnesses'; physicians diagnose and treat 'diseases'. Let me make clear the distinction I intend: illnesses are experiences of disvalued

> changes in states of being and in social function; diseases, in the scientific paradigm of modern medicine, are abnormalities in the structure and function of body organs and systems."
>
> (Eisenberg, 1977, p. 11)

My choice to rely on the language of illness as opposed to disease reflects a desire to centre my participants' experiences rather than the condition which is in some ways shaping various aspects of their life. Participants referred to their conditions and state of health in a variety of ways – this included as illnesses, as diseases, as conditions, as syndromes, or as a specific medical diagnosis. For clarity, I try to keep my language consistent – I most often use the language of chronic illness, and occasionally of chronic health conditions. This was the vocabulary used in recruitment, and so all participants were aware of this framing. I use 'condition' as a middle ground between disease names and illness experiences in quotes or participant descriptions: I describe some participants as living with, for example, a "neuroimmune condition", and use "[condition]" to preserve anonymity when there is a disease-label in quotes.

One choice I wish to draw attention to is my preference to use the label 'illness' over 'health condition'. In some ways, health condition sounds more neutral than illness, even though in a technical sense any definable health condition is a disease and therefore comes with an illness experience. Experiencing illness does not equate only to suffering and impairment, and rather than rely on the sanitised idea of a 'health condition' to move away from suffering-focused research, I seek to demonstrate throughout this thesis that there is a way to discuss illness without assuming an overwhelming cloud of negativity.

Some of my participants identified as disabled and some did not. Some participants told me that they had no issue in identifying as disabled, but, in our interview, it was not the terminology that they used to describe themselves conversationally. There is significant literature on the relationship between illness and disability, much of which is explored in my Chapter Two literature review. Two participants used mobility aids, and both they and some others used the terminology of disability in a way which echoed the sentiments of disability scholarship that describes the "unhealthy disabled" experience (Wendell, 2001). That said, I generally avoid using the terminology of disability when closely analysing or discussing data given that it is not terminology all participants saw as appropriate to their situation.

In general, I use person-first language in this thesis – I often, for example, use the phrase "young people living with chronic illness". There is not a consensus on whether person-first or identity-first language is the most appropriate way to discuss disability, and by extension chronic illness (Dynn & Andrews, 2015). That is, there are drawbacks and benefits to both the person-first language of ‘a person with a disability (or chronic illness)’ and the identity-first language of ‘a disabled (or chronically ill) person’. I take seriously the concerns that have been raised with person-first language, namely, that it may further stigmatise disability by suggesting a person is in some way damaged by a particular condition (Gernsbacher, 2017), and that it may imply that someone’s condition is in some way external to them and/or not a meaningful part of who they are (Taboas & Zimmerman, 2022). That said, person-first language overwhelmingly aligned with how participants spoke about themselves, and participants were often concerned that people would see their chronic illness before they saw their personhood. This, for me, was a clear indication that person-first language was appropriate for this thesis.

One additional reason I prefer this language is that I wish to capture the diverse and fluctuating ways that chronic illness can exist in a life. In saying this I do not mean to suggest that someone’s condition is necessarily external to their identity, but rather that it enmeshes itself in one’s life, and is therefore a component of how they learn and choose to live in this world. Living with chronic illness can mean any and all of: living with multiple illness; living with physical symptoms that may or may not be tied to your diagnosed illness; living with the spectre of illness within you but not being sure how sick you really are; living with a health condition that is well managed but still categorises you as in some way ‘diseased’; and/or living with the knowledge that your current state of health is precarious. Participants lived in this ambiguity, and my hope is that this thesis can contribute to a better understanding of the multitudes of experiences and meanings that come when ‘living with chronic illness’.

The phrase ‘young people’ is again intended to capture a plethora of non-exclusive feelings that can exist from childhood to well into ‘adult’ life: feelings of being young and carefree; of being young and inexperienced; of being young and having so much ahead of you; of being young and vulnerable; of being young and underestimated; of being young and having others expect that you will act in a particular way; of being young and wanting to behave like you think young people should; of being young now, but so much older than you once were.

Young people’s encounters with chronic illness

Discussions of chronic illness often focus on its development in later life, and the political and medical focus on this subset of chronic illness experiences has influenced the social sciences literature on chronicity more broadly (Frank, 1995; Hajat & Stein, 2018; Prince et al., 2014). Chronic illness is, however, experienced at all stages of life, and its incidence in young people is both increasing (Perrin et al., 2014; Rosen et al., 2015) and routinely underreported (Bradford et al., 2015; Chapron et al., 2019; Joyce & Jeske, 2020; Sommer et al., 2023). For children, the need to have an adult see their pain and advocate for their care is a hurdle which can make diagnosis difficult (Bradford et al., 2015; Chapron et al., 2019; Sommer et al., 2023). Indeed, young people seeking to achieve a formal diagnosis are often challenged both by medical professionals and other adults with authority, such as parents and teachers, when they do not fit the normative model of sickness (Monaghan & Gabe, 2019; Werner & Malterud, 2003). Once in the healthcare system, there is often an absence of care that is specific to the needs of children, adolescents, and young adults (Christie & Viner, 2005; Williams et al., 2002).

Due to the issues outlined above, it is difficult to establish the incidence of chronic health conditions amongst children, adolescents, and young adults. Most population studies include mental health conditions in rates of chronic illness – those studies suggest that 20-30% of teenagers have a chronic illness, and 10-13% of teenagers have a condition that significantly impacts their daily life (Yeo & Sawyer, 2005). Rates of chronic physical illness symptoms, such as fatigue or pain, are consistently and significantly higher than rates of diagnosed physical conditions – estimates have suggested that 20-46% of children experience some form of chronic pain or fatigue (Bradford et al., 2015). In the 2013/2014 Health Behaviour in School-aged Children (HBSC) study, completed by over 200,000 people aged 11-15 years, 44.2% reported that over the past six months they experienced pain in the same area about once a week, or more frequently, and 20.6% of adolescents reported weekly pain in at least two sites (Gobina et al., 2018). These findings mirror a recent review of studies on childhood and adolescent chronic pain (defined as recurring or persistent pain for three months or more) which found that the overall prevalence of chronic pain was 20.8% (Chambers et al., 2024). Regrading fatigue, a longitudinal study in a population of high-school students in Germany found that 16% of students experienced moderate fatigue and 4.4% experienced severe fatigue (Sommer et al., 2023).

The data in relation to specific diseases is somewhat patchy. Some conditions are easier to quantify than others. Epilepsy impacts just under 1% of those aged under 30, and in the majority of cases it emerges before the teenage years (Fiest et al., 2017). In Australia, approximately 0.4% of those aged 15-19 years live with type 1 diabetes (AIHW, 2024c). Endometriosis impacts approximately 5-10% of reproductive age women and girls globally (Greene et al., 2016; Vercellini et al., 2014).

Data also exists for broader categories of illness. For example, population surveys suggest that almost 10% of Australians aged 15-24 years live with a chronic musculoskeletal condition (AIHW, 2024a) and 35% live with a chronic respiratory condition (AIHW, 2024b). There is also some information on traumatic brain injuries (TBI), which are responsible for many experiences of chronic illness for younger populations – approximately 20% of teenagers have experienced a TBI, and estimates suggest that, across all ages, 15-30% of people who experience a TBI continue to experience chronic symptoms three months post injury (Haarbauer-Krupa et al., 2021; Ilie et al., 2020).

There are some areas where statistics are obviously lacking. Autoimmune diseases, for example, are a series of diverse conditions with a particular lack of clarity about prevalence and onset of disease. However epidemiological studies indicate that 5-10% of people are diagnosed with an autoimmune condition at some point in their life, and it is clear that the incidence of these conditions in childhood, adolescence, and overall, is increasing (Amador-Patarroyo et al., 2012; Conrad et al., 2023; Dinse et al., 2022; Lerner et al., 2015; Wang et al., 2015).

What this means is that at, say, a five-year reunion of a 200-person high school cohort, it is quite likely that one person will be living with type 1 diabetes, one or two people will have been diagnosed with epilepsy, one or two may be living with chronic impacts of a TBI, and approximately twenty may be living with chronic pain from a condition such as a musculoskeletal injury or autoimmune arthritis. While at school, over half the cohort would have experienced either chronic illness, or symptoms like chronic pain and chronic fatigue.

Study overview

Research questions

This thesis is based on 33 in-depth, semi-structured interviews with adults aged 19-29 years who were living in Australia at the time of the interview. Participants lived with one or more chronic physical illness – that is, conditions that cause chronic, somatic symptoms (or would do without medical management). Participants' conditions included autoimmune illnesses, inflammatory conditions, fatigue syndromes, neurological conditions, and chronic pain. Chapter Three goes into detail about the reasons for the recruitment criteria, and the ultimate make-up of the research cohort.

A series of research questions guided this project:

1. *How do young adults understand chronic illness, disability, and impairment?*
2. *How do young adults navigate their life with and around their chronic illness?*
3. *How does the digital environment influence young adults' experience and understanding of their health?*
4. *What do young adults want to see change about how individuals, society, and institutions respond to chronic illness?*

In considering these questions, two broader aims emerged. First, I hope to reveal the gaps in our vocabulary and understanding about the experiences of young people living with chronic illness. Second, I hope this thesis contributes to a conversation about what it might look like to fill those gaps.

Towards the end of all interviews I asked participants what they hoped for in the future when they thought about chronic illness. It was a broad question, and answers varied, but I want to highlight one extended response from a participant which encapsulated the deep and entangled problems that face young people who live with chronic illness.

Grace[1] lived with extremely serious, and recently deteriorating, neuroimmune symptoms. Before this recent series of painful and disabling events, she had lived with other significant chronic illnesses. What she wished that people understood about chronic illness and disability was:

> "I never smoked, didn't drink […] active, intelligent […] eating healthy, all that stuff. And I got sick and now I'm in a wheelchair and I will be for the rest of my life. And potentially things could get a lot worse. I think, particularly among young people, there's this idea that we're invincible in some way, an, 'if I do the right thing nothing bad will happen to me' sort of thing. And then the flipside is that if something bad does happen to someone, people look for a reason for it. Maybe they deserved it in some way. So I think that storyline needs to change. […] Everyone is going to know someone in their life who gets sick or becomes disabled, and when it happens young there's this grief and disconnect that happens, and if we talked more about it, and it was something

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[1] All participant names are pseudonyms.

> people were aware could happen to them, and there wasn't this invincible attitude, I think it would be much easier for peers to deal with their friends being disabled, and for families to accept it, and for people to seek mental health help for it."

I hope this thesis contributes to some of what Grace wishes for: I hope it helps people talk about chronic illness and disability more, and to realise that it is not rare, just hidden. The reality is that some people are both young and ill, and that anyone could find themselves in this situation, or knowing someone in this situation. Our lack of understanding and vocabulary around youth and illness comes from an avoidance of the issue, and this avoidance is not okay.

Conceptual approach

This thesis takes the accounts of those who have lived with chronic illness as an important form of knowledge. These accounts contain information and observations that are a product of lived experiences, and while they might not be an objective or representative look at all aspects of chronic illness, the testimony of participants speaks to a crucial, and often overlooked, perspective (Haraway, 1988). In the context of illness, injury, and disability, depicting these knowledges as individual, powerful, and contingent is an act of resistance against dominant paradigms which diminish individuality and instead promote a homogenising narrative of helplessness and deficiency (Peters, 2010; Thomas, 2010). The insights from these interviews are an opportunity to use knowledge and stories to instigate processes of resistance and ambitious new imaginaries of the future (Mishler, 2005; Stone-Mediatore, 2003).

Although this thesis is not written primarily as a way of communicating findings with the public, I do still hope that it can be part of a broader conversation on health and illness. I have sought to share the insights and experiences of my participants in a way which helps others learn, and I also hope that this thesis contributes to a sense of explanation, narrative, and *realness* when my participants reflect on their experiences. In this sense I take up Michael Burawoy's challenge to sociology: "[sociology is] more than ready to embark on a systematic back-translation, taking knowledge back to those from who it came, making public issues out of private troubles, and thus regenerating sociology's moral fibre" (Burawoy, 2005, p. 5).

In making this argument for a 'public sociology' in his 2004 Presidential Address to the American Sociological Association, Burawoy drew on the history and potential of 'emancipatory sociology' – an ethical orientation not always incorporated into the practice of the discipline. One example that Burawoy gave was the early 20th Century work of W.E.B. Du

Bois – a reference Aldon Morris further explored in his 2021 Presidential Address to explain the power of a sociology that combines biographies, histories, and social structures to understand “how it feels to be a problem” (p. 3) in order to then partake in the “science of human emancipation” (p. 14). My arguments are orientated in this tradition – I aim to not just explain what is a problem, but to give a voice to the *people* in these situations, and work towards sociological analyses that help combat the power structures that create and perpetuate these issues.

Relatedly, my sociology is also indebted to the work of critical disability theorists, and particularly feminist disability scholars, who have demonstrated the need to recognise and examine the complex interactions between the disabling and ableist structures of society, and the meaningful, personal, embodied phenomenon of struggle and impairment (Garland-Thomson, 2002, 2011; Kafer, 2013; Wendell, 1989). In particular, I acknowledge the criticisms disability theorists have made of sociology’s propensity to uphold (or create) an individualised, deficit model of disability and illness (e.g., Oliver, 1996; Thomas, 2007) – here, I explicitly commit to recognising and working against ableism (Brady et al., 2023; Mauldin & Brown, 2021). Again, I hope that my thesis moves beyond treating those with chronic illness simply as subjects of inquiry, and instead contributes to analyses that also aim to understand how systems of power influence everyone’s relationship with, and experience of, illness and disability (Friedner & Weingarten, 2019).

Structure of thesis

Following this Introduction, there are two further chapters to help orient the framework and contribution of this thesis. Chapter Two explores the existing literature that conceptualises what it means to be ill and the ways in which chronic illness impacts the way one exists in the world. Chapter Three outlines the methodology of this thesis, with particular attention to the reasons for selecting a broad participant cohort. Following this, five chapters go on to outline discrete, data driven contributions to sociological literature on chronic illness.

Chapter Four outlines the events and interactions that resulted in many participants not receiving the care they needed for their chronic illness. This chapter establishes the concrete instances of communication, care, and medical oversights which universally appeared in participants’ histories. While Chapters Five to Eight all examine the complex and fraught experiences of young people living with chronic illness, this chapter will look at instances where there was a clear disconnect between what participants needed and the responses of adults they were in some way reliant on. In particular, this chapter reveals the many ways in which healthcare professionals often failed to provide symptomatic and diagnostic care. For many participants, these experiences were recounted as a foundational part of their illness experiences, and participants often told me that sharing this element of their story was the key reason they wished to participate in this research. This chapter is therefore important for two key reasons: it is crucial context for the subsequent chapters, and it provides witness and care for the stories of participants.

Building on this, Chapter Five focuses on the ways in which youth and illness interacted in participants' lives. When participants became ill, the social and educational settings they existed within were not well-equipped to help them with their emerging chronic illness. Participants also reported increased feelings of isolation and that they were often treated in a way that was condescending or infantilising. Further, participants also feared that they were missing out on experiences of 'youth', and struggled with the ways in which illness disrupted and shaped how they could think about their future. What is clear from their words is how powerful the concept of a 'timeline' becomes when it is disrupted. Participants also emphasised that they needed (but rarely could access) a range of supports specifically for young people.

Chapter Six then looks at how participants managed the tensions and difficulties in regards to recognition and concealment. Participants demonstrated an emergent *chronic consciousness* of how others perceived their health, which created a series of fraught affective tussles centred on relational recognition and feared judgement. This chapter explores the difficulties and concerns participants had when communicating the nature and realities of illness; the emotional toll of attempting to avoid attention and judgement from others regarding their conditions; and the ways in which others could productively and sensitively acknowledge participants' illness experiences.

Chapter Seven turns to the role of technology and the online world in participants' lives. These themes arose naturally in interviews, and demonstrated how both interactions with, and the spectre of, technology, the internet, and social media have become an important part of current illness experiences. Participants reported that their online behaviours were in some instances harmful for their mental state, while at other times they provided a crucial form of connection, support, and information. In all cases, participants' behaviours reflected desires for information, community, and connection. Their recounts and reflections are therefore instructive for those considering what young people want and need when living with chronic illness. This can help us imagine an online world that provides digital intimacy and information for those experiencing chronic illness, without amplifying and intensifying their anxieties and concerns.

Chapter Eight focuses on one particularly salient aspect of illness experiences: the spectre and meaning of diagnosis. This final results chapter examines the way that diagnosis was talked about – or avoided – in interviews, and reports on the way participants iteratively decentred the role of diagnosis in various circumstances. Having read the previous chapters, one might wonder how the 'validation' of diagnosis helped alleviate the discussed issues. In this chapter I argue that while the way young adults live well with chronicity may involve seeking a diagnosis, the work of illness goes well beyond what is captured by a diagnostic lens. Further, I argue that the failure to see the shortcomings of diagnosis is in fact a significant way that the experience of chronic illness when young can be misunderstood.

The final chapter – Chapter Nine – reflects on the findings of this thesis, and elucidates what a study of chronic illness in young people offers to our understanding of illness experiences and youth. It reframes the findings of this thesis around three themes that could guide further sociological research: what the 'unspeakability' of illness when young tells us about how illness and impairment are constructed in medical and cultural discourses; how the dual fluctuations of chronic illness and a developing body require new ways of thinking about illness as an embodied experience; and what young people's creative adaptations to illness management and narratives tell us about the potential for illness and disability to be more productively and sensitively acknowledged.

Overall, this thesis contributes to empirical understandings of young people's experiences of chronic illness, and to sociological theory regarding social constructions of illness, embodied experiences of illness, and social constructions of youth. In drawing on interviews with people living with a diverse range of chronic illnesses, this thesis suggests that decentring medical categorisations of illness can help uncover some shared aspects of illness experiences, and that, practically, there are situations where support and education do not need to be structured around specific diagnoses. This helps orient future discussions towards tangible changes regarding how illness is talked about and managed in a range of settings including schools, healthcare, and personal relationships.

CHAPTER TWO | conceptualising experiences of illness

Culture, technology, and healthcare institutions all shape the experience of living with chronic illness. Current understandings of the body, health, and medicine have developed over time, and these histories reverberate throughout society. This means that conditions with various origins, diagnostic tests, symptomologies, and prognostic trajectories all entail “kinds of living” (Wahlberg, 2009) that reflect our social ideas around illness, as well as the specific circumstances of each individual (Manderson & Wahlberg, 2020).

The experience of chronic illness is contingent on many facets of society and culture, and different but complimentary conceptual frameworks can help interrogate what influences a life with chronic illness. The experience of living with a chronic illness cannot be disentangled from the series of highly politicised and influential debates at play when attempting to understand and respond to the bodies, minds, and lives of people who are ill. Much of this literature is underpinned by questions of how power dynamics operate at different levels of health and illness. In many ways, this chapter traces how various scholarly debates approach the question ‘who gets to do what in relation to illness, and why?’ This thesis engages with a number of literatures, but is most firmly situated in the sociology of health and illness (Nettleton, 2021).

The first section of this chapter – “What does it mean to be ill?” – looks at the debates and areas of inquiry which are concerned with how society thinks about disease and illness. This is a preliminary overview of the existing literature on some of the conceptual themes that arose explicitly or implicitly in interviews: medicalisation; the relationship between the mind and body; the role of diagnosis; and the ways in which illnesses are made (in)visible.

The second section – “Living with illness” – outlines ways in which experiences of illness can be analysed. This is both in relation to different lenses for exploring lives with illness (e.g., experiences of contestation, recognition and visibility, and epistemic injustice), and thematic concerns about how people live with illness (e.g., the role and impact of biography and narrative, the impact of illness at different life stages, the contributions of disability studies, feminist discourses on care, and the conceptualisation of offline and online illness communities).

What does it mean to be ill?

Complex questions arise when one examines what constitutes a disease, who gets to be ill, and how to categorise illness experiences. Below I outline various concepts and areas of inquiry that engage with how illness and disease are defined in healthcare, political, and everyday settings.

The boundaries of medicine and disease

What one's experience of illness should and does look like is often contested. Explicit documents such as diagnostic criteria, therapeutic guidelines, and healthcare policy are subject to challenge and reform, while the social and political approach to both specific illnesses, and health, wellbeing, and disability, are ever evolving (Moss & Teghtsoonian, 2008). These contestations can be conceptualised as a power tussle between those with different beliefs about, and investments in, what it means to be ill. Many of these tussles appear in debates regarding medicalisation, an important and foundational concept for understanding and analysing the place of medicine in society (Busfield, 2017; Conrad, 2007; Conrad & Stults, 2008; Parsons, 1991[1951]; Varul, 2010).

Medicalisation, at its most general, refers to the process of bringing something into the epistemological and/or institutional purview of medicine – an act that does not inherently carry negative consequences, but that can cause significant harms (Conrad et al., 2010). In a positive sense, medicalisation may lead to treatments which, say, prolong life or ease pain. There are, however, significant critiques of medicalisation. These critiques primarily explore how processes of medicalisation increase the power of medical authorities while exposing individuals to various forms of subjugation, judgement, and observation by powerful others (Lupton, 1997). The issues raised in discussions of medicalisation echo some of the themes and questions that haunt the experience of chronic illness, especially where it is in some way contested. It is therefore useful background when thinking through the nuances of first-person testimony about the tensions of living with chronic illness.

The task of distinguishing between 'good' and 'bad' forms of medicalisation is entangled with complex issues such as the (desirable) goals of health and medicine, our lack of knowledge about the biological functioning of the human body and mind, social concerns about the treatment of those who are ill, the role of political and economic actors (e.g., pharmaceutical companies), and healthcare costs. For Erik Parens (2013), the need to keep interrogating when medicalisation may or may not be helpful comes down to "helping flesh-and-blood human beings to engage in meaningful activities and relationships" (p. 35). Parens considers a series of questions that can help think this through, which include: Is there a ‘thing’ causing a problem with how someone can engage with the realities of their life? Does dealing with this in a systematic, medical way help that person? Is the medicalisation of their ‘symptoms’ obscuring social, material, or emotional conditions that are causing pain? These questions are rarely easy to answer, and even in clear cases of disease, some implications of that disease – such as emotional states or more ambiguous physical symptoms – could still be in the purview of medicalisation debates. Alistair Wardrope (2015) extends on this in his argument that the lens of epistemic injustice (explored in more detail later in this chapter) helps these debates, and allows analyses to focus on the question of whether the medicalisation of a condition “obscures” or “illuminates” the testimony of individuals.

In everyday life, patient advocates frequently argue for forms of medicalisation (Dew et al., 2016). For example, some advocacy groups seek to establish the legitimacy of formally unrecognised conditions, such as multiple chemical sensitivity syndrome or chronic Lyme disease (Nordmarken, 2020; Swoboda, 2008). Other groups campaign to recognise the medical impacts of environmental factors, such as toxic waste (Brown et al., 2003, 2004; Brown & Mikkelsen, 1997). In this research project, the most common way that participants recounted a desire for medicalisation was in their criticisms of systemic lack of care and under-research for certain medical conditions (Frickel et al., 2010; Kempner, 2014), and of the frequent underdiagnosis and/or undertreatment of conditions by doctors and healthcare institutions, especially along the lines of gender and race (Barker et al., 2022; Bülow, 2008; Callard & Perego, 2021; Hudson, 2022; Knoebel et al., 2021; Lee et al., 2019; Richman & Jason, 2001; Werner & Malterud, 2003).

These calls for medicalisation do not come without problems. For example, calls to emphasise the biological basis of conditions such as chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME), or to increase the diagnosis rates of endometriosis, can contribute to rhetoric which isolates those without a diagnosis (Whelan, 2007). They also imply that expert medical knowledge on what causes physical suffering is possible and desirable, which is a complicated claim given the potential for medical overreach.

These concerns do not, though, create an inherent, philosophical problem with calls to receive more medical care. A critique of medicalisation which focuses upon the subjugation of individual bodies to expert and biased knowledge should argue that all these issues demonstrate the ways in which, currently, medical power operates with a disregard for patient concerns and knowledge. Our biomedical lens, and the people who enforce it, can fail to recognise the pain of those devalued by society and refuse to acknowledge suffering without an ‘official’ diagnosis, while also pathologizing behaviours and experiences that would otherwise challenge institutional power.

Mind over matter

While the above medicalisation debate sheds light on some of the issues at play when defining illness categories, there are additional ways to explore the different status and interpretation of medical conditions throughout society. How individuals and societies determine – consciously and unconsciously – what is an appropriate response to illness stems from deep-seated cultural beliefs about the relationship between the mind and the body. In particular, continuing struggles to understand how a physical body relates to what at least feels to be a non-physical mind are often tied back to Descartes' articulation of this 'mind/body' problem (Bendelow & Williams, 1995; Eisenberg, 1977; Westphal, 2016).

Symptoms like chronic pain and fatigue, along with psychological experiences like anxiety, depression, or panic, call to our attention the physical implications of something which is supposedly in our mind. The claim "it's all in your head", which many may be familiar with, signals our instinct to demand a mind that can discipline physical and emotional discomfort. The mechanism by which the mind is given supremacy over the physical is outlined by Elizabeth Grosz in her 1994 book *Volatile Bodies*:

> "Feminists and philosophers seem to share a common view of the human subject as a being made up of two dichotomously opposed characteristics: mind and body, thought and extension, reason and passion, psychology and biology. This bifurcation of being is not simply a neutral division of an otherwise all-encompassing descriptive field. Dichotomous thinking necessarily hierarchizes and ranks the two polarised terms so that one becomes the privileged term and the other its supressed, subordinated negative counterpart. […] Body is thus what is not mind, what is distinct from and other than the privileged term. It is what the mind must expect in order to retain its "integrity." It is implicitly defined as unruly, disruptive, in need of direction and judgement, merely incidental to the defining characteristics of mind, reason, or personal identity through its opposition to consciousness, to the psyche and other privileged terms within philosophical thought."
>
> (Grosz, 1994, p. 3)

While this thesis is rooted in sociological traditions that recognise the embodied nature of the everyday mind and body (Nettleton & Watson, 1998), ongoing (conscious or unconscious) beliefs about the supremacy of the mind are highly influential in (chronic) illness experiences. This is true both because ill people might expect particular things of their own mind (and consequently body), and because ill people may be conscious of how non-ill people might be (or are) interpreting physical states as a reflection of the mind. As explored in more detail throughout this chapter and thesis, others' perceptions of illness, and the legibility and legitimacy of illness experiences, can cause serious stress, hopelessness, and doubt (Broom et al., 2015; Glenton, 2003; Jackson, 2005; Rhodes et al., 1999; Sheppard, 2020).

Sociology of diagnosis

Medical diagnoses are key to the contestations outlined above, and they have been the predominant mode of analysing bodily pathology and dysfunction since the biomedical turn of the 20th Century (Clarke et al., 2003; Eisenberg, 1977; Rosenberg, 2002). In this context, diagnosis – as process and as category (Blaxter, 1978; Jutel, 2011) – is a key way in which illness experiences are structured and evaluated. Where discussions structured around medicalisation consider the varied influence of the medical establishment on defining human experience, the sociology of diagnosis takes time to consider the specifics of how conditions are conceptualised, defined, diagnosed, and treated.

As Annamarie Jutel defines it, the sociology of diagnosis comes from the recognition that, (1) what exists as diagnoses provide "a cultural expression of what a given society is prepared to accept as normal and what it feels should be treated," and (2) the process of receiving a diagnosis is a further opportunity for the medical profession to "structure" individual complaints so that symptomatic experiences are validated (Jutel, 2011, pp. 3, 12–13). Thus diagnoses can become "concepts that bind the biological, the technological, the social, the political, and the lived" (Jutel, 2011, p. 13). Without a diagnosis, seeking medical help and understanding one's bodily experiences becomes extremely difficult, and people can find themselves in a liminal and precarious state (Mullard et al., 2024; Nettleton, et al., 2004, 2005; Nettleton, 2006; Overend, 2014).

Diagnoses are not apolitical products of medical research and observation, nor are they categories with stable meanings and domains (Jutel, 2015). In the medical sphere, they reflect what, and who, society deems normal, problematic, and believable (Jutel & Nettleton, 2011; Lupton, 1997; Nettleton, 2006; Rosenberg, 2002). Diagnostic criteria and assessment are also crucial components of economic and political institutions, including pharmaceutical companies and benefit schemes (Barker, 2011; Conrad, 2007).

Diagnoses can also be viewed as a way in which the body is made intelligible, coherent, and obedient, as they order the ways clinicians view patient bodies and how one views their own body (Gardner et al., 2011; Mol, 2002). The process of seeking and receiving a diagnosis can be understood as an important part in the transformation that Sartre describes between ‘body-for-me’ and ‘body-for-Other’ – physical experiences are presented in a specific way for clinical interpretation, and then that clinical interpretation informs how one understands, explains, and even experiences their own body (Wardrope & Reuber, 2022). Indeed, what ‘symptoms’ are in the absence of a diagnosis is a complex philosophical issue (Eriksen & Risør, 2014).

The potential for diagnoses to be highly politicised and variable does not diminish the power or promise they hold: diagnoses structure medical interactions up until the point of diagnosis, and then that diagnosis promises a series of future experiences and actions (Blaxter, 1978; Jutel, 2011). In some instances, the process of filtering down lived experience into ‘diagnosable symptoms’ can be emotionally difficult for patients, given it may involve disregarding testimony that patients believed to be important, and (perhaps consequently) imposing an unfounded certainty about their condition (Boulton, 2019; Lakeman, 2010). Further, as S. Lochlann Jain has described in relation to cancer prognoses, the future that clinical literatures predict exist in a state of abstraction that can never be sustained at an individual level, revealing a deep tension between the supposed certainty of scientific data and the actual uncertainty of life (Jain, 2007). In short, receiving a diagnosis, and prognosis, can raise more questions than it answers.

Tensions between diagnoses’ promised stability and actual instability have many implications for the lived experience of illness. Where diagnosis was delayed or ‘missed’, patients can feel an acute and reasonable concern about the ongoing consequences of these past medical encounters (Ghai et al., 2020; Jain, 2007; Uher et al., 2023). Not only this, but uncertainty which may have surrounded the initial process of diagnosis can make patients ambivalent towards their eventual diagnostic label, in part because of the fear that the current label will limit their ability to seek further help (Boulton, 2019). This speaks to the various ways that the diagnostic process impacts the broader experience of illness and patienthood (Jeske et al., 2024). It is not only healthcare encounters pre-diagnosis that have an impact post-diagnosis: patients themselves may actively and strategically continue to use different categories of diagnosis (e.g., 'autoimmune' compared to 'multiple sclerosis') to make sense of their experiences (Joyce & Jeske, 2020).

Invisible illnesses

Many chronic illnesses are contested in the respect that they "[do] not conform to conventional framings of what being ill involves" (Moss & Teghtsoonian, 2008, p. 7). One major reason for this is that they do not conform to acute, curative models of disease (Dumit, 2006; Kafer, 2013). Another reason is that a lack of medical confirmation of symptoms, disease, or suffering can lead conditions to be regarded as "less legitimate or less 'real' in both the medical realm and in everyday life" (Bülow, 2008, p. 123). This state of contestation is tied most firmly to illness experiences which are termed, both in patient communities and academia, as 'invisible'.[2] Paul Donoghue and Mary Siegel define these conditions as those "characterised by chronicity and symptoms that are not externally manifested [… symptoms that] are not only non-observable, but also typically immeasurable" (Donoghue & Siegel, 1992, p. 4, 7). These conditions, such as CFS/ME, fibromyalgia, and post-viral syndromes, are therefore biomedically invisible in two ways: they often do not show up on medical tests, and understanding their symptomatic manifestation is highly reliant on patient testimony. In turn, their diagnostic validity is often questioned, subtly or not-so-subtly, and those living with them feel an additional sense of social and political invisibility. Chronic pain is a particularly pertinent example of this – it is widespread, emotionally and financially costly, and highly contested in individual clinical encounters, medical guidelines, and public policy (Broom et al., 2015; Buchman et al., 2017; Lewis, 2022; Zajacova et al., 2021)

There have been other attempts to describe what makes a condition 'invisible'. N. Ann Davis gives a comprehensive list of potential ways for a disability to be deemed invisible. She notes that the conditions often "cannot generally be ascertained by someone who is merely looking at the disabled person, or engaging in limited and nonstrenuous interactions with him or her", may have an episodic or recuring nature, and may "severely limit the duration or the circumstances in which the individual can interact with other persons" (Davis, 2005, p. 202).

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[2] When speaking about disability, there are other adjectives that can be used to describe similar experiences. *Hidden disability* is frequently used to specify disabilities that are at various points not easy to discern, while *episodic disability* refers to conditions that are characterised by (often unpredictable) shifts between wellness and impairment (Prince, 2017). Psychological disabilities/illnesses, including mood disorders, panic disorders, addiction, and schizophrenia, are also a subset of invisible disabilities/illnesses.

This highlights that invisibility is felt due to two separate factors: someone is hidden from public view when their condition is at its worst, and then when they are more likely to interact with a broader public, their condition ceases to be obvious. Davis also notes that while some invisible disabilities can be verified by medical tests, “their identification or classification is not purely quantitative but involves interpretation and requires the use of judgement” (p. 203).

There is also significant literature on the challenges which emerge when people attempt (or consider attempting) to disclose their needs (Defenbaugh, 2013; Lingsom, 2008; Lonardi, 2007; Myers, 2004; Samuels, 2003; Teghtsoonian & Moss, 2008; Werth et al., 2018). This speaks to a type of invisibility that exists in different ways within all illness experiences: in a literal sense, individual illness experiences are not knowable to anyone else, and this can be seen to create an emotional strain that is both universal and deeply individual (Davis, 2005).

Ultimately, there is no definite dividing line between visible and invisible chronic illness, but interrogating what is meant by ‘invisible illness’ indicates what aspects of visibility are seen as influential on how illness is experienced. Recognising that invisibility is a product of social, cultural, and medical expectations helps politicise the experience of invisibility in a way that allows for a better understanding of the experience as it exists, and for better remedies to the isolation and mistreatment it may bring. This involves attending to the experiences that coalesce around *not* being seen, which include doctors not believing patient accounts, medical tests suggesting that everything is ‘normal’, or there being little political or social will to accommodate and/or research conditions (Davis, 2005). These experiences all come in part from social forces which demand able-bodied health and easy to read bodies.

Living with illness

An important area of inquiry in the sociology of health and illness is how people manage – and struggle – to ‘live well’ with various physical and mental conditions. From the mid- to late-20th Century, sociological literature has approached this through examinations of the emotional, social, and political challenges that come from living with a chronic illness (Bury, 1982; Charmaz, 1983; Conrad & Barker, 2010; Eisenberg, 1977; Kleinman, 1988; Nettleton, 2006). This “chronic living” (Manderson & Wahlberg, 2020) involves significant work both in regards to health-management and in regards to emotionally coming to terms with the implications of illness for one’s life and identity (Corbin & Strauss, 1985; Mattingly et al., 2011).

Below I outline some ways of conceptualising what makes up an 'illness experience', the various ways that people may seek to make sense of their illnesses, and some healthcare and policy initiatives that have sought to manage the experience of chronic illness.

Uncertainty, humility, and ambivalence

Living with an illness that is in some way medically contested has serious implications for the experience of being ill, both in relation to the emotional uncertainty that comes from medical and social contestation, and the practical difficulties of contested medical care (Costa, Mescouto, et al., 2022; Costa, Olson, et al., 2022; Lewis et al., 2010). Challenges in the clinical and medical world include: scepticism from doctors relating to the reported symptoms of patients, making it difficult to receive psychological or medical validation (Album & Westin, 2008; Barker, 2002; Bontempo, 2024; Dumit, 2006); doctors dismissing new symptoms given the broad symptomology of the diagnosis (Boulton, 2019); the potential for pharmaceutical companies to "define" the symptomology and biomedical explanation for these conditions (Barker, 2011); and personal difficulties in coming to terms with one's own health given the difficult diagnostic processes and the ambiguous nature of the eventual diagnosis (Arroll & Howard, 2013; Boulton, 2019; Dennis et al., 2013; Madden & Sim, 2006; Mullard et al., 2024). Interpersonally, people also live with both the fear of, and actual, scepticism or disbelief from family, employers, and friends (Jackson, 2005; Nettleton, 2006), and the consequent pressure to offer detailed explanations of the condition (Davis, 2005). Finally, accessibility schemes are often poorly catered to people with fluctuating chronic illnesses or episodic disabilities (Anderson et al., 2024; Vick, 2013), and, indeed, people with these conditions can be denied disability benefits or accommodations altogether (Anderson et al., 2014). These experiences speak, in part, to the various challenges around communicating complex and contested health states.

Not only do biomedical models fail to offer understandable diagnostic, symptomatic, and causative vocabulary, but chronic suffering also can create a sense of prolonged liminality and loneliness (Cheung et al., 2024), along with a self-perpetuating cycle of withdrawal, entrapment, and invisibility (Broom et al., 2015). In some cases, there is existing research into the ways in which youth impacts this experience (e.g., Heaton et al., 2016; Monaghan & Gabe, 2015, 2019; Poku & Pilnick, 2022; Polidano et al., 2020) – this will be explored in greater detail later in this chapter.

Structural and interpersonal issues within the clinical encounter are central to these issues. In general, the emotional and practical tensions of managing complex and ambiguous chronic illnesses can be difficult to convey and discuss in clinical encounters (Corbett, 2007; Townsend & Hunt, 2006). Specifically, healthcare systems also struggle financially and organisationally to deal with complex, chronic cases (Album & Westin, 2008; Boulton, 2019; Harsh et al., 2016; Madden & Sim, 2006; Nettleton, 2006; Yon et al., 2015). In some cases, there is a structural lack of medical research, and consequently limited therapeutic guidance, for particular diseases (Barker et al., 2022; Callard & Perego, 2021; Frickel et al., 2010; Hudson, 2022). Further, there can be significant biases directed towards certain identity groups (Knoebel et al., 2021; Lee et al., 2019; Richman & Jason, 2001; Werner & Malterud, 2003). Overall, this leads to medical environments that often exist on a spectrum which ranges from ill-equipped to hostile. For example, Kevin Dew and colleagues (2024) have explored how "exceptional" cancer survivors – who are very much living with a complex condition surrounded by uncertainty – must "wrangle" healthcare and government systems, revealing the "messiness" of "making-do […] in an unequal and shifting terrain of possibility and intervention" (p. 6).

Different forms of uncertainty pervade many clinical encounters. While this uncertainty can challenge the assumed hierarchy, dominance and expertise of medicine, the presence of uncertainty is often denied or ignored to the detriment of patients (Boulton, 2019; Costa et al., 2023; Costa, Karime, et al., 2022; Costa, Olson, et al., 2022; Lian et al., 2021, 2023). There have been some studies which investigate how doctors are taught to manage uncertainty, and various institutional shifts that could aid patient care in these settings. By speaking with junior doctors, Katherine Yon and colleagues (2015) have revealed the lack of training in medical programs in how to treat patients with medically unexplained symptoms (MUS), and how this exists in a context where senior doctors may have little patience for patients with MUS. They show how a lack of appropriate counsel on how to provide help to those with MUS can leave doctors frustrated and anxious about these patients, which in turn leads to worse care. Jennifer Harsh and colleagues (2016) have further suggested that doctors benefit from access to collaborative opportunities when diagnosing and treating patients with complex, chronic conditions. They argue that open discussion with coworkers is necessary for doctors to gain the confidence, humility, and reflexivity required to deal sensitively and effectively with contested-illness patients. This is also mirrored in calls for a more collaborative approach with patients (e.g., Driedger et al., 2008).

One way researchers have responded to these issues is by considering how the role of medicine, and the purpose of a clinical encounter, can be reframed (Mescouto et al., 2022, 2023). Alyssa Overend (2014) suggests that asking four questions of clinical practice — Who cares? What for? Why do we care? How do we care? — will help healthcare "mov[e] away from narrow definitions of the visibility and locatability of illness" and towards more effective care for those who are suffering (p. 78). Tiffany Boulton (2019) also suggests that "it might be beneficial for both patients and doctors to understand medical encounters as 'help-seeking' interactions and to recognise that diagnosis is not the most important, or final, act of health-professionals" (p. 817).

Broadly, this speaks to ethics of medicine that may come from its "healing" role (Pellegrino, 2001). This model is not without concern: Alistair Wardrope and Markus Reuber (2022) warn against becoming overly attached to this metric, which is both broad enough to encompass many professions (which Pellegrino does admit) and which, they argue, is hard to apply to instances where medicine cannot "heal" (p. 398). Instead, Wardrope and Reuber argue that clinical interactions fall short when medicine loses sight of where its expertise lies. They suggest that health professionals and medical research are good at defining, recognising, and interpreting symptoms, and that interactions can therefore become upsetting and potentially harmful both if symptoms are mis-recognised and if the healthcare establishment claims to offer expertise and help outside its field. In some ways this speaks to Elliot Mishler's (2005) call for humane medical care, which he imagined as a medical care that leaves space for, and takes seriously, patients' "narratives of resistance" as they construct their own meaning in a non-medical framework. In this respect, an important form of patient empowerment comes from better equipping and allowing people to describe their concerns on their own terms, rather than immediately directing them towards descriptions that align with medical and social formula (Carel, 2016). The ethics of care (and self-care), along with self-management and peer-support, are returned to later in this chapter.

One way that medical systems have attempted to reform is through establishing 'integrated medicine' practices, where patients are introduced to complementary and alternative medicines as part of their biomedical treatment (Singer & Adams, 2014). The problem is though that as long as the paradigm of biomedicine continues to prioritise certain forms of evidence and knowledge, different healing knowledges can be used inappropriately and ineffectively in biomedical spheres (Hollenberg & Muzzin, 2010). Rupa Marya and Raj Patel (2021) have argued that we therefore need a more radical re-evaluation of biomedicine, particularly in the context of the growing prevalence of inflammatory conditions. This crisis has its genesis, they argue, in colonialism and capitalism, and responding to it requires a return to “deep medicine”:

> “Rather than taking things apart to know (dia-gnosis), deep medicine puts the pieces back together to understand and to heal what’s been divided. It never separates a person or a community away from the web of relationships that confer sickness or health. It is from that place of understanding that healing actions become possible.”
>
> (Marya & Patel, 2021, pp. 330–331)

Much of their book *Inflamed* challenges us to recognise the health implications of environmental destruction, toxic chemicals, and the chronic stress of intergenerational and ongoing trauma. While demanding changes to the political confrontation of these issues, Marya and Patel also lament that medical systems struggle to consider this context when treating people who are unwell. As suggested in the quote above, true care may not be provided by giving patients a single diagnosis or treating their symptoms in isolation. Instead, medical interactions need to focus on putting someone “back together” in a holistic sense – care that would include acknowledging and challenging the systems which inflict emotional, physical, and cultural damage. Further, Marya and Patel emphasise that recent ‘wellness’ literatures, while claiming to move past mind-body dualisms to promote holistic health, only prioritise an individualised (and expensive) form of ‘healing’. Alan Peterson makes a similar argument in relation to supposed efforts to recognise ‘the power of the mind’ and ‘treat the whole person’ – he argues that these discourses place additional burdens on individuals to ‘care for themselves’, which actually works against a more effective rethinking of the power imbalances at play in health discourses and clinical encounters (Petersen, 2006). These debates extend to many individual and social ills. For example, there have been similar calls for caution about the increasing reliance on disease-models of conditions such as addiction, which can be especially alienating for young people and disadvantaged communities (Bryant et al., 2021, 2022; Fraser, 2017; Keane, 2021).

These issues speak to deeper issues concerning the multiplicity of subjectivities that surround chronic illness. Arthur Kleinman and colleagues (1992) explain this well when writing about chronic pain:

> “When reconstituted as a medical problem, however, that experience [of chronic pain] is fragmented into a series of dichotomies that represent the deep cultural logic of

> biomedicine. Physiological, psychological; body, soul; mind, body; subjective, objective; real, unreal; natural, artificial——these dichotomies, so deeply rooted in the Western world and its profession of medicine, are at the heart of the struggle between chronic pain patients and their care givers over the definition of the problem and the search for effective treatment."
>
> (Kleinman et al., 1992, p. 8)

Owen Whooley and Kirstin Barker (2021) have recently extended this literature by arguing for a 'sociology of medical ignorance'. While they recognise that specific cases of complex illnesses and clear medical uncertainties are good exemplars of unknowns in medicine, they argue that "medical unknowns are a much vaster universe" (p. 281):

> "Ignorance saturates all of medicine, from the biomedical laboratory to the design of medical technologies, from the clinical encounter to collective politics of health and illness. An ever-present feature of medicine, ignorance should be an ever-present focus for medical sociology."
>
> (Whooley & Barker, 2021, p. 280)

These arguments speak to a recurring theme in this literature review and thesis: the use of (reductive) binaries around our health and bodies. Feminist disability scholarship (explored in more detail later in this chapter) has outlined how the consistent construction of binaries in society marginalises both women and disabled people – and particularly those at the intersection of these two identities (Garland-Thomson, 2002; Meekosha, 2002; Wendell, 1989). The problem (yet presence) of binaries has also been used to explain the potential for illness to "disorient", as the embodied experience of illness destabilises expected binaries, particularly in relation to health/illness and the familiar/strange body (Harbin, 2012, 2014, 2016; Lajoie, 2019). Ambivalence can also represent a rejection of cultural binaries, emerging as one realises that what one is experiencing does not accord with dominant social narratives (Bauman, 1990; Hillcoat-Nallétamby & Phillips, 2011; Merton, 1976). This thesis contributes a further understanding of how experiencing chronic illness, especially when young, destabilises many cultural, social, and institutional expectations.

This is the context in which chronic illness is continually contested. The literature on the experiences of people with chronic illnesses makes clear that our current medical, political, and social worlds are often ill-equipped to deal with these complex issues, and that many people are left feeling isolated and, in some deep sense, uncared for.

Visibility, recognition, and affect

As outlined previously, the term ‘invisible illness’ (or similar) references situations where illnesses are both not obviously apparent in the everyday, and unseen by the healthcare and political establishments which should be caring for those who are ill. While useful to signify a feeling that may arise in many illness experiences, sociological literature on in/visibility demonstrates the need for caution regarding the evaluative binaries these discussions can entail (Brighenti, 2007). There are many ways that certain things or people can be seen or not seen, and visibility can be both good and bad: for example, certain groups can be perniciously watched to their detriment, while others can be intentionally erased (Casper & Moore, 2009). Additionally, the binary of in/visible implies the categorisation of people into the false dichotomy of either ‘hiding’ their identity or of ‘revealing’ who they are (Gray, 2009). In the day-to-day, visibility is actively managed across a broad spectrum, where, depending on context, different levels or types of visibility can be desired, and ‘being seen’ can mean different things.

These complexities of visibility arise alongside concurrent arguments about the role of recognition in self-actualisation, and the injury caused by a refusal to recognise the difficult work one does to act and be seen as a differentiated individual with moral worth (Honneth, 1995). The idea of recognition is complex though: Kelly Oliver has argued that “recognition” can reproduce an unfortunate relationship of recognis-er and recognis-ed in cases of trauma, and that instead working to “witness” past and present stories is a more ethical way of restoring voice (Oliver, 2001).

In the context of chronic and contested illnesses, there is a significant literature that demonstrates the work people do to manage how they are perceived by others, particularly in relation to the recognition and validation of their illness experience (Dudley et al., 2023; Glenton, 2003; Lonardi, 2007; Moensted et al., 2023; Werner & Malterud, 2003). Other scholars have identified the relational challenges posed by ‘atypical’ aspects of incurable illness, and the strain and rupture of social bonds that often results (Lewis et al., 2024).

This relationship between self and other preoccupies key texts in the sociological canon (e.g., Goffman, 1959, 1963; Hegel, 2003; Mead, 1934). Albeit in relation to race, rather than health, W.E.B. Du Bois’ concept of “double-consciousness” captures the effects of subjugation and misrecognition through an analysis of the dual identity of African-Americans in early-20th Century America (Du Bois, 2007[1903]). Sociologically, it is a rigorous exploration (written before Goffman and Mead's work) of how mutual recognition can function in different social relationships, and it has particular conceptual strength for self-other relationships that are "predicated on domination" (Meer, 2019, p. 52).

Du Bois described in his book *The Souls of Black Folk* how:

> "It is a peculiar sensation, this double-consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity."
>
> (Du Bois, 2007[1903], p. 3)

This resonates with the tensions that emerge across literatures on the experience of chronic illness: rather than receiving acknowledgement for their worth, capacities, and struggles, those with chronic illness can feel a sense of alienation due to the contemptuous observation of them as a pitiable and objectionable 'other' (Monaghan & Gabe, 2019; Reeves et al., 2023; Scambler, 2004). Often, this is done with discourses that reflect a desire for medical and individual mastery of the body (Grosz, 1992; Lupton, 1997; Petersen, 2006; Reeve, 2002) while also imposing a morality on health, illness, and their management (Grønning et al., 2013; Monaghan & Gabe, 2019). Alternatively, legal and social understandings of particular illness experiences, such as living with coeliac disease, can create a false sense of 'recognition' based in individualising, otherising, and trivialising rhetoric, rather than inclusionary policies (Steinhoff et al., 2024).

This social context cannot be disentangled from an individual's feelings surrounding illness. The resulting "psychosocial 'texture'" (Wetherell, 2012, p. 2) of chronic illness is made up of the relationships between the lived physical experience of illness and pain, individuals' previously established beliefs and emotions, and encounters with others which are both real and imagined (Ahmed, 2004a, 2004b, 2015; Sointu, 2016). In other words, social context is paramount to understanding the way in which affect-laden interactions impact those who are ill, and the ways in which symptoms such as pain affect the material world of young adults living with chronic illness (Goodley et al., 2018).

The clinical encounter and epistemic injustice

One way to understand clinical encounters is as exercises in description, translation, and interpretation. Not only are symptoms described by the patient and interpreted by the doctors, but symptoms themselves are the result of both patients and doctors interpreting physical and mental sensations (Wardrope & Reuber, 2022). Deciding to seek out healthcare also usually requires someone to understand their experiences as a medical issue. There are various observations about how these decisions are made, and literature on this emphasises the role of disruption to life, the emergence of vulnerability, and the loss of a predictable body (Carel, 2016; Hay, 2008; Toombs, 1992). From the outset – and this will be clear in participant accounts of illness in childhood in Chapter Four – these demarcations of illness are particularly difficult for children and adolescents, given that they do not have a stable life, are in a constantly vulnerable position, and have changing and unpredictable bodies. Further, the constant pressure on people to defend their belief that they are experiencing a medical problem (Heritage, 2009) is particularly pernicious for young people, given our persistent failures to listen to the testimony of children (Carel & Györffy, 2014) and their related struggles to speak about and/or describe what is happening in their bodies (Wardrope & Reuber, 2022, p. 408).

Another way to look at these issues is by examining what Miranda Fricker (2007) termed 'epistemic injustice' – the harm that is done to someone, or to groups, when their testimony and knowledge is not given credibility, and/or when collective knowledge fails to provide guidance on how they can make sense of their experiences. In the context of chronic illness, epistemic injustice can be a useful way to understand the experiences of individuals while placing their stories in a broader social and political context (Mladenov & Dimitrova, 2023; Sebring, 2021; Wardrope, 2015). The related concept of 'epistemic violence', where 'pernicious ignorance' means that an audience is unwilling or incapable of listening (Dotson, 2011), is also a way of analysing how illness experiences are ignored, and ill people are silenced.

There is clear evidence that there are serious risks of epistemic injustice in clinical encounters, and that it is not unusual for one's knowledge or experience of their body and health not to be taken seriously (Carel & Kidd, 2014; Heggen & Berg, 2021; Kidd & Carel, 2017). This injustice can also exist in research contexts which do not adequately recognise the knowledge of ill and disabled participants, and which are not accessible to ill and disabled researchers (Wieseler, 2020). These enquiries build on work that has demonstrated and explored the long history of science and medicine disregarding embodied experiences and knowledges (Garland-Thomson, 2002; Haraway, 1988; Morris, 1992; Wendell, 1989). As mentioned in reference to medicalisation debates, these failures can be felt particularly by those at the intersection of minoritised identity groups (Mullard et al., 2024; Sebring, 2021), in part because there is a systemic under-research of particular conditions and illness experiences (Frickel et al., 2010), and also because of the disproportionate underdiagnosis and undertreatment of patients along the lines of gender and race (Hudson, 2022; Knoebel et al., 2021; Lee et al., 2019; Richman & Jason, 2001).

Beginning in lay descriptions, and now existing in the academy, the terminology of 'medical gaslighting' can also be used to describe a related set of experiences: ill-people being made to doubt the lived reality of their own illness or disability (Au et al., 2022; Sebring, 2021). For example, accusations of gaslighting might be directed towards a doctor who suggests that a patient's symptoms are 'normal', or a loved one who says that someone's difficulties come from 'motivation' or 'character' issues rather than physical symptoms. Elizabeth Barnes's (2023) detailed examination of what, specifically, goes wrong in cases described as medical gaslighting is also instructive: her argument is that injustice happens when a doctor fails to uphold their reasonable commitment to listen to their patient. This breakdown of trust can also be applied to examples such as a teacher failing to listen to a student, or a parent failing to listen to a child. The role of trust is a component of Fricker's original conceptualisation of epistemic injustice (2007, p. 145), and central to other investigations of epistemic injustice in clinical encounters (Buchman et al., 2017; Ho, 2011). This complements Wardrope and Reuber's argument (2022) that clinical encounters go wrong when doctors fail to recognise and/or interpret symptoms, including because they do respect the patient as a 'knower' of their own bodily sensations.

These experiences can have serious negative impacts on patients (Halverson et al., 2023), and particularly children and adolescents, whose age is an additional barrier to being listened to and believed (Baumtrog & Peach, 2019; Burroughs & Tollesfen, 2016; Carel & Györffy, 2014; Carolin & Milner, 1999; Greenblatt et al., 2024; Wild et al., 2024). The emotional implications of dismissiveness and silencing helps explain the importance of safe spaces where illness experiences can be discussed (Groenevelt & de Boer, 2023). It also can help inform paths forward for encouraging productive and meaningful listening from clinicians (Epstein & Beach, 2023; Hayakawa, 2021; Luong et al., 2024; Naldemirci et al., 2021; Pot, 2022; Rosen, 2021). This is related to calls for doctors to have greater humility in regard to what medical expertise misses (Buchman et al., 2017; Driedger et al., 2008; Ho, 2011; Lakeman, 2010; Porter & Schumann, 2018) and also analysis that differentiates between a clinicians need to 'listen' and need to 'believe' (Harcourt, 2021).

More broadly, an understanding of epistemic injustice is complementary to efforts that seek to recognise and formalise patient knowledge for improved healthcare practices (Cribb et al., 2023; Dumez & L'Espérance, 2024; Halloy et al., 2023). Further, it has resonances with other, earlier literature which has described the epistemological challenges of living with contested illness. Barker, for example, described how people with fibromyalgia can "find themselves in an epistemological purgatory" due to the "realness of their experience in the face of public doubt" (Barker, 2002, p. 281). In a similar vein, Emma Whelan (2007) used the idea of "epistemological communities" to explore circumstances where people with endometriosis form a community which elevates their shared embodied knowledge of the condition.

Illness narratives

Narratives – particularly biographical narratives – are a key component of how individuals understand themselves, and their relationships with others. Narratives give meaning to moments in time: events and decisions can become episodes in networks of relationships and events, which Margret Somers (1994) argues is what makes it so that "struggles over narrations are thus struggles over identity" (p. 631). Often, the stories we tell ourselves are used to project 'coherence' onto life experiences (Alheit, 1994; Kenny et al., 2017). Peter Alheit describes how crisis events can disrupt one's established relationship between 'everyday time', which is what we do on a daily basis, and 'life time', which is how we understand our biography in a way that allows past to be connected to present to be connected to future. Problems arise when

> "daily routines are not simply suspended for a limited period, but where their re-establishment is *fundamentally* questioned. […] In such situations we are forced to exit the time frame of everyday life and to reorganize our whole life. […] Crises of this order always affect the substance of our biography because they put at risk any reconstructable or anticipated continuity of our self-plan. And we are no longer 'the same person' as we were before the onset of crisis."
>
> (Alheit, 1994, p. 310)

Illness disturbs the expected present, and in turn may cast questions over both the past and the future. In this context, stories play an important role in the lives of those who are ill (Kleinman, 1988). Arthur Frank argued in his key work on the process of narrativising illness, *The Wounded Storyteller* (1995), that people with serious illness

> “learn by hearing themselves tell their stories, absorbing others’ reactions, and experiencing their stories being shared. [… T]he body sets in motion the need for new stories when its disease disrupts the old stories. […] The embodied stories have two sides, one personal and the other social.”
>
> (Frank, 1995, pp. 1–2)

Frank goes on to argue that, on a personal level, stories allow the “changed body […] to become familiar” (p. 2), while, socially, stories are needed to communicate the ill individual’s pain and needs.

There is an extensive body of sociological literature which demonstrates that illness can create a need for new stories about one’s past, future, and self (Bury, 1988; Frank, 1995; Locock & Ziebland, 2015; Williams, 2000). Related research has also sought to understand how people live well with illness given a recurring desire for a coherent, integrated, and familiar ‘self’ (Bury, 1991; Charmaz, 1995; Deegan, 2001; Frank, 1995; Kenny et al., 2017).

Michael Bury’s formative concept of ‘biographical disruption’ remains a key contribution to conceptualising the way chronic illness may unsettle a life. Bury’s 1982 article explains the way in which the onset of a chronic illness (in the case of his research, rheumatoid arthritis) disrupts the current organisation, and expected future organisation, of one’s life. The disruption happens in many ways: illness disrupts not only one’s health, but also their social relationships and their access to financial resources (Bury, 1982). Bury later elaborated that there are two forms of disruption: disruption that comes from what illness does to sense of self (‘meanings as significance’), and disruption that comes from the new practicalities of living with chronic illness (‘meanings as consequence’) (Bury, 1988). Later, Bury argued that looking at the subsequent “strategic management of illness” allowed for an analysis of the mobilisation of resources and the different “styles” of response (Bury, 1991).

A similar argument was made by Kathy Charmaz, who suggested that what happens to the self-image of those with chronic illness and disability is best described as a ‘loss of self’ (Charmaz, 1983). Later, Charmaz argued that individuals who accepted their health underwent a process of adaption which ultimately allowed them to integrate loss and suffering into their concept of self, in turn providing a renewed sense of wholeness and clarity (Charmaz, 1995).

Both these ideas are formative to many sociological arguments around chronic illness. Biographical disruption in particular has become a significant concept in medical sociology and the sociology of health and illness, and continues to be refined through debate and revision

(Locock & Ziebland, 2015; Williams, 2000). For example, research has suggested that in many cases chronic illness is, in various ways, anticipated or expected. Key contributions here come from Simon Williams (2000), who argued that, in the case of gay men, HIV could become a ‘biographically anticipated illness’, and from Christopher Faircloth and colleagues (2004), who showed that when older people with existing illnesses experienced a stroke it became a part of their ‘biographical flow’.

The binary between ‘disruptive’ and ‘normal’ has also been problematised. In the case of the elderly, Caroline Sanders and colleagues (2002) showed that, for those with osteoarthritis, the condition was an expected part of old age yet still highly disruptive. Anika Larsson and Eva Grassman (2012) have argued that, as those with existing chronic illnesses collect physical difficulties as they age, this experience is neither a distinct ‘disruption’ nor a smooth, linear path. This binary of disruptive/normal has also been shown to be problematic for those living with chronic conditions that do not have a clear point of diagnosis and treatment intervention, such as chronic pain. In these cases, proactive as well as responsive ‘health maintenance’ actions may be understood as an addition and shift in ‘normal’ living, but not an acute disruption (Sanders et al., 2015). The influence of chronic illness on young people’s biographies will be explored later in the chapter.

Looking at some of this literature in a broader sense, Victoria Cluley and colleagues (2021) note that these applications of biographical disruption do not necessarily provide useful predictions about what illnesses experiences cause what kind of disruptions, and note that it can therefore be difficult to use the concept(s) for more than their descriptive capacity. This is particularly true given how dependent disruption is on one’s other identities, such as their gender, class, age, or ethnicity (Wedgwood et al., 2020). The descriptive potentials of biographical phenomenon can, however, help to understand the role of different elements of the illness experience (e.g., frailty), especially when biographical analysis is used in relation to “more-loosely defined” illness experiences (Cluley et al., 2021, p. 952).

More broadly, there are also reasons to be concerned about analysis which (over)emphasises narrative. Narrative analysis may emphasise destruction as a point of contrast to constructive progress (Kenny et al., 2017), and may also provide both a ‘message’ and a ‘completeness’ that misrepresents how life is experienced, particularly in cases of trauma (Andrews, 2010; Hyvärinen et al., 2010). Practically, Lars-Christser Hydén also notes that theories about how narrative and storytelling is used in everyday life is very different to how narratives are recounted in an interview situation (Hydén, 2010).

Illness across time

A focus on biography can be seen to sit within a broader area of conceptual analysis: the life course and the passage of time. Questions of time underpin many discussions about illness (Ehlers et al., 2024; Olson, 2011, 2015) and chronic illness (Green & Lynch, 2022; Harrison et al., 2024; Morris, 2008; Saunders, 2017). The constructed socio-temporal rhythms of life often dictate the ways we organise, measure, and value our lives (Cipriani, 2013; Southerton, 2020; Zerubavel, 1982). Indeed, time is increasingly understood as a commodity that we can spend, save, or waste, and health is understood as a crucial determinant of how effectively one's time is utilised (Kenny, 2015). Along with this, a (pre)occupation with what is to come – and how we best prepare for it – brings the future to the present as both individually and societally we are primed to 'anticipate' (Adams et al., 2009).

Chronic illness can disrupt these rhythms on every scale: mornings can be disrupted, days and weeks can be disrupted, one's 'youth' can be disrupted, or life itself can be disrupted. In this sense, the usual work of coordinating futures and differing temporal horizons (Tavory & Eliasoph, 2013) is substantially complicated by chronic illness. That is, a person's trajectories could be disrupted by chronic illness if, for example, they need to pause study, they need to re-evaluate their previous life and/or career ambitions, or indeed if they need to re-form the narrative of 'who' they are in this world. Illness is one of many things which can prompt people to undertake significant work and innovation to sequence, connect, and manage their various trajectories, and how people do this can offer insight into what is (or is becoming) socially and culturally permissible and important (Brown & Patrick, 2018).

More broadly though, chronic illness can place one in an uncertain (and not well understood) temporal landscape – one that is poorly described by the ordinary references to calendars and clocks, and which may be better understood in terms of an illness's fluctuations or a body's needs (Sheppard, 2020; White, 2022). One argument Alison Kafer makes in her seminal work, *Feminist, Queer, Crip* (2013), is that the experience of illness and disability is tied closely with a number of temporal constructions: temporal medical terminologies such as 'chronic' or 'intermittent' are an important component of medical labels, while temporal expectations are disrupted by both the practicalities of disability and ableist interactions with people or built environments (pp. 25–26). Kafer further argues that we need to "wrestle with the ways in which 'the future' has been deployed in the service of compulsory able-bodiedness and able-mindedness," where "curative time" is often imposed such that there is "an understanding of disability that not only *expects* and *assumes* interventions but also cannot imagine or comprehend anything other than intervention" (Kafer, 2013, p. 27). Consequently, the argument goes, disabled people and bodies become "obstacles to the art of progress" (p. 28). This argument is relevant for sociology as well, where discussion of futurity rarely consider or incorporate disability (Morgan & Tutton, 2024).

Youth and illness

An important way that youth and illness can interact is in illness's disruption to cultural expectations and assumptions about what it means to be young, and beliefs about what one should be doing at this point in their life. A preliminary understanding of the sociological study of the life course is helpful for examinations of this interaction.[3]

Richard Settersten and Karl Mayer (1997) ended their review of age and life course studies in sociology with this observation and prediction for future research:

> "As we seek to better understand the course of human lives in contemporary and ever-changing societies, the effective empirical measurement of its key concepts simultaneously becomes more pressing and more complicated."
>
> (Settersten & Mayer, 1997, p. 255)

This is indeed an ongoing issue, and there are significant complexities and uncertainties around what it *means* to say that someone is a child, or adolescent, or young adult. Specifically, there are significant variations in what different people's lives look like at different ages (Brannen & Nilsen, 2002; Bynner, 2005; Settersten, 2009), what young people feel will constitute moving into a new 'stage' of life (Barker & Galambos, 2005; Horowitz & Bromnick, 2007; Woodman & Wyn, 2015), and how young people view their 'subjective' age (Montepare, 2009). Youth is also a life stage that can be the subject of significant (intersectional) prejudices, moral panics, and risk discourses (Baumtrog & Peach, 2019; Murris, 2013; Pickard, 2014; Protzko & Schooler, 2019). Young people, and young bodies, are consistently the site of this 'youth-at-risk' discourse, which, in relation to health, centres around conditions that are

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[3] That said, my interest is different from what could be an alternative area of inquiry within life course analysis, which might aim to ascertain the impact that chronic illness when young has on events later in one's life (Elder, 1994; Shanahan, 2000).

supposedly ‘preventable’, such as obesity, mental illness, and addiction and binge drinking (Coffey et al., 2016). In Chapter Four I will argue that this focus (ironically) takes attention away from the body when chronic physical illness emerges.

Previous research on the experience of young people with chronic illnesses has demonstrated the ways in which particular precarities, anxieties, and dependencies of youth influence the experience of illness (Bray et al., 2014; Gabe & Monaghan, 2023; Gannoni & Shute, 2010; Wedgwood et al., 2020). Adolescence and young adulthood are also periods of major identity work (Kroger, 2004), and a period where structure and agency are continually renegotiated (Coffey & Farrugia, 2013; Pais, 2022). The way in which young people think about the future, particularly in relation to the way they exercise ‘hope’, is of increasing interest to youth sociologists (Bryant & Ellard, 2015) with clear resonances in literatures relating to illness (Kylma, 2005; Petersen, 2015; Peterson & Wilkinson, 2015) and to biopolitics (Peterson & Krisjansen, 2015; Rose, 2001; Rose & Novas, 2005). There is also literature in youth studies which seeks to move the conversation beyond ‘resilience’ and towards thinking about how young people imagine the future (Foster & Spencer, 2011) – this literature has important resonances with work in disability studies that demands social, political, and academic discourses move away from deficit models and pity (Oliver, 1996; Priestly, 1998; Thomas, 2010).

The intensity and plasticity of youth is reflected in the variety of responses young people have to living with, and making sense of, illness (Grinyer, 2007). That is, the ways they find (or struggle) to assert ‘agency’ (Coffey & Farrugia, 2013) reveals the complex social and institutional networks that those with chronic illness find themselves in. In some instances this manifests as adolescents and young adults integrating illness and disability into their lives to empower themselves and reconfigure their sense of self around a positive narrative (Brady et al., 2023; Heaton et al., 2016; Polidano et al., 2020). In others, young people attempt to cultivate and project independence, agency, and (other forms of) health (Monaghan & Gabe, 2016; Spencer et al., 2017, 2021; Wicks et al., 2019). Perception is a particularly important aspect of identity management for young people (Barned et al., 2016), and this is represented in part by the reliance on ideas of ‘normalcy’ which appear in some studies with adolescents and young adults (Gibson et al., 2013; Heaton, 2017).

Much of this research focuses on the ways in which chronic illness impacts developing biographies. To begin, the life stage at which conditions develop can result in a sense (or observation) that one has always been ill, which can further differentiate the experience of chronic illness when young from the acute disruption someone older may face (Williams et al., 2009; Williams, 2000). There have also been some youth-specific variations on the concept of biographical disruption, which are described below. Often this literature has resonances with sociological work looking at other groups of young people. In these studies, participants also speak about 'the future' in ways that reflects the influence of both individual agency and structural conditions, and demonstrates that the idea of future planning can become more emotionally and practically difficult in increasingly precarious situations (Anderson et al., 2005; Bryant & Ellard, 2015; Reiter, 2003).

Sarah Bell and colleagues (2016) have proposed that 'biographical oscillation' best explains how Ménière's disease becomes "one of many" ways that life's trajectories are shifted. This, they argue, avoids giving further cultural power to the idea that illness is uniquely destructive and 'bad' by avoiding the pejorative nature of 'disruption'. Lee Monaghan and Jonathon Gabe (2015) propose the idea of 'biographical contingency' to explain how young peoples' descriptions of the impact of their asthma is dependent on the particular situation they are in when it needs management. Benjamin Saunders (2017) suggests, based on two case studies of young people with inflammatory bowel disease (IBD), that IBD creates 'normal recurrent disruption'. Brenda Poku and Alison Pilnick (2022) show that, in the case of children and young people with sickle cell disease, the 'normal' state of their illness becomes disruptive at points of life-transition – they propose the concepts of 'biographical restriction', 'biographical enactment', 'biographical abandonment', and 'biographical reframing' to more specifically explain how biographies are impacted in these moments. Kate Hunt and colleagues (2024), looking specifically at the experiences of young adults living with long-COVID in the early years (2020-2021) of the COVID-19 pandemic, have recently argued that 'biographical retrogression' may better encapsulate the disruption young people experienced in this time of extreme social and medical uncertainty, given the serious derailment of their developing 'adult' lives.

Reframing illness and disability: activism

Disability rights groups and health movements have contributed greatly to our social, medical, and political understandings of health and disability. Part of the power of this activist work is in its creative and ambitious rethinking of interconnected aspects of society, which Michael Prince explains when outlining the scope of the disability movement's activism:

> "Disability movements pursue an expansive understanding of "the political" – one that includes not only governments, public service bureaucracies, legislatures, and the courts but also families and social networks, voluntary and charitable sectors, mainstream and marginal economies, health sciences, and cultural practices. This means that power relationships throughout the whole of society are amendable to disability activism; normative and empirical debates are ongoing about the respective responsibilities of the state, the market economy, and social enterprises, as well as innumerable kinds of communities and households."
>
> (Prince, 2021)

In many respects, this speaks to feminist arguments surrounding the fact that "the personal is political" (Hanisch, 2000; Shakespeare, 1993), which, as Nancy Isenberg (1998) clarifies, argues that "the public and private are interdependent and defined in relation to each other and neither represents universal nor value-free conditions" (p. 453). Jenny Morris (1992) explicitly called for this feminist recognition to be integrated into disability research, arguing that it is this which allows space for the representation of a subjective reality that, in turn, can "assert the value of our lives" (p. 164).

In doing this, disability activists have helped articulate and communicate critiques of ableism and disablism, including through criticisms of tropes surrounding disability and disabled people. Activists and academics have shown how the personal tragedy model of disability suggests passivity, helplessness, and incompetence, while the biomedical model of disability gives medical establishments and state programs the power to define and control disabled bodies (Prince, 2021). These arguments also inform critiques of sociology's treatment of illness and disability, which will be returned to in the next section.

There is also a long history of activism in relation to illness. The behaviour and achievements of AIDS activists are a clear example of when a group with lived experience and proximity to a specific disease played a key role in shaping and contributing to medical research and practice (Epstein, 1996). Activists concerned with environmental health crises have also frequently been a voice in public debate, with varying levels of success (Brown et al., 2003; Brown & Mikkelsen, 1997; Özkaynak et al., 2021; Szasz, 1994). Health movements concerned specifically with the health of women have critiqued how many aspects of society make women unwell, including over medicalisation (Doyal, 1995), poor medical research and medical misogyny (Bobel, 2010; Morgen, 2002), and limited access to healthcare such as abortion and safe birth experiences (Enright et al., 2020; McReynolds-Pérez, 2016; Shaw, 2013).

Broadly, the foundational claim of social health movements is that embodied experiences such as illness and pain, along with healthcare access and outcomes, are important aspects of life which are shaped by political and social forces. Phil Brown and colleagues (2004) offer a three-group model for categorising these movements. 'Health Access Movements' campaign for equitable access to health services. 'Embodied health movements' (EHM*)* work to achieve medical recognition, research, and treatment, into disease, disability, or health risks such as environmental toxicity. 'Constituency-based health movements' draw attention to and protest inequitable health outcomes based on medical discrimination against various identities, or a (discriminatory) lack of research on relevant health experiences.

In the case of contested, unseen, or 'difficult' illnesses, EHMs are most relevant as they seek to challenge and redefine how the illness is understood and treated (Brown et al., 2004, pp. 54–55). Importantly, there a "blur[ring of] the boundaries between lay and expert forms of knowledge, and between activists and the state" (Brown et al., 2004, p. 54). The demand is not just that expert systems listen to what activists have to say and believe them – the demand is that institutions do work within their own systems of expertise to validate activists' intuitions and then use this to provide specialised assistance. This sense of shared knowledge and experience, and a complicated relationship between medical and state institutions, exists outside of explicitly activist oriented groups (Barker, 2002; Whelan, 2007). Recently, the internet has reshaped this landscape – online illness communities will be returned to later in this chapter.

Reframing illness and disability: academic literature

Disability studies scholars have criticised sociology's treatment and analysis of disability and illness. In various ways, sociology (and particularly the sociology of health and illness, medical sociology, and sociology of the body) has been criticised for essentialising disability, treating it as an individual and private issue, taking the category of disability as 'fact', and having a deeply ingrained treatment of disabled people as 'other' (Hughes, 2009; Oliver, 1996; Shuttleworth & Meekosha, 2012; Thomas, 2007). Sociology should recognise these critiques, and incorporate standing recognition that ableism is a dominant cultural norm, that disability is an axis of inequality and oppression, and that disability and illness are social categories worthy of sociological analysis (Mauldin & Brown, 2021).

These criticisms of sociology are tied in part to the emergence of the social model of disability – a model whose development is in turn tied to the aforementioned disability activist movements (Meekosha & Jakubowicz, 2000; Oliver, 1990; Shakespeare, 1993). The social model of disability argues that disability is the result of social and political structures which ‘disable’ people, and that it is these structures that must be examined, rather than the individual ‘suffering’ and ‘deficit’ which infuses the medical model of disability. The research inspired by this new conceptual foundation focuses on how disabling barriers are constructed and can, in turn, be deconstructed (Oliver, 2009, 2013).

Feminist disability scholars provided early critiques and substantive developments to disability studies (Meekosha & Jakubowicz, 2000). These critiques happened in tandem with the growing critiques of disability rights movements by disabled women, and activist explanations of how gender needed to be incorporated into a politics of disability (Meekosha, 2002). There were two key challenges this literature made to the social model of disability. First, feminist disability scholarship argued that ableism is an example of how society consistently constructs binaries to define what is normal and valuable, such that many of the “same attitudes about the body which contribute to women’s oppression generally also contribute to the social and psychological disablement of people who have physical disabilities” (Wendell, 1989, p. 105). Rosemary Garland-Thomson has an expanded explanation of this:

> “A feminist disability approach fosters complex understandings of the cultural history of the body. By considering the ability/disability system, feminist disability theory goes beyond explicit disability topics [… and] addresses such broad feminist concerns as the unity of the category of woman, the status of the lived body, the politics of appearance, the medicalization of the body, the privilege of normalcy, multiculturalism, sexuality, the social construction of identity, and the commitment to integration. […] Integrating disability clarifies how this aggregate of systems operates together, yet distinctly, to support an imaginary norm and structure the relations that grant power, privilege, and status to that norm.”
>
> (Garland-Thomson, 2002, p. 4)

Second, feminist disability scholars took more seriously the importance of the physical body in shaping experience (French, 1993; Morris, 1992; Wendell, 1996). This area of inquiry also argued for more attention to the ‘unhealthy’ disabled, i.e., those disabled by chronic illness and/or experiencing symptoms that caused serious physical and psychological pain (Crow, 1996; Wendell, 2001). This expansion is instrumental in fostering a radical disability theory which demonstrates the other ways in which disability and illness challenge the normative assumptions society is built on. For example, Charlotte Caron (2008) argues that:

> "Temporarily able-bodied communities have much to learn from those of us who live with chronic illnesses. We gain insights from the diversity of our bodily and mental experiences when we are in communities that allow us to speak the truth about our lives, that enable us to participate fully and freely, and that let us know we are accepted unconditionally. Compassion and solidarity are essential; pity is not helpful. […] In a world that focuses on power, prestige, and acquisition of goods, learning how to live with loss, with chronic illness, and with the results of shaming are needed for healthy and inclusive communities."
>
> (Caron, 2008, p. 27)

Many scholars have since expanded their attention in line with the argument that, while society is disabling, there is also the need to recognise that impairment and struggle are meaningful, personal, embodied phenomena, rather than just the product of particular environments or other ableist structures (Shakespeare & Watson, 2022; Thomas, 2007; Watson, 2012). Critical disability studies now occupies some of this space[4] – as a 'critical' social science, it is invested in recognising the ever-shifting dynamics of the social and cultural, which informs a broader critique of the use of binaries in disability discourse (e.g., disability v impairment, social model v medical model) (Meekosha & Shuttleworth, 2017).

There have been a variety of attempts to establish new conceptual models to incorporate the lived bodily experience of disability into emancipatory research (Bhaskar & Danermark, 2006; Pickard & Rogers, 2012; Shakespeare, 2013; Shakespeare & Watson, 2022; Thomas, 1999a; Watson, 2012). Kafer's articulation of a 'political/relational' model of disability is useful in this regard. She seeks to situate the 'problem' of disability in social, political, and physical structures, while still recognising the grief and discomfort that disability can create for an individual:

> "The problem of disability is solved not through medical intervention or surgical normalization but through social change and political transformation. [… T]he

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[4] Recently, Wilde & Fish (2025) have published an article arguing that, as critical disability studies gains prominence, the formative work of feminist disability theorists is being excluded from its canon.

> political/relational model neither opposes nor valorises medical intervention; […] it recognizes instead that medical representations, diagnoses, and treatments of bodily variation are imbued with ideological biases about what constitutes normalcy and deviance. In doing so, it recognizes the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people."
>
> (Kafer, 2013, p. 6)

In line with this, it is worth noting Nick Watson's (2012) warning that becoming overly attached to a particular theoretical framing around disability diminishes the ability of participants to "contribute fully and actively to the research agenda" and "identify what they see as being the most important" (p. 199). There is also more work to be done in imaginative and genuine co-production for research that concerns issues of health and disability, especially with young people (Brady et al., 2023; Cowan et al., 2022; Peters, 2010)

While this literature is in some ways radical in its reimagining of disability, it is important to note though that sociology and disability studies are still very much focused on the Global North, often disregarding disability experiences in the Global South and amongst First Peoples experiencing the ongoing violence of colonialism (Meekosha, 2011).

An ethics of (self) care

The meaning and practice of care is another important theme to think through when considering how normative assumptions have built up our understanding of bodies. Before turning to the more emancipatory conceptualisations of care and self-care, I will look at how they appear in healthcare's self-management and peer-support literatures.

Since the mid- to late-20th Century there has been an explicit desire in government healthcare policy for greater 'self-management' of chronic illnesses (Franklin et al., 2023; Morgan et a., 2016). At their best, self-management programs are ways to empower people to take control of their own care, developed around the concerns and abilities of patients (Lewis et al., 2022; Lorig & Holman, 2003; Ward, 2015). In reality, many self-management programs contribute to rhetoric around chronically ill people creating their own health issues and then being unable to manage them (Grønning et al., 2013; Lynch et al., 2022). A foundational aim of many pieces of health policy is to increase each person's productivity and decrease their 'cost' to society (Kenny, 2015), and this is reflected in the many self-management programs which are built around a desire to minimise government spending (Aujoulat et al., 2008; Bury, 2010; Franklin et al., 2023; Morgan et al., 2016). In some cases, while self-management programs elevate the ‘expert patient’, they do so in a way that still emphasises biomedical understandings of illness and extends medical power (Davidson, 2005; Wilson, 2001; Wilson et al., 2007).

Relatedly, peer support programs have broad theoretical support largely because they align with the frequently stated objective of encouraging the self-management of conditions (Hossain et al., 2021). Peer support programs in health care can offer three broad sources of assistance: emotional support, information, and affirmation (Dennis, 2003). For children, adolescents, and young adults living with chronic illnesses or health conditions, preliminary research has demonstrated the promise of online and in-person peer support, mentorship, and rehabilitation camps (Anthony et al., 2020; Hill et al., 2024; Kohut et al., 2017; Wedege et al., 2024). The research, however, is limited (Dave et al., 2024; Kaufman et al., 2022; Kulandaivelu et al., 2021), and the peer-support programs discussed in this medical literature are very much based in, and oriented towards, their healthcare settings and the general ‘concerns’ health professionals may have for young people in these situations. That is not, however, an inherent issue with peer support and mentorship, which has the potential to create important social networks and affirm the importance of living, expert knowledge (Hayes & Balcazar, 2009).

Likewise, the realities of self-management do not mean that it does not contain actual, or potential, empowering aspects. In particular, recognising the *work* of self-management is an important way to validate and support the many ways that illness and disability impose themselves on one’s time and energy (Cooper et al., 2023; Corbin & Strauss, 1985, 1988; Mattingly et al., 2011; Spray et al., 2021). The emotional and physical tasks involved in living with chronic illness and disability ought be recognised as work both when assessed by policy and welfare schemes and when viewed by others in more social contexts. The insights people gain from a life managing illness and disability are the product of expertise and work, and self-management programs could play an important role in sharing these ideas in political, cultural, and healthcare discussions.

More fundamentally though, the history of political self-care and self-help demonstrates its transformative potential. For some, including, often, those with chronic illnesses, it is radical to survive – never mind thrive – in systems that do not take one’s worth, potential, or care seriously (Ahmed, 2014; Sheppard, 2020). As Audre Lorde declared: “caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare” (Lorde, 1988, p. 205).

Specifically in relation to health, educating populations to care for their own bodies outside of the medical establishment is a site for activist work. Self-help groups in the 1960s to 1980s sought to democratise medical knowledge, and create bodily knowledges based on lived experience, so that people could have greater control over their lives (Ward, 2015). The Boston Women's Health Book Collective's, *Our Bodies Ourselves*, offers an excellent example of this. As they explain in their original preface:

> "For us, body education is core education. Our bodies are the physical bases from which we move out into the world; ignorance, uncertainty – even, at worst, shame – about our physical selves create in us an alienation from ourselves that keeps us from being the whole people that we could be."
>
> (Diskin & Sanford, 1973, p. 3)

In 1978, this was added to the concluding remarks of the British edition:

> "Self-help is a political act. It is deeply challenging to the existing health care system. Through sharing our knowledge collectively we have developed skills – we, not only the 'professionals', will know what is done to us medically [and] why it is done. We do not take the place of the doctor, but we do reverse the patriarchal-authority-doctor-over-'patient' roles."
>
> (Phillips and Rakusen, found in: Ward, 2015, p. 48)

Another important aspect of conceptualising health management in an empowering way is to reimagine the meaning of care more broadly (McLaughlin, 2020). Literature in this area comes from those seeking to appreciate the role of care in society – a task which can be undertaken while still recognising the way that structures of care can be oppressive to both those expected to care and those who are 'cared' for (Held, 2005; Kittay & Feder, 2002; Shakespeare, 2000). Stepping back from the policy questions which surround this, the philosophical departure point from models which emphasise autonomy is explained in Selma Sevenhuijsen's (1998) feminist re-evaluation of care:

> "The ideal of abstract autonomy in fact overlooks what it is that makes care an element of the human condition, i.e., the recognition that all people are vulnerable, dependent

> and finite, and that we all have to find ways of dealing with this our daily existence and in the values which guide our individual and collective behaviour."
>
> (Sevenhuijsen, 1998, pp. 28–29)

Understood with this lens, the experience of chronic illness offers a focus point for how we might – or indeed, the ways we must – reimagine a world that understands bodies on their own terms, rather than in reference to a constructed ideal. This reimagining could take seriously the fragility and vulnerability of bodies and lives (Brown et al., 2017; Mackenzie et al., 2013), while also recognising the power and work of caring for oneself and caring for others (Ecclestone, 2017; Held, 2005; Shakespeare, 2000). An expansive approach to care is beneficial for other reasons, too: when living with chronic illness, there are a multitude of ways in which people seek support and feel supported, and recognising the interwoven roles of organisations, loved-ones, healthcare professionals, online figures, and non-human support helps establish functional and robust networks of informational, emotional, and practical assistance (Virole et al., 2024). This helps promote the understanding that struggles that emerge from living with chronic illness, such as loneliness, should not be seen as issues that are dealt with only at an individual level (Cheung et al., 2024) – it requires a reconceptualisation of connectedness and care.

Online illness communities

These experiences of solidarity between those with shared illness experiences have been expanded and re-shaped by the rapid changes surrounding the internet and social media. The internet has allowed illness to transition from a largely private experience to an experience that can be talked about (more) publicly (Barker, 2008; Conrad & Stults, 2010). Further, in the case of gender and disability – and particularly at their intersection – online environments can provide a more accessible and safer environment to speak, locate oneself in a community, and develop a collective identity (Meekosha, 2002).

One way that scholars have conceptualised this technologically-mediated environment is to argue that that online spaces, such as forums, chat rooms, or other social media channels and accounts, allow for the creation of subcultures or 'worlds' around particular conditions or illness experiences (Ginsburg & Rapp, 2013; Gonzalez-Polledo, 2016; Gonzalez-Polledo et al., 2020). These communities can provide a space where illness experiences may be talked about and treated with care, and this sense of safety is furthered by the fact they are structured around a shared, relatable experience, and can be accessed privately and anonymously (Ask & Abidin, 2018; Broom, 2005; Gibson & Trnka, 2020; Hendry, 2020; Tsai et al., 2018).

Further, these spaces provide an opportunity for members to share and collate different types of knowledge – knowledge which often has at least a tie to experiential 'lay' knowledge (Gunnarsson & Wemrell, 2023). Some exchanges offer support and advice for navigating medical systems and diagnostic processes (Akrich, 2010; Barker, 2008; Foster, 2016). There are also cases where the information shared is about recent medical research, and self-experimentation, which often reflects the community's belief that treating doctors may not be across the newest medical findings (Kempner & Bailey, 2019; Mazanderani et al., 2013). Similarly, there are information exchanges which seek to build self-management strategies for conditions and help improve the medical literacy of patients and carers (Lupton, 2013; Maslen & Lupton, 2019; Schaffer et al., 2008; van Berkel et al., 2015). In addition, information can relate to political activism that may, for example, seek to change clinical guidelines (Lian & Nettleton, 2015).

Together, this leads to what Barker and Galrdi (2011) describe as a way of knowing through connectivity, which they define as "an experiential connection to illness and a virtual connection to others who share that illness" which "enhance[s] the moral authority of lay claims" (p. 1351). In many ways, this is a fundamental reshaping of activism, and the blend of 'lay' and 'expert' knowledge in these online places not only impacts activist demands, but also shifts the way in which economic actors can relate to patient communities (Barker, 2011; Peterson et al., 2019).

It is important to note here that what is 'lay' knowledge and what is 'expert' knowledge is not always easy to define (Williams & Popay, 2001). Lay knowledge comes from simply another form of expertise, and expert knowledge also fundamentally resides in people who have their own experiences and thought processes. Gareth Williams and Jennie Popay (2001) suggest that a more useful model for looking at different knowledges is to ask the extent to which a new system of beliefs or knowledges arises from "movements of opposition" which "[provide] new ways of thinking about problems whose definition is conventionally dominated by professional experts" (p. 37). In the case of illness or disability support groups then, the communication between group members not only gives them space to speak about their experiences and feel "affirmed" in their own identities, but also contributes to a broader set of social movements which seek to "[defend] certain parts of the lifeworld from colonization by an expert system" (Kelleher, 2001, p. 138).

This theorising around internet support groups is enhanced by specific attention to social media interactions and communities. Online spaces shape what people's networks and publics look like (boyd, 2008), and the overwhelming majority of people now live in an ecosystem where digital media technologies are intractably woven into the social, cultural, and practical make-up of their worlds (Horst et al., 2009). In this respect, online to offline is not a binary, but rather, a continuum (Nelson et al., 2020). Individuals rarely engage with only one social media platform or internet page, and a polymedia approach to internet and media usage recognises that media technologies exist as an "integrated structure" of affordances that allows media literate people to move between available technologies frequently and easily (Madianou & Miller, 2012, p. 170). For example, someone seeking privacy and anonymity might be drawn towards a platform like Tumblr (Byron et al., 2019), compared to a site like Facebook which has a 'default publicness' that can make identity exploration on the platform challenging (Cho, 2018). This polymedia perspective is a useful addition to previous research on internet usage for health information. In particular, it helps explain the potential tension between theories surrounding identity and 'world' building social media groups (e.g., Gonzalez-Polledo, 2016), and everyday health seeking information that may be engaged with through a filter of what is 'sensible' and 'quality' information (e.g., Nettleton et al., 2004, 2005).

Zizi Papacharissi (2020) suggests that social media spaces can be conceived of as 'affective publics' based around *connective* rather than *collective* gestures, and that it is this connection which demonstrates to those online the presence of under-represented viewpoints. Therefore, rather than expecting social media usage to cause clear, definable responses, affect theory looks at the more subtle ways that individuals perceive online posts, and may consequently have their own selves shaped. This conceptual focus on affordances and affect leads to important theories on the varying roles of social media, and on the particular forms of digital intimacy present in different online spaces (Lomanowska & Guitton, 2016).

Paul Byron (2021) proposes the concept of 'digital cultures of care' to represent the environment in which digital friendship emerges as an affective practice that challenges traditional definitions of friends, peers, and strangers. Another affordance of social media is that "everyday activism", which describes the deliberate sharing of personal stories to challenge the status quo through visibility and, consequently, reshape social norms (Calhoun, 2020; Vivienne, 2016). Recently, closer attention to how social media users relate to 'activist' influencers – which exist for chronic illness and disability (Cocq & Ljuslinder, 2020; Ginsburg & Rapp, 2013; Gonzalez-Polledo, 2018) – has demonstrated the complex understandings many have of the multifaceted identities and priorities of online personalities and movements (Kanai, 2021; Kanai & Coffey, 2023; Kanai & Zeng, 2024).

The connections between these technological affordances and communities to both individual and group identity are complex (Buckingham, 2008), but an important way forward is to focus on young people themselves, rather than only on the particulars of technology. This means using person-centred methodologies to understand interactions between youth, technology, media, and identity (Herring, 2008). Chapter Seven will examine the variety of ways in which participants engaged with varied forms of online information and communities relating to chronic illness. Allowing participants' accounts of technology to arise naturally within interviews about their broader experience of chronic illness reveals the extent to which technology is thoroughly integrated into all aspects of their lives. Understanding technology and social media as a component of the illness experience, rather than viewing the online world as a separate area of inquiry, is crucial when examining the potentials and pitfalls of these worlds.

Conclusion

Descriptive and theoretical frameworks of illness experiences are important. They can help healthcare professionals understand, emotionally, what their patients might be going through; they can help family and friends intuit how best to show care for someone who is ill; and they can help people who are ill organise their experiences and understand that they are not alone.

This thesis is built on a body of work which has revealed that chronic illness instigates a plethora of complex emotions, interactions, and narratives. It is inspired not only by sociological literature which examines the structure and cause of these relational and emotional experiences, but also by work from disciplines such as history, philosophy, and disability studies which helps contextualise and politicise these experiences. In thinking about the ever-evolving digital world, and the world of youth, sociology also provides useful frameworks for exploring my participants' experiences of illness.

This thesis contributes to several gaps in the existing literature. First, as explained in greater details in the next chapter on methods, having a participant cohort with varied conditions allows for a discussion of illness experiences that arise from living with *chronic illness*, rather than the specificities of disease. Second, it combines with this a broad interest in *youth* as a multifaceted and extended experience, and in particular, an interest in the period of time where one ‘grows up’ or ‘becomes an adult’. Third, it looks beyond the experiences of illness which participants are expected to describe explicitly, and places illness in the broader context of a life being lived.

I look closely at the ways in which participants negotiated their language around illness in interviews, and use this to discuss, first, how the political and cultural narratives around illness impact individuals at the centre of them, and second, what those individuals believe needs to change. In this sense, this thesis not only looks at explicit experiences of illness that are ‘shared’ by many, but also examines what shared social, cultural, and political narratives impact the many different experiences of illness.

CHAPTER THREE | methods

Methodological considerations

Recruitment for interviews

Following ethics approval from the University of Sydney Ethics Committee [HREC 2022/521], flyers were circulated both in-person and online. In total, I conducted 33 semi-structured interviews with young adults who live in Australia with one or more chronic physical illnesses. Eighteen participants were recruited through physical flyers in community settings, four participants through physical flyers in a specialist's waiting room, seven through an advertisement on 'research' pages of relevant organisations' websites, one through a social media post, and three from having the flyer passed on to them by a non-participant.

Recruitment materials stated that participants needed to be born from 1994 to 2004 (inclusive) – this meant that, theoretically, participants could have been aged between 18 and 30 years-old throughout data collection. This age range reflects the "destandardisation" of the life course (Brannen & Nilsen, 2002), and in particular the increasingly prolonged period of 'youth' in post-industrial economies where, for some, more time is spent in higher-education, and, for all, it can take longer to become financially stable and independent (Bynner, 2005; Reiter, 2003; Woodman & Wyn, 2015). This was particularly relevant to consider for this project because chronic illness has the potential to be another 'disruption' in the life course.

The flyers stated that "you do not need a formal diagnosis to participate in this study", and that "if you have had your life impacted by persistent health difficulties for more than 6 months, and you feel that these difficulties are part of a unified 'condition', we want to hear from you." The flyer additionally specified an interest in conditions "that often go unrecognised by others, such as so called 'invisible' illnesses." Recruitment materials listed a range of potential conditions as illustrative, not as instructive.

I chose to keep the inclusion criteria broad most simply because the social construction of illness affects people with a range of conditions. I was also aware that many people with a variety of conditions see themselves as part of a broader community (Swoboda, 2008), and it seemed reasonable to recognise this when constructing a participant cohort. In this sense, I "relied upon the participants' own construction of chronic illness and the way it impacted upon their lives" (Kralik et al., 2010, p. 199). Reference to a "unified condition" was intended to speak to the feeling many have pre-diagnosis – the feeling that something is wrong, and that their health difficulties are in some way connected, but that they do not (yet) have an official name to put it to it (Nettleton, 2006).

I additionally did not want to exclude people who had stopped seeking a diagnosis due to factors such as financial strain, bad experiences with medical professionals, or other frustrations. I felt this was especially important given that people at the intersection of overlapping forms of marginalisation (e.g., due to racial or ethnic background, gender, or social class) may be most likely to experience forms of discrimination or judgement in medical settings which cause them to struggle to receive a diagnosis and/or attempt to avoid clinical encounters (Mullard et al., 2024; Sebring, 2021).

Previous research has contextualised that this experience of being 'undiagnosed' can be a liminal one where it is unclear who is able and willing to help (Nettleton et al., 2004). This was a dynamic that I did not want to emulate by suggesting that my research was not for people without a diagnosis. I also hypothesised that the experiences of people who do not have their physical symptoms explained by a diagnosis would have instructive similarities and differences with the experiences of those who do, and wished to affirm that the boundary between people who have diagnosed and undiagnosed conditions is unstable (Mollow, 2014).

Four participants had not received a diagnosis for their symptoms at the time they registered their interest in the study. Others had a diagnosis which explained some of their symptoms but not others. In all these cases participants reflected on the surprise and joy they felt in seeing that their situation was of interest to researchers.

By listening to the accounts and reflections of people with a wide variety of chronic illnesses, this thesis can look beyond traditional categorisation of illness experiences and instead begin to examine the tensions and possibilities which arise in the grey areas of illness and medicine. This complements previous research that has looked to symptomatic experiences rather than diagnostic groupings to think about what specific physical and emotional experiences within illness impact one's life and identity (Cluley et al., 2021).

This structure was useful for seeing what happens beyond discrete diagnostic categories, but there are particularities which are missed in a broad study such as this one – even in this sample it was clear that, in some cases, there are important shared experiences of people who do have the same diagnosis, or alternatively, of people who sit together in some other category such as gender, race, migration history, or social class.

Ethics

Potential participants could either fill out an online form with their contact details, or email me directly. Once a participant expressed interest I would email them a copy of the Participant Information Statement (PIS) and the Participant Consent Form (PCF) so they could look over it in their own time and ask any questions. If the participant still wished to participate, a time for the interview was organised to maximise convenience of the interviewee. When in person, the PCF was printed and signed before commencing the interview, while participants returned a soft-copy before online interviews. Both the PIS and PCF were written in accessible language so that they were easy to understand. All participants were given the opportunity to ask any further questions about the study and their role in it before signing the PCF. Participants were also reminded that they could end the interview at any time, did not have to answer any questions they did not want to, and could withdraw their interview from the study up until the point data was submitted for publication or the PhD was submitted. The PIS and PCF contained my contact details so they could contact me with further questions or to withdraw. All participants were told that they could review their transcript if they wished, and one participant did so. The PCF also had a section for participants to elect if they would like to be informed about the findings of this study, and if they would like to be contacted about future studies. I was unable to offer a monetary incentive to participate in this study.

Data collection

Interviews were conducted either face-to-face (19) or via video call (14) between March 2023 and February 2024. They lasted between 53 and 110 minutes, and were audio recorded, fully transcribed, and de-identified.

Interview were structured around three themes: experiences of health and illness; care; and relationships. These themes were explored in interviews with a particular focus on how they intersected with participants' youth. The interviews began with a discussion of the participant's current health concerns or management strategies ("How is your health at the moment?"), which was used as a foundation for discussion about how that came to be, and how they thought about their futures. Experiences of the internet and social media were discussed throughout these themes, to reflect their integration in everyday life (Gray, 2009; Herring, 2008).

My goal as the interviewer was to provide a safe and open environment for participants to share their experiences. Space was given for participants to tell stories that were meaningful to them, and for them to construct their experiences through narrative. This was important given that narratives can be a powerful way for many to strengthen their sense of self when dismissed, attacked, or trapped by prevailing narratives (Thomas, 1999b). Open-ended questions were used to assume as little as possible about the life, experiences, and feelings of the individual being interviewed (Charmaz, 1990). I also encouraged participants to reflect in their interviews on what were the 'most important' elements of what they were saying (Watson, 2012).

Participant overview

Participants were aged 19-29 years-old, with an average age of 23 years-old. Nine participants identified as cis-men, one as a non-cis man, and 23 as cis-women. Seven participants had gone to either primary or high school outside of Australia, eight had grown up and/or currently lived outside a metropolitan area, and nine were people of colour. Three participants identified across multiple different illness groups – this is reflected in Table One, where the total number of participants appears higher than the 33 interviewees.

Due to the diverse range of conditions, care had to be taken to anonymise the stories and words of participants, while also recognising the particularities of each condition. Some participants lived with rare conditions and/or very particular constellations of conditions, symptoms, and histories. There are also some situations where very few participants living with a particular condition were interviewed. This is why the number of participants with certain conditions are reported in groups.

The data excerpts that appear in this thesis are accompanied by a pseudonym, age bracket, gender identity (male or female), and an illness description. In some cases, where participants had multiple illnesses, I looked to how participants described their own condition(s) and decided upon a representative but not exhaustive example or range for their condition(s). Where participants did not have a diagnosis when they were interviewed, I list some of the symptoms they reported themselves as most concerned about. I have chosen to convey information in this way in order to maintain a careful balance between useful contextual information and the need to preserve anonymity.

As conditions appear for the first time in the results chapters, I give a brief overview in a footnote of what the condition is and its symptoms. These descriptions intentionally do not describe the specifics of what participants experienced, but hopefully give some indication of what people with that condition may manage and be concerned about. A common discussion in interviews was lack of knowledge about chronic conditions, so I wanted to ensure that any reader was approaching participants' experiences with a frank depiction of what particular conditions entail.

Table One: overview of the chronic illnesses participants lived with

Group	Conditions of participants	Number of participants
Reproductive conditions	Adenomyosis Endometriosis Polycystic ovary syndrome (PCOS) Premature ovarian insufficiency (POI)	7
Neurological conditions	Brain injuries, vestibular issues, and chronic migraines Epilepsy Neuroendocrine conditions Neuroimmune conditions	7
Fatigue, pain, and autonomic conditions	Autoimmune arthritis Chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME) Fibromyalgia Hypermobile Ehlers-Danlos syndrome (hEDS) Hypothyroidism Mast cell activation syndrome (MCAS) Medically unexplained fatigue, pain, malaise, and autonomic disturbance Postural orthostatic tachycardia syndrome (POTS)	16
Other autoimmune conditions	Autoimmune skin conditions Inflammatory bowel disease (IBD) Type 1 diabetes	9

Analysis

Data collection and analysis were conducted concurrently. I went into interviews having read widely on different concepts and ideas in the health, illness, and disability space. These concepts are essential to seeing how the experiences of participants are connected, and assist in creating analytical arguments that help researchers understand the experiences of those who are not participants (Broom, 2021). Throughout the project I would return to the literature to revisit which theoretical tools could be useful for explaining and representing the themes identified (Ezzy, 2002). That said, I did not go in with a belief in what the most important aspects of this research would be, and constructivist grounded theory informed how I conducted and analysed interviews (Charmaz, 1990; Charmaz & Belgrave, 2012). I sought to take seriously the personal and individual struggles of my participants, while also recognising the social structures and institutions which were shaping their lives (Bhaskar & Danermark, 2006; Shakespeare & Watson, 2022).

The first step of analysis was to (re)familiarise myself with the transcripts by "mapping out" the social, relational, and discursive elements of each interview (Clarke, 2003; Clarke & Friese, 2007). This involved writing memos which outlined the ideas that had come up in each interview, described how those ideas were connected, and considered why they might be important for conceptual frameworks of chronic illness.

When writing these memos, I looked at not only what participants said, but also the questions I asked, ensuring that my notes covered how the interview progressed and how meaning was constructed in conversation (Charmaz & Belgrave, 2012; Gubrium & Holstein, 2012; Rapley, 2001). Relatedly, I was also conscious of "sites of silence" in the conversation, in recognition that what is not discussed can speak to the discourse that does (not) surround chronic illness (Clarke, 2003, p. 561).

Guided by these memos, I then developed descriptive categories to represent the themes present in interviews. It was then within these descriptive categories that I analysed the data in order to develop theoretical ideas and concepts that could form a conceptual basis for this thesis and for its individual chapters.

In all analytical steps, care was taken to maintain the richness of and complexities of participants' experiences, which included attending to and highlighting atypical cases and contradictions which arose both between, and within, interviews (Charmaz, 1990; Clarke, 2003). It was also fruitful to analyse how participant stories melded with, or fractured against, dominant discourses around illness – this allowed me to analyse how those subject to these controlling discourses are impacted by them, use them, and react against them (Hacking, 2004). Many interviews involved some form of traumatic testimony, so I also took care to look closely at elements of interviews that did not conform to narrative expectations, given that ambiguous, overwhelming, and difficult to describe emotions and beliefs can be lost when the expectation of a narrative is applied to personal recounts and reflections on trauma (Andrews, 2010).

Reflexivity

At its broadest, the reflexivity of a researcher refers to their reflections on how they, as an individual and as part of a research institution, are impacting the conduct, findings, and communication of their studies. Linda Finlay (2012) gives five specific sub-types of reflexivity, drawing attention to how reflexivity is needed, to varying extents, depending on the specific projects. The five aspects she outlines for consideration are: how methodologies were selected; the social and cultural environment of the researcher and research; the researcher's embodied experience; the relationships between the researched and the researcher; and the ethical implications of the power dynamics of research. These are all interconnected.

My methodological choices were informed by a critical sociological lens which uses in-depth interviews to centre the lived experiences of participants. I approach illness as both an embodied and socially mediated experience, which can be messy, unstable, and complex (Clarke, 2003; Law, 2004). The interviewer always has a role in what is said in the interview (Clarke, 2003; Rapley, 2001), and for me my desire to hold space for the complexity of illness experiences influenced the way I conducted interviews. As outlined in my data collection section, my goal was to create a space where participants felt safe sharing the stories they cared about, and comfortable sitting with feelings that might be difficult to express or in some way contradictory. I wanted to work with participants to understand their experiences, and evaluate what elements of their life were potentially important and instructive for developing a better understanding of the experience of chronic illness when young.

That said, there is a power-imbalance of interviews, and an inherent inequality that cannot be eliminated: the researcher defines the project and the researcher communicates the projects findings. In my case, I had (and have) the social and educational privilege of existing in an academic world, which brings with it respect and social standing (Harding & Norberg, 2005). This power imbalance was palpable in my interviews – many participants sought to clarify if what they were saying was "useful", and some apologised when they, for example, swore.

My own personal experiences inform my relationship with this project and participants, all of which influenced the study. All researchers bring their own perspectives to interviews and data analysis, which Frank suggests researchers embrace, especially where it generates a research project that "reflects one's own unique experiences and asserts membership in a community of those who understand shared experiences in mutually supportive ways" (Frank, 2000, p. 356). Frank emphasises that these standpoints are "not optional" (p. 356), since those who do not share a common experience with those they research necessarily have a standpoint of the other – a standpoint which also needs to be reflexively examined.

Autobiography and autoethnography are an established way of exploring the experience of illness (Nordmarken, 2020; Stanley, 1993; Taylor & Ridgway, 2024). They are not, however, methods of this thesis. There is though an autobiographical genesis to this research:

my interest in this project cannot be disentangled from my own experiences with chronic illness, and the framing of this research arose initially from my personal reflections on the complexities, and potentials, of navigating a poorly understood and fluctuating illness. This thesis is deeply concerned with how the self is understood, how the events of our life are described, and how people claim access to certain knowledges. These are questions I cannot distance myself from.

Practically, having lived experience of chronic and contested illness potentially helped build relationships with participants, in particular because it offered access to certain types of embodied knowledge that could aid in talking freely and easily in interviews (Whelan, 2007). That said, my own experiences of illness involve significant levels of luck and privilege, and I did not begin this research expecting my experiences to be representative of others'. Indeed, living with illness, I think, can help attune one to the deeply personal and contingent nature of embodied health difficulties, social interactions, clinical encounters, and struggles with institutions. Rather than look only at 'shared experiences', I instead seek to ask what shared norms impact our diverse experiences of illness, and what cultural shifts would better accommodate the various realities which many people face.

I did not share my own experiences unprompted in interviews – I was concerned that it might discourage participants sharing what they had been through by implying that I already knew about what they were saying. Towards the end of interviews I always asked participants if they had any questions for me. It was at this point that some asked about why I was interested in the topic or, more explicitly, what my connection with chronic illness was. When this happened, I did speak freely and vulnerably about what had led me to this topic.

My ethical commitments

My methodological choices are bound up in my ethical commitments as a researcher, and it was (and is) of upmost importance to me that I practice an ethics of care in interviews and analysis (Bochner, 2001; Frank, 1995, 2000; Kleinman, 1988; Mishler, 2005; Thomas, 2010). I encouraged participants to offer their own reflections and analysis on what was important to understand about their experiences, and what was important to research, and I am committed to respecting and conveying these elements of the interviews in my writing (Brannelly & Barnes, 2022; Watson, 2012).

I have deliberately constructed my research so that it does not replicate deficit models of illness and disability (Oliver, 1996; Thomas, 2010) that reproduce images of sick and disabled people (particularly children) as passive, dependent, and defined by their conditions (Priestly, 1998). Deficit models recount the ways in which certain identities or experiences detract from someone's life, and have been well documented and critiqued in disability research for the ways in which they encourage pity and infantilising care, do not recognise the individuality and potential of those being spoken about (and for), and do not sufficiently recognise the role of structural ableism in causing pain. Instead, more emancipatory research methodologies would have at their centre the desire and aim to work against oppressive systems and stories (Oliver, 1992).

I have also sought to avoid research that is "damage centred", which Eve Tuck (2009) defines in an open letter to those who researched Indigenous communities across the globe as research that relies on the documentation of "pain and loss" (p. 413) to argue for change. This is homogenising, and creates "feelings of being overresearched yet, ironically, made invisible" (p. 411-412).

To move away from both models there needs to be attention to the ways in which individual experience is socially mediated in a variety of complex ways. More than this though, Tuck (2009) advocates for a "desire-based framework", which would motivate research that was "concerned with understanding complexity, contradiction, and the self-determination of lived lives" (p. 416).

I was also inspired by a broader ethics of 'witnessing' in qualitative research. Witnessing can work as an antidote to the extractivist methods and reading practices which can be taught and encouraged in many academic circles (Liboiron, 2021; Smith, 2021). Further, witnessing is a powerful tool for comprehension, especially when the experiences that are being witnessed exist outside of established vocabularies and understandings. As Sarah Hunt (2018) explains in relation to witnessing methodologies in contexts where there is violence and ongoing colonial trauma:

> "Witnessing, then, might be understood as a methodology in which we are obligated, through a set of relational responsibilities, to ensure frameworks of representation allow for the lives that we have witnessed to be made visible. […] As witness, our role is not to take up the voice or story we have witnessed, nor to change the story, but to ensure the truths of the acts can be comprehended, honoured, and validated. […] At its heart, witnessing is about the persistent reintegration of voices of people who have been

> pushed to the periphery in processes of knowledge creation. It is about making visible and audible those members of our communities who are being silenced, forgotten, erased, and spoken over."
>
> (Hunt, 2018, pp. 284, 292–293)

Further, as Carol Thomas (2010) explains in relation to illness and disability, standing witness is different to feeling pity and sentimentality towards participants, which are reactions that are rarely appreciated by those living with chronic illness (p. 657). My commitment therefore is not only to listening, but also to thinking about how this research can improve the lives of those living with chronic illness.

CHAPTER FOUR | seeking and receiving care

Introduction

This chapter is about instances where participants did not receive the care they needed for their chronic illness. As outlined in the Introduction, rates of chronic illness in young people are believed to be significantly underreported (Bradford et al., 2015; Chapron et al., 2019; Joyce & Jeske, 2020; Sommer et al., 2023). While some specific diagnostic barriers are outlined in this literature, the scale and variety of these problems across illness experiences and contexts has not been comprehensively outlined.

For many participants, initial symptoms were not recognised as indicators of a physical illness, and the first section of the results explores why it was difficult for the emergence of a chronic illness to be recognised by family, teachers, and doctors. The second section examines how, even after diagnosis, there were continued failures from healthcare institutions and practitioners to provide adequate care, and ongoing barriers for participants when seeking financial help or other accommodations.

Many of the themes in this chapter recur throughout the thesis – all the results chapters look in detail at the different and specific ways that the experience of chronic illness when young is not well understood, and how this can make it difficult for young people to feel (and be) seen, heard, and cared for. This chapter outlines and examines the more acute instances where bids for care and medical attention were rejected, dismissed, or stifled.

Many participants emphasised in interviews that these experiences were deeply significant to them. Participants reported strong feelings of anger, frustration, and disappointment at the ways they had been denied care – sometimes those feelings were present early in their illness journey, but often they had developed only with hindsight. It is important to continue to draw attention to how widespread these issues are, and this chapter represents experiences that all the people I spoke with had endured at some point. Resoundingly, participants explicitly wanted these struggles to be shared, and therefore highlighting these experiences is a crucial component of ethical research practice (Brannelly & Barnes, 2022; Thomas, 2010). I have written this chapter with the hope that it makes visible the difficulties my participants have faced in their lives, validates them, and reintegrates their voices into our understanding of clinical care, chronic illness, and the experiences of young people (Hunt, 2018).

Background[5]

This chapter seeks to expose the multidimensional problems young people face when seeking medical care. It therefore builds on recent literature that explores the various ways that healthcare can fail patients, particularly when they are young and/or chronically ill. One way to examine these experiences is by focusing on the contestations that surround diagnostic definitions and medical care, and how this in turn leads to emotionally turbulent illness experiences (Barker, 2002; Broom et al., 2015; Bülow, 2008; Donoghue & Siegel, 1992; Dumit, 2006; Madden & Sim, 2006; Moss & Teghtsoonian, 2008; Nettleton, 2006; Overend, 2014; Zajacova et al., 2021). More recently, epistemic injustice (Fricker, 2007) has proved a useful lens for revealing the ways in which clinical encounters can silence patients as knowers, most often by dismissing the descriptions they give of their symptoms and needs (Carel & Kidd, 2014; Halverson et al., 2023; Heggen & Berg, 2021; Kidd & Carel, 2017; Mladenov & Dimitrova, 2023; Sebring, 2021). There is also existing literature on why healthcare settings may be poorly structured in relation to chronic and complex illnesses (Album & Westin, 2008; Boulton, 2019; Harsh et al., 2016; Nettleton, 2006; Overend, 2014; Yon et al., 2015).

Some recent research has looked at specific instances where it is difficult to quickly diagnose chronic illness in young people (Bradford et al., 2015; Sommer et al., 2023; Wild et al., 2024). More broadly, literature suggests that often what prompts people to recognise the emergence of illness is a newly unpredictable, ‘limiting’, and vulnerable body (Carel, 2016; Hay, 2008; Toombs, 1992) – this ‘emergence’ may be far less obvious to children and adolescents. Existing literature also demonstrates how, in general, children are not listened to and, relatedly, struggle to communicate their problems (Baumtrog & Peach, 2019; Burroughs & Tollesfen, 2016; Carel & Györffy, 2014; Carolin & Milner, 1999; Greenblatt et al., 2024; Heritage, 2009). Literature on the persistent negative judgements about the honesty and capability of children, adolescents, and young adults (Baumtrog & Peach, 2019; Coffey et al., 2016; Murris, 2013; Pickard, 2014; Protzko & Schooler, 2019) also helps us understand the ways in which institutions, and those representing them, may often dismiss young people’s testimony.

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[5] More detail on the literature summarised in this section can be found in Chapter Two, pages 18-28 and 33-35.

Results

Anything but chronic illness

For over three-quarters of participants in this study, symptoms of chronic illness emerged before they turned 18-years-old. There were some participants who had been diagnosed shortly after their physical condition began to change, but more often participants could only recognise the signs of illness with hindsight, after receiving an official diagnosis as a (young) adult. Many participants therefore had stories of how they, as a child, had struggled to communicate with adults what was going on in their body and mind when they became unwell. The challenge was two-fold: they had lacked an understanding of what was normal, and they had lacked the vocabulary to express how their experiences were deviating from that expected norm. These communication challenges existed in a context where adults were not expecting to see chronic illness in a young person, and therefore a third challenge arose when their words and actions were misinterpreted.

This was the case for John, who, now in his late-twenties, had likely lived with a neuroimmune condition[6] for over a decade before getting diagnosed. Despite experiencing serious physical and psychological symptoms, he had not been directed towards any tests that could have led to the diagnosis of a physical illness. He wished that, in the future, people would understand that "when you are a kid, you don't know what's normal," and that consequently there needed to be "much more awareness and attention to the fact that they [kids] can't tell you what's going on." John underwent many years of psychological and psychiatric care before having his condition discovered, and his diagnosis came from a series of routine tests unrelated to his serious and ongoing physical and psychological symptoms.

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[6] Neuroimmune conditions are a collection of diseases where the immune system attacks the brain, spinal cord, and/or nerves. Common neuroimmune symptoms include fatigue, chronic pain, vision impairment, muscle weakness (culminating potentially in paralysis and loss of speech), bladder and bowel dysfunction, and cognitive impairment. Two examples of neuroimmune diseases are multiple sclerosis and Guillain-Barré syndrome.

Jack, who had only recently been diagnosed with CFS/ME[7] in his mid-twenties, had begun experiencing debilitating fatigue and brain fog during high school. While adults recognised something was wrong, they offered help "aimlessly," since, as he recounted:

> "I really didn't know what was going on, and they didn't know what was going on. They can see things, and I can try and say things, but nobody really knows what's happening."
>
> (Jack, 21-25, male, CFS/ME)

For both John and Jack there were some attempts to provide care, but they were ultimately misguided. Experiences like these led John, Jack, and others to believe that more care should have been taken to see if their changed physical and mental condition was the result of a physical illness.

There were other instances though where the issue was that adults were dismissive of the symptoms all together:

> "I'd cop a lot of flak for not only arriving late to school or class, but also for not keeping up with homework and struggling to focus or understand the instructions that were given to me to do. I can remember a few times that they went off at me and described me as difficult, a problem child, a bad person, careless. I was sent to the principal's office a few times, lectured, things like that. And all along I was really struggling."
>
> (Stacey, 22-25, female, CFS/ME)

> "I always grew up with aches and pains. But it would always be something else, like, 'oh you're not stretching enough,' or, 'oh you shouldn't be sitting like that.' So I guess it really got internalised that I'm making it all up, or that it's not so bad."
>
> (Susan, 22-25, female, fibromyalgia[8])

---

[7] Chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME) is characterised primarily by serious fatigue, unrefreshing sleep, post-exertional malaise, and brain fog. It often comes with additional symptoms such as chronic pain, muscle weakness, sore throat, and gastrointestinal issues.

[8] Fibromyalgia is a chronic pain disorder that causes widespread pain and tenderness throughout the body, along with other systemic symptoms such as fatigue, brain fog, malaise, and trouble sleeping.

Theoretically, the suggestions given to Susan could have been helpful for another person – stretching and different postures can alleviate pain. But these were not suggestions that, when ultimately unhelpful, made way for the recognition that a young child was experiencing chronic pain. Instead, when the suggestions did not work the conclusion that Susan was encouraged to make, and did make, was that she was in some way "making it all up" or overly sensitive to pain that was "not so bad."

Susan's experience was common amongst participants who had experienced a gradual onset of chronic pain. Catherine also felt that her early experiences of injury impacted how she related to her health and body more broadly:

> "As a kid I was also really clumsy, so I would fall down a lot, and my parents would always scold me for getting injured. In school my teachers would be like, 'you fell down again, why are you so clumsy?' So I was like, 'ok, I just won't talk about it.' So I feel like that changed how I perceived my health."
>
> (Catherine, 19-21, female, autoimmune arthritis[9])

An exchange later in our conversation exemplifies the uncertainty that many participants still had about what was going on in their childhood, and what they could have done differently:

> Catherine: "When I look back, I should have really gone with my gut feeling and said something about it. Instead of being like, 'ok, definitely a muscle ache.' Because I feel like muscle aches don't last when you're not doing anything. I should have been more aware. But also, when you first experience it, when you're 12, 13, there are so many things you don't know. I don't blame myself, but if I could go back in time, I would say to my 12-year-old self, 'please tell your mum about this.'"
>
> *Imogen: "I definitely don't think a 12-year-old can be blamed. You said before though that you were telling your sports coaches?"*

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[9] Autoimmune arthritis is an umbrella term that refers to conditions where there is joint inflammation from the immune system attacking surrounding tissue. Autoimmune arthritis can also lead to degenerative injuries from the gradual deterioration of bones and joints.

> Catherine: “I was, but she was like… I think she just kept thinking I was lying. That also made it difficult for me to want to tell someone about it. Because when I had to sit out for some training activities, obviously the rest of my teammates would look at me sitting out and think, ‘why are you sitting out again? Everyone here is tired.’”

In these cases, a major barrier to receiving medical attention was that the first-line authority figures and care providers in children’s and teenagers’ lives did not see the symptoms they presented with as a sign of physical illness. Parents, teachers, coaches, and peers were all capable of denying that physical symptoms were abnormal – everyone’s tired, you’re just being lazy – and they also failed to consider that symptoms such as fatigue, or even migraines, could be coming from physical illness. Children were not well equipped to explain how they were feeling, and this meant that they could do little to correct the course when adults went down the wrong path in relation to their care. Further, instances where care was denied quickly taught children and teenagers to not ask for help.

In cases where parents did try taking their children to the doctor, it often just became the doctor’s turn to deny that the described symptoms correlated to a physical illness. This was the case for Farah, whose family doctor did not believe that her physical pain was a cause for medical concern:

> “[My doctor] had always told me it was kind of just my own issue, that I’m kind of making up the pain myself, when I very obviously wasn’t. He kind of said it was very normal, that you just had to walk it off. […] Because I was so young, the first time I believed him [… and] my parents – it wasn’t their fault of course – but they believed the medical professional in the situation.”
>
> (Farah, 19-21, female, autoimmune arthritis and degenerative spinal injuries)

If a parent believes doctors that there is no reason for medical concern, it becomes extremely difficult for children to advocate for themselves against this unified front from adults. In the end, Farah was another participant who had her condition found through a scan unrelated to her ongoing physical symptoms.

Even where parents did continue to advocate for their children, doctors did not necessarily change their mind. Often, ‘growing up’ was a key reason doctors believed there was little cause for concern:

> “I didn’t know what was happening, so I went to the doctors, but they were like ‘oh, it’s probably because, like, you turned 14,’ and I was like ‘ok.’ And then the next year […] they were still like ‘oh no it’s probably because you’re growing up, you’re really tall for your age, so you might be going through growing changes,’ and I was like ‘ok.’ […] The next year I started getting these really, really bad pains, and it was like stabbing pains, and like, I remember, the most awful one I had was during an exam at school, and I started crying during the exam, and the teacher just thought I was really stressed out. […] So my mum was like ‘you’re seeing a gynaecologist,’ and we went to like four of them, and they were all like ‘look, it’s probably just that you’re not 18 yet, it’s probably just changes in your body from growing up.’”
>
> (Maya, 19-21, female, endometriosis[10])

Maya’s story touches on another recurring explanation that doctors gave for their young patients’ concerns: stress and mental health. Participants spoke at length about the relationship between mental and physical health, and how doctors’ decisions to pursue psychiatric diagnoses or psychological explanations can mean physical chronic illness is missed. Stress or mental health issues were often given as an explanation for physical symptoms – sometimes in a manner which flippantly turned someone away, and sometimes in a manner which instigated years of psychological and psychiatric treatment.

Most simply, the stress of school was used to explain both participants’ physical symptoms, and why participants may be over-exaggerating, or fabricating, their illnesses:

> “The first gastroenterologist that I saw told my parents that I was making things up for attention, and that I needed to go and see a psychologist and there was nothing wrong with me. […] Everyone assumes that the HSC[11] is so hard that – I know for myself, and it might be similar for the other people who weren’t diagnosed – things just kept getting

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[10] Endometriosis is a disease where tissue similar to the lining of the uterus grows outside the uterus. This tissue often grows on the outside surface of the uterus, the ovaries, and the fallopian tubes, but it can also grow on organs such as the bladder, intestines, stomach, and lungs. The condition can cause serious pelvic pain both during and outside of menstruation, along with symptoms dependent on where the tissue growth is, e.g. gastrointestinal issues, and painful urination and/or bowel movements. It also causes fatigue, and it can impact fertility.

[11] The HSC (Higher School Certificate) is awarded to students who have completed the final two years of high school in New South Wales (NSW), Australia. It involves ongoing assessment throughout the two years, and final state-wide examinations at the end of the final year of high school.

> attributed to it. You're tired all the time because it's stress from the HSC, and you're vomiting all the time because it's stress because it's the HSC. You're really sick because you're not eating well because you're stressed from the HSC."
>
> (Rachel, 26-29, female, IBD[12])

Participants knew that the relationship between physical health and mental health was complicated, and, as Jack explains below, the process of seeking medical attention does itself have an impact on mental health:

> "It's hard to get good help. And it doesn't help that it makes you pretty depressed. Everything's not working, I'm wondering what the hell is wrong with me, so I'm miserable too, and my GP [general practitioner] is like, well you're depressed. And it's like, yeah, but, I am, but… what comes first? And it's just so hard to convey that – that I don't think that this is what's first. That was very hard for a while."
>
> (Jack, 22-25, male, CFS/ME)

In interviews, participants were cautious of 'denying' the legitimacy of mental health conditions, and they often hesitated as they described the way they felt an emphasis on mental health care had been a barrier to them receiving the physical healthcare they needed:

> "I know this is really bad to say, because obviously mental health is really important, but for me, personally, in my experience, I would have preferred that they kind of moved away from mental health a little bit. […] It makes me doubt what is actually happening to myself. […] Because it just feels like… and I know they do believe me, but sometimes it just feels like they don't believe me as much."
>
> (Georgia, 19-21, female, fatigue and chronic sinus infection)

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[12] Inflammatory bowel disease (IBD) describes chronic autoimmune diseases of the intestinal tract. Most commonly it refers to Crohn's disease and ulcerative colitis, although there are indeterminate inflammatory bowel diseases that have features of both Crohn's and ulcerative colitis. Symptoms include abdominal pain, fatigue, and diarrhea. IBD also causes an increased risk of colon cancer, bowel obstruction, and fistulas (abnormal connections between two body parts, such as an organ and the skin or blood vessels).

Towards the end of Georgia's interview, I told her that she was not the first person who had spoken to me about the experience of having doctors care about mental health explanations to an extent that they missed the potential of a physical illness. This both surprised and relieved her. Participants' opinions existed on a spectrum which ranged from participants who believed that mental health concerns were used against patients, to others who were still, like Georgia, struggling to articulate how doctors needed to better consider physical and mental explanations for symptoms. In some cases, participants deliberately did not disclose mental illnesses when they were seeking care for their physical illnesses because they felt it would be weaponised against them and used to discredit their symptoms as psychosomatic.

Medical doubt about the severity of physical systems existed in a broader social context that also encouraged participants to 'push through' pain and illness. As Georgia explained:

> "The more I talk to doctors the more I'm like, 'is this how I've normally felt? Am I normally this tired and I'm just paying attention to it now because I'm not distracted by work?'"
>
> (Georgia, 19-21, female, fatigue and chronic sinus infection)

Georgia's doubt indicates how difficult it could be for participants to believe themselves in a context where cultural narratives did not give space for young people to be chronically ill, and people in their life also often doubted their illness. Given these pressures, many participants recommended keeping a record of symptoms:

> "When I'm not in pain, I'll always be like, 'oh I was just being dramatic,' so I decided to keep a diary. I kept a diary, and I wrote down everything I was feeling so that I don't change my mind on it. That means I can be set on it, I can know, and sticking to one thing and believing that I know my body was the main factor in trying to keep my mental health ok. So that diary really helped."
>
> (Maddy, 19-21, female, endometriosis)

Maddy's comments demonstrates again the role of self-doubt in illness stories – this difficulty in "believing that I know my body" reflects persistent narratives and interactions where this knowledge was doubted. In particular, the sense was that periods of physical pain and illness could be recast as moments of mental weakness. For many participants, recording real-time accounts of their physical pain helped them assure themselves that they had not experienced something that their mind should have been able to work through, but instead that they experienced significant physical distress.

The benefits of symptom tracking were also felt when participants were questioned by medical practitioners. This was why Lisa (26-29, female, IBD) took notes of her symptoms. She initially explained that she did it because she "can be quite forgetful" when talking to doctors, but then further clarified that "it just helps me talk through what's been happening [… in particular for] ED [emergency department] doctors and staff, because they kind of scare the shit out of me."

Participants who undertook symptom tracking recognised that it was a significant amount of additional work, but they all saw it as crucial to receiving good care. This was not only so that it helped them in interactions with doctors, but also so that they could think through their symptoms and how to manage them individually, suggesting that their own expertise and experiments with symptom management was key to living well (enough) with illness.

There were other, more direct, ways that young people were denied help in healthcare settings. While the above excerpts have largely concerned interactions with GPs or doctors who participants had seen repeatedly, another significant pathway through which participants engaged with medical institutions was through the hospital emergency department. No one who I interviewed, however, had received a diagnosis, or any helpful guidance towards a diagnosis, during one of these visits.

In the emergency room, requests for pain management, or even just for an explanation of the pain, were frequently met with participants being accused of drug-seeking behaviour. These accusations distressed participants – they were offended by the implication that they were not in pain, and that their behaviour was suspicious or inexplicable. Phoebe (26-29, female) had presented in emergency departments due to her IBD and chronic pain, and told me that "if you turn up to an emergency too often in pain, they call you drug-seeking." Lisa (26-29, female), who also had IBD, said that she could not help but wonder if her dyed hair and tattoos were the reason that one doctor wrote on her chart that she presented at emergency in search of painkillers.

There was also a structural mismatch between an emergency department's focus on acute danger compared to the chronic concerns of participants. While participants did only come to hospital when they had *an* acute concern, they felt their pain and fear was dismissed unnecessarily harshly and unproductively when they were sent away simply with the knowledge their life was not in danger. Both David and Jess had pithy critiques of emergency departments, which reflected many participants' concerns:

> “[My] experience of the doctor is that, if you’re not dying, they don’t appear concerned.”
>
> (David, 19-21, male, fatigue and dysautonomia[13])

> “They do an ultrasound, they rule out appendicitis, and they send you home.”
>
> (Jess, 19-21, female, endometriosis)

Even where there was an existing diagnosis, healthcare providers might still deny that new acute symptoms were a meaningful development in a chronic condition. This often resulted in participants feeling unfairly dismissed by someone who was prioritising their own technical knowledge of disease over a patients’ lived knowledge of an illness:

> “I was vomiting every morning, which for me is a sign that my flare is very bad – when I’m vomiting, I know it’s bad. And she was just like: ‘vomiting isn’t a symptom of IBD.’ And I was like, ‘well you’ve never been through a flare, so shut the fuck up.’”
>
> (Emma, 22-25, female, IBD)

Where participants had spent significant periods of time searching for a diagnosis, the experience they described was of an extraordinarily frustrating series of dead-ends. Aisha recounted her years-long journey to get medical professionals to take her migraines and pain seriously. When she was finally given an MRI [magnetic resonance imaging] scan, they found a brain tumour that had been causing neurological issues in a variety of a different ways. Given its sustained growth, the emergency surgery could not be done without chronic brain injury:

> “They told me it’s stress. Someone told me it’s the food I’m eating – I changed my diet. Someone told me it’s my pillow – I changed my pillow. Someone told me it’s normal for a student at a university to get these types of migraines, and I was like, ‘are you serious?’ I’m vomiting 4-6 times a week, and the migraines, even if I take painkillers they didn’t go away. And I had that kind of gap to communicate with them. […] I left

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[13] Dysautonomia symptoms come from issues with the autonomic nervous system, which controls heart rate, blood pressure, and digestion. This means symptoms can include fluctuations in heart rate, fluctuations in blood pressure, dizziness, fainting, headaches, and nausea.

> the clinic, and I remember feeling so, kind-of, unheard. […] I ended up leaving the clinic and just crying. […] The patient is not treated as a capable human being. A capable adult."
>
> (Aisha, 26-29, female, neurological condition)

Aisha's sense that she was dismissed because she was young, and because doctors would not treat her as "a capable human being" whose pain should be taken seriously was echoed by other participants. Fiona told me that:

> "Because a lot of these illnesses are invisible, they just look at you and they just seem to think you're overreacting, or that you've got mental health issues because they can't see it. And because you're young, they just think, 'get on and work.' […] As a young person you have to fight for a lot of these tests because they don't believe you."
>
> (Fiona, 26-29, female, vestibular injury[14])

The issue of testing arose in many interviews, as participants were very aware of when relatively routine medical tests could have quickly revealed their condition. This was the case for many participants now diagnosed with IBD, who had not had doctors take a stool sample, and also for Aisha and John, who had not received MRI scans. Participants were aware that their conditions were often 'rare' but so too, they knew, were their symptoms:

> "At the time they were like 'yeah, it's not standard, but it's not wildly out of the question. So no need to do an MRI.' […] I don't know how rare migraines and severe mental health issues are for a [child], but chuck them in an MRI machine, just do it, you could save people a lot of trouble."
>
> (John, 26-29, male, neuroimmune condition)

Because of this, participants frequently felt there was a need to change guidelines and/or educate doctors to make it less likely that cases like theirs were missed. Some encouraged patients to make doctors record when they refused to carry out testing.

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[14] The vestibular system, found in the inner ear, maintains our balance and spatial orientation. Vestibular disorders and injuries consequently cause issues such as loss-of-balance, dizziness and vertigo, nausea and vomiting, blurred vision, migraines, and hearing loss.

While a lack of testing was responsible for the worsening condition of some participants, tests do not guarantee a clear diagnosis or successful treatment regime. This was the case for participants who lived with conditions like fibromyalgia or CFS/ME, for which there is no known biomarker, and the tensions that can surround the resulting contestation of diagnosis and disease is well documented (Bülow, 2008; Davis, 2005; Donoghue & Siegel, 1992; Dumit, 2006; Nettleton, 2006). In cases such as these, Fiona told me, an overemphasis on the existence of biomarkers was partly responsible for the misdiagnosis of mental illnesses in the place of physical illnesses:

> "I feel like the psychiatry doctors and the medical doctors, they treat the brain and the body like absolutely separate entities. They don't work together. So if you're chronically unwell they say that's caused by mental illness. The medical doctors don't realise that your medical stuff can actually cause mental health conditions, they just don't see that. […] If they can't find an answer to something, they can't see it on their modern tests, it's like, it must be psychosomatic. But they're not God, they can't see everything with their machines."
>
> (Fiona, 26-29, female, vestibular injury)

Some participants also felt that healthcare professionals were uncomfortable admitting that they did not know what was going on, echoing literature that has demonstrated how poorly managed uncertainty in clinical encounters detracts from the emotional experience and medical care patients receive (Boulton, 2019; Costa et al., 2023; Costa, Karime, et al., 2022; Costa, Olson, et al., 2022):

> "It's easier to say, 'you're not sick', than 'my job is to tell you what's wrong, but I can't.' […] Long-COVID was always the first thing they wanted to discuss. It's easier for them to be like, 'we've diagnosed you and there's nothing to do about it.' It's easy to put me in that box because it's a long illness they don't know anything about. And it allowed doctors to be ok with not knowing anything about it because they don't have the data on it – they don't often have an illness where they can be open about that."
>
> (Tess, 26-29, female, MCAS[15])

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[15] Mast cell activation syndrome (MCAS) is an immune condition where mast cells (a type of white blood cells) react unpredictably to unknown substances, causing episodes reminiscent of allergic reactions. Symptoms include

Overall, there were varied and compounding obstacles to young people recognising and communicating that they were experiencing symptoms of physical illness, and additional barriers to them receiving a diagnosis to validate their experiences and treat/manage their condition. These difficulties go beyond a protracted diagnostic journey – various institutions, cultural beliefs, and medical decisions worked together to obscure the very presence of physical chronic illness in young people. While aspects of particular illnesses may have been highlighted when care was denied (e.g., their rarity or invisibility), the similarity in participants' stories was not due to a shared disease. Instead, their age, and the various assumptions and vulnerabilities that came with it, was a universal and important factor which shaped how their changed behaviours and requests for care were interpreted.

Barriers to receiving care also appeared across the lines of gender, race, and class. Economic barriers to care are explored in the following results section of this chapter, but, in regards to gender and race, participants explicitly explained how their experiences represented biased medical systems and practices (Frickel et al., 2010; Hudson, 2022; Knoebel et al., 2021; Lee et al., 2019; Mullard et al., 2024; Richman & Jason, 2001; Sebring, 2021). Rachel, for example, reflected on how her gender impacted the dynamics of all clinical encounters, whether or not they were related to her chronic illness:

> "I wouldn't overlook the fact that I am a woman in these situations. […] I feel like people look at me, and I'm not a super strong looking person, I'm quite small and I'm quite feminine looking, and I think people think, 'I know better than you.'"
>
> (Rachel, 26-29, female, IBD)

Fred, who was a white man, reflected on what his own privileged experience in clinical interactions demonstrated about the broader problem:

> "It was like, I'm coming here, I'm telling you this thing, and they're like, 'yeah sure, I guess that could be a thing.' And it seems a bit careless, and you're like, am I going to have to spend even more energy trying to convince you that I am actually have an issue here? It's weird how having experiences like this make you understand the things

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hives, breathing difficulties, vomiting and diarrhea, and potentially anaphylactic episodes, along with corresponding fatigue and fever.

> you've heard people complain about. I'm very well aware of the fact that doctors tend to disregard women talking about things, and they disregard people of colour, and queer people, they just tend to have a bias against that."
>
> (Fred, 19-21, male, CFS/ME)

For Fred, he felt like he was the beneficiary of doctors "just going along with it" because of his identity, even though they were "not actually on board." That was an unpleasant and tiring experience, but he was still "very grateful" for it given the bias he knew existed at the intersections of marginalised identities.

David, who was a person of colour, saw the influence of both his identity, and the identity of who he was talking to, in clinical and social interactions. Socially, he explained that he found it "difficult to talk to other men" because they often did not have health issues, so did not understand what it was like to "look healthy" but be sick, or what it was like to have a doctor doubt you. He told me that women, by contrast, would sympathise both with illness and doctors' scepticism. He had been "researching this frustration," and therefore knew that studies demonstrated that "as a person of colour, you can be disbelieved. […] People of colour and women get worse outcomes from health, and exclusively because doctors don't believe them." His own experience of this was:

> "I've often felt unbelieved or disbelieved by a doctor. […] I don't think I've ever explicitly felt – I don't think they've ever been like, 'we're not going to give you this drug because you're a person of colour,' but I've always felt, particularly if I'm interacting with white doctors, that they're not, sort of, engaging with me fully. […] I will set out, if I'm looking for a health professional, I will set out to find a female health professional or a person of colour, just because I don't want a white man who's going to disbelieve me. Obviously not all white male doctors are not going to believe me, that's not what I'm saying, but the chance of either a person of colour or a female, you know, believing me, is much higher."
>
> (David, 19-21, male, fatigue and dysautonomia)

In his mind, the bias of "white male doctors" came, in part, from their sense of superiority, since he also explained that his experience was that "people with less training or maybe less experience are just willing to listen and engage." By contrast, he believed that those who could identify with the "old guard" of medicine due to media portrayals of healthcare and exclusionary university systems still believed in "master the body" approaches.

These experiences had caused many participants to reflect on the various ways that our medical systems, including medical research, is biased against women and people of colour. These reflections often inspired participants to undertake their own research about medical bias. This was particularly true for women with reproductive conditions, such as PCOS[16] and endometriosis, who consistently felt that they were victims of medical disinterest in women's health. These failures were particularly felt by participants who were faced with limited therapeutic options, and were therefore making ongoing, difficult decisions about whether the benefits of hormonal medication for their condition's management were worth the significant side-effects they experienced. Participants observed an additional dynamic in these situations, which was preoccupation with fertility in clinical encounters. Claire explained how this manifested in her experiences with PCOS:

> "Whenever I brought up alternatives to the pill they'd be like 'oh, when you want to have children, then you can go off the pill and then we can give you this drug that will make you ovulate. People with PCOS have as many children as people without PCOS.' […] I'd really like that awareness to be there so they can get that research into it and find different treatment methods for it other than the pill. Because the pill isn't even really a treatment for it, not at all. They don't know what the cause is, and they don't know how to treat it. They don't know anything about it. […] It's not stereotypically serious."
>
> (Claire, 22-25, female, PCOS)

It was not only women with reproductive conditions who cared about this though. Aisha (26-29, female), who lived with neurological symptoms and brain damage, was particularly passionate about biases in the medical system:

> "I've read about it a lot. I've heard a lot of other women talk about it. […] I've noticed the care that women get during childbirth, […] and in inserting an IUD [intrauterine

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[16] Polycystic ovary syndrome (PCOS) is an endocrine disorder characterised by hormonal imbalance from unusually high levels of androgens. This can lead to irregular periods and ovulation, abnormal hair growth, acne, and weight gain.

> contraceptive device] – they don't get anaesthesia. […] We have a lot of bias in our medical books. I've read them, there are doctors in my family. There is a bias against women in the medical field. They are not taken seriously. They are seen as over-exaggerating. […] This goes back to the fact that a lot of the research we have, even in drug testing, when we do the first clinical trials, we do them on healthy white males. Why they do that? It's because they say the hormonal systems and cycles of women is too complicated to deal with. […] Even different ethnicities – you didn't figure out that there are certain hypertension drugs that on specific categories of east-Asian men acts different. You didn't discover that until 2012. And that drug has been in circulation since the 1970s. So when you limit your sample to one very small sub-set of the population, and you use that sample, and you generalise it on everyone else, you're not going to be able to understand us on a level to be able to treat us. You never studied what it looks like in women. You never studied what some skin conditions looks like in people of colour. It's not going to look like the textbook. And if it doesn't look like the textbook, the doctor is going to say there's nothing wrong with you."
>
> (Aisha, 26-29, female, brain injury)

Aisha, and others, connected their own upsetting experiences with the well-documented biases in the system. In some cases, it was structural issues with medical research that limited the effectiveness of care available to participants, and many participants further understood their experiences of doctors dismissing or disbelieving their concerns as part of a cultural problem.

Overall, the barriers to receiving care manifested in a variety of ways. Participants faced: explicit denials that there was a problem; subtle and pernicious attempts to convince them and their families that there was nothing wrong; social and institutional pressures that made them doubt their own illness experiences; and vocabularies that failed to encapsulate their realities. The breadth and variety of these barriers was exhausting, and also made it difficult for participants to clearly name and confront any individual failure of care. This all worked against participants during periods of their life when they were struggling and vulnerable.

Ongoing barriers to care

So far, I have explored two foundational components of participants' experience of chronic illness. First, I have recounted the various points on a theoretical diagnostic journey where the existence of a physical chronic illness, or a chronic illness flare, could be missed or denied. Second, I have shared how participants understood the context of numerous medical and healthcare biases to be impacting their access to care and treatment.

In addition to the above, there were also failures of medical care for participants who were undergoing relatively routine medical procedures or treatments. The stories below concern instances where participants were very unwell and hospitalised, and then, as patients, experienced hospital staff disregarding their welfare and/or medical reporting systems that would not record their distress.

Grace and Aisha both recounted shocking instances where they simply did not receive adequate care or compassion while in hospital:

> "They left me on a trolley without a call-button – they knew I was in a wheelchair and couldn't walk – they gave me the wrong medications, they wouldn't tell me what medications they had given me. […] I was crying hysterically, and they were ignoring me, and I kept saying my heartrate is too high, this isn't right – it was like 160 – and they were like, 'oh no, it's fine, it's just because you had surgery.' And when I asked about where the painkillers had gone, they were like, 'just take Panadol, it will be fine.' […] They were just really callous and awful, and it wasn't ok. None of the team there were caring or good, other than my anaesthetic nurse, who was great. But other than that, they were awful."
>
> (Grace, 22-25, female, neuroimmune condition)

> "And I remember for one of [my lumbar punctures] they had a resident surgeon do it, and they didn't tell me I was going to have an audience, with my entire back bared to four students, with one student doing it who was nervous to do it, and a consultant sitting next to her. I ended up crying my eyes out, not because of the pain, but because I was physically very vulnerable and also physically very exposed to people without my knowledge."
>
> (Aisha, 26-29, female, neurological condition)

Grace had also had an issue with her experience of lumbar punctures. Not only was the experience upsetting due to the pain and fear it caused – Grace knew that the issues she had faced would not be recorded based on medical reporting systems that prioritised medical definitions of 'issues' rather than what caused patients pain and concern. This was an additional source of distress, particularly because, in her eyes, it rendered the statistics associated with the procedure consent process inaccurate:

> "I've had two [lumbar punctures], and they both ended in CSF [cerebrospinal fluid] leaks, but neither of them would be recorded as an official CSF leak on the data base and included in studies because they didn't have to do a blood patch. And so, I ended up having to lie flat on my back for a week with fluids and caffeine and everything, but because they didn't have to do a blood patch they weren't counted as CSF leaks. And so when they talk to you about getting a lumbar puncture, they say, oh only 5% of people get a CSF leak, but that's not true. And, given that I've had them 100% of the time, and I know plenty of other people who have had them, the statistics for them are not safe or sound or anything."
>
> (Grace, 22-25, female, neuroimmune condition)

All participants had moments in their lives with chronic illness where they did not receive adequate care from people who they felt they should be able to trust. In interviews, it felt as though experiencing a care-failure was inescapable for young people living with chronic illness. It did not matter how many things went 'right' for someone, there was always an instance where the emotional needs or lived expertise of a person as a patient were neglected or denied. This is well represented by Ethan's story. He had a family history of type I diabetes,[17] so it was diagnosed quickly when it appeared, and he had family support in managing it. Yet when he presented at an emergency department with stomach pain, he was still told that he was not allowed to administer the amount of insulin he needed to manage his condition:

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[17] Type I diabetes is a condition where the pancreas makes little to no insulin, meaning that glucose is not metabolised. It is thought that this often is caused by an autoimmune disease destroying insulin-producing cells. An inability to metabolise glucose means that sugar can build up in the blood stream, causing nerve damage and related complications in the long term – insulin therefore needs to be regularly injected to stop this build up. Conversely, when blood sugar is low, stored glucose cannot be metabolised to increase blood sugar, which can lead to hypoglycaemic attacks ('hypos'). Hypoglycaemic attacks begin with feeling shaky, a racing heartbeat, and sweating, but can cause confusion, seizures, and loss of consciousness.

> “I remember, it’s so annoying, this doctor [in the emergency department], she goes, ‘so how many units of insulin do you do per meal?’ And I go, ‘well it changes […] maybe 10 to 16 units.’ And she said, ‘so 10?’ And it’s like, I’m having to explain to a doctor how my condition works? And because they’re trying to monitor me, they’re trying to see everything, and I check my sugar and I have high sugar, with the anxiety of being in the hospital and not knowing what’s wrong with me, my sugar is going up. And so they gave me some food, and I was like, ‘ok well I need to do 16 units now.’ And the doctor was like ‘wow, wow, wow. 16 units? I can’t give you 16 units of anything.’ And I was like ‘well I’m not asking you to do it, I need to do it.’ And then they told me no, she said, ‘don’t do it.’ And I was like, ‘I’ve been diagnosed since I was [very young].’ And they were like, ‘don’t put that in you, because we need to approve everything that goes into you.’ And so it’s my chronic condition, that I know how to manage, that affects how I feel and my general health – and you’re telling me that I can’t do it? It’s like, your instructor for something is someone who knows way less than you.”
>
> (Ethan, 21-25, male, type I diabetes)

The final note in this story of failures is to say that these interactions also all took place in a context where illness was causing difficulties elsewhere in participants’ lives. One way this was true was due to the significant financial burden of chronic illness. Many participants struggled to afford their medications, private health insurance, or treatments. Some participants could not afford private doctors who did not bulk bill, which resulted in many specialists being entirely unavailable to them. As Greg told me early in his interview:

> “I don’t have any money, I’m poor. I can’t go and buy doctors, so I go to the regular doctor. So I’m on the waiting list […] I’ve been on that waiting list for months.”
>
> (Greg, 22-25, male, neuroendocrine condition[18])

Many participants faced financial strain due to illness. For some participants, working was the only way they could be financially supported, and their need to work came with health repercussions, especially when they did not have the capacity to convalesce or seek treatment.

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[18] Neuroendocrine conditions impact the interactions between the endocrine system and the nervous system, leading to hormonal issues that can cause symptoms such as fatigue, weight gain and puffiness, dysregulated responses to stress, and mood disorders.

Participants who had periods where they could not work due to illness were only permitted to have short-term health exemptions to the mutual obligations associated with Australia's unemployment benefit – JobSeeker – which include having a Job Plan, meeting with employment service providers, and actively applying and interviewing for jobs. They needed to prove their illness every two weeks, because they did not meet the disability support pension criteria of an impairment that is "diagnosed," "reasonably treated" and "stabilised" (*Social Security Act 1991, Determination 2023* (Cth)). Phoebe, for example, had recently had a serious IBD flare which stopped her from working, and her reflections on this struggle demonstrate not only the precarious financial position of many participants, but also their continuous reflections on the help from loved ones that allowed them to survive:

> "I had just been working 6 months, so I had lost my JobSeeker payment, so I have to do an interview and go through all of that again. And I feel like, since I was on a disability provider, I should be able to just put that back in when I have a flare. I'm lucky I live with my parents and I had savings, but most people don't have the luxury, and especially when you're chronically ill, most people have very low amounts of money."
>
> (Phoebe, 26-29, female, chronic pain and IBD)

Likewise, many did not meet the criteria for the National Disability Insurance Scheme (NDIS), which requires a disability to be "permanent […] for the person's lifetime" (*National Disability Insurance Scheme Act 2013* (Cth)). A few participants were still attempting to receive NDIS support, and one – John – was now successfully covered by it. He still was anxious about the potential for the NDIS to be defunded, and remembered vividly the year he spent waiting for NDIS approval:

> "So I signed up – tried to sign up – for the NDIS. It took a year because it's… such a shit-show. So, I spent a year… for a year my parents had to pay a lot of money for [medical equipment] that I *need* to *survive*, let alone leave the house."
>
> (John, 26-29, male, neuroimmune condition]

The observation that welfare institutions are poorly set-up to assist those with chronic illnesses – especially young people with chronic illnesses – speaks to a lack of care and awareness for chronic living that also appeared when participants needed to seek accommodations from other institutions. In particular, some participants who had experienced debilitating illness while at university had also struggled to have their suffering taken seriously in a bureaucratic setting. Rosie was particularly upset by her experience:

> "I provided all the documentation and it wasn't enough, and I guess – I found it really difficult to also deal with that and not have any support. […] They said I didn't provide enough evidence and documentation, which is a massive kick in the gut when you are going through the hardest point in your life. It's kind of like a dismissive, 'we don't believe you.' That's what it felt like. And again, it took three months for them to get back to me. […] Whoever was reading my case just didn't understand I was deserving of it. And again, it's just frustration, because it's like, of course I'm deserving of it. I've just had a huge diagnosis that has affected not only my emotions but my physical health and my future. So that was difficult. […] I don't even know who reads the special considerations, but it seems like normal people who are hired from the uni. How are they meant to judge how you've been affected if they've never heard of this condition once in their life? Especially when there's a huge lack of understanding about women's health."
>
> (Rosie, 22-25, female, POI[19])

Rosie's language ties together recurring themes: the emotional weight of actions and words that dismiss the challenges of illness; the prolonged attempts to be taken seriously or given necessary accommodations and support; the need to advocate for oneself at one's lowest and most vulnerable point; and the sense that things are made worse by having a rare, poorly understood condition, particularly when it is a 'women's' illness.

In one respect, what I have outlined in this chapter is a variety of situations where young people might be turned away from medical care or a diagnosis might be missed, and a variety of subsequent situations where they might experience emotional, physical, or financial hardships despite having a diagnosis. What becomes clear in this outline though is that it is an inescapable fact for young people with chronic illness that, at some point, they will not receive the care they have a right to expect.

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[19] Premature ovarian insufficiency (POI), sometimes referred to as primary ovarian insufficiency, happens when there is a loss of ovarian function before age 40. Significant fertility issues, or infertility, are common, along with symptoms such as mood issues, hot flushes, fatigue, and brain fog.

Discussion

The recruitment criteria for this study were deliberately broad. In interviews it appeared that there was one thing this group of 19-29-year-olds had in common, other than their age and sickness: they had been forced to question and/or defend their own physical experiences, and their knowledge of those physical experiences, against both individuals and institutions whose expectations structurally invalidated their pain and denied them adequate care. Many participants told me that they were doing an interview so that people might know about these experiences, and so that there could be more attention to the chronically un-caring systems they confronted. In witnessing these failures, the need for structural reform is clear, as is the need for a more nuanced appreciation of the hidden (and socially imposed) work, grief, and doubt that pervades the experience of chronic illness.

Participants were repeatedly told that they were drug-seeking, stressed, attention-seeking, or just failing to cope with 'normal' experiences. Even if a diagnosis came after all of this, participants still found it difficult to get unfamiliar doctors to trust their expertise or respect their rights as patients. While participants did not experience everything on this list, they knew that all these experiences could come with chronic illness, and they understood their own stories in the broader context of medical and political systems with deeply ingrained cultural and structural issues.

The experiences recounted above are not always understood as part of the same issue. For example, the literature on the medical establishment's difficulties thinking about the mind-body connection and 'invisible' illnesses (e.g., Barker, 2002; Bülow, 2008; Donoghue & Siegel, 1992; Dumit, 2006; Grosz, 1992; Ibeziako & Bujoreanu, 2011; Kleinman, 1988; Marya & Patel, 2021; Nettleton, 2006) is different to the literature on epistemic injustice in clinical interactions (e.g., Carel & Gita, 2014; Carel & Kidd, 2014; Kidd & Carel, 2017; Mladenov & Dimitrova, 2023; Sebring, 2021), which is different to the literature on how the pain of women and people of colour are not taken seriously (e.g., Hudson, 2022; Knoebel et al., 2021; Lee et al., 2019; Richman & Jason, 2001; Werner & Malterud, 2003; Whelan, 2007), which is different again to research on the best practice for diagnostic testing (e.g., Ghai et al., 2020; Uher et al., 2023), and to literature on the best way to acknowledge uncertainty in clinical encounters (e.g., Album & Westin, 2008; Boulton, 2019; Costa et al., 2023; Costa, Karime, et al., 2022; Costa, Olson, et al., 2022; Harsh et al., 2016; Nettleton, 2006; Overend, 2014; Yon et al., 2015).

For participants, many of the oversights in their care were in some way tied to youth. To begin, children and teenagers may struggle to know what physical experiences are abnormal, or how to describe what is going on in their bodies and minds – crucial components in how adults determine when to seek medical help (Carel, 2016; Hay, 2008; Heritage, 2009; Toombs, 1992). Further, it appears that narratives about the problems of 'youth' corrupt the ability of medical professionals and other adults to see what might actually be going on. In participants' stories, adults were often inclined to believe that they were simply another young person who was stressed and mentally ill, dramatic, lying, or lazy (Pickard, 2014; Protzko & Schooler, 2019; Wild et al., 2024). Or alternatively, adults did not take the testimony of a young person seriously, and therefore did not listen (Burroughs & Tollesfen, 2016; Carel & Györffy, 2014; Carolin & Milner, 1999; Greenblatt et al., 2024). Ironically, the discourse which focuses adults on "young bodies at risk" (Coffey et al., 2016) steers people away from seeing the very real, embodied risk of chronic illness. The way participants spoke about their identities, particularly as women and people of colour, also echoed existing literature on the intersectional roots of bias and epistemic injustice directed towards children and young people (Baumtrog & Peach, 2019; Murris, 2013).

Participants were often careful to clarify with me that they had eventually found a doctor who believed them and provided much-needed care. In these cases, participants appreciated doctors who recognised the various tolls of illness but did not attempt to over-promise (and under-deliver) on what medicine could offer (Mescouto et al., 2022). This supports the importance of work that clearly, realistically, and sensitively considers what the role of medicine and doctors should be (Mishler, 2005; Wardrope & Reuber, 2022). Participants also often had family, friends, and loved ones who were now able to support them. Due to the chronically un-caring nature of their past interactions, part of that support involved recognising the impacts of chronic doubt and anxiety in relation to receiving care and compassion. Currently, it appears that the experience of being denied care is an underlying experience of young people living with chronic illness. This dual experience of both institutional invisibility and interpersonal doubt forms a foundation which shapes future experiences of illness, regardless of whether support systems improve.

CHAPTER FIVE | to be young, to be ill

Introduction

Chronic illness in young people disrupts many of the normative assumptions that pervade cultural understandings of bodies and health. Participants recounted how this disruption led to frequent feelings of being out of place. There was a dual disconnect: chronic illness could make them feel disconnected from the expectations of 'youth' in a variety of social situations, but they also did not feel that they belonged in the medical settings in which their chronic illness so often forced them to reside.

The fact that chronic illness was unexpected and (supposedly) unusual in a 'young' body made it more difficult for participants to talk about, emotionally manage, and receive support for their illness. In participants' opinions, these difficulties arose in part from the lack of education they and their peers had been given on chronic illness, never mind chronic illness when young. On top of this, many participants had experiences of adults taking away the control and agency that they had been carefully cultivating both as an adolescent and as someone looking to regain control after encountering illness.

In many ways, chronic illness unsettled participants' sense of life stage and imagined futures. Participants often discussed this destabilisation of youth with reference to their timelines and what they 'expected' their life to look like as young person. In most cases, due to the age of participants, this was not so much an acute disruption of an already developed way of life, but rather illness drew into focus a series of unspoken social and personal assumptions about youth. Some participants found much needed support from other young people living with chronic illness, and their reflections on what they recognised in others who were chronically ill gives some indication of where support and education might be productively provided. Without this though, and in the context of other social and educational shortcomings, youth can become a vector through which institutionalised and normative fears of illness and disability materialise.

Background[20]

The role and perception of time has been established as one important way to analyse and understand experiences of illness (Ehlers et al., 2024; Green & Lynch, 2022; Harrison et al., 2024; Kafer, 2013; Morris, 2008; Olson, 2011). This literature has demonstrated how chronic (and other) illnesses can disrupt life across a variety of time scales, from the everyday rhythms of life to the way one can conceptualise the future. One concept which is useful for thinking about this in relation to chronic illness is the idea of 'timeline management', which describes how people think about and plan for their future (Brown & Patrick, 2018; Tavory & Eliasoph, 2013). This literature can be used to provide an additional perspective on scholarship that has demonstrated how illness requires the adaptation, regeneration, or creation of new biographical stories and understandings (Bury, 1991; Charmaz, 1995; Deegan, 2001; Frank, 1995; Kenny et al., 2017). All this materialises in particular ways for young people, given that their previous life experiences, perceived maturity, expected futures, and current social situations have a significant influence on their experience and management of chronic illness (Bray et al., 2014; Gabe & Monaghan, 2023; Gannoni & Shute, 2010; Monaghan & Gabe, 2019; Wedgwood et al., 2020).

Childhood, adolescence, and young adulthood are ambiguous categories which are defined in part both by the liminality of those in them (Brannen & Nilsen, 2002; Bynner, 2005; Kroger, 2004; Montepare, 2009; Pais, 2022; Tait, 1993) and their instability as social categories (Barker & Galambos, 2005; Horowitz & Bromnick, 2007; Settersten, 2009; Settersten & Mayer, 1997). Youth sociologists have paid close attention to the ways that young people think about and negotiate their futures, and have demonstrated the need for scholars to consider how structural factors and individual agency are proactively and powerfully negotiated in young people's lives (Anderson et al., 2005; Bryant & Ellard, 2015; Coffey & Farrugia, 2013; Foster & Spencer, 2011; Reiter, 2003).

Previous research has demonstrated the significant diversity in responses to illness present amongst young people (Grinyer, 2007; Poku & Pilnick, 2022), ranging from careful acts of concealment and projections of 'health' (Heaton, 2017; Monaghan & Gabe, 2016, 2019; Spencer et al., 2017, 2021), to the side-lining of illness as just another challenge when 'growing-up' (Bell et al., 2016; Gibson et al., 2013; Monaghan & Gabe, 2015; Saunders, 2017),

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[20] More detail on the literature summarised in this section can be found in Chapter Two, pages 29-35.

to the deliberate incorporation of illness into their identity in order to empower themselves through positive illness narratives (Heaton et al., 2016; Polidano et al., 2020). Alternatively, there are also instances where the sudden but long-lasting disruption of illness is extremely troubling to young adults and their sense of biography and life-momentum (Hunt et al., 2024). Peer support mentorship is an underexplored possibility in this area (Dave et al., 2024; Kaufman et al., 2022; Kulandaivelu et al., 2021), that has the potential to greatly help young people as they learn to live with illness (Anthony et al., 2020; Hayes & Balcazar, 2009; Hill et al., 2024; Kohut et al., 2017; Wedege et al., 2024).

Results

Without guidance, without control

Participants reported that their ability to take control of their illness was hindered by their youth in two key ways. On the one hand, they had not been properly educated about chronic illness, and schools often did not have the ability to help them with (or help them identify the emergence of) their illness. On the other, their youth meant that adults in their life did not trust their expertise and did not give them the autonomy or freedom to advocate for the kind of care they wanted and needed.

For many participants, the way that school had failed to prepare them for chronic illness was front of mind. As explored in Chapter Four, there were some cases where the school had failed to see the existence of chronic illness, and in those cases the disciplinary nature of schools often worked against them, punishing them for not being able to keep up, and teaching them to see their illness as a shortcoming of their character. In an educational sense though, participants felt that they had not been taught about the existence or realities of chronic illness.

The implications of this were explained by John (26-29, neuroimmune condition), whose illness (he now knows) had appeared before puberty. People who become ill when young, John explained, “have no bearing” about what is normal, which makes illness particularly difficult to identify without a theoretical and explicit education on how chronic illness can manifest. John’s story reveals the various elements of education about chronic illness that were lacking, and he could now articulate what it was that he did not have throughout childhood and adolescence: he did not have an understanding that his physical and psychological experiences could indicate physical illness; he did not have the vocabulary to explain what he was going through; he did not have the ability to advocate for himself; and he was not taught emotional or psychological tools to assist him to come to terms with physical illness when it was diagnosed. The implications of this are not isolated to childhood, since, in John's words, "if a kid doesn't know and isn't told, they get to be an adult and they still don't know."

In his interview, John spoke in general terms about what he had not known at school. Other participants were more explicit in their descriptions of what was missed in the curriculum:

> "We didn't learn about it all. We didn't learn about disability, we didn't learn about chronic illness. So even just being represented would be incredible. Because the idea to me when I was young was, if someone got sick, they got better – that's what I knew."
>
> (Grace, 21-25, female, neuroimmune condition)

> "I think the idea that your body could limit you was never really explored or discussed at school. […] I think in general we make medicine out to be something it's not. We just assume that unless there's a drug to fix it it's not real thing, and we assume that if you find a drug, that will just negate the effects of the illness."
>
> (Sarah, 19-21, female, CFS/ME)

The sense of a failure in the education system was particularly pronounced for women who were frustrated that, although there was ostensibly education about reproductive health, it felt short in several ways. Notably, female participants with non-reproductive chronic conditions still saw these failures in their education as evidence of the broader shortcomings of school curriculums:

> "Even things like, 'you have your period every 28 days.' As in, obviously you do learn 'that can vary,' but I literally don't know anybody whose body seems to follow the cycle that we learned at school. And that just interests me. Like, obviously that's something that should at least just pop up, that that's just literally a theory and not so much the practice of what a human body will probably be like."
>
> (Helena, 22-25, female, endometriosis)

> "And even women's health is so not educated on, so something like invisible illness is so far away. […] There are all these health things we aren't educated on, things that could empower women to understand their own health."
>
> (Tess, 26-29, female, MCAS)

> "I wish that maybe in the education system, in PDHPE[21], that we weren't just talking about regular cycles, that we were also talking about rarer cases, so people would just at least know they exist, so that when someone tells you they do have it, it's not the most surprising thing."
>
> (Lara, 22-25, female, hypothyroidism[22])

Grace also felt that the curriculum elements on the need to "be healthy" furthered the idea that health was something moral, and that those who become ill must have done something wrong:

> "I think, particularly among young people, there's this idea that we're invincible in some way, an 'if I do the right thing nothing bad will happen to me' sort of thing. And then the flipside is that if something bad does happen to someone, people look for a reason for it. Maybe they deserved it in some way. […] I think that was fairly ingrained in what we were taught."
>
> (Grace, 21-25, female, neuroimmune condition)

Part of this concern is essentially about biology and health curriculums lacking information on chronic illness, and indeed suggesting harmful and incorrect information about what causes illness. But some participants also explained that they would have benefited from

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[21] PDHPE [Personal Development, Health and Physical Education] is a mandatory subject for the first four years of high school in NSW. It seeks to help students develop their knowledge about their own and others' health, safety, and wellbeing.

[22] Hypothyroidism is a condition where the thyroid gland is underactive, meaning it does not produce enough thyroid hormone. Symptoms may include fatigue, muscle weakness and pain, low mood, and constipation. It is often caused by Hashimoto's disease, an autoimmune disease, attacking the thyroid gland, but it can also come from other causes, including infection, or the cause can be unclear.

more education on how to be resilient in the face of chronic illness and pain, given that, without life experience, the disruption they faced threatened to be completely overwhelming:

> "You are so impressionable, and you just don't have the outlook on life. You just don't know what life is like, maybe as much as people who are older, or people who have had those life experiences to build up some resilience or a general understanding of the world."
>
> (Matt, 22-25, male, autoimmune arthritis and degenerative spinal injuries)

The impacts of an inadequate education were compounding: it took longer for illnesses to be recognised, people did not have the vocabulary to make sense of their symptoms, and they had to live with the repercussions of having learnt (and others having learnt) to see their symptoms as personal weakness and not deserving of attention.

On the other hand, when conditions were diagnosed, young people wanted to maintain control of their bodies and illness management strategies. It was rare though that the adults in their life and/or the institutions they interacted with managed to help them exercise this agency:

> "I remember my teacher once said, 'whenever you need to just treat your hypo, go get food if you need it.' And we were playing sport one time, and I was having a hypo, I had the shakes, so I was just like, ok I need to go back to the classroom. […] And I came back, and she got so mad. She was like, 'you can't just leave.' And I was like, 'but you told me…' It was really confusing, because it's like, I feel like I'm about to pass out, and I need to take care of myself right now, but you're mad at me?"
>
> (Ethan, 22-25, male, type I diabetes)

> "When you're younger, when you're under the care of your parents still, they are definitely a huge influence and impact on how you are feeling about the situation, and how well you feel you are in control of the situation. Because I think part of it for me, thinking back, is that sensation of, that idea that you don't really have control, because you've just drifted into this whole situation. You're so young, you can't really comprehend what is happening […] And then to have someone just being over-archingly too helpful, it's also quite bad. Because again it's making you further feel like you're not in control."
>
> (Adam, 26-29, male, IBD)

In Ethan's case, the potential damage from the disciplinary instincts of school is again clear, as he was made to feel bad for taking care of himself. In this story, it is not just that Ethan was in trouble when he tried to look after himself and exercise control over his medical care – the teacher and school had also presumably given inaccurate or ill-thought-out advice upon his diagnosis, and then upon realising that they were not actually comfortable with a child walking off when having a hypoglycaemic attack, did not engage him in a conversation about what would make sense going forward.

Adam succinctly brings together, then, the compounding way that control is taken away from young people: they feel out of control in relation to their body and situation, and the response of adults can be smothering, particularly at an age where you might otherwise be seeking to explore and exercise newly emerging independence.

Many participants felt that they were now better able to articulate how this loss of control had further demoralised them in the face of illness. Matilda, for example, who started having seizures during high school, told me about how much she had hated the "fuss" around her as a teenager. She was pleased that she was now better placed to assert control over her own medical care by, for example, taking herself to the hospital rather than having someone else call an ambulance even though she was conscious after a seizure:

> "People kept trying to tell me what to do with it. Saying, 'well if this happens you have to do this, and let me know about this, and we'll go and do this.' Back when it started, I was like, 'cool, yeah, ok, cool, whatever.' Basically, whatever is easiest for you, because I'm a burden. But nowadays it's like, 'no, if this happens, and I'm not there, then you can do whatever you want. If I'm there physically, and mentally I have control, don't touch me, don't talk to me, I'm ok.' I'm old enough to deal with it myself now.
>
> (Matilda, 19-21, female, epilepsy[23])

Matilda's recount of the evolution in her ability to advocate for herself was echoed in other interviews. Catherine, for example, explained her increasing frustration at her parents 'babying' her:

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[23] Epilepsy is the umbrella term for neurological disorders that cause repeat 'epileptic' seizures – unprovoked instances where abnormal, excessive, and synchronized electrical activity in the brain causes either absence seizures or convulsive seizures.

> "I get that [my parents] are worried as well because I am overseas, so they don't see me. But sometimes I'm like, 'ok, can you please stop worrying so much?' […] I don't like having to be babied, or constantly watched over. I'm not an *adult* adult, but I'm still independent. I feel like having someone constantly be like, 'Are you ok? Are you ok? Are you ok? Are you ok?' I don't know how to describe that feeling."
>
> (Catherine, 19-21, female, autoimmune arthritis)

The ways that adults with authority (e.g., parents and teachers) do not allow young people to exercise agency in their own medical care are a part of the same systems and assumptions which do not give children and adolescents education about chronic illness. The attitude is one that neglects to take seriously young people's need and right to understand what is happening in their own bodies, to treat these health experiences on an individual basis, and to value and trust the expertise that they can develop if they are given the practical and psychological education to do so.

This dual lack of guidance and autonomy was deeply upsetting for participants, both as it happened and in hindsight. It was additional pain in an isolating experience and, given the ways in which illness can make one feel like they are losing control of their body, it was particularly frustrating and disturbing. This lack of knowledge, and discomfort with how authority figures reacted, also played into the ways that illness made socialising difficult as a young person.

Disrupted youth, disrupted futures

Participants did not feel comfortable talking about their illness with peers, and when they did talk, their peers rarely knew how to effectively offer support. The next chapter (Chapter Six) will look in detail at the emotional toll of not being able to talk about illness, but here the focus is on the ways in which chronic illness interacted with the social expectations of youth.

Participants who had been ill while at school recounted difficulties specific to the school environment. Matt explained that:

> "I was in quite a few different leadership roles and other capacities in Year 12 [the final year of high school]. It's a very kind of, intensive year, not just academically. And so I think that was also really difficult, because it lead to a lot of… a lot of situations where

> I found that I probably didn’t at least feel like I was living up to my potential in those areas. […] I think socially as well, [sport is] a huge part of your identity. I think one thing I really struggled with from a self-image perspective was that suddenly I was on the outer, after growing up having always been on the inner.”
>
> (Matt, 22-25, male, autoimmune arthritis and degenerative spinal injuries)

These school-imposed and age-related expectations were present in all participants’ stories, but the contexts in which they were felt by participants varied. Stacey was in a very different situation to Matt – she had experienced gradually worsening fatigue and brain fog throughout school, rather than a sudden injury which triggered the diagnosis of a chronic illness. Her memories of school demonstrate another way in which school can create difficult circumstances for young people living with chronic illness:

> “I was not only needing to deal with the physical symptoms, [I was] dealing with the sadness of not being able to keep up with people my age, [and] then I was getting in trouble, punished, for those things.”
>
> (Stacey, 22-25, female, CFS/ME)

This idea of sadness and grief resonated in all interviews. Both at school and beyond there were issues of chronic illness threatening (and ending) connections with peers – the repercussions of “not being able to keep up”. Often, even though peers may have been able to superficially acknowledge their friend’s illness, there was not a meaningfully change to how a group of friends socialised, thus still locking out those living with chronic illness:

> “Sometimes it’s… frustrating when I do share it with people, and I get a kind of, ‘oh ok, that sucks,’… but that’s kind of the limit of it. […] Most of the time it’s like, ‘oh you can’t come? Catch you next time maybe.’ But next time I could be out of it again, and it doesn’t fix the problem. […] They’ll make the consideration of, ‘oh, that explains his absence,’ but they won’t go to the step of trying to work around that. They’ll just be like: That sucks. I’ll go enjoy myself now. […] Maybe next time?’ And it’s like, but it’s chronic, it’ll still be here next time.”
>
> (Fred, 19-21, male, CFS/ME)

> "You get to the situation that is quite common, I think, which is that you say no once, you say no twice, and then the invitations stop coming."
>
> (Adam, 26-29, male, IBD)

Some participants told very specific stories of how their access to 'classic' elements of (a notably gendered (Gibson et al., 2013)) youth was subtly but meaningfully disrupted by illness:

> "[When I was 15 and 16 years old] my friends were all off riding bikes, playing basketball, surfing, whatever, and it would just be like, 'oh, shit, I'm having a hypo,' and grabbing a handful of jellybeans and throwing them back. […] Especially at high school, I was so hyper aware of what people thought of me. […] I was very hyper vigilant of how I was perceived. All boys as well, so it was like, I don't want to be perceived as weak."
>
> (Ethan, 22-25, male, type I diabetes)

> "A lot of time girls go to the bathroom when they're drunk, or just in general girls go into the cubicles together, and I would always try not to do that because if I need to go to the toilet, I won't necessarily have anything come up, but it feels like period pain in your stomach area and you just need to sit there and chill out a bit. You can't do that if you have three other girls there waiting to use the toilet. Stuff like that. I'm not saying I want to go to the toilet with someone else, that's weird, but like… yeah."
>
> (Emma, 22-25, female, IBD)

These stories are not of overt exclusions, as both Emma and Ethan were engaging with their groups of friends, presenting, on the surface, as any other member of the group might. However they were still extremely aware of their illness and how they needed to manage their bodies within these settings. Things that they had to do, or had to avoid, were not even necessarily noticed by others, but, for them, they were heavy with meaning.

Social relationships were also strained when friends and acquaintances tried to connect by saying some version of "I have something similar" – a response that frustrated participants:

> “When I was younger, 17, 18, 19, […] if I tried to bring [endometriosis] up it wasn’t seen as a specific thing, like an illness or something I was struggling with, it was just something everyone was dealing with.”
>
> (Helena, 22-25, female, endometriosis)

> “Because when doctors don’t even understand something, and your parents don’t even understand something, how are your 12-year-old friends going to understand it? The times when I even just scratched the surface of it, people would be like, ‘oh I had a cold last month, is that the same? [Sigh]. It’s like, I appreciate the empathy, but no.”
>
> (Sarah, 19-21, female, CFS/ME)

As Sarah said though, what else could people do – especially children – if they have not been taught any better? David had a similar perspective:

> “Because they wouldn’t expect someone to have chronic illness they’ll play it down – you say, ‘I’m going through X’ and they say, ‘oh I’m also going through X.’ You’re not, you’re just a bit stressed, or you’re just a bit sick, or you’ve got the flu. It’s not the same, it’s different. It’s almost like they can’t process the fact, unless they get sick themselves, that young people can get sick to this extent.”
>
> (David, 19-21, male, fatigue and dysautonomia)

Some participants now had friends that were accepting and supportive of chronic illness, but despite an improved friendship dynamic, participants often still felt a deep desire to not let their chronic illness be ‘disruptive’ to the group:

> “I think no matter how much [my friends] comforted me I was just like, ah, I feel so… like, stupid. I don’t know how to describe it. It’s like, sometimes I’m going out with them, and then midway I’m like, oh my god, my knees are in pain, let me sit down, and I bring down the whole vibe. And I’m like ok… should I just push through? Do I push through and worry about how my friends will feel? Or do I just rudely take it slow? […] It really depends on how painful it is. Like, if I’m about to break down in tears, maybe I’ll take a break.”
>
> (Catherine, 19-21, female, autoimmune arthritis)

This final assessment, that “if I’m about to break down in tears, maybe I’ll take a break” speaks accurately to the extreme lengths many participants went to when concealing the impacts of their illness. This fear of the repercussions of illness being seen is explored more in the next chapter, but, for now, what this quote reveals is participants’ discomfort at disrupting the pace of youth: something like “taking it slow” became a “rude” request that would make others uncomfortable and “bring down the whole vibe.” Illness was at times reported by participants to be directly contradictory to what their peers would want to do to live well as a young person. In this respect, chronic illness created temporal frictions with the expected velocity of an ‘unencumbered’ youth.

For participants, these perceived and actual disruptions were a significant source of pain, insecurity, and grief. Participants believed that their social circles of young people were ill-equipped to deal with chronic illness. The temporal friction of chronic illness and youth also arose when participants were forced to think about their future, which, as the next section explores, amplified both the uncertainty they faced and their need to consciously plan their life around illness.

The ways in which chronic illness disrupted youth-specific forms of socialisation form a part of the broader feeling participants reported of having a “disrupted timeline.” The disruption was varied, spanning from a feeling of difference that pervaded some participants’ lives, to the very clear way that illness impacted some participants’ major life-decisions. Grace, for example, had needed to pause her studies, and explained that:

> “My life experiences at the moment are so different to [those of my previous friends and peers]. They are travelling and doing this and that, and I’m living appointment to appointment and taking 30 medications a day and all this sort of thing. I just feel that there’s a massive gap between us in terms of life experiences.”
>
> (Grace, 22-25, female, neuroimmune condition)

Many participants felt that their illness was disrupting their youth and forcing them to behave in a way that was unusual and unfortunate for someone their age. These feelings were made worse for some participants by the fact that people told them that this was supposed to be “the best period of [their] life” (Georgia, 19-21, female, fatigue and chronic sinus infection).

In interviews, participants explicitly discussed how their illness made them feel ‘old’ and disrupted their expectations around being ‘young’. What was disrupting one’s expectation of youth varied. Stacey, for example, was acutely aware of all the things she could not do, which was a near-constant source of disappointment and insecurity:

> "I've always struggled with the fact that every day I have to see people, young people, doing ten times more than me, while I'm feeling weak and incapable. It's definitely had a big impact on my self-esteem."
>
> (Stacey, 22-25, female, CFS/ME)

For other participants, it was the way that illness was providing a structure to their time and lives – the "living appointment to appointment" that Grace described. Often, participants explicitly said that their discomfort came from the fact that they had believed that chronic illness was supposed to structure your later life, not your youth. David (19-21, fatigue and dysautonomia) for example, explained that it was "very weird" to be needing to spend significant time seeking out doctors because he was "not the age I would expect to be going to the doctor this often." Lara also explicitly tied her sadness and loneliness at being diagnosed with hypothyroidism to the fact that she was going to need to manage a diagnosis and daily medication from her early 20s, which she saw as something that most people only needed to deal with later in their life:

> "I just remember talking to my doctor and feeling really devastated. The feeling of having to take a medication for a lifetime, every day. Now that I think about it, it's not such a big deal. But because I didn't know anyone my age who's going through something similar, it felt… yeah, pretty sad. And my mum has hypothyroidism as well, but she was only diagnosed in her 40s. So to think that something affecting my mum late in life was affecting me in my early 20s… just, yeah, that I think felt a bit bad."
>
> (Lara, 22-25, female, hypothyroidism)

Catherine also reflected on a sense of "aloneness" that came from her diagnosis with arthritis – "an old person thing":

> "I got the diagnosis when I was 19, and I was like, 'isn't this an old person thing?' I don't really know how to feel about it. I think it's also the fact that you can't see it physically manifest in someone, especially at a young age, at least in my case. It's like, how do I be taken seriously? […] Even up until now I don't know anybody who has

> arthritis unless they’re in their 70s or 80s. And it just makes me feel a bit… alone. Alone in this journey.”
>
> (Catherine, 19-21, female, autoimmune arthritis)

Catherine’s comment about her fear that an “old person” disease cannot be taken seriously in a young body reflects not just her anxiety about other’s perceptions, but also a struggle that some participants had to feel connected to their own diagnoses. Farah told me that during her first bad arthritis flare she “just felt like a really old person, even though [she] was literally 20.” Later she explained that she had never expected her chronic pain to be caused by arthritis, and when I asked her what it felt like to now have a diagnosis, she admitted:

> “I guess I kind of just feel… I feel like because, um… I don’t know, I just feel like even after getting all of these diagnoses I still can’t claim it. I can’t say I have it, even though I do. It just feels like I’m lying when I say it out loud sometimes, even though I know I’m not.”
>
> (Farah, 19-21, female, autoimmune arthritis and degenerative spinal injuries)

Consequently, participants were often sensitive to situations that drew attention to the (perceived) difference in the age of a participant to the ‘average’ chronically ill person:

> “A lot of the time I do see support groups [on Facebook], but they’re older than me, they just seem a bit weird, and yeah, they’re a lot older. I haven’t seen anyone post who is my age. I’m sure at the hospital they do have people who are younger, but it would be cool to connect with people who are actually my age and get it a bit better, rather than random 40-year-old men on the internet.”
>
> (Emma, 22-25, female, IBD)

> “So I had to go to a fertility specialist and a fertility clinic, and that was really difficult for me because all the women there were in their 30s or late 20s, ready to have children, and I just felt really out of place. […] I guess when I’m older I’ll have other women around me who might be going through fertility problems as well.”
>
> (Rosie, 22-25, female, POI)

It was not just that participants' current lives were not on the timeline they expected – their ability to think about the future was also disrupted, or at the very least changed. Prognostic uncertainty made thinking about the future practically and emotionally difficult:

> "The uncertainty of the future, and not knowing what's going to come of your life – for me that's a big thing, a big part of the experience. I see other people who are my age and they've got a set plan for themselves, a 5 year plan, things like that, whereas in my case I just have to take it day by day."
>
> (Stacey, 22-25, female, CFS/ME)

> "In some ways it's harder when you're looking at the future and you just don't know what it's going to look like, [harder] than it is to just have to get through each hour."
>
> (Grace, 22-25, female, neuroimmune condition)

> "And you keep thinking, hopefully by then I'll be better – but you won't."
>
> (Greg, 22-25, male, CFS/ME)

This refrain about what we might call the hopelessness of hope was common. Participants often described their current situation as something they had "hoped" would not happen in the early stages of chronic illness. Now, having been let down repeatedly, they reported frustration when other people told them to hope for some kind of improvement in their future. Still, though, this frustration that was accompanied by some form of guilt. As Rosie explained:

> "I love the hope, but I also get frustrated, because you've got to be realistic. So sometimes I just give up explaining things."
>
> (Rosie, 22-25, female, POI)

The weight of expected timelines and the future was particularly heavy when discussions about fertility arose. In my sample, it was only women who spoke about this issue. In the case of reproductive conditions especially, fertility issues were a huge cause of anxiety and grief:

> "I think it's a huge fear amongst women – we have this expectation, this clear line of sight that we will fall pregnant and have children, but a lot of the time it's definitely not that easy. So yeah, I wish there was more education about it. And conversation as well."
>
> (Rosie, 22-25, female, POI)

> "In terms of careers and stuff… it's weirdly another pressure, that I don't know if I can have children. It's just a big thing – it shouldn't be, but it can be. It's such a big thing when someone's thinking what career do they want to do and do they want a family. There's another element of that for me, where I'm like: 'Should I even bother worrying about this? That might not even be a problem for me. Do I want it to be a problem for me?' That can be a little confusing. And I feel like it's something I have to worry about a lot earlier than almost all of my friends. It's something on my mind: 'Do I want children?' And it's quite often on my mind, or more often: 'Will I be able to have children?' Which I feel like just doesn't worry – so far as I've heard from my discussions with people – anyone else who is my age as much as it worries me."
>
> (Helena, 22-25, female, endometriosis)

This anxiety about pregnancy and family planning was not, however, isolated to women with reproductive illnesses. Other illnesses could impact one's ability to carry a child, and many medications both cannot be taken while pregnant and cannot be assumed to keep working if someone takes a break from them for pregnancy:

> "I think this is probably what I found hardest to deal with: being told that now I take a lot of medications that, if you get pregnant and you want a baby, you've got to talk to us about it because you can't get pregnant on these medications. […] It's like, ok cool, well because I can't take all of this do I want to make myself really sick to have a baby and then still not be able to fully start back on after the child? Because you can't breastfeed either. Of course there are alternatives, but there are just all these things that people don't realise. And I think that was definitely the thing that took the biggest impact, finding out that these things have an impact on your fertility. [… Someone] was like, 'oh you'll be happy about that because you don't even want kids.' And it's like, I think there's a difference between wanting kids and being told that you probs can't have them, or it's going to be higher risk for you or potentially the child. […] And they meant well, and it's like, you're not wrong, right now I don't want them, but you can aways

> change your mind when you're 30. And I think it's something that's really hard to hear in your mid-twenties, just 'hey, all of this is going to start to have a really big impact on your fertility.'"
>
> (Lisa, 26-29, female, IBD)

Lisa and Helena's quotes exemplify the circular anxiety that many participants found themselves in when thinking about the future – they were not only lacking prognostic information, but they also just did not have a sense yet of what they wanted their future to look like.

In many ways participants' futures were explicitly unknowable because of the uncertainty of illness, and this created a dual, paradoxical loss: the future became both a constant source of preoccupation and painfully unknowable. This contradiction was clear in Stacey's lament that "a big part of the experience" was living with "not knowing what's going to come of your life… I just have to take it day by day." What Stacey is describing is not at all a lack of *awareness* about the future – it is a hyper awareness that the future is there but unknowable.

Participants lost the ability to think un-seriously about the future, because illness made it difficult to ignore questions of, for example, fertility and family planning. This is similar to what Greg described when he explained how "you keep thinking, hopefully by then I'll be better – but you won't." Usual fantasies of youth are of course also subject to the various realities of life, but for Greg, his dreams were haunted by his own constant, brutal reminder to himself that "you won't [be better]". His stern certainty actually contradicts the extreme prognostic uncertainty of his condition, CFS/ME, and perhaps suggests that, for some people and in some situations, certainty about misfortune is easier than living with a constant awareness that your hope may be misguided.

Affinity and connection in unknown territory

Given all this, participants found it extremely meaningful to connect with other young chronically ill people. This is important context for Chapter Seven, which looks at the actual and potential role of online support. Chapter Seven will explore further the ways that participants' insights on support are instructive for what kinds of programs could and should exist, but for the purposes of this chapter, participants' discussions of support are also helpful for understanding what can cause feelings of isolation.

Although most participants had not had the experience of someone with lived experience helping them, they wished that they had. Matt explained that:

> "It just would have been nice to… meet other people, or even speak to them. […] That's one thing I'd definitely change. Just some sense of comradery and not being so alone."
>
> (Matt, 22-25, male, autoimmune arthritis and degenerative spinal injuries)

Adam could imagine a program of mentorship also, which he felt was particularly well-suited to young people going through chronic illness:

> "Because it's one thing to sort of build your mental health and learn strategies to deal with it, but it's another thing to find someone in a similar situation that can understand you a bit more. […] And sometimes you do feel – not lonely – but the fact that there are no other people who I have met personally who have the same condition, sometimes it's hard. Even though you have your loved ones you can talk to, do they really understand the full situation? […] I can envision that if I were to have someone from a very young age who was going through the same thing, we would be able to support each other in ways other people can't, no matter how loving that person is, how caring that person is."
>
> (Adam, 26-29, male, IBD)

Sarah had met someone who also had CFS/ME, and she saw that relationship as very important to her understanding and management of her illness:

> "I had a youth group leader who had gone through chronic fatigue. And she was fantastic. […] And I remember just being so grateful for that, and just thinking, 'ok, you get it, because you went through that experience, and I am benefitting from that.' And I think that really just showed the value of shared experiences, and knowing people who know. […] She showed me how to care for myself […] and seeing her having come through the other side was really helpful."
>
> (Sarah, 19-21, female, CFS/ME)

The words of participants speak to the ways in which various aspects of youth and illness interact to create a very particular experience. There is not 'one thing' that participants wanted people to understand – their experience was one where misunderstandings came from all around. Both Aisha and Grace spoke about the support that they had found online, from other young people with very varied conditions. Their descriptions of these connections indicate some often-present components of chronic living while young:

> "There's an understanding that we all share – it's the same feelings with different conditions. You're worried about being a burden. It's difficult to accept people taking care of you, especially if you are young. You're worried about the responsibility – financial or otherwise. Or life-wise, you're worried about – my timeline is very far behind my peers in school, I'm studying a degree where I have people in my class who are 19. It is difficult to see yourself integrating back again in normal life."
>
> (Aisha, 26-29, female, neurological condition)

> "I find it much easier to connect with people who are also ill. […] I think a lot of it is around: all of us have lost that trust with our body. And also a degree of independence, whether it's because you faint or have seizures or whatever. That trust of your body and independence, it's easy to relate about that stuff. And also, all of us have been essentially human pincushions with tests and blood tests, procedures, all that sort of thing. And even the medical system and some of the trials and tribulations that come with dealing with that a lot. And so there's a lot we have in common even if our diagnoses are completely different. And there are people in that [support] group who don't have any physical illness, but who have a mental illness, and there are still massive similarities that come with not knowing what the future holds, and trust, that sort of thing. It's pretty easy to connect to anyone who is young and has that experience."
>
> (Grace, 22-25, female, neuroimmune condition)

Grace's description of how "all of us have been essentially human pincushions" speaks to the way that the crucial experiences of establishing independence and identity when young can be subsumed by medical experiences and narratives of illness. Further, "not knowing what the future holds", losing "trust" and "independence", being a "burden" and having a "timeline [that] is very far behind my peers" all take away the usual points of connection people may have with others and with 'youth'. As Aisha explains, this is not only upsetting, but it also makes it "difficult to see yourself integrating back again in normal life."

As discussed in greater detail in the next chapter, simply being able to talk about these things is important. Further though, Sarah's observation that meeting a (still young) mentor with CFS/ME was important because it allowed her to see someone who had "come through the other side" and "showed [her] how to care for [her]self" speaks to the reverberations that can come from a lack of education on chronic illness. Sarah appreciated guidance on how she could exercise her agency in caring for herself, and also found the presence of another person who could relate to her life important for imagining what her future could look like.

Discussion

For participants, a central aspect of the unsettling nature of chronic illness was how it disrupted their youth and life-course expectations. These disruptions contained multitudes: usual patterns of 'learning' while young were non-existent in regards to chronic illness; rather than gaining agency, independence and identity as they grew older (Coffey & Farrugia, 2013; Kroger, 2004; Pais, 2022), illness caused people to feel and be infantilised; key social experiences of youth – school leadership and learning, friendships, playfulness – were disrupted and risked being lost; life became defined by appointment and medication schedules; bodies felt 'old' and untrustworthy. Despite the current ambiguity of what it means to be 'young' (Barker & Galambos, 2005; Brannen & Nilsen, 2002; Bynner, 2005; Horowitz & Bromnick, 2007; Montepare, 2009; Settersten, 2009; Settersten & Mayer, 1997), the cultural potency of youth becomes clear in the grief and instability felt by young people living with chronic illness. This attention to life-course trajectory has appeared in a small number of previous studies in the sociology of health and illness (Hunt et al., 2024; Poku & Pilnick, 2022; Saunders, 2017). This study, which engages with a participant cohort living with a variety of diagnoses and health histories, indicates that young adults develop and maintain nuanced and varied understandings of their relationship with illness, biography, and life-course expectations.

Much of the literature surrounding biography and timelines is focused on how, either, 'crises' disrupt life plans and identity (Alheit, 1994; Bury, 1982; Charmaz, 1983; Frank, 1995), or, how potentially conflicting narratives of self and others are managed (Brown & Patrick, 2018; Monaghan & Gabe, 2016; Spencer et al., 2021; Tavory & Eliasoph, 2013). To some extent, the instability reported by participants in this chapter affirms the emotional importance of biographical narratives and future planning (Deegan, 2001; Frank, 1995; Kenny et al., 2017; Kleinman, 1988; Somers, 1994; Tavory & Eliasoph, 2013). The disorientation of participants went beyond this though, since there was rarely a clear point of disruption, or different life plans to be reconciled. Instead, participants reported a pervasive tension between youth and chronic illness that defied deliberate management. This unease in young adulthood seemed to echo the way that, as children, participants had often been in some way disciplined in relation to their illness, and made to feel out of place and lost. Their references to ‘timelines’ and ‘youth’ suggests that the social and cultural importance of these ideas were reinforced when they were felt to be absent, particularly in the context of experiences and narratives that made participants feel shamed, othered, or out of (and unworthy of) control. Feeling not like other young people, and not like other ill people, was one way to articulate the absence of suitable narratives and vocabularies about their experiences.

Consequently, participants’ attempts to “coordinate their futures” (Tavory & Eliasoph, 2013) were not only challenged by prognostic and temporal uncertainties (Ehlers et al., 2024; Jain, 2007; Kafer, 2013; Olson, 2011; Sheppard, 2020; White, 2022) – participants also struggled to place themselves in a life course timeline. This was compounded by the broader narratives that paint chronic illness as a disruption that emerges in later life, as people shift from ‘well’ to ‘ill’ in what is depicted as a deterioration that is regrettable and should be resisted (Kafer, 2013; Larsson & Grassman, 2012; Manderson & Wahlberg, 2020; Prince et al., 2014; Sanders et al., 2002). There is an increasing body of evidence that explores the ways in which precarity complicates young adults’ relationships with the future (Anderson et al., 2005; Bryant & Ellard, 2015; Foster & Spencer, 2011; Reiter, 2003), and this study suggests that chronic illness creates a related but specific complication for young adults undertaking this task.

Living with potentially compromised independence and identities, participants became hyper-aware of their unknowable futures. The pain associated with this was again inflected by their youth – their peers could both “have a five year plan” and “not worry” about their future. Participants grieved the freedom to plan – or not plan – their days, weeks, and lives. In the context of what could be described as a “regime of hope” in medical spheres (Petersen, 2015; Reddy, 2001), the failed promise of hope resonated with the failed promises of youth and medicine in participants’ lives.

Practically, some of the friction between chronic illness and the expectations of youth can be addressed with more sensitive and informed understandings of what young people need and desire. While participants were in some ways experts in their own condition and needs, they also recognised that, particularly at the onset of illness, guidance and support was crucial, especially given their age. The absence of education on chronic illness was partly responsible for participants’ struggles to interpret and manage their experience, and their peers’ struggles to respond supportively. Moreover, participants could now explain that the avoidance of chronic illness at school implied that it was a rare, unimportant, or individual issue – a message that could have been internalised subconsciously, even if the construction of school curricula was only interrogated as adults.

Participants’ grief was often not understood by their peers. When participants did find people who understood, this bond was immensely meaningful. There needs to be more ambition and creativity when thinking about how to foster meaningful peer support and mentorship opportunities for young people living with chronic illness (Hayes & Balcazar, 2009). These relationships not only helped participants feel understood, but it gave them opportunities to develop new connections between individual experiences and the timelines which chronic illness had now placed them on.

CHAPTER SIX | chronic consciousness

Introduction

From the onset of chronic illness, a variety of challenges emerge which both persist and evolve as life continues. For young adults living with chronic illness, the age-specific difficulties of becoming ill while young form a foundation that shapes their experience of illness in enduring ways. In this chapter I argue that participants demonstrated an emergent *chronic consciousness* of how others perceived their health, which created a series of fraught affective tussles centred on relational recognition and feared judgement. The process of learning how to navigate these issues became one important way that participants began to integrate their illness (and its implications) into their emerging sense of self and adult life.

In interviews, participants consistently recounted their concerns about how their illness and health was viewed by others. This concern often came from their own sense of disorientation in illness – illness felt indescribable, and they reported losing trust in their body. This embodied sense of instability furthered fears about how others would view them. Participants therefore engaged in concealment practices due to a concern that the 'healthy other' would see them as someone defined and limited by illness. The pressure to hide or deny the impacts of illness was exacerbated by institutional and social rhetoric that promoted normalcy, cohesion, and control of one's body. That said, participants did find ways to understand and discuss their illness outside of the shadow of social and institutional binaries, and these stories are instructive for how a different social construction and cultural discussion of illness could better serve young people with chronic illness.

Background[24]

The lived realities of chronic illness cannot materialise overnight. Deciding to seek medical help, protracted diagnostic processes, and even longer trajectories towards any available treatments, can take months, and for many, years (Jeske et al., 2024; Sheppard, 2020). In addition, it takes time to come to terms with what it *means* to live with a chronic illness,

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[24] More detail on the literature summarised in this section can be found in Chapter Two, pages 16-26.

especially given so much of this experience is tied up in the cumulative weight of looming and/or disruptive chronic symptoms (Halloy et al., 2023; Sanderson et al., 2011; Saunders, 2017).

There continues to be considerable medical uncertainty surrounding many enduring and emerging chronic illnesses, with possible treatment regimens and prognostic trajectories often remaining unclear after diagnosis (Boulton, 2019; Bülow, 2008; Ghai et al., 2020; Harsh et al., 2016; Overend, 2014; Uher et al., 2023). This ongoing lack of clinical clarity and everyday uncertainty has serious medical, social, and emotional consequences, including around the perceived legitimacy vis-á-vis stigma associated with many chronic conditions (Broom et al., 2015; Dumit, 2006; Jackson, 2005; Mescouto et al., 2022). In this sense, the legibility and recognition of one's illness is an important component of what chronic living looks like for each individual (Barker, 2002; Boulton, 2019; Dudley et al., 2023; Moss & Teghtsoonian, 2008; Nettleton, 2006; Overend, 2014; Whelan, 2007). Sociological literature on visibility and recognition provides additional and important contextual framing – visibility exists on an actively managed scale, where in some cases visibility can be sought/denied, and in others observation can be hostile and dangerous (Brighenti, 2007; Casper & Moore, 2009; Goffman, 1959, 1963; Gray, 2009; Hegel, 2003; Honneth, 1995; Mead, 1934). Of particular relevance to this chapter is Du Bois' quote describing self-other relationships in the context of power imbalances, hostility, and discrimination:

> "It is a peculiar sensation, this double-consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity."
>
> (Du Bois, 2007[1903], p. 3)

The "psychosocial 'texture'" (Wetherell, 2012, p. 2) of chronic illness is therefore made up of the relationships between the lived physical experience of illness and pain, individuals' previously established beliefs and emotions, and encounters with others which are both real and imagined (Ahmed, 2004a, 2004b, 2015; Goodley et al., 2018; Sointu, 2016). The tussles between care, visibility, and privacy are also explored in critical disability studies (Kafer, 2013; Kittay & Feder, 2002; Shakespeare, 2000; Wendell, 1996). In particular, feminist disability literatures provide a rich conceptual understanding of how binaries permeate society, disorienting individuals and denying embodied knowledges (Garland-Thomson, 2002;

Haraway, 1988; Harbin, 2012, 2014, 2016; Lajoie, 2019; Meekosha, 2011; Morris, 1992; Wendell, 1989).

Results

Disorientation

When recounting the onset of illness, all participants reported points in time where they felt disoriented, overwhelmed, and suffocated. Their descriptions of these feelings extended beyond the difficulties of managing symptoms: they recalled a sense that something fundamental was changing or had changed, but that they did not know how to articulate what was going on.

When Matilda (19-21, female) had her first seizure over four years ago, she and her family were told that it was likely a one-off event. A few months later though she had another seizure, but when she was taken to hospital the epilepsy diagnostic tests – which seek to trigger a seizure – could not find anything abnormal. What followed was a cycle of trialling epilepsy medication, having 4-6 months seizure free, having a seizure, and then needing to either increase her dose or try a new medication all together. Doctors still cannot tell her what type of epilepsy she has.

Her description of the first three years of this cycle revealed the ways in which these feelings of disruption and doubt cast a shadow over her whole life. It was precisely that though, a shadow, and the impact was everywhere but difficult to grasp or define:

> "Because when it first happened, it was just this sense – just this overwhelming sense that did take a long time to really process – it was just the whole thing of: this has changed my life forever. Even if I get over it, even if it passes, even if it turns into something worse or better, it still is a big block on my life. It took a long time to get through the whole thing of, 'what do I do now?' […] You feel locked out, but also surrounded. Like… I don't know how to describe it. I felt pushed to the side of who I was before, but at the same time just constantly surrounded by questions."
>
> (Matilda, 19-21, female, epilepsy)

Another participant, Jack (22-25, male), recalled the way in which the onset of fatigue in high school had an immense emotional toll on him. He knew that something was wrong, but he could not explain to himself or to others what was going on:

> "Over time these things start stacking up. And it just… it gets to this point where it just… you're so alien from – you just feel so alien from yourself. These things that are so mundane and easy become so challenging. And there's just not words for it, because how do you describe something that is the total lack of anything happening at all?"
>
> (Jack, 22-25, male, CFS/ME)

These descriptions extend beyond a loss of self that comes from no longer being able to partake in activities that usually help construct one's identity and life. Instead, participants described the uncertainty of illness overwhelming their ability to know who they were – there were so many questions, and so much difficulty in articulating the disruption of illness, that they were too disoriented to keep sight of themselves.

When participants had not initially received the help they needed, this often continued to undermine their confidence and ability to speak to others about what was going on and the support they craved. Some participants had previously been convinced by health professionals that nothing physical was wrong with their body or health, while others had suspected something was wrong, but had sufficient uncertainty around their experiences that seeking help felt impossible. As Jack said when reflecting on his time at school:

> "And how do you approach a teacher when you're like, 'I'm in pain and really confused.' That's a lot, and it's so broad, it's just really hard to get help. Unless you already… unless you're really able to be honest with yourself and with teachers, and you have a lot of experience in that, how are you supposed to suddenly open up to these people and get the support you need?"
>
> (Jack, 22-25, male, CFS/ME)

When participants discussed the difficulty of seeking help, they often spoke of struggles they faced internally. Difficulties in describing their illness, or admitting they needed help, were barriers to identifying, never mind advocating, for their own needs. Often, the intermingling of physical concerns with mental health issues led to participants doubting themselves as well as being doubted by others. Further, symptoms like fatigue and pain made it so that participants felt they did not physically have the capacity to seek help. Sarah (19-21, female), who had been living with CFS/ME for almost ten years, admitted that while at school "in many ways it was easier to just not talk about it, let them think what they want to think, and go alone." While at times framed as an individual issue, participants' difficulties in speaking about their experiences also reflect that the institutionalised expectations of illness did not reflect their embodied experiences, rendering it unspeakable.

Trust was another recurring theme in participants' discussions of their illness experiences. Trust was not only an important (and often missing) dynamic with their treating physicians (Boulton, 2019; Gilbert, 2004; Jain, 2007) – participants often recalled losing trust in themselves and their bodies. This was the case for Grace (21-25, female), who had begun experiencing dysautonomia symptoms over five years ago. While her initial diagnosis had helped her make some helpful lifestyle changes and explain to others what was going on with her health, it did not resolve her own anxiety and distress at the realities of living in her body:

> "I guess I had lost a sense of trust in my body. Particularly with my fainting, I was always worried about where I would faint, if there would be someone around me who could help or who would know what was happening, who could explain it to others. I was like, 'I don't want an ambulance called, I don't want that.' I would get my friends and be like, 'can I go faint in your car instead of being in a public place?' So that sort of… I didn't trust my body."
>
> (Grace, 21-25, female, neuroimmune condition)

Participants spent significant time describing their emotional distress and confusion about the onset of their illnesses, and considering how this impacted their subsequent actions. However, as outlined below, the sense of being lost – for words, for direction – cannot be separated by the fact that the guidance they needed was not there.

Chronic concealment (and its consequences)

The above descriptions of chronic uncertainty, combined with a persistent struggle to articulate the need for help, was a precarious foundation for young people to make decisions about when to disclose their conditions and how to discuss the impact of their health on their life. The stories told by some participants about hiding their condition from others reveals persistent anxieties about, and avoidance of, conversations on what was going on with their health.

As above, personal difficulties in coming to terms with a condition were combined with a fear that the condition would not be taken seriously. This tension – between not wanting to make it real by talking about it, but also being deeply concerned that, if a condition were to be disclosed, others would not see it as real – loomed over participants as they repeatedly negotiated how and when to discuss their condition. For example Lara (22-25, female), who has hypothyroidism, explained that she often avoided talking about it both because “it feels like there is another layer to me that is hard to express to others, because I want to not be dismissed, I want to be validated and understood, but I’m not sure how others will take it,” and because, “I didn’t want to admit to myself that I had an invisible illness – I think I always hoped that it would go away, that it would be curable.”

One concrete consequence of this was an avoidance of registering with disability services with schools and universities. In some cases, this happened through iteratively denying to themselves (and sometimes to others) their need and worthiness to access accommodations. Matilda offered a particularly stark example of this when she recounted her decision not to report a seizure she had during an end-of-school exam:

> “I had [a seizure] during one of my [final year] exams, my [subject] exam. The teacher who was watching us thought that I had just had a mental breakdown. They commented, they just said, ‘oh, this student has just fallen off their chair and started sobbing.’ And it was actually that I was in the middle of a seizure. And then I just came out of it and went, ‘ok, well I’ll just get on with it.’”
>
> (Matilda, 19-21, female, epilepsy)

More often, decisions to hide their illness came in social situations. One anxiety which commonly prompted participants not to disclose their illness, or not to discuss how it influenced them, was a fear of being judged as ‘less than’. The experiences which created these anxieties varied. In some cases, interactions that explicitly cast judgement on others who were ill loomed in the minds of participants as they considered what to disclose and to whom. For Rachel (26-29, female), who was diagnosed with IBD after leaving school, the way she initially spoke about her illness with friends was impacted by that same group’s reactions to another friend was who diagnosed with IBD when they were at school:

> “When I was diagnosed I had been in a group of friends at school where someone else had been diagnosed with [IBD] a couple of years before. […] And a few friends at the

> time kept talking about how I didn't make [IBD] my whole life, and they couldn't understand the fact that she would talk about it all the time. […] People ended up stopping talking to her because they felt like they couldn't have a conversation with her about anything without it coming back to [IBD]. And then I felt this really big fear of not mentioning my [IBD] after that, because there had been such a big backlash to her. […] It's such a vivid memory. And it was specifically one person who was like, 'you're so different because you never mention it, and we like you more because of that.'"
>
> (Rachel, 26-29, female, IBD)

The need to manage the perception of illness here is clearly not just a product of internal anxieties – Rachel's friends explicitly compared her lack of emphasis on illness favourably to another's externalised distress at being ill, and Rachel continued to stay quiet about her illness accordingly.

Lisa (26-29, female) had also decided to not discuss the impact IBD had on her life based on reactions she had seen others have when people discuss their own mental illnesses:

> "I'm a bit more reserved about [telling people] because you've kind of seen people's reactions when someone talks about, let's just say for example you've got someone who has quite a lot of depression and anxiety and they're very open about their depression and anxiety, there's a lot of people out there who kind of roll their eyes and are just like 'ugh, she's talking about it again, no one cares, why are you talking about this?' So I kind of have the feeling that there's a lot of people out there would have the same reaction to me talking about this."
>
> (Lisa, 26-29, female, IBD)

Lisa went on to further articulate her anxieties about how people would interpret her discussion of illness:

> "I just don't want people to think it's my personality. […] Every so often you can lie in a hospital bed, you can have cords, everything running off you, people are looking down at you in pain, and you can be a bit scared, and think, 'I wish someone was here.' But no, I'm not going to tell anyone, because I don't want to be that person who's like 'hey, I'm in hospital, give me attention.'"
>
> (Lisa, 26-29, female, IBD)

For Lisa, this concern that people would equate her illness with her personality and see her disclosure that she was in hospital as a bid for attention resulted in her censoring her illness experience. Throughout interviews it was rarely the diagnosis itself which needed to be hidden – instead participants sought to hide that the emotional and physical impacts of illness were an ongoing and important part of their lives.

It was not only participants who had memories of judgement that did not want others to observe the impact of illness. There was an extremely strong sense from participants, regardless of past experiences, that the gaze of the healthy other would see only their illness, and the ways in which it compromised both their identity and their abilities. The complexity of this concealment often made participants hesitate in their descriptions of it, since it was not so much that they were hiding illness, but rather obscuring its impact. Ethan (22-25, male), who had been diagnosed with type I diabetes as a young boy, found himself reflecting on the stress he felt at school, and continued to feel now, when he needed to manage his insulin levels with others around:

> "It's very much sort of trying to keep it… hidden, but not like hidden, but you don't want to be a hindrance to the fun of the group. […] I don't want any attention, I don't want to be the one slowing things, I don't want to be the weak link. […] Because, you know, it's ok to be different if it's a good thing, but that's not a good thing. […] It definitely is something that even now I try and hide. Because I don't want the attention, I don't want the unwanted eyes."
>
> (Ethan, 22-25, male, type 1 diabetes)

Aisha (26-29, female), who managed neurological symptoms such as tremors and migraines throughout school without a diagnosis or therapeutic interventions, maintained that, had she not concealed her symptoms at school, it would not have been possible for her to receive equal treatment:

> "[At school] I thought, if I keep it under control, no one needs to know. […] I completely and utterly refused to acknowledge the issues I was going through to my peers. Because they had a healthy body. The fact that I don't have a healthy body means that I'm going to be an outcast between them. […] So it's… it's hard to talk to people.

> Because no matter how hard they try, they will treat you differently. It's subconscious. They'll see you as someone they need to take care of. And I don't like that."
>
> (Aisha, 26-29, female, neurological condition)

In Aisha's interview it was clear that her concerns did not just relate to individuals who might misunderstand illness, but that the whole social ecosystem of school was not capable of treating her outside of the binary of 'healthy and capable' / 'sick and incapable'.

Participants believed that any discussion of a chronic illness could perpetually corrupt others' ability to see them beyond their illness. Matt (22-25, male), who in his final year of high school had needed to lie down in class due to his autoimmune arthritis and degenerative spinal injuries, wished that he "could have just suffered in silence" rather than reveal the extent of his pain. Everyone knew something had happened because he had to stop playing competitive sport, but the fact it was a chronic illness with an unclear progression and treatment program made the situation far worse than a "season-ending injury." He described the whole experience as "claustrophobic". Again, there were perhaps institutionally acceptable ways to be impaired, but chronic illness was not one of them.

While Matt was now far better equipped to deal with the mental and emotional stress of his pain, he was still cautious when telling others:

> "Let's say I tell them, because in that week I've had a flare up and I'm really in pain that week, and then the next week it has subsided. Now I've told them and the cat's out of the bag, and they won't see me the same after that. And I guess there's a paradigm shift in how you're dealing with people afterwards."
>
> (Matt, 22-25, male, autoimmune arthritis and degenerative spinal injuries)

This echoes Aisha's sentiment that, were others to see the true extent of her illness, they could not appropriately integrate it into their treatment and understanding of her as a whole. In this sense a consciousness of one's chronic illness does not just mean a concern about others' immediate reactions – there is a struggle to trust that others will be able to bring illness in and out of focus in a way that reflects its ever-present yet fluctuating roles in one's own life.

In this context, participants found ways to negotiate between their need to manage their health and their desire to deflect away from their illness. Georgia, who was managing serious fatigue symptoms, explained that:

> "I just say, 'oh, I'm not really feeling well, so can we do something in the day so I can get a good night's sleep?' To me, that's the best way to deflect it without talking about myself. I don't want to look like I'm looking for attention, I just don't really want people to know."
>
> (Georgia, 19-21, female, fatigue and chronic sinus infection)

These attempts to obfuscate the impacts of chronic illness took their toll. The toll was often understood by participants through moments when emotions had physically boiled over, as Matt explained when remembering his final year of school:

> "And at that point […] I certainly felt like I was struggling, even if the [academic] results stayed the same. There's a phenomenally greater amount of effort going in to try and maintain that baseline, which had the flow on effect of impacting my mental health. I remember, kind of, you know… crying, a lot… just to myself. I found it was just such an incredibly isolating feeling."
>
> (Matt, 22-25, male, autoimmune arthritis and degenerative spinal injury)

In this case, a key dimension of Matt's struggle was his continual insistence on keeping as many things as possible the same – where he did this, however, it had the compounding effect of making it more difficult for others to recognise his pain. His personal expectations here are impossible to disentangle from institutional and social expectations. Indeed, his fear of dropping below the "baseline" he saw for himself speaks to larger social anxieties surrounding 'regression'. It also echoes other participants' desires to disallow illness from being something that 'detracts' from how they are externally valued.

For Ethan, who was otherwise just trying to "figure out all the complexities of a normal life", an un-expected second diagnosis, related to his type I diabetes, was an additional and overwhelming pressure:

> "So I go in, and they say I have [another autoimmune condition]. And I hear it like three times, but I can't remember the name, because they're saying so much. […] And then he says to me, […] 'If you don't stay on top of this you will become paraplegic because it's all in your spine. You need to be on top of this and never miss a single one because you will be a paraplegic.' And that's just [hits hands to together]. […] I'd gone in expecting like, you know, 'oh you're iron deficient.' […] But it's actually like, this is

> a lifelong disease, another one, another lifelong disease, and if you don't manage it you'll be in a wheelchair. And yeah, I just went home and collapsed on the floor and cried."
>
> (Ethan, 22-25, male, type 1 diabetes)

The conflict between fearing observation and longing for recognition runs deep, but time and time again, especially in adolescence, fear won. The anxieties felt by participants did not come from nowhere – participants had experiences of being treated differently, or of seeing others being treated differently, and did not trust that a healthy other could see their illness without losing sight of the fact they were the same person. In some cases, participants explicitly did not want to be cared for by others, but there was also a fear that a need for care would be interpreted as a bid for attention.

Given the pre-occupation participants had that they would be seen in a way that was 'wrong' if someone knew about their illness, there was also a struggle to express what it was that they *would want* to be recognised. This burying of what they needed – regarding care, concern, and recognition – took an immense emotional toll, which was often felt intensely at certain points where this constant control became overwhelming.

Re-calibration, recognition, and re-integration

The process of learning to live with illness was not emotionally linear, and a sense of ease did not necessarily emerge for participants as they learned more medical information about their condition. The need to make sense of illness outside of medicine was a recurring theme, and it was particularly important for those who had limited treatment and management options. Tom (22-25, male), for example, had lived with an autoimmune skin condition[25] that developed while he was a teenager, and he had only ever found temporary, impractical, symptomatic relief. Given that otherwise no one could do much to help, he found that "the most important part of it is making sense of it mentally."

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[25] Autoimmune skin conditions are a set of diseases where the body's immune system attacks its own skin. They often cause painful and visible lesions (as is the case, for example, with psoriasis), and can also impact eyes and other types of connective tissue. They are closely related to, and often comorbid with, other inflammatory skin conditions and allergies.

Where participants did begin to learn to live well with illness, relief could again be felt intensely. David (19-21, male) remembered how he had started crying when he received his best marks yet at university, despite having to navigate ongoing fatigue with no diagnosis. The fact he could say "ok, I am making progress" offered immense relief from the constant invalidation of doctors not being able to offer a diagnosis, and his family insisting he continue to seek one.

In the context of an actual and perceived onslaught of doubt, uncertainty, and judgement, participants reported that developing a sustainable, emotional relationship with their illness was an important act of re-calibration amidst the initial disorientation of becoming sick. Sometimes it was the ability of others to respond in a supportive, non-judgemental way that allowed individuals to go forward with more honesty about the role of illness in their life. Sarah, for example, had eventually decided to post on Instagram about her CFS/ME after deciding that she should not be angry about people "not understanding" if she had never tried to tell them about her experiences:

> "I was determined to not make it a cry for help – I didn't want it to be a pity post. It was just a, 'this is how it affects me' kind of thing. And it was really cool, it was really cool the response people had. Because it wasn't a kind of, 'oh my gosh I'm so sorry for you' type of thing. It was just an 'oh ok, thanks for telling me that.' And I was like, 'oh, you're welcome, cool, great.' It was such a relief talking about it, but not in a depressing way. Not a, this is ruining your life kind of way, just a, this is my life."
>
> (Sarah, 19-21, female, CFS/ME)

Matilda had also eventually found a way to talk about her epilepsy in a way which gave her relief from her concealment of the anxiety around her seizures and their physical repercussions. She had recently come to integrate epilepsy, and natural discussions of it, into her life:

> "I had to slowly tell more and more people [… and] it got to the point where I didn't hide taking my drugs. At parties, or sleepovers, or schoolies[26] or what not, it just got to the point, where people were like, 'oh, what's that?' and I was like, 'those are my

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[26] The Australian term for the traditional week-long holiday that high-school graduates take after their final exams.

> epilepsy drugs, I have epilepsy, if you ever see me do this, this is what happens.' It just became a speech that I rehearsed. My uni friends knew straight away because I just straight away was like, 'by the way I have this, if you ever see me do this, this is what happens, I have epilepsy.' It's now just a defining personality trait, which I think is what initially I tried to make sure it wouldn't become. But now it's like, well it's here, it's happening, I may as well have a bit of fun with it, which is why I dyed my hair purple after coming out of the hospital. I just went, 'I've had all this glue in my hair for a week, I'm going to treat my hair, I'll dye it the colour of the epilepsy foundation.'"
>
> (Matilda, 19-21, female, epilepsy)

What these stories of recognition share is that participants felt that they were talking about their illness on their own terms, and that others were not using these stories as a way to judge them. In short, relief and reintegration came when their disclosures did not result in their illness being overly (and incorrectly) interpreted. Sometimes, this came after a leap of faith and was a surprise (as in the Instagram example where the response was "thanks for telling me that" instead of "I'm so sorry for you"). Other times, such as for Matilda, trust built up gradually through deliberately casual disclosures.

Not all participants had found a stable, confident, and clear sense of how to talk about their illness. That said, many had still learned more sustainable ways to manage their illness, and with this came a definite sense of pride and relief. Self-recognition of the work it took to live well with illness was explicitly contrasted by participants to the binary expectation they felt existed in society, which was that their illness needed to either be demoralising or inconsequential.

Discussion

This chapter demonstrates the various ways in which there can be critical failures in community recognition of the experience of chronic illness when young, which accentuates struggles to articulate what is going on and, relatedly, live well with chronicity. The testimony of participants demonstrates how these critical failures present themselves in everyday life, and also how they become 'felt' in the experience of illness. Looking at instances where constructive recognition is found also demonstrates how a more nuanced social construction of illness would be less destabilising and suffocating.

Participants accounts of learning to live with chronic illness involved a series of dilemmas which arose when expected presentations of illness and binaries of life did not reflect their experiences. A primary dynamic of this was in their conflicting desires around concealment, recognition, and care. This highlights how webs of secrecy, unspoken assumptions, and cultural silencing can further limit communication about the body and health challenges while simultaneously creating a *chronic consciousness* of illness itself.

As participants discussed what they wished for in their life regarding care and recognition, it was clear that they were navigating a precarious terrain, full of nuances if not outright contradiction. Some participants feared acknowledging their illness both because it made it 'real' and because they thought others would invalidate their experiences. Others would say they did not hide their chronic illness, but still lived with a great deal of anxiety that, if they spoke about illness in the wrong way, others would roll their eyes and believe them to be attention seeking and self-absorbed. Consistently, participants stated that they believed others would see their illness as a defect, inconvenience, or cause for pity, and that a 'mis-handled' moment of disclosure would hinder others' ability to understand them into the future. These conflicting feelings, which contradicted expected binaries, were difficult and disorienting (Harbin, 2012, 2014, 2016; Lajoie, 2019). Participants were thus forced to navigate desires for visibility in the confines of institutions and social settings that did not discursively accommodate the embodied reality and nuance of their situation.

Put another way, a recurring theme in interviews was participants' concerns about how the 'healthy other' may perceive their illness. As outlined by feminist disability scholarship, the neglect and stigmatisation of embodied experiences is felt particularly at the intersections of marginalised identities (Garland-Thomson, 2002; Meekosha, 2002; Wendell, 1989). Therefore, in conceptualising a healthy other, it becomes clear that this could take on other dominant identities, i.e., a healthy male other, healthy white other, or healthy settler other. These dynamics can be understood as "looking at one's self through the eyes of others" (Du Bois, 2007[1903], p. 3), revealing how the social construction of illness impacts the ways in which young adults conceive of and express the role of illness in their life. The social context which participants described reflected literature which explores how morality is tied to health (Grønning et al., 2013; Monaghan & Gabe, 2019), and how bodies and pain are constructed as things to be dominated (Grosz, 1992; Reeve, 2002). This influenced the affective nature of illness for participants, given that they sought to project an illness experience that aligned with those norms, even though their illness experience did not.

In the elaborate practices of concealment in young people's worlds, concealment is not merely hiding the existence of illness, but rather, it is downplaying the spectre of fear, vulnerability, and uncertainty that is persistently present. These often exhausting attempts to bury the emotional toll of chronic illness were themselves an ongoing and building source of pain in participants' lives. Finding ways to live well with illness was a struggle – a struggle compounded by the economic, medical, and social barriers to receiving care that exist for all with chronic illness, and especially for those at the intersection of other minoritised identities (Boulton, 2019; Conrad & Barker, 2010; Frickel et al., 2010; Knoebel et al., 2021; Mullard et al., 2024; Sebring, 2021).

By building on these accounts, and by incorporating broader lived experiences of chronic illnesses, we can begin to tease out and give better supports to adolescents and young adults who fall outside the expected trajectories and priorities of youth. The expectation that others did not have an understanding of, or interest in, the consistency yet changeability of what chronic illness means to life was one of the key issues that young adults did not trust others to engage with. The normative belief that two things cannot be true at once – whether that be grief and joy, relief and frustration, hope and resignation – created an urge to conceal the life of contradictions that a youth with chronic illness can feel like and be. Despite this ever-present dynamic, participants' stories of finding those who could react appropriately and supportively demonstrate the potential for these exchanges to be enormously meaningful and helpful. Increasing awareness of the concerns outlined in this chapter is an important foundation for promoting recognition, and providing support, for those living with chronic illness.

CHAPTER SEVEN | digital possibilities

Introduction

Technology, social media, and internet spaces are now ubiquitous in everyday life, and they are therefore woven into young people's experiences of illness. For participants, the digital world was not separate from their broader life, and what participants did online both reflected and impacted how they felt at other times. Online spaces had a significant influence on what participants knew about their illness, and on how they thought about it – online support was at times extremely meaningful and helpful, but the intensity and extent of negative experiences online could also be overwhelming and distressing.

Participants universally looked online for more information about their illness. Their investigations could take on a number of forms, and participants used a variety of methods to seek more details about their condition: they looked up medical research papers; they read websites devoted to explaining health conditions, such as WebMD; they searched YouTube for in-depth videos on illness and disability; they read forums such as Reddit to follow questions and answers about their condition; and they scrolled through social media platforms such as Instagram or TikTok to see how their condition, or chronic illness more broadly, was discussed. All these actions took on different intensities and intimacies which impacted participants' understanding and experience of illness.

Participants tied their online behaviours to their deep desires for information, community, connection, and distraction. For many, the shortcomings of the online world were recounted as an inevitable and unavoidable reality of being ill – of course they were going to research their condition online, and they were not surprised that this often ended up being distressing. While participants' desire for knowledge and connection sometimes led them to spaces that felt suffocating, there were also online spaces that did provide crucial support and information. These positive experiences are instructive for what could be productively fostered in digital and social platforms.

Background[27]

Activist and social communities formed around illnesses or illness experiences are important actors in the way that health knowledge, medical care, and perceptions of illness are shaped and expressed (Brown et al., 2004). These practices of support have been influenced by the creation of the internet, subsequent technological innovations, and ongoing changes to the affordances of various online platforms.

Most broadly, the internet makes it far easier for people to talk about their illness experiences publicly, and it also allows there to be readily accessible information relating to illness, disability, and disease (Barker, 2008; Conrad & Stults, 2010). For illness and disability, a whole range of online 'worlds' exist, with a variety of epistemic, political, and cultural desires and consequences (Barker, 2002; Barker & Galardi, 2011; Foster, 2016; Ginsburg & Rapp, 2013; Gonzalez-Polledo, 2016; Kempner & Bailey, 2019; Whelan, 2007). In many ways, what ties these platforms together is their elevation of lived-experience and lived-expertise, and their related commitment to provide a space for people to talk to about often dismissed and contested illness experiences.

Outside of these analyses of online illness and disability spaces, work on digital cultures provides important tools to help conceptualise online worlds. Today, we have an offline-online ecosystem of integrated medias (Horst et al., 2009; Madianou & Miller, 2012; Nelson et al., 2020), which each come with their own affective affordances, intensities, and intimacies (Byron et al., 2019; Cho, 2018; Lomanowska & Guitton, 2016; Madianou & Miller, 2012; Nettleton et al., 2004, 2005). Social media platforms in particular have seen the emergence of varied ways to demonstrate care and connection (Byron, 2021; Papacharissi, 2020), and to engage with activism and social movements (Calhoun, 2020; Kanai, 2021; Kanai & Coffey, 2023; Kanai & Zeng, 2024; Vivienne, 2016).

This chapter examines digital landscapes through the person-centred methodology of interviews (Herring, 2008), which allows for a focused examination of the complex relationships between offline and online worlds, and how these interactions shape the experience of chronic illness for young people.

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[27] More detail on the literature summarised in this section can be found in Chapter Two, pages 43-46.

Results

Intensities

Participants were driven online by their desire to better understand their condition both before and after diagnosis. In particular, participants often wished to hear about what living with a condition was like – they wanted to hear the testimony of people who were ill, not just the medical descriptions and advice that came in a clinical encounter. As Phoebe explained, while doctors did have medical knowledge,

> "sometimes there's stuff they don't see because they are not themselves ill and living with that condition. Unless you are living with that condition, you are not as aware of the impact of something."
>
> (Phoebe, 26-29, female, chronic pain and IBD)

The decision to look online for information and guidance therefore reflected the significance that illness had in participants' lives, and their belief that more understanding may give them the tools they needed to better manage their illness both symptomatically and emotionally. Participants found, however, that this research could be emotionally difficult and destabilising. The experience of reading online information was marked by an isolating intensity that perpetuated the emotional weight of illness:

> "I think I only looked regularly for a couple of weeks and stuff, because for me that focuses a lot of time and energy on having PCOS, and I think because of my past experiences I'm just like – that's very, it's exhausting. It puts the rest of your life on hold, if you're trying to focus on solving something that can't be solved."
>
> (Claire, 22-25, female, PCOS)

Many participants described themselves spiralling online and getting into a 'rabbit hole', where an initial desire for some information lead to an online world consumed with the risks and devastation of a particular condition:

> "Because even though I'd been recommended not to read stuff online by my GPs, it was like, it's just an itch you've got to scratch. Yeah, that was quite depressing. And I think one of the more awful things in some regard was, ok, well I'll try and find some forums, and even if I don't – I had no intention to participate, but I was hoping to read what other people had experienced. […] People seemed to be turning to the forums only when they felt an element of desperation. Or that maybe they didn't have their own system to ventilate and deal with how they were feeling at that current time, so they would post it online. So that, compounded with the fact that not only were they desperate but they were probably going through a pretty bad time with the condition itself, meant that all of the testimonies online were just pretty grim. […There was] a real sense of hopelessness and despair. I certainly don't think, in hindsight, that that was good to read as a kid."
>
> (Matt, 22-25, male, autoimmune arthritis and degenerative spinal injuries)

> "In reality, the more I Googled the more terrified I got. […] Recently I – well the doctor suggested I change my medication – and I went back into the rabbit hole of going to Reddit. I should not have done that. […] I was down that rabbit hole for a few days. […] There is a validity in seeing how people's actual experiences are, compared to clinically what the data is. So there is some validity in it, but in doing so you are still scaring yourself."
>
> (Adam, 26-29, male, IBD)

These excerpts further reveal how people go online based on reasonable and natural desires that are not met elsewhere. Matt's "itch you've got to scratch" speaks to the consistent feeling that participants recounted of having not been told enough to understand what was going on with their bodies. Adam's final comment – that "there is a validity in seeking how people's actual experiences are" – also speaks again to how participants looked to these online spaces to fill the gaps in what health professionals offered them upon diagnosis, including insight into the lived experience of illness.

Not only were participants faced with big and difficult embodied changes, they were also often faced with a medical system that actually knew very little about their condition – a medical ignorance and uncertainty that participants had often not previously confronted. As Claire explained, this left many participants "trying to focus on solving something that can't be solved." Participants who were dealing with a condition (or a presentation of a condition) that was poorly understood by their healthcare team were especially likely to be researching their symptoms, despite the lack of success:

> "That was just the whole thing of, every time there was a symptom, or I thought I felt tired, or I got a headache, it would just be straight onto the Google machine. Symptoms of epilepsy, symptoms of this drug. It just spirals and keeps going, and then you suddenly realise you've got cancer somehow. And mum is like, 'you've got to get off the internet.' Anxiety driven and anxiety provoking."
>
> (Matilda, 19-21, female, epilepsy)

A significant part of the problem was that online spaces such as Reddit seemed to attract experiences of despair and hopelessness. Matt now understood this as the fact that "people seemed to be turning to the forums only when they felt an element of desperation" and did not have their own support system. This resonates with Ethan's (22-25, male) description of the forums concerned with his illness, type 1 diabetes: "[They] can be such a hive of panic and negativity, it can be really sort of freaky."

This had clear and unsurprising impacts on participants' mental wellbeing: they became consumed with reading about worst-case scenarios, unknowns, and despair. It also was scary – many chronic conditions have the potential to get progressively worse, and often part of the "pretty grim" online testimony were descriptions of symptoms that were presenting in some of their advanced forms. This level of uncertainty, and being surrounded by others' pain, can be psychologically challenging in any context. As Sarah explained:

> "The thing I struggle with looking at other people's social media illness posts, is when it comes from a place of pain, then I struggle with it because I just can't take that on, personally."
>
> (Sarah, 19-21, female, CFS/ME)

Further though, as Tom explained, the stories could focus participants on their own challenges in their current illness experiences:

> "I'm on a Reddit page for the [condition] community or whatever, and they're all like 'I'm so miserable' and it's like 'fuck, true, because it sucks.'"
>
> (Tom, 22-25, male, autoimmune skin condition)

Sam had a particularly difficult experience of this, where he felt that the Facebook support groups for hypermobile Ehlers-Danlos syndrome (hEDS)[28] that doctors advised him to join were largely concerned with sharing advice to avoid the scale of symptoms he lived with permanently:

> "[On Facebook groups] I had an awful time – really, really terrible experience. [… It was people] who were a lot more able-bodied than I was […] terrified about ending up not even half as disabled as I was."
>
> (Sam, 19-21, male, hEDS)

These shortcomings were understood by participants to reflect issues in how chronic illness is spoken about and treated more broadly in society, especially because these online forums were often populated by people who were not receiving adequate emotional and/or medical care. In participants' own lives, unhelpful online support was also understood in the broader landscape of poor chronic illness care:

> "GPs are useless, dermatologists are too expensive, [and] Reddit makes me depressed."
>
> (Tom, 22-25, male, autoimmune skin condition)

While most of the difficult online experiences that participants reported were concerned with this despair and fear in online spaces, there were other cases where participants had come across overly positive testimonies that were also disheartening. Susan explained how this reflected the binaries that seek to categorise illness stories as ones of either devastation or overcoming:

> "It's either, 'I quit my job' or 'I'm thriving.' Well, I'm surviving, raise a flag for me."
>
> (Susan, 22-25, female, fibromyalgia)

Participants went online to fill gaps in the 'offline' information available: they wanted advice on how to cope emotionally; they wanted to quickly access information about unfamiliar

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[28] Hypermobile Ehler's Danlos syndrome (hEDS) is a genetic connective tissue disorder that causes unstable, hypermobile joints (leading to chronic pain and injury), gastrointestinal issues, and dysautonomia.

or newly anxiety provoking symptoms; and they wanted to hear from people living with illness about what it was like for them. However the social discourses and assumptions that lead to this lack of information could in turn make online spaces anxiety provoking and upsetting: without social and medical support people would go online to share their deepest fears and darkest thoughts, which could in turn reflect the binaries and disablism that existed elsewhere in society. When online spaces become the outlet for unrecognised and unsupported experiences, there is a significant risk that the negative aspects of illness are highlighted and intensified in a self-perpetuating cycle of fear.

Information

Despite these shortcomings, some online spaces provided participants with vital information and support. In a practical sense, some organisations for particular chronic illnesses had information sheets and support guides that participants were grateful for. One example that a participant spoke about was that *Crohn's & Colitis UK* have liquid diet guidelines and recommendations. Another example came from Rosie, who appreciated the material provided by the *Daisy Network*:

> "They also provide information sheets. […] Just things you should be aware of. Questions you can ask your doctor – they've got a list of different questions, and say, 'have you considered asking your doctor this and this?' It's really nice to have that secondary information that's not from a medical professional. Whilst I always trust medical professionals, I'm always curious about what new research is out there. Because doctors go through so many different patients, so it's hard for them to keep up with every single bit of research."
>
> (Rosie, 22-25, female, POI)

This kind of information was at its best when it was targeted at specific issues. Lara had not found a space that consolidated useful information for her, but she could imagine it:

> "A consolidated repository of information would be nice. Especially for young people. Because when I was going through some things it talked so much about the older populations."
>
> (Lara, 22-25, female, hypothyroidism)

Participants who had more positive experiences online had the same motivations for their research as those who had become overwhelmed with the fear and despair on certain online forums – once again, their primary desire was often to hear about people's experiences of illness. Reassurance could be found despite the overwhelmingly negative spaces that were described above, and in that context, supportive spaces were an important salve for the intensity elsewhere online. Where participants found testimony that was reassuring, it meant a great deal to them:

> "I did Google the drugs and people's experiences of those. But I'm on a really mild medication that has no side effects. And everyone says that online. And I think that did help me when I first started taking the medication, being like, 'ok, these drugs aren't going to cause any scary side effects.' It's good to know what other people's experiences are."
>
> (Sally, 26-29, female, IBD)

> "I think there's a difference between a ranting group and a support group. Maybe people can share resources about what has helped them when they experience it, things that are more positive. And the knowledge that there are other people out there in the world who experience the same thing as you."
>
> (Catherine, 19-21, female, autoimmune arthritis)

> "Now I look on a Reddit thread for people who have [IBD]. And I can look up things that I didn't think were related to my [IBD] and I now think are related to my [IBD]. And people are constantly commenting, 'I've just been diagnosed, what is this treatment?' Or you know, 'my 10-year-old child has just been diagnosed, what do I tell them?' I think it's really helpful as a space to just let people know that they are not alone in these things."
>
> (Rachel, 26-29, female, IBD)

As is clear in the above excerpts, these spaces also served an important purpose in demonstrating that participants were not alone. A sense of solidarity on social media sites also helped participants manage the gaps in their previous education and understanding of illness which was described in Chapter Five: participants learnt about their body, the politics of illness and disability, and how to emotionally manage the stress of chronic illness. Platforms like TikTok, Instagram, and YouTube were particularly well suited to this, since participants could dip in and out of more discrete and contained forms of content, and gradually come across more information that shared helpful guidance:

> "Ever since I was diagnosed with [first diagnosed condition], I absolutely devoured any content from online creators about living with chronic illnesses. They were like, 'you have to compartmentalise it because otherwise you are going to get so stressed.'"
>
> (Phoebe, 26-29, female, chronic pain and IBD)

> "[People with endometriosis on TikTok] talk about their experiences, and how they've found the same sorts of things with doctors, and how it is so hard, and how, kind of, vague the treatment and research is, and how lots of doctors are uneducated on it – they think that birth controls fix it permanently, or the hysterectomies fix it, which it doesn't, it doesn't."
>
> (Jess, 19-21, female, endometriosis)

> "I was like, time to hop on the internet, because that's what is accessible to me right now. So I was seeking out disabled people who had public profiles, and that weren't kind of buying into the traditional narratives of pity inspiration and all that. […] That helped me on the more emotional level, because I very much internalised the fact that like, I am not the problem here."
>
> (Sam, 19-21, male, hEDS)

The information that was available on online spaces could therefore provide crucial, specific guidance about how to medically manage a condition, and also broader information that contextualised otherwise difficult to understand experiences such as aloneness, emotionally difficult medical encounters, and the foundational ableism that structures many interactions and institutions.

Intimacy

In the conflict between distressing intensities and useful information, a sense of digital intimacy was often present in online content that participants felt connected with and supported by. Participants wanted to both look online and see rounded people, rather than just disease, and to consume content that was aimed at whole people, rather than someone 'suffering' from some specific symptom.

Participants consistently reported that being able to read or see stories of people living with chronic illness was important because it allowed them to understand someone as a person rather than become unduly focused on the 'deficit' of illness:

> "So they [the Daisy Network] have an Instagram and usually every week they will post a woman's story, which is really interesting to see, how different people have experienced this and how their contexts have played a massive role. […] There's this one girl I follow, and she'll post, 'I felt this way today,' 'I'm trying this new medication,' or she does post about – she did this one about, which I felt nice to see, because my biggest concern was my uni and my ability to keep up with uni, and she did a post on cognitive function being a uni student. It was good to see. […] And she'll do life updates, and lives, and she's my age, so it's nice to have Instagram for that."
>
> (Rosie, 22-25, female, POI)

> "I've found that reading people's stories about what they went through, and what they tried, a lot more helpful than just a factsheet on the disease. Because that would sort of just be quite objective, compared to everyone's different stories and what they've tried. So that was really helpful. […] I feel like when people are talking about their story that's pretty reputable because it's their own lives, so they know it best."
>
> (Sally, 26-29, female, IBD)

> "I have found a nice community online. […] It's like 'oh, hi, it's Tidy Tuesday, today we all fold our laundry together. Rant about what you want in the comments below, but you've got this.' So I guess like that kind of support system, as opposed to being stuck on our symptoms […] I think ultimately what I would like to find is people with chronic symptoms, as opposed to just raising up the chronic illness as what this place discusses. So I guess, just to have a group of people going about their daily lives. We are all coping, but we all have it, and there are good days and there are bad days, but then at the end of the day it would be nice to have a safe space to just say, 'oh I had a good

> day,' but that could be completely unrelated to the pain, or just tangentially related to the pain. […] I think that's what I'm looking for: the person first, the people and the community first, who just happen to have chronic illness."
>
> (Susan, 22-25, female, fibromyalgia)

Participants did not need to contribute to these spaces to feel supported by them. This was important, especially when thinking about people who were diagnosed at a younger age. As has been a theme throughout this thesis, talking about chronic illness is challenging for a variety of difficult to remedy reasons. Participants were greatly benefited when they could look up how other people were describing illness and begin to learn a new language and worldview, which in turn helped them speak more openly about their experiences and needs:

> "I think as a 17-year-old you wouldn't be able to open up and talk about emotions, […] but I guess that's where the digital stuff could come in, because the younger generation does just go online and look for advice, so that might bridge that gap a bit better."
>
> (Adam, 26-29, male, IBD)

One way of "bridging the gap" was also through humour. Grace (22-25, female, neuroimmune condition), for example, described how she had found some chronic illness meme pages on Instagram that could "make fun" of chronic illness and be "light-hearted," which was "really good, really helpful." While negativity around chronic illness perpetuated a focus on the difficulties participants were facing, being able to confront these difficulties with humour could in turn help the experience feel a bit less heavy.

Some participants were actively engaging in online support systems. In these instances, the affordances of the online world as a private, accessible, and potentially global space were key:

> "I have a Discord[29] group of people who went through, um, life-altering events, healthcare events, things like that. […] I'm an introvert, and I prefer the online

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[29] Discord is an instant messaging and voice call platform that contains both direct, private messaging functionality and chat rooms ('servers'). In some cases, there are large servers for fans of a specific subject (e.g. a 'fandom' of a particular band, game, book, television series, or movie might have their own Discord server). Within servers there are 'channels' for particular discussions.

> discussion groups. [… In a fandom Discord there is a channel] for major health issues, chronic illnesses that impact your life. […] We kind of created our own support group to help teach each other. Because for some people they don't have much of a medical background. […] Me and another girl, we provide like, better understanding of the medicines you're taking, like side-effects, when should you discontinue and go to your doctors."
>
> (Aisha, 26-29, female, neurological condition)

> "I recently went to my first support group for young people with [condition], and that was amazing. Because it's a one in a million disease, I know no one in Australia who has it, so all these people were in America and Canada, and it was just amazing to speak to someone who had the same kind of – I mean, all of our stories are different, but some of the same experience. That was really powerful. We had an hour Zoom call and I hung up and cried, because it was just amazing to speak to someone who, while they're young, had gone through something like that."
>
> (Grace, 22-25, female, neuroimmune condition)

Social media also could help people talk to their friends about chronic illness – it was less pressure than a face-to-face interaction and gave them more control of their story. One instance of this was described in Chapter Six, when Sarah (19-21, female) recounted her post on Instagram that spoke about her CFS/ME – posting meant she could let people know about her illness all at once while allowing her to feel more confident that she could carefully select her words "to not make it a cry for help [… or] a pity post."

As a platform to inform friends about their illness, the functionality of social media also meant that participants could easily share 'authoritative' information to help explain their experiences. Not only was this a useful explanatory tool, but participants also appreciated that they could widely share what they had learnt during their experience of illness:

> "March was the Endometriosis Awareness Month, and every year I put up a bunch of infographics. If someone asks me about it, I don't like talking to people, I don't like bringing up my problems. But I'm posting [infographics], and then randomly I'll also post stuff on my close friends' story, and be like, 'for the girls, you need to get checked in case.' Because a lot of my female friends have random period problems, but they

> won't get it checked because they think it's normal, and I'm like, 'no, you need to get it checked.'"
>
> (Maya, 19-21, female, endometriosis)

The way in which this sense of intimacy was cultivated in the online world varied, but in all its forms it was an extremely meaningful source of solidarity and support for participants. Spaces which were not overtly constructed around a specific condition were often important to participants because they better facilitated a focus on the people and community rather than symptoms or disease. The problem, though, is not just that these spaces may be small in number – it seems likely that these spaces are also harder to find without a consolidated effort from doctors or other 'first point' contacts to direct people towards them. This is because they do not obviously 'answer' searches about specific medical concerns, even though they would serve the purpose of providing connection while also potentially directing those with chronic illness towards safe information that comes from both healthcare providers and lived expertise.

Discussion

In interviews, participants' accounts of technology and online worlds arose naturally as they discussed their experience of chronic illness. This revealed how the online world could come in and out of focus as they went about their lives. These spaces often first came into focus when information, support, or guidance about chronic illness was lacking. The first results they found online were, however, often created by of people who were also otherwise unseen and uncared for. This could lead to a self-perpetuating sense of isolation and fear that was difficult to break free from. This depiction of online worlds is perhaps the most closely aligned with the online world that participants were 'warned' not to engage with, but these warnings are futile for as long as people feel ill-equipped to deal with their emergent chronic illness. There were, however, innovative and meaningful demonstrations of illness communities and solidarity online, and by listening to these stories the significant potential of a variety of virtual illness spaces becomes clear.

Much of the existing literature on online illness communities focuses on the construction of 'lay' lived-knowledge as opposed to 'expert' medical-knowledge (Barker & Galardi, 2011; Conrad & Stults, 2010; Kelleher, 2001; Peterson et al., 2019; Williams & Popay, 2001). Participants' reports of what they found online did include the specific pieces of knowledge outlined in this literature: they found advice on how to successfully navigate medical institutions and interactions (Akrich, 2010; Barker, 2008; Foster, 2016); they read relevant medical research for themselves (Kempner & Bailey, 2019; Mazanderani et al., 2013); they tried to better understand how to manage their condition (Lupton, 2013; Maslen & Lupton, 2019; Nettleton et al., 2005; Schaffer et al., 2008; van Berkel et al., 2015); and they became more engaged with activism (Lian & Nettleton, 2015), particularly the "everyday activism" of visibility that social media may be particularly well suited to (Calhoun, 2020; Vivienne, 2016). However the benefit of lay and lived expertise could break down when social and medical disenfranchisement of people with chronic illness was so great that online spaces were overwhelmed by people who had not had the opportunity to develop their own expertise.

Reading or listening to illness stories were an important way that participants could connect with others' illness experiences, and in turn their own. This required online spaces that talked about illness as an enmeshed and evolving component of broader life. Participants explained that they were grateful for spaces that talked about those who were ill as whole people, living with illness, rather than focusing exclusively on the ways that illness might 'detract' from a life, or how it can be 'managed'.

Digital worlds are a constant presence in our lives (boyd, 2008; Horst et al., 2009; Madianou & Miller, 2012; Nelson et al., 2020) and, as a part of this, there are ways for illness solidarity and community to be gradually and non-obtrusively integrated into everyday technology use. This is theorised and analysed in existing digital cultures literature outside of illness communities. In particular, near incidental interactions on social media can foster a sense of affective connection (Papacharissi, 2020), and can lead to complex relationships of care (Byron, 2021) and intimacy (Lomanowska & Guitton, 2016) both between people who otherwise know each other, and between individuals, online personalities, and their followings (Kanai, 2021; Kanai & Coffey, 2023; Kanai & Zeng, 2024).

This theorisation extends on literature which looks at the care and solidarity present in some online illness communities (Cocq & Ljuslinder, 2020; Ginsburg & Rapp, 2013; Gonzalez-Polledo, 2016; Whelan, 2007). By conducting interviews where technology and social media came up naturally, participants could recount the varied ways that they engaged with online spaces concerning illness, which revealed how the intensity, intimacy, and information of these spaces came in and out of focus (Herring, 2008).

It was rare that participants used the online world for a discrete and completable task, and it was also rare that their understanding of illness (both 'online' and in the everyday) came from one specific online space. Instead, participants negotiated the affective potentials and realities of online spaces to best serve their needs. Sometimes they did not find what they were looking for, and risked becoming ‘trapped’ in the negativity that was present online. Despite this, the support that some participants found reveals the potential of online worlds: they can accessibly and safely offer important and varied forms of information and support.

Understanding what people desire when they go online is crucial when directing people towards potentially beneficial spaces, as well as constructing and fostering them into the future. There was a clear wish from participants to hear about the ‘real stories’ of people with illness – a wish that reflected both a distrust of medical information that did not incorporate lived experience, and the need to see others who lived like them so they felt less alone. Recognising this can both influence how healthcare professionals impart medical information, and the online support that patients are directed towards: rather than allow people to stumble across negativity (as is encouraged when people are told to not look up their illness online), they should be guided towards spaces that tell the stories of *people* who are ill, and of lives where illness is a well-managed and relatively neutral component. These stories could contain the much needed political and emotional guidance that helps others get to this place.

CHAPTER EIGHT | navigating the limits of diagnosis

Introduction

This chapter focuses on the role of diagnosis – as category and as process (Blaxter, 1978; Jutel, 2011) – in the lives of young people living with chronic illness. The spectre of diagnosis was clear throughout the interviews, and in this chapter I examine the function and meaning of diagnosis in participants' stories, especially when it proves evasive, illusive, or even inconsequential.

The process of seeking, receiving and reckoning with a diagnosis has frequently been an in-road for qualitative examinations of the lived experience of chronic illness. Biomedical diagnoses therefore often take centre stage in research concerning how uncertainty is managed and/or more stability is found. This reflects how diagnosis can be held up as a crucial component of illness in social, medical, and cultural discourses (Jutel, 2011; Jutel & Nettleton, 2011). This chapter therefore focuses in on diagnosis as a crucial structure that pervades illness narratives and expectations. I argue, however, that the significance of diagnosis can shift over time, and that in many cases the promise of diagnosis deteriorates as life unfolds.

Here, I illustrate how diagnosis can be a highly contested epistemic and emotional space, and find that diagnosis plays a multivalent and variable role in the journey each young person undergoes as they make sense of their experiences living with chronic illness. To begin, I outline immediate responses to diagnosis, which builds on Chapter Four's outline of the frustration that participants remembered feeling when they were seeking a diagnosis. Next, I look at what diagnosis failed to provide to participants, and examine how the resulting pain was tied with the experience of being 'let down' by the promise of diagnosis. Finally, I ask how diagnosis was iteratively decentred by participants, and what narratives and concepts they used beside their diagnosis and to go beyond its descriptive potential.

Background[30]

The onset of illness can trigger serious re-evaluations of who one is and what one's life can be – questions which are often thought through with the help of various forms of stories (Frank,

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[30] More detail on the literature summarised in this section can be found in Chapter Two, pages 16-18 and 20-25.

1995). Diagnosis is a part of this, given that it both structures medical interactions up until the point of diagnosis, and then promises a series of future experiences and actions once diagnosis has been achieved (Blaxter, 1978; Jutel, 2011). In particular, since the biomedical turn of the 20th Century (Clarke et al., 2003), medical diagnosis has been the predominant mode for defining, analysing, and predicting bodily pathology and dysfunction (Eisenberg, 1977; Rosenberg, 2002). In this sense, diagnosis can delimit what is considered normal rather than pathological, therefore imposing meaning on otherwise ill-defined suffering, placing one within an expected narrative, and giving one access to treatment and benefits (Jutel, 2011; Jutel & Nettleton, 2011; Nettleton, 2006).

That said, this supposed promise of biomedical explanation, and prognostic certainty, is not always found with diagnosis (Boulton, 2019; Jain, 2007; Lakeman, 2010). Moreover, in everyday life, the different meanings and roles of diagnosis cannot be neatly divided and distinctly managed – diagnoses move between, and are, categories, events, processes, topics of inquiry, and ways of making sense of illness (Blaxter, 1978; Jutel, 2011; Jutel & Nettleton, 2011; Weinberg, 2020).

This chapter contributes to literature in the sociology of diagnosis which has revealed the ways in which the meaning, practice, and purview of diagnosis shifts in everyday life (Bell et al., 2024; Boulton, 2019; Jeske et al., 2024; Jutel, 2015). I also draw on sociological literature which paints ambivalence in the context of conflict, especially around cultural binaries, as a lens with which to view the ambivalence towards diagnosis that some participants conveyed in interviews (Bauman, 1990; Hillcoat-Nallétamby & Phillips, 2011; Merton, 1976).

Results

Relief, numbness, and uncertainty upon receiving a diagnosis

All participants had been attempting to understand and manage symptoms prior to their diagnosis, which often involved the frustration and invalidation predicted by existing sociological literature (Boulton, 2019; Dumit, 2006; Mullard et al., 2024; Nettleton, 2006; Werner & Malterud, 2003). In many cases the eventual diagnosis was not entirely unexpected, somewhat relieving, but in turn entangled with feelings of frustration:

> “They didn’t even apologise for the fact that they refused to do an MRI for like 7 years [… the doctor had] said: ‘You put too much stress on yourself and that’s why that’s happened.’ I told him: ‘Ok then, tell me how to make the stress go away? If the stress is coming from the migraines and it’s causing the migraines, how do I fix that?’ I ended up leaving the clinic and just crying. [… When I was diagnosed] I was happy. […] My family was worried about that, but I told them, ‘ok, I finally have an explanation for what is going on with me, and there’s a way to try and fix it. I’m happy.’ So, I was happy at the fact they figured out what was wrong with me. I was still angry a bit.”
>
> (Aisha, 26-29, female, neurological condition)

In line with the recent paper from Jeske et al. (2024) which explores how diagnosis is just one moment in patients’ broader narratives of illness, participants often described their relief at receiving a diagnosis as directly related to their past experiences of diagnosis being denied. Participants’ responses reflect that in many ways what they were relieved from was their frustration at not having their suffering acknowledged and the self-doubts which came from the frequent scepticism of doctors:

> “When I was finally diagnosed I was just like, ‘yay, at least I’m not going crazy.’ […] It just sends you a little bit crazy on the inside. Like, maybe I am just overthinking these symptoms, maybe there’s nothing wrong with me. […] I think it’s more or less relief. I think that part of you is starting to just sort of think ‘maybe I am making this up in my head, maybe I am going crazy, am I just wanting the strong painkillers in the hospital? Maybe this is just normal pain for everyone else.’ Sort of: what’s going on? So it really validated my own feelings. I wasn’t really *happy* about it, but I also wasn’t sad. I was just sort of relieved that I knew what was going on, and it’s like, at least it’s something, and something that explains why I am feeling the way I am feeling.”
>
> (Lisa, 26-29, female, IBD)

> “It is a relief. I think at some point you start to believe, oh, I’m being dramatic, there’s nothing wrong with me, I’m just trying to get attention. But then actually having it, it was so validating, honestly, I was so happy. Even though I know it’s not a great thing, it’s confirmation that I’m not crazy.”
>
> (Maddy, 19-21, female, endometriosis)

This sense of being “crazy” was linked to doctors essentially implying this, but it also speaks to the deeper belief participants were exposed to, which was that there should be a way of controlling their symptoms of illness. One participant, Greg, was explicit in his description of this:

> “It was such an incredible relief. I felt a lot that – the primacy of the psychological, that it was my personality and stuff. Because I was trying so hard to live a normal life and do the things that I wanted to do and everything. But I was so overcome with anxiety that I sometimes couldn’t leave the room and stuff. So to be told that it was a physical thing, that it wasn’t my moral fibre, was incredible.”
>
> (Greg, 22-25, male, neuroendocrine condition)

In a practical sense, diagnosis was often what allowed medical treatment to progress. Participants reported a sense of empowerment from accessing treatment, in part because it relieved them from the guilt of not “doing enough”:

> “As soon as I felt like I had a diagnosis I felt like there was something I could do about it. Because I think that was one of the frustrating things, worrying that I wasn’t doing enough or that I wasn’t doing anything to help myself or help my body.”
>
> (Helena, 22-25, female, endometriosis)

The meaning of a diagnosis therefore came from what participants had been denied when without one: legitimacy, care, and treatment (Jutel, 2011; Jutel & Nettleton, 2011). Relief and even happiness came largely because participants knew that a lack of diagnosis had stopped them receiving what they needed, rather than because they themselves desired a diagnostic label. In that sense, the feeling that diagnosis should or did ‘solve’ a problem came from the fact that a biomedical and cultural emphasis on diagnosis made one a requirement for receiving care and gaining legitimacy. This formed the foundation for one issue that arose throughout participants’ illness experiences: interpersonal and emotional tensions emerged when the expectation was that diagnosis would equate to success and stability, but the reality was that one’s diagnosis only addressed very specific aspects of their illness experience.

While relief was the response for participants who had been experiencing growing frustrations at both their symptoms and their lack of explanation for them, in situations where participants described themselves as having been in some way avoiding confronting their symptoms, they reported a similar sense of emotional paralysis and numbness when they were given a diagnosis:

> "I was in that weird mode of not really engaging with it when I developed the symptoms… that kind of ramped up even more when I had that appointment with the doctor who told me it was [condition]. And then from there for the next couple of months I was kind of just in a completely detached kind of thing…"
>
> (John, 26-29, male, neuroimmune condition)

Likewise, where participants *were* struggling to believe that they could be experiencing a physical illness, a doctor's diagnosis did not mean that they suddenly and easily claimed that pathology. This was explained by Fred (19-21, male), who, despite a diagnosis of CFS/ME, still found himself preoccupied by the thought that he might just have a life that was more exhausting than his peers:

> "It culminated in realising that, I do have circumstances and reasons that could be pushing me down, but there's the practical realisation that, either you somehow find the energy within you to keep resisting circumstances, or, you realistically accept that you don't have that energy, and you accept that you have chronic fatigue. Honestly, maybe I don't have chronic fatigue, maybe we just live in a world that puts way too much pressure on young people, and I'm struggling with that. But practically speaking all the signs point to you have… either way, I'm out of energy all the time, I'm lethargic all the time, and I find it really hard to get myself to do anything. It gets to the point where there is no other option than to just accept that I have a fatigue syndrome and that I need to take steps to work within that. Which is what I've come to recently."
>
> (Fred, 19-21, male, CFS/ME)

In his interview, Fred's choice to describe his condition as "a fatigue syndrome" seemed to be a clear, if subconscious, discomfort with medical diagnostic nomenclature and the certainty around physical illness it implies. His diagnosis, which he reported accepting as a pragmatic decision of last resort, did little if any of the work needed to think through what ill-health meant for his identity and life choices.

Within this context, Fred also distinguished between doctors who sought to help him, rather than just diagnose him, and reflected on the former favourably. Another participant, Tess

(26-29, female, MCAS), echoed this sentiment when she was recounting her decision to not pursue more diagnoses with a different specialist, since “it would just be a diagnosis, and I’m tired of that, I want someone who helps get me out of the situation.”

For those who had diagnoses that did not meaningfully impact symptom management or treatment, there seemed to be a consequent reduction in the importance placed on diagnosis, and indeed an absence of any clear sense of a defined point where a diagnosis was received. This was often because a GP would give a presumptive diagnosis, and then a specialist would (many months later) simply say that the initial doctor was most likely right, and not prescribe any new treatment or forms of lifestyle management.

In this sense, diagnosis was not capable of doing the *emotional* work of living well with illness for someone – coming to terms with illness, and learning to live well with it, were actions that could begin pre-diagnosis, or could come significantly after diagnosis. At best, diagnosis allowed practical interventions (although not always) and confirmed that participants were, as they suspected, experiencing symptoms of physical illness.

Creeping ambivalence and recurrent frustrations

Years after receiving their diagnoses, participants reported that they were still struggling with unanswered questions. It quickly became clear to participants that the promise of medical mastery which came with diagnosis was not going to eventuate, and the letdown of diagnosis caused additional emotional pain.

Participants often felt that they could not query the terminology or medical implications of their diagnosis. One participant described her apprehension about voicing her confusion at how a diagnosis of “mild” IBD related to her broader experiences of ill-health, which appeared to result in continued uncertainty and feelings of misrecognition:

> “It’s meant to be quite mild, I’m on mild medication. So that’s something I’m still quite confused about because my fatigue, and my other symptoms that aren’t gut related seem so severe compared to having a mild… yeah, not sure.”
>
> (Sally, 26-29, female, IBD)

The feeling of being letdown by diagnosis also came from the fact that diagnoses often did not come with clear treatment regimens or prognostic trajectories. This suggests that Boulton’s (2019) argument that a fibromyalgia diagnosis is sometimes an “empty promise” (p.

817) also speaks to some elements of many other chronic illness diagnoses, as participants reported similar feelings in relation to illnesses that did show up, undeniably, in biomedical tests. Helena, who was quoted above remembering the feeling of relief that she could "do something" about her endometriosis when she was first diagnosed, explained that she was now struggling with her frustration at the fact there was "no rhyme or reason" to her pain, and that there was "nothing you can do to help yourself in [my] situation." The confusion of illness post-diagnosis was made worse by the fact that participants initially felt they had gained an organising structure to understand their health, only to find that diagnosis answered very few of the questions they had about chronic living in their day-to-day lives.

While participants were managing their own sense of betrayal at the failure of a diagnosis to thoroughly explain their situation to themselves, diagnosis also did not provide an easy way to communicate the realities of ill-health to others. Participants continued to be concerned that debilitating symptoms, like fatigue and pain, might just be seen as something many people experienced:

> "I was like crying in the car, thinking, 'what is this? Why can't I move my body because of some random thing called [condition] which no one can help with apparently, it's just something I have?' It was like someone had cursed me. And I had to call the [school] and be like, 'sorry I can't do [my commitment], because I can't move.' And they were like 'why?' and I was just like 'because I have bad skin.' Like what?"
>
> (Tom, 22-25, male, autoimmune skin condition)

Given these letdowns, some participants reported scepticism about the importance others placed on diagnostic labels as a tool for understanding illness experiences. In one illuminating case, despite the participant's diagnosis with autoimmune arthritis leading to quick and ongoing therapeutic intervention, the details of her diagnosis were not well understood by (otherwise supportive) family members, and they were also not of much interest to the participant herself. She expressed frustration at others' expectations that a diagnosis would contain all the answers, and indeed expressed caution about those who were interested in her diagnosis, since she did not want it to be used to make assumptions about her experience:

> "I was diagnosed with rheumatoid arthritis, or some sort of arthritis, I can't really remember my diagnosis. […] I think especially with my diagnosis –I can't even remember if it's rheumatoid arthritis or seronegative, I feel like it's seronegative, but

> my mum thinks it's rheumatoid – I'm just going to go with it is seronegative. But even under seronegative arthritis there's many different things, so it's just an umbrella term for so many other things. So when people ask, which one do you have? I'm like, girl, I don't know either. And even if I give you the name of the diagnosis, what are you going to do with it? Fit me into that box?
>
> (Catherine, 19-21, female, autoimmune arthritis)

Diagnosis did not alleviate the administrative and financial burdens of illness, nor did it help people decide how to discuss their illness, and its difficulties, with others. In some cases, needing to explain the impacts of a difficult diagnostic journey became an additional burden:

> "It's also difficult to explain… how hard it is to seek help. Because my mum is very proactive, she's very: 'if you're feeling depressed, do something about it, yada yada yada. This and then this, this and then this.' But then my experience I guess, with the doctors and stuff, it's like, no, I have to consider what's important for me, and figure out my own healthcare plan going forward. And it's kind of staggered because of having to balance everything else, but we're getting there."
>
> (Susan, 22-25, female, fibromyalgia)

> "I guess the less people who know about something the less people who can be concerned. And it's not like I don't want people to be concerned, but I guess, in a way, I don't. There are situations where you know you are ok, there's no problems, no immediate worry to be had, so it seems like, why just confuse people with that concern where it's not an immediate worry? If that makes sense. So, I guess in that way I guess there are definitely situations where I'm like, this is a benefit because no one is taking it very seriously, and that's kind of good because it leaves me to deal with it by myself."
>
> (Helena, 22-25, female, endometriosis)

> "Sometimes I'm like, I can't be bothered to say it. Because the anger I sometimes feel when someone doesn't get it, I'm like, how do you not get it? So sometimes I don't bother telling people how an appointment went, because explaining something over and over again can be really draining."
>
> (Rosie, 22-25, female, POI)

These excerpts not only reveal a complex ambivalence towards medical and interpersonal care, but also that it can be exhausting to explain – and indeed justify – that ambivalence to others. This was true to an even greater extent for those who did not have diagnosis, where the pressure from others to keep looking for answers could be even more significant and unwanted:

> "I don't talk to [my parents] as much, because they sort of just stress me out rather than be helpful. Because they are concerned because they are like 'what's going on with you? We've got to try and figure it out.' I think their reaction is to over research and always send me articles. And the other thing is, I just don't want to be constantly thinking about it."
>
> (David, 19-21, male, fatigue and dysautonomia)

In a cruel irony, participants' emotional discomfort surrounding the role of diagnosis could also come from friends and family adapting their behaviour post-diagnosis. This was interpreted by participants as revealing that a medical diagnosis was necessary for them to be believed even by loved ones, despite the fact they had been reporting their symptoms for years:

> "I'm like, 'oh ok, nice to know [about the diagnoses].' But my parents are like, 'oh my God, what's going to happen?' All this stuff, when it's… it's interesting, because I've been living with the same, living with these symptoms, for so many years [… but] now they know it's quote unquote 'real' they're always asking about it. […] Every single day my parents are like, 'How are you? How's your back? Don't unload the dishwasher, we'll do it for you.' That kind of stuff."
>
> (Farah, 19-21, female, autoimmune arthritis and degenerative spinal injuries)

All this suggests an ongoing and frustrating tension between the internal work young adults do to live with their illness, and the medical and cultural expectations about the worth and role of diagnosis as a tool for understanding illness experiences. These tensions between the clarity promised by diagnoses and the far more unstable reality of living with chronic ill-health seemed to embed in participants a general feeling of uncertainty, and caused an apparent sense of ambivalence towards medical care and concern from others. The failure of diagnosis to provide clarity increased feelings of intractable precarity, which in turn limited many participants' patience for people in their lives who did not appreciate their ongoing and consistent confrontation of unpredictability and hopelessness.

The fluctuations of life and the static-ness of diagnosis

Amongst these questions around the role of diagnosis, participants found other ways to understand their experience of illness. While medical diagnoses may seek to define the contours of illness, a diagnosis is a static label, while the life it categorises is ever evolving. The way in which diagnoses were sidestepped when coming to terms with illness varied. For some participants there was real pain when confronting the failure of a diagnosis to help them consider their life and identity more broadly:

> "Even after I got diagnosed and I learned that there was a reason for all this stuff, and that it wasn't my fault, it was only then that I realised I thought it was. I still had this – because in one sense, I was right, my whole life, I grew up thinking there was something really wrong with me, that I was something awful, and I was like 'yeah, I told you.' It just ended up being not how I was thinking about it. So it still… that didn't go away with the diagnosis. That's something that I sometimes think is pretty surprising. Surely once you discover that there's this thing and it's not… […] But even then I'm like, I still don't feel, it's not like suddenly my self-esteem is fine, or suddenly I didn't feel like I was at fault in some way, even though it's hard to make that argument. But you don't have to make an argument to yourself about how you feel, that's not how feelings work. […] How much of me, how much of the amount I struggled with just life stuff is because of [diagnosis] and fatigue, and how much is just because I'm a piece of shit? Sorry. But yes, that thing of, I don't even know if I'm… where does the [condition] start, or [condition] end and I start?"
>
> (John, 26-29, male, neuroimmune condition)

For John, diagnosis was unhelpful in his consideration of identity questions about what in his life was attributable to his condition and what was attributable to his own 'self'. Indeed, after being equipped with the supposedly helpful explanatory tool of a diagnosis, John instead felt like his diagnosis justified his belief that he was "something awful", as it was confirmation that there was something in him that was inherently "really wrong". While a diagnosis was necessary for him to receive life-saving treatment, learning to live well with chronic illness was in fact made harder by the failure of diagnosis to live up to his sub-conscious expectations.

When diagnosis did not offer relief from some of the more existential questions of chronic living, participants found other ways to make sense of their complex life. The below example comes from Matt's interview, after he had described how his diagnosis of autoimmune arthritis and degenerative spinal injuries as a teenager had done little to help him come to terms with his new lived reality. He explained though that now, as an adult, he found himself focusing on the idea of pain, and chronic pain, to articulate and understand his condition:

> "It's easy to fight one issue at a time, but the nature of chronic pain and chronic health is that it suddenly makes everything more difficult. […] I saw this weird thing where it's like, people write down what they're afraid of or what their goals are, and suddenly it's a lot more tangible, a lot more achievable, or you're not as afraid or daunted by it. And I think metaphorically it's the same for me with pain. It's all it is, is pain. […] To the extent that it's just pain – just pain, that's all it is – you can start to compartmentalise it and just be a bit more hardened to it."
>
> (Matt, 22-25, male, autoimmune arthritis and degenerative spinal injuries)

Similarly, Sarah (19-21, female), who was diagnosed with CFS/ME as a child, spoke about her experiences growing up with little attention to when she was diagnosed or started receiving treatment, despite going through many specialists and a paediatric program at a major hospital. She remembered her ongoing disconnect with the way her parents saw illness as something currently weighing on her and which needed to be removed, rather than a part of who she was:

> "I think I always knew deep down that this was just a reality. And [my parents] would always say, 'this is just the winter of your life', but I was like, 'is it?' I don't want to let this define what the seasons of my life are. I always saw my life as within my illness, but they always saw my illness as just a little pothole, that we would, you know, just get out of. So they had to go through a lot of grief. And they tried to come up with a lot of theories, and they did a lot of problem solving, […] but I just never really cared, because for me it wasn't about why or how to get better, it was just about living within it."
>
> (Sarah, 19-21, female, CFS/ME)

The way in which Sarah decentred diagnosis demonstrates that individuals can make sense of their illness experiences in ways which do not represent the biomedical model of disease and medicine (Clarke et al., 2003). As Leon Eisenberg (1977) and Charles E. Rosenberg (2002) have described, diagnosis is key in these models as it both constructs the 'disease' as an entity which is separate from the person who is sick, and justifies expert medical management and treatment. For Sarah, however, illness remained inseparable from her life and sense of self post-diagnosis.

Finally, for David (19-21, male) who had been living with various symptoms of fatigue and dysautonomia for about twelve months, diagnosis seemed unlikely – he described his condition as "probably something psychosomatic." Instead, "trial and error", even in the absence of a diagnosis, constituted meaningful steps towards managing his health. This went along with deprioritising the desire for a diagnosis that might not, ultimately, serve him:

> "I just go, 'you know what, we don't actually know what's going on, we just sort of got to ride the wave, you have your good days, you have your bad days.' Which I think is the best approach. I mean, I'll keep trying what I can with doctors, but I think in the meantime I just need to know that this is something that's going to happen. Which is not great, I hoped it wouldn't, but it does, and there's nothing I can do more of to change it. I'm taking all the steps. I'm not just saying 'oh I'm sick' and letting it happen to me. I'm going to the doctor, I'm eating healthier, I'm taking iron tablets, sleeping more, I've reduced my workload to account for that, seeing my therapist, I'm doing all these steps. It's not fully getting better but there's nothing more I can do. So I just make peace with that fact. […] It was a difficult process, but trial and error has got me to a better point."
>
> (David, 19-21, male, fatigue and dysautonomia)

In line with Julia Coffey and David Farrugia's (2014) conceptualisation of agency as a "generative process" (p. 470) that young people engage in to find a 'self' amongst social, structural, and institutional forces, the above passages demonstrate participants' growing ability to find their self amongst both their embodied experience of illness and the expectations about illness that surrounded them. The assumption that diagnosis would make this process easy could, in fact, be disruptive to a more organic consideration of the meaning in one's individual experience of illness.

For participants, frustration at others' preoccupation with diagnosis came, in part, from their own disappointment with the fact that diagnosis did not have all the answers, and a subsequent disconnect between the expected and actual experience of illness. This disappointment is an important component of what people live through, as is the subsequent work they do to build a contrasting set of values and beliefs. Beyond this though, the stories that emerge of living well with chronic illness offer insight into how, particularly at an age of broader identity work, ill-health can be integrated into a sense of self.

Discussion

As social science scholarship has regularly shown, chronic illnesses, in all their varieties and complexities, have a tendency to unsettle, unravel and/or redefine an individual's lifeworld. Chronicity can cast difficult questions over one's past, present, and futures, very often reordering life and self (Bury, 1982, 1988; Charmaz, 1983; Frank, 1995). Diagnosis may be one way of "bind[ing] the biological, the technological, the social, the political, and the lived" (Jutel, 2011, p. 13), but, for participants, it did not succeed in creating a stable and satisfactory bundle.

In interviews, participants often described how the power and potency of diagnosis was eclipsed by their own personal understandings of illness that they utilised to live well in the day-to-day. Participants' descriptions of coming to terms with their various experiences of chronic living sat somewhat separately to their discussion of the role of diagnosis in their lives, with the two converging at points but diverging at others.

Participants most often described diagnosis as one tool to access practical help, rather than as an essential point of validation or even a particularly useful explanatory lens. While a lack of diagnosis had often diminished the ability of participants to receive treatment, and had increased their feelings of chaos when symptoms were unexplained and unpredictable, diagnosis was often unhelpful, and at times stifling, in participants' ultimate "quest" to transform their illness into something emotionally and socially manageable (Frank, 1995).

Participants' experiences provide further evidence, and additional depth, to the scholarship of the sociology of diagnosis, including a further understanding of how "diagnosis is simultaneously a place of contest and of consensus" (Jutel, 2015, p. 20). For the participants in this study, the work of chronic living (Corbin & Strauss, 1985; Manderson & Wahlberg, 2020) came in part from navigating how diagnosis was perceived and portrayed as the achievement of clarity, but, for them, actually still carried questions and doubts. This draws further attention to our need to be aware of how “the diagnostic moment sidelines the temporal aspect of living with illness” (Jeske et al., 2024, p. 226). This chapter demonstrates that it is not only that the diagnostic journey influences how one experiences illness, but that the emotional expectations one held about diagnosis, and the expectations others continue to hold about diagnosis, also have an ongoing influence.

For participants, the “structure” (Jutel, 2011, p. 13) that diagnosis provided to an illness experience could be both limiting and disappointing. Tensions arose between the stasis of medical diagnostic categories and the dynamic unfolding of these young people’s lives. Put differently, the *static-ness* of diagnosis could not accommodate the evolving and vital world/body. When we speak about static electricity, we are talking about currents that do not flow as they should, and it is this lack of movement that creates disruption and noise in electrical systems, creating the static we hear or (historically) see. This same irony exists for diagnosis. A diagnosis (or a desired diagnosis) can loom over people, unable to shift as needed when various challenges emerge and evolve. This static-ness was routinely experienced by participants as disruptive to their ability to communicate with others, and as an interference in their relationships as they tried to understand what illness and pain meant to them. This offers a broader perspective on the ways in which an (over)emphasis on diagnosis can lead to emotionally difficult clinical interactions for patients (Boulton, 2019; Jutel, 2011; Nettleton, 2006) – too much attention to diagnosis can also diminish the perception and success of care in many other social encounters.

Participants still found ways to navigate the contested yet biomedically celebrated experience of diagnosis. They sought to strategically distance themselves from the unhelpful structures of diagnosis, and reported that the emotional work they did for their own sense of self was separate from the work they undertook to receive a diagnosis. In interviews it became clear that young people can respond to the instability of chronic illness with important and creative adaptations of traditional illness narratives, reflective of how youth can be a time of finding agency amongst previously controlling social and institutional structures (Coffey & Farrugia, 2013; Pais, 2022). For participants, their consequent “self-directed transformation” (Deegan, 2001) was an important part of their chronic living.

The work participants did while moving away from diagnosis represents both their perceived need for an individualised understanding of illness, and their ambivalence towards certain aspects of medicine. In the context of chronic illnesses, ambivalence represents a rejection of cultural binaries, and this resonates with where disorientation and ambivalence has appeared in participant testimony earlier in this thesis. Here, ambivalence is very much a product of relational experiences, emerging in tandem with the reactions of others to diagnosis, and the recognition that what one is experiencing does not accord with dominant social narratives (Bauman, 1990; Hillcoat-Nallétamby & Phillips, 2011; Merton, 1976). In this sense, diagnosis as a discursive construct – as well as a medical one – influenced how participants related to the medicalisation of their conditions more broadly.

By examining the ways that young adults do (and do not) talk about their diagnoses, we can see that one important response to the various shortcomings of diagnosis is to decentre it from their illness narrative entirely. As participants moved away from their diagnoses as defining components of their illness story, new paths, parallel to medical interactions, emerged as ways to make sense of their own ill-health and incorporate it into their understanding of self.

In listening to the testimony of people with a wide variety of chronic illnesses, who each have different relationships with diagnostic labels and varied diagnostic trajectories, the tensions and possibilities which arise in the grey areas of illness and medicine become clear. With this in mind, the above findings are instructive for the family members, friends, and loved ones of young adults living with chronic illness. Diagnosis was rarely, if ever, a topic of discussion that they wanted others to raise with them – participants consistently reported discomfort and frustration at conversations instigated in this way. There needs to be a greater awareness of the fact that, even after receiving a diagnosis, accessing adequate care can still be emotionally and practically difficult, and that it can remain difficult to advocate for one's needs. Further, the suggestion by others that someone needs greater care post-diagnosis can be perceived as invalidating previous experiences. Health professionals also need to be aware of these tensions, and should recognise that their bestowal of diagnosis does not define the processes that their patients are going through as they begin to understand their body and what their health means for their life and identity. A final learning is that, for research to contemplate more fully the experience of living with chronic illness, there must be a willingness to move away from diagnosis as a dominant resource for these inquiries.

CHAPTER NINE | the chronic living of young people

The prevailing normative narratives regarding health and illness do not encompass the diverse, nuanced, and prevalent experience of chronic illness when young. Social narratives and healthcare settings often focus on acute, curative models of disease (Dumit, 2006; Kafer, 2013), and attention to “chronic living” has arisen largely with reference to aging and extended lifespans (Greco & Graber, 2022; Kenny, 2015; Manderson & Wahlberg, 2020). Yet, for those who are chronically ill when young, the context of youth is essential for understanding their experiences, and for fostering appropriate social and therapeutic support. The consequences of this mismatch between the cultural and medical imaginaries of chronic illness, and the lived experience of it in youth, are far-reaching. They remain, however, difficult to recognise, record, and articulate. This thesis has engaged with these current gaps to contribute new and adapted conceptual frameworks for understanding and supporting young people living with chronic illness.

In the absence of a nuanced and meaningful vocabulary for the experience of chronic illness when young – and amid stigma, denial, and the assumed ‘health’ of youth – it becomes increasingly challenging for young people to realise and articulate what they are going through. The often-hidden nature of chronic living amongst young people, which is even more accentuated than it is in older populations, is also a serious barrier for those who wish to provide them with support. More perniciously, the secrecies and shadow landscapes of youth chronicity have the effect of concealing the ways in which institutions diminish, dismiss, or deny necessary accommodations and care.

While a current lack of attention to chronic illness when young makes the experience itself significantly harder, this thesis has examined the experiences and actions of young people to gain insight and guidance for a comprehensive rethink of how we can live with illness, vulnerability, and unpredictability. This examination was made possible, in part, by speaking to participants with a broad range of conditions – the resonances between interviews helps highlight the ways that shared social, cultural, and political narratives impact the many different experiences of illness.

Going forward, the ways young people incorporate illness into their lives helps us imagine how we might better confront – and accept – illness and disability. Below, I tease out this overall argument in more detail, and suggest that there needs to be specific priorities for the sociological study of young people’s experiences of chronic illness.

Research contributions and future directions

Silence and the unspeakabilty of illness in youth

This thesis has demonstrated the extent to which illness in the context of youth is rendered 'unspeakable.' Sometimes, young people are silenced: Chapter Four recounted the variety of ways that teachers, parents, doctors, and other adults would explicitly (if not always consciously) discourage and eventually silence participants when they attempted to speak about their pain, fatigue, or other difficulties of chronic illness. Further, as explained in Chapter Five, institutional and cultural silence about chronic illness in youth creates an environment in which whole cohorts of young people do not know how to appropriately respond or adapt to friends' needs. It is unsurprising that these compounding failures to recognise the challenges of chronic illness cause young people to stop speaking about their experiences – the need to constantly justify oneself, and the recurring experience of being misunderstood, is tiresome and isolating. This frustration, ambivalence, and exhaustion appeared in various ways throughout all five results chapters.

It was common for the young people who took part in this study to police their own descriptions of illness. Chapter Five explored how the expectations of 'youth' became a pressure that dissuaded young people from speaking openly about the adaptations which would allow their chronic illness to be more effectively or easily managed. Pervasive social rhetoric furthered the participants' sense of isolation, while medical settings and generalised 'support' opportunities that were not catered to young people also made participants feel distanced from both their age-cohort and their illness-cohort. Chapter Six then looked more specifically at how young people described their responses to institutional, cultural, and interpersonal pressures to not speak about illness. It is not just that young people feel they miss out on opportunities to talk about an important element of their life, or that their experiences of chronic illness go unrecognised. Rather, it is that young people are consistently anxious about how their illness will be interpreted by others, inflicting an immense emotional and physical toll on them as they live their lives. Sociological examinations of illness when young therefore require a renewed awareness of the interplay of youth and illness. Further, sociological examinations of youth should pay greater attention to how illness experiences shape relationships with the future and feelings of precarity (Anderson et al., 2005; Bryant & Ellard, 2015; Foster & Spencer, 2011; Reiter, 2003).

As outlined in Chapter Seven, one arena in which the promise of visibility and connection is clear is the online world. This builds on literature that discusses how online spaces influence the experience of illness, particularly in relation to connection and different ways of knowing (Barker & Galrdi, 2011; Conrad & Stults, 2010; Gonzalez-Polledo, 2016; Gunnarsson & Wemrell, 2023, Williams & Popay, 2001). Participants wanted to know more about what it was like for others who lived with their illness, to know more about how to manage illness, and to know more about how to negotiate and re-evaluate the expectations in society. At times, participants found this in online spaces that allowed people to connect over stories of and by people living with illness, where those lives were still presented as whole lives by whole people. The intimacy and connection of these experiences demonstrates the importance and potential of explanatory vocabularies and frameworks for illness. This in turn demonstrates the applicability of literature on digital cultures of care and activism around other identities and interests to online illness and disability content (Byron, 2021; Lomanowsk & Guitton, 2016; Papacharissi, 2020; Vivienne, 2016). That said, the fear and despair in some online forums also demonstrates the cycle of isolation and anxiety that can arise when people are not given the medical and social care that they need and deserve. These experiences are made clearer with reference to literature that theorises how online spaces increasingly function as an integrated element of life (Horst et al., 2009; Madianou & Miller, 2012; Nelson et al., 2020).

Unstable illnesses in unstable bodies

Current methods for recognising and understanding illness are largely situated in adult bodies, which can create significant and varied barriers for young people seeking medical care. The most common way to get a disease diagnosed is by, one, going to the doctor, two, getting a doctor to agree to do some tests, and three, having tests come back that ‘confirm’ the presence of disease. The contested, political, and potentially fraught nature of this is well established by literature on contested illness experiences (Bülow, 2008; Moss & Teghtsoonian, 2008; Nettleton, 2006) and the sociology of diagnosis (Jutel, 2011, 2015; Jutel & Nettleton, 2011). For young people living with a chronic illness, this chain of events often contains specific and frequent acts of disregard, doubt, and denial. As explored in Chapter Four, the similarities in participants’ experiences, despite their spectrum of diagnostic trajectories, biomedical legibility, and therapeutic options, demonstrates underlying issues with chronic illness care for young people.

The clinical interpretation of symptoms, whether in a pre-diagnosis encounter or through a specific diagnosis, is a way that bodies are made intelligible to both healthcare professionals and patients (Eriksen & Risør, 2014; Gardner et al., 2011; Mol, 2002; Wardrope & Reuber, 2022). Our current social, medical, and philosophical understanding of what requires interpretation revolves around the emergence of a vulnerable, disruptive, and unpredictable body (Carel, 2016; Hay, 2008; Toombs, 1992). This is not sufficient for young people. For them, there is an existing explanatory framework for vulnerability (youth), and for disruption and unpredictability (growing up). These frameworks, especially when combined with individualising risk discourses about youth (Coffey et al., 2016), mask the emergence of illness. There is therefore a clear need for a deliberate and age-appropriate rethinking of how to better recognise the emergence of illness in young people, particularly when it is a chronic illness that emerges over time and comprises of fluctuating symptoms that exist on a spectrum of concern, such as pain and fatigue.

Moving forward

In the context of these barriers, the young people who have been profiled in this thesis are finding creative adaptations to illness management and narratives. Centring and profiling this innovative work is crucial for imagining, fostering, and upscaling new vocabularies and understandings of illness and disability. One example of this work was explored in Chapter Eight: my participants often iteratively decentred the importance of diagnosis. This is a novel contribution to the sociology of diagnosis, and is an important indication that researchers, healthcare professionals, educators, family, and friends should also be willing to decentre diagnosis as a way to analyse and understand illness experiences. In future, more collaborative research approaches might be one important way to imagine together how there can be better understandings, conceptualisations, and celebrations of young people's lives with chronic illness (Brady et al., 2023; Cowan et al., 2022; Peters, 2010).

The online world described in Chapter Seven is also an important indication that support for people with chronic illness must not lose sight of the whole, rich, and varied lives that they live. These frameworks must move beyond the binaries that haunt illness experiences: healthy/sick, healing/worsening, the familiar/strange body, visible/invisible illness; diagnostic clarity/undiagnosed. Given the current proliferation of binaries, ambivalence is a recurring and potentially useful response to illness (Bauman, 1990; Harbin, 2012, 2014, 2016; Hillcoat-Nallétamby & Phillips, 2001; Lajoie, 2019; Merton, 1976). Reports of ambivalence occurred frequently in interviews, namely, ambivalence towards online spaces, towards care and concern from others, towards diagnosis, and towards illness itself. Alongside ambivalence though, there were also instances of deep connection, and one productive question when looking at these moments is to ask, on what basis is it that participants identified with others? Here, again, participants recounted in their interviews that it was often that they deeply appreciated a sense that others understood their feelings of betrayal and uncertainty towards medicine, the future, and others.

Conclusion

In researching and writing this thesis, I committed myself to listening to the concerns and reflections of young people with chronic illness, and working with those testimonies to think through the ways they, and future generations, could be better supported. I have attempted to partake in a research practice that maintains the individuality and wholeness of each participant story, but I have also sought to honour their time and expertise by constructing analytical arguments and theoretical frameworks which can, first, help people better understand their own experiences of illness, and second, assist others in supporting those who are ill. Constructing a research program around the experience of chronic illness, rather than the existence of a specific diagnosis (or a specific diagnosis being denied) was one important element of facilitating this broader, person-centred rethinking.

In summary, and returning to my original research questions, this thesis has sought to open up a discussion specifically centred on the experiences of young people who live with chronic illness. This thesis has made clear that young adults come to nuanced and complex understandings of chronic illness, disability, and impairment. They do creative and extensive emotional and physical work to construct a life that respects their body's needs and their sometimes fluctuating, unpredictable, or limited capacities. This work is both a crucial component of their life, and a component that can be inappropriately fixated on by others, in part due to fear and silence around illness and vulnerability. From the reflections of my participants on childhood and adolescence, it is also clear that this ongoing work in young adulthood is often built on unsteady foundations.

In my participants lives there were people – friends, colleagues, family members, loved ones – who helped them with these challenges. There were also, on occasion, healthcare professionals who found a way to help those who health and medical institutions often leave behind. Overwhelmingly though, institutional, cultural, and social expectations of young people obstructed my participants' attempts to receive care, and care for themselves, while ill. When these barriers arise, or people fail to provide care, there are insufficient options for support, and a serious lack of guidance about how to find that support.

If we are to take seriously the experiences of the participants of this study, change is needed. Individuals and institutions need to listen better to children, adolescents, and young people when they talk about their illness, or potential illness, experiences. Relatedly, we need better vocabularies and explanatory frameworks around chronic illness: to help young people articulate what they are going through, and to help others understand what young people are saying. The barriers to these developments reflect, in part, broader systems of power that marginalise and fear those whose existence highlights the inherent presence of unpredictability, vulnerability, and complexity in our lives.

This thesis therefore contributes to an emerging body of literature which seeks to uncover the complex experiences of young people living with chronic illness. In doing this, it offers some contributions to how we might understand these experiences, and demonstrates that witnessing chronic illness experiences can be done in a way that does not fall into narratives of misfortune or deficit.

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Appendices

Appendix A: Research flyer

THE UNIVERSITY OF SYDNEY

This study has received approval of the HREC of the University of Sydney [2022/521]

A study on the experiences of people with chronic health conditions

Do you live with a health condition that affects your life in an ongoing way?
Were you born between 1994 and 2004?

Researchers at The University of Sydney are studying young peoples' experiences of chronic health conditions and would love your input.

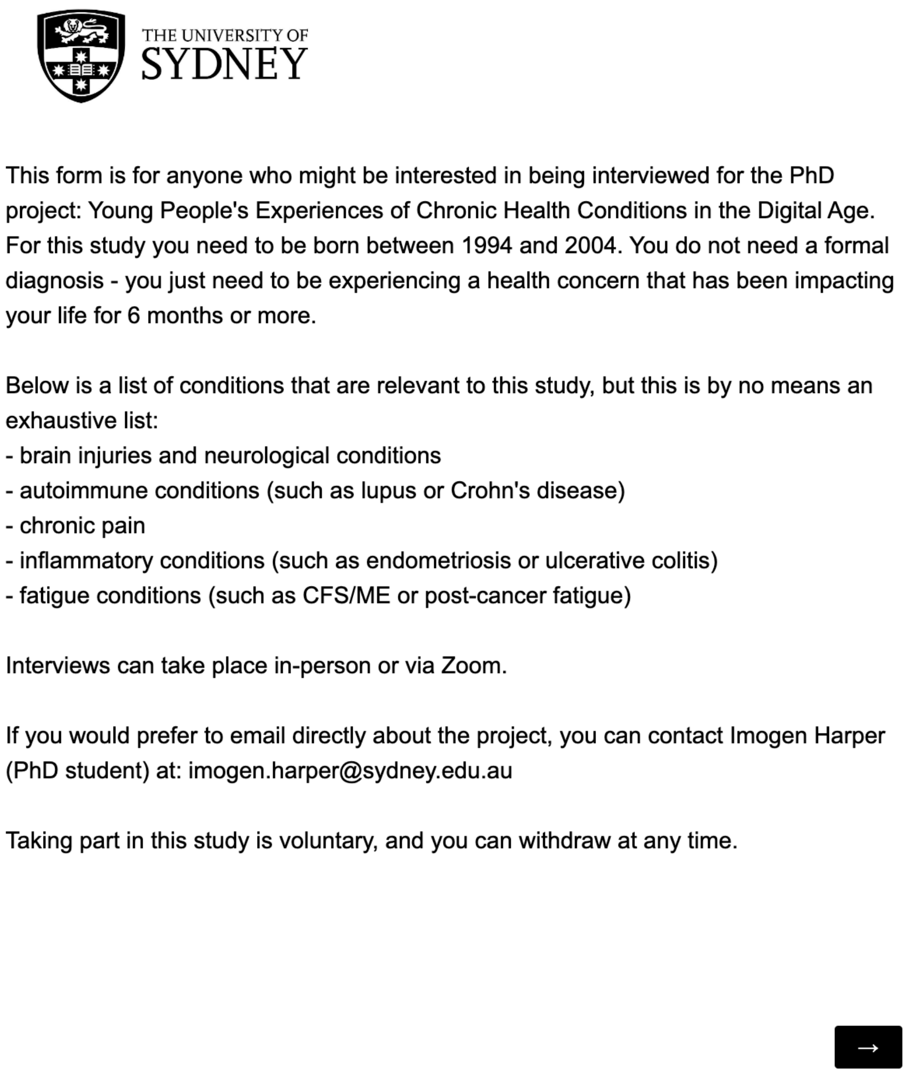
You do not need a formal to participate in this study – if you have had your life impacted by a persistent health difficulty for more than 6 months, we want to hear from you. We are particularly interested in conditions that often go unrecognised by others, such as so called 'invisible' illnesses, and conditions that can be difficult to diagnose.

Conditions might include, but are not limited to:

- Autoimmune conditions
- Crohn's Disease
- Chronic pain
- ME/CFS or other fatigue conditions
- Traumatic Brain Injury
- IBS
- Endometriosis
- Post-viral syndromes
- Ehlers-Danlos syndromes

- *This study involves a 1-2 hour interview that can be done either face to face or online.*
- *Please scan this QR code to learn more about the project and register your interest in an interview.*
- *Alternatively, you can contact Imogen Harper (PhD student) a: imogen.harper@sydney.edu.au*

Appendix B: Qualtrics form introduction



This form is for anyone who might be interested in being interviewed for the PhD project: Young People's Experiences of Chronic Health Conditions in the Digital Age. For this study you need to be born between 1994 and 2004. You do not need a formal diagnosis - you just need to be experiencing a health concern that has been impacting your life for 6 months or more.

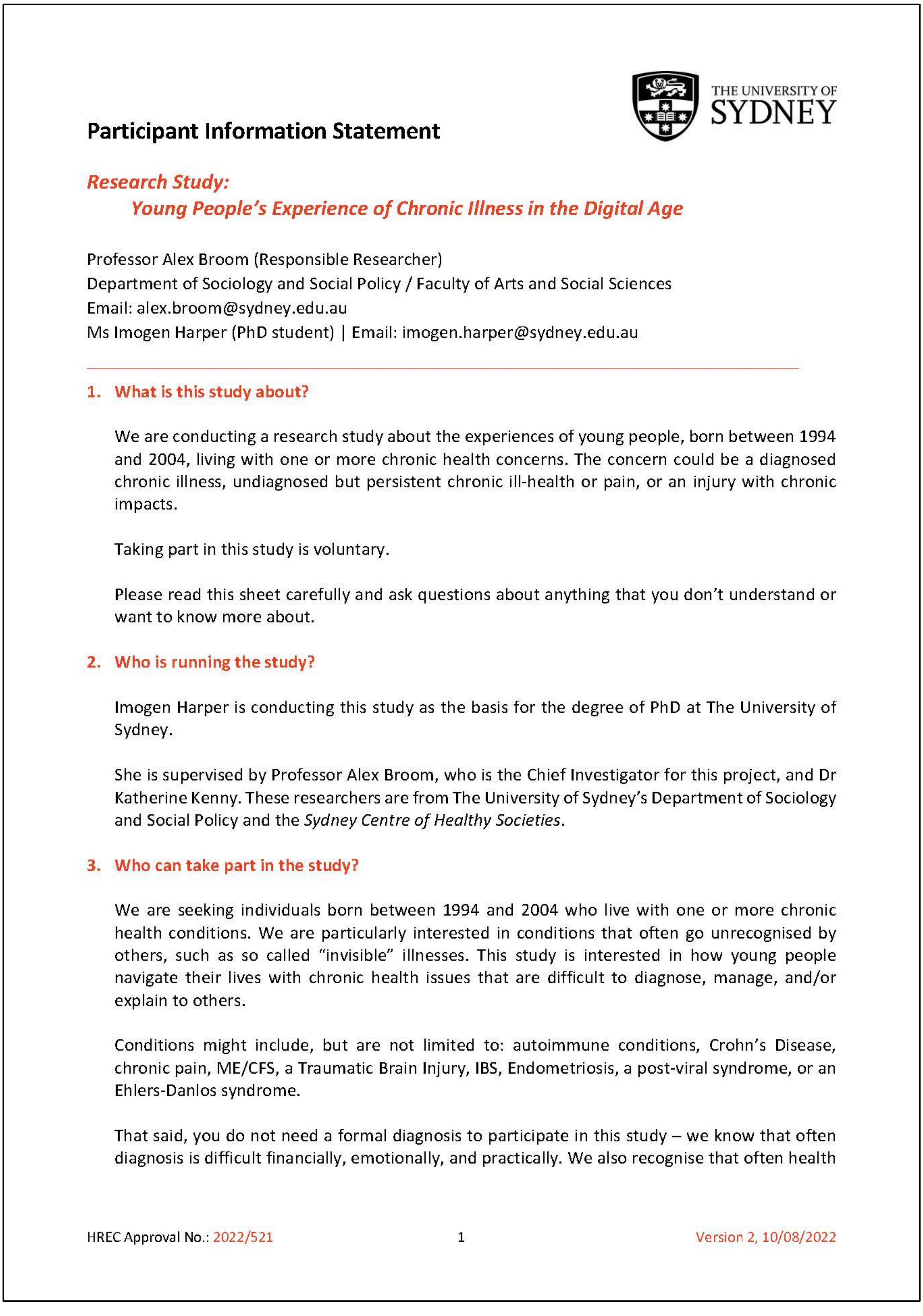
Below is a list of conditions that are relevant to this study, but this is by no means an exhaustive list:
- brain injuries and neurological conditions
- autoimmune conditions (such as lupus or Crohn's disease)
- chronic pain
- inflammatory conditions (such as endometriosis or ulcerative colitis)
- fatigue conditions (such as CFS/ME or post-cancer fatigue)

Interviews can take place in-person or via Zoom.

If you would prefer to email directly about the project, you can contact Imogen Harper (PhD student) at: imogen.harper@sydney.edu.au

Taking part in this study is voluntary, and you can withdraw at any time.

Appendix C: Participant Information Statement



THE UNIVERSITY OF
SYDNEY

Participant Information Statement

Research Study: Young People's Experience of Chronic Illness in the Digital Age

Professor Alex Broom (Responsible Researcher)
Department of Sociology and Social Policy / Faculty of Arts and Social Sciences
Email: alex.broom@sydney.edu.au
Ms Imogen Harper (PhD student) | Email: imogen.harper@sydney.edu.au

1. What is this study about?

We are conducting a research study about the experiences of young people, born between 1994 and 2004, living with one or more chronic health concerns. The concern could be a diagnosed chronic illness, undiagnosed but persistent chronic ill-health or pain, or an injury with chronic impacts.

Taking part in this study is voluntary.

Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

2. Who is running the study?

Imogen Harper is conducting this study as the basis for the degree of PhD at The University of Sydney.

She is supervised by Professor Alex Broom, who is the Chief Investigator for this project, and Dr Katherine Kenny. These researchers are from The University of Sydney's Department of Sociology and Social Policy and the *Sydney Centre of Healthy Societies*.

3. Who can take part in the study?

We are seeking individuals born between 1994 and 2004 who live with one or more chronic health conditions. We are particularly interested in conditions that often go unrecognised by others, such as so called "invisible" illnesses. This study is interested in how young people navigate their lives with chronic health issues that are difficult to diagnose, manage, and/or explain to others.

Conditions might include, but are not limited to: autoimmune conditions, Crohn's Disease, chronic pain, ME/CFS, a Traumatic Brain Injury, IBS, Endometriosis, a post-viral syndrome, or an Ehlers-Danlos syndrome.

That said, you do not need a formal diagnosis to participate in this study – we know that often diagnosis is difficult financially, emotionally, and practically. We also recognise that often health issues do not fit medical criteria, and that seeking a diagnosis might not be helpful. We are interested in talking to you if have had your life impacted by persistent health difficulties for more than 6 months, and you feel that these difficulties are part of a unified “condition”.

If you know someone who might be suitable for this study, you are welcome to pass this information on.

4. What will the study involve for me?

If you decide to take part in this study, you will be asked to participate in a 1-2 hour interview. If this interview takes place in person, you will be able to decide on a convenient location. The interview can also take place via a video call on Zoom.

The interview will cover your experiences living with chronic health condition(s), including your life pre-diagnosis. You will be given space to talk about what is important to you and will not have to answer any questions you do not want to.

If your health makes it difficult for you to participate in a 1-2 hour interview, we can discuss the possibility of you providing written responses to interview questions, and engaging in follow up discussions with the research team over email or another form of online messaging.

5. Can I withdraw once I’ve started?

Being in this study is completely voluntary and you do not have to take part.

Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

If you decide to take part in the study and then change your mind you can withdraw by letting any of the research team know. You can withdraw up until the point of thesis submission.

If you take part in an interview you may refuse to answer any questions that you do not wish to answer.

6. Are there any risks or costs?

This study involves the discussion of potentially emotional subject matter, but only in so far as you choose to discuss it. The interviewer will not push you to answer anything you do not wish to and will not question anything you wish to share. You will be able to end the interview at any time.

Otherwise, aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

7. Are there any benefits?

We hope that the interview offers you an opportunity to discuss aspects of your life that are important to you, to be listened to, and to contribute to important research on the experience of living with chronic health conditions.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you for the purposes of this study.

Interviews will be audio recorded and transcribed. These transcripts will be kept on a password protected, secure server, in a de-identified form. Transcripts will be used so that the researchers have access to a detailed record of the conversations, and closely analysed for emerging themes and ideas. Transcripts will only be accessible to the core members of the research team.

Any information you provide us will be stored securely and we will only disclose it with your permission, unless we are required by law to release information.

We are planning for the study findings to be published. You will not be individually identifiable in these publications.

We will keep the information we collect for this study and we may use it in future projects. By providing your consent you are allowing us to use your information in future projects concerning the themes of this project, such as the experience of young people, the experience of chronic health conditions, or communities and information on social media platforms. We will seek ethical approval before using the information in these future projects.

You will have the option of choosing if you would like to be potentially contacted about further studies related to this subject matter.

9. Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. Please tick the relevant box on the consent form if you would like to receive a brief lay summary of results.

10. What if I would like further information?

When you have read this information, the following researcher will be available to discuss it with you further and answer any questions you may have:

- Imogen Harper, PhD Candidate, imogen.harper@sydney.edu.au

11. What if I have a complaint or any concerns?

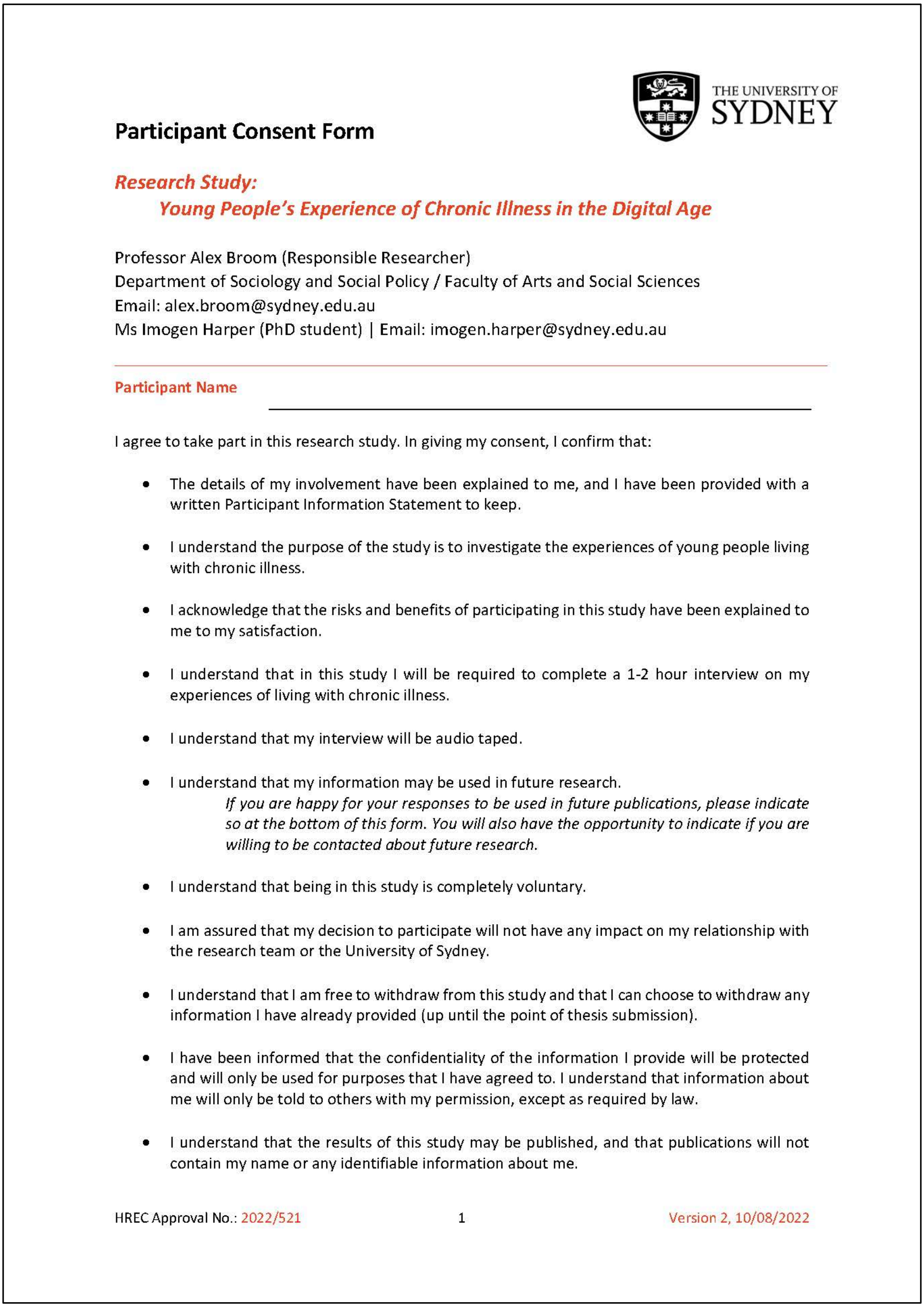
The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [2022/521] according to the *National Statement on Ethical Conduct in Human Research (2007).*

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

This information sheet is for you to keep

Appendix D: Participant Consent Form



THE UNIVERSITY OF SYDNEY

Participant Consent Form

Research Study:
Young People's Experience of Chronic Illness in the Digital Age

Professor Alex Broom (Responsible Researcher)
Department of Sociology and Social Policy / Faculty of Arts and Social Sciences
Email: alex.broom@sydney.edu.au
Ms Imogen Harper (PhD student) | Email: imogen.harper@sydney.edu.au

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Participant Name ______________________________

I agree to take part in this research study. In giving my consent, I confirm that:

- The details of my involvement have been explained to me, and I have been provided with a written Participant Information Statement to keep.
- I understand the purpose of the study is to investigate the experiences of young people living with chronic illness.
- I acknowledge that the risks and benefits of participating in this study have been explained to me to my satisfaction.
- I understand that in this study I will be required to complete a 1-2 hour interview on my experiences of living with chronic illness.
- I understand that my interview will be audio taped.
- I understand that my information may be used in future research.
  If you are happy for your responses to be used in future publications, please indicate so at the bottom of this form. You will also have the opportunity to indicate if you are willing to be contacted about future research.
- I understand that being in this study is completely voluntary.
- I am assured that my decision to participate will not have any impact on my relationship with the research team or the University of Sydney.
- I understand that I am free to withdraw from this study and that I can choose to withdraw any information I have already provided (up until the point of thesis submission).
- I have been informed that the confidentiality of the information I provide will be protected and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
- I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

- I confirm the following:

  I consent to being contacted for future studies Yes ☐ No ☐

  I consent to my data being used in future research Yes ☐ No ☐

  If you answered **yes**, please provide your preferred contact details (email/telephone/postal address):

  ____

  ____

  ____

  ____

- I understand that after I sign and return this consent form it will be retained by the researcher, and that I may request a copy at any time.

Participant Name ______________________________

Signature ______________________________

Date ______________________________

Appendix E: Interview schedule

Indicative Interview Guide

Consistent with our inductive qualitative approach, these questions are indicative only. The specific questions each participant is asked will depend on their history of illness and what they are comfortable talking about. Questions will also be adapted in real-time to facilitate a smooth and natural discussion of the research themes. This baseline interview schedule will be revised as data collection progresses to reflect emerging findings and concerns.

Demographics and Background

- Age
- Gender
- Race/ethnicity
- Employment status
- Relationship status
- Location (urban, regional, rural)
- Conditions diagnosed with (and do you connect with this label?)
- Any conditions you are seeking diagnosis for, or you suspect you might have

Theme: The experience of health and illness

- How would you describe your health right now?
- And how about your health in the past?
- What are some key moments for you when you think about your health?
- At what point did you start engaging with the idea you might be diagnosed with a chronic health condition? Who was involved in that?
- What did this diagnosis offer you then? What does it offer you now?
- Is there anything you wish you had done differently in the past, in regards to your health?
- What have you felt are the expectations others have had around your experience of illness?
- Have you incorporated any principles into how you live your life with chronic illness? How do you manage the competing expectations of work/study, relationships, and your health?

Theme: Care

- Who has been involved in advice, treatment, and care for your health and wellbeing?
- What has been your experience of diagnosis, intervention, and subsequent care?
- Have you found some doctors more supportive and helpful that others? What do you think made it that way?
- How does having a chronic condition shape your interactions with providers of care?
- Do you, or have you considered, seeking support from disability support services or similar?

Theme: Relationships

- What does your health mean for how you interact with others in your life?
- How have those around you shaped your experiences of chronic illness?
- Do you talk to people about having a chronic illness? How do you choose what to tell people about?
- Do you feel that these experiences shape how you feel as a person, or who you are as a person?

Theme: Engagement with digital spaces

- Did you look up your symptoms on the internet? How about your diagnosis? Was that helpful?
- Do you see yourself as someone who gets a lot of support from social media? How do you find them helpful/not helpful?
- How do you think your life would be different without social media?
- Do you share information about your health on social media? If so, why? If not, have you considered it? Why/why not?
- Has your relationship with social media changed as your relationship with your health/illness has changed?

Final thoughts

- Do you have ideas about what could happen to improve the lives of people with chronic illness?
- Is there anything else you would like to talk about, or would like to add?

Appendix F: Safety Protocol for face-to-face interviews

SAFETY PROTOCOL FOR FACE-TO-FACE INTERVIEWS

Young People's Experiences of Chronic Illness in the Digital Age

- The researcher (PhD student Imogen Harper) will be conducting the interviews alone.
- Interviews will take place in a location decided upon by the participant. This location will most likely be either a private home or a relatively private space in a public area, such as a meeting room at a university or library.
- The time and location of the interviews will be communicated to a third party. This will be the researcher's supervisors: Professor Alex Broom and Dr Katherine Kenny. Imogen will communicate with this third party prior to commencing the interview and after the interview is completed.
- When interviews take place in a private home, Imogen will take steps to ensure that she is able to leave at any time. This includes only entering 'public' areas of the house where possible (such as kitchens and living rooms), ensuring that the exit route is clearly known, and watching to ensure that the door is not locked after entering.
- Should anything untoward happen, or Imogen becomes uneasy for any reason, the interview will be terminated immediately, and she will leave. Her supervisors will be contacted as soon as practically possible.
- Where possible, interviews will be conducted in daylight hours or in the early evening.
- Transport to and from the interview will be by public transport, or Imogen will drive herself to and from the interview.
- Imogen will always have her mobile phone on her.

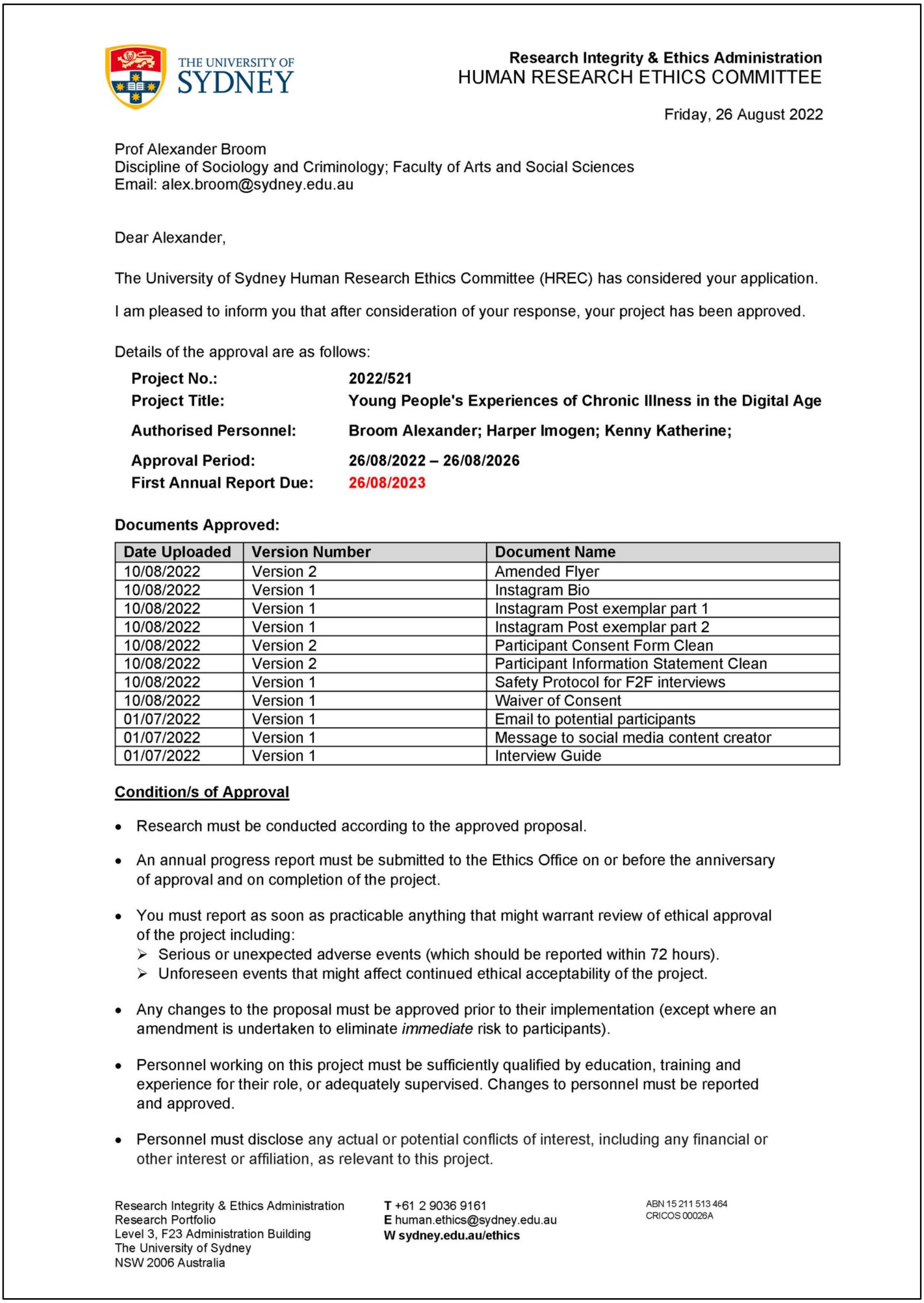
This safety protocol has been agreed and accepted by the researcher and the supervisors.

Imogen Harper: [redacted]

Professor Alex Broom: [redacted]

Dr Katherine Kenny: [redacted]

Appendix G: Human Research Ethics Committee approval



THE UNIVERSITY OF
SYDNEY

Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Friday, 26 August 2022

Prof Alexander Broom
Discipline of Sociology and Criminology; Faculty of Arts and Social Sciences
Email: alex.broom@sydney.edu.au

Dear Alexander,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

I am pleased to inform you that after consideration of your response, your project has been approved.

Details of the approval are as follows:

Project No.:	**2022/521**
Project Title:	**Young People's Experiences of Chronic Illness in the Digital Age**
Authorised Personnel:	**Broom Alexander; Harper Imogen; Kenny Katherine;**
Approval Period:	**26/08/2022 – 26/08/2026**
First Annual Report Due:	**26/08/2023**

Documents Approved:

Date Uploaded	Version Number	Document Name
10/08/2022	Version 2	Amended Flyer
10/08/2022	Version 1	Instagram Bio
10/08/2022	Version 1	Instagram Post exemplar part 1
10/08/2022	Version 1	Instagram Post exemplar part 2
10/08/2022	Version 2	Participant Consent Form Clean
10/08/2022	Version 2	Participant Information Statement Clean
10/08/2022	Version 1	Safety Protocol for F2F interviews
10/08/2022	Version 1	Waiver of Consent
01/07/2022	Version 1	Email to potential participants
01/07/2022	Version 1	Message to social media content creator
01/07/2022	Version 1	Interview Guide

Condition/s of Approval

- Research must be conducted according to the approved proposal.
- An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
    - Serious or unexpected adverse events (which should be reported within 72 hours).
    - Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.
- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.

- Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.
- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- The Ethics Office may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,

[redacted]

Associate Professor Helen Mitchell
Chair
Human Research Ethics Committee (HREC 1)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2018) and the NHMRC's Australian Code for the Responsible Conduct of Research (2018)