From self-management to shared management in chronic care: an empirical ethics investigation into the lived experience of chronic disease in England

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A thesis submitted for the degree of
Doctor of Philosophy

University College London
Centre for Multidisciplinary & Intercultural Inquiry
Health Humanities

27th August 2021

Declaration

I, Francisca Stutzin Donoso confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Even within universal health coverage systems, there are significant health inequalities caused by differences in patients' abilities to adhere to long-term treatments, and inequalities in long-term treatment adherence are correlated with, and aggravate, existing health inequalities. To better understand the mechanisms underlying this cumulative effect of disadvantage, a qualitative empirical ethics study on the lived experience of chronic disease and long-term treatment was conducted within the National Health Service in England.

Overall findings suggest that chronic diseases and long-term treatment can threaten belonging to the social world, sense of agency and self-concept or identity. Furthermore, findings also suggest that current views of long-term treatment adherence ignore the dynamism and interdependence underlying the management of chronic disease. Drawing on these findings and adopting a complex systems approach, this thesis describes adjustment to chronic disease as the ongoing effort towards balancing multiple demands to live lives people have reason to value across time. Specifying this ongoing effort contributes to identifying key psychological, social and healthcare-related challenges and injustices faced by people living with chronic disease.

Wellbeing is not always best promoted by maximising treatment adherence, so patients do not and should not always prioritise long-term treatment over competing concerns and projects within their lives. Still, it is morally problematic that structural injustice puts the disadvantaged in a position in which they are more likely to lack the freedom to prioritise treatment. By analysing the role of healthcare in patients’ efforts towards balancing competing demands, this work further specifies person-centeredness for chronic care, highlighting the frailty of the illness and treatment processes and the need for continued socially aware support. Building on this, this thesis outlines a normative framework to orient ethically driven chronic care, calling for shared responsibility to ameliorate the cumulative effect of disadvantage amongst people who live with chronic disease.

Impact Statement

Chronic diseases are the main disease burden worldwide leading to premature deaths and poor individual and population health outcomes. Although modern medicine has made significant progress in developing effective treatments for chronic diseases, also expanding the number of conditions that fall under this category, around 50% of people follow long-term treatment recommendations. This thesis argues that relying on disruptive treatments to stay alive or live lives less affected by illness can raise significant practical, social and psychological issues that disproportionately affect those who live in disadvantage. By analysing the lived experience of chronic disease and long-term treatment, this thesis develops a multidimensional understanding of the problem of long-term treatment adherence and health outcomes inequalities in this context. This expands the normative framework of the cumulative effect of disadvantage amongst people living with chronic diseases and contributes to inform ethically driven care for chronic diseases.

Thus, this work helps further specify current academic knowledge about life with chronic disease and long-term treatment, contributing from an interdisciplinary perspective to the conceptual definition of chronic diseases and the dynamics involved in psychological adjustment and mourning processes in the context of chronic diseases. It also advances current knowledge on the injustices suffered by those who live with chronic disease and the mechanisms by which chronic diseases are agued to become risk multipliers for disadvantage. This significantly contributes to the normative discussion on how to improve health equity for chronic diseases in England. Still, because this work focuses on the potential and limitations of universal health coverage systems, this thesis' outcomes might also inform similar processes in other contexts where people living with chronic diseases have access to universal health coverage.

By developing shared tools for social interpretation of the experience of chronic disease and long-term treatment, this thesis has the potential to impact the understanding, learning and participation of the general public in this issue. As already suggested, this mainly includes informing the practice of healthcare professionals delivering chronic care and clinical supervision models for healthcare practitioners delivering chronic care, but it can also inspire stakeholders and policymakers aiming to develop interventions to reduce health inequalities in chronic diseases. Furthermore, this work can enhance general knowledge about life with chronic disease amongst the broader society of the 'healthy' and support individual processes of illness amongst people who live with chronic disease.

Through peer-reviewed publications, conference presentations and public engagement events, this work can reach the academic community, stakeholders, healthcare professionals, the general public and people living with chronic diseases. By reaching key actors, this thesis' findings can inform workshops aiming to enhance public awareness and the development of school curricula aiming to raise awareness and increase social integration; orient further research for clinical guidelines and policy developments; and serve as a starting point for peer-support groups for people living with chronic diseases. Furthermore, this thesis’ findings have the potential to inform and inspire further research on specialised individual and group psychotherapy models to better support people living with chronic diseases.

Acknowledgements

My first acknowledgement goes to my research participants for their bravery and generosity to share an important and sensitive aspect of their lives with me. Getting to know each of them was a privilege and keeping their stories in mind helped me stay grounded throughout the research and writing-up processes. I would not have been able to work with them without the support of Professor Joanna Porter and Dr Fiona Burns who trusted me and believed in the value of the project enough to act as principal investigators of the study at University College Hospital and The Royal Free Hospital, respectively. I thank them and their clinical teams for finding the time to support me throughout the recruitment of participants and completion of the research activities. I also thank Professor Stuart Bloom, Professor Stephanie Baldeweg, Dr Sarita Naik and their clinical teams for supporting the study and finding the time to collaborate with the recruitment and the completion of the research activities. I thank the UCL-UCLH Joint Research Office coordinators for their guidance and the NHS Research Ethics Committee members for their consideration of the project, feedback and eventual favourable opinion that allowed the Health Research Authority to approve the study.

I thank my two supervisors, Professor James Wilson and Professor Sonu Shamdasani, for their dedicated and generous mentoring, insightful feedback, trust in my abilities and respect for my work. Their example and support allowed me to play freely across disciplines to address and develop my research interest, guiding me in the process of generating a rigorous and meaningful academic output. This experience was significantly enhanced by the regular interdisciplinary discussions within the Health Humanities Centre and fellow PhD students across the Centre for Multidisciplinary and Intercultural Inquiry. Following the complex systems approach I apply in my thesis, engaging with people from diverse academic backgrounds and using a multiplicity of research methods significantly informed my work in a non-linear way, mainly by sparking my creativity and helping me keep an open mind and critical attitude towards my work. I am particularly grateful for my colleagues and friends at Health Humanities Centre and the co-research mentoring group who took the time to read and discuss my work. Their feedback informed this thesis and working collaboratively gave me the confidence to deeply enjoy the writing-up process.

I thank the National Research and Development Agency (ANID) of the Chilean Government for the award of Becas-Chile Scholarship, which allowed me to take on the challenge of doing a PhD at UCL and live in London for the past four years. This life decision and opportunity changed the way I see the world and live my life. Everyone I have shared my life with during this time, close or far, has contributed to this thesis. I am especially grateful for those who encouraged the choice of doing a PhD and have supported me in the process, but I also thank those who, sometimes without noticing, challenged it. Seeing what this means for others has helped me understand and own what it means for me. Although I feel like I threw a stone and cannot quite see yet where it is going to land, I thank everyone whose love has made me feel that it is safe to fly, no matter what.

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List of Abbreviations

AIDS: Acquired Immunodeficiency Syndrome

CCM: Chronic Care Model

CI: Chief Investigator

GP: General Practitioner

HIC: High-Income Country

HIV: Human Immunodeficiency Virus

HRA: Health Research Authority

ICESCR: International Covenant on Economic, Social and Cultural Rights

IRAS: Integrated Research Application System

JRO: Joint Research Office

LMIC: Low and Middle-Income Country

LTC: Long-Term Conditions

MUS: Medically Unexplained Symptoms

NCD: Non-Communicable Disease

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

PI: Principal Investigator

PPI: Patient and Public Involvement

RCT: Randomized Controlled Trial

REC: Research Ethics Committee

RFH: Royal Free London Hospital

SDH: Social Determinants of Health

SFP: Self-Fulfilling Prophecy

UCL: University College London

UCLH: University College London Hospitals

UHC: Universal Health Coverage

UK: United Kingdom

WHO: World Health Organization

Introduction: A Complex Systems Approach To Chronic Disease Health Outcomes Inequalities

1. *Introduction*

About eight years ago, while working as a health psychologist in Chile with people living with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS), I was confronted, in my daily practice, with the fact that some people died of this controllable disease despite having access to comprehensive treatment through Universal Health Coverage (UHC). Generally speaking, the healthcare team I worked with found comfort in the idea that people had all the medical care they needed to cope with the disease, so if they died it was because they were silly, they did not listen, or did not follow their recommendations. The underlying rationale of this line of thinking is that in a context where the state offers free care at the point of access, it is the ill person's responsibility to manage their care and thus, their fault if they die from a treatable disease.

This always struck me as extremely harsh for similar reasons to those posed by the 'harshness objection' to luck egalitarian accounts of justice. Although Section 6 of this introduction will provide the context to better understand this claim, in general terms, egalitarians argue that what is required for justice is for people to be treated as equals and luck egalitarians add to this that bad outcomes resulting from risks people voluntarily accept, namely option luck individual choices are the individual's own responsibility and thus fair (Voigt 2007). However, Voigt (2007) has argued that this perspective on option luck is too harsh because it unjustifiably limits people's freedom to take risks, as will be discussed further in Chapter 9 specifically concerning responsibility for health.[1] Simultaneously, this also struck me as too linear and simplistic considering that it is plausible to think that most people would not want to die from a treatable disease, and so the complexity and seriousness of the issue were being overlooked by the well-established idea that health services are always doing everything they can.

HIV/AIDS is a potentially lethal infectious disease, but through highly active antiretroviral therapy it has become a chronic disease. Evidence shows that low rates of adherence to long-term treatment for HIV/AIDS are not just a local challenge in Chile, where I worked (Manriquez and Stuardo 2015). A meta-analysis from 2011 synthesising 84 observational studies across 20 countries—including Low and Middle-Income Countries (LMICs) as well as High-Income Countries (HICs)—showed that the average reported rate of satisfactory adherence to treatment was 62% (Ortego et al. 2011). Furthermore, despite relevant illness-specific characteristics, adherence to long-term treatment for all chronic diseases seems to be in crisis. The estimates are that adherence to long-term treatment for all chronic diseases is around 50% in HICs and presumably even less in LMICs, contributing to

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[1] Voigt (2007) Draws on Dworkin's (2000, 73) definition of option luck as "a matter of how deliberate and calculated gambles turn out—whether someone gains or loses through accepting an isolated risk he or she should have anticipated and might have declined" as opposed to brute luck, which is "a matter of how risks fall out that are not in that sense deliberate gambles".

premature deaths and poor population and individual health outcomes worldwide (Sabaté 2003).

In my clinical work, I confirmed the association often established by researchers studying the ‘social patterning of disease’ (Link and Phelan 1995) and chronic disease self-management, namely that

> the life situation of the patients may determine health outcomes as much as the actions of healthcare professionals and healthcare systems do. Access alone does not ensure benefits of available medical services (Pincus et al. 1998, 406).

Furthermore, I identified social isolation and psychological distress as fundamental features of my day-to-day work. From a clinical perspective, it seemed that these were not only some of the variables that may have predisposed patients to illness in the first place but also relevant disadvantages for adhering to long-term treatment.

After trying to raise awareness within my clinical team about the ethical consequences of ignoring patients’ different needs and unsuccessfully suggesting to tailor our practice, I found that challenging strongly-held ideas about complex phenomena can face significant resistance if it implies changing the comfortable and known ways in which powerful groups, such as medical professionals, have been operating. This resonates with the story of the Hungarian physician Ignaz Semmelweis and his great observational and analytical skills, which led him to significantly reduce deaths by puerperal fever in the maternity wards of the General Hospital in Vienna back in 1846 by introducing strict hygiene protocols to isolate the post-mortem room from the maternity wards. Semmelweis intuitively traced the source of puerperal fever to contaminated doctors' hands and despite the overwhelmingly successful outcomes of introducing cleaning and hand-washing protocols, challenging common practice while lacking detailed understanding of the mechanisms by which this worked only lead to scepticism and criticism (Tyreman 2018).

Semmelweis' great sanitary insights were ridiculed and he was eventually made redundant from his job at the hospital, although it is difficult to know if other variables might have played a role in that. Still, old practices returned and mortality rates of puerperal fever raised. This was seventeen years before Louis Pasteur and Robert Koch were able to identify the microorganisms responsible for infectious diseases and introduced the germ theory. This gave birth to microbiology, which fully supports Semmelweis' work and, as it is well known today, increased hygiene outside hospitals and hygiene protocols in hospitals became key public health measures in the 20th century contributing to significantly reduce the burden of infectious diseases (Cohen 2000).

Tyreman (2018), an osteopath and academic who worked in philosophy of medicine and healthcare, argues that the moral of Semmelweis' story is that for new ideas to be accepted they must fit with what is known and with the stories we tell ourselves about the world and how we experience it. Although this could mean that new ideas cannot be all that new to be accepted, it seems to be intended as a strategic path to develop new thoughts or approaches to problems in which people play a role and present them in such a way that these make sense. Retrospectively, and lacking all clarity, I think this was what I was assessing while making the choice whether to continue swimming against the current in the clinical environment I worked in or to step aside and learn more about what I intuitively thought was a problem, but neither fully understood nor had the skills to argue for. As might be obvious by now, I decided to step aside and learn more about health inequalities and ethically driven care for chronic diseases.

1.1. Brief overview of the introduction

The next section of this introduction discusses the underspecified category of 'chronic disease' and, by reflecting on the epidemiological transition, it challenges the traditional epidemiological distinction between infectious and non-communicable conditions. This distinction obscures the currently relevant intersection between these two groups of diseases, as the data collected to guide public health interventions and clinical practice does not account for a comprehensive category of chronic diseases. The third section reflects on health inequalities for both communicable and non-communicable diseases. By looking at the rights framework that supports the operationalisation of UHC as equality of opportunity to access healthcare services and focusing on data from the United Kingdom (UK), this section argues that equality of opportunity to access healthcare has been an insufficient strategy to tackle health inequalities. This introduces the idea that there is a cumulative effect of disadvantage, as those more likely to carry the burden of disease are those who also do not benefit as much from UHC systems. Building on this, the fourth section discusses current approaches to the delivery of chronic care and its main limitations, highlighting the lack of understanding of self-management as embedded within and facilitated by social contexts and support, the little acknowledgement of the emotional impact of chronic disease and how this may hinder individuals possibilities to mobilise resources to cope with chronic disease. Building on this and Wolff and de Shalit's (2007) theory of disadvantage, section five further specifies chronic diseases as risk multipliers for disadvantage and describes a double inequity affecting those who live with chronic disease. The latter argues that even within UHC systems, there are significant health inequalities caused by differences in patients' abilities to adhere to long-term treatments, and inequalities in long-term treatment adherence are correlated with, and aggravate, existing health inequalities. Thus, this work stresses the need for healthcare systems to go beyond equality of opportunity for access in order to become a more effective instrument for distributive justice. As will be discussed in more detail in section 5 of this introduction, this work suggests that when assessing the justice of distributions across society, the focus should be on the freedoms people actually enjoy to choose between different ways of living that they can have reason to value (Sen 1990). Drawing on the dynamism introduced by the idea of fertile and corrosive functionings facilitating or hampering self-management of chronic disease, the last section of this introduction presents the potential of adopting a complex systems perspective to do so.[2]

By adopting a complex systems approach, this introduction proposes a connecting thread between the lack of attention current self-management models play to the broader context of people's lives and narrow or atomistic policy approaches to address health outcomes inequalities in the UK. Thus, drawing on the value of co-production in truly person-centred care, this work suggests focusing on the experience of people living with chronic diseases to learn about the context, processes and interactions shaping the complex system of chronic care and health outcomes inequalities for chronic diseases. This approach motivates an empirical ethics study aiming to learn more about the life of people living with chronic diseases and long-term treatment to inform the discussion on how to improve equity for health outcomes for chronic diseases in the UK. As will be discussed in more depth in section 3 of this introduction, improving health equity refers to counteracting social inequalities in health that are avoidable and thus unfair (Krieger 2011; Wilson 2011).

2. Chronic disease epidemiology

Although the concept of 'chronic disease' has been broadly integrated into the health and healthcare-related vocabulary—largely reaching lay

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[2] An earlier version of this argument was published in the Journal of Medical Ethics in 2018 (Stutzin Donoso 2018).

people's vocabulary, there is no clear-cut definition for this term, which implies that the number of conditions that fall under the umbrella of chronic disease varies accordingly (Bernell and Howard 2016). While there may be different readings of this problem, at least to some extent, this might be related to the main four groups of non-communicable diseases (NCDs) (cardiovascular disease, cancer, diabetes, and obstructive pulmonary disease) replacing infectious diseases as the main burden of disease, and therefore becoming the main focus of attention in public health only rather recently (Bernell and Howard 2016; Busse et al. 2010; Chan 2017).

This epidemiological transition explaining the rise and current predominance of chronic diseases has been argued to comprise three main transitions between prehistory—approximately 10.000 years ago; the early modern period; and the late 19th and 20th centuries. The first transition is titled Age of Pestilence and Famine, the second Age of Receding Pandemics, and the third Age of Degenerative and Man-Made Disease. Although there are different explanatory theories, these three transitions are largely explained by environmental variables such as changes in population density, birth and mortality rates, life expectancy, among others, all strongly associated with social and economic developments that contribute to long-lasting conditions taking over infectious diseases. Furthermore, some of the anthropogenic determinants of health marking the latest transition linked to the current consolidation of degenerative and chronic diseases as the main burden of disease, include harmful effects of human activity, such as pollution, unhealthy foods and other substances, unhealthy lifestyles, etc. increasing the risk for certain diseases (McKeown 2009).

This explanatory model, largely founded on economic and social development, inevitably implies a significant difference between economic contexts both at a global scale and within countries. At a global scale, mostly thanks to better nutrition, housing, securer access to food and water, and improved hygiene and sanitation, life expectancy in developed countries increased significantly between the 18th and the 20th century. Thus, morbidity and mortality from infectious diseases had significantly improved in the developed world by the 20th century, and by the end of the century morbidity and mortality from infectious diseases in this context had been largely replaced by NCDs such as heart disease and cancer. However, because the developing world did not have the same social and technological improvements, this context did not manage to control infectious diseases at the same pace, and by the end of the 20th century, infectious diseases were still the major cause of morbidity and mortality in developing countries (Cohen 2000).

Thus, before the 2000s, global health efforts were still largely focused on controlling the large and devastating burden of infectious diseases in the developing world, and these seemed to pose a specific kind of challenge that in the first instance, appeared very different to that arising from emerging NCDs. Infectious diseases are strongly associated with living conditions, thus affecting those who live in poverty the most, whereas NCDs initially affected the affluent, who managed to live longer mostly because of better conditions, possibly justifying the infectious/chronic distinction in public health (Chan

2017; Cohen 2000). However, at present, evidence shows that the burden of NCDs tends to cluster amongst countries where economic resources are scarce and amongst the poor within wealthy societies (WHO 2005; 2021c). Marmot's (2005; 2010) epidemiological research has proved and helped specify that this does not mean "poor health for the poor and good health for everyone else" (Marmot et al. 2020, 7), but that disease burdens follow a social gradient amongst socioeconomic groups, disproportionately affecting those who live in relative disadvantage. Thus, the social gradient in NCDs has been largely attributed to the fact that the main social determinants of health (SDH) and individual health risk factors for NCDs, such as poor diet, sedentary lifestyle, tobacco and alcohol consumption began affecting the lives of those living with wealth first, but this pattern rapidly changed and currently all of these SDH affect individuals from lower socioeconomic levels the most, following a gradient across socioeconomic groups (Chan 2017; Wardle and Steptoe 2003). Taking this distribution of the burden of disease into account, NCDs are the main cause of death worldwide today, accounting for 71% of all deaths per year globally—37% of which are considered premature[3]—and affecting people from all ages, regions, and countries (WHO 2021c).[4]

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[3] These are deaths occurring before the age of 70 years and that could have been prevented or delayed (WHO 2021c).

[4] About 85% of these premature deaths occur in LMICs, but taking into account that approximately 84% of the world's population concentrates in LMICs these statistics broadly show that premature deaths caused by chronic diseases represent a significant and similar challenge across the world—in HICs and LMICs (WHO 2021c; The World Bank Data 2021).

Just as infectious diseases, NCDs disproportionately affect or tend to cluster among the poorest and furthest behind not in an absolute measure of poverty, but income inequalities leading to social disadvantage within each context (Wilkinson 1994). Although no global statistics account for a category of chronic diseases that includes chronic communicable diseases, it could be argued that if statistics for NCDs were to include those for chronic communicable diseases, the numbers would only add to and follow the same pattern of distribution.[5] Thus, Marmot's (2006, 1306) causal framework explaining the relationship between socioeconomic status and ill health suggests that "it is not position in the hierarchy per se that is the culprit, but what position in the hierarchy means for what one can do in a given society".[6] Following this rationale, the World Health Organization (WHO) (2017, 5) states that there are multiple variables driving today's NCDs epidemic, including "poverty, globalization of marketing and trade of health-harming products, rapid urbanization, and population growth".

Alongside social, economic, and environmental variables, the development of new health technologies in the 20th century including effective

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[5] As mentioned before, there is a strong association between poverty, poor environmental health, and infectious diseases (Smith et al. 2004). The statistics for HIV/AIDS, tuberculosis, and malaria, for example, show that these diseases are most prevalent and deadly in disadvantaged contexts (WHO 2021a; 2021b; 2021d).

[6] Marmot's (2006) framework focuses on fundamental processes related to how societies are organised to explain the relationship between socioeconomic status and health. These processes highlight low degrees of social participation and autonomy as risk factors for health.

antibiotics, antiretroviral, and long-term treatments that contribute to control or slow down the progression of varied diseases, helped to broaden the scope of chronic conditions, and currently, this category can include various infectious diseases such as HIV/AIDS and Hepatitis B and C, as well as some mental disorders, and extending over certain disabilities (Bernell and Howard 2016; Busse et al. 2010).

Thus, the epidemiological transition did not imply that infectious diseases, in general, had been eradicated—though some were, but merely reflect a shift in the main burden of disease. Currently, aside from the burden of COVID-19, mostly but not only the developing world struggles with a double burden of disease (infectious and NCDs) and, at a global scale, the world is foreseeing significant challenges arising from re-emerging and antimicrobial-resistant infections (Cohen 2000). Still, the idea of 'transition' may have been misleading in the sense that it stressed the idea of movement from A to B, implicitly, and erroneously, undermining the importance of infectious diseases as something that belongs to the past—at least until the COVID-19 pandemic broke out in early 2020.

In this manner, the epidemiological transition theory may have contributed to the currently confusing epidemiological division between infectious and chronic diseases. This is important because such a division in public health leaves the currently relevant intersection between chronic and infectious diseases (A+B) unattended by comprising an incompatible classification system that in one case stresses the cause (infectious) and in the other the effect (chronic) (Choi et al. 2007). Furthermore, this intersection may be even more complex than already described since many viral agents have been identified as the cause or important cofactors in NCDs such as cancer, coronary heart disease, and others (Cohen 2000). Similarly, Fuller's (2018) constitutive model of disease classification[7] states that the opposing monocausal (infectious) and multifactorial (NCDs) models of disease fail to distinguish the two, since recent scientific learning about NCDs and infectious diseases show that some infectious diseases might have a multifactorial cause and, conversely, some NCDs may also be monocausal.

Thus, at present, the cluster of chronic diseases challenges the traditional epidemiological distinction between infectious diseases and NCDs, condensing at an individual level what has been described as the double burden of disease at a population-level in the developing world,[8] suggesting that 'chronic'—merely understood as long-duration—is at the heart of this

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[7] This model argues that chronic and non-communicable diseases are classified according to what the condition is, namely what is described as their constitutive necessity (C) and not based on a specific etiologic agent or cause. Thus, "*a* is a case of disease D if and only if *a* is a C. Applied to the example of osteoporosis, a bodily state (a) is a case of osteoporosis (D) if and only if a is a bone density that falls 2.5 standard deviations below the demographic mean (C)" (Fuller 2018, 11).

[8] Although the concept of double burden is broadly used to describe two burdens—thus sometimes applying to cases of comorbidity, in epidemiology this concept refers to the overlapping of the burden of infectious diseases and non-communicable diseases at a population level. However, chronic infectious diseases, such as HIV/AIDS, condense this at an individual level, which is not the same as one individual suffering from two different conditions—comorbidity.

category of diseases, removing almost completely the component of (non)-communicability that was once seen as the most fundamental feature of the category.[9] Focusing on the effect of disease—chronic or long-duration, common health risk factors, long-term treatment requirements, and pattern of distribution, a category of chronic disease comprising, at least, chronic infectious and NCDs seems more representative, comprehensive, and precise for current times.[10] Still, statistical information used to guide public health and clinical practice is based and focused on the main four groups of NCDs (cardiovascular disease, cancer, diabetes, and obstructive pulmonary disease), which account for about 80% of premature NCDs deaths worldwide (Chan 2017; WHO 2021c).

3. *Health inequalities and healthcare*

After the United Nations' proclamation of the human right to health in 1948 (United Nations 1948), in 1966, the International Covenant on Economic, Social and Cultural Rights (ICESCR) defined this right as "the right of everyone to the enjoyment of the highest attainable standard of physical

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[9] Chapter 3 develops this idea further and engages with the conceptual challenges of 'chronic disease'.

[10] In the United Kingdom, the category 'long-term conditions' accounts for a comprehensive cluster of chronic diseases that includes NCDs, infectious chronic diseases, and chronic mental disorders, and its very high prevalence distributes according to the social gradient of health (Department of Health 2012).

and mental health" (United Nations 1966, 4). Because the full realisation of this right was still a distant goal for many State Parties by the year 2000, in order to work towards better chances of realization, this definition was narrowed down in the General Comment No. 14 and operationalised as a "right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health", in other words, a "right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health" (United Nations 2000, 3). Still, the General Comment No. 14 is highly ambitious and it specifies that the right to health is not confined to the right to healthcare, as it also "embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment" (United Nations 2000, 2).

This introduces a rights framework in which social inequalities in health need to be addressed by all State Parties. Although the philosophical literature on whether and why inequalities in health might be considered inequities or injustices is extensive and complex, Daniels' (2008) account of justice in health has been particularly influential. Very broadly, this account argues that if the SDH were distributed fairly, then inequalities that could be traced back to individual choice would be fair. Still, as highlighted by Voigt (2013), in so far social inequalities shape and constrain individual choices, there may be few health inequalities in the real world that luck egalitarians would regard as fair. Thus, drawing on Krieger's (2011) work, the focus has been on health inequities, which are broadly understood avoidable social inequalities in health. In this sense "a health inequality is a health inequity if and only if it is an inequality which a just society would seek to counteract" (Wilson 2011, 217).

Despite its broader implications for the SDH, the operationalisation of the right to health has had a significant impact over how UHC is understood and implemented worldwide, raising a significant ethical problem. By offering equality of opportunity to access healthcare services, UHC systems may comply with ICESCR but it does not seem to be an appropriate response for the broader moral duty of addressing health inequalities. This work will be focusing on the UK's National Health Service (NHS), which has been providing UHC since 1948. Drawing on Wolff's (2019) reflection about studying poverty in HICs, although the problem of health inequalities in the UK might be argued to have little urgency compared to much harsher inequalities and disadvantage experienced in LMICs, this does not justify undermining the reality of those who disproportionately suffer from ill health in HICs. Furthermore, as one of the oldest and most extensively researched examples, valuable data on the ethically driven performance of the NHS makes further research possible, potentially orienting local research and developments in UHC systems beyond the UK.

As stated in the NHS constitution, its main principles include providing comprehensive care that is available to all, explicitly committing to the "wider social duty of promoting equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population". The provision of services is based on clinical need and not on the individual's ability to pay, thus, most NHS services are free of charge, except in limited circumstances (NHS 2015, 3). Despite all this, since the introduction of the NHS in the UK, inequalities in terms of access to healthcare and health outcomes across the population remained. Thus, focusing on delivering equality of opportunity for accessing healthcare services has not been enough to improve populations' health as a whole and tackle health inequalities (Marmot 2005; Whitehead, Townsend, and Davidsen 1992; Wolff 2011). On the whole, the health of individuals from higher social classes improved, while the health of those of lower classes showed small differences (Whitehead, Townsend, and Davidsen 1992).

This variable benefit from available services is partly explained by the fact that from a population health level what makes people sick are socioeconomic variables that fall outside healthcare systems (Marmot 2005), but is also explained by what Hart (1971) described as the inverse care law. After analysing the performance of the NHS specifically regarding health inequalities in terms of morbidity and mortality, Hart (1971, 405) argued that "the availability of good medical care tends to vary inversely with the need for it in the population served". This means that fewer healthcare professionals and services are available in deprived areas, and amongst disadvantaged populations, where the burden of disease and healthcare need tends to cluster. From Hart's (1971) perspective, this distribution is sustained by free-market features of the system, which go against the simple socialist principle on which the NHS was conceived. This principle was redistributing care by offering “a comprehensive national service, available to all, free at the time of use, non-contributory and financed from taxation” (Hart 1971, 409). Thus, leaving dental care and family planning out of these comprehensive services from the beginning and introducing direct flat-rate contributions has hampered the redistributing effect of the NHS.[11] In addition to this, the better off have been argued to be able to make better use of the healthcare services, than the rest of the population and this leads to the better off getting more and better services from the system (Wolff 2011).

By challenging the strong individual focus of epidemiological research linking risk factors with morbidity and mortality, Link and Phelan (1995) suggested a fundamental cause theory of disease. This argues that individual risks should be contextualized to develop effective interventions, examining what puts people at risk of developing or contracting disease. Following this, it specifies that social factors such as socioeconomic status and social support

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[11] Although Hart (1971, 409) acknowledges that the main determinants of morbidity and mortality are social and not the medical services, he stresses that this is not a good reason not to “match the greatest need with the highest standards of care”, clearly stating that, ultimately, this is a political issue. Hart’s (1971) views remain relevant as several changes aiming to ‘liberate the NHS’—in economic terms—resulted in the largest NHS reform in 2010, known as the ‘White Paper’ (Whitehead, Hanratty, and Popay 2010). This reform mainly focused on reducing economic regulation and increasing competition, which was argued to represent “a huge untried experiment with profound equity risks” (Whitehead, Hanratty, and Popay 2010, 1374).

can indirectly affect health outcomes. More specifically, Link and Phelan (1995) argue that knowledge, money, power, prestige, and beneficial social connections are key flexible resources that influence multiple disease outcomes. Access to these resources can contribute to the prevention of diseases and their negative effects, and the flexibility of these resources implies that there is a variety of mechanisms through which this can happen. Fifteen years later, this theory was further specified as the fundamental causes of health inequalities and used to orient policy developments aiming to ameliorate this problem. Much in line with broader literature on the topic, this mainly suggests fairer distribution of SDH and or interventions that are less sensitive to social inequalities (Phelan, Link, and Theranifair 2010). Still, because of the complex relationship between social variables and health outcomes that this model suggests, Farmer (2013) argues that there is a know/do gap which causes clinical outcomes to be uneven and health disparities to persist despite effective treatments being available.

Research looking at nation-wide statistics on income, poverty, wealth, unemployment, infant mortality rates and life expectancy from the 1980s and 90s shows that the health gap widened following the socioeconomic polarisation in the UK (Shaw et al. 1999). At present, with a Gini coefficient of 0.35, the UK has the 5th most unequal distribution of income compared to other developed countries, the 4th most unequal in Europe, and an even more unequal distribution of wealth, where the richest 10% holds 44% of all wealth and the poorest 50% just 9% (The Equality Trust 2021). Thus, despite overall improvements in health outcomes, “as the poor have become relatively poorer and have become concentrated into particular areas of the country, poor health has similarly become more concentrated both by social group and by area" (Shaw et al. 1999, 107). Marmot's (2020) research has actualised these conclusions suggesting that health stopped improving and there has been further widening in the health gap between the 2010-2020 period. Furthermore, it confirms the validity of Hart's (1971) inverse care law, as the budget cuts over this period have been regressive and inequitable, this is, "greatest in areas where need is highest and conditions are generally worse" (Marmot et al. 2020, 9). At present, crucial measurements such as morbidity, mortality, and clinical outcomes are consistent with pro-rich inequalities mentioned before (Cookson et al. 2016), suggesting that there might be a social gradient in adherence to long-term treatment underlying the uneven health outcomes for chronic diseases. All this hints towards a cumulative effect of disadvantage, as those more likely to carry the burden of disease are those who also do not benefit as much from UHC systems. Thus, it might be argued that despite contributing to improve overall health outcomes to some extent, the UHC offered by the NHS reproduces existing inequalities.

Following on from this, health inequalities might be argued to be an intrinsically plural phenomenon that results from a myriad of variables interacting in complex ways, and thus addressing it is not a simple or linear task.

4. Long-term treatment and the psychological hardship of chronic disease

In line with the global tendency, the burden of disease for the main four groups of chronic diseases (cardiovascular disease, cancer, diabetes, and obstructive pulmonary disease) in the UK accounts for 90% of all deaths, and the risk of dying prematurely from one of these chronic diseases is 11% (WHO 2017). This means that 1 in 9 of those living with one of these four disease groups will die prematurely (Woloshin, Schwartz, and Welch 2008). In 2015, avoidable mortality[12] rates in England and Wales were led by cancers and cardiovascular diseases, with respiratory diseases and infections also accounting as relevant categories in this context (Office for National Statistics 2017).

Despite UHC, treatment adherence is a significant problem for chronic diseases. Estimates show that the rate of adherence to long-term treatment is around 50% in the UK, which, as already mentioned, contributes to high rates of premature deaths and poor individual and population health outcomes (Sabaté 2003; WHO 2016; Naylor et al. 2015; Department of Health 2005). People living with chronic disease are often described as their own principal care givers as they are largely in charge of the daily management of their disease (Bodenheimer, Wagner, and Grumbach 2002b; Bury 1982; Furler et al. 2008; Kendall et al. 2012). Following treatment recommendations is an important aspect of self-management so low rates in treatment adherence suggest that, at the time of measurement, only around half of those living with a chronic disease succeed in this task, and that medical care for chronic

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[12] These are deaths that are considered treatable, preventable or both at the time of death (Office for National Statistics 2017).

diseases fails to meet different individuals' needs to facilitate them becoming effective self-managers of their disease (Bodenheimer et al. 2002; Bodenheimer, Wagner, and Grumbach 2002b; McDonald et al. 2015; Wagner et al. 2001).

At least to some extent, this failure is explained by the fact that healthcare in the UK, and in general, is still very much structured around acute care (Bayliss et al. 2003; Bodenheimer, Wagner, and Grumbach 2002b; Busse et al. 2010; Naylor et al. 2015; Department of Health 2005). This, however, does not explain the differences in adherence that arguably contribute to poorer health outcomes among those who live in disadvantage. This suggests that individuals of low socioeconomic level may have disadvantages that preclude them from effectively making use of available resources for the management of chronic disease and that these disadvantages may overlap those which predisposed them to chronic disease in the first place. This is consistent with research showing that low socioeconomic level has a negative impact on adherence to long-term treatment (Kardas, Lewek, and Matyjaszczyk 2013)

In the UK, it is recognised that systems do not offer adequate support for people living with chronic disease, and relevant efforts to address these challenges are sometimes framed within the concept of co-production in the delivery of services (Realpe and Wallace 2010). Applied to the health sector, this concept is highly focused on the unique needs of people, and regarding the ill person as an active expert in the consultation context, thus stressing the importance of patient-centeredness and involvement. Following this, the generic care model for chronic disease in the NHS follows the chronic care model (CCM) developed by Wagner et al (2001) in the United States (Realpe and Wallace 2010).

Within this framework, some of the specific policy and programme development initiatives to improve health outcomes for chronic diseases in the UK include the ‘Expert Patient Programme: A New Approach to Chronic Disease Management for the 21st Century’ (Department of Health 2001) and ‘Supporting People with Long-Term Conditions. An NHS and Social Care Model to support local innovation and integration’ (Department of Health 2005). More recent initiatives are the King’s Fund report ‘Delivering Better Care for People with Long-Term Conditions: Building the House of Care’ (Coulter, Roberts, and Dixon 2013) and the King’s Fund recommendations to the clinical commissioning groups ‘Transforming our Health Care System’, which focuses on how to improve healthcare delivery and outcomes for chronic disease (Naylor et al. 2015). Similar to the individual focus of epidemiological research on risk factors for disease, which Link and Phelan’s (1995) work criticises, all these programmes emphasise self-management as the key to success, largely ignoring the role that social variables play in health outcomes.

Furthermore, although the CCM highlights the importance of self-management education, it also makes explicit that this can only deliver problem-solving skills and improve health outcomes to some extent, and that how to sustain these changes in the long-term remains a problem (Barlow, Turner, and Wright 2000; Bodenheimer et al. 2002). Although the general idea of co-production might be regarded as a well-oriented framework, the UK's practical efforts do not seem to fully acknowledge these limitations or the key role that cumulative or overlapping disadvantages can play in chronic disease health outcomes.

In line with this, it has been argued that the limitations of the CCM may be attributed to the lack of understanding of self-management as embedded within and facilitated by social contexts and support, in addition to—and closely connected with—the little attention that healthcare for chronic conditions pays to the psychological and emotional issues those who live with chronic disease face (Furler et al. 2008; Kendall et al. 2012). The 'Expert Patient' initiative has been criticised for failing to acknowledge and support the skills that people living with chronic disease need to make sense of their disease and the impact the disease has on people's sense of self or identity (Edgar 2005). As highlighted by Tyreman (2018, 2), providing truly person-centred care implies "recognising that human beings face up to the challenge of illness, pain, and disability differently to how we might understand and seek to correct a fault in a car, say". This suggests that different aspects of people lives will affect and modify each other in ways that only focusing on fixing or supporting one aspect will not be able to correct.

Building on qualitative research with people living with rheumatoid arthritis, Michael Bury, a well-regarded medical sociologist, described the often-quoted concept of 'biographical disruption' associated with chronic disease. He said that in chronic illness

> the structure of everyday life and the forms of knowledge, which underpin them, are disrupted. Chronic illness involves recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others […]. Further expectations and plans that individuals hold for the future have to be re-examined. Thus, chronic illnesses must be regarded as critical situations, a form of biographical disruption (Bury 1982, 169)

To move beyond the burden associated with chronic diseases, people have to face the process of being transformed by this experience. Since illness experiences, symptoms and treatments are heterogeneous, for methodological reasons most studies on the experience of chronic illness focus on the transformation associated with specific diseases and generalise their findings to the poorly defined category of chronic diseases (Asbring 2001; Kalitzkus and Matthiessen 2010; Karademas 2014; Prodinger and Stamm 2010). However, these studies do not address the fundamental question of what chronic diseases may share that is relevant for adjustment, self-management and adherence to long-term treatment, and so do not contribute to understanding what is it that people have to adjust to when living with a chronic disease.

It is indisputable that illness experiences can be heterogeneous in terms of disease-specific variables, the existential level, cultural context, social situation, and historical framework, among many more (Carel 2016), thus requiring focused and contextual approaches. Nonetheless, at a different level of analysis, it has also been argued that people living with chronic disease face a common set of challenges that is fundamental for a comprehensive understanding of disease and healthcare interventions, receiving special attention in self-management education (Swendeman, Ingram, and Rotheram-Borus 2009; Wagner et al. 2001). Overall, this common core comprises difficult lifetime changes in physical health, psychological functioning, social relations; the adoption of complex disease-specific medication regimens; negotiating how to obtain helpful medical care; and dealing with symptoms and emotional impacts (Wagner et al. 2001; Swendeman, Ingram, and Rotheram-Borus 2009).

In the spirit of thinking beyond specific diagnostic categories, Dubouloz and colleagues' (2010) model of the process of personal transformation in a primary care context for people living with chronic illness builds on two diseases, HIV and diabetes, but does not address the issue of what these conditions may have in common at the level of experience. Still, these authors' work offers an interesting starting point for further reflection on the experience of chronic disease. This three-stage model (initial response; embracing the challenge; and integration of new ways of being) is an example of a prescriptive or normative process of transformation marked by a positive approach to chronic illness, which is driven by a narrative of success and acceptance in which people are expected to achieve personal growth from the experience of illness. However, it might be argued that describing this set path of experience does not contribute to understanding what happens to people at a subjective level when they are diagnosed and live with a chronic disease. Furthermore, this can negatively affect the experience of chronic disease by hindering the possibility of healthcare professionals paying attention to unique stories of illness (Telford 2006). This might be especially critical for the case of chronic illness stories, which, contrary to what stories of positive transformation or growth tell, have been argued to be often governed by a sense of disorganisation or chaos, with no clear story development or sense of progressive time, being marked by deep uncertainty and lack of control (Frank 1995).

Dubouloz and colleagues' (2010) model of personal transformation considers the challenge of adjusting future expectations and differentiating the self from the body, arguing that more research is needed to better understand the characteristics of people who embrace transformation as a goal and those who do not (Dubouloz et al. 2010). This suggests that 'positive personal transformation' might be a matter of personal choice. Although this might be the case in certain cases, chronic diseases have been argued to lead to isolation and dependency (McDonald et al. 2015; Carel 2014; Bury 1982). Social networks and an overall sense of belonging to the social world have been identified as one of the most important fertile functionings contributing to overcome a broad range of difficulties, showing that being well-supported by friends and or family correlates with greater agency or capacity to act (Schlosser 2019) to implement desired health behaviour changes, such as adhering to long-term treatment (Vassilev et al. 2014; Wolff and de-Shalit 2007). A good example of this is that the main variables linked to successful outcomes in self-management courses are associated with creating a social context characterised by collaborative coping, shared learning, and belonging, which mainly provide a solution to the social isolation experienced by people living with chronic disease (McDonald et al. 2015). Still, more research is needed in order to understand the qualities of patient-professional relationships that allow flexibility, questioning and change over time, and how this relates to longer-term health outcomes (Furler et al. 2008).

5. The vicious circle of disadvantage amongst people living with chronic disease

Overall, criticism about current approaches to chronic care and self-management support are perceptive in the sense that they highlight nuances within an approach that might be regarded as descriptively appropriate, but failing in its level of understanding and application by missing the complexity that people's lives and social matters entail. In other words, these criticisms identify that person-centeredness is not the problem, but how this is interpreted and applied. Because of this problem, some authors have started using 'truly person-centeredness' and 'genuine person-centeredness' to stress how fundamental it is to embrace the full complexity of people's situation—beyond their role as patients living with a specific disease—to make progress in healthcare delivery and health outcomes (Tyreman 2018; R. L. Anjum, Copeland, and Rocca 2020). A good example of this is the 'house of care' (Coulter, Roberts, and Dixon 2013) as a person-centred bio-psychosocial approach to chronic care. This most likely requires a multidisciplinary team to offer emotional, psychological and practical support for people living with chronic disease still, as Anjum (2020) explains, such team might either reproduce the atomistic approach of attending each aspect of a person's life separately—failing to offer person-centred care, or each member of the team might think and function in a whole-person way—offering genuine person-centeredness.

Health inequalities, chronic care, treatment adherence, and the experience of chronic disease are complex issues interacting in complex ways. Thus far, it has been argued that chronic diseases disproportionately burden those who live in disadvantage; health outcomes for chronic diseases are poorer within those who live in disadvantage; there are good reasons to think that there might be a social gradient in treatment adherence underlying the unequal distribution of health outcomes for chronic diseases; there are good reasons to think that there are significant psychological and emotional issues associated with chronic disease; and that such issues may hinder individuals possibilities to mobilise—arguably already scarce—resources to successfully self-manage chronic disease. All these suggest serious ethical implications that require further analysis.

Wolff and de-Shalit (2007) propose a theory in which disadvantage is described as an intrinsically plural phenomenon, arguing that when it comes to understanding disadvantage, relations of simple direct causation and linearity do not apply. These authors' theory of disadvantage builds on Sen's (1990, 115–16) capability-based assessment of justice, where

> individual claims are not to be assessed in terms of the resources or primary goods the persons respectively hold, but in terms of the freedoms they actually enjoy to choose between different ways of living

> that they can have reason to value. It is this actual freedom that is represented in the person's 'capability' to achieve various alternative combinations of functionings, that is, doings and beings.

Drawing on their empirical qualitative research in the UK and Israel, Wolff and de-Shalit (2007) identified six high-weight categories of functionings: life; bodily health; bodily integrity; affiliation or belonging; control over one's environment; and sense, imagination and thought often operationalised in terms of education.[13] These categories of functionings draw on Nussbaum's (2000) capabilities approach, which suggests ten central human capabilities.[14] From this perspective, a capability would imply having the opportunity to be healthy, for example, not actual healthy functioning—as people would have the freedom not to choose that functioning (Nussbaum 2000). Wolff and de-Shalit (2007) incorporate the notion of functionings but propose a relevant distinction between formal and genuine opportunity to achieve functionings to replace the concept of capability or freedom to achieve functionings. Thus, according to Wolff and de-Shalit (2007, 155), "the least advantaged are those who experience a clustering of disadvantages in the sense that they find it extremely difficult to secure several of the high-weight functionings".

This is important in terms of responsibility because whether it is

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[13] Although most of these capabilities are self-explanatory or have been clarified, full definitions can be found in (Nussbaum 2008, 78–80).

[14] The remaining four basic human capabilities described in this account include emotions; practical reasoning; other species; and play (Nussbaum 2008, 78–80).

reasonable to expect individuals to be able to function (beings and doings) in certain ways, will depend on whether they have a genuine opportunity to achieve it (Wolff and de-Shalit 2007). In the context of long-term treatment, this would imply thinking that it would only be reasonable to expect people to adhere to long-term treatment if they have a genuine opportunity to do this.

Following from this understanding of disadvantage, there are mainly two parameters that can determine if individuals have a genuine opportunity to achieve functionings: 1) the cost that achieving one currently lacking functioning can have on an already achieved functioning, which depends on 2) the individual's already achieved functioning level (Wolff and de-Shalit 2007). Therefore, equality of opportunity for healthcare services might only constitute a genuine opportunity for healthcare if everyone enjoys a level of secure central functionings that is not jeopardized by making use of healthcare services.

The previous section highlighted social networks and support—functioning of affiliation—as particularly relevant for self-management of chronic diseases. Having a sense of belonging or affiliation refers to the ability to develop relationships with others, have people to rely on, feel cultural or class-related belonging amongst others, and be loved, liked and thus accepted by others (Nussbaum 2000; Wolff and de-Shalit 2007). From an empirical perspective, affiliation has shown clear elements of clustering with the functionings of sense, imagination and thought; control over one's environment; and bodily health, thus working as one of the most fertile functionings, or corrosive disadvantages. Fertile in the sense that it allows overcoming disadvantage by facilitating the achievement of the other functionings, and corrosive in the sense that lacking affiliation probably implies lacking all of them (Wolff and de-Shalit 2007). Furthermore, all these functionings have been argued to correlate with socioeconomic level and follow a gradient amongst socioeconomic groups (Marmot 2005).

Since people living with chronic disease are likely to be disadvantaged in terms of their socioeconomic level and the previously described clustering functionings, it would follow that those who live with chronic disease are unlikely to enjoy a level of secure central functionings and therefore, unlikely to have a genuine opportunity to benefit from healthcare services despite having access to UHC, as this would imply jeopardizing other central functionings. This implies that it would not be reasonable to expect them to always comply with long-term treatment recommendations, suggesting a more complex approach to personal responsibility. In simpler words, it might be argued that people living with chronic disease are likely to face the challenge of having to negotiate their health with other central needs, and thus, understandably, their treatment might not always be prioritised. Furthermore, since chronic diseases have been argued to negatively affect relevant functionings for chronic treatment adherence such as affiliation, there might be a cumulative effect of disadvantage leading to a vicious circle of disadvantage amongst people living with chronic disease. Furthermore, this might be specified as a double inequity in so far, even within UHC systems, there are significant health inequalities caused by differences in patients' abilities to adhere to long-term treatments, and inequalities in long-term treatment adherence are correlated with, and aggravate, existing health inequalities. This means that chronic diseases might be regarded as risk multipliers for disadvantage, aggravating existing inequalities.

6. Complex systems and justice in healthcare

The last section focused on the role of affiliation and social support for successful self-management of chronic illness suggesting that the concepts of 'fertile functionings' and 'corrosive disadvantages' can be key to tackle the reproduction of disadvantage in health. Although Wolff and de-Shalit (2007) do not present their theory as a complex systems approach, the ethical implications introduced in the last section in terms of a 'vicious circle' of disadvantage and chronic diseases as 'risk multipliers' for disadvantage, as well as ideas of 'corrosive' and 'fertile' interactions between functionings, suggest a language of flows and balance resulting in unwanted outcomes for those who live with chronic disease that resonates with a complex systems rationale. This section explores how adopting a complex systems perspective can offer an opportunity to continue reflecting on the ethical issues around chronic disease, long-term treatment adherence and health justice.

As discussed throughout this chapter, linear or causal relationships often fall short when trying to understand the complexity of social processes. Complex systems approaches, include models such as 'complexity science' or 'systems theory' which have been applied to multiple fields, ranging from computer science to the study of the workplace and organisations, and family therapy—to mention a few. Complex systems approaches offer a model of thinking about any given problem composed and shaped by different interacting elements or parts, and have been recently argued to be particularly helpful in the study of ethical problems in public health and public policy, such as health inequalities (Wilson 2021)

In general terms, a 'system' "is an interconnected set of elements that is coherently organized in a way that achieves something", thus systems consist of elements, interconnections and a function or purpose (Meadows 2009, 11). Complex systems are a subset of systems, that is, interconnected systems.

> Every person we encounter, every organization, every animal, garden, tree, and forest is a complex system. We have built up intuitively, without analysis, often without words, a practical understanding of how these systems work, and how to work with them (Meadows 2009, 3).

The different elements or stocks (e.g. amount of wood in a tree or one's own self-confidence at any given time) are the foundation of the system and the information flowing through their interconnections is what holds the system together. Still, inflows (positive flow) and outflows (negative flow) rates determine how stocks can change over time. While the behaviour of each element or part of the system may be simple, their interactions will often be complex. Such interactions involve multiple levels of balancing and reinforcing feedback loops that help stabilise or amplify the behaviours of other parts of the system, potentially resulting in either virtuous or vicious circles (Meadows

2009).

‘Systems theory’ helps make sense of complex patterns and interconnections of certain aspects found in the world, such as the growth of a tree or the digestive system, and the ‘system’ metaphor helps describe the complexity feature of certain aspects of the world, such as how hospitals or healthcare systems work. Thus, drawing on Wilson’s (2021, 65) work on complexity in the context of public health policy, “the crucial thing is to think of complexity as a way of structuring assumptions about what the world is like, and thus what good inquiry, whether scientific or philosophical should look like”.

Thinking about disadvantage, chronic disease, and long-term treatment adherence in terms of interconnected elements in the form of a vicious circle or runaway loop of damage, implies adopting a complex systems perspective. From this perspective, the assumption that equality of opportunity to access healthcare services implies that individuals equally benefit from that opportunity errs in that it ignores the relevance of the relationship arising from these interacting elements. As long as there are at least two independent processing elements interacting in a system, difference is created; this is new information that is immanent in their mutual relationship of double description. (Bateson 2002). Drawing on the example that one eye can only see two dimensions and that two eyes can see three dimensions because depth is created as new information in their interaction, Bateson (2002) argues that two interacting descriptions, interpretations or points of view are always better than one because of the added value of the new information emerging in that relationship. Although the positive value of new information might be contested, the relevant point for systems thinking is that when at least two independent processing elements interact, such as people, groups or institutions, new information that neither party could have created independently will emerge altering the behaviour of the system.

Following this line of thought, UHC—broadly understood as equality of opportunity to access healthcare services—with one of its goals being tackling health outcomes inequalities might be described as a ‘fix that fails’ or ‘policy resistance’ system trap (Meadows 2009). As seen throughout this introduction, health inequalities constitute an undesired and problematic long-standing behaviour pattern fed by a multiplicity of variables that go beyond healthcare, thus being particularly difficult to change despite helpful interventions, such as UHC. Following the ″fixes that fail″ rationale, by focusing on a partial goal—access to healthcare, this intervention misses the complexity of the broader system, losing sight of the new information being created and how this re-enters the system to alter its behaviour more broadly.

In light of the vicious circle of disadvantage, thinking in systemic terms about chronic disease health inequalities means that the core of the problem of justice would not just lie in having enough of the X, Y or Z resources that matter for justice—arguably enough UHC, but on how all the relevant variables involved, including UHC, interact in someone’s life and achieve balancing feedback loops that can deliver both partial and whole-system goals. Wilson (2021) describes this as an indirect perspective on justice, as it focuses not on distributing a particular good but on designing systems that are conducive to equitable human flourishing.

As a subset problem within health justice, the same applies to chronic disease health outcomes inequalities in contexts where people have access to healthcare. In healthcare, the tension between evidence-based medicine and the individual patient reflects this same problem, namely missing the complexity of the broader system and the new information being created. Evidence-based medicine is our time's gold standard for clinical practice, and it is based on population-level statistics that are systematised in clinical guidelines. Such guidelines are supposed to orient clinical practice with individual patients despite their lack of detailed contextual information. Since healthcare professionals deal with individual persons in unique situations, it has been argued that when clinical guidelines are followed as rules—pathways or flowcharts, the best possible outcomes are not achieved, and should thus be taken as a flexible web of possibilities or interconnection between different pathways (Copeland 2020). Although this is a contested idea, this web approach implies that clinical guidelines need to be creatively tailored for different patients in the clinical encounter. Regarding how to act in such cases, Tyreman (2016) highlights that even the most technical decisions cannot only be based on the best evidence available but also on the values or judgements of patients, practitioners and others involved in the clinical situation, this is, value-based practice. Taking this further and thinking about the ethical problems associated with healthcare practitioners' workarounds such as shortcuts, bending the rules and turfing, Berlinger (2016) argues that working in healthcare contexts is adaptive, as it demands continuously accommodating to changing internal conditions and managing external pressures affecting the system.

Just like isolating relations of direct causation and doing evidence-based medicine have been argued to inform less than it is usually thought by failing to meet the world's complexity, Wilson (2021) challenges the value of what he calls a High Theory approach to moral inquiry. Such approach regards principles of justice to be fact-free and thus true in any possible context, only meeting the complexities of the world and facing empirical constraints when moral principles are being applied, not when their analytical structure is being examined. The High Theory approach is argued to be unhelpful to the aim of achieving justice in the world—with all its complexity, thus undermining the seriousness and complexity of the challenge that moral philosophy faces. Furthermore, this approach is argued to overlook the partially socially constructed nature of ethical concepts, which would imply that the real world and its complexity are not external, but part of the ethical inquiry (Wilson 2021). This leads Wilson (2021, 78) to argue that moral inquiry needs to focus on "how to understand the complex systems that constitute the realm of social policy, in order to do better in designing ethically defensible policies".

Going back to the ethical issues raised by chronic disease in terms of a double inequity, a systems approach to justice in this context would imply thinking about a person's general circumstances in terms of stocks and flows within a complex system of interactions working towards minimising the negative effects of chronic disease in a broad sense. Building on what has been discussed thus far, this broadly refers to boosting everyone's opportunities to benefit from available healthcare services, but this requires further analysis and will be specified throughout this thesis. As already mentioned, paying attention to the new information continuously arising from the interaction or relationship between elements is the key to achieving the dynamic equilibrium that supports a systems' behaviour pattern or stability around an explicit or implicit goal, such as the specific temperature at which a thermostat is set or reducing health outcomes inequalities for chronic diseases. Going back to UHC as a "fix that fails" or "policy resistance", this means that long-standing health inequalities within a society are sustained by the system's dynamic equilibrium.

Using the example of a bathtub that manages to retain the same amount of water in it while keeping the tap running and the drain stopper open, Meadows (2009, 187) defines dynamic equilibrium as "the condition in which the state of a stock (its level or its size) is steady and unchanging, despite inflows and outflows. This is possible only when all inflows equal all outflows". Although this definition seems rather static, considering that the water is constantly being renewed, complex systems might be argued to work with a continuously *new* dynamic equilibrium that, through its interactions, flows or processes, can also contribute to adjusting the goal or state of a stock if needed. Wilson (2021) describes this altering effect of feedback loops over stocks and how the system behaves more broadly in terms of complex systems' performativity.

However, in a rather problematic way, dynamic equilibrium is often equated to ‘homeostasis’. This describes the dynamic equilibration process through which biological systems re-establish a previous, fixed and finished state (Johnson 2018). Building on Johnson’s (2018, 2) work on Dewey’s conception of moral cognition, morality is argued to arise “from social embeddedness and interactions with others within communities of interdependent persons”. From this view and much in line with complex systems approaches, life does not simply take place in an environment but because of it through a rhythm of disequilibration and search for equilibrium broadly understood as coordinated interactions between elements and their context (Johnson 2018). This idea of dynamic equilibrium as a continuously changing explicit or implicit effort towards a specific—positive, negative or neutral—balance in context seems central to reflect about whole-system goals in the context of people living with chronic disease.

Thus, focusing on the ‘mobilisation’ of resources instead of ‘resources’ themselves when describing ethical issues around health outcomes for chronic disease resonates with the dynamism introduced by the systems language and framework. Furthermore, this is also where the capabilities approach might be argued to depart from egalitarian theories of justice focused on the distribution of resources as the currency for justice,[15] focusing

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[15] Both John Rawls and Ronald Dworkin, by focusing on ‘primary goods’ and ‘resources’ respectively think about justice in terms of means rather than what people can obtain from the means (Sen 1990). Rather than criticising John Rawls’ and Ronald Dworkin’s views, this shift shows philosophy’s increasing engagement with context.

on what people can achieve with what they have (capabilities as opportunities to be and do). As Sen (1990, 112) puts it

> fairness must be directly concerned with the *actual freedoms* enjoyed by different persons—persons with possibly divergent objectives—to lead different lives that they can have reason to value.

This perspective on justice highlights that people are diverse in different ways, including their ability to convert resources into actual freedoms, in other words, mobilise resources. Many different features (such as sex and age for example) give people unequal powers to build freedoms in their lives even if they have the same resources available or, as specified by Wolff and de-Shalit (2007), they have a genuine opportunity to achieve functionings. By tapping on a different bundle of functionings people with the same capabilities and goals may achieve different results. More importantly, it also embraces the reality that people may face naturally or socially generated difficulties in turning primary goods into actual freedoms (Sen 1990; 1995).

Drawing on examples such as inequalities between women and men that arise from biological (e.g. related to pregnancy) and social (e.g. conventional household roles) factors and can place a woman at a disadvantage even when she has the same resources as a man (Sen 1990), Sen (1995, 1) later argued that “equal consideration for all may demand very unequal treatment in favour of the disadvantaged. The demands of substantive equality can be particularly exacting and complex when there is a good deal of antecedent inequality to counter”.

This helps further specify the idea that different people will have different possibilities to work towards dynamic equilibrium in the context of chronic disease, despite having the same opportunity to access healthcare. The operationalisation of the right to health in terms of equality of opportunity to access healthcare services is aligned with the egalitarian claim that everyone has a right to equal treatment, this is, to "the same distribution of goods or opportunities as anyone else has or is given" (Dworkin 2013, 327). However, this right is derivative from the more fundamental right to be treated as an equal. This refers to "the right to equal concern and respect in the political decision about how these goods and opportunities are to be distributed" (Dworkin 2013, 327). Although this more fundamental principle has been argued to result in different treatment in certain cases[16], Sen's (1995) argument further specifies this by claiming that unequal contexts justify preferential treatment for the disadvantaged, making the case for 'attainment equality' (helping those in disadvantage to come closer to the achievements of the better off) as opposed to 'shortfall equality' (levelling down the achievements of the better off). Following on from this, and in contrast to Nussbaum's (2000) sufficientarian approach to what justice requires about the distribution of capabilities, that is, a basic social minimum required for human dignity, Wolff and de-Shalit (2007, 165) argue for a proritarian approach, specifying that

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[16] Based on Dworkin's (2013) example that if a disease is affecting two children differently, it is justified to provide different treatment.

> when absolute priority of the worst off is extremely expensive and only marginally effective, this should encourage governments not to abandon the least advantaged but look for more cost-effective forms of support.

This perspective might be argued to support the core idea of this introduction: that in order to achieve better and more equal health outcomes for chronic diseases, the specific circumstances of people, and the multiple and complex ways in which these may interact and have an impact on their health results, need to be taken into account and tailor the delivery of chronic care. More specifically, and in light of the vicious circle of disadvantage, this would suggest a moral duty to feed this complex system of interactions in such a way that it brings those in a disadvantaged position closer to those achieving better outcomes.

Building on the core ideas presented in this introduction, a crucial element in what achieving justice in terms of dynamic equilibrium of health outcomes for chronic disease may look like involves starting from the basis of how each person in the relevant moral situation, that is living with chronic disease and long-term treatment negotiates the stocks and flows or leads a life she has reason to value. Thus, this thesis explores the questions of how can the experience of chronic illness inform the normative discussion on how to improve equity in health outcomes for chronic diseases. By conducting an empirical ethics investigation that pays attention to the complexity of individual's lived experience of chronic disease, long-term treatment in the context of the NHS and life beyond illness in England, this thesis will aim to inform and orient ethically driven long-term. This implies further specifying how to support people who live with chronic disease to live lives they have reason to value and thus tackle the reproduction of disadvantage and reduce health outcomes inequalities.

7. *Summary of the introduction and brief overview of the thesis*

This introduction to the problem of health outcomes inequalities for both communicable and non-communicable chronic diseases has argued that there are significant health inequalities that are caused—within systems of UHC—by the fact that patients' abilities to adhere to treatment for chronic diseases are widely different. This raises ethical issues relating to people who live with chronic disease suffering avoidable morbidity and mortality as a result of uncontrolled chronic disease, and also because there are good reasons to think that inequalities in adherence to long-term treatment are correlated with, and aggravate, existing health inequalities.

Mainly drawing on Wolff and de-Shalit's (2007) account of disadvantage—and the capability-based assessment of justice of which this is derivative, this section proposed a normative framework[17] for interpreting and responding to treatment adherence differences in chronic diseases, although

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[17] Throughout this thesis, the concept 'normative framework' is used descriptively as a set of ideas, arguments or principles, which entail one or more normative claims or value judgements and suggest a path to think through a given ethical problem.

it extends this account by applying their theory of disadvantage to the particular case of chronic diseases. This normative framework suggests that individuals living in disadvantage in terms of their socioeconomic level and their achieved functionings level might be more likely to 1) get a chronic disease and live shorter lives; 2) lack the functionings that could allow them to successfully self-manage their disease; and 3) be at risk to become more disadvantaged as a result of chronic disease.

Although this work does not dismiss the value of UHC, it does stress the need for healthcare systems to go beyond equality of opportunity for access in order to become a more effective instrument for distributive justice highlighting the potential of adopting a complex systems perspective to do so. This highlights the need to learn more about the life of people living with chronic diseases in order to better understand the complexity associated with the system of chronic disease, long-term treatment adherence and life beyond illness, informing how people negotiate different stocks and flows to live lives they have reason to value. This was argued to have the potential to inform ethically driven care for chronic diseases that can ameliorate the cumulative effect of disadvantage and reduce health outcomes inequalities amongst people who live with chronic disease.

Therefore, this thesis starts by focusing on the empirical aim of learning about the experience of people living with chronic diseases by generating qualitative data. It then draws on this data to inform the ethical aim of contributing to the normative discussion on how to improve equity in health outcomes for chronic diseases.

How these two elements (empirical and normative) come together is discussed in detail in Chapter 1, but the general foundation of this relationship rests on the idea that "policymaking must be understood as an improvisatory activity in which citizens are key partners" (Wilson 2021, 63), so how we work towards and sustain any valued goals in society requires paying attention to the constant feedback loops between the multiple actors shaping the process. This thesis reflects this improvisatory activity by fostering a dialogue between participants' experience and health policy outcomes. This dialogue supports the normative analysis informing the discussion on how to improve equity in health outcomes for chronic diseases in the UK.

Part I of this thesis focuses on the empirical element, covering the methodological framework, the study design, data generation and analysis, and the empirical findings. By highlighting an inherent hermeneutical component in social research, Chapter 1 stresses the importance of language and meaning-making processes to approach human actions, such as those related to long-term treatment within people living with chronic diseases. Considering that people interpret their lives and values within a shared hermeneutic horizon is central to the claim already discussed that linear approaches to policy development are likely to fail. More specifically, and building on integrative approaches to bioethics, the empirical study draws on phronetic social sciences and the normative case study to orient the study design. After detailing the empirical study's research questions and aims, Chapter 2 brings together the theory of how to conduct a qualitative study and a detailed description of how this went in practice throughout the six-month fieldwork in two NHS hospitals in London. Chapter 3 discusses the theory and the practice of the narrative thematic analysis of the interviews and presents the findings through the description of five emergent themes: (1) Illness narratives, ruptures in belonging and the value of support networks; (2) Finding and keeping the balance between chronic illness, chronic care and life beyond illness; (3) Considering chronic diseases as controllable diseases seems to be a matter of perspective; (4) The place of chronic disease and long-term treatment within individuals' inner world; and (5) Values and judgements around chronic care and the healthcare practitioner-patient relationship.

Part II of the thesis draws on the empirical data generated in this study to develop conceptual clarity. Chapter 4 introduces a contextual definition of 'chronic disease' that distinguishes between chronicity in a thin sense—merely as long-duration—and chronicity in a phenomenological sense, which describes 'the paradox of chronicity' as a key understanding to reflect on long-term treatment adherence and practices of chronic disease self-management. Building on this, Chapter 5 presents an overview of the main complexities associated with living with chronic disease and long-term treatment, which highlights how people face the challenges of negotiating competing demands in the context of chronic disease and life beyond illness. Adopting a complex systems approach to think about this negotiation, this chapter introduces the idea of 'dynamic equilibrium' as the continuous effort towards balancing competing demands to live lives people have reason to value. This adds a new layer to the vicious circle of disadvantage amongst people who live with chronic disease, as those who live in disadvantage arguably live in a relatively precarious balance due to higher competing demands. By pushing the boundaries and further specifying current understandings of ‘chronic disease’ and life with chronic illness this part of the thesis is described in the conclusion of Chapter 5 as a stepping-stone for the normative work in the rest of the thesis.

Part III explores participants’ experience in more depth and it develops a multidimensional perspective on the experience of chronic disease. Overall, this multidimensional perspective helps identify key social and psychological challenges and injustices faced by people living with chronic diseases, which further specify this work’s understanding of the ethical problem of the vicious circle of disadvantage. As in so far chronic diseases and long-term treatment can threaten belonging to the social world, sense of agency and self-concept or identity, these can significantly affect people’s possibilities to live the lives they have reason to value and thus play a crucial role in the process towards dynamic equilibrium. Although living lives people have reason to value can sometimes jeopardise disease outcomes by disregarding long-term treatment, this process is described as a negotiation aiming to protect another subjectively crucial aspect of life and the self.

Closely linked to the discussion on affiliation in Section 5 of this introduction, Chapter 6 describes participants’ experiences of stigma, lack of place and lack of empathy. This chapter argues that people living with chronic diseases suffer from prejudiced hermeneutical marginalisation—injustice—that contributes to their withdrawal from social situations, isolation and loneliness. This hinders their possibilities to keep previous social support and build new social connections resulting in further disadvantage. Chapter 7 explores participants' experience of having no to little sense of control over the disease and their bodies and their quest to regain some sense of control. Harmonising the body as subject and object through monitoring and healthcare monitoring is a main task in this quest for control and a micro-level task contributing towards dynamic equilibrium. Still, this chapter argues that because self-management tasks can become alienating people living with chronic disease face the challenge of—more or less consciously—choosing between an increased sense of control over the disease, and their sense of agency over their lives more broadly. Chapter 8 expands on the difficulties associated with the subjective change of giving up a previous favoured status by reflecting on participants' resistance to acknowledging chronic illness. This resistance is framed as a feature of the protective function of the 'dynamic porous boundary of identity' (first introduced Chapter 5), as it helps people living with chronic diseases to avoid developing negative feelings and attitudes towards themselves. Still, during the onset of disease, this is argued to contribute towards delays in diagnosis, which might be amplified by healthcare professionals who fail to listen to patients' experiences. Such failure to listen is argued to lead to physical and psychological harm, constituting a testimonial injustice.

Building on the overall understanding of the dynamism of chronic diseases and the interdependence underlying the management of long-term treatment, Part IV of this thesis further specifies the patient-healthcare professional relationship in the context of chronic care as a key element in the normative discussion about long-term treatment and health justice. Chapter 9 draws on participants' experience and participant observation sessions of specialist healthcare appointments to reflect on socially aware and ethically driven goals for long-term treatment. After discussing the tensions between 'narrow' (rather instrumental) and 'truly' (whole-person) person-centred care in the specific context of chronic diseases, this chapter highlights: 1) respectful and collaborative patient-healthcare professional relationships; 2) chronic care understood as a shared project or activity mainly involving healthcare professionals, clinical teams and patients but also patients' broader social context; and 3) a sensible understanding of continuity of care as key features of truly person-centred care for chronic diseases. These three main aspects operationalise an overall attitude towards chronic care, which embraces the ongoing challenges of living with chronic illness and long-term treatment, recognising the process, its frailty and the need for continued socially aware support. By adequately supporting people's efforts towards dynamic equilibrium, this approach can arguably help compensate for pre-existing inequalities and prevent further disadvantages.

Finally, the conclusion of this thesis draws on intersectionality and interdependence to discuss issues around responsibility and justice for chronic disease health outcomes inequalities. This helps further specify the cumulative effect of disadvantage amongst people living with chronic diseases and introduce three new principles that can help orient individual action for ethically driven chronic care. These principles are: 1) practising socially aware testimonial justice with people living with chronic diseases and contributing to hermeneutical justice by building tools for shared understanding specifically regarding the experience of chronic disease and chronic care; 2) respecting that long-term treatment is not and should not always be prioritised and thus adherence to long-term treatment is not a stable achievement; and 3) understanding chronic care as a truly person-centred shared project mainly between patients and healthcare professionals, but also involving the broader social context.

Drawing on the position of power that healthcare institutions and professionals hold relative to those who live with chronic diseases, these principles are mainly aimed at healthcare institutions and professionals delivering chronic care. Still, these principles might be argued to contribute to the hermeneutical tools for shared understanding of chronic illness within the broader society of the ‘healthy’ and individual processes of illness and long-term treatment amongst people living with chronic disease. These principles build on shifting the focus of chronic care towards supporting dynamic equilibrium for people living with chronic diseases as the genuine opportunity to live lives people have reason to value (be and do) across time, contributing to improve equity in health outcomes for chronic diseases in England and potentially informing further research and practice in other contexts where people have access to UHC.

Part I

The Theory and Practice Of The Methodological Approach

Chapter 1

Methodological Theoretical Framework

1. Introduction

This research aims to learn more about the experience of people living with chronic disease and long-term treatment to understand the double inequity introduced in the last chapter.[1] Following the complex systems approach discussed in the introduction, the second section of this chapter argues that the best theoretical background to orient the methodology of the empirical study is interpretative social sciences. By highlighting an inherent hermeneutical component in social research, this section stresses the importance of language and meaning-making processes to approach human actions, such as those related to long-term treatment within people living with chronic diseases. Considering that people interpret their lives and values within a shared hermeneutic horizon is central to the claim discussed in the introduction to this thesis that linear approaches to policy development are likely to fail.

Still, considering the importance of developing a flexible methodology that can adjust to the requirements of complex research, the third section

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[1] That is, even within UHC systems, there are significant health inequalities caused by differences in patients' abilities to adhere to long-term treatments, and inequalities in long-term treatment adherence are correlated with, and aggravate, existing health inequalities.

introduces a critical view towards an absolute ontological and epistemological distinction in research between objectivist and subjectivist approaches. This argues that, in the case of conducting social research in health, researchers often draw on mixed methods to respond to the complexities of such objects of study. Following this critique and by stressing the importance of context, judgement and practical knowledge in social research, this section introduces phronetic social sciences as a flexible and suitable method for this study's aims. Section four further specifies the methodology by discussing the place of empirical bioethics methodologies and the naturalistic fallacy—namely that 'ought' cannot be drawn from 'is'—in the context of interpretative and phronetic social sciences, arguing that such a dichotomy does not apply. Finally, building on integrative approaches to bioethics that support the ontological view that facts and values are intertwined, phronetic social sciences and the normative case study are considered a strong methodological approach to conduct this empirical ethics study on chronic diseases.

2. Learning about chronic disease experience through interpretative social sciences

As discussed in the introduction to this thesis, the empirical study will focus on learning about the experience of chronic disease to inform the discussion on how to improve equity in health outcomes for chronic diseases.

Thus, this study demands a methodological perspective that can encompass and deliver its descriptive and normative goals.

The fundamental principles of interpretative social science draw on the work developed by Max Weber and Wilhem Dilthey in the 19th and 20th centuries regarding the study of social action, and are based on the strong theoretical distinction between positivist (objectivist) natural sciences—*Naturwissenschaft*—which aim at abstract explanation—*Erklärung*—and human sciences—*Geisteswissenschaft*—aiming at an empathetic understanding—*verstehen*—of the everyday lived experience of people in specific historical settings. Therefore, interpretative social sciences are founded on the assumption that people construct reality through interactions and beliefs, so researching under this framework implies that what we can learn through research is determined by the participants' subjectivity as well as the researcher's subjectivity and interpretations (Neuman 2014).

Methods within this perspective are fundamentally based on hermeneutics as a theory of meaning that reaches deep understanding through a close reading of texts that reflexively includes the reader's subjective experience. Language is very important in this framework since it comprises social constructions, conveying worldviews that help researchers understand how people see and experience the world, therefore fieldwork (participant observations, interviews, etc.) often offers a way for researchers to acquire detailed qualitative data that helps them reach an understanding of social phenomena and what actions mean to people who engage in them (Neuman 2014).

In the specific context of this study, these fundamental understandings offer a path to investigate the individual challenges of life with chronic disease and long-term treatment, as well as the relevant context or world of interactions and meaning brought into play in individual actions related to treatment adherence. As previously discussed, self-management programmes for chronic disease founded on cognitive behavioural interventions to increase adherence to long-term treatment deliver problem-solving skills and improve health outcomes to some extent, but fall short in their attempt to explain and tackle non-adherence to long-term treatment in the long-term (Barlow, Turner, and Wright 2000; Bodenheimer et al. 2002). Cognitive theory has been progressively more able to improve its capacity to address complex, non linear human phenomena, but this model still does not seem to be complete enough or comprehensive enough to address the fact that despite having access to long-term treatment and self-management support individuals often still struggle to adhere to long-term treatment recommendations (Sabaté 2003; Stutzin Donoso 2018; Entwistle, Cribb, and Owens 2018).

Thus, this research embraces Taylor's (1971) idea that it is not possible to do social science without considering its inherent hermeneutical component. In part, this draws on Gadamer's (2003) [2] idea that the development of positivistic social sciences in the 19th century failed to acknowledge that there is a fundamental difference in the nature of natural and human kinds of sciences' object of study, namely nature and beings. To

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[2] 'Truth and Method', first published in 1960.

make this point, Gadamer (2003) highlights Hume and Mill's work as good examples of applying a positivistic inductive logic to the study of human sciences and how this confuses the aim and sense of human sciences.[3] In the author's words,

> the experience of the sociohistorical world cannot be raised to a science by the inductive procedure of the natural sciences. […] The individual case does not serve only to confirm a law from which practical predictions can be made. Its ideal is rather to understand the phenomenon itself in its unique and historical concreteness. However much universals are involved, the aim is not to confirm and extend these universalized experiences in order to attain knowledge of a law, […] but to understand how this man, this people, or this state is what it has become, or more generally, how it happened that it is so (Gadamer, 2003, p. 4).

As briefly mentioned before, language plays a key role in this view since it is seen as a means of understanding. Thus, in verbal speech, understanding and interpretation are bound together just as in the hermeneutic process of coming to an understanding of written text. It is through understanding, and thus also interpretation, that the subject and the world meet. It is through language that the subject—or I—and the world

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[3] As explained by Gadamer (2003), the failure of positivistic inductive logic in the study of human sciences focuses on its failure to account for the need for *verstehen*. Furthermore, in terms of complex systems thinking, this also suggests that positivistic inductive logic fails to account for feedback loops, as exemplified in the 'fix that fails' system trap analysis of UHC in section 6 of the introduction to this thesis.

manifest their original belonging together. Language allows for understanding in terms of interpretation as this forms the hermeneutical limits within which meaning of a written text or conversation takes force (Gadamer 2003).

Like this, Taylor (1971) argues that doing social sciences implies a view in which problems regarding individuals and societies are seen as an object of study that presents itself as confused, incomplete, and even contradictory, and thus interpretation constitutes an attempt to shed light over underlying coherence or sense of this particular object of study. Thus, the meaning-making process of interpretation always refers to what is expressed by or for a subject or subjects. Certain interpretations can only become common understandings as long as the researcher offers systematic, clear readings of different expressions available in the text or text-analogue, that altogether back up every particular reading suggested, thus building a solid, context-relevant system of interpretation. Nonetheless, this approach implies an inescapable hermeneutical circle, in which others can always reject interpretations when common understanding of expressions is not achieved (Taylor 1971). Implicitly drawing on the systems metaphor discussed in the introduction to this thesis, the author argues that this

> circle can also be put in terms of part-whole relations: we are trying to establish a reading for the whole text, and for this we appeal to readings of its partial expressions; and yet because we are dealing with meaning, making sense, where expressions only make sense or not in relations to others, the readings of partial expressions depend on those of others, and ultimately of the whole (Taylor, 1971 p. 6).

This perspective also sees human behaviour as action, hence in terms of meaning—meaningful action. However, this does not imply that all actions have to make sense, this means, be rational. It is particularly because human action often fails to be consistent on the surface that 'sciences of man'—as labelled by Taylor (1971)—has been argued to have an inherent hermeneutical component. Still, this does not imply that it is not possible to understand an individual's inconsistent or, in this sense, irrational action since meaning is not determined by the rationality of the action, but by the coherence between the agent's action and the meaning that the agent's situation has for him or her (Taylor, 1971). Thus "making sense in this way through coherence of meaning and actions, the meanings of action and situation, cannot but move in a hermeneutical circle" (Taylor, 1971 p. 14).

Although attempts have been made to break the hermeneutical circle through rationalist (objectivist) approaches to hermeneutical material, these have been argued to be too limiting, even sterile, to understand important dimensions of human life. This is particularly because on the phenomenological level—in this specific context understood as that of speech—a specific notion of meaning is essential for the characterization of human action. Meaning is for a subject or group of subjects; of something; and in a field, that is, in a relation to the meanings of other things within the context of a society structured around hierarchical relations of power and command, amongst others. This understanding of meaning could then be described as experiential meaning (Taylor, 1971).

This view significantly opposes the aspirations of universalism in positivist science, and contradicts ontological and epistemological objectivism since meaning is not found ‘out there’ but built by subjective experiences in particular contexts. Although this may seem like a very context/individual-specific approach to social phenomena, it is founded on the idea that societies are based on common meanings—in terms of a common reference world—that constitute an intersubjective social reality (Taylor, 1971). Taylor (1971) argues that people experience the world in relation to others—as a ‘we’—first and then individually—as an ‘I’, so by exploring individual meaning, social researchers also learn about the social environment within which individuals live and act. As an interconnected system of relationships, learning about individual’s experience of chronic disease and long-term treatment opens a path to learn about people’s broader social context and the healthcare services in England that are of central importance in this study. Thus, Taylor’s (1971) understandings about social research provide particularly well-suited overarching guides for the study design for this research.

Taylor’s (1971) understanding of rationality as the coherence between meaning and action within the individual’s hermeneutical circle is particularly relevant for this study’s interest in actions regarding long-term treatment. Thinking about adhering to long-term treatment as rational and not adhering or irregularly adhering as irrational presupposes that achieving optimal health outcomes through long-term treatment is 1) in the individual’s self-interest and 2) that the individual herself consistently believes this is in her self-interest, always putting it before other beliefs and desires. From Elster’s (1983) perspective, this might be justified because of the evidence that is available to judge the consistency between actions and meaning—according to Taylor (1971), and between actions, beliefs and desires—according to Elster (1983). Elster (1983) argues that rationality in the thin sense is basically about logical consistency between actions, beliefs and desires, but in the broad sense, rationality requires beliefs and desires to be rational in a substantive way, which means that these are founded on available evidence. Still, Elster (1983) argues that if someone behaves otherwise than told by rationality, he or she is not necessarily acting irrationally, suggesting that human rationality is complex and perhaps not all evidence is always apparent or available to others or the individual herself.

This view opens an alternative approach to the public health problem of non-adherence and irregular adherence to long-term treatment, as it determines that a central task in the work of social researchers is making sense or better understanding the context and experience around these actions. Thus, one important aspect of this research subscribes to the goal of expanding current presuppositions and understandings of actions regarding long-term treatment adherence. This means exploring the judgements and desires underlying actions related to individuals adhering, not adhering or irregularly adhering to chronic treatment recommendations within the broader context of the lived experience of chronic disease and chronic care.

Although interpretative social sciences provide an overall theoretical framework to guide the study design of this research, adhering to a strong distinction between natural and social sciences (Gadamer 2003) has been argued to limit the possibilities to account for the complexity of most research problems (Alexandrova 2015; Fitzpatrick 2011). This is precisely why this work cannot only build from the experience of people with chronic disease, but also needs to take into account relevant quantitative data regarding chronic diseases and treatment adherence to frame, build and understand the research problem and people's experience—and vice versa. The next section will argue that this should not be seen as a methodological conflict or inconsistency, but as an acknowledgement of the more current view regarding the flexibility of research methods, while keeping an overall epistemological approach that guides how these methods are used and its data interpreted.

3. The elusive justification of absolute ontological statements in research

Alexandrova (2015) argues that thinking in terms of naturalism or objectivism—as causal generalizations and measurements—and interpretivism or constructivism—as value ladenness and lived experiences—is an out-dated division or opposition in social research and the natural sciences. This view offers an interesting counterpoint to the simplified distinction described before and is particularly relevant for this research, as an interdisciplinary health study drawing on a complex systems approach. By working on the specific example of wellbeing Alexandrova (2015) concludes that health sciences, in general, are unavoidably mixed sciences, suggesting that the very project of studying general features of social science should be abandoned. Although it seems sensible to say that a traditional, strong division of research strategies and techniques does not always allow for the best methodological approach possible for a particular social research project, it also seems that social science as understood by Taylor (1971) offers a solid rationale to say that even if a particular science justifies the use of mixed methods, it still requires a declaration and acknowledgement of ontological and epistemological assumptions. This refers to the general view under which these methods and techniques will be applied, mostly determining how social researchers see and approach their object of study, present their research results, and build their recommendations. As Bonell et al (2013) put it, methods—in themselves—do not make ontological assumptions, but researchers do.

Bonell et al (2013) argue that undertaking particular research methods does not mean researchers taking absolute ontological statements regarding their field or problem of study. In other words, these authors argue that it is possible and valuable to conduct randomized controlled trials (RCTs) in health research, for example, without ascribing to every aspect of objectivist ontology and epistemology, and without denying the importance of qualitative data.

Still, in so far RCTs aim to erase context as ‘confounding variables’ these studies significantly reduce complexity, which can typically be beneficial only when the role of *verstehen* is very limited.[4] Wilson (2021) reflects about this in terms of the usefulness of abstraction in the context of complex systems. Although it might be necessary at times to isolate one part of the

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[4] The next section expands on this describing how RCTs establish relations of causation at the cost of external validity (Wilson 2016).

system to better understand the whole, this often leads to simplification. Exercises of abstraction or isolating parts need to be situated in the broader context of the system that these are trying to better understand in order to achieve their aim. When this effort of integration is lacking, any understanding achieved through the abstraction becomes an atomistic outcome, that is, disconnected from the whole.

Alexandrova's (2015) argument regarding the integration of ontologies in social sciences seems to embrace the complexity of working with parts of systems and whole systems. She makes the point that social sciences, such as the science of health and wellbeing, do not need to subscribe to a strict naturalist approach to validate their results because interpretivist social science knowledge is valid, and also because the search for causal generalizations—often seen as belonging to the aims of natural positivist science—does not exclude concerns with subjective experiences, in this case, of how ill-being feels like and its social, intersubjective, common meanings (Alexandrova 2015).

Following the previous discussion on rationality, Alexandrova's (2015) view suggests that health science's object of study is one that requires both rationality and sensitivity, suggesting that for the case of social science not only a strict division of methods and research techniques is out-dated, but also more generally, these traditionally distant ontological and epistemological orientations are, thus advocating for a worldview in which reality, in regards with human beings, is both 'out there' and constructed through social interactions.

This perspective suggests a bottom-up relationship with existing categories, in which ontology and research methods are at the service of the complexity of real-world problems:

> the existing categories of social versus natural science, interpretivism versus naturalism, ideographic versus nomothetic methods, will retain relevance only to the extent that they help us address real problems of these new disciplines. If they are of no discernible help, then it is best to ignore them for this case (Alexandrova 2015, 224).

The discussion about strict objectivist and subjectivist views extends over how research connects theory and data. This refers to the type of relationship to be established between theoretical constructions about the matter under study and the empirical data generated as part of the research process. In general terms, it has been argued that empirical research can either follow a deductive or an inductive process, which means using data to test theory or build it, respectively. Under such views, researchers can either aim at abstract universal causal relations or aim at describing correlations that can contribute to deeper and contextual understandings (Bryman 2004).

Deductive research projects generally use quantitative research techniques that emphasise quantification in the generation of data, thus relying on a positivist ontological and epistemological framework. Whereas inductive research projects mostly use qualitative techniques that focus on rich, insightful descriptions and observations, which are usually driven by constructionist ontological and epistemological assumptions (Bryman 2004).

Nonetheless, as highlighted in Alexandrova's (2015) critical view, researchers should—and often do—use a mixture of these two traditional methods since most social research problems require a more flexible study design to be more comprehensive. Good examples of this are recent developments in big data research. As described by McAbee et al (2017), by using large amounts of data to inductively explore feedback interactions and understand processes, big data research can develop theories that can then be tested deductively.

While respecting the overall principles of interpretative social sciences, Flyvbjerg's (2001) phronetic social science encompasses the complexity and flexibility highlighted by critical views on strict divisions in the sciences. This approach is concerned with both *verstehen* and *erklären,* stressing the importance of context; judgement; and practical knowledge, being particularly well suited to develop the complex systems approach discussed in the last chapter. One of the main features of this methodology is highlighting the value of examples, or cases, to study broad social research problems, as it builds on the idea that values and human action must be seen in relation to the particular. Going back to Aristotle's philosophy, Flyvbjerg (2001) makes the case that studying human action requires the practice of phronesis, that is, to engage oneself with values as a point of departure for praxis. This means to acknowledge that the only way to enquire into human action is through the researcher's subjectivity not in spite of it, just as stressed earlier when briefly discussing Gadamer's (2003) work. Thus the power of cases—as examples—relies on the unique opportunity of closeness to real-life or common practice and their richness of detail, which give place to the achievement of fundamental features of social research. Some of these features involve the development of a nuanced view of reality, including that human action cannot be meaningfully understood as ruled-governed acts, in other words, understanding that reality is multiple, and human action complex. This perspective adds to the argument that if studying human action, it is only possible—and desirable—to produce concrete, context-dependent knowledge. In the author's words, "predictive theories and universals cannot be found in the study of human affairs. Concrete, context-dependent knowledge is, therefore, more valuable than vain search for predictive theories and universals" (Flyvbjerg, 2001, p.73).

4. Phronesis and the normative case study

As a social health research project aiming to inform a normative discussion, this study's methodological quest unavoidably leads to empirical bioethics methodologies. These methodologies combine social science (descriptive) and bioethics (prescriptive) research. The interest to unite these two fields arose from the necessity to include the views of actual moral agents in bioethics deliberations as a result of what has been labelled as the 'social sciences critique' of bioethics (Hedgecoe 2004). Namely, that since moral theory draws heavily on moral judgement or empirical background assumptions, then these assumptions should come from judgements that are representative of actual moral people, instead of solely relying on thought experiments and the thinker's ability to set up and analyse a moral question or situation.

Thus, this critique encourages and stresses the importance of doing bioethics through the generation of relevant data and systematisation processes (Draper and Ives 2007; Firth 2010; Molewijk et al. 2004; Sheehan and Dunn 2013). By highlighting the importance of actual moral people's judgements in a specific moral situation, this approach certainly takes into account the importance of context for moral theorising. Following the discussion in the last section, this might be considered a significant methodological strength.

Following Wilson's (2016) argument, context is particularly important when it comes to normative ethics. This author poses that since thought experiments are indeed a kind of experiment aiming to be transferable to wider contexts, they should be subject to both internal and external validity. The former refers to the quality of the study design and the latter, precisely to the applicability of the results to other contexts (Wilson 2016). Interestingly comparing these experiments to RCTs, this author concludes that thought experiments in normative ethics not only have serious problems of internal validity but face significant and similar challenges to RCTs when it comes to external validity, specifically because of what the author defines as normative contextual variance and non-transferability of causal structures (Wilson 2016). Although this analysis focuses on external validity as a measurement for transferability, in a broader sense it inevitably stresses the idea that context—even the most neutral and controlled context achievable—should never be overlooked since this unequivocally provides the boundaries and keys necessary to interpret and understand research results, properly acknowledging their potentialities and limitations.

Just as highlighted in Flyvbjerg's (2001) phronetic social science, empirical bioethics argues that moral decision-making must take place in the real world and specific cultural contexts. However, specifically for empirical bioethics, this poses the challenge of figuring out the terms on which the relationship between the real world and moral decision-making is founded (Draper & Ives, 2007). Part of this challenge has to do with the meta-ethical problem posed by the Humean dichotomy, widely accepted by the traditional bioethics research view, that an 'ought' cannot be inferred from an 'is' (naturalistic fallacy). This is generally assumed to mean that how things are or how people act cannot, by itself, generate normativity or dictate what is right and wrong (Putnam 2002). As stressed by Garrard and Wilkinson (2005), no amount of data can allows us to say that something is right or wrong, arguing that ethical principles are needed to bridge the two and concluding that empirical data is peripheral to ethical reasoning.

Although this worry is sensible, and many researchers accept and defend this dichotomy, it has been argued to be an incorrect interpretation of Hume's initial argument (Putnam 2002). This argument follows closely from the discussion in the introduction to this thesis regarding High Theory approaches to moral inquiry (fact-free and thus true in any possible context) overlooking the partially socially constructed nature of ethical concepts (Wilson 2021). Putnam (2002) argues that the fact/value dichotomy represents the thesis that ‘ethics’ is not a ‘matter of fact’, however, Hume’s ‘matters of fact’ are represented by ideas that can involve sentiments and emotions.

> Hume’s criterion for ‘matters of fact’ presupposed what might be called a ‘pictorial semantics’. Concepts in Hume’s theory of the mind, are a kind of ‘idea’, and ‘ideas’ are themselves pictorial: the only way they can resemble any ‘matter of fact’ is by *resembling* it (not necessarily visually, however—ideas can also be tactile, olfactory, and so on). Ideas have, however, nonpictorial properties as well; they can involve or be associated with sentiments, in other words, emotions. Hume does not just tell us that one cannot infer ‘ought’ from ‘is’; he claims, more broadly, that there is no ‘matter of fact’ about *right* and no ‘matter of fact’ about *virtue* (Putnam 2002, 15).

As discussed in the last section, by looking at the examples of RCTs, wellbeing and big data research, science has changed since Hume and strict positivistic views have been revisited on account of the world’s complexity and the methods through which our understanding of the world has been expanded. Einstein’s general relativity theory being developed through inductive and deductive processes probably represents one of the greatest examples. Only years after having established his main predictions about the theory of general relativity, these could be confirmed by the observation of how gravity bent light during the solar eclipse on May 29th, 1919, from the west coast in Africa (A. Robinson 2019).

By adopting a complex systems approach to the problem of health outcomes inequalities for chronic diseases and stressing the value of hermeneutics to understand how people act within the system of long-treatment adherence and life beyond illness, this study subscribes to the idea that facts and values are unavoidably entangled (Putnam 2002). Within empirical bioethics, integrative approaches acknowledge a hermeneutical component that implies looking at moral judgements as socially constructed in the sense that these largely depend on individuals' understandings or interpretations and their experience within social practice and what is ethically required in specific contexts (Molewijk et al. 2004). Thus, this study draws on a reading of phronetic social science as a way to conduct integrative bioethics research.

To better understand phronesis in practice, Frank's (2012) analysis of Tolstoy's character Nikolay Rostov offers a fine parallel for the interest and starting point of this research, helping to clarify why it makes sense to frame it in terms of applied phronesis. Once Nikolay settles down and dedicates himself to work, he openly rejects new theories and ideas about estate management. Instead, his attention is captured by peasants' practical, context-bound knowledge and thus, he develops his own practice focusing on what he can learn from peasants' daily labour experience. Somehow like Nikolay, what motivates this research is learning about the ethical problems raised by chronic disease by paying attention to first-person accounts of illness and the practical, context-bound knowledge about disease and long-term treatment that emerges from the experience of living with a chronic disease.

Following the fact/value dichotomy discussion, there is a divide between empirical bioethicists who argue that the empirical and the normative require active integration in research processes and those who regard these as inevitably entangled, such as integrative approaches including phronesis (Carter 2018). Within the first group, Garrard and Wilkinson (2005) suggest that normative principles are needed to reach normative conclusions that can account for empirical findings. More recent developments within this group of empirical bioethicists draw on John Rawls' reflective equilibrium method for moral reasoning and suggest methods such as 'Reflexive Balancing' (Ives 2014) and 'Normative Empirical Reflective Equilibrium' (Van Thiel and Van Delden 2016) to guide the process of building partly on empirical data to reach a normative conclusion.

As already argued, this study falls in the second group and looks at the issue of integration in empirical bioethics from the hermeneutical lens of the "complex and always-morally-charged nature of every day sense-making" (Carter 2018, 2). This means that this work will aim to transparently and clearly generate and draw on empirical data about the experience of chronic disease and long-term treatment in the UK to inform the theoretical discussion on how to improve equity for health outcomes for chronic diseases. Thus, this meaning-making process will focus on understanding the complex system of interactions at play in the continuously changing dynamic equilibrium of how people live with chronic disease and engage with healthcare services. This will, in turn, inform the broader complex systems of interactions feeding the persistent health outcomes inequalities for chronic disease in the UK. At a more abstract level, Flyvbjerg's (2001, p.60-61) four value-rational questions for phronetic social sciences: (1) "Where are we going?"; (2) "Is this desirable?"; (3) "What should be done?"; and (4) "Who gains and who loses; by which mechanisms of power?" will serve as a tool for ethical reasoning throughout the research and writing-up process. These questions are a method and not an aim in itself, so the study will not focus on providing full answers for these specific questions.

Although phronetic social science welcomes quantitative and qualitative methods for the generation of data, adopting a qualitative ethnographic approach and conducting a case study has been argued to be particularly well suited to produce the kind of detailed and contextual knowledge that this kind of research aims at (Flyvbjerg 2001; Schram 2012). 'Ethnography' has been defined as "the study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities" (Reeves, Kuper, & Hodges, 2008, p. 1), and in the case of conducting health research, this approach has been argued to

> open the door to the world of meanings attributed to health-related events, and moral decisions, and understanding the broader socioeconomic and political factors shaping cultures and how cultural members frame, interpret and respond to such phenomena (Draper and Ives 2007; Molewijk et al. 2004).

Therefore, it is an adequate and justifiable approach to generate the empirical data relevant to this particular study.

‘Case study’ is broadly defined as a detailed and intense analysis of a single case (Bryman 2004). Social researchers often use this research strategy to build theory from cases, but it fundamentally helps the aim of understanding the dynamics present within single settings. It typically combines different methods for generating data such as archives, interviews, questionnaires, and observations, which can provide quantitative data, qualitative data or both (Eisenhardt, 1989). Thus, case studies examine many features of a few cases, individuals, groups, organizations, movements, events, or geographic units. By looking at details of each case, as well as the contextual situation, this research strategy allows to link micro level, or the actions of individuals, to macro level or large-scale structures and processes (Neuman 2014).

As already argued, this research embraces an interpretative approach to case studies that implies looking into the subjective meaning that individuals’ actions have for them and focusing on the power of case studies in terms of providing detailed information and a unique opportunity of closeness to real-life in relation to the object of study (Flyvbjerg 2001; Thacher 2006). More specifically, since the aim of this study is using this empirical data to inform the normative discussion on how to improve equity in health outcomes for chronic diseases, Thacher’s (2006) account of the normative case study seems to be the most adequate research method to achieve this goal and conduct a case study within the framework of phronetic social science. This approach to case studies contributes to the understanding of important public values, combining empirical observation with normative assessment, and has been argued to be particularly promising for policy oriented research (Thacher, 2006), which fits, in a broad sense, the aims of this study.

Much in line with Flyvbjerg's (2001) view, by depicting and analysing different examples Thacher (2006) shows how, by looking into real-life cases, it is possible to draw normative conclusions. Cases confront social research with the world, which is considered multiple in terms of being continually surprising, and by encompassing facts and values this method has the strength to promote and enrich discussion about social phenomena and normative thinking (Thacher, 2006).

5. Conclusion:

This chapter presented the fundamental methodological assumptions of this study under the broad umbrella of interpretative social sciences, highlighting an inherent hermeneutical component in social research and giving particular importance to language and meaning-making processes to approach health-related actions. Keeping in mind the importance of the researcher's overall ontological and epistemological assumptions, this chapter discussed the problem of absolute ontological and epistemological distinctions in social health research, stressing the value of flexible methodologies.

This argument led to highlight the importance of context, judgement and practical knowledge, and thus embrace phronetic social sciences as a well-suited methodological background to understand human action and values in relation to particular cases. Furthermore, as an integrative bioethics method, this approach was argued to support the descriptive and normative purpose of this research, suggesting a qualitative ethnographic approach and a normative case study to produce detailed and contextual knowledge.

The next chapter introduces the study design of this research discussing both the theory and practice of the different steps involved in the completion of this study within the context of the NHS England.

Chapter 2

Empirical Study Design And The Fieldwork Journey

1. Introduction

Following the theoretical discussion in the previous chapter, this chapter presents a detailed road map of the concrete practical steps leading to the production of relevant qualitative data through a normative case study. It brings together the theory of how to conduct such research and a detailed description of how these went in practice throughout the fieldwork. The second section briefly presents the empirical study's research questions and aims. Section three introduces semi-structured in-depth interviews as the main research tool for the generation of data, and participant observation sessions as the secondary or complementary tool. This section also presents the theoretical background of the interview guide and the non-academic feedback that helped refine this tool. The fourth section introduces purposive sampling and the relevant arguments supporting the inclusion and exclusion criteria for the specific aims of the empirical study.

After theoretically defining the 'how' and the 'who' of the study design, the fifth part of this chapter introduces the theory and discusses the practice of the recruitment process and the final sample of this study. This leads to a detailed description of participants and how the research activities went in practice.

2. Research questions and aims

Following the discussion in the introduction to this thesis and the last chapter, the main research question guiding the empirical study is: how can the experience of living with chronic disease and long-term treatment be described across different diagnostic categories of chronic disease in contemporary England?

The specific questions helping address this general question are:

1. What does it mean in terms of experience to be diagnosed with a chronic disease in contemporary England?
2. What are the main elements of the experience of long-term treatment and self-management across different diagnostic categories of chronic disease in contemporary England?
3. How do people living with a chronic disease negotiate long-term treatment demands in the broader context of multiple life demands in contemporary England?
4. What is the role of the healthcare professional-patient relationship in the negotiation of long-term treatment demands in the broader context of multiple life demands in contemporary England?

In line with this, the main aim of this empirical study is to describe the experience of people living with different diagnostic categories of chronic disease and long-term treatment in contemporary England. The specific aims contributing to this general aim are:

1. To explore chronic illness narratives of people living with different diagnostic categories of chronic disease and describe the biographical disruption associated with chronic disease in contemporary England.
2. To identify the main elements of the experience of long-term treatment and self-management across different diagnostic categories of chronic disease in contemporary England?
3. To describe how people living with chronic disease negotiate long-term treatment demands in the broader context of multiple life demands in contemporary England?
4. To explore the healthcare professional-patient relationships in the negotiation of long-term treatment demands in the broader context of multiple life demands in contemporary England?

3. Research tools

From a humanities perspective, elements of the experience of illness and suffering have been argued to escape the possibilities of traditional structures of language. Virginia Woolf (1926) and Elaine Scarry (1985) compellingly write about the need to expand the use of language and adjust the hierarchy of the passions in order to represent such experiences, resorting to creative forms of language—such as poetry or plays, and in doing so, also to the world of images and the arts more generally. Spence's (1991) deeply moving photography work representing her experience of terminal Leukaemia provides a good example of the complex and encompassing virtues of communicating through images. Although this makes an interesting point and qualifies the centrality of narratives to some degree, these are still argued to offer a creative path for expression and have a privileged status to approach the complexities and contradictions of real-life, and are thus considered fundamental to conduct rich case studies (Flyvbjerg 2001).

Ricoeur (1991) argues that it is paradoxical to think in terms of stories being told and life being lived. By making direct reference to Gadamer's hermeneutics, the author builds the argument that the process of composition of a text or story, as a fictional plot, is a process of configuration that cannot be completed in the text but in the reader, which leads him to suggest that through the narrative, this configuration process is mutual, allowing for the reconfiguration of a life (Ricoeur 1991). So in this sense "the meaning of the significance of a story wells up from the intersection of the world of text and the world of reader" (Ricoeur, 1991, p. 430).

From this view, fiction cannot be completed without life, so stories would be both told and lived, in the imaginary sense. And since life cannot be understood other than through stories, life is also seen as both lived and told (Ricoeur 1991). This suggests an understanding of subjectivity in terms of narrative identity, which implies thinking that identity is what emerges from the narrative composition as a dynamic process of configuration and reconfiguration of life and storytelling (Ricoeur 1991).

In this manner, the active lived process of the narrative is inseparable from the self in first-person accounts. This means that narratives accounts are the experience and the meaning of that experience at the same time. People's selves are created from the telling of stories about themselves to themselves and others (Frank 1995; Kelly and Dickinson 1997). This view about the privileged place and paramount role of narratives within people's identities and ways of life is a popular and well-supported perspective. However, it is important to note that it is a contested approach mainly counter argued by the idea that subjectivity is not necessarily narratively constructed as people might also have the experience of relating to themselves, others and their biographies in an episodic and diachronic way, without this undermining the self's status (Strawson 2004).

Nonetheless, and even if not universal, the narrative perspective offers valuable insights to reflect on the body and thus also about illness. This mutual relationship between life and storytelling also describes the process of configuration and reconfiguration of body and self by the means of narrative. "Stories do not simply describe the self, they are the self, the self's medium of being" (Frank 1995, 53). People organise, make sense of and give coherence to their experience in personal narratives. In illness, the personal narrative does not merely describe the sick body, or reflect the illness experience; it contributes to the experience of symptoms and suffering, while at the same time bodies shape and direct these illness stories. In illness narratives it is possible to hear the unity body-self or embodied being; both the self talking about the ill body, and the ill body creating the person (Kleinman 1988; Frank 1995).

Furthermore, Frank (1995) argues that serious illness interrupts the continuity of the experience of the body, and thus also of the self, constituting what Bury (1982) defines as biographical disruptions. In illness "people who have always been bodies have distinctive problems continuing to be bodies, particularly the same sorts of bodies they have been", thus losing a unified sense of temporality that is central to any storyteller, to any body, to any self (Frank, 1997, p. 28). This is especially relevant for the case of chronic illnesses since these are not a self-contained—temporal—disruption, but an irreversible condition for which narratives constitute a link between the body, the self and society, connecting psychology, meanings and relationships, and showing how the social world is linked recursively to the individual's inner experience (Bury, 2001; Kleinman, 1988).

Following from this, the study of illness narratives has received considerable attention in social and human sciences (Flyvbjerg, 2001). As mentioned before, opening the door for narratives offers the researcher the opportunity to enter the subjective world of meanings in illness, but just as importantly, it increases the participants' freedom to express valuable things that the researcher may not and probably has not thought of (Becker 1998).

3.1. Semi-structured in-depth interviews

Therefore, this study's main research tool for generating data was one-to-one semi-structured in-depth interviews allowing for illness narratives to emerge. These interviews explored the experience of people living with chronic disease and aimed to shed light on questions regarding the subjective disruption brought by chronic illness; illness-specific and common challenges of self-care; central disadvantages and functionings hampering and facilitating disease self-management and adjustment to life with illness; and the patient-healthcare professional relationship.

Interviewing is considered an adaptable and reliable research tool that is particularly adequate to produce the kind of data needed to do research on bioethics issues. Semi-structured interviews rely on a structured guide and set of questions—with no right and wrong answers—while at the same time allowing the interviewer to generate spontaneous follow-up questions if looking for a more detailed answer or clarification. This combination of closed-ended and open-ended questions allow for comparison across interviewees while facilitating the richness of more in-depth individual stories. Furthermore, semi-structured interviews have proven to be particularly beneficial to study sensitive topics, thus offering valuable grounds to take on this approach to gather data about the lived experience of chronic disease and long-term treatment (Sankar & Jones, 2015).

As described by Sankar and Jones (2015), I started by drafting an interview guide that focused on 'what could be done' while taking into account what previous research on the topic had shown, in other words, 'what has been done'. This first exercise of bringing possible interview questions together helped me clarify the aims, cover the relevant topics and find a balance for an adequate level of specificity in the questions. It has been argued that to give place to illness narratives it is fundamental that the effects of social phenomena are interpreted in terms of process, so I put significant effort in developing interview questions that were focused on highlighting such processes. In practical terms, this meant drafting questions that focused on learning about the 'how' instead of the 'why' of each experience*.* This is based on the idea that 'how' is a dynamic question—process, whereas asking 'why' is associated with more structural aspects of social phenomena (Becker, 1998; Flyvbjerg, 2001).

Taking into account relevant theoretical backgrounds to develop the interview guide has been argued to increase the possibilities of producing relevant empirical data according to the aim of the empirical study, in this case, describing the experience of people living with chronic disease and long-term treatment (Sankar and Jones 2015). Building on the ideas about storytelling and the concept of biographical disruption mentioned before, I developed an interview guide that aimed at learning about participants' illness and healthcare experiences, as well as getting to know them beyond their illness. This included learning about their activities and relationships, their past and their ideas about the future. I also drew on the vast research on illness perceptions, which identifies relevant elements for coping in terms of self-management, to structure and narrow down the interview guide. Some of these elements include symptoms, cause, consequences, and curability or controllability of disease, beliefs, attitudes, values and prejudice regarding treatment and the disease. In addition to this, and although the Illness Perception Questionnaire (IPQ)[1] is not a tool aiming to explore illness narratives, it adds illness identity and time-line to the elements mentioned before, so I also included these dimensions in the interview guide (Benyamini 2012; Manriquez and Stuardo 2015; Weinman et al. 1996).[2]

Before I started conducting the interviews with participants, I asked for feedback on the interview guide from five people living with chronic disease, who were members of the University College London Hospitals Biomedical Research Centre Patient and Public Involvement network. I tested the interview guide by conducting a mock interview with a fellow PhD student living with a chronic disease, and I ran a pilot interview at the beginning of the study with a potential participant.

Patient and Public Involvement (PPI) in research has become a central element, almost a requirement, in most methodological settings for health policy research in the UK. Its main benefits can be summarised in its positive impact on governance and legitimacy, research quality, efficiency, and implementation, the so-called ‘feel good’ effect on participants, and equity issues (Pizzo et al. 2014), which build into this study’s interest and epistemological standpoint.

Evidence on PPI’s effectiveness has been strongly criticised, being considered weak and anecdotal mainly because of the lack of quantitative

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[1] Based on Levental et al. (1980 in Benyamini 2012; Weinman et al. 1996) model of self-regulation.

[2] The interview guide is attached in appendix A, alongside other study documents.

data. Nonetheless, and as stated before, it has been argued that hard quantitative information that explicitly clears data from contextual factors and variations in involvement, struggles in terms of external validity. This means that such evidence is ultimately weak in terms of predicting the impact of PPI in other contexts (Staley 2015). Thus, following Staley's (2015) approach to strengthen the evidence on PPI's effectiveness, it is particularly important to describe, in detail, the effects of the PPI on this study. This approach focuses on the amount and quality of details provided in researchers' accounts of PPI processes, thus helping others understand 'how it works' (Staley 2015).

The written feedback from five representatives from the PPI network and oral/experiential feedback from the mock and pilot interviews contributed towards research quality and efficiency, as I reflected further and adjusted the interview guide accordingly. The most notable adjustments included time/length of the interview and some cultural aspects in the questions. Initially, the interview guide was too extensive, trying to cover too much ground and anticipating too many follow-up questions. This probably speaks to my own anxieties as a researcher in training with no previous experience interviewing in English, but it meant that the interview was very long, and significant time was spent covering secondary or unrelated topics. The feedback motivated me to identify central and secondary questions, reduce the number of questions and narrow down the interview. Furthermore, as I am from Chile and was testing the interview guide with a fellow international PhD student, the PPI network was particularly helpful in pointing out that some questions and ways of asking things seemed or could be experienced as too invasive or intimate, so this was another filter to identify central and secondary questions. This was also good feedback to rephrase some questions to be more open and respectful—in context, safeguarding the participants' integrity and trying to assure that they felt as comfortable and well supported as possible throughout the interviews.

The Research Ethics Committee (REC) approval allowed for a maximum length of 1 hour and 30 minutes for the interviews, and although the length of the interviews varied slightly, I managed to cover the interview guide and explore participants' experiences in-depth within this time. The shortest interview was around 1 hour long, but most interviews were in between 1 hour and 20 minutes and 1 hour and 30 minutes.

In addition to phronetic social sciences, and empirical bioethics more broadly, being methodological perspectives that give power to the voice of actual moral individuals, it has been argued that working in collaboration with a PPI network contributes to this aim. PPI increases the legitimacy of research and lessens the power dynamics and epistemological injustices that may take place while conducting qualitative social research (Fricker 2007).

3.2. Participant observation of healthcare appointments

Since many deep-seated values and practices may be difficult to grasp through dialogical interaction, this research complemented the type of data generated by interviews with data arising from the 'participant observation' of the patient-healthcare professional relationship. This practice is an ethnographic technique that implies engaging with individuals in the field situation and facilitates gaining knowledge through first-hand observation of the social interactions of interest to the study. This is predominantly inductive, rather than deductive work, thus promoting the generation of emerging data through the examination of several dimensions of a social situation simultaneously—physical, behavioural, verbal, nonverbal, and interactional in the context of broader social and physical environment (Gordon and Levin 2015).

Implementing this technique of data generation was particularly relevant to contextualise and have a more in-depth understanding of participants' experiences in general, but especially regarding the patient-healthcare professional relationship, and the challenges and opportunities arising from this relationship for the specific case of chronic disease and long-term treatment.

In the interview setting, researchers either need to make assumptions about what puzzling elements communicated by the interviewee mean, or they have to interrupt the interviewee to ask clarification questions. These interruptions may stop the flow of the interviews, potentially risking rapport and making the interviewee feel that communication with the researcher is failing (Becker and Geer 1957). 'Participant observation' can help solve this dilemma. Through this research tool, "the meaning of words can be learned with precision through study of their use in context" (Becker & Geer, 1957, p. 29), allowing researchers into a bigger picture that helps in the process of understanding diverse materials from a participant. Thus, 'participant observation' can allow researchers to interpret puzzling elements, without interrupting the flow of interviews. Furthermore, this research tool also opens the door for the researcher to identify relevant expressions or interactions that the participant is not sufficiently aware of to share in the interview, or may decide not to share in the interview because of a particular understanding of what is expected from him or her in that context.

To achieve this, 'participant observation' traditionally requires that the observer gets involved in the daily life of the participants to observe, listen and question them in several opportunities—enough to get an in-depth understating (Becker and Geer 1957). However, committing to this in full was not feasible for this particular research since the relevant interaction under study—chronic care delivery and the patient-healthcare professional relationship—took place with a frequency of every 3 or 6 months, which did not allow for more than one observation session within the 6 months empirical data generation timeframe of this study. Still, having the opportunity to observe the participants in one healthcare appointment of their choice provided valuable information and contributed to the aim of better understanding the participants' experience of chronic disease and long-term treatment.

An unexpected and positive outcome of implementing this technique of data generation was joining the participants during their waiting times before starting their appointments, which lasted from 3 minutes to roughly 25 minutes. Some participant observation sessions also included joining the participants to collect their medication from the hospital pharmacy or go for lab tests after their appointment, thus spending from around 20 minutes to 2 extra hours together in the hospital environment. During this extra time spent together, I could see how they moved around their healthcare environment and I was able to get to know them in a more relaxed environment, without the pressure of either being interviewed—and recorded—or in front of healthcare professionals. Although both the participants and I considered all this time spent together as part of the research activities, and these were recorded in my fieldwork notebook, participants also got to know me outside of the 'interviewer role' and the 'observer role' during their appointments. In some cases, the participant observation sessions took place either a few weeks, days or right before the interview, and in other cases, these took place a few weeks, days or right after the interview. On the one hand, when the participant observation sessions happened before, they served as a positive introduction and rapport building experience for the interviews, as well as further context to frame the information shared in the interviews. When these happened after, they mostly served as further context for the interviews, but I could also identify a positive effect in having a less intimate, and thus less vulnerable, interaction following the interview in which participants could be more in control and contextualise some of the experiences shared in the interview. Although this highlights a certain level of variation and nuance associated with the different ways in which the research activities took place, I did not identify any systematic differences following from this in the data generated. All interviews and participant observation sessions went well and no issues or interpersonal impasses came up.

4. Sampling

How many interviews are enough? Theoretical saturation usually determines the number of interviews—and participants, but this is based on the expectation of building testable, generalizable theory from cases. Since this research does not hold such aim and focuses instead on the bridge between cases and normative discussion, its emphasis was on the richness of the data generated regarding the experience of chronic disease across different diagnostic categories, and not on the number of cases (Sankar & Jones, 2015). Therefore, since participants were interviewed one time, the number of participants recruited for the study, namely the sample, determined the number of interviews.

In general terms, cases may be selected based on whether they are representative of phenomena, setting, or demographics, and whether they offer an opportunity to learn or to access the research site (Gordon and Levin 2015). The rationale behind the case selection in ethnographic case studies depends on the aim of the research and what the information wants to be used for, so it is defined as theoretical sampling (Eisenhardt 1989).

According to the aim and methodological framework of this research, the case selection aimed at generating relevant empirical data about the experience of chronic disease and chronic care to inform the discussion regarding equity and chronic disease. Furthermore, because the aim of this research does not require a representative sample, the population from which it was drawn from was not relevant in a probability sense,[3] but highly significant as the concrete social context framing the experiences of chronic illness explored. Thus, the technique of purposive sampling offered a solid methodological tool to achieve an appropriate selection of participants based on the purpose of the study. This sampling method is also known as judgemental sampling because it is based on the researcher's expertise and individual judgement, offering a systematic way to select relevant cases for this particular study, not aiming to be exhaustive. However, purposive samplings could aim to represent a broader group of cases as closely as possible and set up comparisons among different types of cases if including all possible cases that fit a particular criteria (Neuman, 2014; Teddlie & Fu, 2007).

Generating a nonprobability sample that fitted the purpose of the study did not need or justify a large number of cases, nor to determine the exact sample size in advance of the fieldwork (Neuman 2014). In purely ethnographic research projects the concept of theoretical saturation—this is the point at which interviews stop providing new information, alongside pragmatic considerations such as time, resources and capacity to analyse data is often considered a good reference point to determine when to stop adding cases and iterating between theory and data (Eisenhardt 1989; Sankar and Jones 2015). Nonetheless, it is important to take into account that as

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[3] Probability samples are based on the random selection of participants within a population where each unit of the population has a known chance of being selected. 'Representative samples' are usually the outcomes of this sampling method (Bryman 2004).

many things in qualitative research, the final answer to how many participants or cases to include is that it mainly depends on the research purpose. Thus, sample numbers can vary significantly, starting from a single case and going beyond a hundred, but general recommendations say to include something between 12 and 60 cases or participants, with 30 being the mean (Adler & Adler, in Baker & Edwards, 2012).

Following this rationale, this study aimed at recruiting a minimum of 12 participants and a maximum of 50 participants to generate qualitative empirical data. Although this sample range may be catalogued as a small to medium sample, it must be taken into account that having more than one technique for generating data (interviews and participants observations) is often considered as a significant variable to determine the number of participants since it enlarges and deepens the data emerging from the study, strengthening the outcomes of the study without the methodological requirement of increasing the sample (Adler & Adler in Baker & Edwards, 2012). Following from this, a margin is preferable over a pre-established fixed number, since it is arguable that the amount of data needed for this study will change as the researcher learns more about the topic and revises her ideas. Furthermore, it's been argued that there is no right place to stop, so this decision will always be somewhat arbitrary and its strength will depend on the coherence of the study, particularly stressing the importance of strictly concluding what the data generated can support (Becker in Baker & Edwards, 2012).

4.1. Inclusion and exclusion criteria

This study builds on the idea that although experiences of illness are varied and their particularities can be of great importance, there might be a common core of experience shared by chronic diseases that is fundamental for reflection on ethically driven care for chronic diseases. Although the next chapter develops a detailed discussion on the conceptual definition of 'chronic disease'—also integrating empirical findings, for recruitment purposes this study focused on people living with long-term diseases that were not followed by complete recovery and required long-term treatment. These are diseases that can be categorised as incurable despite there being treatments available to control them or slow down their progression. Long-term treatments for such diseases could include prescribed regular intake of medicines (tablets, inhalers, injections, etc.); prescribed regular rehabilitation/physiotherapy appointments; and or prescribed specific lifestyle changes (exercise and/or diet, cessation of cigarette smoking and/or alcohol consumption) alongside prescribed regular health check-ups (whether these include tests or an appointment with a healthcare professional).

Furthermore, since this study is particularly interested in the subjective disruption brought by chronic diseases in the sense of loss of unity between the self and body and its impact on identity, it was key that all participants were diagnosed after reaching the age of adulthood. This implied that participants had an experience of continuity between an overall healthy body and the self during the identity crisis and the process of identity formation

(Erikson 1980). This is based on the idea that throughout the stage of Adolescence, which is the concluding stage of childhood, individuals reach a sense of inner continuity and social sameness, integrating the individuals' conception of themselves and how their social contexts recognise them, which contributes to the process of identity formation (Erikson 1980).[4]

Therefore, this study's sample included individuals going through the stages of Young Adult (approximately between 18 and 40 years of age) and Adulthood (approximately between 40 and 65 years of age), excluding Adolescents, Young Children (under 18 years of age) and individuals going through the stage of Mature Age (over 65 years old) to reduce the methodological complexities associated with increased chances of comorbidities in old age, such as dementia or reduced mobility, among others (Erikson 1980).

Furthermore, focusing on the disruption between the body and the self, this work highlights an experience of chronic illness that comprehends the phenomenological changes that can be directly or indirectly attributed to changes in the body or the disease's biological process, thus excluding the possibility to recruit people diagnosed with chronic mental disorders which often lack a disease biological process (Carel 2016; Fuller 2017; Spitzer and

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[4] Although Erikson's (1980) psychoanalytic theory of the life cycle is somewhat contested and some interesting critiques have been developed, specially regarding gender for example, it is still considered a key reference to think about the process of identity formation that is of central importance in this project (Horst 1995).

Endicott 1978; Wakefield 1992). Still, this is a theoretically challenging distinction and so it is addressed in more detail in Chapter 4.

Lastly, to produce relevant reflections about the communicable and non-communicable epidemiological distinction for the case of chronic diseases, it was very important to include individuals diagnosed with communicable chronic diseases and non-communicable diseases. To the degree that was possible, the recruitment process aimed at a rich heterogeneous sample in terms of socioeconomic and educational levels and tried to have a balanced number of male/female participants. All participants had to speak English.

In sum, the inclusion criteria for potential participants were English speaking adults between the ages of 18 and 65 years, diagnosed with at least one chronic disease after the age of 18 years and prescribed at least one long-term treatment. All these criteria needed to be met for people to be invited to take part in the study. In addition to these, further desirable criteria included the sample being heterogeneous in terms of socioeconomic and educational level of participants, and relatively balanced in terms of the number of male and female participants.

The exclusion criteria for potential participants included being younger than 18 years old or older than 65 years old; not having a chronic disease diagnosis; having been diagnosed with a chronic disease before the age of 18 years; not having been prescribed a long-term treatment; having a cognitive impairment, and not being able to speak English. Each of these separately was enough to render someone not eligible for the study.

5. Recruitment and the final sample

As mentioned before, I was aiming to recruit between 12 and 50 participants living with a broad range of chronic diseases. This sample split between four specialist care units (respiratory medicine, gastrointestinal disease, endocrine disease and infectious disease) across University College London Hospital (UCLH) and the Royal Free London Hospital (RFH),[5] so I was aiming at recruiting between 3 and 12 participants from each unit. This was considered a strength of the study design for two main reasons. Firstly, having a small number of participants to recruit per service increased the feasibility to reach the total sample expected and allowed me to balance the numbers in different ways according to the practical possibilities of each unit. Secondly, but just as important, aiming to recruit a small number of participants per service implied that I did not significantly overburden the clinical and administrative staff—already dealing with significant workloads—when I asked them to help me screen the clinics for potential participants, and then make the first contact with potential participants—to get their consent to be approached by me.

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[5] More details about the process of securing the feasibility of the study and recruiting clinical units are attached in appendix B.

After the REC gave a favourable opinion for the study and the Health Research Authority (HRA) approved it,[6] in February 2019 I started coordinating with all four units simultaneously to agree on days and times in which I would join them in the hospital to start screening the clinics looking for potential participants. Each unit had a different way of handling this part of the study, so I had to be flexible and adjust to each unit's expectations and procedures. When I first approached potential participants, after introducing myself, I would hand them the participant information sheet and give them some time to read through it and get familiarised with the study. When developing these documents, I also received feedback from the PPI network and their comments helped to make the documents relevant, clear and concise for lay readers. If participants showed interest in taking part in the study, we would go through the information sheet together, and I would answer any questions they had about the study and what their involvement would imply. If they agreed to take part, I would hand them the consent form and we would follow the same procedure. If people needed time to think about it, they could take the documents home with them and follow-up with me after one week. Only after the informed consent form was signed we could proceed to schedule the research activities.

Some clinical units allowed me to use their consultation rooms to conduct the interviews, while others did not have this option and I would invite participants to do the interview at University College London (UCL). Moving

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[6] REC's favourable opinion letter and HRA's approval letter are attached at the end of appendix B.

between hospitals became my full-time job during the first month of the fieldwork, and as soon as potential participants started joining the study, the research activities began to overlap with the recruiting. Because one of the central interests of this research is exploring the common core of the experience of chronic diseases, beyond diagnostic groups, I tried to keep a balanced sample and recruited participants from all clinical units simultaneously. When I had conducted a couple of interviews with participants from each clinical unit, I had a first supervisory meeting to reflect on preliminary findings and the sample size. Drawing from the richness found in the interviews and marked commonalities, we decided that aiming at 25-30 participants would raise enough data for the aims of this research. I continued recruiting while conducting the research activities and as I started getting closer to the final sample size, and so the burden of recruiting started to decrease, I began transcribing the audio recordings from the interviews in order of occurrence. I took notes during the participant observation session, and later on the same day of each session, I sat down to organise my notes and complement them with any extra information I could remember. By July 2019 I had a total of 27 participants and research activities scheduled until August 2019, and we decided to close the recruitment.

I had to approach something between 3 to 5 potential participants to successfully recruit 1 participant, and although participants were explicitly told they could abandon the study without explaining at any point, all recruited participants followed through with the two research activities planned. Thus, I conducted a total of 27 interviews and 27 participant observation sessions, adding 54 sources of data.

5.1. Sample description

The final sample included 6 participants from the endocrine diseases unit, 6 from the gastrointestinal diseases unit, 8 from the infectious diseases unit, and 7 from respiratory medicine. These 27 participants represented 10 different chronic diseases, without considering other comorbidities, but 14 out of the 27 participants declared living with at least one other chronic disease. 3 participants had been diagnosed with type 1 diabetes, 3 with a chronic hormonal disorder (one being acromegaly) associated with pituitary tumours, 4 with Crohn's disease, 2 with ulcerative colitis, 8 with HIV, 1 with asthma, 1 with Lupus, and 5 with pulmonary fibrosis (2 of which were secondary to chronic rheumatic disease).

The average time participants had been living with chronic disease was 15.4 years (ranging from 3 to 44 years). 19 Participants were recruited from UCLH and 8 participants from the RFH. 19 interviews were conducted at UCL, 6 at the RFH and 3 at UCLH. All participant observation sessions took place at the hospital from which participants had been recruited and involved a total of 15 healthcare professionals (mix of consultants, registrars, and specialist nurses); 4 from the endocrinology team, 4 from the gastroenterology team, 6 from the infectious disease team, and 5 from the respiratory medicine team. Although the clinical leads for each unit had agreed to their units taking part in the study and had informed their clinical teams about it, REC and HRA approvals still required me to go through the process of handing in and discussing, if necessary, an information sheet for healthcare professionals and obtaining their written consent to observe the healthcare appointments.

14 participants were female and 13 male, with an age average of 46.6 years (ranging from 21 to 65 years).[7] The sample was mixed in terms of country of origin including 14 participants from the UK and 13 participants from 11 different countries spread across Europe, Oceania, Asia, Africa, and North America (the Caribbean). More specifically, 12 participants were from England, 1 from Scotland, 1 from Northern Ireland, 3 from Ireland, 1 from Australia, 1 from Portugal, 1 from Angola, 1 from Afghanistan, 1 from Sri Lanka, 1 from Saint Lucia, 1 from Morocco, 1 from Uganda, 1 from the Netherlands, and 1 from Egypt. In terms of broad qualification classifications, 19 participants had professional qualifications and 8 had non-professional qualifications. 21 participants had either full-time or part-time jobs, and 6 were unemployed (2), retired (2), or full-time mothers (2). 22 participants lived in London, and the remaining 5 participants in Greater London, Essex St. Albans, Suffolk, and Sussex. 10 participants were single, 10 had a partner and 7 were married. 10 participants lived alone and 17 had shared

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[7] Age average and ranges per disease group vary slightly. For chronic endocrine conditions these are 46.6 years and 30-65 years, for chronic gastrointestinal conditions 31.6 years and 21-47 years, for chronic infectious condition 52.6 years and 41-65 years, and for chronic respiratory conditions 52.7 years and 41-63 years.

households with friends/flatmates or family. 12 participants were parents and 9 still had dependant children.

6. Conclusion

This chapter presented a detailed description of the concrete practical steps leading to the production of relevant qualitative data for this study. It brought together the theory supporting each step and the descriptions of how these went in practice. Very briefly, the chapter started by briefly presenting the research questions and aims for the empirical study and theoretically defining the ‘how’ and the ‘who’ by introducing the research tools and the sampling method. This set the scene to present the actual ‘how’ and ‘who’ of this study, discussing the recruitment process and the final sample.

By integrating theory and practice this chapter highlighted the value of engaging with and learning from the real-world aspects of conducting social research in healthcare contexts while it also provided the necessary context to situate the empirical findings presented in the next chapter. Although ‘data analysis’ is part of the study design, for practical reasons regarding how to organise the materials in this work and continue with the ‘theory and practice’ approach taken in Part I of this thesis, the next chapter introduces the theory and practice of narrative thematic analysis and coding, a summary of the central empirical findings and their early dissemination.

Chapter 3

Data Analysis And Empirical Findings

1. Introduction

This chapter starts by introducing the theoretical approach to narrative thematic analysis of qualitative data. This brings together a narrative approach to research and thematic analysis, which results in a meaning-making process that sees the findings as a co-production between the researcher and participants, in a specific context. After introducing the details of the processes involved in going from interview transcripts and field notes, to identifying linguistic structures in participants' narratives and the emotional, relational and analytical elements reflected in the emergent themes, the chapter presents the main empirical findings resulting from such processes. The findings include an introduction to the value of understanding narratives as a whole, detailed analysis and description of how stories were told and reflections about what these may mean in light of the characteristics of the final sample. This last point leads to reflect on the research tools and their potential limitations to explore different experiences of chronic disease. The section on empirical findings ends by briefly presenting the main ideas covered in the five emergent themes. Finally, this chapter reflects on the writing-up process of two empirical findings documents for early dissemination to the HRA, the collaborating clinical teams and participants, and specifies the role of these findings in the writing-up process of this thesis.

2. Data analysis

From a broad perspective, this research adopts the argument that a narrative approach to research can be framed as a method in its self since data generation, interpretation, and writing are regarded as meaning-making processes (Frank 2002; Gudmundsdottir 1996). Conducting a narrative analysis of the qualitative data emerging from the study has been argued to be particularly appropriate for phronetic social science, and for this study, given its focus on illness narratives and understanding of stories as "attempts of a self to find identity in terms outside itself" (Frank, 2002, p. 115; Landman, 2012).

Taking on this perspective introduced a significant 'dialogical' element to phronetic social science, which might be regarded as a rather 'consultative' approach in terms of the role of participants and the relationship between the researcher and the participants (Davies, Ives, and Dunn 2015). Drawing on Taylor's (1971) argument about the inherent hermeneutical component in social science, Frank (2002, p.115) argues for the dialogical or interpersonal character of authenticity in storytelling and poses that

> the researcher who solicits people's stories does not simply collect data but assents to enter into a relationship with the respondent and become part of that person's ongoing struggle ("la lotta continua") toward a moral life. As I suggested earlier, that struggle is about narratability and legibility.

This was a central aspect of my experience as a researcher from the very beginning of the fieldwork. As I was interviewing and observing, taking notes and systematising them, transcribing the interviews and reflecting on these, I was very aware of how much I was a part of participants' stories (as these were told to me), and how much my work consisted in bringing together—context and time-bound—stories and experiences in a particular way. This clarity about research in itself being a meaning-making process and narrative construction is central to this work, and so the doctoral thesis resulting form this research process is both inevitably and desirably something other than the fluid, multidimensional, and complex individual stories shared by participants.

More specifically, the method of narrative analysis—as a meaning-making process—challenges the assumptions represented in the stories told by helping to unpack these from each particular rhetoric (Frank 2002). This 'unpacking' can be done through different approaches and can include different levels of analysis. Some of the main approaches include thematic analysis, structural analysis, dialogic and performance analysis and visual analysis. And the different levels of analysis might be organised from the simplest, to the most complex as: linear (linguistic structure), relational (relationships), emotional (feeling, beliefs, values) and analytical (attributing meaning by drawing connections across narratives) (Landman 2012). For this study, I conducted a thematic narrative analysis looking at all four levels just described.

Thematic analysis is a traditional technique consisting of a qualitative coding process that involves mapping interview transcripts so that recurrent themes in the data can be identified, retrieved and analysed. To do this, the researcher inductively develops concepts (codes) that represent and describe central contents in the data, which are then grouped into themes. This helps organise and analyse the new empirical information generated through the study (Sankar and Jones 2015). Following expert standards, I used NVivo, a specialised qualitative data analysis computer programme that facilitates the management of the data and increases the consistency of the thematic analysis (Landman 2012; Sankar and Jones 2015).

In August 2019, I completed the research activities and finished transcribing all interviews and organising the notes from the participant observations. All data generated amounted to a total of 664 pages of text. Both of my supervisors helped prepare the stages of coding and thematic analysis. Together, they listened to the audio recordings and or read all interviews, and we held regular meetings to discuss and reflect on the materials while the fieldwork was still in progress and after it had ended.

After generating an NVivo database with all the data, I began the coding process analysing the information participant by participant. This means that I coded each participant’s full interview transcript and observation notes before moving to another participant’s data. As with transcriptions, I completed this process in order of interview occurrence. Initially, I thought this process could have also been informed by relevant literature on chronic illness, so I tried to keep some relevant notions, such as bodily doubt (Carel

2016), social death (Sontag 2006) or different notions of loss (Toombs 1987; Carel 2016; Kleinman 1988) in mind and use them as codes. However, these concepts did not flow naturally at this stage and limited the descriptive value of the data, so I decided to follow a purely inductive coding process for most levels of analysis, except the linguistic structure of narratives. For this aim, Frank's (1997) systematisation of illness narratives according to the categories of restitution, chaos and quest narratives, and Bury's (2001) framework to analyse illness narratives according to contingent, moral and core narratives were particularly helpful. In December 2019, after completing the coding process, only 7.4% of all data was regarded as background information not directly relevant to the research questions and aims, though crucial for building rapport with the participants during the interviews. Thus, 92.6% of the data generated was analysed further, leading to the systematisation of five emergent themes purely informed by empirical data. The next section presents a summary of the key empirical findings emerging from this narrative thematic analysis.

3. *Narrative thematic analysis and discussion of empirical findings*

3.1. Narrative analysis: brief theoretical background

Having an understanding of the narratives as a whole and overall illness trajectories shared by participants offers the opportunity to engage in more depth with the complexity of the emotional world of life with chronic disease and contextualise the discussions in the following chapters of this thesis. Although Frank's (1995) and Bury's (2001) works look at illness narratives in general, they share an interest in chronic illness narratives, providing a language and understanding of narratives that helps in the meaning making process of the different ways in which participants shared their illness stories in this study.

Frank (1995) argues that although people tell their stories in unique ways, they do so by combining narrative types available to them, and suggests to organise these around three broad narrative structures: 'restitution', 'chaos' and 'quest'. Restitution stories start from the general assumption that ill people want to be healthy again and are described as the most common illness narrative structures in modern western societies. These stories are about health insofar their focus and aim are on the restitution of the previous healthy status, being particularly well suited to share acute episodes of illness and much in line with modern medicine. By matching overall cultural expectations, these stories are described as easier—relative to other narrative structures—to tell and to listen to. Chaos stories are the opposite of restitution stories, being marked by uncertainty, lack of control and the anticipation of illness never getting better. In terms of structure, these stories lack a narrative order, meaning that the flow of the contingency of illness is presented with no logical sequence or causality. This has been argued to make these stories difficult to hear, not just because of the lack of order, but because they are threatening—for the shared belief in restitution—and anxiety generating. As mentioned in the introduction to this thesis, chronic illness stories have been argued to tend to be chaotic, as there is often little clarity on disease causation, controllability and progression. Finally, quest narratives embrace the suffering associated with illness and transform it into something positive, thinking about illness as a stable and progressive journey and holding the belief that something can be gained from the experience of suffering (Frank 1995). Although Frank's (1995) analysis of illness narratives and how these are embodied goes far beyond this brief introduction, this will suffice for the specific purpose of describing and discussing the stories of participants in this study.

A few years later, and building on Frank's (1995) work, among others, Bury (2001) introduced a framework of analysis for illness narratives that includes three different types or levels of narratives: 'contingent', 'moral' and 'core'. Because contingent, moral and core narratives refer to different levels of analysis, stories are not either one or the other, but comprise these elements in unique ways. Contingent stories are descriptions of people's understandings and beliefs about what is going on, what might be the cause of illness, and its effects on the body, daily life, the self and others. These beliefs and explanations of illness can be 'categorical' or 'spectral' in relation to what is regarded as normal and what is regarded as pathological. Spectral views on the contingency of illness see illness and health as a matter of degree and a function of social process—depending on social context and reactions, while categorical views clearly separate the two. Although these might be thought to represent the personal experiences of illness and the biomedical discourse of disease respectively, the author explains that there is overlap between the two, somehow linked to the initial observation about the stories of participants in this study. Moral narratives introduce an evaluative element associated with the disruptive experience of illness, especially in relation to the social context. Examples of moral narratives include links between illness and political ideas, religious beliefs, financial issues, ideas of fairness, strength, weakness and shame, among many more. Still, specifically within those who live with chronic disease, moral narratives have been argued to play an important role in keeping normal appearances and a virtuous presentation of the self (Bury 2001). Finally, mainly drawing on the work of Robinson (1990) and Gergen and Gergen (1986), Bury (2001) describes core narratives as those which present the personal and cultural meanings of illness. These meanings become evident in how illness stories are told, but these are not necessarily clear to, or intended by, the ill person constructing the narrative. Thus, core narratives offer a way into how participants relate to themselves and others through their illness stories, which may take the shape of one or more common literary genres such as comic, epic, tragic, romantic or didactic. Within these different story shapes, story lines might be, generally speaking, regressive, stable or progressive. These refer to whether stories move towards (progressive), away (regressive) from or remain neutral (stable) regarding personally valued goals (Bury 2001).

3.2. Narrative analysis: discussion of main findings

The central narrative lesson emerging from this empirical study is that stories of chronic illness were not consistent narratives, in that they integrated moments of hope and confidence (restitution), despair and frustration (chaos) and growth and learning (quest). This resonates with the idea that narrative consistency may not always be achieved, despite being sought (Bury 2001). The content of the stories analysed was highly based on the contingency of life with illness and treatment, associating chronic disease to mostly negative values that, as described by Bury (2001), reflect the changing relationship between the person, the illness and the social identity. Although some participants' stories on the whole fell either on a rather positive (progressive), or rather negative (regressive) end of what might be described as a continuum of experience, all participants' stories shared the complexity of mixed experiences closely intertwined with the twists and turns of life beyond illness.

More specifically, within the 27 semi-structured in-depth interviews conducted for this study, most participants organised their illness story chronologically, starting with when they first got symptoms, seeking medical help, getting a diagnosis, and starting treatment. In part, this might be explained by how the question about participants' illness stories was asked, namely 'can you tell me the story of how you first got ill and how has it been since then?' In some cases these stories resembled a restitution story in which being on treatment equated the restoration of health, normalising the contingency of a life with treatment, but in many cases life with treatment was described as a rollercoaster.

There were a few exceptions in which participants did not follow a chronological description and the whole story was a rollercoaster or chaotic narrative, jumping back and forth in time, having trouble remembering when things had happened, and mixing different conditions or periods of illness. Other less linear narrations were associated with participants not having a clear diagnosis, so their stories went from symptoms to treatment and conveyed an overall sense of disorganisation and lack of answers. Still, in general terms, all chronic illness stories analysed might be thought to be incomplete in narrative terms, as treatment did not seem to offer a robust story resolution after the climax of identifying a pathological process.

Following from this, the main content of the stories shared was ‘contingent’, with participants sharing their thoughts about their disease and its lesser or greater impact on their lives both in terms of their daily activities and relationships. Furthermore, most participants’ accounts of the illness process were spectral, as participants described a process of symptoms’ normalisation in which the boundaries between health and disease blurred. This was sometimes attributed to chronic diseases having an insidious onset that made the clear identification of symptoms hard, but even within those who had clearer symptoms from the beginning, identifying these as pathologic was described as hard. Still, some participants described the illness process in categorical terms, clearly separating what was normal from pathologic in their telling of the story.

Chronic illness stories were highly loaded with moral content. Bury’s (2001) idea of the ‘virtuous presentation of the self’ might overlap with many participants' self-descriptions as hard workers or fighters. This was sometimes associated with being successfully ill, but for other participants this was associated with constantly trying very hard in general, feeling ashamed, not good enough and having to justify themselves to others because of illness. Specifically about the cause of disease, there was an interesting inconsistency because even though participants described the multifactorial aetiology of their diseases, most of them still tried to find something in their particular biographies that could help them make sense of why they got the disease—and others did not. Examples of this included having been born prematurely, having suffered acute stress because of an accident, having led a carefree lifestyle (smoking, partying, taking drugs), being involved in an experiment in school, and having been exposed to antibiotics, chemicals, or air pollution. In this way, chronic diseases were integrated or became a part of people's lives through stories about the self.

Just over half of the participants shared a progressive core narrative, namely a story of life with illness that moved towards personally valued goals. In these stories, often after going through a more or less serious period of illness, participants structured their illness stories around illness improvements and their ability to live lives they had reason to value. In a few cases, these core progressive stories had a comic or epic shape. Examples of this included a comic story about the colonoscopy gurney turning into a space ship as a way to describe an invasive and uncomfortable medical procedure. One particularly epic story described riding a bicycle with malfunctioning breaks through a hilly town to meet the GP after the surgery had closed.

Within this type of stories, some participants shared quest narratives, such as valuing the experience of illness as an opportunity to become a more empathetic professional, learning about human mortality, or having an increased appreciation of ‘the small things in life’.

The remaining stories—just under half of them—split equally between stable and regressive core narratives, and both subgroups represented a mix of participants from all disease groups. In stable core narratives participants related to and presented their illness in a straightforward manner after achieving a rather stable health state—or never having experienced symptoms. These stories were often focused around appointments, treatment, and biomedical facts, with illness basically rolling on in the background of their lives and not becoming an impediment to achieve their goals. Finally, participants telling regressive core narratives shared the experience of illness getting worse over time, limiting and hampering—to a greater or lesser degree—their possibilities to achieve their goals and live lives they could enjoy and value. These stories often took the shape of tragedy, as participants described, with great sorrow and despair, how they had lost their career, friends, or house as a consequence of chronic illness.

Thus, most participants shared their experience of chronic illness through stories that suggests the overall understanding that chronic diseases are manageable (stable) or had improved (progressive) since the time of diagnosis, while only some participants presented chronic disease as a mostly negative (regressive) or detrimental experience. Although the recruitment process of participants for this study did not aim at specific experiences or types of illness stories,[1] it might be argued that how people relate to their illness through stories may have an impact on people's willingness to share it in general, but more specifically, in the context of a research study. Drawing on Frank's (1995) idea that restitution narratives are easier to listen and chaos narratives harder, having a progressive (or mostly positive) story to tell about chronic disease might be easier to share, or even be a source of pride, making people more willing or drawn to take part in a research study about their illness experience. In contrast, having a regressive (mostly negative) story to tell might be harder and mostly painful to share, and thus people may be less interested in or even actively avoid taking part in a research study about this experience. For those who might not feel they have much to say about their experience of illness, it might be particularly uninteresting to join a research study about it. Among other variables, this might explain the distribution of narrative structures generated in this study, suggesting that more difficult experiences of illness might need to be purposefully sampled and that one in-depth semi-structured interview per participant might not have been the best way to explore these experiences of chronic illness.

Furthermore, some participants described that one of their main motivations to join the study was feeling grateful for the NHS, thus wanting to give something back and or wanting to help their doctor. These motivations might be in line with a rather positive experience of disease through an arguably rather good experience of chronic care. Still, this might not always be the case, as one participant who had one of the most regressive stories had

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[1] See inclusion and exclusion criteria in Chapter 2, section 3.1.

these very same motivations. Much in line with this non-linear rationale, despite the distribution of narratives described, the evaluative aspect (moral narratives) of most stories shared by participants from all disease groups described how living with chronic disease was associated with negative values such as being weak, irresponsible, an embarrassment, a disappointment, a burden, or lazy, among many more. This might contradict the overall presentation of illness stories as progressive, exemplifying the idea that illness stories are inconsistent and dynamic, condensing a variety of experiences. It is important to bear this in mind, as all interpretations and systematisations—including the multidimensional approach to the experience of chronic disease introduced in Part III—of these stories are, despite all efforts, a simplification of complex, non-linear lives and chronic illness trajectories.

3.3. The thematic organisation of the empirical findings

Alongside the narrative analysis just described, and as briefly mentioned in section 2 of this chapter, the thematic analysis led to the organisation of the data around five emergent themes. These themes are: (1) Illness narratives, ruptures in belonging and the value of support networks; (2) Finding and keeping the balance between chronic illness, chronic care and life beyond illness; (3) Considering chronic diseases as controllable diseases seems to be a matter of perspective; (4) The place of chronic disease and long-term treatment within individuals' inner world; and (5) Values and judgements around chronic care and the healthcare practitioner-patient relationship.

Very briefly, theme 1 describes the rather concrete and emotionally intricate ways in which life with chronic illness could lead to significant isolation and loneliness, as well as how participants managed to maintain their social roles or build new ways of belonging. This theme goes into depth about how supportive and unsupportive networks looked like in the specific context of living with a chronic disease. Theme 2 goes into more detail about how life with chronic illness looked like, the main difficulties participants faced and the strategies they used to manage these while still living lives they had reason to value. Finding and keeping a balance between the disease, chronic care and life beyond illness was described to require constant effort from all participants, but the harder someone's life was in general, the more effortful this became. Theme 3 discusses meanings and ideas around control and chronic disease. It focuses on feelings of vulnerability and dependency, as participants mainly described experiencing little to no sense of control over the body. It also highlights self-monitoring, treatment and healthcare monitoring as key mediators in the relationship with the body and means for claiming and regaining an overall sense of control. Theme 4 adds new elements and also a deeper layer of insight into the more intimate aspects of the experience of chronic illness. By reflecting on the impact that chronic disease had on participants' sense of self and their views on the future, and identifying a paradoxical element in the experience of chronic disease, this theme describes how following long-term treatment could be psychologically hard beyond the competing demands described in theme 2. Finally, theme 5 looks into what people living with chronic disease expect to receive from healthcare services and the value they assign to certain elements of care. It identifies general trends in what characterises better and worse experiences of healthcare across disease groups, providing insight into the relationship between patients and healthcare professionals specifically in the context of chronic care.

A final overarching observation arising from the data analysis is that stories of chronic illness integrate biomedical discourses about disease and the lived experience of illness in a way that academic disciplines tend not to, somehow exposing the arbitrariness of academic boundaries and calling for interdisciplinary approaches to the study of illness. Medical humanities usually put biomedical understandings of disease aside, while medicine usually refrains from engaging with the lived experience of illness, taking disease and illness to be two separate matters of study.[2] It might be argued that Carel's (2016) 'phenomenological toolkit' aiming to aid patients and healthcare professionals in the process of making sense of illness reflects this dichotomy. This 'toolkit' suggests (1) suspending the belief in the reality of an objective disease entity, as this obscures the experience of illness more broadly; (2) paying attention to experiences of illness to make explicit and expand current understanding of particular aspects of it; and (3) focusing on illness as a new way of being in the word, rather than on its biological process (Carel 2016).

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[2] This distinction and its applicability in the context of this specific study are discussed in more depth in Chapter 4.

Still, because life with chronic illness often means living a life in close connection with medical care, participants in this study shown having incorporated, to a high level of complexity, biomedical understanding of disease, pathogenic processes, and mechanisms of treatment, which were harmoniously intertwined with the complexity of their lives beyond the disease, including their wider circumstances, social and emotional experiences, broader ideas about disease and ideas about themselves. This observation about chronic illness narratives speaks to the importance of looking into the stories patients tell to others and themselves about chronic disease and life with chronic disease, as something different from what disciplinary research has to offer. Thinking in terms of the systems metaphor, patients' experiences create new information that goes beyond the mere sum of biomedical understanding of disease and the phenomenology of illness. Furthermore, the specific ways in which people living with chronic disease interweave biomedical ideas about disease and life beyond illness inform decision-making processes about health and treatment, stressing the centrality of values and patient agency in health outcomes.

4. Early dissemination of empirical findings and thesis writing-up

Between January and August 2020, I focused on the writing-up of the empirical findings in the shape of a 'findings report' for the HRA—required to officially end the study within the NHS context, as well as the writing-up of a 'summary of research findings' to share with participants and the clinical teams that collaborated with the study.[3] In these two documents, I draw on examples from participants' experience—and not verbatim quotations—to share the rationale underlying the interpretative process that informed the organisation of the five themes. This reflects a communication strategy based on the audiences of these documents, namely the HRA and participants. Besides prioritising conciseness, it is common practice in qualitative research not to provide funders or regulatory institutions and participants with detailed analysis—and their spoken words, but with core ideas emerging from the study.

Still, verbatim quotations from participants are important in the following chapters of this thesis. Although the narrative thematic analysis orients the main findings of the empirical study and informs the discussions addressed in each chapter, verbatim quotations serve the overall purpose of introducing participants' voice in the co-production of the ideas developed, contributing to balancing power by allowing participants to speak for themselves. Furthermore, using verbatim quotations serves the specific purpose of explaining and deepening understanding of abstract ideas. This means that throughout the thesis, I use quotations from the verbatim transcripts of interviews to shed light on central ideas by providing examples, sharing the intensity and complexity of emotions, underlying assumptions, and detailed descriptions of relevant processes, this is, how relevant events or emotional reactions come about (Corden and Sainsbury 2006)

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[3] This 'summary of research findings' includes a fuller version of the five emergent themes and is attached in appendix C.

Before finalising the ‘summary of research findings’ and sending it out to participants and clinical teams, I reached out to the same five representatives of the PPI network that had provided feedback earlier in the study development, in 2018. This was the last PPI collaboration instance planned for this study and although only two representatives out of the five approached were able to provide feedback at this stage, it was very valuable. Their comments contributed towards the accessibility of the document by suggesting minor but important changes in the writing and phrasing. Furthermore, one of the representatives conveyed the ‘feel good’ effect of contributing with research (Pizzo et al. 2014), especially after having the opportunity of collaborating at different stages of the same research. Finally, generating an outcome especially for the participants with the collaboration of PPI representatives was a good exercise of transparency in the research process and closeness to non-academic ideas, increasing its legitimacy and contributing to lessen the power dynamics in the research context. After sharing the summary with participants—around one year after data the research activities had taken place, although it was not required or expected, a couple of them replied to express their gratitude and one of them specified that seeing the overall findings of the study helped her feel less isolated in her experience of illness.

After completing the data analysis, and in this specific research project also after systematising this to be shared with different audiences, the next methodological stage in empirical ethics projects is setting up a dialogue between theory and the empirical findings. As discussed in Chapter 1, this means that this work aimed to transparently and clearly generate and draw on empirical data about the experience of chronic disease and chronic care in the UK to inform the theoretical discussion on how to improve equity for health outcomes for chronic diseases. Thus, this meaning-making process focused on understanding the complex system of interactions at play in the continuously changing dynamic equilibrium of how people live with chronic disease and engage with healthcare services. This, in turn, helped inform the broader complex systems of interactions feeding the persistent health outcomes inequalities for chronic disease in the UK. At a more abstract level, Flyvbjerg's (2001, p.60-61) four value-rational questions for phronetic social sciences: (1) “Where are we going?”; (2) “Is this desirable?”; (3) “What should be done?”; and (4) “Who gains and who loses; by which mechanisms of power?” served as a tool for ethical reasoning throughout the research and writing-up process. As already mentioned, these questions represented a method and not and aim in itself, so the study did not focus on providing full answers for these specific questions.

The following chapters of this thesis reflect and are the outcome of such dialogue, as each chapter's contribution and the thesis' overall contribution draws both on theoretical and empirical analysis and reflection. The process of systematisation and the final outcome of the early dissemination documents produced were fundamental sources facilitating this dialogue.

1. Conclusion

This chapter presented a detailed description of the theoretical and practical steps involved in the data analysis processes leading to the empirical findings of this study. After introducing and discussing the empirical findings, the chapter reflected on the writing-up processes of early dissemination documents and this thesis, specifying the role and use of data—including quotations and examples—in each of these.

The narrative thematic analysis might be represented in terms of a grid where all participants' stories were entered as rows and the thematic analysis run vertically in columns, finding patterns and commonalities in all participants' experiences as well as motivating reflection on relevant variations. Analysing the stories horizontally helped understand each participant's trajectory and these horizontal findings—how each story was told— were, in turn, analysed vertically to find patterns and reflect on variations. Although clear narrative tendencies and themes were identified, an overarching finding of this study was that stories of chronic illness were not consistent narratives in the sense that they integrated moments of hope and confidence, despair and frustration, growth and learning. Although some participants' stories, on the whole, fell either on a rather positive or rather negative end of the continuum of experience, all participants' stories shared the complexity of mixed experiences closely intertwined with the twists and turns of life beyond illness.

These themes and overall reflections about the stories generated in this study contributed to define and frame the discussions developed in this thesis, and are thus central to contextualise the different dimensions, complexity and dynamism that is argued to define, throughout this work, chronic disease and chronic care.

Part II

Chronic Disease And Long-Term Treatment: An Overview

Chapter 4

Chronicity As Long-duration Of Disease And Its Phenomenological Sense

1. Introduction

The concepts of ‘health’ and ‘disease’ play an important part in everyone’s daily experience of being alive, as well as in how societies understand healthcare and the goals of medicine. Still, and as will be argued throughout this chapter, these concepts manage to escape the descriptive possibilities of language. This chapter will look into the conceptual challenges of ‘health’ and ‘disease’ as the immediate conceptual context of ‘chronic disease’ and its complexities. However, the main focus of this chapter is on the concept of ‘chronic disease’, so it draws on academic literature and the experience of participants in this study to further specify this concept for the purposes of this work.

The next section discusses the conceptual problems of ‘health’ and ‘disease’, highlighting recent efforts to embrace the disjunctive and vague elements of ‘health’ and ‘disease’, allowing and encouraging specific and contextual cluster definitions of ‘disease’. This provides the necessary background to reflect on the conceptual problems of ‘chronic disease’ in the third section, arguing that these somehow mirror the problems of the concept of ‘disease’ by failing to provide a clear category. This is argued to be problematic because a disjunctive group of diseases falls under the concept of ‘chronic disease’, qualifying and hindering the research and practices aiming at making progress on issues around chronic disease. To move beyond this problem, part four of this chapter takes the theoretical discussion forward by introducing the perspective of people living with chronic disease. By looking into the empirical findings of this study and using quotations that help exemplify and reflect in more depth about relevant issues, this section introduces a distinction between a thin sense of chronicity—merely as long-duration—and its phenomenological sense, which is argued to be a distinguishing feature of the category of chronic disease. This helps to demarcate the territory of chronic diseases and argue that the experience of illness requires special attention in the study of chronic disease.[1]

2. The concepts of ‘health’ and ‘disease’: embracing complexity

2.1. The concept of ‘health’

Because this study focuses on the UK, where UHC is provided through the NHS, and on the experience of people living with chronic disease and long-term treatment within this context, it seems relevant background to consider the UK’s main health institutions’ understanding of such concepts before analysing the broader literature.

The current NHS Constitution, last updated in 2015, does not define ‘health’ or ‘disease’, but it states that the NHS aims to improve health and

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[1] An earlier and purely theoretical version of this work was published as a book chapter in 2021 (Stutzin Donoso 2021).

wellbeing, supporting people to keep mentally and physically well, to help them get better when they are ill and, if they cannot fully recover, help them to stay as well as possible till the end of their lives (NHS 2015). Thus, the core idea underlying the use of the concept of ‘health’ mirrors a positive definition based on a state of wellbeing that includes a mental and physical dimension.

The UK’s National Institute for Health and Care Excellence (NICE) does not define health specifically, but health-related quality of life as “a combination of a person’s physical, mental and social wellbeing; not merely the absence of disease” (NICE 2018), which paraphrases the WHO’s definition of health, as stated in the WHO Constitution enforced in 1948—which has not been changed since. According to the WHO, “health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (WHO 1948). Like this, although indirectly, the official health institutions in the UK seem to embrace a positive understanding of ‘health’, rejecting negative definitions based on the absence of disease.

The WHO definition, by suggesting a positive operationalisation of the concept of ‘health’, aims to represent an improvement over previous negative definitions, but it nonetheless raises significant problems. These are mostly related to the idea of ‘complete wellbeing’, which NICE omits. This is an important omission because health, as ‘complete’ wellbeing, does not allow for measurement or operational specification. Thus, NICE’s definition invites for disease classification systems (quality of life, disability, functioning, etc.) to allow for degrees, avoiding the problem of labelling most of the population as unhealthy most of the time and justifying unlimited development of drugs or treatments that create serious challenges for healthcare systems (Bircher 2005; Huber et al. 2011)

Although there is no consensus within the broader literature on a satisfactory positive definition of the concept of ‘health’ or even on whether this is possible or there should be one (Boorse 2011), many interesting new definitions have arisen from the discussion. Bircher’s (2005) and Huber’s et al (2011) positive definitions of ‘health’ are particularly useful to think about what ‘health’, and thus the goals of medicine, could mean in the context of people living with chronic disease, but also in a context in which disease is common or at least to be expected from time to time. Bircher (2005, 336) suggests conceptualising ‘health’ as

> a dynamic state of wellbeing characterized by a physical, mental and social potential, which satisfies the demands of a life commensurate with age, culture, and personal responsibility. If the potential is insufficient to satisfy these demands the state is disease.

Although this definition resorts to controversial or difficult concepts—‘potential’, ’demands’, and ‘personal responsibility’—that would require further specification for this concept of ‘health’ to be practicable in specific contexts, it seems to be an overall improvement over the WHO definition, briefly discussed in the introduction, because it allows for health to be a variable state within the life span of an individual attending to relevant dimensions, being thus more realistic.

In contrast to this rather longwinded definition, Huber et al (2011, 2) define ‘health’ as the “ability to adapt and self-manage”, with specific characterisations in the three domains of health: physical, mental, and social. ‘Adaptation’ and ‘self-management’ would also require further specification and context, but it is interesting how this understanding of ‘health’ completely diverges from the WHO legacy, stressing capacity or functioning of the individual in a broad range of spheres. Thinking about ‘health’ in these terms seems to completely normalise and introduce disease as an inevitable part of human life, shifting focus to people’s possibilities to live well despite illness and regardless of whether this is a self-limited demand or a long-term one. Much in line with this perspective, concepts such as coping, adjustment, personal transformation, and resilience are at the centre of the discussion about life with chronic disease and long-term treatment, but this is the focus of the following chapter.

2.2. *The concept of ‘disease’*

Regarding positive definitions of ‘disease’, that is, not merely as the absence of health, the overall picture is just as dynamic and unresolved, offering an even more prolific discussion in terms of literature generated, and the many working definitions (Lemoine 2013; Walker and Rogers 2018). However, specifically in the context of official health institutions in the UK, neither the NHS, nor NICE acknowledge or define the concept of ‘disease’ or any other related concepts such as ‘disorder’, ‘condition’, ‘sickness’, ‘infirmity’, or ‘illness’. Therefore, it might be thought that such institutions, by setting their focus on health, implicitly embrace a negative definition of disease.

Boorse (2011) suggests—in an effort to systematise the extensive literature on this issue—that there are mainly five commonly present elements in most health and disease definitions. These elements include (1) medical treatment, (2) pain, discomfort, and disability, (3) statistical abnormality, (4) disvalue, and (5) specific biological ideas: homeostasis, fitness, and adaptation. However, counterexamples for each of these elements show that all of these fail to be either necessary or sufficient for a satisfactory definition of these concepts at an abstract theoretical level, thus illustrating how challenging reaching satisfactory definitions seems to be.

Traditional conceptual analysis in philosophy broadly implies aiming at descriptive or naturalist (value-free) definitional criteria by “testing a definitional criteria and exceptions against a set of given cases, while drawing up counter-cases against an opponent’s definition”, thus clearly identifying conditions that are both necessary and sufficient to define a concept, and the exceptions to these conditions (Lemoine 2013, 310). However, when this proves to be difficult (such as in the case of ‘health’ and ‘disease’), conceptual analysis can also provide normativist (value or value-laden definitional criteria) definitions, which would broadly assume that ‘disease’ is bad for the person, and ‘health’ is desirable (Lemoine 2013).

Following this, most authors provide some kind of normativist definitional criteria for ‘health’ and ‘disease’, which may be soft in the sense that they may also include some descriptive conditions. Still, some very influential definitions adopt a strong descriptive approach, stressing the importance to continue working on value-free definitional criteria for ‘health’ and ‘disease’ (Boorse 2011; Lemoine 2013). Thus, there are two separate questions underlying this discussion, namely are ‘health’ and ‘disease’ the kind of concepts for which necessary and sufficient conditions can usefully be given? And should definitions of ‘health’ and ‘disease’ be value-free?

Engaging in depth with these questions goes beyond the scope of this work, but considering the lack of successful descriptive definitions for ‘health’ and ‘disease’ (Lemoine 2013), these concepts might be seen as thick ethical concepts where values and descriptions are unavoidably entangled.[2] To represent the complexity of this discussion, but with no aim of embracing any specific definition, what follows offers a synthesis of some of the most influential definitions of ‘disease’ and where they stand in the value discussion.

According to Boorse’s (1977) Biostatistical Theory, ‘health’ is defined by normal functioning, where what is ‘normal’ is statistically determined, and ‘functioning’ refers to biological functions. ‘Disease’ consists of deviations from the species biological design, so identifying disease is considered a matter of natural sciences, rather than an evaluative judgment (strong descriptivist position). The overall rationale and assumptions underlying this definition imply four main criteria: (1) definition of the reference class—an age group of a sex of a species; (2) definition of normal function within members—

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[2] Putnam’s (2002) analysis of the word ‘cruel’ (in page 34) is an example of a thick ethical concept, which has descriptive and ethical uses.

based on statistically typical contribution to the individual survival and reproduction; (3) definition of health in a member of the reference class as normal functional ability; and (4) definition of disease as an internal state which reduces functional abilities below typical efficiency (Boorse 1977).

Spitzer and Endicott (1978) provide a rather normativist (value-laden) definition of the concepts of medical and mental disorders, which states that

> a medical disorder is a relatively distinct condition resulting from an organismic dysfunction, which in its fully developed or extreme form is directly and intrinsically associated with distress, disability, or certain other types of disadvantage. The disadvantage may be of a physical, perceptual, sexual, or interpersonal nature. Implicitly there is a call for action on the part of the person who has the condition, the medical or its allied professions, and society. A mental disorder is a medical disorder whose manifestations are primarily signs or symptoms of psychological (behavioural) nature, or if physical, can be understood only using psychological concepts (Spitzer and Endicott 1978, 18).

This definition comprises three fundamental ideas in the notion of 'medical disorder', which altogether convey the overall message that something has gone wrong in the human organism, giving special importance to the evaluative aspect of the concept. It is important to note that these authors' ultimate interest is to define the concept of 'mental disorder', and since they decide to do this by considering it a subgenre of 'medical disorders', they also provide a definition of 'medical disorder'. However, because of this ultimate interest, the definition avoids using the word 'disease' as, according to these authors, it generally denotes a progressive physical disorder of known physiopathology, which is not the case for most mental disorders. Therefore, the concept of organismic dysfunction, or its negative consequences, do not imply these having a physical nature (Spitzer and Endicott 1978).

Wakefield's (1992) Harm Dysfunction Analysis emerges from a detailed critical analysis of several accounts including that of Boorse (1977), and Spitzer and Endicott (1978). This author's main point is that a definition of the concept of 'disorder' requires both evaluation (nomativist) based on social norms and a scientific (descriptive) understanding of failure of a physical or mental mechanism to perform natural functions for which it was designed by evolution. However, even the clearest concepts pose areas of vagueness and ambiguity, and, in this particular definition, this indeterminacy rests on how to distinguish mental from physical mechanisms (Wakefield 1992).

All these working definitions of the concept of 'disease' share the idea that there is a discontinuity between 'health' and 'disease', this is, 'health' and 'disease' can be either present or absent. Nonetheless, the concept of dysfunction—that all these definitions share—admits of degrees, therefore raising the problem of using a continuous variable (dysfunction) as the basis for a categorical definition. This has been described as the line-drawing problem in disease definition (Rogers and Walker 2017b). Furthermore, it has been argued that the more the scientific community learns about what constitutes 'disease', the more difficult it is to determine the relevant dysfunction associated with a condition. As such, the philosophical absolute perspective on 'disease' does not reflect everyday medical practice with borderline cases drawing boundaries as necessary for decision-making and practical purposes (Rogers and Walker 2017b). Although this is contested and some keep working towards a definition of ‘disease’, Walker and Rogers (2018) suggest that this concept does not seem to be classically structured since it fails to be defined in classical ways (conceptual analysis leading to exact necessary and sufficient conditions), and thus it should be approached as a disjunctive and vague concept for which developing specific and contextual cluster definitions for specific reasons or aims is needed.[3]

Building on this and to continue reflecting on ‘chronic disease’ as a kind of ‘disease’ it seems important to acknowledge and keep in mind the indeterminateness of the whole reference class to which ‘chronic disease’ belongs. Furthermore, this revision suggests a reflexive and open perspective towards possible specific and contextual definitions of chronic disease in the context of this research, understanding that any working definition that might be taken on is likely to change in light of further insights and reflections.

3. ‘Chronic disease’: conceptual analysis

3.1. Main definitions

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[3] Rogers and Walker’s (2017a, 277) working definition of borderline diseases is “X is a disease$_{ODx}$ iff there is a dysfunction that has significant risk of causing severe harm”.

In the UK, the Department of Health uses the concept of ‘long-term condition’ (LTC) as a synonym of ‘chronic disease’, thus assimilating ‘chronic’ to ‘long-term’ and ‘disease’ to ‘condition’, and defines ‘LTC’ as “a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies” (Department of Health 2012, 3). Therefore, from this brief and open definition, it is possible to think that the main characteristic of ‘chronic diseases’ is their specific duration as treatable, but incurable conditions. Thus allowing for the inclusion of NCDs, chronic communicable diseases, any other mental, somatic, or structural ongoing condition.

The King’s Fund (2018) also uses ‘chronic disease’ and ‘LTC’ interchangeably and defines them very broadly as “conditions for which there is currently no cure, and which are managed with drugs and other treatment”. Still, when providing a list of conditions that would fit this definition, only includes NCDs such as diabetes, chronic obstructive pulmonary disease, arthritis and hypertension, leaving chronic infectious diseases such as HIV/AIDS out (The King’s Fund 2018).

The NHS’ dictionary understands ‘chronic conditions’ as ‘long-term physical health conditions’ and defines these as health problems that require “on-going management over a period of years or decades”. In addition to this, it mentions that these are health problems “that cannot currently be cured but can be controlled with the use of medication and/or other therapies” and explicitly includes

> non-communicable diseases (e.g. cancer and cardiovascular disease); communicable diseases (e.g. HIV/AIDS); certain mental disorders (e.g. schizophrenia, depression) and on-going impairments in structure (e.g. blindness, joint disorders) (NHS 2018).

This definition seems to be particularly comprehensive since it explicitly includes mental disorders and ongoing impairments in structure, which may sometimes fall in a borderline territory between 'chronic diseases' and 'disabilities'. However, this definition specifies LTCs as 'physical health problem' appearing to remain oblivious to the technical discussion about mental disorders not being classified as physical diseases. As already mentioned, mental disorders are often described by phenomenological and behavioural criteria instead of a disease biological process (Fuller 2017). Furthermore, the NHS' definition provides an arbitrary, unspecific and unnecessary period of time, since it is contained in the definition that unless a cure is developed, the condition is going to last for as long as the person lives. Thus, although these three definitions share a common idea of what chronic diseases are, these also reflect how difficult it is to set clear boundaries and know exactly which conditions would be included in this category, and which would be left out.

This seems particularly problematic considering that, at present, the WHO uses 'chronic disease' as an alternative term to refer to 'chronic NCDs', defining these as those that "tend to be of long-duration and are the result of a combination of genetic, physiological, environmental and behaviours factors" (WHO 2021c). In 2016 the same fact sheet entry defined them as "diseases that are not passed from person to person, are of long-duration and slow progression" (WHO 2016). This change may evidence certain intention to make the concept more flexible by losing the focus on communicability and progression while highlighting duration and adding a broad idea of the multiple factors involved in their cause. However, since 'NCD' and 'chronic disease' are still used by the WHO as interchangeable concepts, this definition does not allow for the inclusion of infectious chronic disease, thus not contributing to address the complexity underlying the current state of chronic disease epidemiology—in a comprehensive sense—leaving the door open to significant confusion.

3.2. Chronicity as long-duration: a central and unifying feature of chronic disease

The word 'chronic' is an adjective making reference to something of or relating to time, and alongside the word disease—'chronic disease', it is used to give a certain disease the attribute of long-lasting, constant or continuous (OED 2019). In this sense, the chronic quality or *chronicity* of disease, merely understood as long-duration, is a core element in all four definitions of 'chronic disease' discussed before, although what counts as long-duration varies.

From the perspective of conceptual analysis, although the specialised literature is scarce, Fuller (2017) condenses current definitions of the concept of chronic disease and states that

> unlike our paradigmatic acute diseases, chronic diseases are generally not infectious (though some are). They are usually multifactorial in their aetiology. They are often progressive in one sense, but always static in another sense (they remain for a long-duration of time). They are incurable, despite the many curative miracles of modern medical science (Fuller, 2017, p. 2).

This definition mainly focuses on differentiating 'chronic disease' (long-term) from 'acute disease' (short-term), thus referring to a compatible classification system (effect versus effect) where flexibility regarding cause—communicable/non-communicable—is not conceptually problematic, thus being a comprehensive category that also highlights multifactorial aetiology.

Looking at the empirical findings of the study conducted for this research, participants also gave less importance to the cause of disease mainly focusing on the consequence or effect of disease, this is, its long-duration. Participants described that the multifactorial aetiology of chronic disease mainly implied not being able to know what exactly may have caused their condition, attributing it to a combination of factors and thinking that there was little point in worrying about causation. The following quotation exemplifies this, as expressed by participants.

> *I just think I was bloody unlucky…I have always just looked at it like that…everyone gets a card or a set of cards…I just got a shit card so I just go with it…(31-year-old man living with a pituitary disease).*

Thus, participants' descriptions of disease causation were mostly consistent with biomedical discourses about the aetiology of non-communicable diseases, as chronic infectious diseases might be thought to have a clear and specific aetiology—the infectious pathogen. However, as seen in the following vignette, the lack of clarity and sense of 'bad luck' also applied for some of those living with HIV, as the process of becoming infected can be far less straightforward than it might be assumed.

> *I mean, it's impossible to, to ah… always been impossible to know exactly, you know? where or who you contracted something from […] there are a number of people who I… slept with in the days when we were all carefree and young and foolish mmm […] ah… and… any of us can or even sort of could have, could have caused it… it was a lifestyle that one was living if you like and so mmm I never really felt necessary to say it must have been then or it must have been that but ah…(65-year-old man living with HIV).*

The last quotation strikes as one that could very well be describing the process of developing type 2 diabetes or another cardiovascular disease, as it describes the risk of infection as associated with a particular lifestyle and little awareness about risks. This description stresses lifestyle as a common risk factor for both infectious and non-communicable diseases, in which there is a mix of variables involved—more or less concrete and manageable, but still no intention of exposure or self-harm, simply a weighing of risks, or lack of awareness about risks that can go wrong and result in chronic disease.

This refers to the out-dated division between mono-causal and multi-causal theories of disease. The former was the main disease explanation theory starting from the 19th century after the identification of microbes, and pathogens causing infectious diseases, but with the rise of NCDs in the 20th century, the latter was developed to explain multifactorial disease aetiologies (Furman 2020). However, reflecting on the disproportionate prevalence of AIDS in South Africa in the 2000s, Furman (2020) argues that although it is crucial to acknowledge the salience of the virus in the disease causation of HIV/AIDS, socio-economic and behavioural aspects play a fundamental role, thus also having a multifactorial aetiology.[4] This rationale, however, goes beyond HIV/AIDS, as the social gradient affecting the distribution of the burden of disease applies to both communicable and non-communicable diseases—as explained in the introduction to this thesis.

By looking at certain diseases, Fuller (2017) makes inductive generalizations about chronic diseases and suggests that these are bodily properties. Although progression in chronic diseases is often a relevant element, some chronic diseases can stop progressing without being cured, and thus chronic diseases cannot be defined in terms of their progress or process. This means that although (pathogenic) biological processes—dysfunctions—are involved in chronic diseases' properties arising, once these arise, these become the disease since there might or might not be further changes in the pathogenic process, but the properties endure (Fuller 2017).

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[4] After detailed consideration, Furman (2020) suggests that Susser's (1973) layered and nested account unifies mono-causal and multi-causal theories in a methodologically sound way.

Fuller (2017) observes that chronic diseases are mostly dispositional properties, this means, that are realizable under certain circumstances, such as in the case of asthma. Even if a person diagnosed with asthma is not, at present, having difficulty breathing, under certain circumstances—such as poor air quality—breathing difficulties may appear. However, chronic diseases can sometimes also be manifest properties, meaning that they are present when the characteristic manifestation is present, such as in the case of HIV. Whenever a person has acquired the virus, the infection is manifest since, even if the viral load is undetectable and the person is not dangerously immunosuppressed, the antibodies developed in response to the presence of the antigen (HIV) are always manifest. Thus, chronic diseases are a state of the body that is either realizable or fully manifest whenever present and, in this manner, chronic diseases cannot be conceived as separate or independent from the body (Fuller 2017).

Although this highlights the long-duration of dispositional and manifest properties as a central element defining chronic diseases, by stressing the idea that what makes chronic diseases long-lasting today are mostly the health technologies providing life-sustaining treatments for many diseases that only thus become chronic, Fuller (2017) raises the argument that long-duration of disease is not an essential feature, but rather a historically contingent one.

In some case, it will be contingent whether an infection results in a chronic disease or not. Furthermore, there might only be minor differences between self-limiting infections, those that can be treated with a course of antibiotics and those that may last an indefinite amount of time due to drug resistance. Still, Fuller's (2017) argument seems to overlook that there might be something fundamentally different between diseases that are of short duration either because of effective or curative treatment, such as curative surgical interventions—appendectomy—or spontaneous short term duration, such as self-limiting infections—influenza viruses, and those of intrinsic longer-duration for which it has not been possible to develop effective cure mechanisms, regardless of whether there are treatments available to manage symptoms and or stop their progression (LAM disease, multiple sclerosis, diabetes, etc.).

Therefore, although life-sustaining treatments may have contributed to increase the number of diseases that can have a long-duration (without treatment, HIV and type 1 diabetes, for example, are deadly diseases of quick or slow progression), improve the quality of life and reduce the disability associated with some chronic diseases (reduce pain and increase mobility for people living with arthritis), and increase the life expectancy associated with NCDs (control cardiovascular risk factors reducing the risk of stroke or cardiac arrest), it seems that the most fundamental aspect of the subgenre of 'chronic diseases' is their long-duration.

To exemplify this, participants living with HIV highlighted life-threatening diseases as markedly different from chronic diseases as their stories reflected how HIV has, to some extent, transitioned from one to the other in the last thirty years due to treatment effectiveness and availability. For those diagnosed in the late '80s and early '90s, HIV was delivered as a terminal diagnosis, and people were incentivised to enjoy whatever time they had left and offered support to prepare for dying. Slowly, as this started to change, after mainly focusing in the present and adjusting their expectations and plans to live shorter lives, some participants shared progressively adjusting their mind-sets and lives to the idea that they might not die of AIDS. For others, however, this perception was described as a difficult concept to shift. This is exemplified in the following vignette.

> *The thing that…the illness there's more medication and support and it's considered to be chronic and manageable and that's fine and that how I logically would think about it… what I can never take away from the thinking is the fact that I was, I and many other people who were conditioned to the fact that we were going to die and we were supported in that process because that's all we knew at the time…that's a very, very big concept to shift (50-year-old man diagnosed with HIV in the '90s).*

One of the participants diagnosed with HIV after the introduction of antiretroviral therapies shared how although it was not delivered as a terminal diagnosis anymore, it was still experienced as some sort of life sentence which lacked a clear label.

> *We don't die so I am a little…something is quite confusing when it comes to like you are disabled, but you can't cluster disability rights, well you can't cluster disability, I can't go and ask PIP [Personal Independence Payment], I am not classed as disabled, but why do you call me disabled? I am disabled because I've got a long-term condition,*

> *but I am not treated like someone with a long-term condition (46-year-old woman diagnosed around 10 years ago).*

Another participant, diagnosed with HIV even more recently, shared that it was not experienced as a life-threatening diagnosis at all, managing to keep expectations and plans intact, but generally feeling more vulnerable health-wise. This description is very similar to other participants living with a range of other chronic diseases.

> *I do know, there is a theoretical chance that the drugs may not work forever or, but then also…science is evolving, as we know so it's mmm I kinda think something else will kill me first, probably cancer because it has killed most of my family [laughs] so ah…maybe something else will get…I am more worried about cancer than I am worried about HIV (54-year-old man diagnosed with HIV around 5 years ago).*

Following from the discussion of various definitions of 'chronic disease', the conceptual analysis offered by Fuller (2017) and the reflections arising from the experience of participants, it might be argued that the main element that helps distinguish chronic diseases from all other diseases is that the bodily state—whether dispositional or manifest—arising from a somatic dysfunction, is of long-duration. This long-duration implies that chronic diseases cannot be removed from the body, becoming a part of it and thus of the person (Fuller 2017). In this sense, this work suggests that the noun *chronicity* helps demarcate and identify the nature of 'chronic disease'.

Having such a strong focus on somatic pathogenic processes may imply that chronic diseases are “mind independent (i.e. real) entities that are causally responsible for a patient’s chronic ills” (Fuller, 2017, p.14). This introduces a marked line excluding chronic mental disorders (such schizophrenia), and chronic medically unexplained conditions (such as chronic fatigue syndrome), which are physical ails that may include physical or mental symptoms and for which there is no identifiable somatic cause, but are not considered mental disorders.

Like this, the concept of ‘chronic diseases’ inherits its reference class ills (concept of ‘disease’) both in the sense that also for ‘chronic diseases’, dysfunction admits for degrees and that the unclear distinction between mental and physical mechanisms of ‘disease’ challenges the distinction between mental and physical chronic diseases. Although it does not seem possible to draw a clear line between mental and physical chronic diseases, there is something particularly interesting arising from a conceptualisation of ‘chronic diseases’ as dysfunctional bodily states that, because of their long-duration, are not something ‘other’ than the body, but become part of it and thus also a part of the person potentially having a deep transformative dimension. This idea will be developed in the following section drawing on phenomenological research and the experience of participants, further specifying ‘chronicity’ to include a phenomenological sense that follows from but exceeds the qualities of ‘long-duration’ in chronic diseases.

4. Chronicity: long-duration in a phenomenological sense

Toombs' (1993) description of the lived body perspective suggests that 'diseases' are not independent of the human body, which, in turn, is not independent of the mind and the subject's experience. Phenomenology stresses time and space as the fundamental structures or conditions of possibility without which human experience would be impossible. Human subjectivity is understood in time—thus the present is constantly being shaped by the past and the future—and entrenched in the world—space, with the body acting as mediator. Hence, human beings are a body-subject unity in which the body and perception are the centre of personhood or subjectivity, the body is both an organ of perception and a lived physical body that is central in the study of illness (Carel 2016).

Because 'disease' is still largely associated with objective bodily states (naturalist definitions), there is a conceptual divide between 'disease and 'illness', where the latter is largely associated with how diseases are experienced—being more in line with normativist definitions and the lived body perspective. Kleinman (1988, p. 3-4) defines 'illness' as the lived experience of bodily dysfunction, comprising "how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability". More recently, Carel (2016) has defined 'illness' in terms of changes in the lived experience that can be directly or indirectly attributed to the effects of the disease process. If 'illness' is taken to be linked to the 'disease' state, the former should not be understood merely as the existential dimension of disease, but as a way of understanding 'disease' that cannot be separated from how such a state is experienced. Furthermore, in the specific case of chronic disease, given the lack of a successful and agreed naturalist definition and that even from Fuller's (2017) naturalist perspective chronic conditions were argued to be bodily properties that because of their long-duration become a part of the body and thus a part of the person, defending a strong divide between 'disease' and 'illness' might be problematic and rather unnecessary in cases, such as those included in this empirical study, where, as highlighted in Chapter 3, people experience both 'disease' (biomedical diagnosis) and 'illness' (lived experience) closely intertwined. [5] Following from this, 'disease' and 'illness' will be used interchangeably in this work from now onwards.

From the phenomenological perspective, chronic diseases imply a bodily metamorphosis in which the bodily disruption becomes the norm, whereas in acute illnesses the bodily disruption is known to be temporary, and the body is anticipated to return to its previous functioning (Toombs 1993).[6] Although in both cases the sick person experiences his or her body as a

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[5] Although this might not always be the case, it might still be argued that this distinction is problematic and rather unnecessary. People living with medically unexplained symptoms (MUS), for example, might be argued to suffer from 'illness', but not from 'disease'—as lacking a diagnosis. Nonetheless, MUS is still defined in relation to 'disease'—as a 'non-disease'—and in the search for biomedical answers and symptomatic relief, people living with MUS might still experience 'disease'.

[6] It might be worth noting that this distinction only accounts for acute conditions which prognosis is known at the time of experiencing the disease.

malfunctioning biological entity, chronic illness “does not allow for dissociation from the diseased body, its on-going permanent nature represents a fundamental change in one’s manner of being” (Toombs, 1993, p. 224-225).

Carel’s (2016, 2) ‘phenomenology of illness’ defines ‘illness’ as “serious, chronic, and life changing ill health, as opposed to a cold or a bout of tonsillitis […] where the onset of illness is not followed by complete recovery within a short period of time”. This working definition seems to equalise ‘illness’ to ‘chronic illness’, somehow undermining the role that temporality of disease has both in terms of conceptually distinguishing the two and in terms of experience. Simultaneously, this definition undermines the definition and experience of short-term illness, somehow limiting the concept’s availability to also refer to these.

Carel (2016) argues that substantial bodily changes modify the contents of experience, its structure, and conditions of possibility, thus also representing changes at the core of the self by broadly disrupting the individual’s experience of being in time and being in the world. This perspective suggests a straightforward one-way direction in which illness can alter the self, namely by introducing changes to the body. However, as from the crucial place that being-in-time has in phenomenology and Carel’s (2016) definition of illness itself, not only changes in the body but also in the temporality of the diagnosis (acute, chronic, terminal) are important to understand how illness disrupts the body, experience, and the self. Precisely because of chronicity as long-duration, chronic illnesses represent a specific kind of change to the body, one that is irreversible in the sense that remission and complete recovery are very infrequent and, if ever happening, these outcomes are unpredictable.

One of the most described and significant changes that this experience imposes is the loss of the past and the future as known and imagined until that point, which is represented as a present experience of rupture in the unity between the body and the self, leading to significant discontinuities in biography and self-concept (Bury 1982). By analysing the dimension of time in terms of mortality, the future and a paradoxical element in participants' experience of chronic disease, the next section explores the idea of chronicity in a phenomenological sense. This aims to specify what long-duration, in the specific context of chronic disease, implies at the level of experience. Although mortality, the future and the paradoxical element in participants' experience of chronic disease are helpful to think about time and chronic disease, other elements might become relevant in light of further analysis and reflection.

4.1. Chronic disease and mortality

Following diagnosis, many participants described experiencing a moment of shock. This was described in terms of having difficulty understanding what the diagnosis meant, needing time to compose themselves, and suddenly feeling out of control. A few participants described feeling punished and rejecting the information by ignoring it or thinking it must be a mistake. As exemplified in the following vignette, other participants also described their minds going to the worst possible scenarios, experiencing a sudden fear of dying, feeling vulnerable, anxious, and in panic.

> *And also there were a lot of changes to my life to adjust to it so…and when you have got children as well it's just…because of course you are gonna catastrophise, you are gonna think 'oh I am going to die' I am going to, this illness is going to be really aggressive (49-year-old woman living with rheumatic disease).*

Specifically about illness and mortality Frank (1995, 85) claims that "any sickness is an intimation of mortality", but specifically in the case of serious, chronic, life changing ill health, Carel (2016) argues that this intimation is often seen as the first sign of the end of life, confronting the sick individual with the fact that human life is finite. As discussed before, because of HIV's rather recent shift from 'terminal' to 'chronic' diagnosis, ideas around death and mortality within this group of participants may be thought to have a special status. Nonetheless, some participants from other disease groups also shared having this experience and, beyond this, described chronic diseases' introducing thoughts about their death or, in broader terms, reflections about human mortality that they think would not have otherwise arisen.

> *I remember been feeling like I had just been given a death sentence…you know? I was like…here is your, here is your destiny and you could see there, you know? it's like…you really you kind of believe all the scarier stuff at the start you are just thinking about all the like 'I am gonna go blind and gonna lose my legs', what's gonna happen to me? (30-year-old woman living with type 1 diabetes).*

Other participants did not experience this initial fear of dying and described chronic disease as something they most likely would not die of, while still knowing that their illness could indeed threaten their lives or develop potentially deadly complications. Thus, although death and mortality somehow manage to remain distant, the idea of death and loss becomes more familiar as participants described it as an opportunity to become more aware of their own mortality or talk about death with their children, as the following quotation shows.

> *There was a time when I fell ill, I think I had a…a headache that was really, really so painful that I had to sleep and my son said 'oh mom I was so worried that I didn't want you to die'…and I said 'oh' and I actually thought of it and I said 'you have to understand [son's name] anyone can die'…yeah so…that brought in the thought if I had died, my child needs to know that anyone can die (45-year-old woman living with HIV).*

As briefly mentioned before, for a couple of participants living with HIV, death was so strongly introduced in their lives that they described never really getting their heads around or adjusting to the idea of surviving, living with a sense of imminent death and baffled by what to do with their lives. Similarly, a few participants living with chronic respiratory conditions shared living with a more imminent sense of death either due to how they felt, or a lack of clarity regarding diagnosis and prognosis. Still, being diagnosed with a chronic disease introduced a sense of vulnerability and bodily limits, which was progressively integrated by most participants as they found ways of normalising this experience.

> *I think humans are very odd in that we all know that we are going to die and…we…just don't…let it into our heads much (64-year-old woman living with pituitary disease).*

Toombs (1987) argues that the healthy body is lived unreflectively, whereas a chronically ill body is lived as unavoidable evidence of the body's organic composition, suddenly shaping the self as finite. Frank (1995, 33–34) acknowledges this tension when he states that

> as long as the body is healthy and mortality is beyond the horizon of consciousness, associating the self with the body comes easily. The recognition of mortality complicates this association.

In this way, acknowledging mortality might differ from acknowledging dying soon, as reflected in some of the stories of participants initially receiving HIV as a terminal diagnosis and then surviving. The following quotation reflects this, as the participant describes being puzzled by where to place mortality in his case.

> *Why haven't I died yet? So there is a sort of paradox going on, you know? so…oh I'll get sick, oh I am sick which is awful […] God no, I am dying, just get me away from there… no, not me I just recover again, you know?…go back to work and all this stuff and then just go again so*

> *it's… it was, it was a…I always think of myself as lucky…but probably I wasn't that lucky really (55-year-old man living with HIV).*

Like this, a terminal diagnosis seemed to introduce some degree of certitude regarding death within a certain timeframe, whereas acknowledging mortality through chronic illness would impose the experience of living a life in which bodily limits are somehow more present, but there is overall little certainty about how things are going to be.

In this process, the link between chronicity and the future seems to be particularly relevant.

> Normally, we act in the present in light of future goals and anticipations. However, in chronic illness the future assumes an inherently problematic character. One can never be certain, from one day to the next as to the extent of one's physical capabilities (Toombs, 1993, p. 225).

To this Bury (1982, 169) adds that "further expectations and plans that individuals hold for the future have to be re-examined", which implies that ″chronic illnesses must be regarded as critical situations, a form of biographical disruption".

4.2. Chronic disease and the future

In general terms, most participants from all disease groups described being aware or knowing that at present there was no cure for their conditions, and how this implied living with the illness and its treatment until they probably die of something else. The main feelings associated with chronic diseases' long-duration were uncertainty and worry about the future specifically in relation to the disease.

> *Because you just have to, you never know what's going to come the next day like you, you never you never know it's going to get thrown at you so you just have to learn to flexibly deal with these things (21-year-old man living with Crohn's disease).*

Uncertainty around financial security emerged as a key worry and participants shared taking steps to increase it at a time in life when they said they would not otherwise have, or experiencing significant levels of stress and anxiety as they think they might be incapable of taking good care of themselves in the future or not trusting that the state would support them well in old age, for example.

> *Also made me realise that I am definitely going to get sick again so I need to like financially plan for that so… making sure that my pension is set up properly, that I... that my job, making sure that the benefits are good in any other job that I go to the benefits and the sick pay…is good…is important…mmm (29-year-old woman living with Crohn's diseases).*

Furthermore, participants shared not taking their health for granted, feeling unsure about whether they would be well enough to book holidays ahead, treatments failing, their symptoms getting worse (or not improving), living a shorter life, missing out on important moments in the life of their children, and having to plan and prepare for a harder future.

> *I think if I can manage my colitis then it will be fine, but I just then worry that if it gets bad again then it's just gonna be this like cycle of like getting better and getting ill again and then I can never like progress or never like do anything that I really want to do, but I don't actually know what I have to do so it's quite, it is hard I don't know (23-year-old woman living with ulcerative colitis).*

Beyond this, experiences about chronic disease progression and its impact on future life projections varied significantly. Some participants described shifting their main focus towards the present as a direct reaction to how unpredictable life became after diagnosis. Others described how being diagnosed with a chronic illness specifically affected their outlook with regards to having children, as exemplified in the following vignette.

> *Planning just for practical things so like one thing might be having children…I probably would like to have children maybe a little bit earlier than I had planned…just so that I am young enough and well enough to look after them…but equally my sister is adopted so if my illness meant that I couldn't have children or there's some great risk…that I would go and do that so…(29-year-old woman living with Crohn's disease).*

Other participants described facing the question of whether they wanted to, or could, take the risk of somehow passing on the disease to their children, while others described thinking that they could not or would not have children because of their illness.

More generally, participants from all disease groups described how living with a chronic disease significantly affected their plans. A few participants from all disease groups, except those living with a chronic respiratory condition, described feeling either constantly, or at times, very unmotivated about the future after their diagnosis, feeling disappointed at not being able to achieve their goals, having lost the drive or desire to find a direction, and feeling frustrated about every aspect of life revolving around illness, for example. Furthermore, a few participants living with chronic gastrointestinal and respiratory conditions described how their future plans completely changed due to illness or were fully dependant on treatments and illness progression.

> *You know they say it's chronic, well I don't know…I am, it…I mean people say it's chronic…it's been disabling for me…you know? I have any plans I try to make…are either defeated by an illness, defeated by some stigma or whatever in my….by myself. I can't achieve anything because…because of what…because I can't predict whatever… I've got an illness (55-year-old man living with HIV).*

Still, some participants from all disease groups described their outlook on the future not being affected by their diagnosis, expecting to continue developing their personal and professional aspirations, such as buying a house, starting a business, going back to work or study or getting married. To manage this, participants shared adapting to illness-related demands by changing their daily lives in ways that do not significantly affect their future projections. Still, some participants added depending on the unlikely possibility of the illness not progressing for it not to interfere with their plans. Thus the frequency and seriousness of the flare-ups or crisis of symptoms were described as key variables in the experience of the illness being projected as bearable in the future.

> *Touch wood, you know? it's not as bad as…I do look into, I don't worry about it really too much, it's hindering now, it's a pain but until it gets to a point where 'wow, it's getting serious' or this drug doesn't work, then I am all right, ok mmm…(37-year-old man living with ulcerative colitis).*

Despite most participants knowing that chronic illnesses are not curable and likely to get worse over time, many participants from all disease groups, except those living with chronic endocrine conditions, described having a hopeful outlook on the future. Although it sounds rather sarcastic, the following quotation describes one participant's way of adopting a hopeful outlook on the future, despite having one of the worst prognoses.

> *You can get up to 20 years but only 2% of people get to that sort of level, having said that the longer the odds for me the more likely I am meant to get it, you know? so if you know? 1 in 20 thousand get it, I have got it…. 1 in 100 thousand get it, I have got it [laughs] (52-year-old man living with pulmonary fibrosis).*

Although rationally unjustifiable, Carel (2016) argues that healthy people have a powerful sense of tacit and ongoing faith in the body being capable to do things such as digesting food, which strongly supports an existential feeling of trust, familiarity and normalcy that enables people to pursue everyday goals and plans. Participants' descriptions regarding the future seem closely linked to Carel's (2016) description of loss of faith in one's body, which leads ill people to experience vulnerability and hesitation on a bodily level, confronting the individual with the weak epistemic status of our everyday explicit beliefs. This loss is one of the three losses—alongside loss of continuity and transparency—leading the overall experience of bodily doubt, which is argued to make the ill subject feel exposed and threatened, revealing the extent of human vulnerability, and making people feel incapable (Carel 2016).[7] However, participants' descriptions also seem to reflect how people living with chronic disease may normalise this experience and re-establish a sense of trust that may also sometimes be rationally unjustifiable. The next chapter explores this in more depth by looking into research on psychological adjustment, coping, resilience, and personal transformation in the physically ill.

4.3. Chronic disease and the paradox of chronicity

Fuller's (2017) definition of 'chronic disease' comprised an interesting tension between its progressive character—in terms of the biological

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[7] Loss of continuity and transparency will be discussed in Chapter 7.

processes leading to further biological deterioration—and the static element of incurability specifically linked with the duration of chronic diseases—stressing the importance of chronicity as long-duration. Fuller (2017, 2) writes “they are often progressive in one sense, but always static in another sense (they remain for a long-duration of time)”. This tension is reflected in participants’ descriptions in previous sections about time and the experiential challenge of harmonising bodily vulnerability, lack of certainty with regards to future capabilities and long-duration of disease. This tension is well exemplified in the following vignette.

> *I think that’s what you have to adjust to, that’s what, what you have to accept, that it’s not going to be something which goes away, but on the other hand it’s not gonna kill you either and that’s the benefit, you know? that’s the positive you have to take about that, from that, it might…affect your physical health in little ways now, but noticeable ways regularly, but you are still living your life (47-year-old woman living with rheumatic disease).*

Progression or change in chronic disease is closely linked with symptoms that tend to be cyclical. In the efforts towards conceptual clarity, Roder and Boekaerts (1999, 311) suggest that

> it is notable that some chronic diseases differ from physical handicaps when they entail periods of exacerbation, followed by symptom-free periods. This cyclical course characterises them as unstable.

Although there might be some elements of progression associated with physical handicaps too, the idea that chronic diseases are particularly unstable is useful to continue reflecting on this concept.

Chronicity seems to conflate the idea of something static in one sense, and cyclical in another, adding a paradoxical dimension to the concept of ‘chronic disease’. Most participants, from all disease groups, described their illness manifestations or symptoms having irregular and mostly unpredictable patterns of days, weeks, months, or years. Chronic diseases’ manifestations seem to be variable, and this variability also seems to include different aspects. For those for which symptoms are mostly irregular and unpredictable, chronic diseases might be experienced as rather whimsical or random, but for those for which the frequency is known or predictable to some degree these might be regarded and experienced as rather cyclical. This varies both between and within disease groups showing how, on different levels, chronic diseases’ experiences are specific (personal), and also relatable beyond diagnostic categories. The following quotation describes this cyclicality.

> *I think they [symptoms] come and go, sometimes I feel really tired and weak and get headaches, but sometimes I am perfect…I wake up good…energy…I could go for the whole day, you know?…probably 2, 3, 4 days I am good, you know? I …sometimes I wake up and I don’t feel, you know? all right, wake up with a headache, you know? I am slowing down, you know?…it varies (46-year-old woman living with pulmonary fibrosis).*

Although a couple of participants shared how their illness was always present through symptoms, most participants from all disease groups described how, to a greater or lesser degree, living with a chronic disease was characterised by it being constantly present as information in the back of their heads. This was described to shape how they acted even if not in very meaningful ways, and regardless of the lack of symptoms. Although particularly those participants living with chronic endocrine and gastrointestinal conditions described their illness as being very confronting (frequently present through bodily manifestations), they also underlined the constant experience of having to keep their illness in mind and act on it regardless of symptoms, as seen in the following vignette.

> *I don't think about it too much except that I have to get an injection every couple of months, but it…yes was a kind of constant knowledge that you have it (64-year-old woman living with pituitary disease).*

Although it is rather straightforward how chronic disease can be very demanding for those who have to frequently deal with (often painful or hard) symptoms, participants shared how even when asymptomatic, chronic diseases are demanding in terms of being constantly present as information that needs acting on, and in less concrete ways such as worries, uncertainties, or being mindful of the illness. Like this, and although the degree to which this affects people varied both between and within disease groups, chronic diseases seemed to be paradoxical at the level of experience as they are always (to a lesser or greater degree) present regardless of their symptoms or bodily manifestations.

About this, participants' descriptions reflected how emotionally demanding it could be to keep in mind that symptoms would pass or improve when they were feeling ill, as well as remembering that symptoms would come back when they were feeling fine or better. Thus, having experienced symptoms coming and going in the past, and knowing this is how chronic diseases work, somehow helped to keep in mind or to integrate the idea that chronic diseases are cyclical or whimsical, but participants still tended to project based on how they felt at present.

This also came across in the previous descriptions of how participants thought about chronic diseases having an impact (or not), on the way they thought about their future. A couple of participants shared how although they rationally understood that having a chronic diagnosis implied that it was not going away, this could be a difficult idea to hold and there was significant effort in abstracting oneself from present experience. The following quotation describes this challenge.

> *So it wasn't definitely nice when I felt like it was going to go on forever…I had one surgery to drain an abscess and then that failed and I had to go back again and then they found another abscess and I had to go back again and it was like 'oh my God, I am going to be here forever' like…but then they were like no, it's fine we have got this now…so you kind of shift percept…perspective so is that element of like when you are just down in the dumps and you are going through the process and it's sore, it's painful and you just feel rubbish then you*

> *like 'I am sick and I am gonna be sick for ever', but it tends to be like a moment a passing…passing mood or mind-set…(29-year-old woman living with Crohn's disease).*

Closely linked to this paradoxical and psychologically challenging experience, many participants from all disease groups described finding it difficult or deciding not to follow treatment recommendations when they felt well, as the illness was somehow absent.

> *I don't know if it is human or just me but if you are ill and a magic pill comes along you take it, you stop being ill, you take it no problem no question at all, if you have to take 6 pills a day because they might stop you getting ill in 20 years' time the incentive is less if you like, I mean, I am not stupid I know that that's how it works but ah…(65-year-old man living with HIV).*

Regarding the complexities and nuances of this issue, one participant described that reaching a stable state of acceptance of their health situation was hard and that the frustration was re-experienced along the cyclical or whimsical manifestations of symptoms, realising that it was a constant effort to adjust.

> *I accepted that I can... that I'm not always going to be able to do the things that I used to do. I'm like that… I'm fine with not being able to do things you need to do. But then I reach a low point again and like physically I reached the point where I'm in the same amount of pain or the drugs that I'm taking at the treatment that I'm taking at the moment doesn't work. And then I go back to having all these feelings again and*

> *then I realize that they have never really actually gone away, I'm just trying to cope with it by convincing myself that I'm okay but that doesn't really, like for me at least it hasn't really gone away (21-year-old man living with Crohn’s disease).*

Although people living with chronic disease might get used to a constant amount of effort to accommodate themselves and their lives to illness-demands, so it is no longer noticeable while the illness is somewhat stable, flare-ups work as reminders of that constant effort. Adherence and this idea of constant effort are discussed in more detail in the next chapter, but it is useful to note here that participants discussing these issues described going through periods of non-adherence to long-term treatment, having had difficulties to follow treatment regularly (to maintain or prevent periods of illness) or chosen to use the treatment for symptomatic relief (when they had symptoms). The main reason for this was associated with this difficulty of integrating chronicity, as when they were feeling better they assumed they were better and did not need the treatment anymore.

> *Probably differs from other conditions that people may have some people probably have to manage this daily or… it’s or it never goes away, you know? whereas I kind of forget about it and then it comes back so… it’s more like, kinda it’s like it’s gone and then kinda it’s back again so the only reminder might be me going ‘oh shit, I must take those tablets, the red tablets I must take that’… mmm…so…but it’s kind of I am used to…the idea of having it (37-year-old man living with ulcerative colitis).*

Beyond treatment moving between the fore and back of participants' lives, insofar chronicity in illness comprises the long-duration of dispositional and manifest bodily properties (Fuller 2017), chronic diseases introduce a paradox that implies a specific kind of problem at the level of experience. Building on the experience of participants, symptoms may be cyclical, but still somehow static, this is, still present in absence, as likely to recur. In this way, chronic diseases are described as having the quality of being always present even in the absence of their manifestation.

Following from this, chronicity in a phenomenological sense further specifies what long-duration of chronic diseases—chronicity in a thin sense—implies at the level of experience. Closely linked to considerations about mortality and the future, the particular long-duration of chronic diseases—temporality of diagnosis—has been argued to affect experience by having the quality of being irreversible while still cyclical or whimsical, and thus paradoxical as mostly present in the absence of manifestations. Thus, chronicity demands a constant effort of abstraction to keep in mind and act based on an idea of chronic disease as always present, but these only being experienced in the body intermittently. Describing this key feature of chronic diseases helps demarcate the territory of what counts as 'chronic disease' and shed light on what means to live with a chronic disease, opening new paths to think about issues around long-term treatment and health outcomes for chronic disease.

5. Conclusion

This chapter discussed the conceptual problems around ‘health’ and ‘diseases’ as the immediate conceptual context of ‘chronic disease’. Because of the lack of a successful and agreed definition of ‘disease’, this work suggested embracing the disjunctive and vague elements of such concepts, which allow and encourage specific and contextual cluster definitions of disease. Following from this, the concept of ‘chronic disease’ also failed to be structured in a traditional way, allowing for a disjunctive group of diseases to fall under the concept. Building both on theoretical perspectives and that of participants, this chapter argued for long-duration of disease as a core feature of this concept both in a thin sense—merely as long-duration—and a phenomenological sense.

Although the experience of illness varies significantly within and between disease groups, both the theory and the experience of illness describe and conceptualise chronic disease as a significant life event, which introduces a far-reaching shift in perspective towards oneself and the world in terms of life trajectories and expectations. Furthermore, this shift is characterised by a paradoxical experience of long-duration of disease, which implies significant abstraction or awareness of the disease’s presence in the absence of its manifestation, as likely to recur. Thus, chronicity in a phenomenological sense implies a positioning of the individual in relation to this long-duration of disease, which can transfer the quality of continuous and irreversible to an experience that might be thought of as discontinuous in terms of how it is expressed in the body. Following from this, paying attention to lived experience is paramount to the study of chronic diseases and long-term treatment.

In conclusion, and for the purposes of this work, chronic diseases are regarded as manifest or dispositional bodily properties that comprise a thin understanding of chronicity and its phenomenological sense. Although it goes beyond the scope of this work, this conceptualisation invites for further theoretical and empirical reflection on the comprehensiveness of chronicity and its potential to also apply for the cases of chronic mental disorders and medically unexplained symptoms. The next chapter builds on this encompassing and flexible understanding of chronic diseases to discuss central aspects of life with chronic disease and long-term treatment.

Chapter 5

Lives People Have Reason To Value: The More Or Less Precarious Balance Between Chronic Disease, Long-Term Treatment And Life Beyond Illness

1. Introduction

As briefly mentioned in the introduction to this thesis, NCDs are the main disease burden worldwide, accounting for 71% of all deaths globally, 37% of which are considered premature deaths—before the age of 70 years (WHO 2021c). Estimates show that adherence to long-term treatment for all chronic conditions is around 50% in HICs and presumably comparable or lower in LMICs, contributing to the high rates of premature death and poor individual and population health outcomes (Sabaté 2003).

Defining adherence to treatment is difficult because it refers to a process comprising the initiation, implementation (daily self-management) and or persistence of treatment (Vrijens et al. 2012). Although most research focuses on implementation, many studies lack a definition of adherence, leaving the results open to interpretation (Kardas, Lewek, and Matyjaszczyk 2013). Beyond this issue, there is broad agreement that adherence is highly complex, being affected by a large number of factors. Evidence shows that there are at least five dimensions that play a significant role in adherence rates: social and economic factors, therapy-related factors, patient-related factors, condition-related factors, and healthcare team and system-related factors (Sabaté 2003).[1] However, these do not differentiate between the determinants of short-term adherence for acute conditions and those of long-term adherence for chronic diseases (Kardas, Lewek, and Matyjaszczyk 2013).

Furthermore, there is no ‘gold standard’ approach to measure adherence to treatment and literature often shows a mix of objective and subjective approaches. Objective approaches include proxy measures of service usage, prescriptions filled, medication pick-ups, among others, which do not ensure patients taking their medication and thus miss important information. Subjective approaches ask providers and patients about their adherence behaviours, but these have been shown to be inaccurate, as providers tend to overestimate patients’ adherence and patients tend to deny failures in adherence (Sabaté 2003). Following from this, it is not only difficult to specify and measure adherence, but also to predict it. ‘Good’ adherence and ‘bad’ adherence remain elusive conceptualisations, as these do not only vary across conditions but across treatments and individual patient responses as dose-response is a continuum function (Sabaté 2003).

Most of the contextual elements affecting adherence require multi-level complex interventions, but most efforts to increase adherence focus on patient-related factors (e.g. self-management education)—despite one-

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[1] In order of appearance, examples for each of these dimensions include: long distance from treatment settings, complex treatment regimes, fear of injections or anxiety about adverse effects, poor understanding of the disease and its symptoms, poor delivery of care education to the patient and or family and carers (Sabaté 2003).

dimensional approaches having been argued to have limited effects (Kardas, Lewek, and Matyjaszczyk 2013; Sabaté 2003). Chronic diseases are considered a major life stressor requiring adaptation in multiple life domains, and although the relationship between adjustment to illness and self-management is bidirectional, and causality is not always obvious, it is well documented that poor psychological adjustment to illness contributes to difficulties in self-management (Chronister and Chan 2007; Ridder et al. 2008; Stanton, Revenson, and Tennen 2007).

Adjustment to illness is commonly defined as the “presence or absence of diagnosed psychological disorder, psychological symptoms or negative mood” (Stanton, Revenson, and Tennen 2007, 568) or the “healthy rebalancing by patients to their new circumstances” (Ridder et al. 2008, 246). It is considered a dynamic process, which unfolds over time and is sensitive to fluctuations and prognosis of disease among other variables, such as culture, gender and socioeconomic status (Stanton, Revenson, and Tennen 2007). Although it has been argued that most people adjust to illness, around 30% of people go through an extended period of adjustment that can sometimes be unsuccessful, meaning that some people do not adjust (Ridder et al. 2008). Still, it is not yet clear which strategies and dispositions are most effective for adjustment of chronic disease, which makes it difficult to know in advance how to better support this specific group of patients to adjust and adhere to treatment (Chronister and Chan 2007).

Even if considered dynamic, such perspectives on adjustment are still prescriptive in the sense that lack of adjustment and poor self-management or adherence to long-term treatment are seen as failing at something that is expected, considered healthy and, once achieved, must remain stable. Drawing on the experience of participants in this study, this chapter will argue that there is a central dynamic element in adherence to long-term treatment, as living with chronic disease is described as an ongoing effort towards balancing different, often competing, demands to live lives people have reason to value. Thus, drawing on the discussion on complex systems in the introduction to this thesis, this effort towards balance is described in terms of an effort towards an ethically desirable or positive dynamic equilibrium in a broad sense—live lives people have reason to value—where new information is constantly being created and nothing is static (Meadows 2009). This dynamic equilibrium can be more or less precarious as it is closely intertwined with a myriad of variables both disease and non-disease related. By exploring in detail what life with chronic illness looks like and how, quite understandably, people living with chronic disease cannot always prioritise the disease and long-term treatment, this chapter offers the necessary context to reflect further on treatment adherence rates.

Although this chapter introduces several relevant aspects of life with chronic disease, it goes beyond its scope to thoroughly engage with all of them. Part III of this thesis will expand on issues around belonging; the paradox of chronicity; and identity, by introducing a multidimensional perspective on the experience of chronic disease that helps understand some of the key social and psychological challenges and injustices faced by people living with chronic diseases. Part IV of this thesis will pick-up issues around self-management; responsibility; the patient-healthcare professional relationship; and healthcare systems, suggesting what good chronic care would look like considering the empirical and ethical issues raised throughout this thesis.

2. Adherence in context: a constant negotiation of competing demands

2.1. Why choose side-effects or inconveniences over illness?

Most participants from all disease groups described that some of the main limitations or negative aspects of living with chronic illness were associated with having less energy and or physical strength to live the life they used to live. Thus, managing energy and stress levels was particularly important. In some cases, this implied delaying, reducing, or no longer doing certain activities. Still, even after these and other adjustments had been made, participants sometimes felt tired and or needed days to recover after doing such activities. The following quotation exemplifies this.

> *I think I have got less energy to do things, in the evening I am quite exhausted mmm...so I don't have a baby sitter and even if I did [laughs] I am not sure I could…you know?…that much more energy mmm…like I said I would like to do…maybe play some more sports and things like that, but again I am tired (41-year-old woman living with lupus).*

Long-term treatment can add to and become one of the main negative aspects of life with chronic disease, as many participants stated having a particularly hard time enduring certain treatments or medical procedures. Examples of these included rather regular colonoscopies or brain scans, handling their stools, taking tablets that may be too big to swallow, have a bad taste or be too many, and having fear of, or a bad reaction to, needles and injections, among others. In some cases treatment could be modified or slightly adjusted to avoid these difficulties, but most of the times, participants had to endure these to keep their illness controlled. These negative sentiments towards treatments or procedures were strong enough to cause some people to avoid, skip or delay certain treatments or procedures, and either hope for everything to be fine or deal with the consequences.

> *I can't remember what the side-effects were, but I didn't like to take it…yeah, it made you tired…there's no day you want to take a drug, which makes you feel tired or exhausted or unable to get out of bed. You don't want to take it in the weekend because it ruins the weekend, you don't want to take it in your on-call day…so I…I think it gave me muscle aches or something, I know I didn't want to take it (64-year-old woman living with pituitary disease).*

Many participants described treatments as too challenging or demanding. This was particularly so for those living with gastrointestinal and endocrine chronic diseases, for which treatments are complex and can be affected by many variables. Some of these participants felt that it was not actually possible to get the treatment right, or that committing to it would have taken up too much of their time and energy. For the other two groups of illnesses (infectious and respiratory) this included issues around tablet administration.

Most participants identified side-effects and complications associated with treatment or medical procedures as a big hurdle for treatment. Some of these could be temporary, directly associated with treatment administration, or irreversible, sometimes affecting participants lives more than the illness itself. Some side-effects described as particularly hard included persistent low energy, shaky body, acne, osteoporosis, immunosuppression, damage to kidneys and liver, headaches, insomnia, sickness, and diarrhoea.

> *I was taking drugs to reduce my immune system, I still am, but it's more focused now and obviously I had some changes…because of that I can't catch as much sun as I use to and I need to be more worried about [other] diseases (33-year-old man living with Crohn's disease).*

Side-effects can be part of the process of finding 'the right' treatment, changing medications or adjusting doses, but sometimes there are no alternatives available and some may choose not to take the treatment if it means feeling worse than they would otherwise feel. If so, people living with chronic diseases may not share this with the healthcare team, fearing they might be judged for not being able to overcome the side-effects and prioritise the medication, as a few participants described.

> *I didn't want her [doctor] to know that I was so stupid I wasn't going to take the treatment against my brain tumour growth hormone, yeah so…unsurprisingly it didn't get any better [laughs] and then I think I must have said 'I can't take it because…' so they offered me lanreotide (64-year-old woman living with pituitary disease).*

Overall, benefits need to be perceived by people living with chronic disease as outweighing the issues, so it is worth living with treatment. Although there might be less of an idea of having a choice if conditions are perceived as life-threatening, participants' experience suggests thinking about 'adhering to treatment' in terms of a spectrum since what was considered acceptable in this search for overall balance varied. The following quotation shows how organising different treatments in a hierarchy does not necessarily follow a biomedical logic.

> *The only thing that I would say is very serious is taking this now the steroids you can't be messing those up, the steroids, that's a proper course of medicine…so with no symptoms take two every day, I mean, you can easily go…I have gone without taking it if, you know?…so it depends on the scenario…for that I would be regimental…for the mesalazine, if I don't have any issues, I probably won't be as regimental, being honest, you know? (37-year-old man living with ulcerative colitis).*

Some participants from all groups except those living with a chronic infectious condition described how long-term treatments could be a significant source of frustration, especially when these do not have the outcomes expected. Participants described how, despite all efforts, chronic diseases were often not controlled and they still suffered from symptoms, which could be the main limitation to live the lives they wanted like to live. This experience led some participants to feel angry at their ‘malfunctioning body’, feel tired, confused, not knowing how to act, depressed, or simply not being able to make plans and constantly feeling they were letting friends down.

> *When I go see the endocrinologist it’s always tiny bits of adjustments to…to improve…the tiredness but, you know?…so I am always reading and understanding and asking lots of questions and…try…you know? trying little things…to improve that mmm…it’s kind of…a little bit hopeless because I don’t think there’s much answer, I mean, there might be slight improvement, but you know? (54-year-old man living with pituitary disease).*

For others this was a passing experience as they could try other treatments, or an occasional experience associated with flare-ups or side-effects, allowing for a more hopeful perspective. In any case, as discussed in Chapter 4, it can be difficult to take treatments if people do not have the experience that these are helping. Many participants from all disease groups identified—more or less concrete—gains from treatment, and described this as a helpful experience to see the role of treatment in their wellbeing and overall capacity to live a life they can enjoy. Such gains included being able to stay alive, seeing an increase in their energy levels, having less or no symptoms, being able to work better, preventing flare-ups or developing other serious diseases, among others.

> *Well my friends used to ask me before actually, like, how do you remember to take it all the time? you are so good, I would be so shit at it like I was like it's not like that it's not just number on a machine…and it's not long-term effects like you very much feel it like…twenty minutes…half an hour…your mouth will start getting really sticky and then you need to go to the toilet like you feel really cathartic and you are like totally like tired and drained (30-year-old woman living with type 1 diabetes).*

When gains from treatment are more abstract and therefore more difficult to identify a few participants from all disease groups, except those living with chronic endocrine conditions, explained that it was helpful to know how the treatment worked to understand why they should take it, and also the consequences of not taking it. Sometimes having trust in their doctor and or in the medical sciences was enough, but especially for people who had conflicting systems of beliefs, understanding also worked as a positive reinforcement to sustain a positive attitude and follow treatment.

The idea of conflicting systems of beliefs seems particularly interesting because faith, for example, is described as a positive resource for resilience[2] within the physically ill, as it can help make sense of illness and be a source of strength (Stewart and Yuen 2011; Chronister and Chan 2007). Although this is not opposed to participants' experience, as seen in the following

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[2] Resilience is broadly described as "the capacity of individuals to successfully maintain or regain their mental health in the face of significant adversity or risk" (Stewart and Yuen 2011, 199).

vignette, having faith sometimes meant that treatment was not seen as central to achieve health.

> *I had stopped my medication mmm…because of…mmm religious mmm…thoughts…that mmm…and then doctor [doctor's name] said 'no no no you mmm your CD4 is really getting down you need to take your medicine' and I thought 'OK I'll take my medicine [laughs]' […] there are people who have got off treatments through their faith and prayers and they are OK, they are surviving…there are even those who have recovered…and I thought maybe I will be part…one of them, but maybe spiritually I am not that strong, as strong as mmm…I am supposed to be so, but I know one day I will be…I believe it (45-year-old woman living with HIV).*

Drawing on Wolff and de-Shalit's (2007) theory of disadvantage—discussed in the introduction to this thesis, people living with chronic diseases facing competing demands in their efforts towards balancing chronic disease, long-term treatment, and life beyond illness—making decisions that ultimately may undermine their health, might be thought to reflect insecure functionings, this is, achieved functionings that have a precarious status, such as employment in the case of informal workers. Reflecting on how functionings interact and create new complex situations contributing to disadvantage, Wolff and de-Shalit (2007) describe cross-category risks and inverse cross-category risks. The former are those likely to spread to other functionings, such as the risk to employment generating risks to nutrition for people who rely on their income to buy food, and the latter also spread to other functionings but are generally driven by the person at risk while trying to secure another functioning. Participants in this study undermining their treatment by living accordingly to their beliefs or prioritising present wellbeing over future complications, would be cases of insecure functionings due to inverse cross-category risk to healthy functioning.

2.2. Keeping treatment in mind and organising care on top of everything else

Another main difficulty of long-term treatment is remembering to regularly take medication to avoid getting sick—already introduced in terms of the paradox of chronicity described in Chapter 4. Many participants from all disease groups described remembering as a significant mental burden. In most cases, people did not experience symptoms or became used to the way their body felt, so treatment needed to be somehow present for them to remember to take it. In turn, especially for those who had negative feelings about being ill, having to constantly take medication or somehow act on their health became a reminder of being ill, and a burden in this sense. The following quotation reflects this ambivalence, as the participant does not complete her sentences and implies, perhaps not fully convinced, a certain resistance to fully engaging with treatment, as it might be too much.

> *I don't know if I want to end up with one of those Monday to Friday boxes beside my bed [laughs] you know? like…I mean… I think we all could be a bit more disciplined in taking the tablets when… you gotta remember…the tablet…you are supposed to take it every day for life…*

> *like that's very…I don't know (23-year-old woman living with ulcerative colitis).*

Still, some of the most concrete elements helping many participants remember and follow treatment were blending their lives and routines with the disease and treatment by keeping their treatment visible and somehow integrated into their daily routine.

> *But you know?…if am at the girlfriend's, would I have taken them? [pills] Generally no…they are not there…I walk downstairs on my house they are on the side in the kitchen…in a little pot I know they are there because they are in front of the fridge and I would get a drink out of the fridge…so everything falls into place in my house (31-year-old man living with pituitary disease).*

Alongside this mental load associated with taking medication, most participants from all disease groups described that living with a chronic illness involved a significant amount of extra planning in daily life. This makes reference to all the specific things, not evident for others, that people have to do to prevent their illness from becoming a problem or getting worse. Thus, some participants described that thinking and planning carefully were the main consequence of living with a chronic illness, often taking spontaneity and flexibility away from daily life and losing the privilege of being carefree.

> *I mean, it is life changing, it is, I mean it just is, I am just never spontaneous about anything, you know? because I think I can't be, I mean it is stupid to be, I was and it would make me ill or I would be,*

> *you know, away feeling dreadful and then be pushing through and, you know? affect everyone else's good time because I wanted to lay around (47-year-old woman living with Crohn's disease).*

Furthermore, the burden of what one participant conceptualised as 'the logistics of care' could be quite significant, bringing healthcare system-related factors for long-term treatment adherence into the mix. This mostly referred to scheduling and organising care, booking appointments and tests, and getting their prescriptions and medication delivered in time.

Most participants from all disease groups described feeling that organising their care, and not just following treatment recommendations, was up to them. They described having to chase the different levels of care and providers to get products delivered or important tasks completed, making phone calls in the middle of a workday, or physically going to the hospital or surgery to get the outcome they need. This burden was increased by the lack or poor communication between different organisations involved in their care, potentially leading to delays in receiving treatment or care. This implied a significant mental load in terms of remembering everything they need to do, but also in terms of dedicating time and energy on a regular basis.

This introduces a first element of social and economic factors affecting long-term treatment, as time might be considered a costly resource, and thus a proxy for privilege and disadvantage. Before going into more depth about this, if people can afford this time, the burden of the logistics of care might not be considered too heavy or problematic when people are feeling fine or their illness is stable, but when or if they are ill, it can become quite challenging and frustrating. If the healthcare system failed to complete a task or made a mistake, it came back to the patient as another thing they had to worry about and take care of. In such cases, the healthcare system, beyond individual healthcare professionals and administrative staff, was considered unreliable and unempathetic, adding an extra sense of insecurity and responsibility to people living with chronic disease. In the following vignette, the participant shares how, because of what could be described as a runaway loop of damage, the system failed to achieve its goal and demanded her to take care of administrative aspects of her care. The participant describes the internal process of negotiation and the resources allowing her to take on such responsibility. In other words, how she works towards dynamic equilibrium.

> *I have worked out a system for it now…but in the beginning that was difficult because the GP would give out to me…for not having the blood tests results mmm…and I would say, 'but I don't know how to get them'...and she said 'just email the hospital or tell them'…and then I was like…'OK, fine'…I was like, 'I have to take responsibility for this, because there's a gap in the handover between the hospital and the GP' (29-year-old woman living with Crohn's disease).*

This contributed to an overall sentiment amongst participants that their care needed to be prioritised, and their daily lives (work, holidays, child care, etc.) had to be organised around it. About this, a couple of participants described how lacking work flexibility can be detrimental, since this usually means that something has got to give, and they are either not able to continue working, or they have to undermine their care by skipping appointments, for example, in order to keep their jobs. In other words, participants described how achieving the central functioning of bodily health by following long-term treatment might not be a genuine opportunity for them, as they might have to risk the central functioning of employment in order to do this (Wolff and de-Shalit 2007).

Considering that the burden of disease for all chronic diseases has been argued to follow a social gradient tending to cluster among the poor within wealthy societies, such as the UK (WHO 2021c; 2018; 2005; Marmot 2005), this tension between work and long-term treatment sheds light on the mechanism underlying a further cumulative effect of disadvantage amongst people living with chronic disease, as it is plausible to think that lower paid or qualified jobs may tend to be less flexible. This is consistent with recently updated health inequalities studies in the UK stating that

> those with lower socioeconomic position, younger people, those in lower paid jobs and non-white people are all more likely to experience poor quality work with attendant impacts on health (Marmot et al. 2020, 61).

Although participants in this study had enough time available and certain flexibility to organise and complete the research activities—interviews and participant observations, not all of them had much work flexibility on a regular basis. Still, many of those who did (from all disease groups) stressed how important it was to have work flexibility or support from their employers to be able to pick-up treatments and attend appointments, among other self-care tasks, mainly because these take time during working hours. Furthermore, participants sometimes needed time off because of the illness acting up or because of regular side-effects, for example, or needed to work from home in order to manage their energy and physical strength levels. Some needed to get extra time to complete deadlines at work or in their studies, or even change their job or contract conditions to reduce their working hours. Those who had this flexibility felt lucky and were not willing to give it up, or anticipated this could be a problem if they wanted to change jobs, as exemplified in the following vignette.

> *I might begin a corporate job maybe in the future and that might be slightly more awkward it's definitely easier being self-employed mmm you can come when you want mmm so I just don't know if that will get mildly more tricky but mmm probably not, but it's…it might get more difficult (54-year-old man living with HIV).*

Within those who were not working at the time of the interviews, work flexibility also came up as something they thought they would need in order to be able to work. Having or lacking work flexibility might be regarded as part of the central functioning of control over one's environment, which has been described to follow a direct social gradient across socioeconomic groups and cluster with the functioning of bodily health, thus having the potential to be a fertile functioning or corrosive disadvantage (Marmot 2005; Nussbaum 2000; Wolff and de-Shalit 2007). This adds to the idea of chronic diseases as a risk multiplier for disadvantage, which was first presented in the introduction to this thesis in relation to the functioning of affiliation, social networks and support. Since people living with chronic diseases have been agued to overlap those more likely to have poor quality work, which drawing on participants' experience might be overall harder to keep in the context of also dealing with the demands of chronic disease and long-term treatment, these would represent a corrosive disadvantage and a cross-category risk for other central functionings. However, control over one's environment goes far beyond employment and so other life demands on top of chronic illness can also become problematic.

Most participants from all disease groups shared how everything adds up, sometimes making them feel overwhelmed. Mostly being stressed at home (household management, child care, etc.), at work (deadlines, instability, relationships), with their studies or career development, or being acutely ill with something unrelated to their chronic illness meant that other things needed to be prioritised over their long-term treatment or could make their chronic illness act up. Other relevant issues included stress about housing conditions (rent prices becoming unaffordable, dampness and mouldiness affecting respiratory conditions, etc.) and having to care for others (mainly young children and partners within this group of participants). The following quotation reflects how busy days go by and the participant might not find the time to prioritise her own self-care and long-term treatment.

> *I go to work for example, I'll give you a normal day. I woke up early. I go to bed very late and every time, you know moms, they have everything to do, I go home, I cook, I clean, I do this this that then my*

> *mom calling me, my brother, some friends and I go to sleep and I forget [taking my medication] one day. The next day the same routine (41-year-old woman living with HIV).*

If life gets too hard or demanding, as it sometimes does, and people find themselves losing their motivation in general, this was also described to affect participants' motivation towards treatment and other related tasks, which have been said to require significant effort, time and energy. Of course, everyone's life can be or become more or less challenging due to a myriad of reasons, but as mentioned before, the degree of 'control over one's life' goes in direct relation with socio-economic status. Stanton's et al (2007) systematisation of research outcomes on adjustment to cancer, cardiovascular disease, and rheumatic disease highlights poverty and low socioeconomic status' negative impact adjustment, as the disadvantaged are argued to experience more stressful life events of greater magnitude while having fewer social and psychological resources to manage them, which in turn contribute to poorer mental and physical health (Stanton, Revenson, and Tennen 2007).

3. The pressure of keeping up with treatment even if it is not always prioritised

Most participants from all disease groups, but especially those living with chronic infectious, endocrine (especially type 1 diabetes), and respiratory conditions, described feeling they were their own carers and largely responsible for their treatment, although one does not imply the other. It might be the case that the frequency of self-care tasks—which are higher for these conditions, and the practical and perceived consequences of not following treatments properly—such as risk of spreading the disease and mortality, may be associated with a higher sense of responsibility for treatment. Regardless of the reason, this was mostly described in terms of something participants felt they had to worry about, keep in mind, try hard to do the best they could and avoid hampering their treatments. As exemplified in the following vignette, participants experienced a stronger sense of responsibility for treatments that were perceived as more important than others, and for treatments that became a problem after irregular or non-adherence. However, when participants found the treatment easy to follow or managed to adhere reasonably well, then they described treatments as less burdening or experiencing a lesser sense of responsibility over them.

> *Remembering to take the tablets does [feel like a responsibility]…so one specially like I say if I forget one of the other ones, which I generally don't…I wouldn't be as worried, but I think not taking my mmm…seizure medicine is a responsibility because…if you go out without having it yeah that would worry me…but other than that I don't feel like it's a big responsibility I feel like it's quite manageable (41-year-old woman living with lupus).*

In this way, responsibility was mainly understood in terms of accountability for unwanted results. As mentioned in the introduction, most efforts to increase adherence focus on patient-related factors (e.g. self-management education), (Kardas, Lewek, and Matyjaszczyk 2013), which means that biomedical discourse around treatment adherence tends to focus on the idea that patients are their own principal care givers (Bodenheimer, Wagner, and Grumbach 2002b). Although this may be true to some extent and participants had incorporated this discourse, it is well known that one-dimensional approaches to increase adherence are unsuccessful (Kardas, Lewek, and Matyjaszczyk 2013), merely putting undue pressure on patients' responsibility for treatment success.

Participants also shared a strong sense of responsibility for keeping others safe, not wanting to scare or put others in the situation of having to save them or help them, and feeling guilty, ashamed, angry, and disappointed in themselves when they failed to do so. This is reflected in the following vignette.

> *I remember being very much at the start as well knowing that I have to take care of myself because I don't wanna put anyone in the situation, you know? how you hear the stories with the hypos? Like where like…you know? people just go crazy or they like faint or they whatever I never wanna put anyone in that position…yeah and I always thought like that way I have a big responsibility (30-year-old woman living with type 1 diabetes).*

Feeling distracted, tired or emotionally overwhelmed by illness and treatment related demands could sometimes interfere with participants' ability to complete self-care tasks, but they did not think this was justified, or that they were allowed to fail or have a hard time following treatment. This was reflected through a strong internalised discourse that they were stupid and silly if they did not take the treatment, constantly committing to try harder and, as seen in the following vignette, worrying about healthcare professionals' concerns about their test results.

> *I use to [feel a sense of responsibility] when I was having problems in taking it and it was all too difficult and I use to come up here and feel guilty that I was causing trouble and haven't taken them, you know? (41-year-old woman living with HIV).*

Closely linked to this, participants described a strong discourse of self-improvement and the idea that they should do better in general, somehow constantly being in a position of fault. In the following quotation the participant explains how this also implied doing better by their families and the healthcare system.

> *Yes, because the consultant is putting their trust in you to take the treatment that they prescribe is no good then seeing you in six months' time and you haven't taken the tablets or miss your blood test or something because that's just wasting two people's time…so it is a responsibility to take what you are supposed to and do all the tests you are supposed to test…and then they'll do their best for you…I suppose yeah…(63-year-old man living with pulmonary fibrosis).*

This dynamic between patients and healthcare professional around treatment adherence might reflect the lack of more comprehensive views on different aspects affecting adherence, which go beyond blaming conceptualisations such as ‘low compliance’ and ‘lack of patient interest’ as barriers for disease control (Jallinoja et al. 2007). This also hints towards described power dynamics in healthcare where patient experience has an inferior epistemic status relative to medical knowledge.

Fricker (2007) originally introduced the idea of epistemic injustices distinguishing two main forms: testimonial and hermeneutical injustices. The former refer to contexts in which someone’s testimony is dismissed or downgraded due to unjustified power dynamics determining the value of such individual’s—or group’s—voice (a common example of this is women’s voice being regarded as less important solely based on the fact of being female), and the latter, to similar power dynamics generating a deficit on shared tools for social interpretation of experiences of underrepresented or marginalised groups or individuals (Fricker 2007). Kidd and Carel (2017a) further specify this theory to the context of illness and describe participatory prejudice as a form of epistemic injustice, which refers to the sense of relevance that patients think their experience of illness has for the broader context of their care (Kidd and Carel 2017a). This might help explain, at least to some extent, why participants regard their actions about treatment as non-valid and their reasons irrelevant.

Much in line with responsibility being understood in terms of accountability, a few participants living with chronic endocrine and gastrointestinal conditions described that healthcare professionals taking responsibility for the treatment could become a hurdle to access regular treatment or try new treatments. This is exemplified in the following vignette.

> *The nurses seemed worried about responsibility…'oh your blood results are normal, I wonder if you still need your injection'…I said 'my blood results are normal because I get the injection' and then she felt she had to phone another doctor (64-year-old woman living with pituitary disease).*

In this way, healthcare professionals and patients are mostly responsible for the negative consequences, and less so about seeing the best treatment possible through together. However, many participants from all disease groups highlighted that being able to share the responsibility for their treatment with the healthcare team and or service can significantly reduce their burden. This means that after people living with chronic disease do everything they have to do to manage their illness, they can trust that the healthcare team and or service will also complete its tasks. Feeling that they can rely on the system and or on healthcare professionals to take care of them gives them a positive sense of trust and collaboration.

From a complex systems perspective, this might be understood in terms of the processes or feedback loops shaping the system of long-treatment adherence and life beyond illness. In other words, the actions that people living with chronic disease and healthcare services and professionals complete 'separately' feedback into each other, affecting the process of negotiation or dynamic equilibrium that allows people living with chronic disease to live lives they have reason to value.

Other participants seemed frustrated about the lack of collaboration as they stated that healthcare, in general, should be able to help more with symptoms, or that the system did not seem to worry too much about facilitating treatment adherence, or that it simply did not see this as part of its job. As seen in the following vignette, when the healthcare system fails to take this processes or interacting feedback loops into account, a vicious circle or runaway loop of damage can be triggered, hampering the specific goal of delivering the care it is supposed to offer and the overall goal of contributing to the dynamic equilibrium of people living with chronic disease.

> *I said 'I missed my injections because of you guys [healthcare team] and now I have no gel'…I said 'you need to sort something', 'oh, we will try and get a doctor to call you at some point', but they don't really care because obviously it doesn't affect them so you are talking to a receptionist that's not overly bothered, they are just there to do their job for the day, whereas actually what they are doing is pretty harmful and it really does affect you and the more I have to chase it the less I am interested in chasing it…you, you start thinking why, why am I chasing this? (31-year-old man living with pituitary disease).*

4. *Keeping life as normal as possible: adjusting expectations and shifting perspectives*

According to the systematisation developed by Chronister and Chan (2007), coping strategies are broadly described as dispositions or efforts people use to face stressful situations, increase wellbeing, and avoid being harmed by a stressful situation. Research on coping is vast and complex, but macro-level coping strategies are cross-situational, relatively stable, problem-solving tendencies in individuals or psychological orientation either towards (approach) or away (avoidance) from a threat. Examples of these include denying or dwelling on difficulties and taking an active or reactive stance. People are described to use a mix of strategies, and behaviours do not always necessarily correspond with coping conceptualisations (Chronister and Chan 2007; Roth and Cohen 1986).

There are several coping conceptualisations, measurement approaches, outcomes, and types of stressors, so no specific coping strategies have been found uniformly effective (Chronister and Chan 2007). Still, Roth and Cohen (1986) proposed three important factors to evaluate coping effectiveness: “time at which effectiveness is evaluated; controllability of aspects of the stressful situation; and the fit between coping style and certain demands of the stressful situation” (Roth and Cohen 1986, 816). These factors contribute to the point that due to the dynamic nature of the stress process, people use different strategies in different moments of the process (Chronister and Chan 2007). Furthermore, these factors focus on the controllability/uncontrollability of the stressor, and how strategies fit or do not fit with the stressor.

It has been argued that chronic diseases regarded as controllable stressors (such as diabetes and asthma), benefit from approach strategies to follow through with self-management tasks, while chronic diseases regarded as uncontrollable stressors (such as paralysis), where little can be done, benefit more from avoidant strategies helping reduce anxiety, for example (Roth and Cohen 1986).

However, building on the paradox of chronicity—introduced in Chapter 4—it might be argued that chronic diseases, more generally, compress or simultaneously represent the qualities of controllable and uncontrollable stressors. Roth and Cohen's (1986) research focuses solely on biomedical discourses about chronic illness equating controllability to treatment availability. From this perspective, all participants in this study had a 'controllable' chronic disease. Still, they mainly described experiencing vulnerability and dependency, with little to no sense of control over the body regardless of treatment. This included participants sharing that treatment did not have a great impact on their daily experience of illness, or that even if symptoms were controlled by treatment, flare-ups, recovery times, and related or unrelated complications were still largely unpredictable. Those who described experiencing an increased sense of control through treatment still highlighted feeling dependant on it, and vulnerable in terms of the treatment remaining effective and being available (or affordable) in the future. In the following vignette, the participant describes experiencing a strong disconnect between treatment and control.

> *I don't have control over my chest. I have control to take inhaler and inhale it, but how it will work I don't have control about that. All I do is just follow, you know? what they say and that's it… I wish I had control (56-year-old woman living with asthma).*

This sense of lack of control introduced a fundamental change in people's ways of life and relationship with the body, largely mediated by self-monitoring, treatment, and healthcare monitoring, which also helped asserting agency over life beyond illness. Closely linked to Carel's (2016) idea of bodily doubt already introduced in Chapter 4, many participants from all disease groups described how living with a chronic illness made people more aware of their body and how they treated it. So by spontaneously making healthier choices, such as stop drinking or smoking, eating healthier, or getting the flu jab every year, participants felt they were contributing to their overall wellbeing, somehow helping their body endure the disease better and not having their lifespan shortened because of it. The following quotation shows how the participant directly associates being diagnosed with HIV with feeling she has to be healthier in general, so she can somehow compensate for the diagnosis.

> *I do my best…that's one of the things that probably kicks in when you get a diagnosis…you think 'come on, I have got to [laughs] sort myself out…and make sure I live as long as I can [laughing]'…you know? but mmm…I might have gotten there anyway…I don't know, but it does make you more conscious… […] [I] go to the pool…so mmm…yeah and I cycle, so I do quite a lot really…so fitness things…(65-year-old woman living with HIV).*

On a micro-level, Chronister and Chan's (2007) systematisation of the literature describes a large number of specific coping strategies including emotional, behavioural, and cognitive efforts used in anticipation or in response to a stressful situation. Once again, either emotion-focused or problem-focused coping strategies can be more or less helpful depending on the specific situation and moment in the stress process (Chronister and Chan 2007).

Research shows that problem-focused coping strategies increase adherence to treatments for ‘controllable stressors’, while emotional-focused coping strategies, such as emotional-self control and finding emotional support, help increase adherence to treatments for less ‘controllable stressors’ (Chronister and Chan 2007; Stanton, Revenson, and Tennen 2007). Following the discussion about chronic diseases compressing the qualities of controllable and uncontrollable stressors, and building on the complexity described in how different aspects of care and life beyond illness interact making it harder or easier to adhere to long-term treatment, dynamic equilibrium might require the constant negotiation of problem-focused and emotional-focused coping strategies. Building on the idea of inverse cross-category risks, this might be particularly challenging. Developing coping strategies to face some aspects of life with chronic disease may have a negative impact on someone’s ability to cope with other aspects of life with chronic disease and, more broadly, live a life they have reason to value. This suggests that coping in the context of chronic disease might be interpreted as precariously getting by (e.g. disregarding treatment-related demands due to caring responsibilities) versus securely getting by, that is, finding dynamic equilibrium through the continuous negotiation of multiple demands and coping strategies.

When the threat or stressor is long-lasting or chronic, such as in the case of chronic illness, research has shown that people use strategies such as wishful thinking, faith and fatalism, positive thinking, intellectual denial, drawing strength from adversity, perseverance, and rational action (Chronister and Chan 2007). Some of these already resonate with participants' experiences discussed, but the rest of this section focuses on such micro-level strategies shared by participants.

Most participants—including those who struggled with illness the most—from all disease groups shared making an active effort to avoid negative lines of thought regarding life with chronic disease. This meant thinking about the negative aspects and limitations associated with chronic disease as things participants could do little or nothing about, so there was no point in dwelling about them. Instead, the following quotation exemplifies how participants described actively choosing to focus on the positive things in life, and do their best to try to make things work.

> *I have a very positive attitude and as long as I can do the things I want to do or… if I can't do the things I want to do, I can still do stuff that gets me from A to B, so I can still work if I gotta work, or live a life that is not restricted by having a cylinder 24 hours a day through my lungs. Then I am quite, yeah you know? I can, I have to I find routes around things (52-year-old man living with pulmonary fibrosis).*

This, however, seems sensitive to context, including severity or disruptiveness of illness. Such active effort can take up considerable energy, which might not always be available as people go through moments of weakness, have their illness acting up or increased life demands beyond the disease. The following quotation describes this challenge.

> *I wish I could do many more things…for the kids, with the kids, with my other half, with my business mmm…yeah…so…that's hard to live with, but at the same time I feel I can't ignore, I have been for many years, I have been trying to ignore those…the tiredness and, and, and…I feel I can't…I can't do that anymore…mmm (54-year-old man living with pituitary disease).*

Having a positive attitude towards treatment and chronic disease more broadly was also important in participants' narratives of chronic disease. Most participants from all disease groups described how they eventually got used to the inconveniences of treatment and, overall, felt happy with their health state and treatment results. For some, this implied accepting side-effects as they found them manageable, for others, it was appreciating not having had any complications or side-effects, and for others, this might have been represented in having hope in treatment. As exemplified in the following vignette, participants seemed to find comfort in, or gain some perspective from thinking that their situation could be worse. This is described in terms of optimism and hope in resilience research within the physically ill, and it has been regarded as helpful to overcome immediate disease-related hardship (Stewart and Yuen 2011).

> *I personally, like if I have to have some condition I am like right I'll take this over being diabetic or having terminal disease it's like… at the end*

> *of the day it's… it's, I am lucky that I don't have a really bad, I could have had my bowel removed or something if I had a really bad version of it (37-year-old man living with ulcerative colitis).*

Following on from this, many participants from all disease groups described feeling lucky overall by holding the belief that other conditions can be significantly more demanding or debilitating, that others living with the same diagnosis they live with seem to have a harder time with treatment and or symptoms, or that they have been in a worse place before. This also sometimes included feeling privileged for having good access to healthcare or good support from family and or friends. Closely linked to the idea of the paradox of chronicity presented in Chapter 4, having a positive assessment of their position in what seems to be a continuum between being healthy and being sick blurs the binary division between the two and helps sustaining this positive attitude about their own situation. As seen in the following vignette, this might not be, however, how other people see them.

> *I visited my family a while ago and I said I am perfectly healthy like I am absolutely fine…and then they all laughed…I was like why are you laughing? Like …yeah I have Crohn's but I am fine…I am very healthy otherwise like…aside from this issue [laughs] I am actually in very good health [laughs] and they all laughed so that's been really interesting in that like…the perception of sickness and health like really varies (29-year-old woman living with Crohn's disease).*

In a few cases, this positive view can lead to the experience that living with a chronic illness allows for personal growth—also highlighted in resilience research (Stewart and Yuen 2011)—by offering a new perspective over life, sometimes encouraging life changes that led them to being happier overall or living lives they liked better. Part of this positive attitude has to do with a more practical approach to chronic disease in which some participants from all disease groups weighted pros and cons concluding that they won more than they lost by taking treatment. Being able to do this was identified as something that facilitated following treatment and enduring the hard aspects of it. This, however, seemed to require experiencing treatment as something participants were overall capable of doing, regardless of how demanding it might seem. The following quotation reflects this positive attitude in a participant who had a very 'matter of fact' approach to her disease.

> *All I do is take four tablets a day two in the morning, two in the evening there's nothing hard about that…it is because I know because I have got into the routine of making sure there's always some in whatever bag so if you go into my bags each will have a little bit of mycophenolate (49-year-old woman living with rheumatic disease).*

This was the case for many participants from all disease groups, but it is worth noting that this was not always consistent with people rigorously following their treatment or recommendations as some participants found their treatment easy to follow, and still experienced the need or desire to take breaks, for example, as seen in the following vignette.

> *Yeah, I do take it I don't take it all the time, but I do…I mean, when I say all the time I mean OK…sometimes on a weekend…I'll just give it a*

> *break…I would not take it on weekend, but Monday morning I am back on it yeah (46-year-old woman living with pulmonary fibrosis).*

Although this is referred to in the literature as ‘self-efficacy’ and ‘mastery’ and is associated with good self-management and adherence to treatment (Stewart and Yuen 2011), this angle of research does not consider the possibility introduced by participants in this study of not fully adhering to long-term treatment despite having such resources—self-efficacy and mastery. This might be understood in terms of what Campbell et al (2003) call strategic non-compliance and Walker (2019) calls intentional non-adherence. However these are complex concepts with challenging ethical implications—as arguably difficult to isolate from broader and more structural social variables affecting adherence, and so these will be discussed in detail in Part IV of this thesis.

5. Chronic disease and the porous boundary of identity

Following the idea of positive life changes encouraged by chronic disease, research on personal transformation or growth achieved through chronic disease is another important angle in the literature on psychological adjustment. As discussed in the introduction to this thesis, Dubouloz and colleagues’ (2010) model of the process of personal transformation describes that after the turning point associated with the diagnosis, people reflect on what changes need to be made in order to respond to the new state of illness and face the challenges of adjusting future perspectives and discerning the self from the body. Once this is achieved, people enjoy a more intense sensitivity to life, better understanding and acceptance of the self, and an increased appreciation for significant others (Dubouloz et al. 2010). Still, drawing on participants' experience, this prescriptive and linear model might not reflect the complexity of the transformation process and potentially less 'successful' outcomes.

Almost all participants in this study described finding ways, even if only at times, to continue living their lives as they did before the diagnosis, or preserving enough central aspects in their lives so they could still live a life they had reason to value. This, however, ran parallel to the struggles described in the previous sections of this chapter, suggesting a dynamic and comprehensive perspective of the impact of chronic disease. As seen in the following vignette, some of the elements that seem to contribute to such adjustment imply displaying both internal and external resources in order to come up with strategies that can allow them to continue doing meaningful activities.

> *Having Crohn's it did affect my…look for the future…but not in terms of limiting what I want to do…more in the case of having to…think and plan more carefully to do those things…so that's what I would say…like I still like I can do everything I just need like a little bit of time to think about it and plan it, organise it and then it's fine…(29-year-old woman living with Crohn's).*

Participants described an understanding of adjustment to life with chronic illness as a process that requires time and other resources, but that even if having these, it may not be a stable achievement or a linear process, as it is sensitive to context, periods of illness, severity of disease and how disruptive each experience of illness can be, among others.

As mentioned in Chapter 2, the process of identity formation integrates the individuals' conception of themselves and how their social contexts recognise them (Erikson 1980), thus 'identity' might be regarded as sensitive to contextual aspects such as illness, but not only. Building on the ideas introduced in Chapter 4 about chronicity in a phenomenological sense, in the process of chronic illness becoming a part of the person, participants described this dynamism as they shared how the disease sometimes would take over their schedule, social content, and in a deeper sense, their experience of themselves or their identity. However, having the self-awareness to introduce a harder boundary and protect non-disease related aspects of the self was highlighted as a particular strength allowing them to live the lives they had reason to value.

In the following vignette, the participant describes the process of developing such a boundary by getting used to her disease and having the confidence and knowledge that allows her to keep certain disease features from taking over her life and sense of self. In this sense, this harder boundary helps to keep the disease at arm's length.

> *Five years ago I would have said I am diabetic like that would have been how I describe myself as a person because it just took up…everything…everything was affected by, if my sugar level was…not good I would not be having a good day, you know? like it dictated everything…whereas now it's just, it just rolls in the back so it doesn't feel like a…it doesn't feel like as big a part in my life at all…so maybe that's why I don't think about these things because it's just…it' not at the fore of my mind probably…possibly…I genuinely don't think about it very much, I really just…it's all second nature…(30-year-old woman living with type 1 diabetes).*

Thus, the boundary between the self or identity and chronic disease might be described as having a dynamic porous quality, which might become more or less permeable throughout illness and life trajectories. Participants also described that keeping the disease at arm's length included negotiating how to complete self-care tasks without entirely giving up the things they felt made them, in part, who they were. The next quotation shows how smoking cessation for health reasons can be difficult in this way.

> *It [smoking] is kind of in a way part of who I am… mmm… it's something that […] I don't know I am use to thinking and smoking and writing and smoking so it's something I wouldn't give up because of that, because it is kind of linked to something that I really like to do and it calms me in a way or it makes me…(33-year-old man living with Crohn's disease).*

A similar idea was introduced before in the section on the paradox of chronicity, as some participants described the effort of abstraction required to keep the future cyclical or whimsical manifestations of their illness in mind during symptom-free periods. This was described in terms of the difficulty of integrating chronicity, which made long-term treatment adherence problematic at times but allowed them, in the short term, to live the lives they have reason to value. This might be further specified now as a function of this dynamic porous boundary of identity. Still, it differs from the previous examples as a less proactive or aware introduction of the harder boundary, which is facilitated by the absence of disease manifestations and not by a sense of habituation and confidence regarding disease manifestations or an active effort to protect non-disease related aspects of the self.

Linked to ideas around identity and asserting agency, most participants from all disease groups described how important it was to have a certain level of choice or flexibility margin regarding their treatment, so they felt they had the opportunity to deal with their illness in their own terms and set the boundaries, at least to some extent, of how, when and what they were willing to do.

It has been argued that in order to move beyond the burden and suffering associated with living with chronic diseases and effectively manage their diseases, people living with chronic disease have to face a process of being transformed by the experience, aiming at the integration of new ways of being (Dubouloz et al. 2010). This process of transformation acknowledges to some extent the challenges that chronic diseases raise for people’s sense of identity, but as already mentioned, it is presented as a rather linear and static progression, which does not account for the hardship, precarity and dynamism in the process of chronic disease, often disturbed by periods of illness (cyclicality of chronic diseases) among other environmental variables. Following this dynamism, in the following quotation the participant describes introducing a harder boundary between illness and her idea of herself, as she says that how she was while ill was not 'really' her.

> *I obviously got sick…mmm…and I was there for quite a while and that was fundamental like it felt like a fundamental set back so I needed to and I lost all of that control that I had like…you know? I went from like running the show to…crawling into [hospital] and crying on the doctor's shoulder…which isn't really me anyway, but it was like the shock of it mmm…(29-year-old woman living with Crohn's disease).*

Reflecting further about the idea of a more or less permeable boundary protecting the self from chronic disease, after being prompted with a general open question about themselves and before being asked about their illness story, many participants from all disease groups described themselves without immediately including or making reference to their diagnosis or their experience of illness. Participants' self-descriptions tended to focus on their origins, their family lives, activities and demands, and what they do for work and in their free time.

Within this group, participants highlight a positive view of themselves and their lives, which might be seen as resources or protective factors helping keep the illness as—not the main—part of themselves, while living lives that, to a greater or lesser degree, they like and enjoy. In other words, having a strong sense of professional achievements, or positive and strong family lives may help support and keep a strong sense of self or identity, which is not taken over by ill health. One participant explained this process using a stool metaphor:

> *It's making sure that you always have like an independent or a balanced identity maybe that your identity is made up of like different pillars like your like your like, work, health, friends, family…and if one those falls you are still probably going to be able to sit on the stool…but if…too many of them go or…like work and health went for me at the same time…so my stool had fallen over…(29-year-old woman living with Crohn's disease).*

This image of identity as a stool supported by different dynamic elements resonates with the metaphor of balance—understood as dynamic equilibrium—discussed throughout this chapter. Identity is represented in relation to the flow of different stocks, also highlighting the complex interaction between them as, in this case, the stocks of work and health affected each other corrosively. Closely linked to this, many participants from all disease groups described themselves proudly as hard workers, fighters, strong, self-made, overcoming difficulties, wanting to do as well as possible, or not giving up, which might speak to participants' resilience, as already discussed. Most participants in this group overlapped with those not including their chronic disease as a very important part of their identity, suggesting that, in some cases, having the sense of being resilient might be a strength for adjusting, allowing participants to preserve their identity and keep the illness from ‘seeping in all aspects of life’, as one participant said. In other cases, or perhaps in addition to this, being resilient might be the result of adjusting to the challenges of living with chronic disease, becoming a way of living beyond illness.

Still, when prompted with the same general open question about themselves some participants from all disease groups included their experience of chronic illness or diagnosis as part of their self-descriptions. In a few cases within this group participants described how the illness temporarily affected their sense of self as, after an initial acute period of illness, they regained the ability to do activities that were important to them, either in the same or in a sufficient way. All participants in this group had strong support networks such as supportive nuclear family and or work environments and professions before being diagnosed, which is regarded a crucial fertile functioning or resource for resilience overall (Wolff and de-Shalit 2007; Stewart and Yuen 2011; Vassilev et al. 2014). The following quotation offers a glimpse of the mechanism underlying this fertile process.

> *What can I say about myself? [laughs]…so…you know? I am a mom, I am a psychiatrist, I combine working with…well having brought up my girls with my husband and I suppose my illness had an effect in the family in that I went from working full-time to part-time and I stayed working part-time…my husband…so he put his career on hold to look after the children a bit more so change, had a lot of effect on us as a family, but it’s been good…(49-year-old woman with rheumatic disease).*

The other participants in this group shared how chronic disease significantly changed their lives irreversibly by taking away core elements of their identity, such as the possibility to work or be physically active and able. All participants in this subgroup lacked substantial support networks, thus lacking other strong elements to anchor and or continue developing their sense of self. This is seen in the following quotation from a participant's self-description.

> *Ectomorph…mmm I am 6 foot 3 I am tall and skinny basically…and always have been mmm sporty guy used to be…mmm sadly rheumatic disease took most of my sporting pursuits away mmm…and I have been suffering from rheumatic disease since…diagnosed in about 91 or 1992 (62-year-old man living with rheumatic disease).*

Thus, although conceptualisations and research findings focusing on macro-level coping strategies, personal transformation, and resilience all contribute to understanding the experience of chronic disease, these have been developed as normative conceptualisations focused on what is normal or healthy and thus expected from people living with chronic disease. This means that when people struggle or do not cope, transform themselves, or are not resilient, they are failing. This might be argued to be in direct conflict with the dynamism and variability engrained in the concepts of coping and resilience. Drawing on participants' experience, this dynamism might be described as the effort of finding and keeping a balance that is not a stable achievement, but in constant flux and negotiation with their context. Thus, this *effort*—towards balance as dynamic equilibrium—in itself would be at the centre of life with chronic illness, and what adjusting means, comprising moments in which balance is both achieved and lost. In line with participants' experiences described thus far, variables such disease severity and uncertainty regarding prognosis, among many more—such as social support and socioeconomic status—have been argued to impact a person's resilience, coping strategies, and adjustment more broadly (Stewart and Yuen 2011; Stanton, Revenson, and Tennen 2007; Chronister and Chan 2007).

6. Conclusion

This chapter argued that life with chronic disease implies finding, keeping, and unavoidably sometimes losing the balance between controlling the illness, taking care of the logistics of care, and continue living the lives people have reason to value. In this ongoing effort, people living with chronic disease endure a myriad of challenges and burdens and display several resources and strategies.

In the search for balance understood as dynamic equilibrium, participants shared how justifiably hard and demanding long-term treatment can be, meaning that it cannot always be prioritised and thus adherence may be hampered. 'Strategic non-compliance' or people living with chronic disease departing from medical advice in order to achieve this balance between disease-associated demands and the life they want to live has been described as positive for health outcomes (Campbell et al. 2003), but this cannot always be the case. Sometimes deviations from medical recommendations may lead to unwanted health consequences, and not all non-adherence is strategic or voluntary, as discussed in this chapter in terms of competing demands and the cumulative disadvantages taking place amongst people living with chronic disease. This might reflect a certain degree of tension present throughout this chapter. Dynamic equilibrium focuses on understanding participants' dynamic choices in context—without judgement, while simultaneously drawing on rather static understandings of adjustment and the normative idea underlying the capabilities approach that participant's preferences can be more or less adaptive. Still, this chapter's effort towards a new understanding of life with chronic disease might be seen as a stepping-stone for the normative work in the rest of this thesis.

This chapter introduced the fundamental idea that adherence to long-term treatment is not a stable achievement both because it is highly sensitive to context in a broad sense, and because even if near-perfect adherence is considered possible, this might not always be desirable from the perspective of people living with chronic disease. This latter point has to do, at least in part, with the porous boundary between chronic disease and the self, also introduced in this chapter. Who people are seems to be strongly based on what people do, and more specifically, on what people feel they are good at. Therefore, and following from the ideas presented in Chapter 4 regarding what are chronic diseases, the degree to which and how chronic disease and long-term treatment change what people can do, can also to some degree change people’s identity or sense of self. Drawing on participants’ experience and interdisciplinary research on the experience of illness, the next part of this thesis will focus on such disruptive aspects of life with chronic disease, proposing a detailed multidimensional perspective of the experience of chronic disease that is crucial to continue the discussion about adherence to long-term treatment.

Part III:

Multidimensional Perspective On The Experience Of Chronic Disease

Introduction to Part III

The following three chapters (6, 7 and 8) integrate the experience of participants in this study with the ideas developed in an earlier phenomenological framework I developed mainly drawing on the work of Susan Sontag, Arthur Kleinman, S. Kay Toombs, Michael Bury, Arthur Frank, and Havi Carel.[1] The new multidimensional perspective on the experience of chronic disease introduced in the following chapters builds on the three dimensions of the original framework, namely 'failing to recover as a failure to belong', 'being at a loss', and 'breaking-up with oneself'. Still, the following chapters add significant detail to the complexity of the processes described, introducing relevant nuances, new concepts and tensions that contribute to further specify current understandings of the struggles associated with chronic disease at an individual level. Just like in the original framework, the three dimensions in the multidimensional perspective are neither stages nor necessary conditions of experience. The word 'dimension' refers to the emotional space within which the experience of chronic illness takes place, proposing a particular lens to conceptually organise the complex and multi-layered struggles of living with a chronic disease.

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[1] This work was published in the Journal of Medical Humanities in 2020 (Stutzin Donoso 2020) and it specified academic literature on the experience of illness in general, to chronic diseases in particular by underlining the role of chronicity in its phenomenological sense. This systematisation helped to describe the relevant context to better understanding the problem of long-term treatment adherence.

Very briefly, Chapter 6 – Dimension 1 will focus on the relationships between chronic illnesses, sense of belonging to the social world and support networks. Building on participants' experience of stigma, lack of place and lack of empathy, this chapter will argue that people living with chronic diseases suffer from prejudiced hermeneutical marginalisation that contributes to their withdrawal from social situations, isolation and loneliness which, in turn, hinders their possibilities to keep previous social support and build new social connections. Thus, this will be framed as a hermeneutical injustice, which seems somehow disconnected from—still crucial—isolated experiences of testimonial justice, adding a new layer to the vicious circle of disadvantage among people who live with chronic diseases.

Chapter 7 – Dimension 2 will examine the give-and-take between the contingency of illness and the quest to regain some sense of control while also preventing the disease from taking over people's subjective worlds. This chapter will begin by exploring participants' experience of having no to little sense of control over the disease and their bodies and their quest to regain some sense of control mainly through monitoring and healthcare monitoring. After arguing that harmonising the body as subject and object is a main task in this quest for control and a micro-level task contributing towards dynamic equilibrium, this chapter will go into depth about the agency struggle, described by participants, between the disease, monitoring and treatment, and the self. In so far self-management tasks can become alienating people living with chronic disease have to—more or less consciously—choose between an increased sense of control over the disease, and their sense of agency over their lives more broadly.

Finally, Chapter 8 – Dimension 3 will reflect on what the previous two dimensions imply for participants' relationship with themselves in the processes of becoming ill and living with chronic disease. Thus, this chapter will expand on the difficulties associated with the subjective change of giving up a previous favoured status by reflecting on participants' resistance to acknowledging chronic illness. By helping people with chronic disease diagnoses avoid developing negative feelings and attitudes towards themselves and work towards dynamic equilibrium, this resistance will be framed as a feature of the protective function of the dynamic porous boundary of identity. Still, during the onset of disease, this is argued to contribute towards delays in diagnosis, which might be amplified by healthcare professionals who fail to listen to patients' experiences. Such failure to listen will also be argued to lead to physical and psychological harm, constituting a testimonial injustice. In this context of both acknowledging and resisting illness, this chapter will also introduce the idea that people may go through a process of mourning for a rather complete and more or less abstract loss of health, but not for the reiterative losses experienced along with the cyclical or whimsical manifestations of chronic diseases. Although emotionally challenging, this will also be framed as part of the protective function of the porous boundary of identity.

Alongside the varying degrees of physical suffering and or limitations associated with chronic diseases and long-term treatments, these three dimensions argue that in so far chronic diseases and long-term treatment can threaten belonging to the social world, sense of agency and self-concept or identity, these can significantly affect people's possibilities to live the lives they have reason to value and thus will play a crucial role in the process towards dynamic equilibrium. Although dynamic equilibrium can sometimes jeopardise disease outcomes, this work suggests that this will often be to protect another subjectively crucial aspect of life and the self.

This multidimensional perspective represents an effort to embrace the complexity and variability inherent to human phenomena, instead of risking oversimplifying the matter by suggesting a prescriptive guideline for normalcy. This means that this multidimensional perspective—as the theoretical framework—does not claim to be a complete account of the experience of chronic disease.

Chapter 6 - Dimension 1

Ruptures in belonging and the limited value of support networks

1. Introduction

The first dimension of the experience of chronic disease focuses on the relationships between chronic illness, sense of belonging to the social world and support networks. The complex relationship between these variables is central in the literature on chronic disease and was consistently central in the experience of participants in this study, as briefly presented in the summary of the thematic analysis in Chapter 3.

Intersubjectivity plays an important role in the lived body approach to chronic illness. Zeiler (2013) argues that people are immersed in a world already inhabited, shaped, and made familiar to them by others, and it is this familiar world which gives people the capacity to be oriented. Bury's (1982) work suggests that living with a chronic disease implies a profound disruption of such explanatory systems, leading to a fundamental re-thinking of the person's biography and self-concept, mostly in terms of relationships with others. More specifically, chronic diseases have been argued to impose changes in personal and community involvement, social roles and activities which often lead to significant withdrawal and isolation (Bury 1982).

Chronicity implies that cure or full recovery is off boundaries, anticipating the subject's departure from the social world—as that of the healthy, and its forced reallocation to what Frank (1995) calls the remission society and Carel (2016) describes as introducing an experience of unreality, estrangement and detachment. Building on participants’ experience of stigma and isolation, the second section of this chapter argues that people with chronic diseases are sent into a fight they cannot win, systematically failing to comply with the compulsory able-bodiedness that surrounds them. Building on this, the third section introduces the prejudiced hermeneutical marginalisation of the experience of chronic disease in terms of a lack of place, which contextualizes experiences of lack of empathy. Section four examines this hermeneutical marginalisation and its consequences, arguing that people with chronic diseases suffer from a hermeneutical injustice that contributes to their withdrawal from social situations, isolation and loneliness which, in turn, hinders individuals’ possibilities to keep previous social support and build new social connections. Finally, section five analyses participants’ apparently contradictory experiences of ruptures in belonging and good support: these are argued to represent structural hermeneutical injustice and individual practices of testimonial justice, respectively.

2. Meanings of illness and the experience of stigma in chronic disease

Almost all participants described chronic illness threatening their sense of belonging to the social world either because of visible bodily changes, invisible effects, treatment or a combination of these. This lead to isolation insofar as it limited participants’ possibilities to take part in social activities that can be central for engaging in or developing meaningful relationships.

Besides the more evident physical difficulties of engaging in activities, such as playing sports or going out with friends, participants also described less evident hurdles to taking part in the social world, as they no longer felt safe or comfortable in certain contexts and simple, previously enjoyable experiences became effortful and or stressful.

Reflecting on the meanings of illness can be particularly helpful to reflect about chronic disease and issues around belonging. Diseases that have a multifactorial aetiology and non-curative treatment, like chronic diseases,[1] have been characterised as capricious and unacknowledged, challenging the current biomedical premise that the body can be fixed (Sontag 2006). The military metaphor of illness implies regarding illness as a fight, attributing agency to disease processes that need to be countered by the person with the disease, often with the help of medicine. However, when it comes to chronic illness there is no winning, killing the enemy or eradicating the disease. As discussed in Chapter 4, chronic diseases become a part of the body and thus a part of the person, regardless of treatment and the cause of disease. As one participant described, people living with chronic diseases have to get along with life and

> *learn to live around your problems [symptoms] rather than continuously fight them, because you can't win, there's no winning, you know? (31-year-old man living with pituitary disease).*

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[1] See discussion on mono and multi-causal theories of disease in Chapter 4, section 3.2.

Although Sontag (2006) wrote about illness metaphors reflecting on tuberculosis, cancer and HIV in the late 1970s and 1980s, when illness and medicine might have been somewhat different, her insights continue to shed light on current understandings of illness. Insofar as medicine works on the assumption that the body is other than the self, it also assumes that treatment attacks the ill body and not the self. However, and as discussed in Chapter 4, this dissociation is particularly hard in the case of chronic diseases, so fighting the disease means fighting the body and the person living with the disease. Even if people do not experience symptoms from the disease, they might still have to deal with the side-effects of treatment and fighting the disease can significantly affect a person's life. As discussed in Chapter 5, although this may lead people to stop or alter their treatment this is often not seen nor experienced as a valid choice, implicitly demanding people to fight regardless of the consequences. Like this, although the military metaphor might help individuals share their experiences of illness, it seems problematic when it becomes a taken for granted social discourse.

Because the boundaries between the disease and the person who has it can become particularly blurry in chronic diseases, by associating the disease with evil, the military metaphor of illness very easily turns against and blames those who are ill. This resonates with the currently common and widely accepted descriptor of 'self-inflicted illnesses' to refer to chronic diseases. As already discussed, chronic diseases have a multifactorial and often unclear aetiology and their main risk factors are associated with lifestyle. These individual health risk factors are often called 'lifestyle choices' despite evidence showing a social gradient in the burden of chronic diseases and their risk factors, establishing a correlation between life circumstances and lifestyle.

This process has been described to contribute to the stigmatisation of the disease and the person, rushing a social death in anticipation of biological death (Sontag 2006). This seems particularly relevant for the case of chronic diseases, for which the military metaphor can only imply struggling, a failure to recover from illness. Although fighting chronic illness could also be seen as heroic or noble, like soldiers are usually portrayed especially after wars are over regardless of the outcome, as highlighted in the last quotation chronicity implies that there is no ending to the fight, no big moment. Thus the 'fight' loses meaning and is often taken for granted, merely seen as what needs to be done to continue living or to live the best life possible.[2] Like this, life with chronic illness has been argued to disrupt people's sense of ordinariness or normalcy (Carel 2016), which makes direct reference to the stigma of illness.

Goffman's theory on social stigma (1974), originally published in 1963, describes how some—often considered deviant—attributes or behaviours become socially discrediting, leading to a social division in which those who are stigmatised are somehow undesirable or rejected, whilst those who are normal enjoy the status of being accepted by others or belonging. Sontag's (2006) essays stress how this social process takes place in illness across time and within specific contexts, showing how important it is to understand

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[2] This refers back to Chapter 5, where life with chronic illness was described to imply a significant invisible burden of the logistics of care and a constant effort towards balancing competing demands.

stigma as a flexible phenomenon in the sense that it is strongly associated with language and context. Goffman (1974) makes this point by explaining that attributes are not discrediting in themselves, so to understand stigma it is necessary to understand the relationships involved in attributes or personal circumstances gaining discrediting meaning in a specific context.

Many participants described experiences of or having the fear of being rejected, judged or discriminated against specifically because of having a chronic disease. Building on the experience of people living with epilepsy, Scambler (2004) labelled these as two different experiences of stigma, namely felt and enacted. On the one hand, enacted stigma would describe episodes of discrimination against people living with chronic diseases solely on the grounds of chronic diseases' social and cultural unacceptability. On the other, felt stigma would describe the shame associated with having a chronic disease, as well as the fear of encountering enacted stigma (Scambler 2004).

Some participants described experiences of enacted stigma, this is, being judged and rejected due to their illness as they described being fired, seen as less capable to work, friends distancing from them, or being shunned. Still, the experience of felt stigma dominated within participants in this study. Participants described feeling embarrassed about things like having difficulty eating or diarrhoea, having a sexually transmitted disease, being physically weak and fragile, gaining weight, developing acne, coughing too much, or having a shaky body. Thus, some participants described self-secluding to avoid being questioned or having to explain themselves to others, finding it difficult to break that circle and make new friends or find new social contexts.

Furthermore, many participants described fearing to be judged or discriminated against because of their illness. Although some participants did not say this so directly, they described adjusting how, when and to whom they talked about their illness to avoid judgement, assuming that illness is something negative, which somehow limits their capacity, or simply wondering and worrying about what people may think of them.

Although participants' experiences offer many examples of felt stigma, the following quotation shows how the mere fear of sharing a diagnosis and being judged for it is enough for the participant to feel that she needs to justify herself.

> *It's quite difficult not to tell them [other mothers in school] so I have had to more, so more people know mmm…but yeah I worry about…because I have seizures I don't want people to think that I can't [laughs] like look after their children, you know?…things like that so that worries me I think, but I only ever had them at night, I have never had one in the day…mmm…so mmm…so I don't want someone to think 'she can't look after my children' and things like that, you know?…I don't want people to think I am not…able to (41-year-old woman living with Lupus).*

Specifically in the case of people living with HIV, felt stigma included worries around being labelled as a prostitute, being a disappointment for their family or thinking that people would blame them for getting infected and assume they could have prevented it. As the following quotation shows, one participant had not registered to receive primary care because of this fear.

> *I am not even registered with a normal doctor yet because I am like…if I register I have to tell the receptionist and if I tell a receptionist then you feel like people talk…people do say things, it's just natural human nature…people do talk, I know they say about things with confidentiality, but I have worked in care, so I know that's not always kept, it's not (46-year-old woman living with HIV).*

Beyond HIV, participants from all disease groups described deciding not to disclose their health situation unless strictly necessary, fearing that people may be insensitive or change the way they treat them. In the context of queer and disability studies, this processes of disclaiming is often described using the metaphor of 'coming-out of the closet'. Although Samuels (2003, 238) discusses the limits of using this analogy to reflect about the personal and social experience of disability, her work highlights the process described by participants in this study as she states that because of the fluctuating nature of chronic illness, as opposed to disabilities, the 'coming-out' is not about claiming the label of 'disability' but constructing a narrative to explain one's "body to a sceptical, ignorant, and somewhat hostile audience".

Following from this, and much in line with the idea of the porous boundary between chronic disease and identity introduced in Chapter 5, participants also shared making an effort to put the illness aside, if possible, to keep their place amongst others, reflecting a deep sense of what McRuer (2006) calls compulsory able-bodiedness, at least on a descriptive sense. Building on compulsory heterosexuality and in the context of critical disability studies, this author argues that able-bodiedness is a dominant identity seen as the natural order of things that limits other ways of being and, as argued in this work, significantly limits or ruptures ill people's sense of belonging (McRuer 2006). Still, the normative implications of 'compulsory able-bodiedness' are far-reaching and not fully consistent with the normative implications of the findings of this study.

As seen in previous chapters, living with a chronic disease can be frustrating and a big part of this feeling had to do with the experience and the idea amongst participants that their lives would be better, or would have been better without chronic illness. The following quotation reflects this core narrative and specifies how the meanings attached to illness can come together with intimate experiences of illness, while also being experienced as two independent phenomena.

> *They [her parents] weren't really educated about this [illness] in school or anyone that is educated is educated that it is a bad thing, and I am not saying it is a good thing to have because it is not, but if someone does get it in the situation of how they get it you can't really judge people and you have got to be more supportive (46-year-old woman living with HIV).*

Much in line with the critical disabilities theory within which McRuer's (2006) work on compulsory able-bodiedness sits, this quotation reflects how judgements on chronic illness come from the social context and its shared meanings of illness. Broadly speaking, critical disability theory moves away from individual and medical understandings of disability, proposing to frame this as a social, cultural, historical and political phenomenon. The core normative implication of this shift suggests that disabilities are not deviations from normal or healthy bodies and negative consequences derive from socially, culturally and politically constructed limitations that can more or less concretely affect the lives of people with impairments (Hall 2019). Still, as seen in the previous quotation and as will be discussed in depth in chapters 7 and 8, chronic illnesses also bring pain and suffering—other subjectively unpleasant symptoms—in themselves, at least at times, which led participants to experience these as a least favoured status relative to their previous experiences of being healthy. As highlighted by Walker (2019), this is consistent with pain being regarded as unpleasant and bad in itself, and that alleviating unpleasant sensations contributes to wellbeing.

3. Lack of place and lack of empathy in chronic disease

As discussed in Chapter 5, chronic illness may endanger people's possibility to work both because of rather straightforward limitations and or because of these more subtle challenges, risking their participation in the social world. Some participants described significant suffering and isolation after being fired because of their illness—medically retired—or other reasons, and then struggling to find a new job because of their illness. Closely linked to this, participants also described having to be protective of their place and prove their capabilities at work. The following quotation describes this negotiation after the participants' employer realised, two years later, that she had informed them of a chronic disease in her induction form.

> *They were trying to like you know? say that 'you can't go anywhere on site alone'…and I was like 'don't even start that shit with me' like I was 'I have been working here for like nearly two years…I am not gonna be treated any way differently now, I am fine I can manage my condition' […] so he was like 'OK' [laughs] (30-year-old woman living with type 1 diabetes).*

Although there have been improvements to the benefits system in the UK over the past ten years, a few participants described feeling misjudged by it and thus alone in seeing their needs recognised and addressed. Following from the discussion about working conditions in Chapter 5, participants underlined the importance of the benefits system closely following-up their situation, thus accompanying and facilitating their most likely multiple and non-linear transitioning to more and less functional states. This refers to the unstable nature of chronic diseases and the constant efforts of those living with a chronic disease towards balancing different and varying demands. As seen in the following vignette, being able to work may satisfy needs far beyond mere subsistence, including social integration, self-esteem and sense of purpose.

> *I got put on disability allowance […] anything that came up then I had to refuse because I got the money coming in, which is good and bad in a way because mmm…ok I didn't need the money, but for that from a self-esteem point of view and also kids were all growing up I probably would have taken more work on than I did (65-year-old woman living with HIV).*

Thus, chronic diseases might be regarded as difficult to judge or as an intermediate, changing or fluctuating state affecting people's capabilities in complex ways. Susan Wendell's account of chronic illness[3] analysed in Samuels (2003, 240) work describes this as living "in between the world of the disabled and the non-disabled". This poses the question of what might be the place in society for those who have a chronic disease. Parsons' (1975) work on the sick role focuses both on the functionally significant features of the role of the sick person and the role of the therapeutic agents. Within the sick person's role, the author distinguishes between the state of illness as such and the role of patients in interaction with therapeutic agents, stressing the latter's functions of social control (Parsons 1975). Reinforcing the idea of compulsory able-bodiedness introduced before, Parsons' (1975) sick role understands illness as an impairment for integration in society, stressing the role of medicine and treatment as a reintegrative process, but this view does not distinguish between acute and chronic illnesses. Nonetheless, precisely because in chronic illness medicine fails to provide complete recovery, it might be said that it also fails in its aim to reintegrate the people with chronic diseases to society.

Bury (1982) argues that chronic illness conflates features traditionally associated with disability—as rather stable long-term lifestyle adaptations—and strategic handling of symptoms and features of acute illness, as periods of classic sick role behaviours. These behaviours include an undesired state

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[3] See Wendell (1996).

of illness, exemption from ordinary daily obligations and expectations, and seeking medical care. This conflation of stable and cyclical aspects in chronic disease resonates with the concept of chronicity in a phenomenological sense, which largely builds on this paradoxical element of chronicity, as discussed in Chapter 4. This was argued to demand from those who have a chronic disease to transfer the quality of continuous and irreversible to an experience that might be thought of as discontinuous in terms of how it is expressed in the body. This chapter reflects how chronicity in a phenomenological sense seems to impose the same challenge to the broader society when engaging with people who have a chronic disease diagnosis. This is, understanding that chronic diseases can be both absent (as invisible[4] and or asymptomatic) and present (as likely to recur), and what this means for the people who live with a chronic disease.

Although many people may seem understanding and respectful of life with illness, most participants shared the experience or thought that people do not—or would not—understand how it is like to live with chronic illness. This was described to imply both a lack of information about illness in the general public and a lack of understanding of the emotional difficulty of acknowledging chronicity, both as mere long-duration and its phenomenological sense. The

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[4] Although there are no official national statistics for hidden or invisible long-term illness, impairment or disabilities in the UK, estimates show that these may go up 70% out of a total of 11 million people who fall under this broad category (Brookes, Broady, and Calvert 2008; Department for Work & Pensions 2014).

following quotation shows how hard it can be to express this and fully grasp what it means.

> *Chronic conditions, in general, I think it's very hard for…for people to…to…just understand it when you're describing. Like how…how…it like…that actually emotionally, mentally makes you feel when you…when you know that you have to deal with it for the rest of your life. It's very hard for someone outside that circle to…to…to just get what you're saying. And it's…it's not even that, it's hard for...for me to express how I'm feeling (21-year-old man living with Crohn's disease).*

In Fricker's (2007) terms, this might be thought of as a hermeneutical disadvantage or circumstantial epistemic bad luck, merely highlighting a hermeneutical lacuna that hampers a shared understanding of chronic disease. However, this quotation reflects hermeneutical challenges commonly faced by people who live with chronic disease, namely inarticulacy—difficulty communicating the experience of illness—and ineffability—aspects of the experience of illness that cannot be communicated (Kidd and Carel 2017b; Woolf 1926). Furthermore, the power dynamics around compulsory able-bodiedness, chronic disease mostly carrying negative meanings and participants' experiences of stigma suggest background social conditions leading to this hermeneutical lacuna and a prejudiced hermeneutical marginalisation of people living with chronic diseases.

Drawing on participants' experience and borrowing Scambler's (2004) distinctions on stigma, lack of empathy towards the people who live with a chronic disease—which Carel (2014) describes as one of the most painful experiences of illness—might also be thought of as enacted and felt. Enacted lack of empathy would refer to cases in which people who have a chronic disease diagnosis experience others being insensitive regarding their circumstances, while felt lack of empathy refers to cases in which the people who have a chronic disease underplay their suffering and fear having unempathetic encounters. This latter experience is closely linked to the ideas around participatory prejudice—sense of relevance—in the medical encounter discussed in Chapter 5. Opposite to stigma—where felt stigma dominated over enacted stigma in participants' experience, enacted lack of empathy dominated in participants' descriptions and felt lack of empathy was largely taken for granted, as many participants shared that they did not talk about their illness or shared their diagnosis very often, and when they did it was mostly with healthcare professionals, close family members and or very few friends they felt safe with.

Descriptions of enacted lack of empathy included friends or family not knowing what to say or how to react to their suffering, not listening or paying enough attention to the illness aspect of their lives, repeatedly asking them the same questions, telling them how to act usually based on partial or inaccurate information, and experiencing that sharing their suffering pushed people away. One participant highlighted how particularly hard it can be to depend and rely on others to help out with their care if they do not empathise with their situation. Overall, the lack of empathy discouraged people with chronic diseases to talk about their illness and share their experience, contributing to their isolation.

Most examples of enacted lack of empathy were associated with chronic illnesses being mostly invisible or hidden conditions, and so not evident for others. This might contribute to making these diseases harder to be acknowledged, remembered and kept in mind among people who know or might be expected to know and potentially justify unempathetic behaviours among those who could not be expected to know. Nonetheless, participants who were visibly ill and carried an oxygen machine, for example, also shared the experience that people did not understand or did not know how to react.

> *My wife she gets really annoyed with people who stare at me and I just look at them and smile because it's like what are you gonna do? I don't think they are going out of their way to be horrible I just think that they are not conscious of the fact that they are doing things (52-year-old man living with pulmonary fibrosis).*

4. Hermeneutical injustice and chronic disease

The last quotation introduces the structural element of the hermeneutical marginalisation of people who live with a chronic disease. Participants described living in a society where dominant able-bodied identities are allowed to not understand their experience and lack awareness of their marginalising behaviours, suggesting that, and paraphrasing Fricker (2007), it is no accident that the experience of chronic disease has been falling through the hermeneutical cracks.

Many participants from all disease groups described blurry, or more flexible, boundaries between health and disease, as many identified as healthy despite their condition, feeling and looking fine most of the time. In this way, keeping their illness mostly to themselves might be a way of protecting themselves from enacted stigma as well as prioritising and giving continuity to their healthier experience of illness. This, in turn, and in addition to not looking typically sick even when they might feel ill, may contribute to increased enacted lack of empathy and unsupportive reactions. This might reflect a lack of a unifying referent of experience for people who have a chronic disease diagnosis or an unclear place in society, as they are neither fully sick nor fully healthy both for themselves and others.

This resonates with Gergel's (2014) paradoxical idea that, in the context of mental disorders, stigma stems both from regarding the ill as intrinsically different—as somewhat alien to society—and simultaneously grouping them around stereotyped similarities. Trying to break free from these imposed inaccurate labels, people with chronic diseases might enact compulsory able-bodiedness as a means for belonging to the social world at the cost of silencing their illness experience and lacking the support they might need. This might be argued to significantly harm those with chronic disease since, as already discussed, this plays a key role in chronic diseases becoming a risk multiplier for disadvantage.

Participants described how chronic illnesses can be confusing in terms of whether they have a special status or not, not knowing how to act, nor what to expect in terms of being entitled to special treatment or not, as well as wanting to demand such treatment or not. The following quotation represents this confusion and reflects how, by feeling mostly healthy, this participant also seems to resist the sick role.

> *A friend of mine has it as well and he gave me this card to say, it's a card that says I really need to go to the toilet. I was like, so what, so funny, so I am gonna put that in my wallet and go around with that? It's like when I want to jump the queue or…who's even gonna read that and take it like…maybe some people do but… […] You are a card-carrying colitis victim or something like that, like fff…. That nearly would…it's like tempting fate, you know? …I don't know, I wouldn't be…I don't want to go around wearing a badge or like 'cry me a river', like I have this thing (37-year-old man living with ulcerative colitis).*

The experience of lack of place seemed to be augmented for participants who had rare diseases. This sub-group described an extra layer of hermeneutical difficulty when sharing their experience of illness with others as people did not understand or forget, and they themselves did not know how to explain it better as there is little information available and no clear 'path'—as progression or general reference—for them. Some participants argued that if they had cancer, for example, it might be easier because people know what that means. Still, more generally, participants described that people's ideas about diseases can be rather narrow and stereotyped, not always fitting their experience and so having a clearer path was neither necessarily easier, nor made them feel more understood.

This was described as difficult both in their personal experience of illness, and when discussing their health situation with others. Regarding their personal experience, participants shared realising that sometimes their experience of illness did not match what they thought the disease was or would be like, having thus misleading expectations or lacking reference points to reflect and make sense of their experience. When discussing with others, stereotyped ideas about disease also implied feeling misunderstood, as people imposed their general and often uninformed ideas about illness on participants. The following quotation reflects the frustration associated with personal stories of illness being silenced by stereotyped ideas about illness or single stories of illness.

> *I think that stereotype of Crohn's is very…is very prevalent and it sticks in people's minds of like, you know? like of constant diarrhoea, really bad fatigue or you know? vomiting and stomas and it's all the horror stories that I think are the stereotype and I don't really aside from the fatigue and I am actually in one way fortunate I don't have so many of those like very disruptive symptoms…mmm…so I find that quite…I suppose I found it frustrating that people would go and look online get all these ideas in their head rather than just ask me (29-year-old woman living with Crohn's disease).*

Thus, participants described also experiencing the harm of not being understood and being "socially constituted as […] something they are not and it is against their interest to be seen to be" (Fricker 2007, 168). As described by Zeiler (2013), Merleau-Ponty's concept of sedimentation refers to the strong process through which a particular way of being acquires a favoured status after receiving frequent confirmation. Thus, some culturally shared and corporally enacted beliefs and norms can become part of peoples' taken-for-granted being-in-the-world and shape embodied agency (Zeiler 2013). Starting from McRuer's (2006) compulsory abled-bodiedness and also drawing on Bury (1982) and Gawande's (2014) work, it might be argued that healthy bodies belong to the culturally shared and corporally enacted beliefs and norms reinforcing youth and independence in western societies. Thus, in rejecting or failing to acknowledge chronic illness as a way of being, the social world has the potential to significantly interfere with someone's process of sedimenting this as a new way of being, confirming their social death (Sontag 2006) or reallocation into the remission society (Frank 1995). In sum, considering the disadvantaged position that people who live with chronic disease are likely to be in and the harmful effects of their prejudiced hermeneutical marginalisation, they might be argued to suffer from a hermeneutical injustice (Fricker 2007). Although people who live with chronic diseases have been argued to suffer from hermeneutical injustice before,[5] this work describes new and far-reaching consequences for the kind of harm this injustice inflicts over those who live with a chronic disease because of its cumulative effect over disadvantage more generally.

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[5] Kidd and Carel (2017b) have argued that people who live with chronic diseases suffer from semantically-based (not having access to the semantic resources needed to get their experience across) and agency-based (being denied the agency to participate in meaning-making processes relevant for their care) hermeneutical injustice in healthcare contexts.

5. Social support and the efforts of people living with chronic diseases towards dynamic equilibrium

As already mentioned, the ruptures in the sense of belonging introduced in this chapter raise ethical issues because of what has been described as the vicious circle of disadvantage among those who live with a chronic disease. Having a sense of belonging or affiliation and social networks have been largely identified as one of the most fertile functionings or corrosive disadvantages contributing to overcome a broad range of difficulties (Wolff and de-Shalit 2007). Being well-supported by friends and or family has been argued to significantly help mobilise resources thus correlating with greater agency to implement desired health behaviour changes (Bury 1982; McDonald et al. 2015; Vassilev et al. 2014).

However, as presented hereunder, the findings of this study suggest that participants experienced significant ruptures in their sense of belonging while still considering they had been well-supported by friends and or family, at least at some point throughout their illness trajectory. More specifically, the average time participants had been living with chronic illness at the time of the interviews was over fifteen years and, over time, most participants shared having mixed experiences of, and attitudes towards, sharing their illness with others. Beside the unempathetic reactions described before, participants also described experiencing helpful reactions from others that allowed them to have the support they needed. Still, these were seen as exceptions and did not change participants' overall idea that others generally do not or would not understand their situation. This might be seen as an inconsistency or as part of the complexities of living with a chronic disease. The latter option resonates with the dynamism of chronic illness stories discussed in Chapter 3 and invites for further reflection.

Hermeneutical injustice is, by definition, a structural phenomenon in which there are prejudicial flaws in the shared interpretative resources, but even within this context, there might be skilled or virtuous hearers that can practise testimonial justice. This, however, is not enough for hermeneutical justice (Fricker 2007). Thus, it might be argued that participants' experience of being well-supported through life with chronic illness might follow from positive experiences with skilled hearers, but this is not enough to overcome participants' overall sense of lack of belonging if this is seen as the result of the hermeneutical injustice described in this chapter.

Testimonial and hermeneutical justice are both virtues of reflexive social awareness (Fricker 2007), so reflecting on what testimonial justice can look like in the specific context of chronic disease can also orient the discussion on hermeneutical justice for people living with chronic diseases. Participants described that support was especially appreciated around the time of diagnosis or during times of illness and increased dependency, but it could also be very important for the daily management of disease. Drawing on participants' descriptions, feeling well-supported comprised an emotional and a practical dimension. In more abstract terms, participants described feeling loved without judgement, having people around with whom they could talk about the more difficult aspects of life with chronic illness, or simply knowing that someone was available to help them if needed, as significant sources of strength and encouragement to keep up with the demands of chronic disease. More concrete forms of help and support included having people who could take care of them during periods of illness—picking up their groceries or medications, learn about illness management with them, or know their situation well enough so they did not need to explain much. This implied people being able to recognise symptoms and knowing how to treat them in case of an emergency or make spontaneous adjustments for them to continue to take part in meaningful social activities, among others.

Although this emotional/practical division helps organise participants' descriptions, these two dimensions were often intertwined in their experience, as shown in the following vignette.

> *Yeah so…those practical sides of things so…mmm…say…for…after rituximab, there was always someone to…in a way I would, I am very independent so I was, not really want anyone with me, but someone would always turn up mmm just even to have 10 minutes and then go away, they know to give me my space they are not over…overbearing so if I say I want to do something by myself…they know I mean I want to do it by myself, but they would just…remind me that they are there yeah?...mmm…I think just…I am very lucky, I am very supported and…we are always there for each other in whatever so I knew…I felt very mmm secure (47-year-old woman living with rheumatic disease).*

Thus, although being well-supported is a personal experience suggesting significant variation from person to person, on a more abstract level, it implies feeling able to share, at least to some extent, the daily responsibilities of chronic care, making it easier for those who have a chronic disease to rely and depend on others when they need to.

Although participants generally described feeling well-supported with gratitude and joy, some participants felt frustrated about chronic illness disrupting the normal rules of reciprocity and mutual support (Bury 1982; Carel 2016). This rupture in reciprocity did not only make some participants feel bad about family and friends constantly worrying, or guilty for putting this burden on them but it jeopardized opportunities to build close relationships of support, as it prevented participants from starting new relationships. This might reflect the individual and structural levels of the problem of belonging in the context of chronic disease. No matter how virtuous the hearer is, because of the power dynamics already described, in the broader scheme of things chronic diseases are seen and experienced as a lack, a failure, a burden that limits equal participation in the social world, this is, hamper hermeneutical justice. About this, Anderson (2012) argues that although it is virtuous for the advantaged to help the disadvantaged, this, on its own, cannot cope with the problems generated by the system.

Beyond going into detail about the qualities of helpful support from friends, and family members, and how failure to experience this negatively affected their sense of belonging by contributing to their withdrawal and isolation, participants also stressed how their relationship with healthcare professionals could have similar positive and detrimental effects. This is discussed in more depth in Part IV of this thesis, but it resembles the dynamics described in the context of friends and family. Participants described feeling well-supported by healthcare professionals in terms of long-term relationships in which people living with chronic disease felt known, safe and cared for. Although they mostly referred to their specialist care teams, a few also described this kind of support from their general practitioners (GPs) and mental health care professionals. As briefly mentioned in Chapter 5, in general, support from healthcare professionals was described as proactive, this means, being approachable, invested and covering a broad range of needs that also intertwined emotional (such as being encouraging) and practical (such as following-up on their care) dimensions. This was described to significantly help in the efforts towards dynamic equilibrium, this is, finding the balance that allowed people with chronic diseases to live lives they had reason to value.

> *It makes you feel safe as if you're in, you're in good hands and they know what they're doing for you and they want to see you reach the things that you like, they go with you into reach that and that makes it, like mentally and emotionally makes a difference, which I feel as important as, important …not as important as the treatment you're getting but it's very important to have it alongside your treatment (21-year-old man living with Crohn's disease).*

Going back to Parsons' (1975) sick role stressing the role of medicine and treatment as a reintegrative process, and drawing on the value participants assign to being well-supported by healthcare professionals as a fertile functioning, it might be argued that even if medicine fails to restore the health of people living with chronic diseases and in this sense allow their reintegration to society—the world of the healthy, the medical world can play a significant role in supporting the process of redefining the terms in which people living with a chronic disease can belong to a social world that is not limited to the healthy. It has been argued that healthcare systems and the medical profession hold a position of epistemic power, relative to patients, regarding illness (Kidd and Carel 2017b). Thus, drawing on Fricker (2007), practices of testimonial justice in healthcare, which are reflexive and aware of the prejudiced and harmful hermeneutical marginalisation suffered by people living with chronic diseases might be particularly powerful in mitigating the negative effects of hermeneutical injustice. Anderson (2012, 164) takes this argument further and states that on a structural level healthcare institutions have "powers to correct or prevent problems that virtuous individuals cannot solve or avoid on their own".

Although describing the relationship between individual and structural levels is difficult, the idea that these interact affecting the overall outcome is consistent with the complex systems approach to health justice in chronic diseases discussed in the introduction to this thesis. Drawing on Wolff's (2020) idea of differential social inclusions to represent the complexity that the binary inclusion/exclusion overlooks, Part IV of this thesis explores how this work's specifications about the experience of chronic diseases could inform healthcare systems and professionals' hermeneutical justice practices. Focusing on the power position instead of the structural/individual divide, this is argued to have the potential to contribute towards the development of shared tools for social interpretation of the experience of chronic disease that can counteract prejudice, stigma and lack of empathy, increasing the chances of those who live with a chronic disease receiving adequate individual support and developing an overall sense of belonging to the social world.

6. Conclusion

This chapter introduced the social dimension or emotional space of the experience of chronic disease. By looking into meanings of illness and processes of stigmatisation, lack of empathy and place, people with chronic diseases were argued to suffer from a hermeneutical injustice that contributes to ruptures in their sense of belonging, withdrawal from social situations, isolation and loneliness, hampering their possibilities to keep previous social support and build new social networks. This is particularly relevant because good support networks are described as one of the most fertile functionings or corrosive disadvantages, and so ruptures in the sense of belonging associated with chronic diseases represent significant difficulties to mobilise resources to face the state of illness and work towards dynamic equilibrium.

Still, in light of the complexity and multiplicity of stories contained in each participant's experience of chronic illness, this chapter suggested that fertile and corrosive processes are less straightforward than it might be assumed. By reflecting on the structural quality of hermeneutical injustices and the important, but limited effects of testimonial justice practices, being well-supported and experiencing ruptures in belonging are not mutually exclusive. This means that even if people living with chronic diseases have good social support and networks, on a more general level, they might still be prevented from developing a deeper sense of belonging to the social world due to structural issues. Fricker (2007) argues that although hermeneutical injustices affect everyone collectively, they do not affect everyone uniformly, as individuals' skills to express themselves and listen to others vary significantly. Besides cultural and historical contexts, testimonial and hermeneutical skills are associated with education level, socioeconomic group and social and psychological resources, suggesting that the advantaged within a society may have better chances of rebelling against injustice relative to the disadvantaged (Fricker 2007). Although this is a helpful point, its focus on rebellion seems slightly off focus both because the advantaged are less likely to suffer from hermeneutical injustice and thus have to rebel, and because it might be morally problematic to suggest that structural justice somehow depends on individuals' skills to rebel. Still, this point suggests that hermeneutic injustice in chronic diseases would affect the disadvantaged the most, adding another layer to the cumulative effect of disadvantage among those who live with a chronic disease. Thus, this chapter further specifies the mechanisms of the vicious circle of disadvantage among those who live with a chronic disease and reasserts the systemic dimension of this ethical problem.

After having explored the complex dynamics involved in chronic diseases significantly affecting people's experience of the social world, the next chapter focuses on people's changing relationship with their bodies in the context of chronic disease and chronic care, specifically in terms of people's sense of control and agency.

Chapter 7 - Dimension 2

The precarious balance between control and agency

1. Introduction

The second dimension of the experience of chronic disease focuses on the give-and-take between the contingency of illness, the quest to regain some sense of control, and preventing the disease from taking over people's subjective worlds. As introduced in Part II of this thesis, chronic diseases are commonly referred to as 'controllable' diseases in biomedical contexts. Although treatments cannot cure chronic diseases, they can 'control' them by eliminating or reducing their symptoms, and stopping or slowing down their progression. Although arguably accurate, this language might lead some people to assume that as long as someone is on treatment, the disease is controlled and people's overall sense of control over bodily functions might be restored. Still, most participants in this study described having little to no sense of control over their disease despite treatment, which significantly affected their experience. Chapter 3 introduced the idea that chronic diseases have the quality of being irreversible while still cyclical or whimsical, and thus paradoxical as mostly present in the absence of symptoms. Drawing on participants' experience, chronicity was argued to demand a constant effort of abstraction to keep in mind and act based on an idea of chronic disease as always present, but these only being experienced in the body intermittently. This chapter further specifies this paradoxical aspect of chronic diseases by analysing the tensions around control through disease agency, monitoring and treatment.

Chronic diseases have been argued to be experienced as a sudden betrayal of a fundamental trust in the body, after which “life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair” (Kleinman 1988, 45). By reflecting on the losses, contingency and bodily doubt associated with chronic disease (Toombs 1987; Carel 2016; Kleinman 1988; Frank 1995), the second section of this chapter explores participants’ far-reaching experience of being at a loss in terms of lacking control over the disease and their bodies, thus feeling physically vulnerable and dependent on the disease and or its treatment. Section three goes into depth about individuals’ quest to regain some sense of control through monitoring, healthcare monitoring and other sources of information about disease and treatment, which all become mediators in a new relationship with the body and harmonising the body as subject and object emerges as a main task in this quest for control. Finally, the fourth section goes into depth about the agency struggle described by participants between the disease, monitoring and treatment, and the self. Reflecting on self-tracking practices in the context of the Quantified Self movement (Sharon 2017) helps articulate participant’s frustrating experiences of feeling alienated by illness self-management tasks, thus, more or less consciously, having to choose between an increased sense of control over the disease, and their sense of agency over their lives more broadly.

2. Lack of control and contingency in chronic disease

Although the personal meaning of illness is always intertwined with a particular life history, thus having a very personal form, the idea of loss has been identified as a common and recurrent content in the experience of chronic illness (Kleinman 1988). Some of the losses associated with chronic disease are more concrete and some more abstract. Toombs (1987) offers a detailed description of five sequential losses in which chronicity has an amplifying effect. These five losses include loss of wholeness, certainty, control, freedom to act, and the familiar world. These are understood as sequential losses, this is, one leading to the other. Loss of wholeness refers to the rupture in the body-self unity that is described in terms of experiencing the ill body as other-than-me, which leads to a loss of certainty specifically in terms of having to surrender the assumption of personal endurance, experiencing vulnerability and anxiety. This loss then leads to the loss of control understood as control over the body, breaking the spell that medical science can protect people from and cure illness, thus leading to the next loss, loss of the freedom to act specifically regarding medical treatment precisely because of the serious lack of knowledge about which the best course of action might be. All these losses together lead to an overall experience of loss of the familiar world, which is characterised by the new and distinctive way of being that is imposed by illness, isolating the ill person from his or her everyday familiar world (Toombs 1987).

Toombs' (1987) work is very consistent with and helps frame most participants' experience of little to no sense of control over their disease and their body. However, looking into people's experience adds significant detail to this sequence of losses mainly by laying out people's reactions and thus, what these mean for life beyond illness. Participants described feeling worried or scared, looking more after themselves trying to prevent diseases and be as healthy as possible by spontaneously deciding to eat healthily, exercise more, drink less (alcoholic beverages) or stop smoking. Still, as exemplified in the following vignette, the overall experience of little sense of control mainly referred to the possibility of chronic diseases getting worse or acting up, feeling that there is nothing they can do to prevent it.

> *I don't feel like I have a valuable input on myself, you know? other than taking my pills and telling people how I feel there's not really anything I can do (31-year-old man living with pituitary disease).*

Frank (1995, 30) reflects about this in terms of the embodiment problem of control raised by illness, arguing that "people define themselves in terms of their body's varying capacity for control", stressing the idea that all the losses associated with illness, and specifically the loss of predictability of the body, implies a significant loss of control that requires learning to live in contingency, as opposed to the state of predictability enabled by a healthy adult body (Frank 1995). This idea of learning to live in contingency seems particularly representative of how lacking a sense of control over the disease and the body can shape the lives of people living with a chronic disease. This contingency is exemplified in the following vignette, as the participant describes the function of wearing an emergency bracelet.

> *I have had this [bracelet] ever since I was diagnosed mmm…just in case people think I am drunk rather than diabetic…but yeah it just says type 1 diabetes on insulin… and it has a number for someone to ring…and then they can get all of my medical, well not all of it, but some of my medical history so…mmm…yeah I just thought it was a sensible thing to do…if I collapse in the streets, I hope it never happens (36-year-old woman living with type 1 diabetes).*

Other emotions arising from the contingency associated with the unpredictability of chronic diseases included feeling stressed about changes in their schedule affecting their treatment regimes, worried about not being able to leave the house fast enough in case of a fire or having to wait for healthcare professionals to provide treatment and timely appointments in case of a flare-up. This rendered participants significantly vulnerable and or dependant especially over periods of illness where the loss of physical autonomy can be most evident, leading to an overall sense of surrender or 'being at the mercy of' the disease, as seen in the following vignette.

> *How much control…mmm…none? I don't think I have any…very much control, it does what it wants… mmm…I do, there is some medication that I can take when I need to (62-year-old man living with rheumatic disease).*

Although this was often taken as a reason for participants to avoid dwelling on illness, it could also lead to suffering due to a limited sense of agency. In general, having a chronic disease implied an overall sense of being more vulnerable to get and overcome other conditions. More specifically, it sometimes implied difficulty planning as participants described depending on ‘how the disease is doing’, thus experiencing the body and the disease as having their own agency. This aspect of participants’ experience might be thought to reflect Carel’s (2016) idea of loss of continuity, briefly introduced in Chapter 4 as one of the losses contributing to an overall sense of bodily doubt associated with illness. This bodily doubt is argued to invade the normal sense of things and make the ill person feel incapable, exposed and threatened, revealing the extent of human vulnerability. Loss of continuity refers to the continuity of experience and purposeful actions, and these being replaced by a modified awareness of the self and the environment. This represents a breaking point that defines a before and after in the ill person’s experience specifically regarding past abilities (Carel 2016). This experience is represented in the following vignette.

> *All my work stopped because I couldn’t be on location I couldn’t be on a studio I just couldn’t do anything because I was going to the loo so often and I worked on shows and they couldn’t just stop filming like the whole set for like one person so it was just absolutely awful (47-year-old woman living with Crohn’s disease).*

Carel's (2016) work builds on Toombs' (1987) losses and helps specify these for the case of chronic illness, implicitly highlighting the importance of chronicity in a phenomenological sense. Although bodily doubt is argued to be experienced in illness in general, the ill persons' temporal sense is radically changed by a poor prognosis. Part of the experience of dealing with an acute illness is the understanding that the experience of bodily doubt is a temporary suspension of the tacit trust in the body, but when this suspension is expected to return, the experience of bodily doubt becomes the norm and this profoundly changes the structure of one's experience (Carel 2016). As discussed in Chapter 4, the idea of the paradox of chronicity—central to chronicity in a phenomenological sense—highlights that the likelihood to recur in a cyclical or whimsical way is a core feature of the experience of chronic disease. This feature further specifies the experience of being at a loss in the specific context of chronic diseases.

Drawing on the disconnect between treatment and control discussed in Chapter 5, although many participants from all disease groups shared the experience of chronic disease being, at least to some degree, controlled through treatment, they still described feeling highly dependant on treatment to live a life less disrupted by illness or, in some cases, to stay alive. This also meant that participants described feeling vulnerable to the contingencies affecting treatment, as seen in the following vignette.

> *I have lost my stuff [medication] a couple of times and that's been scary […] I was in Bali two years ago and then just…drunk I don't know where I left it…left it in the taxi or in the toilet in the club…but luckily*

> *they give everything over the counter over there like so I had…it all back very quickly (30-year-old woman living with diabetes type 1).*

Although a few participants described experiencing a reasonable degree of control through treatment and described it as an extension or proxy for their own sense of agency, most participants still highlighted an overall sense of lack of agency over treatment. Some participants described worrying and feeling anxious about the possibility of not getting their medication in time, or there being a shortage because of the political situation in the UK (Brexit), feeling that moving abroad might jeopardize their treatment, or worrying about carers properly managing their disease if they cannot do it themselves in older age.

The following quotation exemplifies how important it can be agency-wise to be able to act independently from healthcare professionals in case the disease acts up, even if healthcare professionals are ultimately regarded as the ones in control.

> *I think I have a lot of control I think that really helps actually mmm…because of course the doctor has the main control in terms of my medication, knowing when to give me treatments…knowing if I need any changes in dosage, but they have let me control the acute episodes (49-year-old woman living with rheumatic disease).*

In this way, although people who live with a chronic disease find ways to increase their sense of control over chronic disease, their experience transmits a sense of powerlessness, being caught between disease agency, treatment agency and all the environmental and healthcare system variables potentially affecting both. The following quotation seems particularly insightful to continue reflecting on this agency struggle, as the participant describes feeling more in control after she adopts a new perspective on the treatment, which lessens its agency.

> *Right now [I feel in control] because before I used to think 'oh without the medicine' or 'oh if haven't taken the medicine' or this and that time and…it was…driving me mad and ah…making me lose control of myself (45-year-old woman living with HIV).*

This introduces the idea that there might be a balance to be struck and that the challenge of living in contingency seems to be about not losing oneself in this powerlessness. About this, Frank (1995) argues that where someone's experience is in the continuum of control does not merely depend on the body's predictability but on how people choose to interpret their bodies, namely as completely out of control relative to previous abilities and seeking to restore predictability at all costs, or accepting varying degrees of contingency. Frank's (1995) work states that people tend to do both. The next section continues to explore this problem and reflects on the competing demands arising from this double attempt by looking into the role of monitoring in the quest for control of people living with chronic diseases.

3. Monitoring and loss of transparency in chronic disease

Closely linked to the intimate experience of bodily doubt, chronic illness has been argued to lead to close monitoring of bodily processes with the hope of becoming capable to identify, anticipate and potentially prevent sources of worsening (Kleinman 1988; Carel 2016). Most participants from all disease groups described how having a chronic disease changed their relationship with the body by bringing it to the fore. On the one hand, this included the body being difficult to ignore because of often painful or uncomfortable symptoms, and on the other, through increased attention or awareness of the body and health risks in general. Thus, participants expressed both a passive (unwilling), and an active (willing) monitoring of bodily states and signs to decide how much they can or should do not to overload themselves and stay as healthy and functional as possible. In the following vignette, the participant finds it difficult to ignore his body during the interview, offering an example of passive monitoring.

> *I am sitting here talking to you now mmm trying not to lean straight against the middle of the chair because it's kind of a [knocks on the back of the chair] that's the back of the chair and that's a very bony chair and I can only lean against it on one side, I am leaning on my right side or my left side I can't put my spine against it because it hurts a lot…mmm…bending over in bad, on bad, in bad seats and slouching in bad seats bring quite a lot of pain mmm (62-year-old man living with rheumatic disease).*

As seen in the following vignette, active monitoring is described as a state of alert that could be anxiety provoking especially when no clear path of action can be identified.

> *I am quite worried when I go to bed…because I think 'am I going to have seizure tonight?' Because seizure obviously there's something that brings them on because I don't have them every night…and there's various things that can bring them on, you know?…like tiredness, stress, things like that so every night I think ohh [laughs] so if I don't get enough sleep I am quite worried that the next night I will have a seizure or that…so that affects my life quite a bit mmm (41-year-old woman living with Lupus).*

Identifying bodily signs of chronic disease can be more or less straightforward depending on the disease and its variations, individual differences and environmental variables. Particularly in the case of participants living with a chronic infectious disease, monitoring of the body focused mostly, but not only, on reading blood tests (such as viral load and CD4+T cells count) to know how their body was doing, as they mostly did not have a corporeal experience of the disease. Still, more generally monitoring implied a combination of interpreting bodily signs (such as dry mouth and tiredness) and tests (such as HbAc1 glucose level tests, colonoscopies and lung function tests), as the interpretation of symptoms was not always easy. Thus, although active monitoring could sometimes be prompted by passive experiences of monitoring—the body spontaneously coming to the fore, this was not always the case. This is directly linked to the paradox of chronicity insofar active monitoring becomes a way for the disease to be present even in the absence of its manifestation. The following quotation offers a way into the amount of analytical work that can be involved in monitoring bodily signs.

> *The adrenalin like that feels very much like your sugar is gone low so like maybe confusing…thing to…maybe you going for a work interview…or like a presentation or something them feeling very much feels like your sugar has gone low, but then you are in a situation in which you can't check…if you think I am going to go low, but you have to go and check in case they are and you are in the situation with a lot of people like…so there's the…there's anxiety around that type of situation definitely (30-year-old woman living with type 1 diabetes).*

In the context of the disease agency being experienced through a disconnect between biomarkers and participants corporeal experience, the monitoring—in this broad sense—of the body in chronic illness might be seen as the effortful, and not always realisable, task of harmonising or tuning the body as object and subject, otherwise often transparent. On the one hand, the more or less conscious effort of harmonisation described by participants suggests that chronic disease would introduce an irreversible divide between the body and the self, which further specifies the theoretical discussion in Chapter 4 on chronic diseases becoming a somewhat disjointed part of the person, and not one with the person. On the other, this task might be seen as a micro-level task contributing to achieve and further specify adjustment to chronic disease as a constant effort towards dynamic equilibrium, which, as argued in Chapter 5, allows those who have a chronic disease to live lives they have reason to value.

This idea of harmonisation resonates with Toombs' (1987) concept of loss of wholeness and Carel's (2016) concept of loss of transparency, which also contributes to the overall experience of bodily doubt. Carel's (2016) loss of transparency builds on Sartre's work regarding the idea that as long as the body does what it is expected do—in the way healthy bodies are regarded to do, it remains transparent in the sense that the body's orders as object and subject are experienced as harmonious. This means that the body's key feature as the fundamental medium for encountering the world implies it remaining in the background (Carel 2016).

Much in line with the experience of participants in this study, Carel (2016) argues that in illness transparency is lost as the body becomes explicitly thematised as a problem leading to an explicit attitude of concern, anxiety, and fear. However, transparency of the body might be frequently disturbed by the encounter with others and non-disease features of the body, requiring further analysis.

Reflecting on the experience of pregnancy and building on Gadow's (1980) work, Young (2005) suggests that although loss of transparency is often described as a negative, painful, experience in which the body imprisons the self limiting its possibility to be, transparency might also be lost in experiencing the body being in an aesthetic mode, this is, people may be aware of themselves "as body and take an interest in its sensations and limitations for their own sake, experiencing them as a fullness rather than as a lack” (Young 2005, 51). This might be argued to apply to body practices that focus precisely on becoming aware of the body, such as in the case of practising yoga or meditating. Drawing on this, whether transparency of the body is lost in a positive or negative way will follow from complex evaluation processes largely founded on cultural and historical contexts shaping the experience of embodiment.

Following this line of thought, Zeiler (2013) reflects on how some culturally shared and corporally enacted beliefs and norms can shape embodied agency. Physical objects and skills, but also cultural patterns of understanding and behaving, can—as the transparent body does—become part of peoples’ taken for granted being-in-the-world. Thus, building on two examples of sexed and racialised embodiments, this author argues that bodies can be transparent, and thus enable smooth and harmonious interactions with others, as long as these others share the same norms and beliefs. However, if this seamless experience somehow changes—either by changes in the body or the context, this may result in painful experiences of excoporation or loss of transparency (Zeiler 2013). This highlights the power dynamic involved in some bodies being more transparent than others in specific contexts and suggests that transparency might be regarded as something that is achieved—rather than a natural condition, probably in adulthood as the stage in which the body reaches a rather stable state, and it can be disturbed in many ways having different outcomes. This argument departs from Toombs’ (1987) and Carel’s (2016) lived body perspective on wholeness and transparency, which take this to be a natural condition.

This work suggests that bodies that have a chronic disease lose transparency willingly, unwillingly and more or less cyclically—or whimsically—and painfully through symptoms, monitoring and encounters with others, while also achieving some degree of transparency or harmonisation. As already introduced in Dimension 1, healthy bodies are transparent insofar they fit within culturally shared and corporally enacted beliefs and norms, namely the strong current cultural values that reinforce youth, health and independence in western societies. Bodies that have a chronic disease mostly carry negative meanings, lack a place in society and can only expect growing dependency, often result in painful intersubjective experiences of loss of transparency. Some of this is condensed in the following vignette.

> *So this disease affects your life because it is shown in your behaviour like inhaler makes you shaking and people go scared from you shaking that means that you have something very dangerous. Makes you coughing, people feel disgusting if they are next to you and they are eating or something (56-year-old woman living with asthma).*

Still, as discussed in Chapter 5, finding dynamic equilibrium was described as a state in which the disease and the body were experienced to stay in the background or be transparent/harmonious. This might be argued to happen both in the subjective experience of people living with chronic diseases, as the disease and monitoring become normalised, and in the encounter with others, as chronic diseases are often invisible and, drawing on participants' experience, mostly kept private. In the following vignette, the participant describes how health monitoring and care tasks became part of a 'new normal', which was still regularly disturbed in the various ways described before.

> *I think I have been doing it for so long now [forty-four years] mmm…that it's just habit, it is like getting up, you know? I get up it's a habit and then, you know? I know this is what I have got to do (64-year-old man living with type 1 diabetes).*

Furthermore, drawing on the concept of sedimentation introduced in Dimension 1, it might be argued that adjusting to a body with a chronic disease in adulthood implies giving up a previous favoured status—healthy—and adopting a new way of being that has been argued to be rejected, rather than frequently confirmed by the social world, so this must be regarded as a difficult change (Zeiler 2013). How particularly challenging it may be to transit from a healthy body-self to a chronically ill body-self suggests a corrosive interaction between chronic illness and power, contrary to what is implied in restitutive processes of personal transformation through the experience of chronic illness.

As discussed in Chapter 3, some participants described experiences of growth from illness, such as developing an increased appreciation of relatively simple activities due to illness. This is exemplified in the following vignette.

> *I am also a bit more grateful as well for like all the small things in like…having a coffee outside on a sunny day like…there were loads of days when I was sitting at [hospital] looking out the window…and I couldn't go do it (29-year-old woman living with Crohn's disease).*

Although this might be experienced as a significant subjective positive change due to illness, potentially contributing to people's overall sense of wellbeing, others might neither identify nor attribute it to the disease. Drawing on previous discussions on hermeneutical injustice and sedimentation, this lack of acknowledgement might limit both the reach that these experiences can have over the shared understandings for social interpretation of chronic disease and the sedimentation of chronic disease. Thus, building on Zieler's (2013) work, enjoying being able to drink coffee in the sunshine is unlikely to capture others' attention and receive frequent confirmation for people who have a chronic disease diagnosis to sediment their new way of being. Someone for whom this is a simple experience, of no particular added value, this intimate feature will likely go unnoticed, focusing instead on how difficult it must be not being able to play sports, for example. This difficulty to sediment chronic disease as a new way of being contributes to further specify the idea of chronic diseases introducing an irreversible divide between the body and the self, and highlighting the constant, not always realisable, task of harmonisation as a key feature of the experience of chronic disease.

4. Monitoring and the agency struggle between the subject and chronic disease

Participants described that integrating different types of information in their monitoring was important to increase their sense of control. These different types of information included participants' previous bodily experience, daily monitoring with or without specific at-home testing, healthcare monitoring through tests and appointments, and scientific or official information about disease and treatment. Having an increased sense of control implied having information to act on or at least help them prepare regarding what to expect. Participants explained that this could allow them to take a more rational approach and feel less vulnerable. In this context, only one participant wished he could have a self-tracking device, as he thought this would significantly increase his sense of control and agency over the disease. Although this seems quite straightforward, it is interesting that no other participants discussed using or wishing to use a self-tracking device. Thus, reflecting on this participant's experience might shed light on what other participants did not speak about.

> *It [self-tracking device] would give me knowledge mmm…and knowledge that I…I can act on so…if I…if I know that mmm well if I know that I am ok mmm…and I can look at the time and think well ok I am gonna eat in half an hour anyway so I am not gonna, you know? have anything that's absolutely fine…if I know that I am going down and down quickly then it means that, you know? I can I'll eat something to compensate…so it…it…again it's it's a more precise way of*

> *identifying how I am mmm…at this particular moment, but it also mmm it also gives me an idea, you know? if I am making notable these things you know? I can build up a picture of, of mmm not just in the micro-moment, but mmm you know? in a much mmm in an overall week over a few weeks (64-year-old man living with type 1 diabetes).*

In this vignette, the participant highlights that having quantified information from a self-tracking device specifically on his glucose levels can be a more precise way of identifying 'how he is', than his intuition or account of his bodily experience. Similarly, self-tracking practices promoted by the Quantified Self movement,[1] are celebrated for their potential to inform personalised healthcare—facilitating more targeted and preventative care. Furthermore, one of the main promoted outcomes of self-tracking practices arguably lies on the empowerment of ordinary people, allowing them to gain independence and take more control over their health (Sharon 2017). This, however, has been argued to conflate empowerment with individual responsibility for health (Sharon 2017) in a way that is particularly relevant in the context of chronic care. Drawing on the last vignette, although the agency gained through self-tracking data might be accurate and also reflect, to some extent, participants' experience of reasonable control through minor treatment adjustments during flare-ups, in the specific context of chronic disease,

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[1] The Quantified Self movement promotes self-knowledge through self-tracking of daily life including sleep patterns, diet, weight and exercise despite people's health state ('Quantified Self Institute' 2021). However, self-tracking projects typically focus on aspects of life that are disturbing, painful or embarrassing, such as disease (Sharon 2017).

participants described feeling dependant on healthcare and having an increased sense of control mostly through regular healthcare monitoring.

By providing healthcare professionals with information about treatment effectiveness, comorbidities, complications, or undesired effects of treatment, healthcare monitoring was described to be reassuring as it provided a sense of reality that acted as a proxy or externalised route for trusting that their bodies were working as they should, even if within their new parameters. The following quotation reflects this powerful reassuring effect as the participant describes it going beyond the management of his disease, which was a commonly described benefit of increased healthcare monitoring.

> *The very fact that I was coming up here every three months for a check-up meant that my general state of…of health and…and being looked after if you like was better than it would have been otherwise because otherwise you don't mmm […] you wouldn't get that sort of mmm… constant…maintenance, if you like (65-year-old man living with HIV).*

Nonetheless, participants also described how the increased monitoring of the chronically ill body could sometimes imply that healthcare professionals established a relationship with the body and its performance on tests, with participants having a rather passive role that refers back to the idea of being caught between the agency of the disease and the agency of the treatment. Much in line with this, Sharon (2017) argues that the empowerment provided by quantified information about the body is limited to externally defined biomedical understanding of health targets, reflecting a reductionist understanding of health and potentially alienating people.

Participants described how this increased focus on biomedical data about the disease might facilitate a context where healthcare professionals can overlook their priorities or, as seen in the following vignette, the cost that a recommendation based on achieving a specific health target could have over life more broadly. This particular participant was a doctor herself, so she had access to privileged information, support and connections that helped in the decision-making process to decline such recommendation. In other words, there was little to no power imbalance between her and her medical team.

> *The surgeon who took out the tumour, he is retired now, he was absolutely lovely and when I was offered radiotherapy I emailed him and said '[doctor's name] I really don't want radiotherapy' and he said, 'neither would I'…and I think that influenced the committee that was looking after me…it's multidisciplinary team, it's not a committee, but…the multidisciplinary team was angling to get me radiotherapy and I strongly didn't want radiotherapy (64-year-old woman living with pituitary disease).*

Drawing on her knowledge and with the support of the surgeon, this participant could put her wellbeing and health risks on a scale, eventually deciding to live with the risk of the tumour re-growing but preserving pituitary function—secreting the hormones for many vital physical functions and processes. Although this participant still required long-term treatment, she described finding a balance between the disease, treatment and life beyond illness that allowed her to live the life she had reason to value.

Still, going against or challenging medical recommendations might be hard because of the power imbalance generated by the knowledge gap between doctors and patients, which participants described working hard to close by learning as much as possible about their disease. Knowing the side effects, but trusting the healthcare professionals' assessment, another participant shared having the radiotherapy treatment for a similar condition and losing all pituitary function, so his long-term treatment consisted of hormonal replacement. Although he did not live with the risk of the tumour re-growing, his life and wellbeing were significantly affected, as seen in the following vignette.

> *It's definitely got worse and worse because initially I was hoping things would improve, but they didn't…they got worse…and…and the realisation…the constant realisation that you know? so many things I hoped to have done and I still haven't been able to have done, you know? it's just, you know? very basic small things mmm…I just feel constantly swimming in an…in mud, you know? everything is very hard (54-year-old man living with pituitary disease).*

The point here is not to judge treatment decisions, but to highlight the importance of reconciling the quest for agency and control of people living with chronic diseases, as well as their dependence on healthcare teams to work towards dynamic equilibrium, as both participants described heavily relying on healthcare professionals' input to make treatment decisions with their overall and long-term wellbeing in mind.

Besides highlighting the importance of integrating different types of information to feel more in control, a couple of participants made the point that there might be a limit to how much information is useful, as having medical information which does not contribute in any way to their sense of agency, mostly led to unhelpful dwelling, making the task of protecting the self from chronic disease harder. Thus, to protect the self and achieve the dynamic equilibrium described in Chapter 5, participants stressed the importance of not over engaging with their health data so they can do and be more than their disease. In the following vignette, the participant describes choosing to limit her monitoring, at the cost of having less control over the disease, to gain time and energy to do other things of value to her.

> *I feel like if I wanted to I could have pretty good control…like…I could spend a lot of time and energy making everything loads better mmm…but I don't […] what I would have to do to get better control it's to kind of…like keep a proper diary of what's going on like what you have eaten what you've done exercise wise mmm what you thought your food was in like a really scientific way […] (36-year-old woman living with type 1 diabetes).*

Drawing on Frank's (1995) idea of accepting varying degrees of control discussed in the previous section as one participant described achieving an increased sense of control by disinvesting agency from the treatment, this tension and balance to be struck between control over the disease and life more broadly add another layer of complexity to the discussion in Chapter 5 on the experiences and processes informing the broad spectrum of what good enough adherence and self-management can mean for people living with chronic diseases.

It is plausible to think that due to the possibly unintended alienating effects of monitoring, many participants from all disease groups described compensating for their lack of control over the disease by asserting agency over what they regard as more controllable aspects associated with illness, which may not have any impact on controlling the disease or even have a detrimental effect over it. Interestingly linked to participants' experiences of stigma and lack of empathy and place discussed in Dimension 1, the participant who reflected on the potential value of wearing a self-tracking device also worried about becoming identifiable as ill and weak through the device, reducing his agency over how he wanted to present himself in front of others. As seen in the following vignette, this was a very emotional moment in the interview and a difficult experience to make sense of.

> *The only…negative thing I don't like to be identified [gets emotional, but tries not to cry] mmm so…[takes a long pause and tries to contain the tears]*
> *Interviewer: it's alright, take your time*
> *Interviewee: yeah [takes a long pause and cries in silence for about one minute] yeah so I think…mmm…it's mmm people would be able to see…that there mmm so and whereas I am very happy to talk to people about it, I think that mmm…mmm…sort of strangers saying 'oh*

> *what's that?' mmm…you know? it's just I don't make a big thing of it so you know? it's mmm it's yeah, it's just one of those things that mmm*
> *Interviewer: would you like to tell me why are you feeling emotional or what are you feeling emotional about?*
> *Interviewee: I think I see it as a weakness [cries] (64-year-old man living with type 1 diabetes).*

Similarly, another participant described being very aware of the importance of managing how her illness was perceived as a way of feeling in control, choosing a narrative in which the disease did not take over all aspects of her life.

Furthermore, drawing on another participant's experience, the following quotation exemplifies how the struggle for agency can be more concrete, directly affecting treatment adherence.

> *Some people, they use adherence to their medication as a way of control when things go wrong […] it's like things are wrong, you can't resolve them…you can't resolve them, you know? […] I don't know about other people, but some names in my mind…but what I can control is medication (55-year-old man living with HIV).*

Although this participant struggled to articulate the logic of this thought, throughout the interview he explained that in the context of chronic disease, even if people know this can be counterproductive, deciding not to take the medication can be a way to reassert agency insofar taking medication is what is expected from them, and thus not necessarily experienced as a choice. Similarly, and drawing on Scott's (1985) work, previous literature on HIV has described practices of taking/not taking medication as a form of 'everyday resistance' to the experience of powerlessness prompted by the illness and treatment, allowing people to reassert agency and re-claim control over life more broadly (Muessig et al. 2015).[2] This chapter has argued that this agency struggle might apply to the broader category of chronic diseases, potentially leading to practices that can both improve and hamper specific health outcomes in the broader context of the efforts of people living with chronic diseases towards dynamic equilibrium.

5. Conclusion

This chapter helped further specify the experience of the paradox of chronicity introduced in Chapter 4 by reflecting on the consequences that living with little to no sense of control over chronic disease can have. Closely linked to this, the task of harmonising the body as object and subject to regain some sense of control emerged as a central task and a key feature of the experience of chronic disease. This was described as a micro-level task

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[2] Scott's (1985) ideas draw on his ethnographic work in a Malaysian village and reflect on the power dynamics associated with class hierarchies, namely the 'rich' and the 'poor'. Although this author's concept of 'everyday resistance', in a broad sense, helps think about participants' efforts to regain a sense of agency and control in the context of chronic disease, Muessig's et al (2015) work suggests a parallel in which patients' medication taking practices resist the power of healthcare professionals. Although this might sometimes be the case, this thesis suggests a quest for control and agency on the part of participants that goes beyond the relationship with healthcare professionals.

contributing towards the broader goal, introduced in Chapter 5, of adjustment to chronic diseases as a constant effort towards dynamic equilibrium.

Furthermore, by looking into loss of wholeness and transparency of the body in illness and life more generally (Carel 2016; Young 2005; Toombs 1987), this chapter specified bodily transparency in the experience for chronic diseases as something that is both lost and achieved—more or less cyclically and painfully—through symptoms, monitoring and encounters with others. Thus, drawing on Zeiler's (2013) work and the difficulties for belonging raised in Dimension 1, sedimenting chronic disease as a new way of being implies giving up a previous favoured status—healthy, and thus must be regarded as a difficult change. In turn, this difficult change is closely linked to the complex dynamics at play in the quest for control over the disease and life more broadly through monitoring and treatment.

Participants' experience suggests that people's sense of agency might compete with regaining a sense of control over the body after having lost it to chronic disease. In a rather paradoxical manner, while monitoring and treatment can sometimes help achieve freedoms and an increased sense of control over the disease and the body, monitoring and treatment can simultaneously hamper participants' sense of agency beyond illness and limit their sense of self, feeling dependent, vulnerable and alienated. Thus, in trying to reassert agency over life and protect their identity, people living with chronic diseases may disregard treatment adherence or take health risks. Taking such risks may or may not lead to their illness acting-up, develop complications or have suboptimal health outcomes. This process contributes to understanding the, more or less conscious, agency struggle potentially underlying situations in which treatment is not prioritised for any seemingly evident reasons, such as not wanting to risk job security or experiencing medication side-effects or toxicity. This helps further specify and highlight the crucial function that the porous boundary between identity and chronic illness can have for people's sense of agency and thus also in the efforts towards dynamic equilibrium.

The next dimension reflects in more depth about the protective function of the porous boundary of identity and explores the tensions arising at the subjective level between the healthy body-self and the ill-body self.

Chapter 8 - Dimension 3

Resisting illness to protect belonging and identity

1. Introduction

The previous two chapters explored key issues arising in the experience of the social and the subjective worlds of people living with chronic disease in current western societies. In this context, chronic diseases were argued to carry mostly negative meanings and significantly burden people living with chronic diseases, at least at times. This chapter brings together the previous two dimensions and reflects on what these imply for the relationship with oneself in the processes of becoming ill and living with chronic disease. As already discussed, living with a chronic disease means giving up a previous favoured status and must thus be regarded as a difficult change. These difficulties imply facing a social world that marginalises and rejects features of chronic illness, and a self built around a healthy body that has both internalised such negative attitudes towards chronic illness and more or less frequently experiences itself in pain, suffering or reduced capacity.

This dimension expands on this difficult change by reflecting on participants' resistance to acknowledging chronic illness during the onset of disease and after this is established. This is argued to be a feature of the protective function of the dynamic porous boundary of identity introduced in Chapter 5, as it helps participants avoid developing negative feelings and attitudes towards themselves and work towards dynamic equilibrium. In the context of participants having a weak epistemic conviction regarding their state of illness, the third section discusses how healthcare professionals can amplify this by failing to listen to patients' experiences, amounting to further delays in chronic disease diagnoses. Still, for those participants who described a state of strong epistemic conviction about being ill, healthcare professionals' failure to listen not only delayed diagnosis but added significant stress, suffering and anxiety to an already confusing experience of bodily becoming and loss of a previously favoured status. Thus, the final section explores the idea of mourning in chronic disease and further specifies this by describing two simultaneous processes. Although chronic illnesses lead to the absolute, and more or less abstract, loss of the healthy body-self, the cyclical manifestation of symptoms, accompanied by symptom-free periods, might represent an extra challenge in terms of the body becoming an unstable (sometimes healthy, sometimes ill) mediator to encounter the world, thus prompting a reiterative experience of loss. Although emotionally challenging, this is framed as part of the protective function of the porous boundary of identity.

2. Resisting illness not to adopt a negative or limiting attitude towards oneself

Chapter 5 described the boundary between the self or identity and chronic disease having a dynamic porous quality, which might be more or less permeable throughout illness and life trajectories. This was argued to play a protective function, preventing chronic diseases and associated care tasks from taking over people's subjective world. Dimension 2 helped specify this function by describing the negotiation involved in participants taking care of the body and the illness while preserving enough central aspects of life to continue feeling like themselves. This section takes a step back and looks at how this function might work before chronic disease is established, as participants described resisting illness and diagnosis by normalising early disease manifestations. Thus, normalisation of early symptoms as resistance is different from the process of habituation described in Chapter 5.

Normalisation as resistance follows closely from the summary of empirical findings in Chapter 3 that described spectral accounts of the illness process in which the boundaries between health and disease blurred. Reflecting on this further through the lens of the dynamic porous boundary of identity contributes to better understand the difficult change implied in giving up a previously favoured status, namely being healthy.

Although for some participants, living with chronic infectious or respiratory conditions, the experience of identifying bodily changes, seeking medical help and reaching a diagnosis was described as fairly straightforward, the experience of most participants was rather slow and difficult. Disease presentations and availability of gold standard tests play a role in the process of participants being referred, tested and reaching a diagnosis more or less quickly. However, in general terms, chronic illnesses tend to have an insidious onset that often leads to a rather late involvement of others, so the process of realising that there is something wrong with the body is generally lived intimately (Bury 1982). This is exemplified in the following vignette.

> *I don't really… like… it wasn't like a short period of a couple of weeks mmm…but I can't remember how long it was where I can… kinda go 'something is not right', but I did know for a while that I wasn't… really…because I felt quite sick all the time (36-year-old woman living with type 1 diabetes).*

The kind of bodily changes participants described—only identified as symptoms retrospectively—varied both between and within diagnostic groups. Still, bodily changes such as inexplicable tiredness or fatigue, low energy, losing or gaining weight, headaches, and a general feeling that something was not right in their body represented a common experience of the onset of chronic disease.

As discussed in Dimension 2, bodily changes or symptoms can be more or less specific or easy to identify. Still, some participants from most disease groups—except chronic infectious disease—described a period of normalisation of bodily changes, resisting the idea that something could actually be wrong and finding other reasons to explain or justify these changes. This might also be described as the 'nonserious phase' before disease diagnosis, described by Stewart and Sullivan (1982) drawing on their qualitative study with people living with multiple sclerosis. This mainly refers to an early phase of symptoms, in which ailments are perceived within the range of normal bodily function.

People might generally normalise gradual changes beyond the body and illness, especially resisting changes that show a decline in whatever sphere by expanding its qualities or underplaying the importance of the changes. A good common example of this might be struggling to identify relationships deteriorating until something is signified as a discrete change. Still, in the specific context of chronic diseases, some common normalising explanations among participants tended to be self-blaming, putting bodily changes down to smoking or drinking too much (alcoholic beverages), being lazy or not being fit enough. In other words, changes were taken to be part of who they were and kept down to their own agency, instead of seen as rather independent bodily processes. The following quotation reflects this process of normalisation.

> *Nobody questioned it…mmm I didn't question it, we just assumed I was eating too much and was very lazy mmm…it was always done like that…so when I was leaning my head against walls it was always me being lazy, but it turns out that's quite a common symptom, you get a heavy head (31-year-old man living with pituitary disease).*

Other common explanations were more contextual, such as being stressed, getting older or having small children.

> *To be honest I was just really tired…and…but I was working full-time, I had two toddlers I just thought I was tired, I didn't think…anything of it (49-year-old woman living with rheumatic disease).*

Although this period of normalisation was mostly unconscious or unintended, and only identified as such retrospectively, some participants described this as a period of confusion in which they did notice that something was not right and pretended it was, although not so purposefully, as seen in the following vignette.

> *Because it was a warm summer and stuff like things I didn't notice…but I didn't lose a lot of weight like people say, so I think that was, just [laughing] shows how much I was actually eating…mmm…I knew I was getting away with murder in terms of, I should…me being me…I would have put on weight very quickly and I knew I wasn't putting weight on so that was something I noticed…(30-year-old woman living with type 1 diabetes)*

This experience might be seen as a similar process or perhaps an underlying process in the difficulty of integrating chronicity—after the diagnosis—first discussed in Chapter 4, which was further specified as a function of the dynamic porous boundary of identity in Chapter 5.

In the context of 'healthy' being regarded as a favoured status, the often gradual bodily changes and lack of specificity of symptoms seemed to create a constellation that contributed to people resisting bodily becoming and not seeking medical help. This view of resistance can also be found in MacIntyre's (1999) reflections on vulnerability and disability. This author makes the point that human subjectivity seems to be constituted in contrast to its organic composition, by resisting and even denying facts of disability and dependence brought by illness, by stressing that there are "habits of mind that express an attitude of denial towards the facts of disability and dependence", which “presuppose either a failure or refusal to acknowledge adequately the bodily dimensions of our existence” (MacIntyre 1999, 4)

It has been argued that once this gradual change becomes discrete and the disease is established, the body appears as an object other than the self and requires the subject’s attention (Frank 1995). However, as discussed in the last section, this might not always be the case. This work has argued that a harder or less permeable boundary between identity and chronic disease helps achieve and sustain dynamic equilibrium by directing people’s attention towards other meaningful aspects of life identity-wise. However, as the body loses transparency and the illness takes over, this becomes harder and the boundary softens or becomes more permeable. When chronic disease and identity merge, participants describe suffering from not being able to be ‘themselves’ because of chronic disease. Thus the dynamic porous boundary might be, in part, subject to the lose-achieve transparency of the body dynamic described in Dimension 2. This connection might be reflected in the following vignette.

> *Whenever I have a hypo I used to get really, really bad side effects mentally and it was only then that I feel like a sick person…do you know what I mean? like I never feel like I have an illness because you can manage it (30-year-old woman living with type 1 diabetes).*

Thus, resisting initially, getting used later, and sometimes—in a partially aware state—ignoring chronic disease allows people to continue living lives they have reason to value. By keeping chronic illness as a somewhat disjointed part of the self, people living with chronic disease can avoid thematising the body as a problem and adopting a negative attitude towards their bodies. As seen in the following quotation and drawing on Carel (2016), this attitude largely focuses on deviation and dysfunction, constituting a reminder of bodily incapacity.

> *Well…I hate, I hate being ill…I don't think I am embarrassed now because I have an age now of sixty-two, which is kind of commensurate with being a little bit rickety … […] but I am absolutely certain there's lots of potential partners that I missed out on…friends and contacts that I missed out on…in not being able to do the things…the things that I was best at, you know? a sporty person and mmm…that's, that's where my physical skills always laid, lay…* […] *I was able…mmm you know? to take out sports…in past tense (62-year-old man living with rheumatic disease).*

As seen in the last vignette, the participant shares negative feelings towards being ill and, as he resists the past tense, holds on to a healthier self by resisting to give up his favourite and identity meaningful skills. Frank (1995) argues that people who live with a chronic disease may cease to consider themselves as desirable to themselves, fearing that they are no longer worthy of the most simple and daily objects and actions (Frank 1995). This may be argued to mirror the previously argued social death hastened by chronic illness in the intimacy of the relationship with oneself. In the following vignette, the participant describes feeling guilty and not allowing himself to take time off to visit his family as a consequence of always being tired and behind on multiple responsibilities because of his illness.

> *Yeah, not enough because […] I don't allow myself…mmm…to mmm…to do that…I mean occasionally I do, but not enough…and occasionally I do something nice for myself mmm…but not enough and it's a funny combination of…ah…well it mainly gives me guilt…so…although it does give me energy the balance I am not sure…(54-year-old man living with pituitary disease).*

This might be considered a rather extreme experience within the context of chronic disease arguably linked to how frequent and significant the consequences of illness are experienced as taking over the self by limiting life more broadly. However, as already mentioned, most participants described feeling depressed, frustrated or disappointed due to illness, at least at some point in their illness and life trajectories. In many of the cases within those who discussed their mental health, negative feelings towards being ill were described to cause anxiety, depression or suicidal thoughts, having resorted to counselling or psychotherapy. As seen in the following vignette, this was not something easy to discuss or that the participant thought received enough attention. Still, anxiety and depression are strongly associated with non-adherence to treatment among people living with a physical illness who have not been previously diagnosed or treated for psychological or psychiatric conditions (DiMatteo, Lepper, and Croghan 2000).

> *I had definitely suffered…almost…you know?…from a bit of anxiety*

> *and depression after mmm [being diagnosed]…that's actually where my GP was really valuable in stepping in and helping me secure that support…mmm […] but…in chronic illness there is a physical side of recovery and there is a mental psychological side of that and everybody focuses on the physical element (29-year-old woman living with Crohn's disease).*

Following from this, most participants sharing this experience, described counselling or psychotherapy as being important and helpful at some point in their illness trajectory. As seen in the following vignette, one participant described how having training as a mental healthcare professional and highly skilled social networks was helpful to navigate the complex emotions arising during the periods in which the disease is experienced as a threat to the subjective world.

> *I think my job…because I have to be aware of my personality…I have quite a lot of self-awareness I think […] that probably helped me when I became ill that mmm I was aware of my emotions, what I was thinking, what I was feeling and also had the capability to be able to talk about it […] When I first became unwell that I didn't know what the prognosis was mmm…that I was able to talk through my fears with my husband and if it's…and I have a very good friend who is a psychologist who…I have a lot of friends who are psychologists, psychiatrists I had a lot of people who I could talk to…about my fears and my emotions (49-year-old woman living with rheumatic disease).*

Still, during less symptomatic periods, this participant resorted to the harder boundary between identity and chronic illness, resisting illness by normalising her reduced capacity. This supports the idea that this function plays an important part in adjusting to chronic illness, namely the constant effort towards dynamic equilibrium.

> *We were in Paris recently, my girls were halfway down the road and I said to my husband they are walking really fast…he said no, you just walk really slowly [laughs] (49-year-old woman living with rheumatic disease).*

3. *Participatory prejudice in healthcare: 'it's probably nothing'*

In many cases, the early normalisation of symptoms—understood as the more or less aware resistance of bodily changes—delayed diagnosis. In some cases, participants described waiting to seek medical help. However, in other cases, healthcare professionals in different levels of care were described to support participants' resistance to illness by failing to listen to participants' experiences and descriptions, identify bodily changes as symptoms and conduct further investigation to reach a diagnosis. This introduces a relevant distinction between the experience of living for a long time with symptoms that may be difficult to identify and acknowledge, and the experience of having identified that something is wrong and struggling to reach a satisfactory understanding of this despite all efforts on the part of those who live with a chronic disease. Although this should be thought of as a continuum where more nuanced experiences of these two extremes can overlap to delay diagnosis, this distinction is useful for clarity purposes.

Sometimes healthcare professionals may have good reasons not to explore symptoms further or simply be unaware of their own resistance, both emotional and statistically founded, to acknowledge that people might be seriously ill. The former refers to the prima facie idea that people might generally prefer others not to be seriously ill, which derives from the idea of 'healthy' being a favoured status. Although prevalence of specific diagnoses is crucial information in healthcare professionals' reasoning during the time of diagnosis, the latter point refers to the fallacy in healthcare professionals thinking that serious diagnoses being statistically unlikely on a population level is a good reason not to think that the person in front of them might have a serious disease, despite presenting red-flag or pathognomonic symptoms.

Still, patients often complain about not being listened to by healthcare professionals, and healthcare professionals, in turn, complain about patients' providing irrelevant information. Thus, Kidd and Carel (2017b) discuss the case of unsuccessfully seeking medical help as a problem of participatory prejudice, briefly introduced in Chapter 5. 'Participatory prejudice' implies that epistemic practices of medicine rely on a scientific rationale, knowledge and language that patients often lack, limiting their possibilities to have an active role in these practices. This implies that patients are objects of medicine rather than subjects in the interaction with healthcare professionals, suffering from a 'refusal to concede' the relevance of the type of information they generally provide and from a 'refusal to consider' the possible significance of their accounts, which in the specific case of chronic diseases has been argued to be particularly relevant due to the far-reaching effects these have over life beyond illness (Kidd and Carel 2017b).

The pervasiveness of science-based epistemic practices highlighted by Kidd and Carel (2017b) might be represented in the experience of three participants in this study who blamed themselves for not being diagnosed earlier because they thought they ‘should have known’ or ‘should have requested the right tests’. Still, participants’ stories generally implied that it was the healthcare professionals’ responsibility to pay more attention, investigate further and reach a diagnosis.

Participants living with chronic endocrine and gastrointestinal conditions consistently described seeking medical care as a struggle of being disbelieved and dismissed, receiving symptomatic relief without proper investigation or diagnosis, being told off for eating badly or being told that their symptoms were psychological. In the following vignette, a participant who was a doctor herself shares the experience of being told off by fellow doctors, suggesting that participatory prejudice might not only be explained by healthcare professionals and patients not sharing a language or understanding but because of the power differential between healthcare professionals and patients when it comes to illness (Kidd and Carel 2017b). This suggests a testimonial injustice, which harms people by delaying treatment and diagnosis.

> *In 200…6 or 7 I saw a consultant […]…who sort of talked me off for being so skinny well he did it properly and mmm…did a quick scan…didn’t find… I mean they thought I had cancer… the symptoms I*

> *had…and…they thought I had cancer mmm, but I didn't had cancer so I got told off for not eating properly and smoking too much so that was bizarre, but looking back on it when I saw the next symptom, God, you have acromegalic colon and we didn't know (64-year-old woman living with pituitary disease).*

This quotation might also present an example of 'confirmation bias'[1] plausibly supported by the power differential and linked to the idea of statistically founded resistance. The participant describes that the healthcare professional came to a likely diagnosis to explain what he considered as symptoms and stopped looking for medical explanations for what the participant was experiencing after his hypothesis was disconfirmed, reaching no conclusion. This participant also initially resisted illness—assuming her shoes were shrinking instead of thinking her feet were growing, so the overlap of illness resistances resulted in her being ill and symptomatic for ten years before being diagnosed. Thus, it might be thought that initial consultations, in general, might come from a weak epistemic conviction and people might either find it hard to insist when being told off or sent away or have their preference, namely 'it's probably nothing' confirmed (another example of confirmation bias).

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[1] The concept of confirmation bias draws on Watson's (1960) experimental research about the extent to which people seek to confirm evidence or confirm and disconfirm evidence to draw conclusions in a simple conceptual task. His results showed that most people were unable or unwilling to test their hypotheses or beliefs, reaching wrong or no conclusions.

Still, after having reached the epistemic conviction that something was probably wrong, many participants described having to push to be listened to, get tested or referred to specialists, feeling frustrated and desperate. In some cases, this went on for months and years adding significant worry and stress. Although participants seemed understanding and argued that their conditions were difficult to diagnose because symptoms are often unspecific, this did not seem to ameliorate the suffering they experienced over the process. Descriptively, this experience seems consistent with what Stewart and Sullivan (1982) describe as part of the 'serious phase' and the 'emotional impact of role negotiation' in the process of reaching a multiple sclerosis diagnosis. During these phases, participants in their study implicitly or explicitly challenged healthcare professionals' wrong diagnoses or dismissiveness, taking an active role in reaching an accurate understanding of their symptoms. They were also described to suffer from being in a 'limbo' situation in which their social status as sick people was uncertain and they lacked appropriate support .

In the following vignette, the participant in this study shares her frustration for a delayed diagnosis. After being turned away by doctors, she started doing her own research and seven months later, with the help of her family, she came up with a likely diagnosis—type 1 diabetes—and specifically requested to be tested for it. The diagnosis was confirmed.

> *They […] told me that I had diabetes and then when I said that I had been in that hospital three or four times with the headaches…and I said 'what about the headache?' And they said 'oh, yeah…yeah that's*

> *just…your sugar levels'…I was like…'for fuck's sake'…not once did they do a sugar test…like…that was frustrating (30-year-old woman living with type 1 diabetes).*

A couple of participants described that after long periods of time seeking medical help it was a junior doctor who finally listened and completed the referral or requested the right tests. This last observation might suggest that as junior healthcare professionals are less experienced, they are less likely to have a hypothesis to confirm and thus be more open to listen and investigate. This might also be thought of in terms of a smaller power differential between junior healthcare professionals and patients increasing the chances of these healthcare professionals practising testimonial justice and achieving the common goal of reaching a diagnosis. This, however, does not mean that experience and the informed likely hypotheses deriving from it would in themselves prevent more senior healthcare professionals from listening or practising testimonial justice. What might prevent them from doing this could be the unjustified epistemic power of such hypotheses and their conflation with the truth. In the following vignette, the participant shares her process of struggling to have her symptoms and worries acknowledged and addressed, as well as the role played by a junior doctor in finally reaching a diagnosis.

> *I started to get really bad pains like…my bottom and my tummy and I was kinda cramping and…you know? it was really, I felt terrible…mmm… and go to the doctor and I am like ahh you have haemorrhoids, you have this, you have that…like…stress…you have*

> *IBS [Irritable bowel syndrome]…somebody told me I had anorexia…like…and it was really…and, and then it wasn't until…I think I can't remember exactly the incident but my mum took me to A&E [Accident & Emergency Services]…mmm…I think a fainted on her or something in like somewhere really funny and…I think something happened and I had really bad rectal bleeding…mmm…and then they, it was…it took forever at the hospital. I went to the local hospital, were useless like…it's probably stress, it's probably nothing [in a dismissive voice] like…we are not going to do anything to manage it so we pushed and we got an MRI and then they were like no…the MRI is fine…but then I came back, I still wasn't really well so we had to go back to A&E mmm…and it was actually a junior doctor there that was like 'look, this is a printout, you need to go and see the specialist' […] and when I finally got into seeing a gastroenterologist things got a lot better…so that's how I got diagnosed (29-year-old woman living with Crohn's disease).*

As discussed in Chapter 4 and mentioned earlier in this chapter, many participants described going through a period of shock after diagnosis, but some participants who had been feeling ill for a long time and had been pushing to get a diagnosis described this moment as a big relief. This was associated with the belief that having a diagnosis could orient a course of treatment or actions that would help them feel better.

> *Having undiagnosed [pituitary disease] was much, much worse than the position I am in now knowing that I have had it and I can live with it, so I am much happier now, much more energetic, so I think it's…so having the diagnosis made was brilliant (64-year-old woman living with pituitary disease).*

However, this was not the case for those whose treatment, and therefore the diagnosis, did not make a significant difference to how they felt.

> *I thought it was going to be this instant cure and the first drug seemed to work almost instantly and then after a few days, and I remember getting really emotional about it thinking 'oh my God, it's come back' and just because I had this kind of [laughs] respite, I just thought I wish I didn't had it almost, I thought now that I know I will remember what it feels like to feel well and I just don't want to be back in this pain again (47-year-old woman living with Crohn's disease).*

Still, participants described feeling better about knowing the medical explanation for their bodily experiences and so the diagnosis worked as a 'reality check', as one participant put it. Like this, beyond the more evident physical harms of delaying diagnosis and treatment, the testimonial injustice resulting from healthcare professionals refusals to concede and consider the importance of the information presented by people experiencing symptoms of chronic disease might also inflict psychological harm that goes beyond the stress, anxiety and suffering of the process. Although an in-depth exploration of this goes beyond the scope of this work, in very simple terms, this harm would consist of disrupting people's fundamental self-confidence regarding being able to tell what is real and what is not, which is a central feature of what is defined in psychodynamic theory as normal personality. According to Kernberg (2016, 145),

> personality derives from the human organism's capacity to experience subjective states that reflect the internal condition of the body as well as the perception of the external environment within which this body functions.

A normal personality is in part constituted by a normal identity, which represents the integration of the inner world—including self-concept—and external reality—internalisation of significant others (Kernberg 2016) . Building on this, healthcare might be thought to play a role in patients' negotiation of identity. Still, the idea of a dynamic porous boundary of identity reflects a tension between identity as a unitary or multiple feature, as discussed in Taylor's (2001) historical analysis of the self first published in 1989. Taylor (2001) argues that the unitary self represents a modernist turn that is limited by the inner/outer world division and an increased focus on rationality. Still, similarly to the dynamic porous boundary of identity described in the context of living with chronic disease, Taylor (2001, 463) makes the point that there has been post-modernist need—arguably following a pre-modern rationale—to escape the unitary limits of the self by "exploring levels of experience in which the boundaries of personality become fluid". Although this chapter focuses on the experience of chronic disease and its impact on the self (the chronically ill self), it might be argued that identity is fluid beyond chronic disease, as people negotiate different roles in different contexts (the working self, the family self, the social self, etc.). The conclusion of this thesis will pick up this discussion and develop it further using the lens of intersectionality.

As argued in this chapter, it might be thought that people who reach the epistemic conviction that there is something wrong with their body are likely—depending on the symptoms—to have been going through a slow and difficult process of losing their sense of wholeness and continuity of experience, not being able to be and do as before (Toombs 1987; Carel 2016). Carel (2016) described this as an experience of unreality, estrangement and detachment, suggesting that during the period of normalisation or illness resistance, as defined in this work, people are going through the psychologically destabilising process of losing trust in their interpretation of themselves and thus also the world, normally achieved in the first six years of life and revisited in adolescence (Kernberg 2016). In this context, the authority that healthcare professionals have over the body might be thought to go beyond medical knowledge and play a meaningful role in people's psychological process of integrating or resisting bodily becoming, and arguably, the retuning of the inner and outer worlds allowing people to navigate life by trusting themselves and others.

4. Mourning and suffering in chronic disease

Kleinman (1988) argues that people living with chronic diseases experience grief "for the loss of a body part, physical function, body—and self—image, and way of life", as well as their own death and anticipated losses (Kleinman 1988, 39). This statement seems to condense the different consecutive and cumulative losses associated with chronic illness, discussed in Dimension 2, and suggest that from a psychological perspective there is a mourning process associated with chronic diseases. This resonates with ideas introduced in Chapter 5 about chronic diseases potentially affecting what people can do and be, as participants described adjusting their expectations and shifting their perspectives.

Much in line with participants' experience of fear of death and worries about the future—discussed in Chapter 4—and their experience of lack of control and agency, Kleinman (1988) argues that psychotherapeutic work with people with chronic diseases often focuses on regaining control over a state of fear and re-establishing confidence in the body and the self. As discussed in Chapter 5, many participants described experiencing a state of shock, an acute fear of dying and a sense of vulnerability following their chronic disease diagnosis. Although the acute state of shock passed and participants described progressively being able to integrate new information about their illness, the increased sense of vulnerability remained and—throughout this work—has been argued to be a central feature of the experience of living with a chronic disease. This, once again, suggests that chronic diseases introduce an irreversible change in which a previous way of being is lost. Dimensions 1 and 2 described how this comprises losing a sense of belonging to the social world as well as varying degrees of control and agency over the body, the disease and life more generally. This marked before and after illness is represented in the following vignette.

> *Before [being ill] I had a career I was busy and travelling and doing things and it was sort of good money as well. So, I was very able to look after myself […] I mean I lost the house and everything because of it [being ill] mmm and in the end, my husband just got bored of it (47-year-old woman living with Crohn's disease).*

Kleinman's (1988) specifications about the mourning process and psychotherapeutic support of people living with chronic diseases also include coming to terms with the anger arising from functional limitations, ameliorating feelings of guilt over failures associated with illness and jealousy towards the healthy. The following quotation reflects some of these emotions, as the participant describes his frustration and emotional reactions to the limiting or invalidating degree of tiredness he experienced.

> *Sometimes I become aggressive…sometimes…I hide in my bed…occasionally I…you know? left the house…so lots of different things really…but yeah mainly anger and…I am not naturally an angry person so…when it happens it…you know?…disgusts me…I, I…feel very much ashamed and letting people down […] [voice breaks] so yeah and also…the guilt is very big…you know? I wish I could do many more things…for the kids, with the kids, with my other half, with my business (54-year-old man living with pituitary disease).*

The previous two quotations represent regressive core narratives in which participants experience, in some way, a complete and irreversible loss of wholeness and continuity of experience of the self due to chronic illness. This means that participants did not feel they could be themselves or continue living the lives they had reason to value, while still working towards and hoping to find dynamic equilibrium, that is, thinking that they might be able to feel better and live lives they have reason to value. Thus, thinking that chronic diseases only imply a complete and irreversible loss might be an oversimplification of the experience, which also oversimplifies the mourning process associated with it. As discussed before, besides these two examples of regressive core narratives, most participants felt well some or most of the time.

Because of Kleinman's background in psychiatry, it is plausible to think that when he makes reference to the concept of mourning he is somehow referring to the Kübler-Ross model of grief—denial, anger, bargaining, depression, and acceptance. These stages follow from irreversible losses (e.g. the death of a significant other, a body part or function, etc.). From this perspective, reaching a state of acceptance is considered normal and healthy. Denial is only justified while it serves a protective purpose in psychological terms, but if prolonged, it is argued to lead to pathological grief (Kübler-Ross 1969).

Kleinman's (1988) views on mourning contribute to specifying the struggles of living with a chronic disease but seem to also—as Kübler-Ross'—be founded on a medical understanding of health and disease. This implies that the emotions arising from this experience, such as anger and fear, are seen as potential interference with normal grief processes (Kleinman 1988). Thus, participants sharing regressive core narratives and struggling to reach a state of acceptance, such as those represented in the last quotations, might be labelled as examples of pathologic grief—stuck at anger, bargaining and depression—for periods of around thirteen and nine years, respectively or ‘failures to adapt’ to life with chronic disease. Although these labels might be accurate within specific disciplinary contexts, such negative labelling—pathologic and failure—might be thought to obscure these experiences contributing to their marginalisation. Furthermore, Chapter 5 argued that prescriptive models of adjustment and success/acceptance narratives suggest a linear progression, which does not account for the hardship, precarity and dynamism of life with chronic disease, so this work specified adjustment to chronic diseases as the *effort* towards dynamic equilibrium.

Thus, on a more abstract level, it might be argued that chronicity in its phenomenological sense represents a complete and irreversible loss of wholeness and continuity of experience. This concept, introduced in Chapter 4, builds on the paradox of chronicity and describes the specific way in which chronic diseases become a part of the body and the person, as they are always present even in the absence of their manifestation, as likely to recur. Drawing on participants’ experience, chronic diseases have been argued to impose a new way of life structured around the ‘logistics of care’, including the monitoring discussed in Dimension 2. This mainly implied losing spontaneity and flexibility in daily life, and more generally, the possibility to lead a carefree lifestyle—specifically in relation to their health. This might be thought to be the most stable and unifying content of the mourning process associated with chronic disease, and thus grief for this loss might follow the five-stage grief process towards acceptance. However, this ‘acceptance’ might be regarded as ‘denial’ from Kübler-Ross’ (1969) and Kelinman’s (1988) perspective, insofar participants described it as a state in which there is a strong protective boundary between chronic disease and identity.

> *I know it’s there, at some level I know that I am ill…not ‘I am ill’, I know that I have got an illness…mmm…but I have accepted that as part of me (49-year-old woman living with rheumatic disease).*

On a more concrete level, however, depending on the way in which and the degree to which chronic diseases disrupt this hard boundary with their cyclical and or whimsical manifestations, this abstract grieving process might be hampered. The cyclical and or whimsical manifestations of chronic disease might be argued to imply that the body becomes an unstable or disorienting (sometimes healthy, sometimes ill) mediator to encounter the world, prompting an ambivalent experience of the body-self and thus also the process of mourning.[2]

In the following vignette, the participant describes how, after living with the disease for twelve years and having ‘accepted’ this, he started relying on his ‘healthy’ body after a long period of time without symptoms, but this was frustrated by a flare-up.

> *Right now… like we are supposed to play tennis, a group of us, we*

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[2] The unstable or disorienting quality of the experience of chronic diseases was discussed in Dimension 1 in terms of the difficulties this raised for empathy and belonging.

> *have a Whatsapp group and I was like ‘Jeez, I don’t think I could be jumping around’ like… with the cramping… […] I couldn’t be jumping around with a tennis racket or running around…I am supposed to be doing this run in Berlin as well in April and I can’t run, train so I am like, I am not even a big runner but I was gonna try and do this and then I was like ‘I can’t’ ... (37-year-old man living with Crohn’s disease).*

In trying to specify how he felt about this, he described adopting an avoidance strategy, as described in Chapter 5, to cope with the lack of control, suggesting this was, nonetheless, a frustrating situation.

> *I just think of people who are in worse situations as well and it’s like I don’t really get to… there’s nothing I can do so it’s like… it’s out of my hands so…(37-year-old man living with Crohn’s disease).*

Insofar the losses described in Dimension 2 have the quality of being, at least to some extent, re-experienced alongside the cyclic manifestation of symptoms, the grief associated with them is too, introducing a confusing element regarding how to continue living both with others and oneself.

> *I didn’t necessarily blame myself, but obviously when you are that ill, like it’s really hard not to hate yourself at least a little bit just because you are like ‘why?.... Why is my body doing this?’ Like…‘why it can’t just be normal?’ (23-year-old woman living with ulcerative colitis).*

Drawing on the last two quotations, it seems understandable to start trusting the body more after a long period of no symptoms and planning on that basis, rather than self-imposing a predicted loss of functionality that is not possible to anticipate. Thus, it also seems understandable to re-experience anger and frustration over periods in which the disease limits people's possibilities to do and be. This suggests that mourning anticipated losses, as Kleinman (1988) argues, might demand significant abstraction and negatively affect dynamic equilibrium.

> *It's very easy to become pessimistic about it [illness] mmm…I think […] that I'll like never be like fully better or it is always going to affect me….and it is going to always affect me I know that, but it's like…unfair…[…] I kind of get angry at my body sometimes, but then I don't know, it's like again it kind of depends on how positive or negative I am feeling (23-year-old woman living with ulcerative colitis).*

Precisely because of the relative dynamism and unpredictability of chronic diseases despite treatment, not thinking or engaging with the losses associated with chronic disease while these are not experienced should not be regarded as a state of denial, but of survival. This follows closely from the discussion on lack of control and avoidant coping strategies, discussed in Chapter 5. Although this implies that people living with chronic diseases go through the process of recuperating both physically and psychologically each time they feel poorly, are in pain and or lose something of value due to the illness acting up, this should not be regarded as 'pathologic grief', but as the cost of having protected their possibilities to be and do over symptom-free periods. Furthermore, even if this is a constant state—for those who continuously experience symptoms or physical and or psychological consequences of long-term treatment, it should not be regarded as ‘pathologic grief’, but as a genuinely extremely challenging living situation.

Thus, introducing a harder boundary between chronic disease and identity when possible is a crucial protective function of identity. Thus, this is also a key contributor towards dynamic equilibrium despite that, as discussed in Dimensions 2, this boundary can sometimes jeopardise long-term treatment.

5. Conclusion

This chapter looked in depth at the protective function of the porous boundary between identity and chronic disease, and the tensions arising from this in the context of long-term treatment. Drawing on the idea that ‘healthy’ is a favoured status both for the self and others, participants were argued to display significant psychological efforts to resist illness during the onset of disease and after the disease was diagnosed by normalising bodily changes as much as possible. Although this sometimes led to delays in diagnosis, this was argued to allow people to protect themselves from developing negative feelings and attitudes towards themselves, thus contributing to the efforts towards dynamic equilibrium, this is, their possibilities to live lives they have reason to value. In addition to people resisting illness, healthcare professionals were argued to also negatively add to the initial process of bodily becoming by resisting to concede and consider the importance of the information provided by patients before reaching a diagnosis. This was argued to constitute a testimonial injustice practice resulting in physical and psychological harm. Although the powerful effect of the social world over bodily becoming was discussed in Dimension 1, this chapter argued that healthcare professionals might have an augmented limiting/facilitating effect because of their epistemic power over the body and illness.

In this context of significant illness resistance, drawing on participants' experience and chronicity in a phenomenological sense, the last section of this dimension introduced a distinction between mourning for the more or less abstract and irreversible loss of health associated with chronic disease diagnoses and suffering the consequences of the losses associated with the cyclical and or whimsical flare-ups of chronic disease. Going through the emotional rollercoaster of experiencing different losses along the cycle of disease manifestations, instead of mourning for anticipated losses, might be the cost of introducing a harder boundary between identity and chronic disease, crucial in the overall efforts towards dynamic equilibrium. Thus, dynamic equilibrium in chronic disease was described to constitute an imperfect negotiation between competing demands, in which some degree of suffering might be constant or inevitable at times.

Conclusion to Part III

By looking into meanings of illness and processes of stigmatisation, lack of empathy and place, Dimension 1 argued that people with chronic diseases suffer from a hermeneutical injustice that contributes to ruptures in their sense of belonging, withdrawal from social situations, isolation and loneliness, hampering their possibilities to keep previous social support and build new social networks. Besides this being a more or less painful individual experience, this was argued to potentially limit the mobilisation of resources to face the state of illness and work towards dynamic equilibrium.

Furthermore, Chapter 6 argued that even if people living with chronic diseases have good social support and networks, on a more general level, they might still be prevented from developing a deeper sense of belonging to the social world due to structural issues. Thus, the disadvantaged within a society were argued to, overall, suffer more from hermeneutical injustice relative to the better off, adding another layer to the cumulative effect of disadvantage among those living with chronic diseases. This discussion introduced the potential value of healthcare systems contributing towards the development of shared tools for social interpretation to increase the chances of those who live with a chronic disease receiving adequate individual support and developing an overall sense of belonging to the social world.

Dimension 2 helped further specify the experience of the paradox of chronicity by reflecting on the consequences that living with little to no sense of control over chronic disease can have. In this context, bodily transparency in chronic disease was specified as something that is both lost and achieved—more or less cyclically and painfully—through symptoms, monitoring and encounters with others. Thus, sedimenting chronic disease as a new way of being was described as a difficult change in so far it implies giving up a previously favoured status. Building on participants' experience this chapter argued that in a rather paradoxical manner, while monitoring and treatment can sometimes help achieve freedoms and an increased sense of control over the disease and the body, monitoring and treatment can simultaneously hamper participants' sense of agency beyond illness and limit their sense of self, feeling dependent, vulnerable and alienated. Thus, in trying to reassert agency over life and protect their identity, people living with chronic diseases may hamper adherence or take health risks.

Closely following from this, Dimension 3 looked in more detail at the protective function of the porous boundary of identity and the tensions arising from this in the context of long-term treatment. Drawing on the idea that 'healthy' is a favoured status both for the self and others, participants were argued to resist illness during the onset of disease and after the disease was diagnosed by normalising bodily changes as much as possible. In addition to people resisting illness, healthcare professionals were argued to also negatively add to the initial process of bodily becoming by resisting to concede and consider the importance of the information provided by patients before reaching a diagnosis. This was argued to constitute a testimonial injustice resulting in physical and psychological harm. Thus, adding to the concluding remarks of Dimension 1, this chapter argued that because of healthcare professionals' relative epistemic privilege or power, their acknowledgement or dismissal of patients' experience may have an augmented negative (limiting) or positive (facilitating) effect over the processes associated with resisting or allowing chronic diseases as a way of being. In this context of illness resistance, this chapter reflected on the mourning process associated with chronic diseases and suggested that going through the emotional rollercoaster of experiencing different losses along the cycle of disease manifestations, instead of mourning for anticipated losses, might be seen as the cost of introducing a harder boundary between identity and chronic disease, crucial in the overall efforts towards dynamic equilibrium. Thus, dynamic equilibrium in chronic disease was described to constitute an imperfect negotiation between competing demands, in which some degree of suffering might be constant or inevitable at times.

Thus, it might be argued that if people living with chronic diseases experience at some point and to some extent in their illness trajectory the emotions and processes described in these three dimensions, they will struggle or be inconsistent when attempting to follow life-long treatment recommendations and self-care tasks, as they work towards dynamic equilibrium. This struggle or inconsistency might be reflected in the measurements of long-term treatment adherence as "non-adherent at the time of measurement". This might contribute to the long-standing and complex discussion on how to conceptualise, measure, and interpret results of adherence[3] specifically for the case of chronic diseases and long-term treatment. Instead of thinking that 50% or one in two people do not adhere to long-term treatment recommendations (Sabaté 2003), this work suggests that everybody might at some point contribute to this adherence rate.

The multidimensional perspective on the experience of chronic disease describes how the different processes involved in people's efforts towards dynamic equilibrium are, overall, more fragile, among those who live in disadvantage. Such descriptions of the cumulative effect of disadvantage help further specify the mechanism underlying the social gradient in chronic disease health outcomes and long-term treatment adherence, as discussed in the introduction to this thesis. This work suggests that long-term treatment adherence most likely comprises periods of optimal adherence and periods of no or partial adherence, introducing the idea of long-term adherence as a lifetime process rather than a discrete and stable outcome. Furthermore, from this perspective, adherence to long-term treatment adherence is argued to be a non-linear and more or less fragile process closely intertwined with individuals' lives beyond illness and illness experience and trajectory. Drawing on this, Part IV of this thesis will focus on the ethical problem of chronic diseases becoming risk multipliers for disadvantage and reflect, on a normative level, about the injustice underlying health outcomes for chronic diseases. The next chapter draws on participants' experience and participant observation sessions of long-term treatment appointments to expand on the

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[3] See Kardas, Lewek, and Matyjaszczyk 2013; Vrijens et al. 2012; Osterberg and Blaschke 2005.

patient-healthcare professional relationship and reflect on socially aware and ethically driven goals for long-term treatment.

Part IV

Normative Thinking in Context: Chronic Care and Chronic Disease Health Outcomes Inequalities

Chapter 9

What does good (and bad) chronic care look like?

Normative and empirical challenges

1. Introduction

As discussed in the introduction to Chapter 5, much academic literature on chronic disease argues that failure to adjust to chronic disease is strongly associated with poor self-management mainly in terms of adherence to long-term treatment (Sabaté 2003; Ridder et al. 2008; Bodenheimer, Wagner, and Grumbach 2002a). In light of low adherence rates and poor health outcomes, health and care systems in the UK have been failing to offer adequate support for people living with chronic diseases. Relevant efforts to address these challenges might be framed within the concept of co-production in the delivery of services. Applied to the health sector, this concept is highly focused on the unique needs of people, and regarding the ill person as an active expert in the consultation context, thus stressing the importance of patient-centeredness and involvement (Realpe and Wallace 2010).

The generic care model for chronic disease in the NHS follows the chronic care model (CCM), which is strongly focused on productive interactions between practice teams and patients (Realpe and Wallace 2010; Wagner et al. 2001). This model is based on Wagner's (1998) research and following suggestions for reshaping ambulatory care for chronic illness in the

United States. Much in line with the experience of participants discussed in this thesis, Wagner (1998) highlights that the needs of people living with chronic diseases are diverse and that an acute care organisation and culture of care is unlikely to meet such needs. Furthermore, and consistently with the idea of adjustment as a constant effort towards dynamic equilibrium introduced in Chapter 5, Wagner's (1998) approach to chronic care stresses the need for regular interactions with care givers focusing on function and prevention of exacerbations and complications, and continuing follow-up initiated by clinical practice. This resonates with the idea that chronic care and adherence to long-term treatment reflect dynamic processes instead of isolated interventions and stable achievements.

The CCM is a comprehensive approach that suggests adjustments on different aspects in the organisation and delivery of healthcare to meet the specific medical needs of people living with long-term conditions (Wagner et al. 2001). This model states that patients themselves become the principal caregivers and highlights the importance of self-management support and education. Still, it also acknowledges that self-management education can only deliver problem-solving skills and improve health outcomes to some extent, specifying that sustaining these changes in the long-term remains a challenge (Barlow, Turner, and Wright 2000; Bodenheimer et al. 2002). This might be associated with the multi-layered challenges faced by people living with chronic diseases, which, as described in this work, often appear as trade-offs or competing demands between the disease, the self and life beyond illness, which may sometimes hinder healthful behaviours and self-management tasks.

As presented in the introduction to this thesis, the specific policy and programme development initiatives to improve health outcomes for chronic diseases in the UK include the ‘Expert Patient Programme: A New Approach to Chronic Disease Management for the 21st Century’ (Department of Health 2001) and ‘Supporting People with Long-Term Conditions. An NHS and Social Care Model to support local innovation and integration’ (Department of Health 2005). More recent initiatives are the King’s Fund report ‘Delivering Better Care for People with Long-Term Conditions: Building the House of Care’ (Coulter, Roberts, and Dixon 2013) and the King’s Fund recommendations to the clinical commissioning groups ‘Transforming our Health Care System’, which focuses on how to improve healthcare delivery and outcomes for chronic disease (Naylor et al. 2015).

All these initiatives closely follow the principles of the CCM and are aligned with the ideas around co-production. The King’s Fund ‘House of Care’ (Coulter, Roberts, and Dixon 2013) is particularly comprehensive and offers a good summary or integration of earlier policy documents and recommendations. Building on the largely agreed importance of patients being engaged in decisions about their care; providing supported self-management; co-ordinated care; prevention, early diagnosis and intervention; and emotional, psychological and practical support, the ‘house’ metaphor describes responsive commissioning as the floor; engaged, informed patients and healthcare professionals committed to partnership working as the walls;

and organisational processes as the roof. Without reading too much into how these choices might reflect certain qualities (e.g. foundation, support, cover or protect) and hierarchy between these elements, the ‘house’ as a whole is argued to provide a space for personalised care planning, which might be understood as person-centred care (Coulter, Roberts, and Dixon 2013).

Despite the multiple variables involved in these recommendations and their focus on co-production, drawing on empirical research in the UK, Entwistle et al (2018) have argued that, in practice, self-management support is narrowly understood as patient education for healthcare desired behaviour change. As already mentioned, this is strongly focused on increasing treatment adherence to improve healthcare in terms of morbidity and mortality while reducing healthcare costs by reducing readmissions to hospital and multi-morbidity for example, thus taking a rather instrumental view on patient input (Entwistle, Cribb, and Owens 2018). This is highly consistent with issues around participatory prejudice and testimonial injustice discussed in Chapter 7, as healthcare professionals were argued to often see patients as objects, refusing to concede relevance to the type of information they generally provide and refusing to consider the possible significance of patients’ accounts (Kidd and Carel 2017b). Thus, there seems to be large agreement on ‘person-centeredness’ but not on what this means in a broader sense. In practice, it can amount to anything from addressing each aspect of the person’s life separately and in a static way to a complex systems approach that works with the continuous new information arising from the interactions between different aspects in a person’s life across time, including chronic care.

Lacking such a ‘complex systems’ or ‘whole-person’ approach might be argued to play a part in current poor and ethically problematic outcomes for chronic diseases. The ‘Expert Patient’ initiative, explicitly focuses self-management support on “developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness” (Department of Health 2001, 6) and aims at people achieving “good quality of life despite chronic disease” (Department of Health 2001, 9). However, building on moral discussions about illness, Edgar (2005) criticised this initiative for failing to acknowledge and support the skills that people living with chronic diseases need to make sense of their disease and the impact the disease has on people’s sense of self or identity. This is closely linked to the little attention that care for chronic diseases pays to the psychological and emotional issues faced by people living with chronic diseases (Furler et al. 2008). Further criticisms of self-management support have argued that its limitations may be attributed to the lack of understanding of self-management as embedded within and facilitated by social contexts and support (Kendall et al. 2012).

These criticisms highlight the importance of chronicity in its phenomenological sense and the issues discussed in the multidimensional perspective on the experience of chronic diseases (chapters 6, 7 and 8). Moreover, although health inequalities significantly affect chronic diseases and the Clinical Commissioning Groups deciding which services are needed and ensuring these are provided have a legal duty to consider this, the King’s

Fund report ‘Transforming our Health Care System’ is the only document, out of the ones mentioned, that acknowledges health inequalities and considers recommendations that can contribute towards tackling this issue as a secondary outcome. Still, its priority is focused on patient self-management support (Naylor et al. 2015; NHS 2015).

Thus, on the one hand, the UK’s practical efforts do not seem to fully acknowledge the social gradient in treatment adherence and self-management underlying chronic disease health outcomes inequalities. As already argued, this draws on the cumulative effect of disadvantage and its effect over people’s varying capabilities—or genuine opportunities—to work towards dynamic equilibrium and live lives they have reason to value. On the other hand, these efforts also fail to fully acknowledge the distinction between helping people manage their chronic conditions—in terms of symptom and disease control—and helping people manage well with their health conditions. Like dynamic equilibrium, the latter aims at a more flexible goal comprising health, wellbeing and overall quality of life (Entwistle, Cribb, and Owens 2018). Besides unsuccessfully focusing on supporting symptom and disease control—drawing on the persistent poor outcomes, in so far these two perspectives of self-management support are not clearly distinguished, it also remains unclear how self-management support, in practice, can achieve such broader and truly person-centred aspirations (Entwistle, Cribb, and Owens 2018; Tyreman 2018). This seems particularly morally relevant because narrow or biomedically oriented approaches to self-management support have also been argued to exacerbate pre-existing inequalities, as the better-off are more likely to find self-management tasks straightforward and have the resources to attend or overcome neglected aspects of their care (Entwistle, Cribb, and Owens 2018).

Building on participants' experience in this study, the following sections of this chapter describe how narrow and whole-person approaches to chronic care can play a role in either breaking the system around chronic disease health outcomes apart or generating reinforcing feedback loops contributing towards dynamic equilibrium, respectively. This analysis puts the patient-healthcare professional relationship at the centre of the interactions continuously generating relevant new information for long-term treatment and health outcomes for chronic diseases. The detailed analysis of this relationship suggests that narrow approaches to self-management support encourage an individualistic view of care for chronic diseases that ignores the strong interdependence required in the management of chronic diseases. Thus, drawing on participants' experiences and judgments of chronic care, this chapter suggests that sharing responsibility for chronic care can facilitate collaboration for dynamic equilibrium, leading to better and fairer health outcomes for chronic disease. On the contrary, insisting on the rationale of 'what one deserves' that underlies individual responsibility can significantly hamper it and negatively affect people's efforts towards dynamic equilibrium, allowing the cumulative effect of disadvantage to amplify existing health outcomes inequalities. The last section of the chapter specifies continuity of care for chronic diseases and highlights its potential as a facilitator in the process of achieving broader, truly person-centred and ethically driven aspirations for chronic care.

2. Performativity in chronic care as an ethical issue

As mentioned in the introduction to this thesis, Tyreman (2018, 2) also highlights the narrow versus complex or more expansive aspirations in person-centred care, as he specifies that providing ‘truly’ person-centred care implies “recognising that human beings face up to the challenge of illness, pain, and disability differently to how we might understand and seek to correct a fault in a car, say”. This comparison reintroduces the value of paying attention to the broader system of interactions around life with illness, considering the new information that is created and how this re-enters and shapes the system. Similarly to what Wilson (2021) describes in terms of complex systems performativity—as discussed in the introduction, Berlinger (2016) argues that this ‘emergence’ feature of complex systems in healthcare contexts can create shared perceptions amongst rotating healthcare providers, family caregivers and the patient, for example, affecting individual’s behaviour potentially also affecting the outcomes of the patient. In the specific context of chronic care, it seems particularly relevant to pay attention to new information emerging in the patient-healthcare professional relationship and how this can affect health outcomes.

‘Quality’ is regarded to be a plural or multidimensional concept by definition and, specifically in the context of healthcare, it has been argued that "different high-level conceptions of quality can be appropriately invoked in different contexts and serve different purposes" (Mitchell, Cribb, and Entwistle 2019, 367).[1] Thus, unsurprisingly, participants' judgement and appreciation of chronic care varied but reflected the value of broader and truly person-centred aspirations. On a general level, most participants' descriptions agreed on what made healthcare professionals 'good' or 'helpful' in the specific context of chronic care. Highlighted attributes included being polite, caring, open, understanding, funny, friendly, calm, confident, straightforward but, as seen in the following vignette, rather than valuing these specific qualities in themselves, such qualities were important insofar they were thought to contribute to establishing and maintaining a 'good' relationship with a healthcare professional. In other words, 'good' healthcare professionals happen in the context of the relationship with the patient.

> *I always try and get an appointment with him because I find him very good he is not particularly empathetic, but he's…just gets it…he understands and he…is…proactive…so if I tell him I am worried about something he…like helps me out with it and gives me the right advice (29-year-old woman living with Crohn's disease)*

Following on from this, expertise and knowledge were especially valued alongside the ability to listen, namely putting the knowledge at the service of context. 'Listening' was understood in terms of validating patients in

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[1] This resonates with the conceptual problems of 'health' and 'disease' discussed in Chapter 4, which also focused on the value of context and purpose to embrace complexity.

their experience and thoughts about their health, being open to negotiating with them and answering their worries and questions. Drawing on the discussion in Chapter 8 and as seen in the following vignette, this might be described as healthcare professionals who practised testimonial justice and did not conflate experience and knowledge with the truth.

> *[You] might see some [healthcare professionals] that are quite arrogant and they are actually like 'hey, I am the consultant here' […] 'I know'…whereas I haven't found that here, I found them very much like they…listen to me…I am…I trust them because they've got [laughs] you know? the experience, but they are not very, they are not trying to force their views on me. They are quite happy for me to say how I feel, they are quite happy for me to suggest reasons behind my illness and things like that (41-year-old woman living with Lupus).*

Furthermore, during the appointments observed, such healthcare professionals dedicated a considerable amount of time finding ways to reach out to participants by asking them open questions and also personal questions, inviting them to share aspects of their lives beyond the illness. Besides this being important for healthcare professionals getting to know patients, even after living with a chronic disease for many years, care for chronic diseases was described as dynamic in itself and interwoven with life changes beyond illness, such as family issues, caring responsibilities or travel plans. Participants asked for support on disease management, other illnesses, their overall health state, life changes, and understanding new aspects of their illness. The following quotation exemplifies this as the participant had the opportunity to speak to her GP about having difficulties with her landlord to find a solution for the humidity and mould in her house. Only with the help and support of her GP, this participant was able to show that mould worsened her asthma and eventually improve her housing situation.

> *He is [a] good listener even if I speak to him about my house problem he writes for me a certificate to the environment department, for example, he is a good support my GP (56-year-old woman living with asthma).*

However, and after going through the process of diagnosis, participants described experiences of testimonial and hermeneutical difficulties in the relationship with healthcare professionals or healthcare teams more broadly. A few participants stressed as particularly problematic healthcare professionals' lack of empathy and emotional investment in the relationship, healthcare professionals being uninterested, arrogant and or unwelcoming, and not taking them seriously by showing unwillingness to consider their worries or questions and making unilateral decisions about their care. In the following vignette, the participant describes a healthcare interaction that, although potentially well-intentioned, disregards the participant's context and, in doing so, contributes to the prejudiced hermeneutical marginalisation described in Chapter 6.

> *I said 'ahh I work part-time', why do you do that? [asked the doctor] mmm…because I like to go to the gym and try and stay healthy because of my, you know? weight loss, I said […] plus I am trying to make up on life, plus I get quite tired…'you should be able to work full time' [replied the doctor], 'I think you should work more hours' [said the doctor]… I actually went and worked more hours because I felt shit, I was like 'oh crap, I am just being lazy just like I was before', 'maybe I am not pushing myself'… actually that was a real struggle at that time, I wasn't ready for it (31-year-old man living with pituitary disease).*

Drawing on the discussions in Chapter 6 and Chapter 8 the last two quotations reflect how, because of their social role and epistemic power, healthcare professionals' practices of testimonial justice and participatory prejudice, respectively, might either help compensate for prejudice and prevent further disadvantage or augment experiences of prejudice, risking further disadvantage by undermining the precarity of dynamic equilibrium.

Closely linked to this, some participants also shared resenting healthcare professionals who did not consider their personal history, going through standard motions that may not apply to them, and disbelieved them or questioned their knowledge of their body. As exemplified in the following vignette, this was described in terms of being objectified by making his individuality disappear in the way he was treated.

> *So often they mmm…doctors didn't really…you are a number, they didn't really listen…mmm…they and I often questioned and they were…just about willing to explain things, but…but you know?…I felt I had to push them and I was frustrated about that…so…and about after*

> *5 years I saw a different doctor and he was the first one who listened (54-year-old man living with pituitary disease).*

Many participant observation sessions offered good examples of some of these elements, showing moments of little receptiveness from healthcare professionals who mostly focused on completing administrative tasks on the computer. In these appointments there was little eye contact and communication was difficult, healthcare professionals asked few open questions and tended to interrupt participants. Although this can be understandable considering that an important aspect of specialist care appointments includes healthcare professionals completing the electronic record, writing prescriptions, ordering tests and explaining new or repeating previous recommendations, drawing on the participant observation sessions more generally, it might be thought that healthcare professionals' general attitude towards the encounter can facilitate or hamper the relationship. In other words, roughly the same appointment—in practical terms—can be more or less of a discussion, with the healthcare professional paying more or less attention to what is relevant to patients.

Other ways in which healthcare professionals might be thought to have contributed to a positive clinical encounter during the participant observation sessions included turning the computer screen towards the participant so they could look at and discuss test results; using a sense of humour to have a friendly and relaxed encounter; and giving positive feedback to participants by highlighting their progress, celebrating some aspect of their management, or their positive attitude towards illness or treatment. These efforts seemed particularly relevant because, much in line with the fears and worries associated with chronic disease discussed in Chapter 4 and the experiences of participatory prejudice discussed in Chapter 7, participant observations sessions suggested that many participants felt anxious or stressed about and during their healthcare appointments. Some signs of this included participants coming in early, bringing a list of questions for the healthcare professional or carrying a folder with test results and other medical documents possibly to avoid forgetting important information, feeling more confident, make the most out of the appointment and or be taken seriously.

More generally, some participants described that when healthcare teams had a ‘good attitude’ in terms of being welcoming, friendly, caring and polite this motivated them to adopt a similar attitude. As seen in the following vignette, the participant stresses the value of feeling good in the care environment in general and how this contributes to building a relationship of collaboration or working partnership for treatment.

> *Interviewee: so, they are great I love the nurses…mmm super helpful, very risk-based approach…mmm…and just really nice people, like they are really kind even though they are super busy they are never rude they are never crossed, they are never short with you…*
> *Interviewer: and how do you think? Do you think this has an effect on your care?*
> *Interviewee: yeah because I am able to ask them things and I am not worried about asking them mmm…yeah, so they are super professional. I really like them (29-year-old woman living with Crohn’s disease).*

In general, participants' descriptions of what they valued and did not value in their relationship with healthcare professionals is closely linked to the egalitarian principle of 'being treated as an equal', this is, being treated with equal concern and respect, where respect means for people to be treated as "capable of forming and acting on intelligent conceptions of how their lives should be lived" (Dworkin 2013, 326). The following quotation from participant observation field notes exemplifies how the patient-healthcare professional relationship can be damaged when this is not the case.

> *The doctor tells the patient about something new they are trying. A carbs free diet to see whether it helps regulate sugar levels. She gives the patient a list of foods she should have in each meal and a chart she is supposed to complete. The patient says she does not think she would like to do it, she does not think she has the time to it. The doctor insists and says: "you don't have to do full days, it can be during the weekend…" the patient replies: "I don't think so". The doctor says: "ok, so if you could complete that before your next appointment that would be useful". When we [patient and researcher] leave the room the patient is upset and tells me [researcher] that she finds this doctor very irritating. She says: "every time I see her it is just a big waste of time" (36-year-old woman living with type 1 diabetes, participant observation field notes).*

As discussed in the introduction to this thesis and Chapter 1, drawing on the complex systems approach orienting the hermeneutic approach to this qualitative study, the idea that how people are treated affects how they react is fairly obvious. Furthermore, how this process changes people and reshapes reality is the topic of a large body of literature in sociology, psychology and philosophy. Looking at the dynamic process of Merton's self-fulfilling prophecy (SFP) or Barnes' performativity—as described by Biggs (2011)—and Hacking's (2007) 'looping effect' might shed light on the virtuous and corrosive effects that being and not being treated with concern and respect can evoke in the healthcare context.

Closely linked but going beyond confirmation bias, as discussed in Chapter 8 regarding the time of diagnosis, SFP is the process by which a false belief or conception evokes behaviours that make the initial false belief or conception come true (Biggs 2011). Drawing on a detailed analysis of social studies, Biggs (2011) describes three plausible explanations for this, which are relevant to then think about chronic care and the new information that is created in the patient-healthcare professional relationship. Building on the example of a teacher-student relationship, the first explanation suggests that when the student believes the teacher's belief that she or he is academically mediocre, regardless of whether this is true or not, the student's motivation to study might be, unintentionally, negatively affected leading to mediocre outcomes. Alternatively, the student does not know the teacher's belief, but still unconsciously fulfils the teacher's expectation. The second explanation draws on the example of a social group, assumed to be violent, responding with violence to the police's violent repression. In this case, the social group knows they are being classified as violent and they do not need to accept that classification to respond violently. Drawing on the example of people who believe they are mistrusted being less likely to behave in a trustworthy way, the third and final explanation for SFPs suggests that people intentionally live up or down to other's expectations (Biggs 2011).

Although this is not discussed by Biggs (2011), it seems rather straightforward that power relations play a role in most of these examples, and thus on the dynamic process of SFP, helping explain even why someone 'unconsciously' may fulfil expectations in social contexts. A student is more likely to accept a teacher's belief about her academic ability over her own precisely because of the hierarchy between them regarding that aspect, accepting or rejecting the police's assumptions does not make a difference because of the power invested in it by the state to assess the situation and although the last example is unspecific, it might be argued that whose expectations are fulfilled and whose are not might depend, to some extent, on epistemic trust, namely whether the person or group holding the expectations is trusted as someone who can introduce new knowledge about the self (Allison and Fonagy 2016). Although the mechanisms by which this trust develops are psychologically complex and not purely associated with the epistemic power of parents over children, for example, or psychotherapists over patients, power does play a role in what is accepted as the truth (Allison and Fonagy 2016).

Such power dynamics are closely linked to Hacking's (2007) work on the classification of people specifically in the context of mental health. Hacking (2007) argues that mental health diagnoses have a dynamic effect because the classifying in itself has a transforming effect over the people labelled, which in turn demands new classifications. This is described as 'the looping effect' of people becoming 'moving targets'. Reflecting on those who first thought of themselves as 'autistic'—after the category came about in 1943—and mysteriously recovered by developing social skills that did not match the diagnostic category, Hacking (2007, 303) describes the looping effect of "a few of those diagnosed with autism develop[ing] in such a way as to change the very concept of autism. They brought into being the idea of high functioning autistic person".

Although the looping effect suggests a mutually altering relationship between 'labelled' and 'label', ultimately the power rests on those who are in the position to classify and either change or, as already discussed, refuse to concede and consider the experience of those being labelled. As highlighted by Essén and Oborn's (2017) study on the performativity of monitoring, measuring and reporting rheumatic chronic disease outcomes, if something is not labelled, measured and reported, it does not exist from the healthcare professionals' perspective and patients struggle to see their experience acknowledged and receive treatment.

Drawing on Hacking's (2007) work, it might be thought that the discussion in Chapter 4 about the concept of chronic disease and participants' experience reflects a looping effect that is only possible after a significant time of chronic diseases having become a classification. Still, returning to the focus of this chapter, rather than focusing on this transforming effect of performativity, the overall idea that the expectations people have of each other are incorporated into their behaviour seems central to the patient-healthcare professional relationship. Furthermore, drawing on Young's (2011) idea that people act within institutions where they know others have certain expectations of how things are done and individuals react with sanction if the implicit or formal rules are violated, it might be argued that narrow and static expectations around ‘good’—compliant—and ‘bad’—non-compliant—patients are likely to shape patients’ health behaviour. In other words, erroneously taking adherence behaviours and measurements as stable achievements, namely assuming that someone who adheres will continue to adhere and someone who does not will continue not to, might play an important role in this becoming true. Because the worst off as a whole have been argued to have to risk the prioritisation of chronic care in a way that the better off do not have to, the former are more likely to be labelled as ‘bad’ patients and the latter as ‘good’ patients, so introducing the idea of performativity in the patient-healthcare professional relationship helps further specify the mechanisms underlying the vicious circle of disadvantage, this is, the reproduction and amplification of existing health outcomes inequalities amongst people living with chronic diseases.

Returning to the complex systems metaphor, this means that how people are treated and expect to be treated will have an impact on how the system as a whole behaves. In so far chronic care is seen as a complex system involving several actors in different contexts, it might be argued that how healthcare professionals and patients incorporate expectations from each other’s behaviours might lead to either vicious runaway loops of damage or virtuous reinforcing loops within the system, affecting the success or failure of the treatment and overall efforts of the system towards dynamic equilibrium.

Although this highlights the relational aspect of systems, the different levels of power that healthcare professionals and patients hold regarding illness and treatment, put them in different positions to affect the systems' performativity. In other words, healthcare professionals and their overall understanding of the patients' situation and context might be thought to have an increased power to affect the system's behaviour and its outcomes.

3. Chronic care as a shared activity

Participants' descriptions of 'good' patient-healthcare professional relationships reflect the value of healthcare professionals caring for them in particular, introducing the idea that being treated in a sensitive and responsive way is important in the context of chronic care. The following quotation exemplifies this.

> *They are always at the other end of the phone if it's like my day off or whatever. [Nurse's name] is the one I usually see but obviously [another nurse's name] knows me quite well mmm and [a third nurse's name] does as well so they've all become…I walk in there and they all just say hello [calling the patient by her name] and…they just, they just treat you really nicely in there...(46-year-old woman living with HIV).*

Entwistle and Watt (2013, 33) take this as their starting point to define what it means to treat patients as persons in the context of person-centred care, namely that "we [healthcare professionals] must be sensitive and responsive to their [patients'] specific characteristics in the particular situations in which we encounter them". Drawing on the capabilities approach discussed in the introduction to this thesis, this definition is further specified as "recognising and cultivating their person-al capabilities" (Entwistle and Watt 2013, 33–34). Although Entwistle and Watt (2013), acknowledge that this concept is still underspecified, they use the hyphenated concept 'person-al' to refer to a subset of capabilities that draws attention to the ethical aspects of the concept 'persons', such as capabilities to reason, experience particular kinds of suffering and participate socially in a group, amongst many more.

Drawing on participants' descriptions, the main characteristics of a 'good patient-healthcare professional relationship' mirrored the characteristics of supportive relationships with friends and family discussed in Chapter 6. These were relationships in which they felt listened to, comfortable, safe, understood and reassured, trusting that their healthcare team was available if needed and focused on finding ways of making things better when problems arose, instead of assigning blame. This challenges the idea of responsibility for treatment being reduced to accountability for past events and potential risks, as discussed in chapter 5. Participants' focus on how to make things better in the present suggests a forward-looking perspective of responsibility for chronic care. A few participants highlighted how harmful it can be for the relationship and its potential for collaboration to feel judged and blamed by healthcare professionals, or as seen in the following vignette, reprimanded after a bad test result.

> *It's not helpful you know? it's hard to get [diabetes] …and have to live with it…and then get a bad result…and then someone trying to give out to you like you are a child, it's like…you know? I remember feeling oh I really don't…I can't even put a face on that doctor…but I do remember mmm…I was cursing him when I got out (30-year-old woman living with type 1 diabetes).*

This suggests that care for chronic diseases might require being sensitive and responsive to individual characteristics and their circumstances as well as the disease characteristics. As already discussed, chronic diseases can have more or less cyclical and or whimsical manifestations, which are often beyond the individual's control and genuinely hard to balance, as largely affected by environmental and contextual variables. Taking this into account, it seems reasonable then that when the healthcare professional handed responsibility for poor outcomes over to the participant in the last vignette, this was experienced as particularly unfair or too harsh. This might be argued to reflect the limits of performativity and the unrealistic expectation to always do well in the context of chronic disease, or as Frank (1997) describes it—drawing on Lucien Goldmanns' sociology of literature: rising to the moral occasion of illness and do the best thing. This moral imperative is exemplified in the following vignette.

> *I am a reasonably good patient because I don't complain about pain I know I have got my pituitary out and I am never gonna make a fuss about things […] I get everything scanned […] I hate that, but it's better than getting bowel cancer and the treatment […] I am on is pretty good*

> *for other things, so I am pretty pleased all around (64-year-old woman living with pituitary disease).*

Despite how controlled or out of control disease was, many participants described themselves as relatively ‘good patients’, meaning that they were doing everything they could to take care of themselves even if this did not always mean following healthcare professionals’ recommendations to the letter.

Thus, participant’s judgements about what being a ‘good’ patient means in the context of chronic care might be in some tension with luck egalitarian views of justice, which have a strong focus on individual responsibility. Healthcare professionals and patients that operate on the basis of accountability arguably incorporate this view of justice, despite how difficult this might be in the context of their required collaboration. Luck egalitarianism sees bad outcomes resulting from option luck individual choices—e.g. risks people voluntarily accept—as the individual’s own responsibility. However, Voigt (2007) has argued that despite taking context into account—the influences of unequal bad brute luck on individual’s choices—luck egalitarianism is too harsh to deny compensation because this unjustifiably limits people’s freedom to take risks. Similarly, but arguably even more morally problematic, it seems too harsh to blame and potentially punish people living with chronic disease for poor health outcomes considering that they are likely to be in the position to have to take risks—lacking the freedom not to take risks—to negotiate competing demands that exceed the management of the disease.

Highlighting the role of collaboration or co-production in chronic care, many participants described that it was very important that the specialist team was somehow available in case they needed to contact them, which is in direct relation to how difficult it can be to anticipate and manage a chronic disease flare-up or complication. Having an available and responsive team made them feel validated in their needs and more in control when the disease spun out of control. This availability and responsiveness included both a practical and a personal angle. On the one hand, participants valued their team being available in terms of being reachable (via email or phone), and responsive in terms of acknowledging the urgency of their request providing a timely and useful response. On the other, participants also highlighted these attributes as part of their personal relationship with healthcare professionals, feeling that they are available at a personal level to empathise with their situation and they know their case well, so they can solve problems in a timely manner, act before symptoms worsen, and make decisions together.

> *So, when it flares-up I will then, you know? I may…I often initiate a course of steroids, I would phone them [hospital team] up and I'll say 'I have done this' and they will say 'yes, that's fine' and together we'll work out what to do for the week (49-year-old woman living with rheumatic disease).*

Following closely from the previous discussion about the performativity of chronic care, it is rather straightforward how healthcare professionals knowing the patient and her broader circumstances can help provide better healthcare recommendations, but participants' experience also highlighted how patients knowing the healthcare professional was particularly important in the specific context of chronic care. A few participants stressed how getting to know their healthcare professional helped them anticipate how healthcare professionals would care for them outside the consultation room, which as discussed in Chapter 5 can increase or reduce their burden in the overall 'logistics of care'. Examples of this included trusting that healthcare professionals will check their tests results and call them in early if needed or send an updated letter to their GP so they can have their treatment delivered in time, versus having to follow up on such tasks themselves.

> *If I got a query or if she [consultant] is finding a problem with the blood test she, you know? she will be on the email and she sorts things out remarkably well so she has…I don't know how many patients she has, but she does put a lot of…you know? not just the appointments at the clinic, but if there's a problem over things she does sort things out (65-year-old woman living with HIV).*

This suggests that chronic care is something that healthcare professionals and patients do together beyond healthcare appointments (Walker 2019). Still, this might be seen as an ethically problematic territory, as collaborative relationships may challenge traditional or narrow ideas of autonomy and paternalism, which do not take into account the sustained relationship that emerges in the context of chronic disease, even if only through patients' records. As highlighted by Owens et al (2017), healthcare professionals often worry about finding a balance between being accessible or responsive, while making sure that patients do not become too reliant on them or the service. Still, and although it is difficult to know what ‘too’ reliant means, drawing on participants’ experience, this work has argued that life with chronic disease implies being physically vulnerable and dependant, heavily relying on healthcare services, professionals and treatment to stay alive and or work towards dynamic equilibrium.

When discussing main sources of support in general, most participants from all disease groups, but notably all those living with a chronic infectious disease and many of those living with a chronic respiratory disease, described feeling well supported by the healthcare system and or healthcare professionals, and stressed its importance. This distribution might be worth further reflection. Although this might have multiple explanations, the most straightforward being these two groups having particularly supportive healthcare teams, building on the experiences of rejection and discrimination discussed in Chapter 6, it might also be that a more frequent or present experience of felt and or enacted stigma within the chronic infectious disease group made them feel safer within healthcare professionals, relying more on their support. Regarding the chronic respiratory disease group, it might have been the case that having rarer conditions and, in two cases, unclear diagnoses might also have represented hurdles for peer and family support, also discussed in Chapter 6 in terms of a lack of role and shared tools for interpretation of their experience. This also supports and follows closely from the idea introduced in Chapter 7 regarding testimonial justice practices in healthcare having the potential to be particularly powerful in mitigating the negative effects of hermeneutical injustice.

Still, from a narrow healthcare ethics perspective, healthcare professionals have the main responsibility of benefitting the patient while respecting their autonomy. This has been thought to imply that any actions beyond providing patients with the knowledge and resources necessary to manage their illness might be regarded as unacceptable on the account of paternalism, and further harms would be the patient's responsibility (Walker 2019). However, much in line with what has been argued in this work, Walker (2019) poses that the main benefits of treatment in chronic illness are:

> 1. alleviating or preventing subjectively unpleasant experiences, and 2. counteracting the ways in which the patient's illness negatively affects, or would if untreated negatively affect, her ability to live her life in her own terms (either now or in the future) (Walker 2019, 134).

Just like dynamic equilibrium aims at allowing people to live the lives they have reason to value, and treating patients as persons demands recognising and cultivating their person-al capabilities (Entwistle and Watt 2013), the second aim in the last quotation combines beneficence and autonomy as the capacity for self-governance, this is, being able to make decisions about one's life free from the interference of others (Walker 2019; Owens and Cribb 2013). However, as seen throughout this work, long-term treatment is complex. It can often affect people's lives in similar or worse ways than the illness itself and adhering to long-term treatment goes far beyond knowing and having the resources to follow healthcare professionals' recommendations.

In healthcare, autonomy tends to be reduced to decision-making and so practices of 'shared decision-making'—generally understood as those that include patients in medical decisions that affect them—tend to focus on offering information to support and respect patients' autonomy and avoid recommendations that can interfere with their deliberations. However, this understanding of shared decision-making has been argued to be too narrow and downplay the potential positive effect that collective deliberations—where responsibility for decision-making is not passed from healthcare professional to patient—can have over patient autonomy (Owens and Cribb 2013).

Furthermore, 'shared decision-making' might be confusing for healthcare professionals, as it might be difficult sometimes—especially without the appropriate ethical training—to draw the line between information that is autonomy-supportive and recommendations that are autonomy-reducing. In trying to be autonomy-supportive, healthcare professionals might give insufficient or unclear information, which would have the exact opposite effect. As highlighted by Entwistle et al (2012), focusing on respecting patients' choices in a narrow sense often means 'stand-back and don't interfere', which makes patients feel like their doctors refuse to use their expertise to guide them. In contrast, broader understandings of shared decision-making focus on healthcare professionals and patients engaging in meaningful processes, highlighting the value of healthcare professionals drawing on their expertise to flexibly offer guidance and recommendations according to individual patients and situation (Entwistle, Cribb, and Watt 2012).

Some participants explained that the illness and or treatment not being properly explained to them resulted in confusion especially regarding the consequences and prognosis of the disease. Examples of this included receiving misleading information regarding the expected outcomes of surgery (often curative), healthcare professionals avoiding questions about the cause of disease instead of acknowledging that in many cases there is not a straightforward answer and healthcare professionals not explaining key management aspects for certain diseases, assuming that patients know more than they do. In the following vignette, the participant shares how she felt about having an umbrella diagnosis without proper explanation of the long-term consequences and the need for long-term treatment, even though she had been receiving regular specialist care for over five years.

> *I don't feel good about it because if there is no answer, how could you get a cure?...if there's no proper diagnosis…how could you get a cure? So […] I know she said to me I might, I might have to be on this medication for a long period of time…yeah […] but I still haven't got enough information yet, so when I see my doctor on the 4th I will ask the questions I need to ask her to find out exactly what it is because the last time I spoke to her she said…so I asked her and she said it's lung disease, but when I spoke to the nurse she said to me something different [pulmonary fibrosis] and I was like, what? And she said to me she is gonna send information in the post, I haven't gotten any yet…(46-year-old woman living with pulmonary fibrosis).*

Chronic diseases can be confusing even if having access to all information available. As exemplified in Chapter 7, even a participant who was a doctor herself relied heavily on a trusted healthcare professional's assessment and recommendation to decide which course of treatment she thought was best. Although it has been over thirty years since Toombs (1987) highlighted the lack of medical knowledge regarding best courses of action for chronic diseases, many participants described aspects of uncertainty regarding their health and treatment, sharing an overall sense that medical knowledge for their conditions did not seem to be very precise. As seen in the following vignette, autoimmune diseases seemed to be particularly challenging in this way.

> *If they don't know why the body starts attacking itself, that's the root of it… you can't, there's… I have just gotta accept that and like right… which is incredible given all the advances made in other medications or areas of illnesses and stuff, you would think they would have cracked it but…yeah…because I think they found mesalazine by accident in, you know? 40 or 50 years ago, or something, and it's like…find that by accident and then there still nothing out, not even more effective anti-inflammatory maybe…it's mental…(37-year-old man living with ulcerative colitis).*

Berlinger (2016) reflects on this uncertainty from the perspective of healthcare professionals and describes the constant pressure of dealing with the question of what might be the best path of action for a patient as the moral stress of healthcare delivery or clinical practice. Rather consistently with participants' experiences in this study, in the face of morally troubling decisions or difficult conversations, healthcare professionals tend to display workaround mechanisms such as ‘kicking the problem’,[2] as exemplified in the last vignette, implicitly or explicitly transferring it to patients (Berlinger 2016). Although healthcare professionals have a moral duty to work with this moral distress, Berlinger (2016) argues that these workarounds often reflect structural problems within the system, including the narrow view of healthcare as curative and hopeful, which can make the delivery of chronic care hard for healthcare professionals.

Beyond autoimmune diseases, many participants described that making informed choices about their disease was difficult in general and experienced frustration about the lack of answers. They also described learning to deal with their condition through trial and error rather than following healthcare professionals’ general recommendations, as individual variability was significant even within diagnostic groups. Some participants reflected on the fragile epistemic status of medical truths as new evidence arises and the uncertainty about recovery after acute episodes of ill health and the overall prognosis of their disease. Thus, as seen in the following vignette, participants’ sources for deliberation in decision-making often included people outside the healthcare context

> *It is quite good because she [colleague] is quite a good source of information. She has this amazing system that she’s got like a, they call*

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[2] This draws on the expression ‘kicking the can down the road’, which is a way of saying when people avoid or delay dealing with a problem (Cambridge Dictionary 2021).

> *it an artificial pancreas, so she's got like a continuous blood glucose monitor and a pump, which works for her and she absolutely loves it whereas for me I wouldn't really like that because mmm it's always attached to you (36-year-old woman living with type 1 diabetes).*

Mainly drawing on Catriona Mackenzie's work on relational autonomy, this is, autonomy understood as a socially constituted capacity, Owens and Cribb (2013) argue that decision-making processes in healthcare are often influenced by people's context and specific circumstances. The quotation in Chapter 6, section 2 about a participant deciding not to register with primary care services because of fear of being stigmatised exemplifies this. Thus, healthcare professionals' recommendations are not, in themselves, autonomy-reducing, but their potential narrow understanding of health gain can be (Entwistle et al. 2010). Much in line with participants' experience in this study, Entwistle et al's (2010) research suggests that healthcare professionals' recommendations are likely to be autonomy-supportive if healthcare professionals listen to patients; take their context and circumstances into account; allow for questions and corrections about their understanding of the patient and ensure that patients can choose against their recommendations without seeing their care being affected.

Implicitly drawing on the complex systems metaphor, Walker (2019) highlights that understanding chronic care as something that healthcare professionals and patients do together—in the way co-production and person-centred care encourage—implies that each of their actions are part of a whole that neither of them can do on their own. The value of this clearly came across in a few participant observation sessions in which the healthcare professional did not seem to be sure about what was going on with the participant's care. In these cases, healthcare professionals had not had time to see the patient's record in advance, were unsure about the current treatment, past and upcoming tests, the reason for the consultation and the expected outcome of the appointment. The following quotation from a participant observation field notes exemplifies this.

> *The doctor says she is a little bit confused because they have been seeing him every three months and usually they see people every six months, so she is worried she might be missing something that needs to be looked at more closely. She asks the patient whether he knows why he has been coming every three months and he replies that he doesn't really know, says "no idea, maybe because I started the growth hormone?" The doctor replies yes, that could be it, but we have a specific clinic for that, this is like a full review consultation. The patient says, "I didn't know about that clinic". The doctor moves on to the checklist (31-year-old man living with pituitary disease, participant observation field notes).*

Opposite to the experiences discussed in Chapter 8 of junior doctors being helpful in the process of getting a chronic disease diagnosis, after being diagnosed and having started long-term treatment, 'registrars', namely doctors in speciality registrar training were described as being less willing to listen and work collaboratively. In part, this might have to do with registrars knowing that they are unlikely to see a patient more than once, seeing their role as rather technical and instrumental in the broader context of chronic care. Thus, drawing on the previous discussion on performativity in chronic care, it might be argued that when both parties know they are unlikely to keep working together an atomistic rationale might take over the encounter. This means that isolated appointments within the broader context or system of chronic care become disconnected from the whole of person-centred care, no expectations of each other's behaviour are incorporated, the interaction is confusing and the appointment loses meaning. In such cases, it might be thought that if the patient was doing well before such an appointment, he or she might continue to do well until something tips dynamic equilibrium. On the contrary, if she or he was not doing so well, such an encounter might worsen the situation. In any case, the healthcare system lost an opportunity to help to prevent further damage.

Thus, much in line with participants' descriptions, Walker's (2019) work suggests taking the discussion beyond individual roles and responsibilities stressing that, ultimately, the success or failure of chronic care will depend on healthcare professionals and patients collaborating, this is, each doing their part in the shared project or activity of chronic care. This leads Walker (2019) to argue that responsibility for chronic care is shared, meaning that although patients are responsible for their circumstances to some extent, what they are owed should not depend on their responsibility. In other words, they should not have less priority, for example, or be punished in any way if they are 'irresponsible' and do not follow treatment recommendations (Walker 2019). Although this argument is part of a larger and still active debate on the application of luck egalitarian views of justice to support rationing and incentive policies for health justice (Voigt 2013), because of the cumulative effect of disadvantage described in this thesis, the idea of shared responsibility might suggest a more profound shift that leaves behind the rationale of ‘what one deserves’ underlying luck egalitarianism. Before continuing the discussion on responsibility in chronic care in the next chapter, the following section discusses continuity of care in the context of aiming to achieve broad and truly person-centred care aspirations for chronic diseases.

4. Continuity of care in chronic disease

Following closely from the previous discussion, and much in line with person-centred care, some participants from all disease groups stressed that a ‘good patient-healthcare professional relationship’ allowed for discussion and agreement over the goals of treatment and treatment approaches. Feeling that communication was fluent and easy was argued to be very important to achieve this, and this, in turn, was facilitated by continuity in the relationship with a known healthcare professional.

> *You get, I think, a bit more honesty if you have got a longer relationship…and I think they [healthcare professionals] give you better advice because they know…what, what you are prepared to do and what you are not prepared to do and you know? they, they can kind of develop that relationship with you and work with you […] So, they, you know? I think…it’s quite hard when you only got whatever they are 10-15 minutes appointments to really address someone’s long-term*

> *overarching condition if you don't have any understanding of…where they are at (36-year-old woman living with type 1 diabetes).*

'Continuity of care' is strongly associated with high-quality care in longitudinal person-centred models of quality measurement, particularly relevant for long-term conditions. Research shows that continuity of care has a positive impact on patients' experience of care, health outcomes (reduced hospitalisations and complications in chronic disease) and cost of care in chronic diseases (Hussey et al. 2014; Gulliford, Naithani, and Morgan 2006). Consistently with patients' descriptions, Gulliford's et al (2006) analysis of different conceptualisations of continuity of care highlights a 'continuous caring relationship' with a healthcare professional and a 'seamless service'—in terms of coordinated care both between and within services, as the two core features of this concept. Thus, different models comprise interpersonal or relational continuity, information continuity, management continuity, and interdisciplinary continuity (Gulliford, Naithani, and Morgan 2006).

The value of continuity of care was exemplified in many participant observation sessions, as healthcare professionals and patients had effective and 'balanced dialogues' in which both parties seemed able to get their respective needs and worries addressed even in rather short (10-15 minutes long) appointments. Participants shared different aspects of their lives with the healthcare professional, asked questions and got detailed answers, discussed treatment changes and confirmed their understanding of the sometimes complex new recommendations, referrals and tests required before their next follow-up appointment. Simultaneously, healthcare professionals also seemed able to gather the information they needed to go through their checklists and complete their administrative tasks.

Many participants shared that continuity of care was important because it allowed healthcare professionals and patients to know each other. In this context, the main value of healthcare professionals knowing their patients personally was described in terms of knowing what mattered to them. Closely linked to this, and much in line with the idea of shifting the goal of self-management support towards health, wellbeing and overall quality of life (Entwistle, Cribb, and Owens 2018; Owens et al. 2017), participants stressed the value of healthcare professionals showing a genuine interest in their overall wellbeing, not just their health outcomes.

Still, some participants described their relationship with their specialist healthcare team as lacking, irrelevant or merely instrumental because their treatment was regarded as particularly straightforward. Nevertheless, following the previous point about isolated appointments losing meaning, participants were critical of the lack of continuity and consistency that resulted from this. In the following vignette, the participant describes how lacking continuity of care meant that there was little gain from seeing the specialist care team. Furthermore, this quotation reflects how open and general questions in the context of a continuous supportive relationship with a healthcare professional or team might become meaningless without this context.

> *I see the doctors up at [the hospital], which sometimes is good, like today, I had a friendly nurse…I think I have had her before or friendly*

> *doctor…she, I am sure, has asked me questions in the past that were useful…I actually find that [in] most appointments [healthcare professionals] just don't care, I walk in and they just ask real generic crappy questions 'how do you feel?' Fine, 'cool'…yeah 'see you in 6 months?' Yeah, cool, no problem…I am out of there in 10 minutes (31-year-old man living with pituitary disease).*

Similarly, in a few participant observation sessions where the patient and the healthcare professional did not know each other, participants expressed being disappointed with the care they received and that seeing the doctor was 'useless'. As seen in the following vignette, the participant describes knowing exactly what was going to happen before he went in to see the healthcare professional.

> *I come in here, I knew what the conversation it's gonna be, right? Fair enough, I got a different version of steroid but the outcome was the same as what I knew it was gonna be…or you kinda, you email, and the nurse is like…look, this is the maximum dose, maybe I'll just do that and then she just gets it signed off so you are kind a like pffff, you know? (37-year-old man living with Crohn's disease).*

These experiences reflect instrumental exchanges, which lack a long-term plan and shared goal for treatment, mainly focusing secondary care for chronic diseases on flare-up management and offering little support regarding overall wellbeing and quality of life. This resonates with criticisms of narrow views of self-management support discussed in the introduction of this chapter, which lose sight of truly person-centred care practice.

Specifically in secondary care, continuity of care was described as having a consultant that is somehow ‘in charge’ of their care, and getting to see this consultant regularly but not necessarily every time. Drawing on the ideas around vulnerability and dependence discussed in the last section, the relationship with the consultant was so important for some participants that they chose to travel from other cities to see them or worried about what would happen to them when their consultant retired. Some participants were more flexible and did not mind seeing a different healthcare professional for regular check-ups, but still highlighted the importance of being able to see their consultant upon request.

The following quotation reflects the special value of continuity of care in chronic disease treatment because of the variable experience of control.

> *I don’t know because I really trusted her [consultant] and I think it was reassuring for me to always see her because she knew me and I didn’t have to repeat the whole story…in each consultation whereas now I think, as my illness has become more controlled, don’t really mind who I see…but if one day I became mmm…if it became more difficult to control…I bet I’ll want to see her again…(49-year-old woman living with rheumatic disease).*

A few participants added that perceiving the specialist care team, as a whole, as strong and well-integrated—where communication flows well and individual approaches are consistent—can compensate for not seeing the same healthcare professional regularly.

Although continuity of care was similarly important in primary care contexts, participants described that it was particularly difficult to see the same GP both because of the limited availability of appointments and continuity not being prioritised in how these were allocated—despite this being a quality marker both in primary and secondary care (Gulliford, Naithani, and Morgan 2006). Thus, unless participants 'got lucky', seeing the same GP implied waiting weeks or months, which is often incompatible with primary care needs. Similarly to what was described regarding specialist care, continuity in primary care was argued to facilitate communication and provide the context necessary to address issues properly. Thus, unless people consulted for something very specific and unrelated to their base condition, continuity of care played an important role in primary care consultations for people who live with chronic disease.

> *Actually, it is quite important to have that continuity and like I always go and try to see the same GP because I am fed up with explaining everything to and whenever I go and see someone who is not my GP. I just think they are useless or not very helpful…sometimes they are fine it depends [on] what you want…if you want a referral to the physio [physiotherapist] then they will do that quite happily (36-year-old woman living with type 1 diabetes).*

Thus, some participants described little gain from seeing GPs and described these appointments as frustrating encounters because their worries were not addressed and or they had to push to get referrals, tests, and treatment. Closely linked to the increased burden that gaps in handover between primary and secondary care system implied for participants—as discussed in Chapter 5—GPs were described as ‘clueless’ regarding participants’ treatment and considerations around their main chronic disease diagnosis. This revealed a certain degree of tension between different levels of care, putting participants in a difficult position as mediators and, sometimes, lone advocates of their care.

> *I was on Humira for a really long time […] and then I just started to develop antibodies and…it was kind of unfortunate, but it just...it just happened like…mmm but I was still taking the azathioprine and then…the azathioprine affected my liver so they reduced the azathioprine and added allopurinol, which is actually a drug that is used for gout, but it tends to make other drugs more effective, more powerful so you cut down the dose…so it’s always hilarious when I go to the dentist or your GP and they are like why are you on allopurinol? Like do you have gout? And I am like…nooo…[laughs] (29-year-old woman living with Crohn’s disease).*

The tension between levels of care came up in many participant observation sessions, as the appointment became a space for participants to complain about difficulties coordinating their GP care or express their disappointment about GP care, sometimes asking the consultant to take action. Some healthcare professionals also expressed their frustration about GP management of some elements of care that affect long-term treatment, having to send letters repeating or explaining specific recommendations or requirements of their patients, for example. As seen in the following quotation from participant observation field notes, participants tended to centralise their care at the specialist level, often asking for the consultant's opinion on something that was 'GP territory'.

> *The patient asks, "I had an eye test and they told me I have early-stage cataracts. What should I do?" The doctor replies, "well, nothing until it gets really bad and you may need surgery. It is age-related, but also because of the diabetes, you may get this earlier" the patient asks, should I ask or tell my GP? And the doctor replies "well yes, in the letter from the eye test you will have more information and they will monitor it" (64-year-old man living with type 1 diabetes, participant observation field notes).*

This underlines how important it was for participants to share the responsibility for their care by having someone overseeing and, at least to some extent, integrating the care.

Furthermore, some participants described valuing having stable relationships with known healthcare professionals because different healthcare professionals within clinical units could have different approaches to treat the same condition.

> *I think people, different consultants have different ideas about treatment mmm…so you can see one and they might mmm put you on something and then you see another and they might wait, and I think that's important, to have the same view if you are happy with that consultant, that same view…(41-year-old woman living with Lupus).*

Following from this, and mainly drawing on the discussions in chapters 5 and 7, life with chronic disease implies dealing with a significant degree of contingency and the resulting negotiation of changing competing demands, so it seems reasonable that reducing contingency as much as possible might be particularly valued to reduce the overall burden of living with chronic disease. Still, during the participant observation sessions some participants from all disease groups not only had appointments with healthcare professionals they did not know, but they also sometimes saw someone different from whom they were expecting.

Furthermore, healthcare professionals that cared about patients personally and knew what mattered to them had enough contextual information to tailor their approaches in such a way that treatment took into account the complexity of participants' personal circumstances, achieving better outcomes. This is highly consistent with the argument that value-based practice helps achieve better outcomes than evidence-based practice because of its consideration of contextual information (Copeland 2020). Although continuity of care cannot ensure better outcomes, it is difficult to imagine this happening without some level of continuity of care.

> *I was having a really hard time with bleeding and stuff and one of them because she knew all the situation properly and stuff, like, she gave me a certain enema that I could take, that really helped me and rather than when I went to the doctor. All he could say was 'yeah, you need surgery'. So it's like when someone, you know? someone listens and takes the time to think sometimes it's easier to just find solutions (21-year-old man living with Crohn's disease).*

Sometimes lack of continuity of care implied that participants had to repeat their illness story every time they saw a new healthcare professional. This came up in a couple of participant observation sessions where participants shared parts of their illness story to provide relevant context for the healthcare professional and orient the outcome of the appointment. In this context, the difference between ‘illness story’ and ‘disease history’ seemed relevant. As highlighted in the overarching findings in Chapter 3 and discussed further in Chapter 4, people living with chronic disease experience both disease and illness as one integrated whole that significantly changes their way of understanding their selves and their bodies. This means that when healthcare professionals ask patients about their disease, this is not an independent entity that patients can report on without its context. The following quotation from a participant observation field notes exemplifies this point.

> *The doctor asks, “how is the Crohn’s?” Participant replies, “my eyes started hurting again”. She shows him an old bruise and says that it is just not going away. The doctor explains that it is a form of scar and that it will not go away, she seems very frustrated and says, “it is just another thing”. She moves on to speak about sleeping problems, the doctor asks questions, she links it to a history of depression and he expresses his doubts about that saying “not necessarily” (47-year-old woman living with Crohn’s disease, participant observation field notes).*

As seen in the last vignette, although the doctor tries to narrow the appointment to the disease by referring to it as an independent entity the participant cannot provide an answer to that question and speaks about herself more broadly. This resonates with and might shed light on the previous discussion in Chapter 8 about patients often complaining about not being listened to by healthcare professionals and healthcare professionals, in turn, complaining about patients providing irrelevant information, which Kidd and Carel (2017b) describe in terms of participatory prejudice.

Consistently with participants' appreciation of knowledge, experience and sensibility, value-based practice draws on population-level statistical evidence as well as on the judgements of the individuals involved in the clinical situation (Tyreman 2016). Thus, although having a stable relationship with healthcare professionals can facilitate consistency of care, these two should not be equated. In the specific context of teaching hospitals, a few participants showed flexibility regarding continuity of care, saying that it is not about actually seeing their healthcare professionals, but knowing that he or she is overseeing their care when someone else sees them—having someone 'in charge' of their care. An example of this took place in a couple of participant observation sessions where the registrars assigned to do the consultation left the room to confer with the lead consultant before completing the recommendations. Still, as seen in the following vignette, this was described to affect collaboration and limit the scope of the aim of healthcare appointments.

> *This new doctor went to talk to my doctor to make sure that he was doing the right thing when taking like changing my medicines and stuff, so is obviously…my doctor still looking out for me […] obviously I would feel more comfortable if it's always the same person taking care of me because, as I said, you create a bond, you know each other and you have been through I don't know how many appointments, so they know the whole history and you are more comfortable talking to… because it's… every time if there is someone new or someone strange you don't feel as comfortable in sharing stuff obviously (33-year-old man living with Crohn's disease).*

As long-term users of the system, a few participants associated seeing over flooded hospital services with continuity in their care disappearing. This idea that increased patient demand or rise in services demand affects the quality of healthcare matches the King's Fund's analysis on the performance of the NHS before the COVID-19 pandemic (Maguire, Dunn, and McKenna 2016). This report does not frame the budget freezing as an effective funding cut putting significant financial and operational pressure on the services. Instead, it presents this as the health budget being protected in the context of other budgets being reduced. Although discussing this in more depth goes beyond the scope of this work, drawing on the systems metaphor and the SDH it might be argued that putting pressure on other services, such as welfare and local government's social services, might affect people's health and increase the demand for healthcare services. Putting such pressure on healthcare systems arguably affects all aspects of care including continuity, which, as already mentioned, has been argued to reduce the costs of care for chronic diseases (Hussey et al. 2014). This would reflect one of Meadow's

(2009) systemic traps of fixes that fail. By ‘protecting’ the healthcare budget but cutting other services’ budgets, demand for healthcare services increases and care for chronic disease arguably becomes more expensive. Thus, it seems that the random occurrence of continuity of care and its progressive disappearance might respond to operational issues or priority settings also reflecting narrow views of self-management support, rather than a direct consequence of increased demand or reduced healthcare staff.

5. Conclusion

Drawing on plural understandings of quality and wellbeing in the specific context of chronic care and life with chronic disease, this chapter specified the role of chronic care in patients’ efforts towards dynamic equilibrium in terms of healthcare professionals recognising and cultivating patients’ person-al capabilities (Entwistle and Watt 2013). Looking into participants’ experiences and insightful judgments about chronic care, this chapter described how respectful and collaborative patient-healthcare professional relationships, chronic care understood as a shared project or activity mainly involving healthcare professionals, clinical teams and patients but also patients’ broader social context, and a sensible understanding of continuity of care are delicately knitted in experiences of truly person-centred care. Such experiences embrace the ongoing challenges of living with chronic illness and long-term treatment, recognising the process, its frailty and the different needs for continued support across social groups.

Following the discussion in the introduction to this thesis on the performativity of complex systems, this chapter drew on Hacking's (2007) looping effect and Biggs' (2011) analysis of performativity to argue that experiences of truly person-centred care impact the broader system of chronic care, supporting peoples' efforts towards dynamic equilibrium and helping to compensate for pre-existing inequalities and prevent or slow down further disadvantages. Although this chapter's specifications about patient-healthcare professional relationship, collaboration and continuity of care in chronic care were argued to facilitate truly person-centeredness, neither of these elements by themselves nor all of them together can ensure the outcomes. This suggests, that just like dynamic equilibrium, chronic care must be seen as a more or less precarious balance and a continuous effort also affected by multiple variables more or less difficult to predict and control. Although further research on the experience of healthcare professionals, stakeholders and policymakers would be needed to better understand the variables and processes at play, this chapter shows how identifying and keeping in mind fertile and corrosive elements for recognising and cultivating patients' personal capabilities might also represent a continuous effort from healthcare professionals and healthcare systems more broadly. This outer circle of the system of chronic care might, in turn, require its own continuous support in the effort towards dynamic equilibrium. As argued in this chapter, embracing the complexity of this challenge has the potential to generate inputs that can orient ethically driven care for chronic diseases. In this outer circle or macro level of the chronic care system, dynamic equilibrium would be focused on the balancing efforts towards reducing health inequalities.

Conclusion: Acknowledging Interdependence And Sharing The Load Of Chronic Disease and Chronic Care

1. From normative theory to experience to normative theory: my first lap in this loop

This conclusion begins by recapitulating what has been discussed thus far to contextualise this conclusion's focus on the normative aim of this thesis, namely informing the discussion on how to improve equity in health outcomes for chronic diseases in England. However, this exercise also allows drawing broader normative conclusions that might serve as tools for thinking about this problem in other contexts where UHC systems—also focused on equality of opportunity to access healthcare services—struggle to tackle chronic disease health outcomes inequalities.

This thesis started by introducing a complex systems perspective on the problem of health outcomes inequalities for both communicable and non-communicable chronic diseases. Mainly drawing on Wolff and de-Shalit's (2007) account of disadvantage and the capability-based assessment of justice of which this is derivative, this thesis proposed a normative framework for interpreting and responding to treatment adherence differences in chronic diseases. This framework argued that individuals living in disadvantage in terms of their socioeconomic level and their achieved functionings level might be more likely to 1) get a chronic disease and live shorter lives; 2) lack the functionings that could allow them to successfully self-manage their disease; and 3) be at risk to become more disadvantaged as a result of chronic disease. This cumulative effect of disadvantage amongst people living with chronic diseases revealed the injustice underlying health outcomes inequalities for chronic diseases, requiring healthcare systems to go beyond equality of opportunity for access to achieve better and more just health outcomes for chronic diseases.

In order to better understand this double inequity[1], this thesis first focused on learning about the experience of people living with chronic diseases and chronic care within the NHS through a qualitative study including 27 participants living with a broad range of chronic disease diagnoses. Then, drawing on theory, empirical research and the data generated in this study, the thesis further specified the cumulative effect of disadvantage described in the introduction. Thus, the empirical aim of this thesis informed the ethical goal of contributing to the normative discussion on how to improve equity in health outcomes for chronic diseases.

Very briefly, Part I of this thesis focused on the empirical element, covering the methodological framework, the study design, data generation and analysis, and the empirical findings. The thematic narrative analysis of the qualitative data led to five emergent themes: (1) Illness narratives, ruptures in belonging and the value of support networks; (2) Finding and keeping the balance between chronic illness, chronic care and life beyond illness; (3) Considering chronic diseases as controllable diseases seems to be a matter of

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[1] 1) Even within universal health coverage systems, there are significant health inequalities caused by differences in patients' abilities to adhere to long-term treatments, and 2) inequalities in long-term treatment adherence are correlated with, and aggravate, existing health inequalities.

perspective; (4) The place of chronic disease and long-term treatment within individuals' inner world; and (5) Values and judgements around chronic care and the healthcare practitioner-patient relationship.

The last question of the interviews was about participants' advice to newly diagnosed people. This question was rather strategic in the sense that it was an invitation for participants to slightly distance themselves from the intimate and sometimes painful stories they had shared and finish the interviews from a less vulnerable subjective place. Still, as participants summed up and weighed their own experiences to present them in a way that could be useful for others, they skilfully summarised the main issues discussed in the interviews. The following five-point list is a summary of participants' advice.

- *Chronic disease is not the end of the world:* many participants from all disease groups would start by reassuring the newly diagnosed reminding them that their illness is manageable. This line of advice stressed the fact that chronic disease is not something people will ever be able to change, encouraging them to focus on finding a new way of living with the disease that works for them. Participants underlined that adjusting to and managing the disease does not mean allowing the disease to take over their lives and define them, so they should try to keep life as normal as possible and let healthcare professionals help them.

- *It will be hard, but try to follow treatment recommendations:* many participants from all disease groups highlighted the importance of following treatment and healthcare professionals' recommendations in general, inviting newly diagnosed people to have confidence and trust that they will eventually find a treatment regime that works if the first one does not. Some of the participants offering this advice did not always follow treatment recommendations throughout their illness trajectory, adding that although chronic diseases are manageable, life with illness and treatment is hard. Thus, participants generally thought people should aim at following treatment and recommendations the best they can.

- *Turn to family, friends or healthcare professionals for support:* some participants from all disease groups gave particular importance to reaching out to people, not ignoring their illness and their emotional needs, not sitting in silence, and asking for help if they need it. If friends and family are not good support networks, then they should tell their healthcare team and ask for their support. Following this, participants invited the newly diagnosed to find healthcare professionals they feel they can work well with.

- *Take the lead. Learn about the disease and the treatment:* some participants from all disease groups, except those living with a chronic infectious disease, would advise others to take the lead on their care and learn as much as possible about the disease and treatment. Participants shared how introducing lifestyle changes and habits requires time, so people should start making adjustments slowly, and not simply follow recommendations, but discuss what works for them with the healthcare team. This implied asking questions, pushing healthcare professionals to find and offer alternatives, learning about their options, and knowing enough to make sure that they are getting the best treatment possible.

- *Do not beat yourself up and take care of your mental health:* some participants from all disease groups except those living with chronic endocrine conditions, and especially those living with a chronic gastrointestinal and infectious disease, thought people should try to be patient with themselves and not blame themselves for the disease and its consequences. This included trying not to feel bad about needing to take time off, worrying about what people may think or say, or doing things slower, for example. In this way, participants stressed that living with a chronic disease can raise emotional difficulties so people should take care of their mental health as well as their physical health.

This five-point list summarising participants' advice to the newly diagnosed highlights the far-reaching impact of chronic disease, the continuous effort of negotiating different elements of life and disease, and the crucial role of different actors involved in the management of chronic diseases. These three elements might be thought to condense the overarching perspective on chronic disease developed in this thesis, gaining significant weight in the last chapter's discussion and this conclusion, as will be seen in the following sections.

Drawing on participants' experience and relevant literature, Part II of this thesis focused on developing conceptual clarity, expanding current understandings of ‘chronic disease’ and life with chronic disease and long-term care. Because of the lack of a successful and agreed definition of ‘disease’, this work suggested embracing the disjunctive and vague elements of such concept, which allow and encourage specific and contextual cluster definitions of disease. On this basis, the concept of ‘chronic disease’ was argued to also fail to be structured in a traditional way, allowing for a disjunctive group of diseases to fall under the concept. Thus, Chapter 4 proposed a definition of chronic diseases for this work, which specified these as manifest or dispositional bodily properties that comprise a thin understanding of chronicity—mere long-duration—and its phenomenological sense.

Drawing on long-duration of disease this work argued that chronic diseases introduce a far-reaching shift in perspective both towards oneself and the world in terms of life trajectories and expectations. This shift was characterised by a paradoxical experience of long-duration of disease, which demands awareness of the continuous presence of the disease even in the absence of its symptomatic manifestation, as likely to recur. This helped specify chronicity in a phenomenological sense in terms of a positioning of the individual in relation to this long-duration, which implies transferring the quality of continuous and irreversible to an experience that was argued to be discontinuous in terms of how it is expressed in the body.

Building on this contextual and flexible understanding of chronic diseases, Chapter 5 argued that life with chronic disease implies a continuous effort towards finding and keeping a balance between controlling the illness, managing the logistics of care, and continue living the lives people have reason to value. However, participants' experience helped specify how justifiably hard and demanding long-term treatment can be also in the context of more or less flexible and demanding lives, meaning that, regardless of the potential consequences, treatment adherence cannot always be prioritised. Drawing on a complex systems approach, this process was further specified as 'dynamic equilibrium'. Drawing on the specifications discussed in the introduction to this thesis, this concept was argued to reflect the continuously new state arising from the ongoing balancing effort underlying people's choices and possibilities in different contexts. This novel understanding of life with chronic disease and long-term treatment highlighted the interdependence and dynamism underlying chronic disease management, stressing the limitations of current—rather static—ideas of psychological adjustment to illness, coping mechanisms and resilience in the context of chronic disease.

Furthermore, this chapter described how people, in general, may intentionally decide not to adhere to treatment as a result of competing demands, risking negative health consequences. Still, because of increased competing demands or a more precarious overall dynamic equilibrium, this disproportionately affected people living in disadvantage. Thus, adherence to long-term treatment was described as a fragile process—instead of a stable achievement—both because it is highly sensitive to context in a broad sense, and because even if near-perfect adherence is considered possible, this might not always be desirable for people living with chronic disease, considering their concerns and projects beyond the disease.

This latter point was argued to be associated with the porous boundary between chronic disease and the self, also introduced in Chapter 5. Following from the ideas presented in Chapter 4 about chronicity in a phenomenological sense, the degree to which and how chronic disease and long-term treatment change what people can do, can also to some degree change people's identity or sense of self. Thus, in their efforts towards dynamic equilibrium people living with chronic diseases were argued to introduce a harder boundary between the disease and their sense of self to protect certain aspects of their identity. By keeping the disease at a safe distance, participants described protecting their sense of agency and belonging at the cost of removing their attention and focus from their health and treatment, potentially hampering their adherence and health outcomes. To better understand these processes, Part III of this thesis developed an in-depth multidimensional perspective on the experience of chronic disease. Adopting this perspective helped identify key social and psychological challenges and injustices faced by people living with chronic diseases.

By looking into meanings of illness and processes of stigmatisation, lack of empathy and place, Chapter 6 argued that people with chronic diseases suffer from a hermeneutical injustice that contributes to ruptures in their sense of belonging, withdrawal from social situations, isolation and loneliness, hampering their possibilities to keep previous social support and build new social networks. Besides this being a more or less painful individual experience, this was argued to potentially limit the mobilisation of resources to face the state of illness and work towards dynamic equilibrium, further specifying the mechanisms of the cumulative effect of disadvantage amongst people living with chronic diseases, which were discussed in the introduction to this thesis. This discussion introduced the potential value of healthcare systems contributing towards the development of shared tools for social interpretation of life with chronic disease. These tools could improve individual support and restore a sense of belonging to the social world amongst people living with chronic diseases.

Chapter 7 helped further specify the experience of the paradox of chronicity by reflecting on the consequences that living with little to no sense of control over chronic disease can have. In this context, bodily transparency in chronic disease was specified as something that is both lost and achieved—more or less cyclically and painfully—through symptoms, monitoring and encounters with others. Drawing on this and in addition to the ruptures in belonging described before, sedimenting chronic disease as a new way of being was described as a difficult change in so far it implies giving up a previously favoured status. Building on participants' experience Chapter 7 argued that in a rather paradoxical manner, while monitoring and treatment can sometimes help achieve freedoms and an increased sense of control over the disease and the body, monitoring and treatment can simultaneously hamper participants' sense of agency beyond illness and limit their sense of self, leaving them feeling dependent, vulnerable and alienated. Thus, in trying to reassert agency over life and protect their identity, people living with chronic diseases may disregard treatment adherence or take health risks.

Closely following from this, Chapter 8 looked in more detail at the protective function of the porous boundary of identity and the tensions arising from this in the context of long-term treatment. Drawing on the idea that ‘healthy’ is a favoured status both for the self and others, participants were argued to resist illness during the onset of disease and after the disease was diagnosed by normalising bodily changes as much as possible. In addition to people resisting illness, healthcare professionals were argued to contribute to the initial difficulties in the process of bodily becoming by dismissing the information provided by patients before reaching a diagnosis. This was argued to constitute a testimonial injustice resulting in physical and psychological harm. Because of healthcare professionals’ relative epistemic privilege or power, their acknowledgement or dismissal of patients’ experience may have an augmented negative (limiting) or positive (facilitating) effect over the processes associated with resisting or allowing chronic diseases as a way of being. As a whole, this multidimensional perspective on the experience of chronic disease contextualised the processes helping make sense of people’s struggles or inconsistency when attempting to follow life-long treatment recommendations and self-care tasks. In order to better understand the context in which long-term treatment takes place, Chapter 9 built on participants’ experience and participant observation sessions of specialist healthcare appointments to expand on the patient-healthcare professional relationship and reflect on socially aware and ethically driven goals for long-term treatment. By analysing the role of healthcare in patients’ efforts towards dynamic equilibrium, this work further specified the value of healthcare professionals and teams recognising and cultivating patients’ person-al capabilities—that is, those related to being and being treated as a person (Entwistle and Watt 2013), in the specific context of chronic care. This work highlighted and specified: 1) respectful and collaborative patient-healthcare professional relationships; 2) chronic care understood as a shared project or activity mainly involving healthcare professionals, clinical teams and patients but also patients' broader social context; and 3) a sensible understanding of continuity of care as key features of truly person-centred care for chronic diseases. These three main aspects might be thought to operationalise an overall attitude towards chronic care, which embraces the ongoing challenges of living with chronic illness and long-term treatment, recognising the process, its frailty and the need for continued socially aware support. Such truly person-centred care for chronic diseases was argued to have the potential to impact the broader system of chronic care by adequately supporting people's efforts towards dynamic equilibrium, helping to compensate for pre-existing inequalities and preventing further disadvantages.

The next two sections expand the theoretical argument of this thesis by drawing on intersectionality and interdependence to discuss in more depth issues around responsibility in chronic care and justice for chronic disease health outcomes inequalities. This discussion helps further specify the cumulative effect of disadvantage amongst people living with chronic diseases expanding this normative framework to also orient ethically driven chronic care. This framework suggests three new principles, which condense the key reflections developed in the thesis to orient individual action aiming to better support people living with chronic diseases and counteract social inequalities in health. The last section of this conclusion, summarises and highlight the main takeaway messages of this wok.

2. Intersectionality and the cumulative effect of disadvantage amongst people who live with chronic disease

This thesis' approach to health outcomes inequalities for chronic diseases resonates with the not so new, but increasingly mainstream concept of intersectionality in the context of race and gender studies. Although Audre Lorde's essay titled 'Age, race, class, and sex: women redefining difference' (2004) first published in 1984 did not use the term 'intersectionality', it might be thought to have paved the way for Kimberle Crenshaw to coin it and kick-off this critical academic discussion 1989.

As discussed in Chapter 6, the social experience of living with chronic diseases in England was significantly marked by its liberal-capitalist social framing, which was argued to reinforce youth and independence and strongly reject other ways of being. Similarly, in 1984, Lorde (2004) introduced the idea of 'institutionalised rejection of difference' to describe processes of systematic oppression in 'profit societies'—liberal-capitalist societies, pushing some to a dehumanised, inferior place in society. Profit societies need outsiders as surplus to function and, in the specific context of this essay, Black people, Third World people, working-class people, and older people compose this 'human surplus' (Lorde 2004). As likely to be the disadvantaged within a society and representing a less favourable status of increased dependency and vulnerability, people living with chronic diseases might arguably be added to this list of human surplus. Resonating with this thesis' analysis of the hermeneutical injustice suffered by people living with chronic diseases, Lorde (2004) states that profit societies lack the tools to relate with (different) others as equals, and so individuals respond to difference with fear and loathing. More specifically, Lorde (2004, 855) argues that people respond to human difference by "ignor[ing] it, and if that is not possible, copy it if we think it is dominant, or destroy it if we think it is subordinate".

In her article titled 'Demarginalizing the intersection of race and sex: a black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics', Crenshaw (1989) argues that dominant conceptions of discrimination suggest that this subordination is a disadvantage that takes place within the framework of a single categorical axis. This is argued to focus on most privileged group members, namely Black men and white women, missing the intersectional experience or obscuring the experience of those who are multiply burdened, namely Black woman. Much in line with the complex systems' rationale described in this thesis, Crenshaw (1989, 140) stresses that it is not enough to include intersectional identities, such as Black women, within single-axis frameworks "because intersectional experience is greater than the sum of racism and sexism". Thus, in this specific case, without considering intersectionality it is not possible to understand the particular way in which Black women are subordinated.

Although—adopting this language—this thesis might be thought to have reproduced a single-axis framework to explore the experience of 'chronic disease' as a broad and homogenising category, it has relied on a complex systems approach and multidimensional perspective on this experience to expand this framework and shed light on participants' stories according to the dynamic nature of intersectional identities (Harari and Lee 2021). In other words, this work avoided using problematic and narrow operationalisation of intersectional groups (Harari and Lee 2021) to analyse the patterns and mechanisms underlying how people's different circumstances can impact their illness trajectories and how social structures and linear healthcare policy perspectives are too narrow to anticipate and contain harmful outcomes.

In support of this, Harari and Lee (2021) argue that quantitative research that focuses on oppressive and rigid categories often limited to race/ethnicity, sex/gender and socioeconomic status to produce empirical data on health disparities fails to account for intersectionality, namely represent the forces generating inequalities amongst marginalised groups. Although including multiple intersections when measuring health disparities provides valuable information, in order to capture intersectionality, it is necessary to look at variations within groups (Harari and Lee 2021) in the way that mostly, though not only, qualitative research does. Such systematised particularity is what dynamic equilibrium, as the continuous effort towards balancing changing competing demands in the context of living with chronic diseases has tried to capture.

Within the studies analysed by Harari and Lee (2021), those that aimed to describe explanatory mechanisms for health disparities highlighted social and emotional support, size of the social network, marital status, having children, coping tools, self-esteem, religiosity and LGBT activism as personal and social resources, while emotional regulation difficulties were labelled as social and personal risks for health. These personal and social resources echo Phelan's et al (2010) fundamental cause theory of health inequalities, first introduced in 1995 and already mentioned in the introduction to this thesis. Drawing on the persistent inverse association between socioeconomic status and mortality rates, this theory argues that; knowledge, money, power, prestige, and beneficial social connections are key flexible resources that, no matter the mechanisms, consistently protect people's health. Thus, the principle is that access to these resources can contribute to the prevention of diseases and their negative effects, and the flexibility of these resources implies that there is a variety of mechanisms through which this can happen (Phelan, Link, and Theranifair 2010). Although the fundamental cause theory introduces a dynamic element often lacking in static quantitative correlation studies, the findings and conceptual specifications developed in this thesis suggest that the simple presence/absence of flexible resources protecting health might not capture the amplified or cumulative negative effect that social disadvantage has been argued to have over people's health.

Thus, by engaging with the complexity of thinking about variations both between and within disease groups, as well as participants' personal circumstances across time through their biographies, this thesis sheds light on such corrosive processes. Although, overall, the resources and health risks mentioned before might be thought to reflect participants' experiences and health outcomes, this thesis engaged with individual stories in-depth and showed how neither of these resources or risks on their own, nor all of these together are enough to explain or anticipate individual health outcomes.

To exemplify this and following from the resources and risks mentioned in the last couple of paragraphs, amongst the participants in this study, there was a 45-year-old Black woman who despite being married, having a son and having a professional qualification, struggled to follow treatment recommendations and achieve the expected health outcomes for her chronic disease. Opposite to this, there was a 46-year-old white woman living with the same chronic disease who despite being in a position of further disadvantage (non-professional qualifications, single mother) did not struggle to follow treatment recommendations and achieve the expected health outcomes. Although race stands out as the main difference shedding light on their outcomes, this would be far too simplistic. The first woman had migrated to the UK in the ‘90s to join a not particularly supportive network of extended family. Soon after her arrival, a close family member, who was her main source of support in the UK, unexpectedly died. She got ill after this and just before completing her specialisation exams. In this context, although she already had a professional qualification, she decided to get married, become a stay-at-home mother and volunteer in the charity sector. At the time of the interview, she was socially isolated, financially dependent on her husband, struggling with her health and facing significant hurdles to find employment. In the case of the second woman, she described relying on welfare benefits while raising her three children and having the support of one close friend during the time of her diagnosis, as well as a minimum wage but stable job. At the time of the interview, she was financially independent, her health was stable and, although she was tired, she enjoyed working and caring for her grandchildren. Although race is probably playing its part in these two scenarios, this is far from linear. Structural context, individual decisions within such context and broader life circumstances are delicately intertwined in people's lives, managing to hold one of the two systems together, while the other—arguably similarly precarious—spins out of control, reflecting the corrosive effects of disadvantage in the specific context of living with a chronic disease.

Thus, this work focused on identifying and describing the corrosive effects of specific systematic injustices suffered by those living with chronic diseases, and how these negatively affect people's continuous effort towards dynamic equilibrium. Like this, tackling health inequalities is argued to require an in-depth understanding of how different variables work in different contexts and the processes through which these can affect each other amplifying disadvantage. From complex systems perspective, the amplified oppression described by the idea of intersectionality and the cumulative effect of disadvantage affecting people living with chronic diseases has been described in terms of a system trap called 'success to the successful' or 'competitive exclusion' (Meadows 2009). System traps describe the processes through which systems lose dynamic equilibrium, namely instead of having balancing feedback loops holding the system together, the reinforcement feedback loops and or runaway loops of damage result in the system collapsing. Thus, 'success to the successful' or 'competitive exclusion' are

> found whenever the winners of a competition receive, as part of the reward, the means to compete even more effectively in the future. That's a reinforcing feedback loop, which rapidly divides a system into winners

> who go on winning, and losers who go on losing (Meadows 2009, 127).

Meadows (2009) describes this trap in contexts where the starting point might be described as a level playing field, using the example of how the game Monopoly works. In this game, everyone is given the same amount to start with, but fairly quickly, those who manage to make a profit are in a privileged position to make even more profit, leaving other players out of the game. She also draws on the concept of 'competitive exclusion principle' in the field of ecology, to describe how two different species cannot live in the exact same environment and compete for the same resources, because their difference implies that eventually, one will thrive faster, leaving the other with nothing. Drawing on Lorde (2004) and Crenshaw's (1989) work, although humans belong to the same species, individual, group and socially constructed differences will prompt the system to this trap.

Furthermore, as discussed in the introduction to this thesis, in highly socially unequal contexts such as the UK, the playing field for health outcomes is not levelled to begin with, so equality of opportunity to access healthcare services as an attempt to counteract 'success to the successful' was argued to reflect a different sort of system trap, namely a 'fix that fails' or 'policy resistance'. As discussed in the introduction to this thesis, this does not mean that equality of opportunity to access healthcare is wrong, but that it is not enough to reduce health outcomes inequalities. Insofar equality of opportunity to access healthcare focuses on achieving a partial goal (providing access), this policy misses the complexity of the broader system and loses sight of the new information being created (persistent health outcomes inequalities despite people accessing healthcare). Therefore, the policy also loses sight of how this information (persistent health outcomes inequalities) re-enters the system to alter its behaviour more broadly through performativity (e.g. people who live in disadvantage and have poorer health outcomes being regarded as ‘bad patients’ and arguably engaging in a healthcare professional-patient relationship that is unhelpful to improve outcomes).

Building on Wolff and de-Shalit’s theory of disadvantage (2007), this work started from the idea that people living with chronic diseases are unlikely to enjoy a level of secure central functionings and have a genuine opportunity to benefit from available healthcare services, as this would imply jeopardizing other central functionings. This thesis told one story of how people living with chronic diseases and long-term treatment face difficult prioritisation choices because engaging with self-management tasks to control the disease can come into direct conflict with their wellbeing beyond bodily health. In this ongoing and multi-layered negotiation, this work described a struggle between at least two conceptions of the self—one that includes the disease and one that does not—and introduced the concept of the porous boundary of identity. This boundary helps protect overall wellbeing by keeping the disease at arm’s length and mostly out of mind. Thus, by developing what might be regarded as a false or partial self, people can continue to be a more accepted—for them and others—version of themselves. Going back to the idea that chronic disease should be added to Lorde’s (2004) list of those who suffer from systematic institutional rejection, her description of struggling between intersectional identities resonates with this work's description of the porous boundary of identity.

> As a Black lesbian feminist comfortable with the many different ingredients of my identity, and a woman committed to racial and sexual freedom from oppression, I find I am constantly being encouraged to pluck out some one aspect of myself and present this as the meaningful whole, eclipsing or denying the other parts of self. But this is a destructive and fragmenting way to live. My fullest concentration of energy is available to me only when I integrate all the parts of who I am, openly, allowing power from particular sources of my living to flow back and forth freely through all my different selves, without the restrictions of externally imposed definition. Only then can I bring myself and my energies as a whole to the service of those struggles which I embrace as part of my living (Lorde 2004, 858).

This sheds light on the dynamic and amplified cost, perhaps invisible for those lacking Lorde's (2004) striking prose, of inhabiting at least one, but possibly multiple disadvantaging identities. As already argued, on the whole, the disadvantaged are more likely to be burdened with a chronic disease, adding the bodily, psychological and logistical burdens described in this thesis to the mix of vital competing demands. In this context, this thesis argued that it is not reasonable to expect people living with chronic diseases in general and especially those who live in disadvantage to always comply with long-term treatment recommendations, despite having access to care.

In a context that lacks the tools for shared understanding of the experience and rejects chronic disease, this work challenges the prescriptiveness of 'illness acceptance' or 'disease integration', shedding light on the vital function that the porous boundary of identity plays in people's efforts towards dynamic equilibrium, despite this potentially jeopardizing self-care tasks. Still, Lorde's (2004) last quotation suggests that this exercise of fragmentation might be particularly exhausting and limiting for those who live with a chronic disease, contributing to live the least oppressed life possible in the present while also adding to the amplified effect of disadvantage in the long run. Thus, although 'illness acceptance' or 'disease integration' might be better in this sense and potentially desired, it might only be possible for those whose advantaged position in terms of secured functionings and reduced risks protects them from the disadvantages associated with chronic disease.

Drawing on this, dynamic equilibrium in the context of chronic diseases might be further specified as the genuine opportunity to be and do across time, which will largely depend on being free from negotiating intersectional identities and vital competing demands.

3. Interdependence and shared responsibility in chronic care

As discussed in the last section, health systems that focus on offering equality of opportunity to access healthcare reproduce pre-existing social inequalities in health. Drawing on the discussion in Chapter 9, this is closely linked to the focus on individual responsibility underlying the idea of equality of opportunity, which, in turn, was argued to reflect a luck egalitarian understanding of justice. Still, The 'American dream' of 'equal opportunity' as a proxy for fairness predates luck egalitarian views of justice, ruling relationships of exchange based on what one deserves and arguably representing common moral sense in profit or free-market capitalist societies—often referred to as neoliberal societies since the 1970s.

As already discussed, because chronic diseases are, in part, attributed to individual health risk factors often called lifestyle choices and their prognosis is largely associated with self-management in contexts where there is access to UHC, the social gradient in disease burden and health outcomes has been largely ignored or addressed through the lens of individual responsibility in health policy responses. Participants' stories reflected a general and broadly shared understanding of responsibility largely in terms of blame and accountability. As discussed in Chapter 5, responsibility, especially for poor health outcomes but also for illness, was described as a 'hot potato' that ultimately landed on the hands of people living with chronic diseases. This was described to contribute to sentiments of shame and guilt, being not just unhelpful to improve health outcomes, but also harmful for individuals.

As highlighted in the last section, the multidimensional perspective on the experience of chronic diseases developed in this thesis highlights relationships of interdependence between individuals within social structures. From this perspective, the strong focus that luck egalitarian views of justice place on individual responsibility might be thought to conflate or presuppose direct causation between the idea of agency deriving from the egalitarian claim that people must be treated as equals (Dworkin 2013) and blame or liability. This presupposition is particularly problematic because it ignores the 'social patterning' leading to the reproduction of privilege or disadvantage (Wolff 2020).

The experiences discussed in this work support and further specify previous research showing that chronic diseases negatively affect the functioning of affiliation or belonging, which has been described to be particularly fertile for other central functionings (Wolff and de-Shalit 2007). Besides the rather straightforward physical reasons why chronic diseases can interfere with social participation and hamper affiliation, Chapter 6 argued that people with chronic diseases suffer from a hermeneutical injustice that contributes to ruptures in their sense of belonging, withdrawal from social situations, isolation and loneliness, hampering their possibilities to keep previous social support and build new social networks. Chapters 7 and 9 discussed the vulnerability of people living with chronic diseases and their increased dependence on others, long-term treatment and healthcare services. Finally building mainly on chapters 5 and 8, this conclusion's discussion on intersectionality further specified how the negotiating of multiple demands takes significant energy and effort, mostly affecting the disadvantaged in their efforts towards dynamic equilibrium. This supports the normative starting point of this thesis and suggests that there is a cumulative effect of disadvantage leading amongst people living with chronic diseases. This was further specified as a double inequity suggesting that chronic diseases should be regarded as risk multipliers for disadvantage.

Furthermore, the hermeneutical injustice described suggested a second turn of the cross-category risk (Wolff and de-Shalit 2007) associated with the lack of affiliation and adequate social support. Even if people living with chronic diseases have good social support and networks, on a more general level, they might still experience social exclusion as they are included in a group of people that is then, in turn, being excluded (Wolff 2020). This was discussed in terms of the individual and structural levels of the problem of belonging in the context of chronic disease, which Wolff (2020) describes in terms of differential social inclusions, rather than as a binary of inclusion/exclusion.

Keeping this in mind, and going back to the question of health justice, Daniels' (2008) influential work on this issue accounts for background conditions and by drawing on the SDH renders most health inequalities unfair. Still, it considers that inequalities that could be traced back to choice would be the individual's responsibility and not a problem for justice, preserving some degree of conflation between undeserved fate and injustice (Young 2011). This leads to the problematic—within the egalitarian framework—judgement of the deserving and underserving ill and being also ultimately liable to the 'harshness objection' (Voigt 2013). Nonetheless, by moving the focus from individual chance-choice to the SDH, Daniels (2011) suggests that the luck egalitarian focus on individual responsibility is ultimately not helpful to think about health justice and proposes a shared understanding of responsibility in which the main responsibility for health and its fair distribution is social.

Although this view seems to capture, at least to some extent, the contextual approach to chronic diseases developed throughout this thesis, focusing on the SDH as independent variables and their fair distribution to fix the problem of health justice might reflect an atomistic approach, ignoring the relationship between variables and the dynamism of life highlighted in this thesis. Similarly, Young (2011) argues that one of the main problems of the liability model of responsibility—of which Daniels' (2008) account would ultimately still be an example of—is their focus on causal connections, ignoring how the institutional relations in which people act render them deeply interdependent, implicitly adopting a complex systems perspective. This interdependence has been a crucial aspect in participant's experience of chronic disease and long-term treatment, which this thesis has tried to capture through the ideas of dynamic equilibrium and long-term treatment as a shared activity.

In the context of poverty, Wolff (2019) argues that to treat people with respect—and thus avoid the problems associated with determining the deserving and undeserving poor—societies have to accept some 'free riding' of people who could work but choose not to. The fundamental insight underlying this moral intuition is that focusing on judging how people prioritise and attend to their needs is ultimately unhelpful to achieve social justice (Wolff 2019). Although the 'free riding' metaphor does not apply to people's use—or arguably misuse—of healthcare services and treatments, the overall idea that focusing on judging how people prioritise and attend to their needs is ultimately unhelpful to achieve social justice does. Similarly to how poor people's needs are argued to go beyond mere subsistence, demanding political and economic action so that all can avoid poverty in this plural sense (Wolff 2019), this thesis has provided a detailed account of life with chronic illness and long-term treatment, arguing that the needs of people living with chronic diseases go beyond mere physical health. This challenges the moral imperative of patients consistently prioritising treatment and disease control above other needs, suggesting a provision of chronic care that besides securing access to healthcare services focuses on supporting people’s efforts towards dynamic equilibrium, beyond self-management and adherence to long-term treatment. Furthermore, on account of respect for all, this line of argument would support the provision of long-term treatment regardless of people’s reasons for poor self-management or non-adherence, which, as discussed in Chapter 9, resonates with Walker’s (2019) ethical reasoning regarding shared responsibility for chronic care.

Although the idea of accepting some ‘free riding’ uses an economic metaphor that validates or reinforces a neoliberal view of societies and luck egalitarian views of fairness understood in terms of what one deserves, it also suggests that people’s unfortunate circumstances are more likely not to have been directly caused by their own actions, which, as a starting point, seems attuned with the egalitarian principle of equal concern and respect (Dworkin 2013). Looking at responsibility in this way resonates with Young’s (2011, 25) idea that “a responsible person tries to deliberate about options before acting, makes choices that seem to be the best for all affected, and worries about how the consequences of his or her action may adversely affect others”. Although many people are ‘irresponsible’ by this standard, Young’s (2011, 25) main point is that “it is doubtful that people of any class, race, gender, religion, or other general category are, as a group, any more or less responsible according to this standard than people of another group generally are”.

Much in line with Wolff’s (2020) idea of social patterning mentioned before, specifically regarding poverty and drawing on empirical research in contemporary USA, Young (2011) argues that most people will experience some degree of poverty at some point in their lives, so it cannot ultimately be associated with individual traits, dispositions or failings. All people are irresponsible or less responsible than they should at some point, but background and social conditions will make these individual actions result in more or less catastrophic consequences (Young 2011). Similarly, this thesis argued that adherence to long-term treatment is a non-linear and more or less fragile process closely intertwined with individuals' lives beyond illness. Thus, in so far as everyone is likely to go through periods of optimal adherence and periods of no or partial adherence at some point throughout their illness trajectories, non-adherence to long-term treatment, as a whole, cannot be associated with individual traits, dispositions or failings. Drawing on the cumulative effect of disadvantage, this work has argued that some are more likely to be in the position to struggle with adherence than others, find it harder to go back to a treatment regime or face more severe consequences because of poor underlying health states associated with their socioeconomic level or disadvantage.

Wolff and de-Shalit (2007, 72) argue that one central way of being disadvantaged is when one's functionings or functional capabilities "are or become insecure involuntarily, or when, in order to secure certain functionings, one is forced to make other functionings insecure in a way that other people do not have to do". Young (2011) thinks that these processes of deprivation or people's vulnerability to it, reflect a 'structural' injustice, suggesting that individual situations are the result of circumstances beyond the individual's control, although circumstances are often linked to choices. Drawing on Wolff and de-Shalit's theory of disadvantage, it might be argued that Young's (2011) specifications consider insecure functionings, cross-category risks and inverse cross-category risks to understand people's choices and thus both perspectives might be argued to stress interactions and pay attention to the position that someone is in within the social structure, which might be similar to many others despite their individual stories (Young 2011).

Building on this, and much in line with participants' intuitions around responsibility for long long-term treatment, Young (2011) proposes a forward-looking conception of responsibility that does not assume blame, fault or liability as the main way of assigning responsibility. This, however, does not undermine the fact that individual action and choice contribute to someone's circumstances. This different kind of responsibility, namely the social connection model of responsibility, derives from the fundamental idea that people belong "together with others in a system of interdependent processes of cooperation and competitions through which we seek benefits and aim to realise projects" (Young 2011, 105). Building on this perspective, responsibility for chronic disease health outcomes, and arguably for health more generally, is always personal and shared, meaning that it is something people personally bear, but they do not bear alone (Young 2011).

Young's (2011) model of responsibility suggests encouraging others to take part in collective action to fix structural injustice. Similarly to the underlying rationale of the cumulative effect of disadvantage introduced in this thesis, structural injustice refers to the social processes generating background conditions that make the life of those who live in relative disadvantage much more insecure and difficult to negotiate (Young 2011). Thus, collective action aiming to counteract this kind of injustice aims to restructure institutions and relationships in such a way that these can prevent threats to people’s basic wellbeing (Young 2011). However, and without denying the value of this, the idea that organised collective action is the only way to contribute to structural justice seems to ignore the power of performativity, as discussed in Chapter 9. Building on Johnson’s (2018, 192) idea of Dewey’s “Pragmatist notion of thinking and reasoning as forms of *doing*, that is, as ways of acting to change the world”, this thesis shed light on paths for individual action that can have a collective impact. These paths described the strength of participants’ own ‘strategic non-compliance’ (Campbell et al. 2003), their ‘everyday resistance’ (Scott 1985) to comply with the imperative of health and the high value of isolated acts of acknowledgement, respect and empathy experienced by participants throughout their illness trajectories.

Thus, continuing the normative framework from which this research started, namely that individuals living in disadvantage in terms of their socioeconomic level and their achieved functionings level might be more likely to 1) get a chronic disease and live shorter lives; 2) lack the functionings that could allow them to successfully self-manage their disease; and 3) be at risk to become more disadvantaged as a result of chronic disease, this thesis suggests expanding this framework by adding three new normative principles to orient individual action aiming to improve equity in health outcomes for chronic diseases in contexts where people have access to UHC.

Following the discussions in chapters 6, 7-8 and 9 respectively, the three principles suggest responding to the cumulative effect of disadvantage amongst people living with chronic diseases by 1) practising socially aware testimonial justice with people living with chronic diseases and contributing to hermeneutical justice by building tools for shared understanding specifically regarding the experience of chronic disease and chronic care; 2) respecting that long-term treatment is not and should not always be prioritised and thus adherence to long-term treatment is not a stable achievement;[2] and 3) understanding chronic care as a truly person-centred shared project mainly between patients and healthcare professionals, but also involving the broader social context.

Drawing on the position of power that healthcare institutions and professionals have been argued to hold relative to those who live with chronic diseases, these principles are mainly aimed at healthcare institutions and professionals delivering chronic care. Still, these principles might be argued to contribute to the hermeneutical tools for shared understanding of chronic illness beyond this context, namely the broader society of the ‘healthy’ and individual processes of illness and long-term treatment amongst people living with chronic disease. These principles build on shifting the focus of chronic care towards supporting dynamic equilibrium for people living with chronic diseases as the genuine opportunity to live lives people have reason to value (be and do) across time, contributing to improve equity in health outcomes for chronic diseases in England and potentially informing further research and practice in other contexts where people have access to UHC.

Thus, the fundamental rationale underlying these principles rests on

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[2] This principle presupposes also supporting the negotiation of chronic disease as an intersectional identity instead of imposing the moral imperative of illness acceptance and psychological adjustment.

treating people with respect and counteracting the health patterning eroding the affiliation and sense of belonging of those who live with chronic diseases. Although these principles are not exhaustive and many more efforts are needed to address the problem of chronic disease health outcomes inequalities as a structural issue, they demonstrate that embracing complexity is a fruitful path to orient ethically driven care for chronic diseases.

4. Conclusion

This thesis argued that, more likely than not, people living with chronic diseases do the best they can to follow healthcare professionals' recommendations and adhere to long-term treatment, while also living lives they have reason to value. Although this is likely to result in periods of partial or non-adherence to treatment for everyone, the social gradient in health outcomes for chronic diseases shows that structural injustice puts those who live in disadvantage in a position in which they are either more likely to go through these periods, find it more difficult to return to their treatment regimes or suffer from worse health consequences because of having, overall, poorer general health. This thesis also argued that in current western societies, such as the UK, it is somehow accepted or structurally expected that healthcare systems, healthcare professionals and society more broadly often fail to treat people who live with a chronic disease with respect, refusing to share responsibility for long-term treatment and contributing to reproduce health inequalities.

Considering the structural forces at play in the cumulative effect of disadvantage amongst those who live with chronic disease described in this work, shared responsibility in this sense might be particularly helpful to think about responsibility for justice in the context of chronic disease and long-term treatment. This thesis established that chronic diseases affect people’s lives in multiple ways and in a dynamic—more or less unpredictable—way throughout life. Thus life with chronic disease was depicted as the balancing exercise of walking through a tight rope of changing width and environmental conditions, making it easier or harder to stay on it. In this balancing exercise, people’s lives as a whole were described as complex systems of interconnection in which living lives people have reason to value depends on the actions and choices of those living with chronic diseases in close interdependence with the actions and choices of others. These include family members, friends, the broader social context and institutions, especially highlighting the potential of those in a position of power, such as healthcare institutions and professionals, as fertile networks contributing to social inclusion and sense of belonging.

Drawing on this and the shift in perspective proposed through the social connection model of responsibility, it might be argued that both the language and current focus on ‘self-management’ for chronic diseases contribute to reproduce a culture and understanding of chronic diseases that are limited to individual responsibility, obscuring the structural processes involved in unjust outcomes. Thus, building on an understanding of shared responsibility that can account for such processes, namely a responsibility people personally bear with others, this work suggests moving the focus to the relationships of collaboration that have been argued to facilitate or hamper long-term treatment and stress the centrality of shared management to improve equity in health outcomes for chronic diseases.

This might be understood as patients having a limited role in their care. Still, the expanded normative framework developed in the concluding chapter of this thesis aims to counteract power imbalances affecting those who live with chronic disease. Thus, shared management aims at co-production without restricting the freedoms and responsibilities—in a paternalistic way—of people living with chronic diseases.

As an exercise of testimonial justice to everyone taking part in this study and by developing tools for a shared understanding of the experience of chronic disease and long-term treatment, this thesis hopes to contribute to restore hermeneutical justice for people living with chronic diseases as well as inform and inspire further research, policy developments and care models for chronic disease health justice.

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Appendices

Appendix A: Study Documents

Interview Guide

The following questions are a general guide for the semi-structured interview. Conducting this type of interview means that the respondents' answers will determine how the interview will cover the relevant topics introduced by the following questions. So this is not a rigid set of questions but a general guide to conduct the interviews. Not every question will necessarily be asked; each section begins with general questions, which are likely to be enough to cover all the relevant topics. Nonetheless, if participants require more guidance to share their experience there are more specific questions to keep the interview going.

The length of the interviews will depend on how each interview goes but the maximum duration will be 1 hour and 30 minutes.

Before starting, all subjects will sign the informed consent form; they will be explicitly told that there are no right and wrong answers; and they will be reminded of their option to not answer a particular question, stop the interview or withdraw from the study at any time.

First part: Basic information

This section aims to collect general background information about the interviewee in order to understand the context of her or his experience.

- Introduce myself
- I want to ask you a few introductory questions and then we will continue with more open questions for you to talk more freely.

1.- How old are you?

2.- Do you have a job?

3.- Where do you live?

4.- Do you live by yourself?

5.- Do you have a partner? Married?

6.- Do you have children?

Second and third part: About yourself, family background, childhood, youth.

This section aims to collect information about the identity and sense of self of the interviewee, his/her life and subjective experience before being diagnosed. These questions also provide valuable information about meaningful relationships of the interviewee and his or her experience of emotional support.

- I will now ask you a few questions to get to know you. You can focus on the present or tell about your past. For example, you can tell me about your childhood and youth, your family and friends, any other important people, activities or events in your life.

7.- What can you tell me about yourself that can help me get a general idea of who you are?

- How would you describe yourself?
- What do you enjoy doing and what do you particularly dislike doing?
- How is your family/social life today?
- Do you participate in any community activities?

- How/when did you first join? What were you looking for? Does this help you or make things easier for you in any way?

Family history:

- How would you describe your family's culture, traditions, values and beliefs?
- Is there any particular childhood memory that you would like to share with me in order to help get an idea of how your family is/was like?
- What can you tell me about your parents and your relationship with them?
- Are they still alive? What do they do now? Do you see them often? Do you enjoy spending time with them?

- If you could change something about yourself, what do you think you would choose?
- Is there anything about yourself we haven't already talked about and is an important characteristic of you?

Fourth and fifth part: About your disease and your lived experience of chronic illness

This section aims to give place to the illness narratives to emerge, focusing on trying to identify the potential biographical disruption brought by illness, and the interviewees' overall illness perception by covering key dimensions such as: illness identity; cause; time-line; consequences; and control/cure.

- Now I want to ask you about the time when you were diagnosed and how is it to live with your disease on a daily basis.

8.- Can you tell me the story of how you became ill, got your diagnosis, and how has it been since then?
- When did you start feeling that something was wrong or had your first symptoms?
- When were you diagnosed? And how was the process of getting a diagnosis?
- How did you feel at that time?
- Has that feeling changed over time? How do you feel about it now?

9.- Have you shared your diagnosis with anyone?

    Yes,

    - Who knows?

    - How long did it take you to tell someone?

- Was it a difficult decision to share this with someone else?
- Did you choose whom you wanted to share it with?
    - How did he/she/they react?
- How did you feel about that reaction? How do you feel about it now?

    No,

- Is there a special reason for that? How is it/does it feel to keep this for yourself?

10.- Has this illness affected your daily life?

  - How so? How has it changed?

11.- Have your social activities changed in any way since you became ill?

  - How so?
  - Do you think this changed because of your illness? How so?

12.- Has anything else that is important to you changed significantly in your current daily file because of your illness?
(Work? Love life? Close relationships? Food? Leisure activities? Holidays, sports, ect.)

13.- Do you have any other chronic conditions?

14.- How would you explain what your illness is or how would you describe it for someone who doesn't know anything about it, like child for example?

  - What are the symptoms of your disease?
  - Do you currently have or ever had any symptoms?
  - How frequently do you have these symptoms?
  - Do these come and go? Or vary in intensity?
  - What helps you feel better?
  - What do you think makes the symptoms worse?
  - How intense would you say these symptoms are?
  - What do you think are the causes of your disease?
  - Do you blame anything or anyone?
  - How long do you think your disease will last?
  - Do you think it may ever go away or go into remission?
  - How would you describe the consequences of having such illness?

- How much control do you feel you have over your disease? Or what do you think you can do about it?

Sixth part: Your future

This section aims to explore in more detail the potential biographical disruption brought by illness specifically with regards to future plans.

- I will now ask you about your future and how your illness may have changed the way you see or think about it.

15.- Can you tell me about how do you currently think about or imagine your future?

- How do you think your disease is going to develop or be like in the future?
- How do you feel about that? How has this been for you?

16.- Has your illness affected your perspective about of the future in any way?

- How so? How was this before you were diagnosed?
- How has this been for you?
- How have you managed to deal with it? Strategies?
- Has it always been like this since you were diagnosed?
- Are there people around you who have influenced this in any particular way? (Make it easier or more difficult?)

Seventh part: Your chronic treatment

This section aims to collect information about the experience of being a chronic treatment patient including the interviewee’s thoughts, values and beliefs about chronic treatment.

- Finally, I want to ask you about your treatment.

17.- Can you tell me about your treatment? What does it consist of and what does this imply on a daily basis?

- How has this affected your life? (Work? Leisure? Socialising? Other personal relationships? Caring for others?)
- Do you care for your health in any other way besides this treatment?
- How long have you been on treatment? Has it always been the same?

18.- What difference does it make if you take your medicine/treatment as prescribed, miss doses or don´t take it at all?

19.- Do you feel that it is possible for you to follow or comply with your treatment?

 - How so? What does this mean for you?

- Do you ever face any difficulties to access your treatment? (Getting your medicine(s), booking appointments, paying for transport, taking time off work, etc)

 No,

- What do you think makes it accessible? Do you think this is important for your care?

 Yes,

- Which? How do you think this could be resolved? Do you think this affects your care in any way?

20.- What would you say is the most difficult aspect of your treatment and why?
- Is there anything (something/someone/time) that makes it easier or you think would make it easier?
- Do you think you have something in particular that helps you follow your treatment? (Strength, belief/faith, worldview, social support, financial support/stability, etc.)

21.- Does your treatment feel like a big responsibility?

22.- Who would you say has played a meaningful role in your care?
- How so? What is your relationship like? How has this been for you?

- Does anyone ask you if you are taking your medication or following your treatment recommendations? How do you feel about that?

23.- How is your relationship with your healthcare team?

    - Do you always go to the same hospital/GP to receive care?
    - How often do you see someone from your healthcare team?

- Do you think this affects (benefit or hinder) your care or treatment in any way?

24.- Do you use the Internet or social media to connect with other people and ask questions about your illness or treatment?

    - How did you first started doing it?
    - What were you looking for?
    - Does it help you or make things easier for you in any way?

25.- From your own experience, would you say there is anything regarding the delivery long-term treatment that should change? Is there anything that the NHS or your healthcare team should do and/or stop doing?

26.- What would you say to someone who has just been diagnosed with a chronic disease? Do you have any advise?

Information Sheet For Participants (patients)

INFORMATION SHEET

You will be given a copy of this information sheet

You are being invited to take part in a research project. This project will be contributing to a PhD research project about patients' experience of chronic disease and health inequalities in England. The person who will be conducting the study is the student researcher Francisca Stutzin.

This information sheet will try to answer any questions you might have about the project, but please don't hesitate to contact the research team if there is anything else you would like to know. Before you decide whether you want to take part or not, it is important that you read this information sheet carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Thank you for reading this.

1. What is the purpose of this study?

The NHS is committed to improving the quality of life and overall health of patients living with chronic conditions. This commitment includes providing individualised healthcare opportunities to help ensure that different groups of people living with chronic diseases can attain more equal outcomes. However, this is still a significant challenge.

Part of this problem is that only half of the people who live with a chronic disease follow long-term treatment recommendations, despite the efforts of the NHS to improve this. Currently, the main method used to improve compliance is having healthcare professionals teach patients how to better manage their disease on a daily basis, but very often this approach does not take into account the experience of the patients.

The research team working on this project has decided to help fix this problem by learning from the experience of people living with chronic diseases. This means that the research team wants to learn about how people manage to adjust their lives after becoming ill with a chronic disease and face the difficulties arising from long-term treatment.

By including the voice of patients in the discussion about how more equal results might be achieved, this project wants to help the NHS make sure that their healthcare programmes meet everyone's needs and all patients can benefit from the treatments offered.

2. Why have I been asked to participate in this study?

You have been chosen mainly because you currently live with at least one chronic disease and you have been prescribed long-term treatment.

Further criteria include: being between 18 and 65 years old, having been diagnosed after the age of 18 years, having been prescribed at least one long-term treatment, and being able to speak English.

If possible, the group of participants will be equally divided between man and women, and will represent different social and cultural backgrounds, professions, income bands, and educational qualifications.

The total number of participants will reach a maximum of 50 individuals.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. Choosing not to take part will not disadvantage you in any way. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw without giving any reason.

4. What if I no longer want to take part?

You may withdraw your participation at any point during the study without giving a reason and without the care you receive or your legal rights being affected. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up to that point.

5. What will I have to do if I take part?

As a participant, you will be invited to take part in a one-to-one interview with the student researcher and to allow the student researcher to conduct one session of participant observation of the patient-healthcare professional relationship. The interview will take place at UCL, UCLH, The Royal Free Hospital or, if necessary, in a different location agreed by both the participant and the student researcher. The length of the interviews will depend on how the interview goes but the maximum duration will be 1 hour and 30 minutes. The observation session will take place in one healthcare appointment agreed by you, the student researcher, and the healthcare practitioner, and its duration will depend on the duration of the appointment. These two instances will constitute the main source of information for this research project.

If you become a participant in this study, you will be officially enrolled in the study until the 31st of December 2019. However, the research team aims to complete all interviews and participant observation sessions by August 2019.

You may contact the student researcher afterwards if you have any questions about the study. Travel expenses will not be reimbursed, but the student researcher might be available to meet with you at a place agreed you and the student researcher.

6. What are the possible advantages of taking part?

Whilst there are no direct advantages for participating in this project, by taking part in this study you have the opportunity to contribute to the discussion on how to improve the delivery of chronic treatments, to better support adherence to the treatment regime and to improve chronic disease patients' quality of life and health state.

Therefore, although you will not receive an immediate benefit regarding your health, you will be contributing to future improvements for your healthcare and the healthcare of future generations of chronic disease patients.

7. What are the possible disadvantages and risks of taking part?

Discussing personal experiences of illness can be upsetting since this implies engaging with sensitive contents. In order to minimise this risk, significant work has been put into planning your interview. A relevant Patient and Public Involvement (PPI) network has been consulted during the process of constructing the interview guide in order to test the questions in advance, making sure that they explore the necessary topics without trespassing unnecessary personal boundaries and safeguarding your integrity.

Furthermore, the student researcher has relevant training doing interviews as a trained clinical psychologist and social scientist, thus having the necessary skills to generate a safe and controlled emotional environment by offering you an empathetic and respectful encounter.

Nonetheless, if you are feeling upset during the interview you will be given as much time as necessary to recover and you will not be in any way pushed into sharing aspects of your experience that you do not wish to share. You will be in control of taking the contents of the interview in the direction you feel more comfortable with and you will be allowed to stop the interview at any time.

Feeling temporarily distressed or uncomfortable immediately after the interview may be expected and should be regarded as normal, since sensitive topics will have just been discussed. However, if this feeling persist and you wish to request support, you should contact your GP for an appropriate assessment of the situation. If this process takes longer than expected, you may also request support from one of the NHS Mental Health Helplines listed below, or find more at https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/

NHS Mental Health Helplines:

- Mind: Promotes the views and needs of people with mental health problems.
Phone: 0300 123 3393 (Mon-Fri, 9am-6pm)
Website: www.mind.org.uk

- Rethink Mental Illness: **Support and advice for people living with mental illness.**
Phone: 0300 5000 927 (Mon-Fri, 9.30am-4pm)
Website: www.rethink.org

- Samaritans: **Confidential support for people experiencing feelings of distress or despair.**
Phone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk

- Depression Alliance: **Charity for sufferers of depression. Has a network of self-help groups.**
Website: www.depressionalliance.org

- Anxiety UK: **Charity providing support if you've been diagnosed with an anxiety condition.**
Phone: 03444 775 774 (Mon-Fri, 9.30am-5.30pm)
Website: www.anxietyuk.org.uk

If any questions regarding the information you shared or the project in general arise after the interview has taken place, you are encouraged to contact the student researcher (contact details at the end of this document) via phone or email to clarify these. If you request to meet with the student researcher in person to ask questions about the study and your participation in it after the interview takes place, the student researcher will agree to one follow-up meeting with the sole purpose of answering questions about the study and the information shared.

8. Will I be recorded and how will the recorded media be used?

The interview will be audio recorded and the student researcher will take notes during the participant observation session. The audio recording will be transcribed by a professional company under a confidentiality agreement and erased once the study is finished. The transcription will be used only for data analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

9. Will my taking part in this project be kept confidential?

All the information collected about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any reports or publications.

10. Will anyone else be told about my participation in the study?

With your consent, the student researcher will inform healthcare practitioner and/or GP if any unexpected results are found in relation to your health. If you are not happy about your healthcare practitioner and/or GP being sent all the relevant information regarding the study please let the research team know. If you wish the research team to tell anyone else of your participation in the study they will be happy to do so.

11. What will happen to the results of the research project?

The results of this research project will be used to inform a PhD thesis and potential journal articles. You will be sent a copy of a summary report if you wish.

12. What if I have any concerns?

If you have a concern about any aspect of this study or the conduct of members of the research team, in the first instance you should speak to the student researcher's supervisor, the chief investigator of this study: Dr James Wilson who will do his best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this through the normal hospital complaints procedure by contacting the NHNN Patient Advice and Liaison Service at UCLH. Their office is based on the ground floor, at the NHNN near the pharmacy and library. Opening hours are 0900-1600, Monday-Friday (except public holidays). Telephone number:

PALS office at the Royal Free Hospital is in the hospital's main reception. Opening hours are 10:00 - 16:00, Monday - Friday, except Wednesday 10:30 to 16:00. Telephone number:

In the unlikely event that something does go wrong during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation – but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

13. Who is funding and organising this study?

This study is organised and led by Francisca Stutzin, the student researcher and Dr James Wilson, the chief investigator.

The study is funded by the National Commission for Scientific and Technological Research (CONICYT) of the Chilean Government through its Ph.D. scholarship programme Becas Chile.

Sponsor for the study is University College London.

14. Who has reviewed the study?

This research project has been reviewed and approved by the Research Ethics Committee (REC) and the Health Research Authority (HRA). A committee of lay reviewers have also commented on the study.

15. Data Protection Privacy Notice

Notice:

The data controller for this project will be University College London (UCL). This means that UCL is responsible for looking after your information and using it properly. UCL will keep identifiable information about you for up to 1 year after the study has finished. During this time your information will be saved at UCL OneDrive cloud storage system and/or secured at UCL premises. The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ucl.ac.uk*.*

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be that it is a task in the public interest (GDPR article 6).

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

16. Study Investigators' contact details:

For further information, you can contact the student researcher of this study Francisca Stutzin at:

Tel:
E-mail:
Address:

Or the research supervisor and chief investigator of this study Dr James Wilson at:

Tel:
Email:
Address:

Thank you for taking the time to read this information sheet and for considering taking part in this research study.

If you decide to take part in this research study, you will be given a copy of the information sheet and

Information Sheet For Participants (healthcare professionals)

INFORMATION SHEET for Healthcare Practitioners

You will be given a copy of this information sheet

You are being invited to take part in a research project. This project will be contributing to a PhD research project about patients' experience of chronic disease and health inequalities in England. The person who will be conducting the study is the student researcher Francisca Stutzin.

This information sheet will try to answer any questions you might have about the project, but please don't hesitate to contact the research team if there is anything else you would like to know. Before you decide whether you want to take part or not, it is important that you read this information sheet carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Thank you for reading this.

1. What is the purpose of this study?

The NHS is committed to improving the quality of life and overall health of patients living with chronic conditions. This commitment includes providing individualised healthcare opportunities to help ensure that different groups of people living with chronic diseases can attain more equal outcomes. However, this is still a significant challenge.

Part of this problem is that only half of the people who live with a chronic disease follow long-term treatment recommendations, despite the efforts of the NHS to improve this. Currently, the main method used to improve compliance is having healthcare professionals teach patients how to better manage their disease on a daily basis, but very often this approach does not take into account the experience of the patients.

The research team working on this project has decided to help fix this problem by learning from the experience of people living with chronic diseases. This means that the research team wants to learn about how people manage to adjust their lives after becoming ill with a chronic disease and face the difficulties arising from long-term treatment.

By including the voice of patients in the discussion about how more equal results might be achieved, this project wants to help the NHS make sure that their healthcare programmes meet everyone's needs and all patients can benefit from the treatments offered.

2. Why have I been asked to participate in this study?

You have been asked to participate in this study because you are the healthcare practitioner (HCP) of one of the patients enrolled in this study. One of the methodologies used for this study include one session of participant observation of the relationship between the HCP and the patient. The aim of this session is learn through first-hand observation of the interactions of interest to the study. This is predominantly promotes the collection of emerging data—without pre-established hypothesis—through the examination of several dimensions of a social situation simultaneously—physical, behavioural, verbal, nonverbal, and interactional in the context of broader social and physical environment.

Implementing this data collection technique will be particularly relevant for the aim of characterising the patient-healthcare professional relationship and better understanding the challenges and opportunities arising form this relationship for the specific case of chronic disease and long-term treatment adherence.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. Choosing not to take part will not disadvantage you in any way. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw without giving any reason.

4. What if I no longer want to take part?

You may withdraw your participation at any point during the study without giving a reason. If you decide to withdraw you will be asked what you wish to happen to the information collected up to that point.

5. What will I have to do if I take part?

As a participant, you will be asked to allow the student researcher to conduct a session of participant observation of the patient-healthcare professional relationship with one of your patients. You don´t have to do anything differently form a normal appointment, thus the duration of this session will depend on the duration of the appointment. If you become a participant in this study, you will be officially enrolled in the study until the 31st of December 2019, but your participation only requires your time for the duration of the participant observation session.

You may contact the student researcher or the chief investigator afterwards if you have any questions about the study.

6. What are the possible advantages of taking part?

Whilst there are no direct advantages for participating in this project, by taking part in this study you have the opportunity to contribute to the discussion on how to improve the delivery of chronic treatments, better support adherence to the treatment regime and improve chronic disease patients' quality of life and health state.

7. What are the possible disadvantages and risks of taking part?

Being observed while performing your professional activities can be uncomfortable specially taking into account that the relationship between HCP and patient is confidential, and some appointments may require privacy to share sensitive information with the patient. In order to minimise these risks, the student researcher has made sure that the patient is well informed about this study and has given consent for the student researcher to be present at this particular appointment. However, if you think this is not an appropriate time to conduct the participant observation session, the research team will respect this decision and the session will not be carried out at this time.

If you decide to become a participant and questions regarding the information you shared or the project in general arise after the participant observation session has taken place, you are encouraged to contact the student researcher via phone or email to clarify these (contact details at the end of this document). If you request to meet with the student researcher in person to ask questions about the study and your participation in it after the participant observation session takes place, the student researcher will agree to one follow-up meeting with the sole purpose of answering questions about the study and the information shared.

8. Will I be recorded and how will the recorded media be used?

The participant observation session will not be audio/video recorded. The student researcher will take notes during the participant observation session. The notes will be used only for data analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original notes.

9. Will my taking part in this project be kept confidential?

All the information collected about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications.

10. Will anyone else be told about my participation in the study?

No one will be told about your participation in the study. If you wish the research team to tell anyone of your participation in the study they will be happy to do so.

11. What will happen to the results of the research project?

The results of this research project will be used to inform a PhD thesis and potential journal articles. You will be sent a copy of a summary report if you wish to.

12. What if I have any concerns?

If you have a concern about any aspect of this study or the conduct of members of the research team, in the first instance you should speak to the student researcher's supervisor, the chief investigator of this study: Dr James Wilson who will do his best to answer your questions.

In the unlikely event that something does go wrong during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation – but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

13. Who is funding and organising this study?

This study is organised and led by Francisca Stutzin, the student researcher and Dr James Wilson, the chief investigator.

The study is funded by the National Commission for Scientific and Technological Research (CONICYT) of the Chilean Government through its Ph.D. scholarship programme Becas Chile.

Sponsor for the study is University College London.

14. Who has reviewed the study?

This research project has been reviewed and approved by the Research Ethics Committee (REC) and the Health Research Authority (HRA). A committee of lay reviewers have also commented on the study.

15. Data Protection Privacy Notice

Notice:

The data controller for this project will be University College London (UCL). This means that UCL is responsible for looking after your information and using it properly. UCL will keep identifiable information about you for up to 1 year after the study has finished. During this time your information will be saved at UCL OneDrive cloud storage system and/or secured at UCL premises. The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ucl.ac.uk*.*

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be that it is a task in the public interest (GDPR article 6).

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

16. Study Investigators' contact details:

For further information, you can contact the student researcher of this study Francisca Stutzin at:

Tel:
E-mail:
Address:

Or the research supervisor and chief investigator of this study Dr James Wilson at:

Tel:
Email:
Address:

Thank you for taking the time to read this information sheet and for considering taking part in this research study.

If you decide to take part in this research study, you will be given a copy of the information sheet and a signed consent form to keep.

Informed Consent Form (patients)

CONSENT FORM

Title of Project: An empirical ethics investigation into the lived experience of chronic disease in England.

Name of Student Researcher: Francisca Stutzin Donoso
Name of Chief Investigator: Dr James Wilson

Please initial box

1. I confirm that I have read and that I understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I would like to take part in (please tick one or more of the following)

- One individual interview ☐
- One participant observation session ☐

3. I consent to my interview being audio recorded and I understand that the recordings will be destroyed within 12 months after the data has been collected or following transcription. ☐

4. I consent to my audio recordings being shared under a confidentiality agreement with a professional company for transcription. ☐

5. I consent to notes being taken by the student researcher during the participant observation session. ☐

6. I consent to the processing of my personal information for the purposes explained. I understand that such information will be handled in accordance with all applicable data protection legislation. ☐

7. I understand that confidentiality will be maintained as far as possible unless during the interview the student researcher hears anything which makes her worried that someone might be in danger of harm, and she might have to inform relevant agencies of this. ☐

8. I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications. ☐

9. I understand that the information I have submitted will be published as a report. ☐

10. I wish to receive a copy of the study report. ☐

11. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without the care I receive or my legal rights being affected. ☐

12. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise. ☐

13. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the sponsor of the study (University College London) and responsible persons authorised by the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

14. I agree that my healthcare practitioner and/or GP may be contacted if any unexpected results are found in relation to my health. ☐

15. I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research. ☐

16. I understand the indirect benefits of participating. ☐

17. I am aware of who I should contact if I wish to lodge a complaint. ☐

18. I agree to take part in the above study. ☐

______________________	__________	________________
Name of Patient	Date	Signature

Name of Person taking consent	Date	Signature
Name of Chief Investigator *(if different to the person taking consent)*	Date	Signature

When completed: 1 for participant; 1 (original) for researcher site file; 1 to be kept in medical notes

Informed Consent Form (healthcare professionals)

CONSENT FORM
Healthcare Practitioners

Title of Project: An empirical ethics investigation into the lived experience of chronic disease in England.

Name of Student Researcher: Francisca Stutzin Donoso
Name of Chief Investigator: Dr James Wilson

Please initial box

1. I confirm to have read and understand the information sheet for the above study. I had the opportunity to consider the information, ask questions and had these answered satisfactorily. ☐

2. I agree to take part in one participant observation session. ☐

3. I consent to notes being taken by the student researcher during the participant observation session. ☐

4. I consent to the processing of my personal information for the purposes explained. I understand that such information will be handled in accordance with all applicable data protection legislation. ☐

5. I understand that confidentiality will be maintained as far as possible unless during the participant observation session the student researcher hears anything which makes ☐

her worried that someone might be in danger of harm, and she might have to inform relevant agencies of this.

6. I understand that the data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications. ☐

7. I understand that the information submitted will be published as a report. ☐

8. I wish to receive a copy of the study report. ☐

9. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. ☐

10. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise. ☐

11. I understand the potential risks of participating and the measures in place to minimize these. ☐

12. I understand the indirect benefits of participating. ☐

13. I am aware of who I should contact if I wish to lodge a complaint. ☐

14. I agree to take part in the above study. ☐

Name of HCP	Date	Signature
Name of Person taking consent	Date	Signature
Name of Chief Investigator *(if different to the person taking consent)*	Date	Signature

When completed: 1 for participant; 1 (original) for researcher site file; 1 to be kept in medical note.

Appendix B: Sponsorship, Ethics Approvals And Access To Research Sites

The administrative process of gaining access to research sites and participants was time-consuming and cumbersome. The first layer of this implied identifying and understanding the institutional relationships, roles, and hierarchies. The Joint Research Office (JRO) is a partnership between University College London (UCL) and University College London Hospitals (UCLH) National Health Service (NHS) Foundation Trust. This partnership supports the development of the clinical research portfolio of UCL and UCLH, facilitating the processes of meeting regulatory requirements, performance targets and quality and safety standards (University College London 2018). Furthermore, The Royal Free London Hospital (RFH) is a founder member of UCL partners, thus the UCL Royal Free Campus and the Royal Free Hospital are natural clinical/academic research partners in the quest for combining "basic and applied biomedical science and clinical care delivery across the university and hospital" (Royal Free London Hospital 2018).

To recruit participants and observe healthcare appointments in these two hospitals, the study had to first be registered with and sponsored by UCL, as well as gaining a favourable opinion from the Research Ethics Committee (REC) and the approvals from the Health Research Authority (HRA). I started by registering the study with the JRO, for which I had to submit a study protocol and the Integrated Research Application System (IRAS) form. After this, the study was assigned a coordinator from the JRO, who completed the sponsorship review. Only after getting the sponsorship for the study, I could submit my application to the HRA for the ethics approvals. The sponsorship process started in February 2018 and was completed in August 2018. Throughout these seven months I had to produce a detailed study protocol, research plan, patient information sheet, and informed consent form; get the data protection registration from UCL legal services; request peer-review and funding letters; present the costing of the study; complete the IRAS form online, statement of activities and insurance forms among many more. Coordinating all this required weekly email and phone communications with different teams within the JRO.

Having the support, trust and collaborative attitude of my primary supervisor, Professor James Wilson, was crucial for the success of this process. As a student, I could not be the Chief Investigator (CI) of the study, so Professor James Wilson agreed to act as CI, which meant he was ultimately responsible for the study both for UCL and the HRA. It also meant that he had to be available providing timely feedback, approving submissions, and signing documents on a weekly basis throughout this process.

Parallel to this endeavour, I was working on securing the feasibility of the project at the research sites. Since March 2018 I started screening for potential collaborators within the hospitals and reaching out to them via email. I would send them a summary of the research project and ask whether they would be interested in taking part by facilitating access to clinical units and helping out with the recruitment of participants. For two months, and after reaching out to at least ten clinical leads, I did not get any responses. In May, I received the first positive and enthusiastic reply from the lead consultant of respiratory medicine at UCLH. She agreed to a meeting where I had the opportunity to explain the research project in more detail. She highlighted the practical relevance of the study and was very enthusiastic about its contribution, so she committed not only to support the study but also act as Principal Investigator (PI) at UCLH for the HRA—if the study was granted ethics approvals. This was a very important milestone for the fieldwork because after getting this support from a well-known doctor in the hospital, it became easier to get other clinical units interested in collaborating with the study. Furthermore, on a few occasions, the PI helped me establish connections by sending introduction emails for me to invite lead consultants to take part in the study. Still, getting other clinical units involved required a lot of time and effort. I would reach out to them initially via email, try to set up face-to-face mattings to present them the study, answer their questions and negotiate their involvement.

I successfully followed this process with the gastrointestinal diseases unit and the endocrine diseases unit. The infectious diseases unit required extra work because they requested me to give a research presentation to the whole team. After this presentation, they referred me to the team at the RFH, as they handled the outpatients' service. I had to go through the same process with the clinical lead at the RFH, including giving a research presentation to the team, before they agreed to support the study. The lead consultant also agreed to act as PI at the RFH for the HRA. Unfortunately, and despite all my efforts, this process was not successful with other clinical units, but with the four units already on board, I had access to a good, varied sample including over ten different—both infectious and non-infectious—chronic conditions.

Having completed all the documentation, and secured PIs for each research site and the collaboration from four clinical units, I got UCL's sponsorship for the study in late August 2018, so I could submit the ethics application to the HRA on the first week of September 2018. A few weeks after this, Professor James Wilson and I met with the NHS ethics committee assigned to assess the study and we were asked to answer theoretical questions and justify methodological decisions. A month later we received their decision, which although was favourable, required a few amendments in some of the study documents—such as the informed consent form and the patient information sheet. After amending the documents, I resubmitted the application and by the end of October 2018, the study was granted REC's favourable opinion and HRA approvals.[3]

After this, it still took three more months to get the study administratively 'live' in both hospitals, through the Research and Development offices. I had to go through the administrative processes of getting a research passport and ID card for both hospitals, which required completing forms and getting signatures from PIs, as well as going through an occupational health assessment. In the meanwhile, I reached out to the lead consultants from each clinical unit, which had agreed to collaborate with the study to inform them about the ethics approvals, confirm their interest in collaborating, and plan the next steps. Luckily

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[3] REC's favourable opinion letter and HRA's approval letter are attached at the end of this appendix.

all four clinical units confirmed their interest and put me in touch with their clinical teams to start organising the recruitment plan.

Research Ethics Committee: Letter of Favourable Opinion

Health Research Authority: Letter of Approval

Appendix C: Summary Of Empirical Findings

Introduction And Overview:

This study aimed at learning about the experience of people living with chronic illness and long-term treatment. In this report, you will find a summary of the main findings that came up in all the interviews and observation sessions of healthcare appointments. These materials have been rigorously analysed and summarised around five themes that are particularly important for the aims of the research project.

The themes focus on specific aspects of mixed experiences of chronic illness. The themes organise and simplify, to some extent, complex experiences of illness. Although the experiences of some participants were either mostly 'good' or mostly 'bad', chronic illness stories contained moments of hope and confidence, despair and frustration, and growth and learning, among others. This summary tries to respect how contingent life with chronic illness is, and so only by considering all the themes together it is possible to present this complex and far reaching experience.

Theme 1 looks at various ways in which life with chronic illness may lead to significant isolation and loneliness. Finding the right support networks throughout this experience plays a central role in preventing and overcoming these difficulties, so this theme also presents how the chronically ill manage to maintain their social roles or build new ways of belonging.

Theme 2 is about the main difficulties the chronically ill face with their illness and treatment, and the strategies they use to manage it while still living lives they like and enjoy. Finding and keeping this balance requires constant effort for everyone, but the harder someone's life is in general, the harder it will be.

Theme 3 discusses the different meanings and ideas around control while living with chronic illness. It reflects on feelings of vulnerability and dependency, with little to no sense of control over the body, and ways of claiming and regaining control through a new relationship with the body. Self-monitoring, treatment, and healthcare monitoring mediate this relationship.

Theme 4 adds new elements and also a deeper layer of insight into the more intimate aspects of the experience of chronic illness. This perspective helps specify some of the main difficulties of living with chronic illness and reflect on how challenging it can be to follow long-term treatment.

Theme 5 looks into what the chronically ill expect to receive from healthcare services and the value they assign to certain elements of care. It identifies general trends in what characterises better and worse experiences of healthcare across disease groups, providing insight into the relationship between patients and healthcare practitioners specifically in the context of chronic care.

The summary ends with bullet-point lists of what participants thought could improve in the delivery of chronic care and their recommendations to newly diagnosed people.

Group Of Participants:

This study included a total of 27 patient participants diagnosed with at least one chronic condition after the age of 18 years, requiring long-term treatment. Patient participants were invited to join the study through four specialist care units: endocrinology, respiratory medicine, infectious diseases, and gastroenterology. No specific experiences of illness or treatment were targeted.

The group included 14 women and 13 men, with an age average of 46,6 years (from 21 to 65 years). The group was mixed in terms of country of origin including 14 participants from the United Kingdom, and 13 participants from 11 other countries spread across Europe, Oceania, Asia, Africa, and North America (the Caribbean). The group was also mixed in terms of broad qualification classifications, employment, living arrangements, family structures, and area of residency.

The observation of healthcare appointments included a total of 15 healthcare practitioners (mix of consultants, registrars, and specialist nurses) from all specialist care units mentioned.

The researchers thank everyone who made this study possible either by sharing their experience of illness and treatment, their clinical work, or facilitating access to research sites and potential participants.

Theme 1: Sense Of Belonging And Support Networks

Difficulties sharing the experience of illness:

There are many ways in which living with a chronic disease may lead to isolation and loneliness. Sometimes illness itself may limit the possibilities to take part in social activities, such as playing sports or going out with friends. Also, having a chronic disease may lead to rejection or a kind of special attention that makes people feel singled out. The chronically ill described feeling embarrassed about their illness and self-secluding not to be questioned or avoid explaining themselves to others, finding it difficult to break that circle and make new friends or find new social contexts. The chronically ill also described experiencing discrimination and harsh judgement because of illness. Some of those who did not experience discrimination and judgement were still afraid of this possibility. So some chose to keep their diagnosis private to protect themselves, wondering and worrying about what people may think of them or assuming that illness is something negative, which somehow limits their capacity. Others also described having to put the illness aside and pretend they feel better than they do in order to share with friends.

In general, the chronically ill identified as healthy despite their condition, as they only feel sick occasionally and most of the time they feel and look fine. Not looking typically sick even when they may feel ill was thought to contribute to unsupportive reactions, such as friends, family or bosses expecting them to constantly perform well, or not taking their pain or suffering seriously. Furthermore, this unclear state may contribute to the common experience among the chronically ill that people do not, or would not, understand how they feel or how life with illness is like. This lack of understanding was thought to be mainly due to prejudice and ignorance, especially regarding the emotional difficulties of living with a chronic illness. These reactions strongly discouraged the chronically ill to talk about their illness and share their experience other than with healthcare practitioners.

Still, some described having positive experiences when sharing their diagnosis, as people were understanding, did not treat them differently, and were supportive in terms of offering reassurance or adequate help, for example. Those that shared their diagnosis often explained that they did it because illness was a big part of their life and sharing it helped to be well supported by others, among other reasons. Still, some did not always know how to explain it in detail and were careful not to share too much to protect themselves from prejudice.

Different sources of support when living with chronic illness:

The chronically ill specified that support from family members and friends is most appreciated around the time of diagnosis, or during times of illness and increased dependency, but it can also be very valuable for the daily management of disease. Feeling well supported included an emotional element, such as knowing someone was available if needed, and a more practical one, such as having people around who could come with them to hospital, or pick up groceries or medications for them, for example. To some extent this implied sharing the daily responsibilities of leading chronic care with others, making it easier for the chronically ill to rely and depend on others when they needed to. Although they generally described feeling well supported with gratitude and joy, some also described feeling guilty of burdening others, not being able to reciprocate their care.

Feeling well supported by healthcare practitioners was also considered very important and it was described in terms of long-term relationships in which the chronically ill felt known, safe and cared for. Although they mostly referred to their specialist care team, a few also described this kind of support from their general practitioners (GPs) and mental health care professionals. In general, support from healthcare practitioners was seen as proactive, implying being approachable and invested, and covering a broad range of needs going from emotional aspects (such as helping them stay positive) to more concrete aspects (such as providing information and following-up on their care).

Despite a few exceptions, different kinds of patient groups were also described as good sources of support especially around the time of diagnosis, but not only. These were described as being both informative and emotionally or morally supportive. Witnessing the achievements and struggles of others was described as a source of inspiration and hope, which helped them feel understood and less lonely in their struggles. Also, these groups offered the opportunity to put their own experience at the service of helping others. Having a common experience of illness or symptoms was described as a way of feeling close to others and helped in the process of defining a new sense of normalcy, so although chronic illness can significantly limit participation and social engagement, it can also offer the experience of closeness and belonging with others.

Following from this, and although the chronically ill mostly described bad experiences using the Internet for peer support or never being interested in using the Internet to find information or reach out to others, some thought that the Internet was helpful to find peer groups that meet online or in person. Meeting with others online was described as a safe space for sharing their struggles with illness. On the contrary, online forums were described as mostly gossipy, self-indulgent, anecdotal, tending to highlight worst-case-scenarios and, as such, not supportive spaces. Also, the chronically ill specified actively avoiding the Internet as a source of information, as it was not considered trustworthy, and sometimes, even dangerous. The chronically ill specified resorting to specific online sources recommended by healthcare practitioners, but in general, they preferred turning to their healthcare team for information, and trusting their personal experience of illness.

Still, as a final note, the chronically ill highlighted that during periods of isolation due to illness, the Internet can be very valuable as the only way to connect with others.

Theme 2: Finding And Keeping The Balance Between Chronic Illness, Chronic Care, And Life Beyond Illness

Chronic illness and long-term treatment demands:

The chronically ill described that one of the main negative aspects of living with chronic illness was having less energy and/or physical strength to engage in the activities they used to, or needing significant time to recover afterwards. So managing energy and stress was very important for finding and keeping things in balance. Long-term treatment added to this challenge, as the chronically ill described having a particularly hard time enduring certain treatments or medical procedures. In some cases, treatment could be modified or slightly adjusted to avoid these difficulties, but most times, the chronically ill just had to live with this. Negative feelings arising from this difficult aspects of taking treatment were strong enough to cause some people to avoid, skip or delay certain treatments or procedures, either hoping for everything to be fine or dealing with the consequences.

Some treatments were experienced as too demanding and complicated in terms of frequency, taste and size of tablets, for example, but also general coordination of prescriptions and appointments, among others. In such cases, the chronically ill considered that it was difficult to get treatments right and that committing to follow these perfectly would have taken up too much time and energy. The chronically ill also identified side effects and complications associated with treatment or medical procedures as a big barrier for treatment. Some of these were temporary, but others irreversible sometimes affecting life more than the illness itself. In such cases, some people chose not to take the treatment without talking to the healthcare team, fearing they might be judged. Like this, the chronically ill needed to come to the conviction that it was worth living with treatment, and for some, this conviction fluctuated over time. The experience or belief that treatment did not help much or enough was described to directly affect this conviction, in some cases. Still, people experienced significant pressure to adjust to illness and the demands of treatment, feeling that the responsibility for the success of treatment was ultimately on them.

This pressure could become especially challenging and frustrating when or if they felt ill and the chronically ill described feeling guilty, ashamed, and angry, among others, when they were incapable of coping and/or managing treatment. Feeling overwhelmed or tired because of the illness and/or the treatment on top of other emotional issues associated with the experience of chronic disease came up as barriers to complete self-care tasks, but the chronically ill did not think feeling this way was acceptable or understandable so they pushed themselves to do better.

Another main difficulty of long-term treatment was simply remembering to regularly take medication to avoid getting sick. In most cases, people did not experience symptoms, or they became used to the way their body felt, so treatment needed to be visible or at hand, but this might not always be desirable. In general, living with a chronic illness implied significant extra planning in daily life, reducing spontaneity and flexibility in daily life, and also including out-of-pocket expenses or financial worries in some cases.

The chronically ill agreed upon the sentiment that their care needed to be prioritised, and their daily lives (work, holidays, child care, etc.) had to be organised around it. Therefore, lacking work flexibility meant that something had got to give. The chronically ill described not being able to continue working or having to undermine their care by skipping appointments, for example, to keep their jobs. Although work flexibility and/or supportive employers was considered very important for chronic care, other pressing life demands also needed to be prioritised over treatment at times. When life got too hard, some did not feel capable of keeping up with the discipline demanded by long-term treatment and felt like they need to take a break from it.

Finding a comfortable balance between life, chronic illness and chronic care:

Despite all these difficulties, the chronically ill found ways to keep their lives from changing too much, and keep enjoying life as they did before becoming ill. Some of the main strategies that helped them achieve this were taking time to learn and get used the illness, allowing extra time to complete activities, being more flexible in general, and finding the right support. But this was not always a stable achievement and, as mentioned before, if for any reason life got harder, the illness sometimes also became harder.

When living with chronic illness, the boundaries between the self and the illness sometimes became blurry. So the chronically ill stressed that to live lives they could enjoy, the illness should not take over all aspects of life. Making an active effort to avoid negative ideas about life with chronic illness, focusing instead on the positive things in life and trying their best to make things work, were described as crucial. But such active effort can take up significant energy that was not always available. Furthermore, taking on this attitude was harder for some than others because of the severity or disruptiveness of illness, among other things.

Coming to terms with illness implied accepting side effects, appreciating not having had any complications or side effects, having hope in treatment, or thinking that their situation could be worse. Feeling privileged for having good access to healthcare or good support from family and/or friends, was also described to help sustaining this positive attitude about their situation. Furthermore, experiencing treatment as not very demanding or better than the alternative, significantly helped following treatment and enduring the hard aspects of it. Yet, some found their treatment easy to follow and still needed or wanted to either take breaks from it or only partially follow recommendations.

Identifying benefits from treatment also helped following it, even if these were long-term effects or not so evident. Sometimes having trust in healthcare practitioners and/or in medicine was enough, but knowing how the treatment worked and the consequences of not taking it was a positive reinforcement to keep a positive attitude and follow treatment. Still, it is important to note that healthcare practitioners and patients did not always agree on how to prioritise different needs and goals.

Following from this, it was particularly important for the chronically ill to have a certain degree of choice regarding treatment, so they felt they could deal with their illness in their terms and consider what they are willing to do. This included declining or delaying specific interventions because of side effects, or accommodating treatment not to change their lifestyle, for example, which heavily depended on having a healthcare team that took their priorities into account.

The chronically ill also identified practical aids that helped them reduce the burden of the logistics of care, such as having well functioning online platforms to request repeat prescriptions and booking appointments, setting alarms and reminders in their phones, using plastic boxes to organise weekly medication, among others.

Theme 3: Taking Chronic Diseases To Be Controllable Diseases Seems A Matter Of Perspective

Vulnerability, dependency, and self-monitoring:

A central aspect of the experience of living with chronic illness was increased awareness about the body. The chronically ill described being more conscious, or even over vigilant, of their bodies and health risks in general. In many cases, people needed to check in with the body to manage their illness (take medication, eat, rest, make an appointment, etc.) and prevent the disease from getting worse. Sometimes these bodily signs were easy to identify, but sometimes these were hard to distinguish from similar signs unrelated to the disease, increasing the anxious around illness. This anxiety included worrying about the illness getting worse or acting up while there was nothing they could do to prevent it. The chronically ill also thought they were more vulnerable to get and/or overcome other conditions, feeling scared and tending to be more careful, trying to prevent diseases and be as healthy as possible.

The chronically ill mostly described the experience of lack or little control over their illness. Some described how even when they did everything in their power to control it, symptoms did not improve, flare-ups and recovery were mostly unpredictable, and self-care, in general, was very sensitive to context and difficult to predict. So especially over periods of illness, living with chronic disease implied feeling significantly vulnerable and/or dependant.

Having a chronic disease made planning difficult, as the chronically ill described depending on how the disease was doing to decide whether they could or could not do something. Most of the times, and especially those who could not notice the effect of treatment, felt there was not much they could do to make things better, sometimes doubting whether taking treatment made a difference at all. Still, generally, they experienced some degree of control through treatment. Although this was reassuring, it also meant feeling vulnerable in terms of depending on the availability of effective treatments to stay alive or to live a life less disrupted by illness. Like this, contextual aspects such as Brexit, NHS funding, and the social care system came up as underlying worries.

Information and healthcare monitoring:

Information was very important to regain or re-establish some sense of control, not only over the disease but also over life more broadly. This included knowing what to expect, anticipating how the illness might be in the future, getting peace of mind, and feeling they could adjust and manage both life and the illness, among others. The chronically ill highlighted the value of scientific or official information about disease and treatment, and also the value of their previous bodily experience combined with tests results, for example. Previous personal experience of illness and how treatment recommendations worked in the past could overrule, in some cases, specific recommendations from healthcare practitioners.

A particularly important source of information was the continuous monitoring of the body by healthcare practitioners. Life with chronic illness implied having regular tests and appointments, which mostly provided information for healthcare practitioners. Sometimes healthcare practitioners could act on this information suggesting treatment changes or adjustments, but this monitoring mostly focused on making sure the treatment was working well, and no complications or undesired effects of treatment needed to be addressed. On extreme cases, such increased monitoring implied healthcare practitioners communicated directly with the bodies of the chronically ill, through its performance on tests, without taking into account the experience of the chronically ill. This could be particularly problematic because, as mentioned before, healthcare practitioners and patients did not always have the same priorities, and recommendations that only focused on helping the condition or the body could go beyond what the chronically ill were willing to do for their health.

Still, regular tests, appointments, and recommendations were mostly described as reassuring and, in some cases, considered and an important aspect of good quality care, so chronic care was described as having to be flexible in the sense that sometimes the chronically ill needed this reassurance, being more dependant on healthcare practitioners, and other times, they needed to have a more active and independent role in their care. Only a few described having the autonomy to make treatment decisions, feeling that they had a reasonable, or a significant amount, of control over their illness. Such autonomy and control meant knowing enough or feeling confident enough to introduce treatment changes to help manage symptoms or flare-ups, preventing things from getting worse.

Healthcare monitoring also provided information about unrelated health issues that might not have been caught otherwise, so the chronically ill stated getting more and facilitated access to healthcare. They also described increased confidence regarding their overall health precisely because of increased risk and fragile underlying state that needed constant monitoring. Chronic diseases were mostly described by the chronically ill as uncontrollable diseases in the sense of being unpredictable and rather independent from their efforts. Some actively compensated for the lack of control over the disease by increasing their control over other aspects of life, or by living as if they had a greater impact on their illness or treatment than they did. A few specifically stated feeling safer, more confident and less vulnerable when they could have some control over the disease, or when the disease was quieter.

Theme 4: The Place Of Chronic Disease And Long-Term Treatment In The Self

The boundaries between chronic disease and identity:

The chronically ill mostly gave self-descriptions that did not make reference to their diagnosis. Having a strong sense of professional achievements, or positive and strong family lives seemed to help support and keep a strong sense of self or identity that was not taken over by ill health. Many also described themselves proudly as hard workers, fighters, strong, self-made, and overcoming difficulties, which might have been a strength for adjusting to the difficulties of a life with illness, and/or a result of such life.

Still, some did include their diagnosis in their self-descriptions. A few of them described how the illness temporarily affected their sense of self, but others described how it irreversibly changed their lives by taking away central elements of their identity and becoming a significant limitation to live lives they could enjoy. Those within this group did not have strong support networks. Who people are seemed to be strongly based on what people did, so the degree to which and how chronic illness changed what a person could do, also affected a person’s sense of self. Although sense of self depends on many variables, this research identified links between strong and varied identity anchor points (such as work, family, friends, or recreational activities) and support networks, as particularly helpful to keep the illness from taking over one’s life.

Ideas about chronic disease:

The chronically ill described the experience of lack of certainty or clarity regarding what may have caused their disease. They often described a mix of variables (such as hereditary or mutations, air pollution, or diet and stress) involved in developing the condition. In most cases, these reflections underlined lifestyle as a common risk factor for chronic diseases, but no intension of self-harm.

Still, the chronically ill tried to find something in their biographies that could help them make sense of why they may have developed the disease. Only a few simply took it to be the “luck of the draw”, adding that there is no point in worrying about why, as there is nothing they could do about it. Trying to find ties to individual biographies might simply be a way of making chronic illness more personal, by telling a story in which illness makes sense, at least to some extent, and finding some comfort in it not being completely random and unfair. Yet, this could also reflect the idea that health and disease are something people can provoke and should prevent.

The chronically ill considered that individuals have responsibility for their health and a few of them blamed themselves for it, at least to some extent. More generally, and although blame for illness was seen as complicated, some described how not being able to assign blame could be frustrating and pushed people to blame something or someone while knowing this probably was not true. Others blamed themselves for not taking better care of their health and preventing the disease or its progression. Interestingly, responsibility and blame mostly mattered when chronic illness became a problem.

How the chronically ill described their illnesses showed that everyone relates to illness in a very personal way, but having a general and shared idea of how each disease worked was important to know what to expect and for explaining it to others. They also reflected around life-threatening diseases being different from chronic diseases mostly because of treatment, but also because of how illnesses were presented and experienced. Many described thinking about dying when they were first diagnosed, despite being told that their disease was chronic and manageable. This initial feeling of vulnerability and acute awareness of bodily limits was progressively integrated as the chronically ill found ways of normalising this experience and death was described as a certain, but mostly absent idea. Still, for a couple, death was so strongly introduced in their lives that they described living with a sense of imminent death and confusion about what to do with their lives. Others did not experience this initial fear of dying at all, while still knowing that their illness could develop potentially deadly complications.

The chronically ill thought about being young and healthy as opposed to being chronically ill, although many of them were young and regarded themselves as mostly healthy. Closely linked to this, doing physical activity was considered important, and a few described it as a way of fighting illness or not giving in to it, preventing future illness or further weakening, or being strong, among others. Like this, and although physical activity may simply be something people enjoyed doing without any further meaning, it could also, in some cases, have helped compensate the feeling of vulnerability associated with chronic diseases.

The chronically ill knew that at present (and for the foreseeable future) there was no cure for their conditions. The main feelings arising from this were uncertainty and worry about what will happen, anticipating that their illness would probably only get worse. So, many described feeling scared about the future specifically because of their illness. Uncertainty around financial security emerged as a key worry, with some taking steps to increase it at a time in life where they said they would not otherwise have, or experiencing significant levels of stress and anxiety as they thought they might be incapable of taking good care of themselves in the future, not trusting that the state would support them well as they got older.

Chronic disease diagnoses were also described to either introduce an actual barrier to have children, or uncertainties about this possibility. Some also described facing the question of whether they wanted to take the risk of somehow passing on the disease to their children. Yet, only some considered that their illness significantly affected their plans and felt significantly discouraged about the future in general, while many described that their outlook on the future had not been affected and they expected to continue developing all their personal and professional aspirations. Still, this was conditioned to the frequency and seriousness of the flare-ups not worsening. Despite all this, the chronically ill mostly described having a hopeful outlook on the future, adding to the positive attitude towards life with illness and treatment described before.

Chronic diseases as present even in the absence of symptoms:

The chronically ill described illness manifestations or symptoms following irregular and mostly unpredictable patterns of days, weeks, months, or years. Still, some specified having identified triggers that made symptoms more predictable. For those for which symptoms were mostly irregular and unpredictable, chronic diseases were experienced as rather random, but for those for which the frequency was predictable to some degree, these were regarded as rather cyclical. This varied both between and within disease groups showing how, on different levels, experiences of chronic diseases were personal, and also relatable beyond specific diagnoses.

Although for a few the illness was always present through symptoms, they mostly described how, to a greater or lesser degree, living with a chronic disease meant having the disease constantly present or at the back of their mind. This was described to shape their actions even if not in very meaningful ways, and even when symptoms were not present. Some considered that the process of getting their heads around the idea that the illness was never going to go away was a central aspect of their experience, as the frequency of symptoms varied significantly, to the extreme of some never having experienced any.

The degree to which this affected people varied both between and within diagnoses, but chronic diseases seemed to be a bit confusing as they were always present, to a greater or lesser degree, while absent in the sense of it not presenting any symptoms or signs. Following from this, the chronically ill described how emotionally demanding it could be to keep in mind that symptoms would pass or improve when they were feeling ill, as well as remembering that symptoms would come back when they were feeling fine, better. Many described not following treatment or doing things they knew could have bad consequences for their health, when they were feeling well, adding that the illness was somehow not present or out of their heads. Like this, the chronically ill discussed going through periods of non-adherence to long-term treatment, having had difficulties to follow treatment regularly, or choosing to use the treatment for symptomatic relief. The main reason for not persistently following treatment was that when feeling better they assumed they were better and did not need the treatment anymore. Chronic care demanded that chronic diseases were present in daily life even in the absence of symptoms, which, as already mentioned, might not always be desirable.

Theme 5: Chronic Care And The Healthcare Practitioner-Patient Relationship

Getting a chronic disease diagnosis:

Although in some cases first symptoms and diagnosis happened roughly at the same time, the chronically ill mostly described a subtle onset of chronic disease that could last a couple of months or years, taking up to 10 years or more in a few cases. Some common descriptions of initial symptoms included inexplicable tiredness or fatigue, low energy, losing or gaining weight, headaches, and a general feeling that something was not quite right with their body. Some described a period of normalisation of these manifestations, which sometimes contributed to delays in diagnosis as people waited to seek medical help. In other cases, healthcare practitioners being dismissive delayed the diagnosis, so there seemed to be a significant difference between the experience of living with symptoms that were difficult to recognise, and the experience of having identified that something was wrong and struggling to reach a diagnosis, despite all efforts.

Following diagnosis, the chronically ill described experiencing a moment of shock. This was described in terms of having difficulty understanding what the diagnosis meant and absorbing the information healthcare practitioners gave them, not knowing how to act and thinking it must be a mistake, among others. Although this initial state of shock passed, they described needing some time (weeks, months or years) to get their heads around it. Yet, for some of those who had been feeling ill for a long time, the diagnosis came as a big relief mainly because they thought it could orient a treatment that would help them feel better, but this was not always the case.

Relationship with healthcare practitioners and teams:

What the chronically ill valued:

The chronically ill highlighted the importance of healthcare practitioners having expertise, knowledge and a positive attitude, including being polite, caring, understanding, friendly, confident, straightforward, and being able to show that they care for them in particular. Furthermore, the chronically ill valued healthcare practitioners offering or facilitating opportunities for counselling or psychotherapy as living with a chronic disease was described by some as frustrating, developing negative feelings towards being ill and mental health issues such as anxiety and depression.

During the appointments observed, healthcare practitioners dedicated a considerable amount of time finding ways to reach out to the chronically ill by asking them open questions and also personal questions, inviting the chronically ill to share aspects of their lives beyond the illness. Another common way for healthcare practitioners to connect with the chronically ill was turning the computer screen towards the participant, facilitating understanding and discussion. Healthcare practitioners also frequently used humour during the consultations, managing to have friendly and relaxed encounters, helping especially those who felt anxious or worried during the appointments. A few healthcare practitioners also gave positive feedback to the chronically ill highlighting their progress or celebrating some aspect of their management and/or attitude, for example.

The chronically ill described a ‘good relationship’ as one in which they felt listened to, comfortable, safe, understood and reassured, trusting that their healthcare team is available if needed, and focused on finding ways of making things better instead of pointing blame. Also, when healthcare practitioners and teams had a positive attitude this motivated the chronically ill to adopt a similar way and build a relationship of collaboration. A good relationship was also described to allow for discussion over treatment approaches and goals. Feeling that communication is fluent and easy was very important to achieve this, and this, in turn, was facilitated by continuity in the relationship with a known healthcare practitioner. Such continuous relationship was also considered central to have a useful and complex appointment in 10 or 15 minutes, which was considered very hard to achieve otherwise.

The chronically ill experienced significant variability between different NHS hospitals and healthcare practitioners within a care unit. So having a continuous relationship with healthcare practitioners also helped towards consistent standards of care and treatment approaches. Chronic care was described as dynamic even after many years of treatment, demanding a relationship in which both the healthcare practitioner and the patient have to uphold their end of the agreement or update it as required for the treatment to succeed. Furthermore, it could be especially difficult to anticipate and manage flare-ups or complications, so the chronically ill stressed the importance of having a responsive healthcare team. This made them feel validated in their needs and more in control when the disease spun out of control. Still, the quieter the disease was, the more willing the chronically ill were to see other healthcare practitioners. But if the disease was perceived as out of control, then seeing a known and trusted healthcare practitioner was very important.

What the chronically ill found unhelpful:

The most problematic features highlighted by the chronically ill were lack of empathy and lack of emotional investment in the relationship on the part of healthcare practitioners. This included being uninterested and arrogant, being unwelcoming, not taking patients seriously by failing to consider their worries or questions, and making unilateral decisions about their care.

During the appointments observed some of these issues came up as healthcare practitioners were mostly focused on completing administrative tasks on the computer. In these appointments there was little eye contact, communication was not very fluent, and healthcare practitioners were not particularly receptive. Taking into account that completing administrative tasks was an important and unavoidable aspect of healthcare appointments, there could still be more or less of a discussion and healthcare practitioners could pay more or less attention to what was relevant for patients.

The chronically ill felt they were not being taken seriously when healthcare practitioners were unclear about relevant information about the illness and/or the treatment, skipped explanations or took things for granted. Some described feeling confused after these appointments, especially regarding what to expect in the future. This could be particularly important for treatment since, as mentioned before, knowledge helped the chronically ill feel more in control and complete self-care tasks.

Some described having no relationship with their specialist healthcare team. This was not a problem for those who did not need or expect much from appointments, but for others, this was particularly frustrating and discouraging. The main reasons for this were feeling that no one was leading their care and that they lacked continuity and consistency in their care, so appointments were not very valuable. Seeing doctors who did not know them or their illness trajectory, and seeing transient younger doctors in training added on to these feelings and made collaboration more difficult. Still, a few stressed that trusting the specialist team more broadly could compensate for this lack of continuity. This highlighted the importance of having someone overseeing and, at least to some extent, integrating their care.

Regarding GP care, the main issues described were the lack of accessibility and responsiveness, as GP appointments were considered hard to get and did not address their worries. Some described that GPs were not up to date or very cooperative with their specialist treatment and chronic care needs. In such cases the chronically ill described little gain from seeing a GP, trying to avoid it and centralising their care at the specialist level instead.

Summing Up:

What Did The Chronically Ill Think Could Improve In The Delivery Of Chronic Care?

1.- Better communication and coordination between levels of care:

The chronically ill mainly focused on the increased burden associated with organising and managing their chronic care. This mostly referred to the poor coordination between GPs, specialist services, and other health services suppliers, which demanded that they had to fill in the gaps. This was described as a heavy mental load, also significantly time-consuming.

2.- Valuing time. Prioritising appointments, respecting bookings and simplifying rescheduling:

Some described HCPs had very little time to see them properly, suggesting that this could be alleviated if 'well-chronically ill check-ups' did not take up face-to-face appointments, for example. Others particularly resented the system cancelling and randomly rescheduling their appointments as this was experienced as inconsiderate with how demanding or tight it can already be to juggle life and chronic care demands, including travelling expenses in some cases. An overly bureaucratic system that made regular tasks, such as rebooking appointments, unnecessarily difficult for them was also added to this mental load.

3.- Pay more attention to social and psychological variables:

Some thought that chronic care should include social and psychological variables more. More specifically, they stressed that the mental and psychological impact of chronic disease is often ignored in medical care and that having the tools to manage anger, anxiety, depression, low self-esteem, and relational difficulties arising from the experience of chronic illness could be helpful. Feeling good about themselves and their illness was described as a motivation to complete self-care activities, and improve their overall wellbeing.

What Was The Message From The Chronically Ill To Newly Diagnosed People?

1.- Chronic disease is not the end of the world:

Many would start by reassuring the newly diagnosed saying that the illness is manageable, so they should not panic or worry too much about it. They should focus on finding a new way of living with the illness while trying to keep life as normal as possible.

2.- It will be hard, but follow treatment recommendations:

Many would also highlight the importance of following treatment and the recommendations of healthcare practitioners, being patient and trusting that, even if not immediately, the treatment would eventually help. Still, as it could be too hard or even impossible to follow treatment perfectly, some thought it was okay to simply try the best they can.

3.- Turn to family, friends, or healthcare practitioners:

Some gave particular importance to reaching out to people, not ignoring their illness and their emotional needs, and asking for help if they need it. If friends and family cannot offer good support, then people should find support in their healthcare team. The Internet was considered a good source of support if other support is not available.

4.- Take the lead. Learn about the condition and the treatment:

Some would encourage people to lead their care and take responsibility for it by learning as much as possible about the illness and treatment. People should start making adjustments slowly, let the healthcare team know what works for them, and push for the NHS to deliver good treatment.

5.- Do not beat yourself up and take care of your mental health:

Some would stress the importance of people not blaming oneself and take the illness to be something that goes beyond our control. People should focus on being kind to themselves and make sure to take care of their mental health as well as their physical health.