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Mara Pieri

CHRONIQUEERS.
TIME, CARE AND VISIBILITY IN NARRATIVES FROM QUEER PEOPLE WITH A CHRONIC ILLNESS

Thesis in Human Rights in Contemporary Societies under the supervision of Bruno Sena Martins (PhD) and Elia AG Arfini (PhD) submitted to the Institute for Interdisciplinary Research of the University of Coimbra.

October 2020

Institute for Interdisciplinary Research

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I was often told that the PhD process is very solitary: however, even when I spent much time by myself agonising over words, I felt supported by many people who contributed to this journey in unique ways. It is now both exciting and intimidating to have the space to acknowledge all of them, since I know words will express only partially the gratitude I feel.

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Abstract

This thesis analyses narratives of young LGBTQ+ adults with a chronic illness. The research is based on 24 narrative interviews conducted in Portugal and Italy between 2016 and 2019.

First, the research aims to explore to what extent the experiences of chronic illness and the self-identification as LGBTQ+ interplay with multiple forms of oppression. Referring to the theoretical framework of crip studies and queer studies, it scrutinises how heteronormativity and able-bodiedness (re)produce norms that affect the perception of bodies both in the private and in the public space. Secondly, the research investigates whether the combination of chronic illness and LGBTQ+ identification in the context of Southern Europe reveals anti-normative (re)productive subjects and a different understanding of human rights from an intersectional lens. Finally, it aims at understanding which practices of time, care, and visibility are put in place to deal with the pressures of heteronormativity and able-bodiedness. Taking intersectionality as a reference, it interrogates what other multiple belongings interfere in the experiences of interviewees, such as class, gender, cultural capital, and education. Moreover, through the analysis of personal narratives, it analyses how interviewees make sense of their identity and to what extent practices of resistance correspond to political claims in this sense.

The research contributes to queer studies, the sociology of health and illness and critical studies of human rights by highlighting the intersections of heteronormativity and able-bodiedness and proposing a queer-crip understanding of time, visibility, and care.

The thesis is divided into three sections. The first (chapters 1 and 2) lays the theoretical foundations through a discussion of the existent literature in the sociology of health and illness around chronic illness and the theoretical shift provided by crip studies; it also analyses the contributions of queer theories on identity and time. The second part (chapters 3 and 4) describes the socio-political features of the Italian and Portuguese contexts concerning LGBTQ+ rights and healthcare. It also outlines the methodology chosen and the challenges encountered during fieldwork. The third part (chapters 5, 6, and 7) provides the analysis of the data through a closer look to three main macro-themes: intimacy and the construction of a significant relationship; the negotiation of care, both in informal and formal networks; the relation with the public space, in particular with work and activism. The dimensions of analysis regarding time, care, and visibility are transversal to all the empirical chapters.

The thesis finally discusses the possibility to consider a political subjectivity named "chroniqueer" that epitomises the LGBTQ+ experience of chronic illness as transformative of conceptions of time, care, and visibility, and, ultimately, of practices of human rights.

Keywords: illness, sexuality, LGBT, care, human rights

Resumo

Esta dissertação analisa narrativas de jovens adultos LGBTQ+ com doença crónica. A pesquisa assenta em 24 entrevistas narrativas realizadas em Portugal e Itália entre 2016 e 2019.

Em primeiro lugar, este trabalho visa explorar em que medida as vivências da doença crónica e da identificação enquanto LGBTQ+ interagem com múltiplas formas de opressão. Referindo-se aos estudos crip e aos estudos queer, a tese examina o modo como a heteronormatividade e o capacitismo (re)produzem normas que afetam a percepção dos corpos, tanto no espaço privado quanto no público. Em segundo lugar, a pesquisa interroga se a conjugação de doença crónica e identificação LGBTQ+ no contexto do Sul da Europa é reveladora de sujeitos anti-normativos (re)produtivos e um entendimento diferente acerca dos direitos humanos a partir de uma lente interseccional. Por fim, visa compreender quais práticas de tempo, cuidado e visibilidade que são postas em prática para lidar com as pressões da heteronormatividade e do capacitismo. Tomando como referência a interseccionalidade, interroga-se sobre que outros múltiplos fatores interferem nas vivências das pessoas entrevistadas, tais como classe, género, capital cultural e nível educacional. Além disso, através da análise de narrativas pessoais, analisa como os/as entrevistados/as fazem sentido da sua identidade e em que medida as práticas de resistência correspondem a reivindicações políticas.

Em suma, do ponto de vista teórico, a pesquisa convoca principalmente os estudos queer, a sociologia da saúde e da doença e os estudos críticos dos direitos humanos, sublinhando as intersecções entre heteronormatividade e capacitismo, e propondo uma compreensão queer-crip sobre tempo, visibilidade e cuidado.

A tese está dividida em três secções. A primeira (capítulos 1 e 2) estabelece as bases teóricas através de uma discussão da literatura existente na sociologia da saúde e da doença em torno das doenças crónicas, refletindo ainda sobre mudança teórica decorrente dos estudos crip. Esta primeira parte analisa também os contributos provenientes das teorias queer sobre identidade e tempo. A segunda parte (capítulos 3 e 4) começa por descrever as características sociopolíticas dos contextos italiano e português em relação aos direitos LGBTQ+ e aos cuidados de saúde, precisando ainda a metodologia escolhida e refletindo acerca dos desafios encontrados durante o trabalho de campo. A terceira parte (capítulos 5, 6 e 7) analisa os dados empíricos através de um olhar atento a três temas principais: a intimidade e a construção de relacionamentos significativos; a negociação do cuidado, tanto nas redes informais quanto nas formais; a relação com o espaço público, em particular com o trabalho e o ativismo. As dimensões de análise que incidem sobre tempo, cuidado e visibilidade serão transversais a todos os capítulos empíricos.

A tese, por fim, discute a possibilidade de considerar uma subjetividade política denominada "croniqueer" que sintetiza a experiência LGBTQ+ da doença crónica como transformadora das conceções de tempo, cuidado e visibilidade e, em última instância, das práticas de direitos humanos.

Palavras-chave: doença, sexualidade, LGBT, cuidado, direitos humanos

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INTRODUCTION

> Each of us is an atlas of sorts, already knowing how to navigate some portion of the world containing innumerable versions of place as experience and desire and fear, as route and landmark and memory.
> (Rebecca Solnit, 2018)

Hic sunt dracones?

Since I started this investigation, I was asked countless times why it is about chronic illness and LGBTQ+ lives. I often met interrogating faces and dubious eyes: the curiosity and the puzzlement generated made me understand that the link between the two experiences is not immediately self-evident. Looking for metaphors to explain what I was doing, I would often think about the images of old maps. In the cartographic attempts made in Western countries in the medieval times, cartographers would populate all unknown territories with monsters, dragons, and bizarre animals. They would identify such creatures with the expression *hic sunt dracones*, here be dragons, or *hic sunt leones*, hic sunt lions. The uncharted territory was at the same time known and unknown: its existence was known but its contours had not yet been explored (by them).

This dissertation is about the exploration of an uncharted territory: it aims to analyse the narratives of young LGBTQ+[1] adults with a chronic illness living in Italy and Portugal. My interest in the topic sparked through different diluted moments that preceded the PhD. As a chronically ill person, I often noticed how chronic illness is *per se* an experience that would challenge ideas of able-bodiedness and vulnerability. During these years, I came to know several people who self-identified as LGBTQ+ and had a chronic illness: we would often end up sharing views that identified connections and unseen links between two experiences of (in)visibility and struggle. I became eager to find a reflection of

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[1] Lesbian, Gay, Bisexual, Transexual, Queer and every other sexual orientation and gender identification and expression which fall outside the cisgender and heterosexual alignment.

these hints in academic literature: when I realised there was not so much about the topic, I felt compelled to investigate it. Emma Willard, feminist and geographer, stated: “This is not so much a subject which I choose, as one which chooses me. It comes unbidden to my mind, and like an intrusive guest, there it will abide, and irresistibly claim my attention” (in Popova, 2018: 143). It is probably not by chance that Willard was also a professional mapmaker that attempted to design maps in which time and space would conflate. In her words I see how the subject of my work progressively chose me, claiming my attention and stimulating my interest.

The research is based on 24 narrative interviews (Poggio, 2004) conducted in Portugal and Italy between 2016 and 2019. Participants are aged between 24 and 40 years old. They all self-identify within the LGBTQ+ spectrum and have one or more chronic illnesses. Moreover, it benefits from contributions from activists and experts encountered during fieldwork.

The objectives of the research are mainly three. In the first place, it aims to explore to what extent the experience of chronic illness and the self-identification as LGBTQ+ interplay in the experience of multiple oppressions. Referring to the theoretical framework of crip studies (Mc Ruer, 2006; Kafer, 2013) and queer studies (Butler, 1993; Halberstam, 2011), I am interested in the ways heteronormativity and able-bodiedness (re)produce norms that affect the ways bodies are perceived.

In the second place, the research points out to the language of human rights to decode how multiple oppressions lead the way to unexpected forms of resistance in the everyday practices. Despite stark differences in the frameworks of rights, in Italy and Portugal LGBTQ+ people still suffer from discrimination, institutional homophobia, and everyday episodes of harassment. Similarly, for those with a chronic illness, access to healthcare, stable jobs, and autonomous lives are often impeded by loose ends in the legislative understanding of chronic illness. The dissertation addresses the experiences of interviewees concerning their access to rights. However, it is also directed at understanding to what extent discrimination, exclusion, and violence give rise to practices of resistance that can suggest a different understanding of the grammar of human rights (Santos *et al.*, 2019). The research thus corroborates whether the conjunction of chronic illness and LGBTQ+ identification, in the context of Southern Europe, provides experiences for the formation of anti-normative (re)productive subjects and, as a consequence, a different understanding of human rights from an intersectional lens.

Finally, the research aims at understanding which practices of time, care, and visibility are put in place to deal with the pressures of heteronormativity and able-bodiedness. Taking intersectionality as a reference (Crenshaw, 1991), it interrogates what other multiple belongings interfere in the experiences of interviewees, such as class, gender, cultural capital, education. Moreover, through the analysis of personal narratives, it analyses how interviewees make sense of their identity and to what extent practices of resistance correspond to political claims in this sense.

The research contributes to a double knowledge gap: in queer studies, where studies on intersections between LGBTQ+ lives and chronic illness are scarce (if we exclude studies on HIV amongst gay men); and in the sociology of health and illness, where sexuality in general and, more specifically, the voices of LGBTQ+ communities rarely emerge as relevant. To a broad extent, the contribution here constructed often refers to critical and feminist disability studies about able-bodiedness, accessibility, and critiques to bodily normalcy.

The analyses makes space for the emergence of silenced and largely unknown experiences, especially in the context of Southern Europe. Both LGBTQ+ identifications and chronic illness are related to multiple forms of social and physical pain (Gonzalez-Polledo & Tarr, 2018). Multiple suffering condemns to a state of wordlessness, to which this work tries to respond following the provoking question by Audre Lorde: “What are the words you do not yet have?” (1980: 11). The narratives analysed compose a collective picture made of intersections and vulnerabilities emerging from a similar *milieu* of heteronormativity and able-bodiedness. They offer a glimpse of what it means to live as LGBTQ+ with a chronic illness in Southern Europe today and thus contribute to expand our notions of (in)visibility, suffering, and human rights.

The choice of operating the fieldwork in Southern Europe was encouraged by the close connection I have with both countries. I grew up in Italy but moved to Portugal at the beginning of the PhD. Whilst conducting bibliographical research and PhD activities in English, I learned Portuguese: at the beginning of the fieldwork I had reached a level of fluency in the language that provided me the necessary basis to listen to participants' stories. The multiple levels of language has been at play in every phase of this dissertation: whilst listening to the narratives in their original language offered a deep contact with participants, writing the thesis in English often required to “love words, agonize over sentences” (Sontag *et al.*, 2007: 166). This thesis is the result of translations that reflect the interdisciplinary and intersectional theoretical approach employed. For example, despite initially considering this option, I prefer not to use “queer” as an umbrella term, as sometimes is used in English-speaking countries. In Southern Europe, queer as an all-encompassing term is not well-known nor always recognised in movements (Pustianaz, 2011; Santos, 2013). To make this work more readable in the first place to the participants to the study and to the local contexts it relates to, I chose to adopt the general “LGBTQ+”. Given that these definitions are always contextual in time and place, I am aware of their possible misalignment with rapidly changing scenarios.

The relation with two countries, three languages and two socio-political environments is thus defining of this thesis. The research is not comparative to the extent that it does not try to offer a specular perspective of one country through isomorphic comparison to the other. On the contrary, it aims at showing the resonances and the common elements, as well as the specificities and the differences of each. Southern Europe works as a hermeneutic device (Santos & Trujillo, 2014) that provides bearings to read the narratives of the interviewees. The framework of human rights, the social pressures, the cultural history at the macro level constitute the context in which the micro-politics of intimacy and vulnerability are enacted by LGBTQ+ chronically ill participants.

Time, care, visibility

The research questions revolve around three transversal lines of inquiry: time, care, and visibility.

The first, time, is fundamental to understand the very concept of adulthood in contemporary Europe. Adults are expected to be autonomous; to provide for themselves and be successful at what they do; to create a family through monogamous coupledom; to reproduce through linear bonds of blood. These expectations obey to a linear conception of time deeply impinged into neoliberal, heteronormative, and ableist patterns. Being LGBTQ+ and chronically ill may represent a potential short-circuit into such linearity. On one side, chronic illness is intimately characterised by a tight bound with temporality: not only it has an endless duration but it also disrupts the everyday time into recursive cycles of peaks and inactivity. Such a combination of long-term and short-term temporalities changes the ability to be autonomous, to work, and to establish relationships. It often implies the necessity to rely on economic assistance and networks of care; moreover, it jeopardise access to (re)production rights. On the other side, LGBTQ+ people often build relationships that fall outside the supposed linearity of normalcy: in many countries, such relationships are not even recognised by the system of rights and parenting is denied, as in the case of Italy. The processes of forming the so-called “rainbow families” are slowed down by laws, but also by discrimination and invisibility. Queer temporalities are thus rooted in different rhythms that often escape the linear normative ones. Therefore, time is a crucial lens to understand notions of social expectations, success, reproduction choices, and productivity. How do chronic illness and LGBTQ+ identifications change the relation to time? How do they influence the trajectories of partnering and choices on reproduction? What are the consequences on working experiences, productivity, and economic precariousness? How strongly are normative expectations on family and work felt in the context of Southern Europe? Are LGBTQ+ and chronic illness experiences that cast subjectivities *out of time* or do they contribute to the formations of new temporalities?

The second line of inquiry is care. Expanding the feminist notion of care as relational (Tronto, 1994), care is here intended as the formal and informal relations that provide support to LGBTQ+ and chronically ill people. Chronic illness demands a constant, often long-term, relation with the health system: medical doctors, nurses, personal assistants, therapists, amongst others. The relations with the healthcare systems are mediated by cultural meanings ascribed to illness and identity: in these relations, for example, being visible as LGBTQ+ may hinder the treatment received as a patient. What relations do LGBTQ+ and chronically ill people establish with healthcare? How is the experience of chronic illness mediated by homo-transphobia in healthcare? To what extent is the formal healthcare prepared to understand the needs of LGBTQ+ and chronically ill adults? What are the other forms of care available to them? Besides formal healthcare, chronic illness requires networks of interdependency for emotional, economic, and practical support. Literature shows that the centrality of families of origin in providing care in Southern Europe resists other social changes and is reinforced by the configuration of the welfare state (Calzada & Brooks, 2013). In LGBTQ+ activism, care is often celebrated as a way to escape the dominant patterns of family and parenthood (Vaittinen, 2015): examples of other forms of care include cohabitations with friends, informal economies, and shared parenthood. The research addresses what kind of networks of care are significant for those who live as LGBTQ+ with a chronic illness. How is support provided, what are the significant persons that effectively take and receive care? What are the challenges in defining such relationships of care? Which unexpected alliances emerge and which are confirmed in their centrality? What is the role of families of origin and partners in these configurations?

The third line of inquiry is visibility, as inherently associated with invisibility. Chronic illnesses are mostly characterised by invisible symptoms and imply strategies of management of visibility, as well as choices on passing as able-bodied according to the context (Samuels, 2003; Wong, 2020). Similarly, coming out and (in)visibility are a common experience for LGBTQ+ people. Whilst visibility is often used in campaigns of awareness to promote the importance of being *out and proud*, invisibility represents a viable strategy to protect LGBTQ+ people in unsafe contexts. Both visibility and invisibility are thus discussed as performative and contextual strategies determined by a vast array of cultural, social, and emotional factors. How are these strategies managed? How does chronic illness contribute to the (in)visibility of LGBTQ+ positionings? How does LGBTQ+ identifications change the strategies of (in)visibility as chronically ill? To what extent is (in)visibility perceived as a political act? What is the role of social and physical pain in the sense of safety and in the choices of coming out?

Time, care, and visibility constitute a red tape throughout the research. They are so inextricably bound that they cannot be considered separate elements of analysis. On the contrary, they represent a recursive frame of interpretation. Not all the questions posed will be answered nor the questions listed above are definitive. This research does not aim at providing answers more than it intends to produce new questions: as Kafer states, “questions keep me focused on the inconclusiveness of my conclusion, on the desire to think otherwise” (2013: 18).

Chapters outline

The research is divided into three sections: the first (chapters 1 and 2) lays the theoretical foundations; the second (chapters 3 and 4) describes the context and methodology; the third (chapters 5, 6, and 7) provides the analysis of the data.

Chapter 1 offers a review of relevant literature produced on chronic illness in the sociology of health and illness. In particular, it focuses on a critical discussion of the concept of “biographical disruption” (Bury, 1982), that constitutes the main reference in the field. It also provides an overview of the literature elaborated on the intersections between chronic illness and LGBTQ+ experiences, which is scarce and scattered. Important exceptions are the works related to HIV amongst gay men, which represent a genre in itself (Carricaburu & Pierret, 1995; Hodges & Rodohan, 2004), and the contributions on breast cancer amongst lesbian communities (Lorde, 1980; Sedgwick, 1999). Crip theory reveals itself as an interesting theoretical support for the lack of instruments to analyse the conundrum of LGBTQ+ identification and chronic illness (McRuer, 2006; Kafer, 2013). Crip studies emerged to provide a deeper understanding of able-bodiedness as a system of compulsory normalcy and its entanglements with heteronormativity. This perspective provides solid arguments to consider how narratives on chronic illness are also constructed along these lines. Indeed, in the last part of the chapter, I outline a discussion of how chronic illness can be considered in its relations with LGBTQ+ identifications through a queer-crip lens, which recognises the systems of oppressions that produce them intersectionally.

Chapter 2 examines the queer debate on temporalities and how it contributes to the understanding of sexuality and illness from a different perspective. Although crip studies stem directly from queer theories, there are elements of debates in queer studies that are worth to be analysed more specifically. First, the works that explore queer as an epistemological lens for the deconstruction of normativity, that suggest queer is not a mere positioning, but a way to be in the world (Ahmed, 2006). Second, the contributions that debate time through the queer lens (Freeman, 2011; Halberstam, 2011). Queering time means to understand the forms of normativity entailed in common conceptions of what is defined as time, in particular in Western societies. Time is socially conceived as linear, arrow-like; it is also necessarily productive and, as such, it is reproductive. The deconstruction of these parameters unveils implicit conceptions of generative family, productive subjects, and reproduction that are inherently part of the definition of "adulthood". The chapter defines queer-crip time as a set of temporalities that embrace failure, asynchronicity, and imperfection as a political deviation from normalcy. This theoretical approach is a crucial element for the research.

The second section includes chapter 3 and 4 and provides a contextual overview of Italy and Portugal. Chapter 3 focuses on the elements of the Italian and Portuguese context that are relevant for the research and, in particular, the framework of rights for LGBTQ+ and chronically ill citizens. There are persistent common aspects between the two countries: the catholic-oriented culture; the familistic system that represents a second welfare; the precariousness generated by the economic crisis of 2008. From this point of view, Italy and Portugal fit into a narrative of Southern Europe as familistic, Catholic-oriented, welfare-centred states (Calzada & Brooks, 2013). However, they also show blatant differences from each other, in particular for what concerns the state of LGBTQ+ rights. In

Italy, legal changes have been inconsistent and scarce: homosexual citizens are denied access to adoption, marriage, and parenting in general, whilst for trans people, gender recognition is still subject to processes of medicalisation (Lasio & Serri, 2019). In Portugal, the evolution of LGBTQ+ followed a rapid and stable pace from 2001 onwards (Santos, 2013). The country has one of the highest number of laws protecting LGBTQ+ people in Europe (ILGA, 2019). The chapter offers also a description of the healthcare system running in the two countries. The traditional Italian and Portuguese systems consistently relies on the informal organisation of society around families. Despite providing free access to healthcare to all citizens, the state expects families, in particular women, to dispense care for their weaker members. This form of organisation contributes to the scarcity of institutional structures that could provide support to chronically ill people; the low flexibility to accommodate parents or caregivers, that often translates into higher levels of precariousness or unemployment amongst women; the lack of specific measures that provide autonomy to chronically ill people.

Chapter 4 is dedicated to the methodology employed. The chapter analyses how the instruments of the research were chosen, through a discussion of queer methodology and queering methodology (Brim *et al.*, 2016; Browne & Nash, 2010). Confronted with the absence of instruments that allow navigation in the field through a queer *and* crip lens, I here put forward a proposal for the composition of a queer-crip methodology, based on a critical stance that values vulnerability in research. The chapter also details the operational phases of the research: the constitution of the sample, the process of recruitment, and the interviews. The research employed twenty-four narrative interviews equally divided between Italy and Portugal. A committed attempt to involve interviewees as diverse as possible led to a great diversity in the sample in terms of gender identification, sexual orientation, relational status. Following the theoretical understanding of chronic illness as an experience of suffering more than a mere medical condition, interviewees also present different chronic illnesses. All of them imply chronic pain, difficulties in everyday activities, and dependence on informal or formal care. Finally, I reflect on the process of learnings and challenges in the encounter with fieldwork: as an Italian living in Portugal, as a person who self-identifies as queer, and as a chronically ill researcher.

The theoretical and methodological chapters constitute the foundations for the construction of the analytical section. Divided into three chapters, the section as a whole is to be understood as a recursive itinerary made of reverberations between the elements of time, care, and visibility at the core of this analysis. The organisation of the analytical process follows a path that goes from the very intimate context of relationships and sexuality, through care networks, to the larger stage of public life in work and activism.

Chapter 5 discusses how significant relationships are constructed through the experience of illness for LGBTQ+ interviewees. The discussion moves from a closer look to the relation with inherited families (or families of origin), to the level of chosen families (intimate and/or sexual partners, friends) to a take on imagined families (parenting and partnering in the future). The chapter illustrates the multiple challenges experienced by interviewees in establishing intimate relationships while they deal with homophobia, ableism, and heteronormative expectations. It also investigates the structural violence in micro-politics of intimacy and the choices of (in)visibility operated in intimacy to manage the struggles coming from chronic illness. The analysis finally explores whether the careful balance between (in)visibility, time, and bodily ability provides the basis for the elaboration of counter-normative practices of intimacy.

At the centre of chapter 6 is the focus on care, as the result of negotiations between silences, (in)visibility, and resistances to expectations. The practices of care enacted are analysed through the meanings that participants ascribe to them. Although relational and consensual, care always involves negotiations on power relations and needs to be carefully managed within significant relationships: it is the case, for example, when care is dispensed as a moral duty felt by families of origin or as a form of control over intimacy. In other cases, care is provided in contexts of less significant relationships, such as by roommates, as the result of strategic choices by interviewees. The narratives, however, also offer less expectable trajectories in the narratives of care, that overturn the dominant image of LGBTQ+ and chronically ill persons as care-receivers and not as care-providers as well. Similarly, they provide accounts on the centrality of self-care and the importance of body-mind balance concerning the psychological costs of being LGBTQ+ and chronically ill. Finally, the chapter turns to the system of formal healthcare, analysing the experiences of LGBTQ+ patients in medical contexts and highlighting the multiple forms of violence, discrimination, and invisibilisation they suffer as LGBTQ+. Many also face dismissal of symptoms and minimisation of pain that are often associated with other forms of violence such as sexism, fat-phobia, and ageism. Amidst the struggles to be recognised as valid subjects, patients often elaborate strategies of resistance against the medical power structures.

The final note on disobedience in chapter 6 constitutes a cue for the reflection on precariousness and activism, the topics at the centre of chapter 7. In this chapter, the interest is devoted to the multiple, often subtle, forms of precariousness that stem from fragility as workers, either because of constraints as LGBTQ+ or because of chronic illness. However, the analysis also shows that precariousness results from a combination of factors and is not only strictly related to working conditions: the multiple vulnerabilities experienced by interviewees lead many to forced cohabitation and economic dependence on their families of origin and to deal with consequences on their relationships, their sexuality, and, ultimately, on their wellbeing. The generational aspects of precariousness are exacerbated by the impact of being LGBTQ+ and having a chronic illness on various aspects of adult life. Furthermore, the chapter discusses how vulnerability is experienced in the context of public spaces: the analysis puts at the centre the attention on accessibility and safety. Again, the strategies of (in)visibility and the pressures to perform in normative ways in some contexts are central to the discussion. Finally, the analysis moves to activism as an arena in which pain is shared and politicised: whilst LGBTQ+ spaces are denounced by interviewees for their lack of accessibility and the reproduction of ableism, activist organisations centred on the struggles of people with a chronic illness seem to ignore the importance of sexuality in the experience of illness, and, inevitably, the relevance of LGBTQ+ stories. This double silence is a grim, but important, final point, that provides crucial points to be discussed further.

In the conclusions, I reflect on the relevant discoveries made through the research and on the surprising elements that emerged in the narratives collected.

I also focus on the possibilities for future research on the topic, highlighting what remains unanswered and what was purposefully left out of this dissertation. The analysis of the transversal dimensions of time, care, and visibility offers lines of inquiry for the future and stimulates new questions to be explored. Finally, I discuss the possibility to consider a political subjectivity I name "chroniqueer" that epitomises the LGBTQ+ experience of chronic illness as transformative of conceptions of time, care, and visibility. The choice of using the notion of "chroniqueers", from the union between "chronic" and "queers", denotes the will to look at chronic illness and LGBTQ+ identifications as two dimensions which work together, although with different dynamics, in a similar space of exclusion from dominant systems of heteronormativity and able-bodiedness. The process of queering and cripping the methodology and the theoretical frame leads to a different perspective on suffering and vulnerability: it creates significant spaces to reconsider the normative understanding of human rights and to undo the invisible ableism and heteronormativity that underlie mainstream concepts of accessibility and inclusion.

The itinerary designed in the three sections of this thesis aims at creating an empirical analysis based on strong theoretical fundaments, consistent methodological orientations, and innovative analytical contribution. However, it does not intend to trace an arrow-like linear path. The state of questions enunciated previously is the key to read the whole dissertation: its main and deepest objective is to critically question dominant perspectives and to design terrains where, amongst some answers, more questions can emerge. Researching on topics rarely explored implies a weight of added responsibility, since it requires to work harder and better to construct solid arguments, to convince of their relevance, and to show the connections they may trigger to other better-known topics. It also offers a privilege: the rare beauty of having doubts, being hesitant, and expressing uncertainty, all of which are rarely considered as good signs in academic work. In this challenging task, I let the words of Adrienne Rich (1973) guide the exploration of this uncharted territory through her poem *I came to see the wreck*: "I came to explore the wreck. / The words are purposes. / The words are maps. / I came to see the damage that was done / and the treasures that prevail".

1. CHRONIC ILLNESS AND CRIP THEORY. MAPPING THE UNCHARTED

Introduction

The definition of a concept is often the result of a complex journey across controversies and uncertainties. Defining what chronic illness is and how we can distinguish it from disability, able-bodiedness, and health is an arduous task: not only because the concept has been at the centre of debate and its contours frequently rewritten, but also because chronic illness itself changes in nature with the fast advancement of medicine in the last decades. After a long and tormented process, in which I tried to write and rewrite possible definitions of it, I came to the conclusion that the best way to approach chronic illness is embracing its fleeting contours and admitting its fluid nature. In this chapter, I aim to reconstruct a part of this process. In the first section, I suggest a review of the relevant literature on chronic illness from a sociological perspective. A considerable space will be given to the work of Micheal Bury, an author who provided fundamental contributions to the understanding of chronic illness as an experience that encompasses all aspects of life, from family relations to projections in the future, from working ability to one's self-perception. From the outline of the concept of 'biographical disruption' (1982), Bury reflected on the disruptive processes that chronic illness cause on identity and relations, often reviewing and expanding its contributions. Other authors provided important perspectives that completed and questioned Bury's concepts, giving life to a rich debate that offers multiple elements for the study of chronic illness. The section thus discusses the limits and the possible alternatives to the concept of “biographical disruption”, as well as its omissions.

In the second section, I introduce what will be the leitmotiv of this whole research: the intersection between the experience of chronic illness and LGBTQ+ identification. Here I will address the literature that explored this double aspect at its juncture. In particular, I discuss the importance (and the side-effects) of the research on HIV/AIDS within gay communities and how it changed the social perceptions of illness. I will also provide an account of another important line of contributions focused on the experiences of lesbian with breast cancer. I will then provide a critical review of the (scarce) literature that analysed other intersections between LGBTQ+ lives and chronic illness.

The third section is dedicated to the inputs elaborated within disability studies, with a specific focus on crip theory: emerged in the last two decades, crip theory constitutes an engaging perspective on compulsory able-bodiedness as a system of oppression. Its foundations are discussed through a critical reflection on the work of authors who recently engaged with it. Amongst other aspects, crip theory provides a theoretical basis for an intersectional reading of chronic illness. Indeed, in the last section, I layout the basis for a crip reading of chronic illness, advancing that through this perspective chronic illness can be read within other processes that involve identity and social interactions, such as LGBTQ+ identifications.

The chapter intends to provide bearings for an unknown territory: thanks to this theoretical map, the following discussion and, above all, the empirical and analytical chapters can develop in a coherent direction. Nevertheless, the attempt is not theoretical for the mere sake of theorisation: just as mapping is a constant work-in-progress, especially after a territory has been firstly discovered, this theoretical framework is expected to be challenged, re-shaped, and contested by the fieldwork itself. In other words, the framework here sketched will gain shape only after (and thanks to) the challenges emerging from the narratives and the experiences it aims to frame: therefore, we might be able to define what chronic illness is only through multiplicity and failures, through attempts and blurred zones.

1. Chronic illness. Between disruption and strategies of management

> Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, [...] it becomes strange indeed that illness has not taken its place with love and battle and jealousy among the prime themes of literature.
> (Virginia Woolf, 1930)

1.1 The birth of chronic illness

Chronic illness represents a broad and controversial issue in the sociology of health and illness. If it is well-established that it is a condition that influences the ability of individuals to manage their everyday life, it is not peacefully recognised what its specificities are. What is exactly a chronic illness? How does it differ from other illnesses and disabilities, if so? What does the chronic dimension of time imply on the social, cultural, and individual level? How do the symbolic meanings of illness, health, and disability, intersect with the ways chronic illness is experienced? The sociological debate on chronic illness addresses these questions privileging the social aspects more than medical definitions. The reconstruction of its genealogy is crucial to understand how different interpretations of chronic illness evolved in time.

The interest in health and illness as sociological issues emerged in the last fifty years following changes happened in Western societies. For much of sociology's history, physical illness was treated as a natural phenomenon (Bury, 1997) which did not have particular links to the social fabric, class or gender. Until the 1960s, mental illness received far more attention as it seemed to involve deeper social involvement also in the aspect of public health. Amongst the few examples, functionalism (Parsons, 1951) considered health a prerequisite of social action and illness a deviation from social cohesion; conflict theory (Freidson, 1970) explored the power relations at work in the encounter between medical doctors and lay patients. Later, studies (Zola, 1982; Dingwall, 1976) explored the growing medicalisation of everyday life and the role of individuals in the management of their illness. Strauss (1975) was the first to underline the importance of studying illness, particularly chronic illness, as a source of individual and social pain. However, such studies remained isolated cases until the many changes in the 1980s triggered a major shift also in the centrality of health and illness within sociology.

Four elements are to be considered fundamental in this shift. First, the defeat of several acute diseases and the general improvement of life conditions determined the extension of life expectancy. Chronic illness became a distinctive trait of the new ageing societies, bringing about new challenges to public health. Second, the increasing importance of health, not just as the absence of illness, but as the result of lifestyles, individual choices, and active life highlighted both new forms of consumption and renewed social fears against illness (Cederström & Spicer, 2015). Third, the rising conflict between welfare states, in particular national health services, and neoliberalist pressures to privatisation. Finally, the influence of feminist theory (Rich, 1980; Sedgwick, 1993; Wittig, 1982) and post-structuralism (Foucault, 1963; 1978) on sociology itself determined a shift from a general focus on social policy to multiple forms of existence, power relations, gender, class, and knowledge in the experience of illness. These four elements contributed to increase the centrality of health and illness in sociology and to encourage the growth of research framing illness as an individual *and* social condition. Studies on chronic illness represent only a part of such advancing field: the first important studies trace back to the 1980s, with the contributions of Macyntyre (1986), Gerhardt (1989), and Burns (1991). Their merit was to first explore the multiple dimensions of chronic illness as a condition that threatened the sense of identity and, at the same time, challenged social belonging.

1.2 Chronic illness as biographical disruption

The turning point in studies on chronic illness can be linked to the contribution of Michel Bury (1982; 1991; 1997; Taylor & Bury, 2007). Bury considers the study of chronic illness "an important way of examining aspects of identity, social interaction, the experience of stigma and the body in late modern society" (1997: 112). In the attempt to consider at the same time the individual and the social aspects of chronic illness, Bury coins the expression 'biographical disruption':

> The onset of illness, especially that which is not evidently self-limiting, fractures this social and cultural fabric, exposing the individual to threats to self-identity and a potentially damaging loss of control. [...] Treating chronic illness as a disruptive event in this way allows for its meaning to be situated in a temporal and life-course context. Changes in the body and the onset of symptoms simultaneously involve an alteration in the person's life situation and social relationships. (*ibid*: 124)

In the experience of chronic illness, “the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury, 1982: 169): its onset requires individuals to recognise the existence of pain, and, eventually, of closer mortality, but also forces them to open to non-horizontal relationships based on dependency and care. Most of all, chronic illness changes the perception of time and creates new frames to make sense of the present and the future. Three aspects of Bury's interpretation are particularly relevant: recognition, uncertainty, and legitimation.

Bury interprets illness as an event that emerges unexpectedly at some point of a healthy life: although this is not always the case, it is true for the most common chronic illnesses. In such cases, illness represents an unexpected event and causes discomfort, in particular, if we consider that often chronic illnesses “do not 'break-out', they 'creep-up'” (*ibid.*: 170). The onset may involve a long time of uncertainty before receiving a definite diagnosis, a time in which the symptoms of pain appear with no immediate explanation: at this stage, individuals may not recognise to what extent their body is changing and how much of a change they are experiencing. Because of the persistence of negative social perceptions of illness, they may also feel anxious, ashamed, or even angry at their destiny. For Bury, the onset of illness creates a breach in normal life that disturbs the sense of self and overturns the narrative about one's own life. In this process of destruction and reconstruction of identity, time plays a central role. Illness generates a “before” and an “after”: not only one's biography splits into two distinct phases, but also individuals are faced with questions such as “why now?”, “what now?”, and “how long will it last?” (*ibid.*, 125). The relation to time is modified also at the everyday level, where activities, relationships, and tasks need to be defined to accommodate the special needs created by illness.

Shaping a new relation to time involves time since it is often hard to recognise illness as a long-term condition. The hope in the advancement of medication and the social burden of stigma may bring to a limbo of denial or dismissal before reaching a recognition of chronic illness as a *new* phase (Lerum *et al.*, 2015): however, Bury insists on recognition as a crucial step to incorporate chronic illness as an individual and social condition in its whole, without surrendering to the social erasure of suffering as part of the human experience.

While disrupting the present, chronic illness also provokes the acceleration of the future, bringing people to experience "premature ageing": as such, it creates "a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging" (Bury, 1982: 171). In Western countries, chronic illness is considered a common, if not normal, collateral effect of ageing and it is culturally accepted as a plausible consequence of reaching a certain age. Hence, its consequences on children or younger adults are perceived as more disruptive, as recent studies also confirm (Bray *et al.*, 2013; Monaghan & Gabe, 2015). The meanings of chronicity thus vary according to the age at which illness is experienced and the different expectations connected to specific phases of life.

Although most chronic illnesses are not directly life-threatening, they can cause indirect damage to vital organs or complications that expose chronically ill people to an overall higher risk of death. Therefore, the acceleration in time is accompanied by a stronger perception of the closeness of death, or, in a broader sense, of the risks attached to life (Brown *et al.*, 2013).

The second interesting element explored by Bury is the uncertainty which overtakes people when the onset of illness forces them to change their routines: "a growing awareness of its potentially disabling effects, as self-care activities and other forms of daily life, whether at work or in the home, become problematic" (1997: 124). Moreover, Bury insists that "we cannot be ill without simultaneously being aware of the need to account to others for our change in status" (*ibid.*: 2). Becoming ill means to learn how, when, and where to manage the visibility (and invisibility) of symptoms. Both private and public spaces become stages where strategies of performance are enacted to come out or hide symptoms and to limit the potential stigma of illness. In this situation of "meaning at risk” (*ibid.*), the social pressure to accomplish certain expectations through body performance is a consistent obstacle in everyday life. For example, young people with rheumatic illnesses (that are quite common in old age) face a double struggle: on one side, the debilitating effects of the illness; on the other, the need to face the stigma which labels as deviant an “out of age” body (Bray *et al.*, 2013). Choices over how and when to make visible the illness are part of specific performance styles which involve preparation, rehearsal, and evaluation of actions (Corbin & Strauss, 1988; Goffman, 1963): with a reference to interactionist theories, Bury insists on the “element of choice, despite the constraints that symptoms and social contexts may entail” (1997: 133). The management of chronic illness in the public and in the private arena to face the uncertainty provoked by illness mobilises individual resources: it requires the ability to negotiate social expectations, stigma, and (in)visibility. The accent posed on agency in the process constitutes one of Bury's most relevant contributions to the study of chronic illness.

The third important aspect highlighted by Bury is the relevance of legitimation that the networks of care provide to the ill person. Since the disruptive experience of illness threatens the capability of individuals to keep their sense of self-identity into a coherent narrative, the validation of people around is a fundamental resource to overcome uncertainty and disorientation. Bury refers to a study conducted by Blaxter in 1992, in which it was evident that “although medical care was important to patients in chronic illness, the main issues had to be faced outside of its orbit” (1997: 122). Outside of the orbit of medical care, social and relational resources can be found not only in the closest people, such as family, friends, lovers but also in the context of activism, communities and, nowadays, in virtual spaces:

> refers to the attempts by people to establish the place of a disabling illness within an already altered daily life and within the web of social relationships in which the person’s life may be enmeshed. (*ibid.*: 125)

Thanks to such legitimation, the activities of cure can become a collective response to the needs of care and dependency caused by illness. A more liveable life is possible for chronically ill individuals also through this type of emotional and material support, to the point that “the story of the illness [...] in many cases was also the story of kinship relations, of who helped and who betrayed" (Veena, 2006: 68). Illness constitutes a form of disruption also for those who live with the chronically ill person, who often become informal carers (Bray *et al.*, 2013).

Legitimation represents a precious process also in its difference from the culture of suspicion that often surrounds chronic illness (Bonino, 2009). The absence of readable signs of impairment, the invisibility of symptoms, and the impalpability of pain to the external observer determine an essential unreadability of illness compared to other forms of physical disability, especially in Western culture, where sight is the paradigmatic empirical mean to categorize the outside world (Pieri, 2019). This aspect will be developed by other authors after Bury (Wendell, 2001; Samuels, 2003), although he recognises how important legitimation is for the overall well-being of chronically ill individuals in making sense of their experiences.

1.3 The multiple facets of chronic illness. Critical approaches to biographical disruption

The contribution by Michel Bury constitutes a milestone in sociological approaches to chronic illness. It centres the focus on the social implications of illness without overlooking the importance of care and time. The concept of biographical disruption travelled far and established an interpretative category that became paradigmatic for all the studies that followed. Bury's work contributed to provide theoretical tools to bridge the gap between the sociology of health and illness and disability studies (Williams, 2000). As it is often the case for groundbreaking theories, Bury's work triggered intense debate - Bury himself intervened several times to modify his original framework in light of more recent social changes (Bury, 1997; Taylor & Bury, 2007). A review of criticism received by the concept of biographical disruption highlights its limits and helps to understand the subsequent advancements in the field.

The first type of critique focuses on the individualistic approach of biographical disruption as a model that centres too much on the suffering self and too little on the social conditions that contribute to such suffering. Kelly and Field (1996) and Williams (2000) denote how this approach is oriented on the individual response to the stigma. Bury recognizes that there exist negative meanings linked to illness but does not particularly address the social origins of such stigma: his interest is focused on the individual challenges faced on the social, relational, and personal level. As we will discuss later, this critique is important in highlighting the missing link between Bury's work and disability studies. In failing to grasp the social conditions of illness in its complexity, biographical disruption does not provide a sufficient ground to locate illness within an experience of intersectional belonging that crosscuts gender, race, age, and so on: in this regard, Wilson insists on the importance of focusing “on the relationship *between* identity and illness, rather than only the effects of illness *on* identity” (2007: 623). Other authors highlight the difficulty of translating the concept of biographical disruption into empirical research. Williams notes that:

> a distinction clearly needs to be drawn [...] between biographical disruption as an explanatory concept on the one hand, and its status as an empirical datum at the other. The usefulness of the concept, from this viewpoint, lies in what it can illuminate, theoretically speaking, about chronic illness. (2000: 42)

If the concept has undoubtedly proved to be useful for many studies on chronic illness on theoretical ground, its empirical integrity tends to lose explanatory power when faced with the embodied experiences of illness. The exclusive focus of Bury's work on adults represents one of the most evident limitations in this regard. The concept of biographical disruption is constructed around the experience of illnesses that emerge unexpectedly during adulthood: “chronic illness is seen as entering lives that were previously free of problems, resulting in a disjuncture between the self, body and society” (Monaghan & Gabe, 2015: 1237). The explanation is not suitable *tout court* but only for a specific temporality of chronic illness. For example, it does not seem applicable to individuals who are chronically ill from birth (Bray *et al.,* 2013), who fall ill in young age (Grinyer, 2007; Monaghan & Gabe, 2015) or who develop a chronic illness due to ageing (Faircloth *et al.*, 2004). Such limitations in the empirical sphere show:

> the need to extend the biographical focus of studies within the sociology of chronic illness to both ends of the life-course, thereby moving away from the hitherto predominant concern simply with the middle years of life. (Williams, 2000: 61)

According to other authors, the concept of biographical disruption is too limited to grasp the prismatic nature of chronic illness in time. For example, Larsson and Grassman (2012) discuss how chronic ill people tend to organize their sense of self, their relations, and their future projections around a “double time-table”: while attempting to manage the fluctuations of illness along the twenty-four hours of a day, they try to situate unpredictability in a longer period. In so doing, they embed chronic illness in a time reference in which it becomes a certain factor of uncertainty. The authors advance the idea that chronic illness represents a continuity within the lifetime: this persistence is, after all, suggested by the word “chronic” itself. The study argues that the focus on biographical disruption gives more importance to what happens during the onset of the illness and shadows the importance of how individuals relate to continuity in time, once they have adapted to the changes caused by the illness. This perspective is interesting since it insists on the centrality of the “chronic” more than on the issue of “illness”, underlining that the specificity of chronic illness lies in its persistence over time more than on a specific moment of change.

Another compelling debate is the one that questions the dichotomy between health and illness around which Bury's work revolves: this aspect has been under inquiry in particular with the emergence of studies on ableism (Campbell, 2009). Bury's theoretical framework assumes that illness is an event that disrupts a regular life and that requires individuals to adjust to a difficult change; on the contrary, health is indirectly considered the normal (read, desirable) condition.

With the intention of addressing the limitations of biographical disruption and expanding its applicability, several authors suggested alternative formulations. Williams (2000), for example, elaborated the concept of “normal illness”: in life narratives in which tragic events and difficult conditions of work are common, such as amongst low-class workers, illness can be perceived as a normal happening in the story of people with no disruptive effect. In other words, in some contexts, illness is experienced as one of the many hardships of a normal life: the grade of its disruptive potential may vary greatly according to personal history, attitudes, and background. In a study on low-class workers, Pound (1998) had already noted how they interpreted chronic illness as an expected, almost natural, consequence of the hard conditions of their job: rather than a disruption, then, chronic illness represented the anticipation of an event, the acceleration of something expected. Similarly, Beck and Beck-Gernsheim (1995) emphasize how health and illness themselves diverge among different cultural contexts and can be intended as one of the adversities to which people are exposed to: for some, chronic illness could simply be an event within the "normal chaos" of existence. The results of a study on stroke survivors conducted in 2004 seem to go in the same direction:

> While some find their lives disrupted by the stroke, others may 'bracket off ' the impact of the stroke, maintaining a sense of a coherent pre- and post-stroke self. As noted, the concept of biographical disruption has been predominant in the stroke recovery literature. It may be, however, that for some, stroke is not an imminent invader of everyday life, but rather part of an ongoing life story. (Faircloth *et al.*,2004: 244)

According to these critiques, the concept of disruption seems to be suitable in particular for the cases of a sudden illness. Moreover, Larsson and Grassmann (2012) show that, when an illness is prolonged in time, people overcome the initial surprise with the awareness that they need to deploy practical strategies to face the ups and downs of their condition: the focus moves from the unexpected emergence of the illness to the management of its uneven pace. The change echoes the shift described by Toombs: a move from the "I-can/I-cannot" to a practice of learning the "I-can-and-will-continue-to" (1995). Such perspectives, which come from a phenomenological approach to disability, reveal to be particularly suitable to describe how "living with progressive illness requires a constantly changing tool-set: with changes to bodies and environments come new skills that must be learned to make routines possible" (Abrams, 2016:7). The focus on everyday practices enhances the empowering dimension of learning how to live with illness without dismissing the potentially disruptive effect of its onset.

Provided these limits, some authors try to mitigate the disruptive aspect of illness into a more comprehensive understanding of it as a moment of change. In this sense, chronic illness would fall into the category of "turning point", a biographical transition (Bonica & Cardano, 2008): a moment diluted in time which creates change within a coherent narrative on past and future. For example, Monaghan and Gabe argue that "a chronic illness may be an 'only sometimes' problem and take account of the 'now you see it, now you don't' nature of a condition that varies in terms of its symptoms, meanings and consequences" (2015: 1238). Their study on young people with asthma shows that the presence of mild symptoms or limitations is not generally perceived as a destabilising factor but more as a consequence of bad luck: they propose to refer to chronic illness as "biographical contingency".

Furthermore, in a study on people with terminal illnesses (Lerum *et al.*, 2015), it was found chronicity was used by medical doctors to give patients a comforting perspective over terminality: reluctant to the idea of telling their patients the truth about their short expectancy of lives, they would insist on the need to adjust to a new chronic condition, made of limited capacities and loss of independence. This alternate use of chronicity and terminality, reflected in some conditions that challenge the differences between one and the other, is defined by the authors as "unstable terminality". This formulation is particularly interesting as it contributes to further expand the notion of time beyond simple disruption.

Finally, the concept of biographical disruption is questioned for the determinism with which the emergence of illness is directly connected to a time of difficulty. For example, Williams (2000) wonders whether not only chronic illness is the cause of biographical disruption, but also if the contrary can happen: that a biographical disruption may be the cause for the emergence of chronic illness. According to the author, it is reductive to isolate the onset of the chronic illness from the context in which it arises. A personal loss, the end of a relationship or economic hardships represent difficult moments that can expose personal fragility and enhance the risk to fall ill. This formulation adds a crucial aspect to the debate: the centrality of social, cultural, and economic contingencies in the ways illness is not only experienced but also managed. Nevertheless, this approach has to be taken carefully because it runs the risk of establishing a slippery connection between illness and individual psychological conditions. This topic will be particularly important in further parts of this work, when the difficult relations between doctors and patients will be explored. For now, it is important to note that the danger to implicitly blame individuals for their illness is a side-effect of the long-lasting stigma linked to illness: if Lorde (1980) and Sontag (in Sontag & Rieff, 2013) described it already in their books on cancer, today that same implicit accusation is always on the verge of being pronounced within the healthist modernity (Cederström & Spicer, 2015; Petersen, 2015).

In conclusion, chronic illness as a biographical disruption still retains a strong explanatory power in theorising the social relevance of the experience of illness in Western contexts. Despite its age, the concept resists as a good basis where to begin analysing chronic illness. Nevertheless, it needs to be questioned and related to other approaches, which can mitigate its limits and blur its boundaries. “Biographical disruption” may not be the only way to understand chronic illness in all ways. Other formulations such as “unstable terminality”, “normal chaos”, “biographical contingency”, “normal illness” contribute to highlighting the centrality of time in the experience of illness, its importance in the life-span, and the need to focus on the interplay between illness and identity.

2. Chronic illness and sexualities: a brief story of silences

> You know the name you were given, you do not know the name that you have.
> (José Saramago, 1997)

2.1 Two grand narratives: HIV and breast cancer

The contributions discussed so far demonstrate that chronic illness determines challenges that go beyond a mere corporeal condition and concern time, expectations, self-perception, relationships, material conditions of living: in other words, it affects the processes through which individuals shape their identity. Similarly, the experiences of sexuality, gender identity, sexual orientation, erotic choices, social constraints, and discrimination affect individuals in all the aspects of their lives: being LGBTQ+ is much more than just being non-heterosexual or non-cisgender (Warner, 1993; Butler, 1990). Although these may seem almost banal statements, they reflect a common separation of topics which recurs both in studies on chronic illness and in LGBTQ+ studies, as it will be discussed in detail in the next chapter. Indeed, few studies have explored the specific experiences of chronically ill persons who identify as LGBTQ+. Such absence is somewhat telling of a general heteronormative bias in the sociology of health and illness (Jowett & Peel, 2009). However, there are several important aspects to add to this.

In the first place, it would be impossible to dig into this topic without acknowledging the impact that studies on HIV/AIDS in gay communities had on the general debate on LGBTQ+ experiences with chronic illness. This *corpus* of literature emerged in the late 1980s when AIDS dramatically hit Western countries. Early studies revealed how the social construction of a public health emergency had been deformed into a matter of sexual health containment and a collective homophobic reaction:

> This 'truth' of AIDS also resolutely insists that the point of emergence of the virus should be identified as its cause. Epidemiology is thus replaced by a moral etiology of disease that can only conceive homosexual desire within a medicalized metaphor of contagion. (Watney, 1987: 73)

The epidemic in Western countries spread into an “epidemic of signification” (Treichler, 1987): AIDS was consistently and intentionally associated with metaphors of immorality, deviant behaviour, danger and it was in this category that gay men were put as whole while their communities were killed by the virus (Sontag, 1978). In these years, the works conducted were focused on denouncing such massive collective construction of homosexuality as a sexual threat (Bersani, 1987; Weeks, 1996). Some authors also explored how AIDS impacted the intimate practices and the everyday lives of gay communities (Carricaburu & Pierret, 1995; Weitz, 1991). These constitute the first attempts to investigate the interplay between illness and LGBTQ+ lives - although only exclusively focused on gay men. In particular, Carricaburu and Pierret examine the narratives of gay men with HIV/AIDS and haemophilia using the concepts of biographical disruption and meaning at risk (Bury, 1997). Their study highlights how people with HIV/AIDS elaborate narratives of illness through “a biographical reinforcement”: the process of acceptance of a double illness leads to “a reinforcement of the components of identity that, prior to HIV-infection, had already been built around haemophilia or homosexuality” (1995: 85). The experience of illness is embedded in a collective narrative that regards a whole generation, a shared destiny. The collective dimension of HIV/AIDS constitutes a crucial element in this literature which cannot be found on other experiences of illness even in later studies. The construction of a collective imaginary that linked (male) homosexuality to illness was cemented also through the vast production of movies[2], novels, and cultural artefacts that populated mainstream culture (Kushner, 1992; Wojnarowicz, 1990).

In the following decades, several authors contributed to expanding the debate on HIV/AIDS beyond the connection with homosexual men. Studies on lesbian women and their experiences with HIV are particularly important in their effort to fill the gender gap in the collective narrative on the illness (Ciambrone, 2001; Jacobs *et al.*, 2018; Sullivan, 2018). Others investigated the persistence of the stigma related to HIV (Ezzy, 2000; Hodges & Rodohan, 2004; Race, 2001; Rier, 2007). In recent years, advancement in medicine transformed what once was a death sentence to a life-long condition: HIV is now considered by all means a chronic illness, although it still carries echoes of the imaginaries created in the earlier decades. The connection between HIV and homosexuality is so strong that some use the term “non-HIV related illnesses” for studies about gay men with chronic illnesses different from HIV (Lipton, 2004).

The second grand narrative that explored the experience of illness and LGBTQ+ sexuality consisted of the narratives of lesbian women with breast cancer. Studies show that the incidence of breast cancer among lesbian women is higher than amongst heterosexual women, due to a combination of factors that can contribute to higher probabilities of developing this kind of cancer: the scarce use of contraceptive methods, the lower amount pregnancies carried out, and a lower attendance to screening, that can be linked to fear of discrimination (Matthews, 1998; Rankow, 1995) These studies are based on a normative and often essentialist perspective on lesbian women as non-mothers; however, from the 1980s onwards breast cancer represented an important collective narrative of illness within lesbian communities. Diaries and experiences told by well-known feminists significantly contributed to this: Audre Lorde (1980), Susan Sontag (1978), and Eve Sedgwick (1999) wrote intense biographical accounts in which

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[2] See, for example, the movies from Derek Jarman and the extraordinary success of the mainstream movie *Philadelphia* (1993).

the embodied experience of cancer is interlaced with politics and activism. Lorde's work is particularly important to the extent to which it sheds light on the meanings of intersectionality through illness: Lorde insists on her being black, lesbian, activist, *and* ill at the same time and reflects on how all these levels intertwine. She also reclaims the importance of transforming the individual experience into a collective story of feminist resistance: “Even survival is only part of the task. The other part is teaching” (1980: 53).

These contributions constitute an important reference because they provide an intense encounter between embodied experience, activism, and feminism, through intersectional readings of the experience of illness and lesbianism that move between the personal and the collective level. As such, they are considered almost as archetypical narratives of what it means to have breast cancer both as a lesbian and as a woman (Rankow, 1995). In recent years, the field has expanded both to include narratives of cancer by trans and non-binary persons (Blank *et al.*, 2015; Clark *et al.*, 2015). Some contributions insisted on the intersectional embodiments of gender, sexual orientation, gender identification with class, race, and age, including, for example, the Latino population or older LGBTQ+ people (Barnoff *et al.*, 2005; Boehmer & Elk, 2015).

As happened for HIV, nowadays the rate of mortality for breast cancer is sensibly lowered: in several cases, breast cancer survivors can conduct a life very similar to the ones who have a chronic illness. This aspect is particularly important for this research. In fact, the two examples of illness within LGBTQ+ communities are both examples of illness that changed their status in the past decades: from death sentences they became sensibly more similar to chronic illness, making the experiences of their survivors more telling today for the study on chronic illness than they were before. However, in this passage, both illnesses bring with them the echoes of the imaginaries of death, contagion, and gloom future that media and culture reproduced during the 1980s and 1980s. Besides these differences, I believe that this change in the temporality of both illnesses an important reflection of the contemporary direction of Western countries: as Bury (1991) had anticipated, it goes towards less deathly diseases and more chronic illnesses. For this reason, although the studies on HIV and breast cancer within the homosexual community are not always relatable to the contemporary ones, they provide a crucial step to unveil features that connect illness, as a social and individual experience, and LGBTQ+ identification, as a prism made of desires, identity, and practices.

2.2 Chronic illness and LGBTQ+ people: a state of the art

If we exclude the illnesses discussed above, the relevance of being LGBTQ+ in the experience of chronic illness, or of having a chronic illness as an LGBTQ+ person, is rarely considered significant in sociological literature, both in LGBTQ+ studies and in studies on illness. According to Jowett and Peel:

> sexual identity is often not thought to be relevant or connected to chronic illnesses. It has been suggested that this is a result of chronic illness being generally understood from a biomedical perspective, as prolonged physical conditions that affect individuals on a biological level. (2009: 456)

Epstein (2003) suggests that one of the reasons for this absence is to be found in the excessive attention given to studies on gay communities in times of HIV/AIDS: such focus contributed to inflecting the research agenda to quantitative studies that almost exclusively considered the LGBTQ+ community special only concerning one illness.

The scarce contributions on the topic can be categorised in two main areas: the former address the encounter between LGBTQ+ experiences and chronic illness in the sphere of sexual health; the latter explores visibility in access to healthcare.

The first type of contributions stems from an understanding of LGBTQ+ lives narrowed on sexuality: the experience of chronic illness as LGBTQ+ people is analysed in its reflections on sexual life, intimacy, and sexual health. For example, Wilton (1997) analyses stories of lesbian women with chronic illness and discusses how the lack of significant networks of care brings many to experience a double form of isolation. However, the author argues, the difficulties of living with a stigma make lesbian women more resilient to the changes brought by illness and an overall better capacity of grappling with it. The argument is sustained by other studies that explore whether the experience of discrimination of LGBTQ+ people facilitates their acceptance of illness. Axtell (1999) conducts a study on lesbian and bisexual women with different conditions, such as diabetes, fibromyalgia, and multiple sclerosis: participants report the need to make sense of fractured identity and a quest for a whole identity both as ill and as LGBTQ+ women. The constitution of networks of support within the lesbian community represents in this story as a crucial resource to overcome the multiple forms of isolation experienced. Similar conclusions characterize studies conducted on gay men such as the one conducted by Perlman and Drescher (2005) on gay men with prostate cancer and by Genke (2004) amongst the elderly. In both studies, illness exacerbates the isolation experienced as homosexuals, even within close communities.

Lipton (2004) explores the narratives of gay men with colon and rectal diseases. His contribution represents a relevant analysis of the consequences of the narrative on HIV within the gay community:

> The HIV epidemic has ruptured the understanding of a continuum of wellness within the gay community. [...] For gay men and many of their service providers, HIV now seems to be the unconsciously accepted litmus test of health. Either you have HIV and 'sick', or you are HIV negative and therefore ‘healthy’. (2004: 4)

The consequences of this process impact the individual perception of chronic illness as a matter of small importance for gay men, compared to HIV. However, they also generate collective responses of devaluation within gay communities when their members fall ill (Courtenay-Quirk *et al.*, 2006; Smit *et al.*, 2012).

The second type of contribution focuses on stigma and disclosure, especially in access to healthcare. In recent years, an increasing interest has been devoted to the needs of the LGBTQ+ population in healthcare in psychology, social service, and critical health research. Theories of minority stress (Lingiardi & Nardelli, 2007; Link & Phelan, 2006; Meyer, 2003) elaborated in social psychology were particularly important in highlighting the impact of social pressures incorporated by LGBTQ+ individuals and experienced in all social interactions, in particular on specific areas, such as healthcare.

Sociological contributions explore in particular the complexities of (in)visibility of sexual identity in relation to health professionals, medical doctors, and healthcare providers. Authors are unanimous in recognising the heteronormative foundations of healthcare regimes, that function around a supposedly universal heterosexual, cisgender, monogamous ideal patient (Eliason & Schope, 2001; Horncastle, 2017; Passanante, 2014). In healthcare, the general implicit rule is often “don't ask, don't tell” (Eliason & Schope, 2001). According to these studies, LGBTQ+ patients adopt different strategies to avoid disclosure unless needed, for fear of discrimination, or because they believe it is not necessary information (Bjorkman & Malterud, 2007). However, studies demonstrate that it does make a difference when healthcare providers are informed of the sexual orientation/gender identity of their patients (Koh *et al.*, 2014). Women are particularly vulnerable in coming out choice because of the overlapping of gender discrimination and homophobia/biphobia. As Austin (2013) and St.Pierre (2012) document, concerns regarding disclosure of sexual orientation/gender identity discourage access to healthcare when not strictly necessary. Moreover, they inhibit attendance to screening programs, regular therapies, or even the access to emergency services (van Dam *et al.*, 2011).

Both types of contributions shed light on important aspects of the connections between chronic illness and LGBTQ+ lives. However, there are still many elements that have not been explored enough. In the first place, it is important to note that, while most studies make an indistinct use of the category “LGBTQ+”, they focus almost exclusively on lesbian women, gay men, and on bisexual persons only in a few cases. The narratives of intersexual, asexual, non-binary, and queer people remain invisible.

The experience of trans people in healthcare is mainly explored in the declination of the pathologisation/de-pathologisation debate: studies on the access of trans people to healthcare exist but explore almost exclusively the aspects related to the transition process, hormone therapies, transphobia in healthcare (Hilário, 2019; 2020; Lombardi & Banik, 2015). No studies were found that expressively addressed the experiences of trans people as chronically ill patients.

In the second stance, the literature discussed struggle to encompass chronic illness and LGBTQ+ experiences as comprehensive dimensions not limited to sexuality or desires. There is a pressing need to bring sexual orientation *and* chronic illness into other areas of study, such as, for example, working life; family relations; activism; public spaces; leisure time. Finally, with some exceptions (Axtell, 1999; Austin 2013), the literature on chronic illness and LGBTQ+ lives does not include ableism as a relevant element that works together with homophobia in exacerbating the stigma associated with illness and homosexuality/transexuality. These uncharted territories of chronic illness and LGBTQ+ lives are thus still to be explored, named, and analysed to find new connections that go beyond the simple equation illness-sexual orientation based on sexual health.

3. Crip theory

> We will not go back to any normalcy, because normalcy is the problem.
> (Graffiti on a wall in Madrid, 2020)

3.1 Shifting perspective on disability

In disability studies sexuality is also often absent. Until the first decade of the 2000s, the debate on disability was conducted mainly through two approaches. The first, the medical model, focuses on the medical aspects of disability, which is seen as an individual struggle. It is rooted in a widespread and implicit idea of disability as a problem to be cured (Kafer, 2013; Clare, 2017). The main interest is devoted to the clinical relations between doctors and patients, while scarce attention is directed at the social and collective dimensions of disability. The second, identified as the social model, emerges from a collective struggle and an intense connection with movements for the rights of disabled people in the U.S.A. and the UK (Barnes *et al.*, 2002; Davis, 1997; Paterson & Hughes, 1999; Siebers, 2008). The social model addresses exclusion through a social perspective: disabled people are excluded from basic access to work, family, and reproduction because society imposes social, cultural, and material barriers to their full inclusion (Martins & Fontes, 2016). As such, the social model has an important role in promoting the advancement of social policies and becomes the main approach adopted both in activism and in public reforms to enhance access to full citizenship (Martins *et al.*, 2016). Feminist theorists, most of them engaged in Feminist Disability Studies, also provide important contributions in adding a gender perspective on disability, through the works of prominent scholars such as Garland-Thomson (1997; 2011), Shildrick (2009), Wendell (1996).

Such models offer relevant reflections on disability and the way it is related to gender, class, and social exclusion. However, they often fail to recognise the importance of pain and invisible symptoms in the experience of illness. Sexuality and intimacy in general and, in particular, the lives of LGBTQ+ disabled people is quite absent as well, despite important exceptions (Brownworth & Raffo, 1999; Rainey, 2011; Siebers, 2012). Further contributions highlight how such absence derives from the ableist assumptions that desexualise disability and place it at the opposite side of pleasure (Shildrick, 2009; Santos & Santos, 2019). Heterosexual sexuality is recognised to be ableist in itself, for the rigid scripts it involves and the normative obsession with penetration (Rainey, 2011): disabled people are implicitly cast out of pleasurable sexualities because they are assumed to be unable to perform such scripts.

Crip theory emerged in 2002 from a formulation by Robert McRuer. It offers a different standpoint both on disability and sexuality, which paves the way for the inclusion of chronic illness and LGBTQ+ existences in a common theoretical framework. “Crip” comes from “cripple”, a term used as an insult against disabled people. The choice of using “cripple” to base a theory on disability openly recalls how queer theory was born: appropriated and re-signified, the term changed from being a pejorative to a proud political claim (Warner, 1999): queer is “a site of collective contestation, [...] the point of departure for a set of historical reflections and futural imaginings” (Butler, 1993: 223). Crip theory emerges to:

> claim critically disabled identities and to position them as permanently contestatory conditions”. To “claim [critical] disability”, it would seem, is to reject the cultural devaluation of disability and to recognize disability as a vital force that constantly reshapes culture despite ableist norms that would relegate it to a supporting role. The verb phrase thus parallels queer, which similarly has been used to describe not just a thing but a process. […] Queering entails rejecting cultural devaluation and reshaping heterosexist norms, and claiming disability entails bringing out the multiple differences that are compelled to pass under the sign of the same. (McRuer, 2003: 96-97)

Crip theory is intended to go beyond a mere theoretical level and to become an epistemology, a perspective that expands the way disability is interpreted and deconstructs the meanings ascribed to able-bodiedness, impairment, and ability. In other words, “claiming crip, then, can be a way of acknowledging that we all have bodies and minds with shifting abilities, and wrestling with the political meanings and histories of such shifts” (Kafer, 2013: 13). The contribution elaborated by McRuer and, after him, by other scholars (Clare, 2017; Kafer, 2013; Patsavas, 2014), revolves around four main pillars: the critique to normalcy; able-bodiedness as a system of compulsion; the centrality of failure as a site of resistance; intersectionality. The next sections discuss each of them.

3.2 Against normalcy

Crip theory states that disability is not a condition in itself but it is defined by difference from able-bodiedness. The word 'disability' remarks a form of failure: it signals the missing ability (the prefix *dis-* indicates a lack) to do what able-bodied people can do. Curiously, able-bodiedness itself is defined by subtraction. The Collins Dictionary defines 'able-bodied' as “people who are healthy and have no illness, injury, or condition that makes it difficult to do the things that other people do”. In the definition of able-bodiedness we find an implicit definition of normalcy and desirability:

> Able-bodied identities, able-bodied perspectives are preferable and what we all, collectively, are aiming for. A system of compulsory able-bodiedness repeatedly demands that people with disabilities embody for others an affirmative answer to the unspoken question, Yes, but in the end, wouldn’t you rather be more like me? (McRuer, 2006: 9)

Crip theory proposes a critical engagement with systems of thought which insist on able-bodiedness as a form of normalcy. Such engagement echoes earlier contributions that denounced the society as disabling: “the disability rights movement, like other social change movements, names systems of oppression as the problem, not individual bodies. In short, it is ableism that needs the cure, not our bodies” (Clare, 1999: 106). However, as much as the critique to normalcy may seem theoretically inviting, McRuer alerts to the contradictions it triggers: “nearly everyone, it would seem, wants to be normal in the able-bodied sense as well. Consequently, the critical interrogation of able-bodiedness has not always been well-received” (2006: 7). If it is important to understand how systems of compulsory norms operate, it is also decisive to maintain a constant state of political contestation. Crip theory thus engages with lessons inherited by LGBTQ+ activism and the alliance with other movements and theories. “To crip” becomes also a verb that denotes this posture of anti-normativity which creates a strong connection with queer practices: “both queering and cripping expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity” (Sandahl, 2003: 37).

3.3 Able-bodiedness as a system of compulsion

Able-bodiedness is intimately bound to other forms of oppression, in particular heteronormativity. In her influential text from 1981, Adrienne Rich speaks of “compulsory heterosexuality” (1980) as a system which equates heterosexuality to normalcy: being the expected standard, heterosexuality is not even considered as a possible subject of criticism. Therefore, since it is everywhere, it is nowhere. Later on, queer scholars opted for the use of the concept of “heteronormativity” to indicate the pervasive norm that reproduces the alignment between sex, gender, and sexual orientation (Butler, 1993). McRuer (2003) inserts his analysis in this genealogy to show the parallelism between heteronormativity/able-bodiedness and homosexuality/disability. While heterosexuality and able-bodiedness represent the normal option, homosexuality and disability equal deviance from the norm by difference or subtraction. The two systems work together and similarly in producing compulsory rules of normalcy: they are, by all means, systems of compulsion. Moreover, they contribute one to the affirmation of the other:

> The system of compulsory able-bodiedness, which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness: […] in fact, compulsory heterosexuality is contingent on compulsory able-bodiedness, and vice versa. (Mc Ruer, 2006: 2)

Some elements are key to understand how this correlation works. In the first place, systems of compulsion are based on the presumption that normalcy can be defined through a supposedly natural standard. This implies that if the normal can be defined, those who deviate from the norm may also be easily detected and their existence is considered less valid. For example, Rich (1980) describes the existence of lesbian women as supplementary and marginal compared to the archetypical experience of heterosexuality. Similarly disability is often narrated as a defect: although disabled people can be happy *despite* their disability, they will not achieve as many things as normal people since their life will be made of adjustments and not full choices (Kafer, 2003). The production of normalcy as a standard implies the creation of a hierarchy of worth (Butler, 1993), for which disabled people inhabit a grey area of sub-humanity together with other oppressed people. Their life is always something less: less important, less intense, less interesting, but also less achieving, less worth, and less successful.

A second important element is that systems of compulsion do not erase alternatives, but they work in reinforcing the stigma associated with deviance (Kafer, 2013). Symbolic and material exclusion makes clear how undesirable it is to misalign with the norms, to the point that those who do not conform can only be tolerated or confronted with their secret desire to be like the others (Bérubé, 1996; Warner, 1999).

Moreover, systems of compulsion work in binary structures: the division between normal/deviant is infinitely reproduced in other declinations, such as good/bad, hetero/homosexual, healthy/ill, able-bodied/disabled, male/female, white/non-white, rich/poor. The binary structure creates a fundamental reassurance on social order and, hence, reinforces the sense of belonging or exclusion. In this logic, the most dangerous act is not to be deviant but to be in-between and to fluidly navigate between dichotomies. As we it will be discussed later, this is a crucial point from where to look at chronic illness through a crip epistemology.

Finally, able-bodiedness and heteronormativity understand identities as monolithic and unchangeable. On the contrary, both crip and queer perspectives are based on the fluidity of identification and potential expansiveness of the term: "cripple, like queer, is fluid and ever-changing, claimed by those whom it did not originally define" (Sandahl, 2003: 27). To a certain extent, disability itself is a condition to which all human beings are destined if they live long enough to reach old age (Wendell, 2001). We could even argue that able-bodiedness constitutes the most precarious privilege: exposed to the possibility of illness, accidents, and ageing, our bodies live on a very fragile balance. Nevertheless, able-bodiedness reproduces an illusion about its stability trough a narrative that confirms that disability is a misfortune that only happens to others: "our ill and dis/abled bodies are literal embodiments of our culture's insecurity regarding the mortality and imperfectness of the human body, and are therefore hidden and rendered 'private' matters" (Klamer, 2009: 27). Bouncing the responsibility of exclusion on an individual level is a typical process through which dominant structures construct the means of oppression, as McRuer recognises:

> the dutiful (or docile) able-bodied subject now recognizes that some groups of people have chosen to adjust to or to even take pride in their 'condition', but that recognition, and the tolerance that undergrids it, covers over the compulsory nature of the able-bodied subject's own identity. (2006: 303)

The privatisation of deviance that sends queers back to their bedrooms and locks crips into their homes (McRuer &Wilkerson, 2003) is thus sustained by the fundamental function of social reassurance that systems of compulsion operate within communities. Not only: it is also a way to avoid taking collective responsibilities for inequalities and minimize the costs of social intervention, a tendency that neoliberalism and capitalism showed in particular in recent years (McRuer, 2018).

3.4 Ableism in the intersectional comedy of normalcy

In her account of how heterosexuality works as a performative reproduction of norms, Judith Butler concludes that it is nothing more than "an inevitable comedy" (1993). Showing how this same process regards able-bodiedness, McRuer paraphrases Butler's definition:

> heterosexuality [able-bodiedness] offers normative […] positions that are intrinsically impossible to embody, and the persistent failure to identify fully and without incoherence with these positions reveals heterosexuality [able-bodiedness] itself not only as a compulsory law but as an inevitable comedy. […] Able-bodied identity and heterosexual

> identity are linked in their mutual impossibility and in their mutual incomprehensibility. (2006: 93)

If the art of failure is an intrinsic part of queer politics (Halberstam, 2011), it is also an important aspect of crip theory to the extent to which it represents a starting point to overcome oppression. The aspect of “inevitable comedy” opens for an imaginative process in which crip and queer together represent “words to help forge a politics” (Clare, 1999: 70). Therefore:

> seeing disability as political, and therefore contested and contestable, entails departing from the social model’s assumption that ‘disabled’ and ‘non-disabled’ are discrete, self-evident categories, choosing instead to explore the creation of such categories and the moments in which they fail to hold. Recognizing such moments of excess or failure is key imagining disability, and disability futures, differently. (Kafer, 2013: 10)

The recognition of how systems of compulsion work unveils the limits of framing disability only by medical or social definitions and pushes for a political and fluid understanding that overcomes the dichotomy between disabled and able-bodied. As such, crip theory recognizes as part of a common struggle all those bodies, or, with Price (2015), all those body-minds that fail to be considered normal: their importance and their value consists in their failure because it is through the cracks that they show that able-bodiedness is nothing more than a comedy.

Moreover, such perspective mitigates the representations of disability as victimised and pitiful and offers a new centrality to disabled individuals as subjects of choices:

> The importance of disability as a site on which to deconstruct social ideologies of perversion, victimisation, and protection, because such ideologies are tied also to the ableist norm of perfect bodies and minds, which construes goodness in terms of health, constancy, energy, wholeness, and strength at the expense of actual bodies that do not conform to these specification. (McRuer & Wilkerson, 2003: 8)

As the authors show, the ideals of body and mind perfection haunt everyone and denote how the spectre of disability and illness are still engrained in public fear. However, claiming that able-bodiedness is a normative tyranny that regards everyone (both the able-bodied and the disabled) equals stating that disability is also an issue that concerns all society (both its able-bodied and its disabled members): “rethinking our cultural assumptions about disability, imagining our disability futures differently, will benefit all of us, regardless of our identities” (Kafer, 2013: 14). The shift to a collective reimagining of disability as a valid political standpoint is not an easy one and, indeed, can be even slippery. It is not about aspiring to be more disabled or iller than one is. Nor it is to let go of all the cures and means that improve the life of disabled individuals and make it similar to the one of the able-bodied (Clare, 2017). Crip authors insist on the role that academic research should have in this process: disability is a valid standpoint that unmasks how social exclusion works and as such it should be included by default within all the disciplines that investigate intersectional forms of oppression. As we will see in more detail in the next chapter, intersectionality (Crenshaw, 1991) has been a trailblazing framework to establish lines of reflection that analysed racism, patriarchy, heteronormativity, and class in their reciprocal interplay. However, ableism is still often regarded as a different topic and “feminist and queer theories (and cultural theories generally) are not yet accustomed to figuring ability/disability into the equation” (McRuer, 2002: 89). Crip theory thus insists on the necessity of an intersectional theoretical work capable of including the workings of ableism within the greater picture of other systems of oppression. Such shift, however, may be difficult for disability studies and, as Kafer affirms, for the disabled community itself, because it requires the ability to acknowledge that “part of the problem […] is the assumption that there is only one side to the question of disability and that we’re all already on it” (2013: 19).

However, intersectionality must be practiced also the other way around: it is not just that ableism is part of a system of multiple oppressions, but also that disabled people are always *not just* disabled. Thus the importance in the recognition of the many declinations that disability takes through gender, class, race, and age: in this intersectional encounter, the symbolic meanings attached to oppression may vary greatly. In this sense, crip theory constitutes an expansion of the dialogue initiated by feminist disability studies (Garland-Thomson, 2011; Shildrick, 2009; Price, 2015) or studies on racialised disabled people (Inckle, 2015) and make space to perspectives from the Global South (Chappell & de Beer, 2019).

4. Crip and chronic. Notes to map the uncharted

> To construct something is to carve the space out of it.
> (Susan Sontag and David Rieff, 2013)

4.1 Cripping chronic illness: (in)visibilities

As in the social and in the medical model of disability, crip theory does not address a specific attention to chronic illness: authors like Kafer (2013), Patsavas (2014), and Wong (2020) include it in a general discourse on invisible disabilities. However, starting from them and valuing the contributions on chronic illness discussed in the first part of this chapter, we can carve out a space to construct a framework for a crip reading of chronic illness. This attempt will be the focus of this section. Although I am conscious of the risks of engaging in such attempt, I believe it is necessary to interrogate the supposed differences between disability and chronic illness: the aim is not to produce more definitions or more categories, but to dig into the blurred areas that make some chronic illnesses also disabilities and other disabilities not at all comparable to chronic illness. The final aim is to expand the possible investigation of disability, acknowledging that "how one understands disability in the present determines how one imagines disability in the future; one's assumptions about the experience of disability create one's conception of a better future" (Kafer, 2013: 2).

The premise for a crip theory of chronic illness is that cripping (and queering, as I will discuss in the next chapter) offer more tools of interpretation than means of description. As such, crip theory shall be considered also as an epistemology - what Patsavas calls "a cripistemology" (2014). One way to understand chronic illness through crip epistemology is to unfold the complexities of visibility. This is an important way to generate ways of understanding also the experience of chronic illness as LGBTQ+. Visibility is a fundamental brick in the construction of normalcy: the separation between the normal and the deviant lies on the premise that all subjects are visible and recognizable (McRuer, 2006). Therefore, "the meaning of disability, like the meaning of illness, is presumed to be self-evident; we all know it when we see it" (Kafer, 2013: 4). The assumed self-evidence of illness plays a part in reassuring social environments about the readability of what is not normal. However, chronic illness escapes this immediate parallel: in fact, most chronic illnesses do not show visible symptoms or readable forms of impairments. Some chronic illnesses are evident only in certain moments of flare, whilst others remain always invisible. Because they are not clearly disabled, chronically ill persons can pass as able-bodied, with all the contradictions it implies. Here we encounter a precious link to the LGBTQ+ experience: in fact, the debate on passing is particularly important for lesbian women and trans persons (Arfini, 2008). Being able to pass means having access to the privileges destined to those that are considered normal:

> in the dominant cultural discourse, as well as in lesbian and disability subcultures, certain assumptions about the correlation between appearance and identity have resulted in an often exclusive focus on visibility as both the basis of community and the means of enacting social change. Discourses of coming out and passing are central to visibility politics, in which coming out is generally valorised while passing is seen as assimilationist. (Samuels, 2003: 244)

In some contexts, the privilege of being perceived as part of the normal majority protects from violence, assaults, and discrimination. However, “traditionally, passing (for straight, for white) has been read as a conservative form of self-representation that the subject chooses in order to assume the privileges of the dominant identity. Passing is the sign of the sell-out of the victim” (Walker, 2001: 8). In the context of identity politics, the claim of diversity despised passing as a betrayal of the collective struggle. Also, blending into the majority is seen as a dangerous disempowerment of political claims for diversity. However, passing can also be used as a strategic means to disrupt dichotomies from within the system (Pieri, 2019). In some cases, chronic illness can *be made* visible through processes of coming out or can *be kept* invisible by choice: therefore, just as being LGBTQ+ can be made visible through repeated performances of coming out, being chronically ill can be made legible in those contexts in which it is considered important or safe. It can, on the contrary, be kept in the closet: in these cases, it will not necessarily be a failure but it can signify just a different strategy of resistance.

The multiple aspects related to passing complicate the dualistic paradigm that equates visibility to affirmation and invisibility to silence and oppression. As Samuels shows in her critique to coming out discourses in queer and disabled activism, the multiple ways in which invisibility can be inhabited and performed are a potential terrain in which we can construct intersectional readings for disabled, queer and other marginal experiences – such as the one of *mestizas* (2003: 250). What crip theory indicate is that visibility and invisibility are performative variables across the line of time and identity: in a similar context, one can be visible as chronically ill but not as LGBTQ+ whilst deciding to make visible their identity but not their illness in a different environment. Therefore, it is possible to deconstruct practices of (in)visibility enacted by chronic ill people not just *as* chronically ill people, but also and always *also* as LGBTQ+, heterosexuals, blacks or young.

4.2 The collective affinity between chronic illness and disability

A second fruitful way to deploy a crip reading of chronic illness is to blur definitions and complicate dichotomies. Chronic illness covers an undefined area in-between the dichotomy able-bodiedness/disability: because it interrogates definitions of disability and it destabilizes the concept of able-bodiedness it may even be unsettling. However, it is also a privileged site from where to observe how the individual and the collective meanings of disability are formed. As Kafer well notes:

> People with chronic illness, pain, and fatigue have been among the most critical of this aspect of the social model, rightly noting that social and structural changes will do little to make one's joints stop aching or to alleviate back pain. Nor will changes in architecture and attitude heal diabetes or cancer or fatigue. Focusing exclusively on disabling barriers […] renders pain and fatigue irrelevant to the project of disability politics. (2013: 7)

Crip epistemology thus brings back to centrality the embodied experience of pain, in particular when not sustained by visible legitimation of the experience of suffering. Pain has been relegated outside the contributions from the social and the medical model of disability, often interpreted as a sign of weakness to be cured or denied at all costs (Patsavas, 2014). However, when chronic pain and fatigue are denied a space of political struggle, "our collective ability to conceive of, and achieve, a world which does not disable is diminished" (Crow, 1996: 60).

Regarding pain as an important standpoint of knowledge and as a political resource exposes compulsory able-bodiedness and the cultural constructions around suffering. Cripping chronic illness thus means to recover the importance of suffering and the centrality of the pain we feel, not just as a bodily manifestation but also as the social pain caused by exclusion, dismissal, and invisibility.

Another important step for a crip reading of chronic illness is contextualising how the meanings attached to disability and able-bodiedness indirectly construct meanings of chronic illness: for example, how and why certain conditions are considered chronic or disabling, whereas others are not (Williams, 2000). Within disability studies, indeed, chronic illness is often considered an issue of minor importance especially when compared with other disabilities and life-threatening conditions. Such dismissals reproduce the ableist assumption that chronic illness is not a real thing or does not imply a valid suffering (Kafer, 2013). On the contrary, chronic illness as a crip experience is not opposed to disability nor substantially different: they both represent fluid states of a continuum of shifting abilities that are not fixed in time and are socially constructed by the shared meanings we attach to them.

Through this reading, we can provide the basis for an intersectional perspective that places chronic illness in relations with other experiences of marginalisation, as in the case of chronically ill people that also identify as LGBTQ+. Echoing intersectional theory (Crenshaw, 1991), chronic illness can be observed within the contexts in which it emerges: differences in gender, class, race, sexual orientation, age, and other positionings are fundamental for the ways illness is experienced and narrated. Moreover, chronic illness does not consist of a singular destabilising force: its disruptive potential, discussed by Bury (1991), unfolds together with practices, choices, and other powers. This element is crucial when we analyse how sexuality and illness are intertwined in the everyday life, since practices of assimilation, (in)visibility, and resistance result from the always-changing balance between all these different factors.

Finally, this intersectional approach leaves behind the centrality of medical definitions of chronic illness and stresses the importance of chronic illness as an experience of displacement which overcomes medical definitions and places individuals outside the definitions of normalcy. Therefore, experiences of chronic illness are part of experiences of disability (and vice-versa) because they share a “collective affinity”: they “can all be discussed in terms of disability politics, not because of any essential similarities among them, but because all have been labeled as disabled or sick and have faced discrimination as a result” (Kafer, 2013: 11). Chronic illness is an experience of suffering and deviation from compulsory able-bodiedness: however, what is at the core of such suffering is not only the embodied pain but also the definitions of able-bodiedness that add forms of stigmatisation and exclusion.

Conclusions

This chapter discusses the approaches to chronic illness developed since it emerged as a specific field of research (Bury, 1991, 1997; Pound *et al.*, 1998) to more recent critical contributions (Armstrong, 2014; Larsson & Grassman, 2012; Monaghan & Gabe, 2015). Afterwards, the analysis moves to the two main strands of inquiry that work on LGBTQ+ issues and illness. On one side, the literature emerged during the HIV pandemic that focused on the experiences of gay men (Carricaburu & Pierret, 1995; Ciambrone, 2001); on the other, the studies that address stories of cancer amongst lesbian women (Lorde, 1980; Sedgwick, 1999). Subsequently, I introduce the few studies focused on non-normative sexualities and chronic illness (Austin, 2013; Lipton, 2004; Wilton, 1997) and discussed the reasons for the scarcity of such contribution and arguing for the importance of further elaborations. Crip theory is then discussed in its main features of crip theory (McRuer, 2006; Kafer, 2013): I advance that it represents a valid theoretical framework which has the merit to encompass intersectionality and sexuality. In the last part, indeed, I put forward a theoretical proposal to build the basis for a crip understanding of chronic illness.

Doubtlessly, this is just one of many possibilities of theoretical dialogue: if the negative data is that chronic illness and LGBTQ+ lives together are an under-explored topic, the encouraging side of it is that much work is needed to create the instruments, theoretical tools, and contributions that can advance knowledge in this field.

The work proposed aims at overcoming a double spell which regards chronic illness and LGBTQ+ studies. The first is the absence of sexuality in general from debates on illness, an absence recuperated only recently but still representing a field of knowledge that deserves more attention. In particular, there is a need to engage in critical discussions that include a wider understanding of sexuality that goes beyond the mere link to intimacy and sexual health. The second spell is the dismissal of chronic illness as a minor issue within disability studies and, therefore, within other fields of knowledge in which oppression and power are discussed.

In this chapter, I outlined why chronic illness is an experience that, while rooted in the stigma attached to disability, challenges the definitions of disability itself. Therefore, it may represent a site where concepts around disability and able-bodiedness can be contested and transformed. In this direction, the attempt for a crip understanding of chronic illness demands more than just an analysis of the condition and the practices through which it is constructed and narrated: it requires a critical understanding of the same conditions and practices; it asks to deal with more than just illness, encompassing also different aspects of identity, such as race, gender, sexual orientation, age and so on; finally, it encourages the exploration of the imaginative potential in the experience of illness to concepts of time, visibility, and bodily fragility and to generate new political horizons.

I began the discussion describing how this is an attempt to make a map of an unexplored territory: cartographers would mark this territory with the expression *hic sunt dracones*, which meant “here be dragons”. Nevertheless, the theoretical map now traced requires that we do more than just recognising that in this territory live extraordinary creatures: we need to sketch their shapes, to understand how they live, to create a genealogy of their origins and a projection of their possible futures. If it is not still possible to provide a satisfactory definition of chronic illness, now it is probably clearer that the journey to explore its contours will offer unexpected twists and important discoveries. The next chapter will examine in which ways a queer and crip understanding of time helps in shaping the theoretical instruments to carry on the journey.

2. TIME'S UP. QUEER THEORIES, CHRONONORMATIVITY AND QUEER-CRIP TEMPORALITIES

Introduction

Similarly to what happens when we approach the study of chronic illness, studying sexuality and intimacy also presents us with many challenges: not only because the debate is populated with a multiplicity of perspectives, but also because the empirical experiences generally exceed any theoretical formulation that attempts to categorise them. The instability of definitions is the important premise on which queer theories arose and that was - years later, as we have seen - adopted as a pillar of crip theory.

Born in the academic context of North-American universities and influenced by poststructuralism and black feminisms, queer theories emerged in the 1990s (Berubé & Escoffier, 1991; Butler, 1990; Warner, 1993). Their anti-normative orientation determined the expansion of queer theory into political practices and epistemologies of knowledge. Later on, as we have seen, they influenced the proliferation of theories and approaches to other fields besides sexuality and intimacy. The deconstructionist approach and the fluidity of definitions represent both the strong and weak points of queer theories. Because of their commitment to deconstruction and fluidity, queer theories have been often accused of being too unstable to be meaningful and their theoretical integrity is regularly under attack. In this chapter, I will discuss the aspects of queer theories that are most interesting for the present research. In the first section, I will thus analyse the birth of queer theories and their evolution into political and epistemological practices. Particular attention will be given to the question of translation: queer theories were born in the North-American academic context and arrived in Southern Europe only years later. The way they were received and re-defined in local contexts is particularly important for the understanding of the empirical chapters that will follow.

In the second section, I will focus on time and temporalities from a queer perspective. Just like space, time is a regulatory dimension of all aspects of life, which defines the multiple ways in which, as individuals and as groups, we live in society. Queer authors showed how the social construction of time is impregnated with heteronormative prescriptions, in particular when it comes to meanings of adulthood and success. The discussion of chrononormativity (Freeman, 2011), that is, the normativity hidden in conceptions of time, will focus in particular on three aspects that are fundamental for the object of this study, young adults: reproduction, productivity, and happiness.

Finally, in the third section, I will expand the notion of chrononormativity to crip theory: recuperating the theoretical fundaments of crip theory outlined in the previous chapter, I will add elements that are specifically linked to the temporality of illness and disability in a crip perspective. Through this composition, I will finally propose how we can use the concept of queer-crip temporalities to analyse experiences. As we have seen in the very first part of the first chapter, chronic illness can be understood through the analytical lens of time. Queer-crip temporalities thus provide a more complete theoretical frame in which the experiences of chronic illness that intersect with other positionings, namely Southern-European geographical provenience, early adulthood, and LGBTQ+ identification, can be understood in their intersectionality.

1. Queer: theory, politics, epistemology

> It was all very queer, but queerer things were yet to come.
> (Billy Wilder, *Sunset Boulevard*, 1950)

1.1 A star is born. A brief history of queer theory

In 1991, the North-American journal *differences*, curated by Teresa de Lauretis, published a special issue titled *Queer theory: gay and lesbian sexualities* that gathered the contributions presented at the conference organised in 1989 at the Santa Cruz University. Although this is considered the formal landmark that gave birth to queer theory, the special issue gave voice to ideas that had been circulating for some time within the cultural studies and sexuality studies. Several elements created the conjuncture for their emergence. In the first place, identity politics emerged in the 1980s, in particular as a response to Stonewall riots and the AIDS epidemic had encouraged special attention towards issues related to discrimination and sexuality. Within a wave of institutionalisation of minority studies in the universities, gay and lesbian studies established as a field of knowledge as well. Moreover, the North-American academic context welcomed the postmodern deconstructionism of the French School (Derrida, 1967; Foucault, 1978) that integrated sexuality into a broader discourse on power and identity in construction. Creating a connection amongst these different influences, Bérubé and Escoffier (1991), Butler (1990; 1993), Duggan (1992), Warner (1993), and others began to question the turn of the lesbian and gay movement into identity politics and how sexuality could be considered at the centre of practices that contested the heterosexual norm.

The term *queer*, until that point, had meant “weird”, “strange”, “odd”, “out of place”. It recalled both a sense of upset puzzlement towards something that was not easily identifiable. Since the end of the XIX century, it was also used as an insult for homosexuals: *queer* denoted something – and someone – who was not aligned, normal, or proper. Therefore, the choice of such word to shape a theoretical approach was in itself quite a queer one: it signalled the political intention to re-signify a history of oppression and subvert the common victimising notion of diversity (Arfini & Lo Iacono, 2012). Queer theory aimed at questioning the naturalisation of heterosexuality, disrupting dichotomic thinking (heterosexual/homosexual; man/woman), and discussing the fluid relations between identity, identification, and sexuality.

After almost 30 years, however, it would be hard to refer to queer theory as if it comprised a unitarian *corpus* of debate. It is more appropriate to refer to "queer theories", or "queer studies" to give justice to the multiplicity of contributions produced since then. During three decades, queer theories travelled inside and outside academia and contaminated art, popular culture, and public space way beyond the white, middle-class, educated North-American élite in which it was born. The bond with activism was always very strong.

The constitutive elements of queer theories emerge from the multiple theoretical references they engaged within their constitutional phase. The influence of feminist theory was undeniable, in particular with the works of lesbo-feminists Sedgwick (1993), Rich (1980), and Wittig (1992), which discussed heterosexuality as a matrix of power and gender not as a natural fact but as the result of social constructions. The contributions of postcolonial and black feminism were also significant (Anzaldua, 1987; Crenshaw, 1991; Davis, 1971; hooks, 1984).

In the same way feminism(s) unveils the pervasiveness of gender and heterosexuality and insists on using them as categories of interpretation of social reality, queer theory uses the discourses and representations of sexuality to decipher social relations. Hence, queer perspectives are not limited to a narrow understanding of sexuality:

> Every person who comes to a queer self-understanding knows in one way or another that her stigmatization is connected with gender, the family, notions of individual freedom, the state, public speech, consumption and desire, nature and culture, maturation, reproductive politics, racial and national fantasy, class identity, truth and trust, censorship, intimate life and social display, terror and violence, health care, and deep cultural norms about the bearing of the body. Being queer means fighting about these issues all the time, locally and piecemeal but always with consequences. (Warner, 1993: xiii)

In queer theories, the theoretical interest shifts from heterosexuality to heteronormativity described as a system of oppression based on the social construction of heterosexuality and gender conformity as the natural, normal, and only orientation possible (Butler, 1993). Heteronormativity is designed as the regulatory system that defines normalcy according to the presumed natural laws of heterosexuality and gender-conformity. Queer theories explore how heteronormativity works in complicity with other systems of normalcy (racism, ageism, class, able-bodiedness) and what meanings are ascribed to gender and sexuality through these intersections.

Besides such an intersectional perspective, queer theories are also based on a deconstructionist approach that owes much to the works of Derrida (1967) and Foucault (1978). By acknowledging that power also works through naming and defining, queer theory resists firm categorisations and insists on the shifting character of identities (Butler, 1993). The objective is not to dissolve all differences into a non-identity: on the contrary, it is to acknowledge all the nuances within a continuum of gender and sexuality (Fraser & Olson, 2008). Sexuality represents the result of a process of construction that lasts all life long and involves sexual orientation, gender identity, sex practices, affect, and relations:

> 'sex' is a regulatory ideal whose materialization is compelled, and this materialization takes place (or fails to take place) through certain highly regulated practices. In other words, 'sex' is an ideal construct which is forcibly materialized through time. It is not a simple fact or static condition of a body, but a process whereby regulatory norms materialize 'sex' and achieve this materialization through a forcible reiteration of those norms. (Butler, 1993: 1)

Deconstruction is related both to the method (the way through which we make theory) and to the content (the way social relations constitute the normative scripts). Deconstruction recognizes sex, sexuality, and orientations as cultural constructs, and focuses on bodily performances, as sites where norms are questioned, incorporated, or rejected. This process is different from the processes of identification at the basis of gay and lesbian studies and of much gay and lesbian activism during the 1980s and 1990s: in fact, queer perspectives questions the immediate connections between identity and identifications as two different phases of a continuous process (Fraser & Olson, 2008). This is not to say that queer theory lacks interest in the way gay and lesbian people live: as Warner affirms, however, “people want to make queer theory, not just to have a theory about queers” (1993: xxvi). Hence, queer theories constitute a ground to interpret homosexuality within the frame of heteronormativity but also to analyse how gender and sexuality matter in the intersectional construction of other power relations.

1.2 “We're here, we're queer, we riot”[3]

Deconstruction and intersectionality orient the theoretical understanding of queer: however, they also constitute the ingredients for the constitution of queer political practices. The meanings of queer extend to “a theory, an adjective, a noun, a verb, and/or a political practice” (Di Feliciantonio, 2014: 27). As a gaze to the world that celebrates differences and disrupts fixed meanings, queer represents a symbolic site where translations are constantly possible. If a translation is the space of redefinition and re-articulation of unknown and unexpected meanings, *queer* can be considered as a translation of itself, to the extent that it engages in an endless re-articulation of the silenced (Burton, 2010). However radical and critical in its original sense, it shall not be forgotten that the word “queer” contains the traces of the specific social and cultural context in which queer theories were first formulated: a white, middle-class, academic environment in which the main language was English (the *lingua franca* of globalisation) and proposing a theoretical standpoint against dominant discourses was possible only from a position of privilege (Bourcier, 2012).

The specificity of the context that originated queer theories creates the need for adjustments when the transposition is made into different contexts and languages. Not surprisingly, the effects of such adjustments are controversial. On one side, it leads activists to engage in a more general process of cultural translation that involves all the meanings, signs, and historical elements contained in the word *queer*. Through the acknowledgement that translation leads to the failure of an exact transposition, queer activism becomes the site of a complex translational process, what Derrida described as “reinterpretation, rework and deconstruction” (*apud* Lugarinho, 2001: 42): the failure of efforts to translate is made visible and becomes part of the process of renegotiation of

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[3] This is a famous slogan used by the activist group Queer Nation (Warner, 1993).

meanings itself. It is a process that involves a political practice located in the "third space" (Bhabha, 1994), where translation constitutes a creative approach coherent with the pyrotechnical potential of queer (Bento, 2006). In some cases, translations made cherish the specific context in which *queer* was firstly enunciated and adapt it to local contexts, without falling in the trap of a rhetorical authenticity. It is the case of the Spanish translations into "etica marica" (Vidarte, 2007), the Italian "teoria frocia" (Pustianaz, 2006), and the Brazilian-Portuguese "teoria cu" (Pelúcio, 2014). More than a single translation, then, *queer* gives rise to different translations in the same local context. It also stimulates practices that stress the heteronormative traces of language, for example, through the use of graphic signs such as "@", "*", "/", "x" to disrupt the binary between feminine and masculine.

Conversely, the impossibility to convey the meaning of the word in all its nuances created what Pelúcio (*ibid.*) defines as a "process of cleansing": in her analysis, the author advances that the English version of the word allowed the introduction of sexuality and gender in curricula in Brazil that would have not been so easy had it been used its Portuguese version. In some cases, indeed, queer was cleansed of its original troublesome meaning and ended up to "sound more like a caress than an offence" (*ibid.*: 30). In its international political use, the word recalls something contemporary, coming from the Global North, that sounds better than the acronym LGBTQAI (Bourcier, 2012; Dehesa, 2010). In Italy, it looked like the arrival of modernity (Bernini, 2017). Therefore, in international politics arena, in particular in the debates on human rights, *queer* acquired the function of an "umbrella term" for all identities which do not fall into the cis-heterosexual norm (Sabsay, 2013; Thoreson, 2011). Moreover, it was deployed to support assimilationism and homonationalism (Duggan, 2004) and to offer a globalised image of *queer* as a universal category. These aspects are in deep contradiction with the radical claim ascribed to the original word, to the point that the meaning of queer itself needs to be deduced by readers through a deep reading of the context in which the word is placed. Moreover, the impossibility to translate the term was often used to "circumvent the usual automatic exclusion and secure access to the public sphere, including knowledge production areas" (Bourcier, 2012: 97).

The intra-cultural translations of *queer* generated a variety of political practices, perspectives, and manifestos. The way queer theories informed the local activist movements and the struggles of LGBTQ+ groups in different contexts is the reflection of its pliability in the engagement with otherness. The dislocation of the theory towards politics transforms queer theories also into ethics, a way of being in relation to other individuals (Bernini, 2017). Hence, besides the long-standing closeness with feminism and transfeminism, in local contexts queer practices were engaged with indigenous struggles (Dehesa, 2010), anti-globalisation/anti-capitalist movements (Peréz Navarro, 2014), squatting collectives (Di Feliciantonio, 2014), undocumented migrants (Pieri, 2016), and movements for the rights of disabled people (McRuer, 2018). At the centre of such political practices persists the orientation towards the right to choose and to self-determination, the central aspect in all the declinations of queer (Richardson, 2017).

1.3 Queering the world: an epistemology of deviation

In the introduction to his influential book *Cruising Utopia*, Muñoz defines queer “not simply a being but a doing for and toward the future” (2009: 1) and provides a reading of queer as an inclination, an epistemology. This inclination turns evident in the use of *queer* as a verb: “queering something” describes the act of looking at it from a queer perspective to identify its twisted sides and let the unknown story emerge.

The epistemological move towards *queering* the world unveils important aspects of the queer political project and some of its limitations. In the first place, it suggests that potentially any aspect of social reality can be queered. If we imagine queer epistemology as the equivalent of wearing a pair of glasses, anything we look at can potentially be seen in its queer side. This posture encourages the mutual contamination of queer perspectives with other fields of knowledge:

> The ‘futural imaginings’ of queer theory lie […] in scholars’ use of it for interrogations of all normative and non-normative acts, identities, desires, perceptions, and possibilities, for those relating not even (directly) to gender and sexuality. (Giffney, 2004: 74)

Queer theories expanded its influence on various topics and disciplines, from international politics (Weber, 2015) to environmental issues (Clare, 1999), from religion (Taylor & Sowden, 2014) to human rights (Thoreson, 2011). Ahmed (2006) indicates that queer epistemology is interested in identifying the deviation lines to read hegemonic grids. It relates to a constant deconstruction firmly unwilling to stick with fixed terms. This perspective values the grammars of resistance inscribed in social relations even and foremost when sexuality is not at their centre (or, at least, it seems not to be). More than focused only on what lies behind heterosexuality, queer perspectives point to unveil the face of normativity. If normalisation is a way to be oriented in the "right way", the straight line of heteronormativity, then queering the world means to inhabit a space of permanent disorientation:

> Disorientation involves failed orientations: bodies inhabit spaces that do not extend their shape, or use objects that do not extend their reach. At this moment of failure, such objects 'point' somewhere else or they make what is 'here' become strange. (*ibid.*: 160)

In this space of contestation and disorientation lies the premise for the connection between the act of *queering* and the one of *cripping*. "Queering something" is about understanding how it has the potential to "disturb the order of things" (*ibid.*) or how relations and representations in which it is embedded presents breaches through which the unexpected, the disorienting, or the twisted can happen. This process is not immune from the risk of romanticisation (Giffney, 2004): it is not about looking for deviation or resistance at all costs, but more about remaining open to the fact that deviation and resistance may lie where less expected (Halberstam, 2005). After all, as Butler signals, queer is a term that can never fully be exhaustive:

> If the term 'queer' is to be a site of collective contestation, the point of departure for a set of historical reflections and futural imaginings, it will have to remain that which is, in the present, never fully owned, but always and only redeployed, twisted, queered from a prior usage and in the direction of urgent and expanding political purposes. (1993: 228)

Therefore, queer epistemology exists only as long as it keeps open to the existence of several points of departure and not a definitive point of arrival. The act of looking for ways to be queer, or to queer, is, in itself, a potentially queer one: “queers do a kind of practical social reflection just in finding ways of being queer” (Warner 1993: xiii).

2. “Anything you like with the clock”: time as normalcy

> “I dare say you never even spoke to Time!”
> “Perhaps not,” Alice cautiously replied; “But I know I have to beat time when I listen to music.”
> “Ah! That accounts for it” said the Hatter. “He won't stand a beating. Now, if only you kept on good terms with him, he'd do almost anything you like with the clock.”
> (Lewis Carroll, 1865)

2.1 We are time: chrononormativity

In *The condition of postmodernity*, David Harvey (1980) affirms that we experience time as a natural part of life to the point that we forget that it is socially constructed. Elements such as progress, austerity, gratification, postponement, and immediacy are assigned meanings that are underpinned by normative ideals. Time is a function of normalcy and regulates every aspect of human life:

> Time comprises a net in which phenomena suddenly appear in a wholly different light. These phenomena include feelings, memories, happiness, language, scholastic and professional achievements, one's sense of self, consciousness, stress, mental illness, and mindfulness of one's own self and body. (Wittman, 2015: xi)

In other words, we are time and time is everywhere. Therefore, the relations we establish with time determine the relations with the social environment in which we live. Since the emergence of positivism, Western countries inflected the concept of time towards a vision of universality and linearity. The logic of universality is based on the idea that Western time is the better system available and that it constitutes a natural fact disjoined from socio-historical influences. However, not only Western time is not the only existent, but, “if we take the world as our unit of analysis, it is not even the most commonly adopted” (Santos, 2006: 251). For example, in some Pueblos in Southern

America, there are no words to express the notion of “not having time”: what people usually say would be something similar to “my path didn’t take me there” or “I couldn’t find a path to that” (Lakoff & Johnson, 1999). Similarly, the conception of time as circular is common in many non-Western cultures (Santos, 2006). In Chinese tradition, for example, the onset of an illness is interpreted as a natural manifestation of a phase in time and not as a rupture (Shippen, 2016). The organisation of time as we know it today dates back to the Middle Age when Benedictine monks began to divide time into fixed sets of tasks. The change overturned the rhythms of nature in favour of the human organisation. This division of time was then adopted in Europe and, later on, in North America. Clock time was standardised for the first time in 1884, with the definition of Greenwich as meridian zero. The Earth was ideally divided into twenty-four equal zones, each one linked to a specific hour: “its establishment constituted the beginning of the global day, a day made up of the same disembedded twelve hours irrespective of context and number of daylight hours” (Whipp *et al.*, 2002: 13). In 1913 a convention signed by the Western countries ratified the adoption of the globally synchronised time set: through its adoption, time was not only divided universally but also measurable through standardised procedures.

Complementary to the logic of universality is the logic of linearity: it presumes that time is projected like an arrow that goes from the past to the future in a coherent succession of events. Life itself is determined as a linear path with some steps in between birth and death:

> It's no accident that teleology is so crucial to our imaginings of time: we're born and then at the end, yup, we die. In between we seem to go from 'prematuration' to maturation to aging and decay: concepts like growing, then growing up, then ageing, getting old, and dying sketch a predictable, inevitable, irrevocable timeline. (Freccero in Dinshaw *et al.*, 2007: 193)

The principles of universality and linearity are not just ways to regulate time: through the organisation of time, they also organise social and individual living around principles of normalcy. Freeman coins the term “chrononormativity” to describe the link between time and normativity: it refers to the “use of time to organize individual human bodies toward maximum productivity” (2011: 3). In her perspective:

> Temporality is a mode of implantation through which institutional forces come to seem like somatic facts. [...] We achieve comfort, power, even physical legibility to the extent that we internalize the given cultural tempos and timelines. (Freeman, 2007: 160)

Time is so ingrained in cultural definitions that the way we relate to it defines our legibility and acceptability within a social group, from the micro-scale of interpersonal relationships to the macro-scale of state regulations. With regulation comes the encouragement of certain practices to the detriment of others:

> Corporations and nation-states seek to adjust the pace of living in the places and people they take on: to quicken up and/or synchronize some elements of everyday existence, while offering up other spaces and activities as leisurely, slow, sacred, cyclical, and so on and thereby repressing or effacing alternative strategies of organizing time. (Freeman, 2011: xii)

Time hence represents the pace of normalcy, to the extent to which it is a socially constructed set of representations and narratives that shape the boundaries of liveable lives (Butler, 1993). The rhetorics about time and its deployment in society are always connected to a political inflection: as such, we can speak of “chronopolitics” to define how power and oppression are also exercised through time. I will focus on three aspects of chrononormativity that are particularly important for the present study and will provide bearings for the analysis of the empirical data: reproduction, productivity, and happiness.

2.2 Good (re)productive citizens

The first aspect of chrononormativity is linked to the social expectation towards reproduction as both a regulatory practice of society and a gate of access to full citizenship. From a temporal perspective, reproduction represents the possibility of establishing a connection between the past and the future, and a guarantee of continuation of linear genealogies. However, “reproductive time and family time are, above all, heteronormative time/space constructs” (Halberstam, 2005: 10). The expectation of reproduction is moulded on the heterosexual (and gender normative) couple model. For the temporal principle of linearity, life is supposed to follow a determined path: we are supposed to be born from a heterosexual reproductive couple and stay under their control through childhood and adolescence; then we are expected to reach adulthood, reproduce within a heterosexual couple, educate our offspring and die. These steps are the contribution we are expected to provide to the common future of humanity and the survival of our community. This temporal pattern reproduces heteronormativity through performative repetition:

> Heterosexuality becomes a social as well as familial inheritance through the endless requirement that the child repays the debt of life with its life. The child who refuses the gift this becomes seen as a bad debt, as being ungrateful, as the origin of a bad feeling. (Ahmed, 2006: 86)

Through the special link of inheritance and family bond between parents and offspring, the chain of reproduction is repeated within the times suggested by the cultural norm of repronormativity (Santos, 2018b). Repronormativity encourages certain forms of reproduction instead of others and establishes:

> The assumption, expectation and cultural demand that biological procreation should occupy the centre-ground of the social formation, that intimate relationships, sexuality and the wider organisation of the social should be driven by, and structured around, a naturalised notion of a primary, fundamental procreative imperative. (Roseneil *et al.*, 2013: 3)

The procreative norm is fundamental in the regime of access to full citizenship, to the extent to which it encourages reproduction amongst those who are considered good citizens, whilst discouraging reproductive politics amongst those who deviate from the heterosexual and gender normative couple. It also impacts differently women and men: the gendered division of procreative expectations unfolds also in gendered differences in expectations around care and education. The good citizens are properly procreative in the proper time frame, which coincides with the cultural boundaries that limit adulthood. Hence, for example, having a child during adolescence is considered a disgrace and becoming a parent after a certain age even obscene.

The debate over reproductive norms involved queer theories and LGBTQ+ politics: the struggle for the extension of reproductive rights to homosexual couples, transgender people or single parents, together with the advancement of new reproductive technologies produced tensions in the narrow definition of proper reproduction and provoked the need for a discussion of these terms in light of new understandings of reproductive politics (Franchi & Selmi, 2020; Lasio *et al.*, 2019; Santos, 2018b).

The second aspect of chrononormativity is centred on productivity. The separation between work and leisure, production and fun, activity and sleep, is normatively prescribed to the point that its maintenance is considered a recipe for success or failure. Several authors underlined how the consecration of linear time as dominant served the purposes of Modernisation and enhanced the development of capitalism and colonialism in Western societies (Adam, 1995; Santos, 2006; Shippen, 2016; Whipp *et al.*, 2002). Overcoming the natural state meant to be able to exploit human forces to produce more and produce everywhere. Through processes of abstraction, de-contextualisation, and rationalisation of time, modern Western countries created a system in which time served human rationalism and economic expansion (Whipp *et al.*, 2002). The notion of disability itself was coined throughout this process, as the inability to perform as a proper worker (Martins, 2006).

Nowadays, the way capitalism controls time goes well beyond the mere division of labour, a phenomenon that Shippen defines as the colonisation of time: “the social use, meaning, organisation, and experience of time are dominated by the needs of capital, rather than the needs of human beings” (2016: 2). Every part of the day and every phase of life are regulated through their relation to productive work. This division of time is impregnated with racism, sexism, and ableism. For example, the relation between power and time is inversely proportional: successful people are also people with less time than the others, or whose time is entirely regulated by the rhythms of their jobs. However, they are also able to pay for services that will make them save time, such as housekeeping, cooking, cleaning, driving: these services are usually provided by racialised and underpaid workers (Gopinath, 2007). Similarly, queer subcultures that celebrate fun through night parties are deemed morally deviant not only because of their gender and orientation but also because they commit to leisure in times in which proper workers are sleeping (Halberstam, 2005): by subverting clock times they threaten the social order. People with disability and chronically ill people face enormous difficulties in finding jobs: in fact, workplaces are centred around standard rhythms and are not flexible in accommodating other velocities

(Kafer, 2013). Chrononormativity hence works as a conjuncture of different systems of compulsion in the construction of socially acceptable citizens who are reproductive, productive, and respectful of the social rhythms.

2.3 The duty to be happy and the obligation to get well

The third interesting aspect of chrononormativity is the expectation to have a good life. While we could affirm that the expectations on reproduction and productivity have always been present in Modern Western time, this one emerged only in the last two decades. The Judaic-Christian religious influence, together with the growing individualism, contributed to the diffusion of metaphors that depict a good life as a journey of improvement (Lakoff & Johnson, 1999): life is conceived as a path in which everyone has the moral duty to have a purpose and to self-improve their abilities. The lack of direction is considered a moral failure. More than a real choice, pursuing a good life is a social duty.

In the last two decades, there has been a growing interest in happiness as a topic of research and debate in different disciplines. Happiness is associated with ideas over the meanings of having a good life. However, the apparent consensus over what happiness is (or should be) is formed through the conjunction of the normative imperatives linked to reproduction and productivity. The science of happiness is based on a performative tautology: “by finding happiness in certain places, it generates those places as being good, as being what should be promoted as good” (Ahmed, 2010: 6). The duty to be happy insists that happiness lies in symbolic places where we are expected to look for it: for example, marriage, parenting, and success. This conception reassures us over the unpredictability of life and reminds us that if we try hard we can find a purpose in life: this way, “happiness becomes a question of following rather than finding” (*ibid.*: 32). Achieving happiness means being well oriented in time towards the directions that are considered inherently right and is the result of the ability to stay in line with this orientation without deviations:

> The unhappiness of the deviant has the powerful function as a perverse promise (if you do this, you will get that!), as a promise that is simultaneously a threat (so don't do that!). Happiness scripts are powerful even when we fail or refuse to follow them, even when desires

> deviate from their lines. In this way, the scripts speak a certain truth: deviation can involve unhappiness. (*ibid.*: 91)

The happiness duty is also declined towards the expectation to take care of our wellness. Western contemporary societies are impregnated with the imperative of self-care: “increasingly, citizens are expected to assumer a 'positive outlook', to remain 'hopeful', and to play an active role in the project of advancing and optimising health” (Petersen, 2015: 4). The pressure over taking care of our bodies and minds is pervasive and takes the form of a moral obligation. This demand takes various forms but is everywhere, to the point of becoming a “wellness syndrome”: “today wellness has become a moral demand about which we are constantly and tirelessly reminded. Wellness has wormed itself into every aspect of our lives” (Cederström & Spicer, 2015: 3). This ideology is sustained by the remarkable growth of the industry connected to wellness, fitness, and beauty, together with the expansion of services linked to mindfulness, meditation, and therapy. If the happiness duty celebrates the normative paths of looking for a good life in a certain way, healthism relates a good life to the precepts of health and able-bodiedness. Implicitly and explicitly, the imperative of healthism depreciates the non-conforming, such as disabled, overweight, ill or depressed people, and condemns unhealthy practices, like smoking, drinking alcohol, or eating irresponsibly (Barnes & Mercer, 2010).

The imperative of healthism charges individuals with the responsibility of making an effort in getting better and for the potential failures in the process (Petersen, 2015). It obscures the social components that guarantee better access to healthcare and the intersections of class, gender, race, ability that influence the way individuals can or cannot choose to pursue a good life: the narrative of the individuals as creators of their destiny impedes to identify the social causes of oppression and put all the burden on the single instead of promoting collective improvement. In a contemporary version of the Latin *Homo Faber*, everyone is expected to do any effort possible to feel better, live better, and be better. The price for failure is guilt: perhaps unsurprisingly, it is directed to those who choose to live outside the imperative healthism or who do not have the resources to live up to these expectations (Ahmed, 2010). Therefore, this entire system represents a regime of bio-morality and bio-citizenship, where, if you are unemployed, it's not because neoliberalism or the economic crisis, it is because you're not trying hard enough and, if you're chronically ill, it's probably because you're not eating well or exercising. The profound consequences of this logic are the de-politicisation of choices and the individualisation of responsibility:

> Such depoliticization is absolutely central to the wellness syndrome, whereby happiness and health become the fundamental criteria for what passes as a moral life. Morality, here, is not just to do with your relation to other people; it is concerned with the relation to yourself, and especially to your own body. (Cedeström & Spicer, 2015: 30)

Within this regime, disability is interpreted as something that can be overcome through the right attitude or an extraordinary love for life - as it happens, for example, in the celebration of supercrips (Kafer, 2013). Similarly, illness represents the result of an unhealthy lifestyle that can be either prevented through responsible choices or overcome with a positive attitude. The result is the "obligation to get well":

> Designed to help maintain a sense of balanced wellbeing, whether that involves taking up a healthy eating habit, exercising more or improving our mindfulness skills. What all these activities have in common is a commitment to homeostasis and balance, to produce a functioning non-excessive person. (Cederström & Spicer, 2015: 89)

These imperatives shape a new form of citizenship "based upon the possession of an optimistic outlook and 'hopefulness'" (Petersen, 2015: 63).

Through the insistence on reproductive, productive, and healthist paradigms, chrononormativity determines specific expectations for each age of life. Unsurprisingly, they are particularly exacerbated in the entrance to adulthood: individuals are considered adults when able to have an autonomous relational life (coupledom and parenting), an independent income (job), and the capability to take care of their wellness (health and happiness) (Torkelson, 2012). While adolescent and old people are dispensed or prohibited from these commands, adults are expected to fulfil the normal path of life:

> In Western cultures, we chart the emergence of the adult from the dangerous and unruly period of adolescence as a desired process of maturation; and we create longevity as the most desirable future, applaud the pursuit of long life (under any circumstances), and pathologize modes of living that show little or no concern for longevity. (Halberstam, 2005: 4)

The ability to fulfil the normative path of adulthood is directly connected to an increased possibility to enjoy full citizenship and access to individual rights

(Roseneil *et al.*, 2013). Therefore, chrononormativity does not just constitute a way of organising time: it is a means of exercising power and oppression over some categories of people in favour of the reproduction of “good citizens” (Shippen, 2016).

3. Time as resistance: queer-crip temporalities

> The time is out of joint.
> (William Shakespeare, 1602)

3.1 Unproductive, unhappy, and failing: the queer art of time

Within the field of queer studies, a growing number of authors in the latest years reflected on chronopolitics. Their contributions aim not only to queer time through a critical discussion of chrononormativity, but also to consider what is the time for queers (Dinshaw *et al.*, 2007; Freeman, 2007; Edelman, 2007; Halberstam, 2005).

Living outside normative paradigms of sexuality, reproduction, and kinship inevitably changes the relation to space and to time (Halberstam, 2005): in this sense, LGBTQ+ people live outside chrononormative temporalities. One of the most blatant examples of this estrangement can be found in the time of the AIDS epidemic, when many gay, lesbian, and trans people faced a short and diminishing future. “It was a landscape for drifting”, wrote Wojnarowicz in his memoir of those years, “where time expands and contracts and vision is replaced by memories” (1990: 55). Halberstam (2005) argues that, while that time was undoubtedly a time of collective mourning, it also produced the circumstances for alternative networks of care and kinship emerge. Afterward, queer subcultures in different contexts of North America and Europe surfaced. Halberstam proposes to rethink the “epistemology of youth” which casts a sharp separation between youth and adulthood:

> Queer time for me is the dark nightclub, the perverse turn away from the narrative of coherence of adolescence - early adulthood - marriage - reproduction - child-rearing - retirement - death, the embrace of late

> childhood in place of early adulthood or immaturity in place of responsibility. It is a theory of queerness as a way of being in the world and a critique of the careful social scripts that usher even the most queer amongst us through major markers of individual development and into normativity. (in Dinshaw *et al.*, 2007: 182)

Although the focus is on queer young subcultures, the proposal offers a theoretical basis for a more general discussion of queer temporalities as forms of relations to time that challenge chrononormativity through opting out of the predicted steps. This perspective is supported by other contributions that engage with queer time as a way to live in the margins of norms:

> Queer time has long been colloquially understood to be about fifteen minutes later than the appointed time. [...] Living on the margins of social intelligibility alters one's pace; one's tempo becomes at best contrapuntal, syncopated, and at worst, erratic, arrested. (McCallum & Tuhkanen, 2011: 1)

The focus of queerness, once again, shifts from sexuality to a general way to be in the world. Being queer refers here to doing “too much of the wrong thing at the wrong time” (Kafer, 2013: 35), where righteousness is defined by normative ways of being in time and through time. It is a way to live the present in a way that disrupts the everyday temporal rhythms that revolve around family, for example (McCallum & Tuhkanen, 2011): queer time is more oriented to living in the rhythms of *Kairos (*the moment of opportunity) than in the pace of *Chronos (*the regular time). This could imply also spending actual time in activities and relationships that “seem pointless to people stranded in hetero temporalities” (Halberstam, 2005: 160) or that, in the chrononormative perspective, are considered a waste of time. Studies on the importance of friendship in LGBTQ+ communities, for example, show how LGBTQ+ people spend more time and investment on friendships in adulthood and old age than heterosexual people (Gusmano, 2018; Silvestri, 2016). Also, the narratives of individuals in non-monogamous relationships often refer to spend a lot of time talking, listening, and bonding to ensure wellness for all the people involved in the relational constellation (Gusmano, 2019).

Queer temporalities also refer to history. The LGBTQ+ community is often erased by official historical accounts and the homosexuality of important people of the past is rarely mentioned. The absence of these stories from history is not a sign that homosexuality or queerness did not exist in the past: on the contrary, it represents the outcome of a heteronormative understanding of historical time, in which LGBTQ+ in itself, as we know it today, was formed as a category through Modernity but remained silenced for a long time (Freeman, 2011). The idea that LGBTQ+ people live outside history is reinforced through the lack of archives and the invisibilisation of narratives from the past. Moreover, the history of LGBTQ+ communities still needs to be further explored through studies on how experience passes from one generation to the other, outside the heteronormative kinship models, and how queer pedagogy is staged (Dinshaw *et al.*, 2007). Attending to queer temporalities means to look to the past differently and try to retrieve all the hidden signs of queerness erased by mainstream history: “queer restaging of the past helps us imagine new temporalities that interrupt straight time” (Muñoz, 2009: 171). The study of the past as a collective narrative made of a variety of individual stories through a queer lens offers the opportunity to understand what gets lost in the heteronormative accounts of yesterday; moreover, it produces new imaginaries about what (a better) tomorrow could be.

Indeed, the preoccupation with queer futurities has been central in the debate on queer temporality. In *No Future*, Edelman asserts that the only way to inhabit a queer future is to refuse hope embedded in the reproductive promise, which he calls “reprofuturity” (2007). The author advocates for the need to embrace the negative drive intertwined to the notion of deviance, to which queerness has historically been attached. Also, he claims that queerness cannot be related to the space of reproduction, intrinsically heteronormative: “to refuse the insistence of hope itself as affirmation, which is always affirmation of an order whose refusal will register as unthinkable, irresponsible, inhumane” (*ibid.*: 4).

In Edelman's though, queerness as politics leads to reject the notion of future and to refuse to live within the logic of linear reproduction. This view generated significant debate and sparked an interesting discussion over queer futurities and the relation between reproductive politics and queer struggles, especially in a time in which LGBTQ+ activism was struggling to obtain the recognition of reproductive and parenting rights in many countries.

In a quite different perspective, Ahmed (2010) introduces the figure of the “unhappy queers” to recognize the shared queer historical genealogies. While the promise of happiness directs us towards straight lines, LGBTQ+ people choose a deviation from the predicted grid, a deviation that takes to a supposedly unhappy future. However, contrary to Edelman, Ahmed calls for a political overturn of unhappiness as an instrument of resistance:

> To be happily queer is to explore the unhappiness of what gets counted as normal. It is as if queers, by doing what they want, expose the unhappiness of having to sacrifice personal desires, in the perversity of their twists and turns, for the happiness of others. (*ibid*: 117)

Queer orientation to the future is characterised by the insistence on opting out of normative paths (Ruti, 2017) while being aware of the unhappiness that can be related to normalcy. However, this orientation is not necessarily immune to other forms of normativity: for example, homonormativity could be seen as a way to straighten a queer temporality towards the reproductive path, to reduce to a minimum the signs of queerness and hence to adhere to the expected lines (Hoang in Dinshaw *et al.*, 2007).

The inability (or the choice not) to follow the normal temporal line is at the basis of the construction of queerness as a failure:

> Queerness has always been marked by its untimely relation to socially shared temporal phases, whether individual (developmental) or collective (historical). More often than not, this connection remains defined in negative or hurtful ways, ways that reinforce queerness as failure to achieve the norm. (McCallum & Tuhkanen, 2011: 6)

Following this perspective, Halberstam (2011) develops the notion of a “queer art of failure”: queers have been cast in the world of failure and disappointment so consistently and for so long that they are exceptionally good in failing in multiple ways. In an attempt to join the criticism to heteronormative promises of happiness but also to go beyond the grim dichotomy between heteronormative happiness and negativity proposed by Edelman, Halberstam suggests that the orientation of queerness is a failure and this is not necessarily a pessimistic perspective:

> There is something powerful in being wrong, in losing, in failing, and [...] all our failures combined might just be enough, if we practice them well, to bring down the winner. [...] The concept of practicing failure perhaps prompts us to discover our inner dweeb, to be underachievers, to fall short, to get distracted, to take a detour, to find a limit, to lose our way, to forget, to avoid mastery. (*ibid.*, 121)

The geography of time constituted by failing queers constructs maps of happiness that can be achieved or, just, an aim towards which to orient. The queer art of failure is about doing all of this as a collective project, not incorporating the individual guilt that comes from the (re)productive and compulsory happy norms but overturning them in unexpected ways. Being unproductive, unhappy, or consistently failing represent possible ways out from the chrononormative path and construct a future in which there are alternatives to the linearity of time.

3.2 The brilliant imperfection of disability: crip temporality

Despite the reference to the AIDS epidemics of the 1980s as a queer time, the literature on queer temporalities surprisingly lacks further engagement with illness or disability. Crip studies, on the contrary, interrogate the meaning of time in relation to bodily ability through reflections that incorporate some of the contributions on queer temporalities.

The temporal dimension is crucial in the definition of illness and disability. Time is the semantic category most used to refer to symptoms (intermittent, acute, frequent), to duration (chronic, constant), to onset (congenital, acquired, sudden), and to prospects (diagnosis, prognosis) (Kafer, 2013). The language that constructs disability is mainly temporal. Following the argument explored by queer theories, Kafer explores whether it is possible to crip queer time and how disability influences the experience of time. She expands the notion of the heteronormativity of time to include able-bodiedness as a power structure that moulds social temporality. In a crip perspective, the notion of chrononormativity already necessarily includes heteronormativity *and* able-bodiedness. The expectations regarding reproduction, productivity, and happiness implicitly presume able-bodiedness: they are all based on the cultural perception of disability as an exception.

In the able-bodied construction of time, cure assumes crucial importance. The mainstream understanding of disability, impairment, and illness evaluate them in relation to the possibility of cure, the hope for a solution, or the attempt for an improvement. A cure is considered intrinsically good and believed to be a moral duty of the individual (Petersen, 2015). However:

> Within this frame of curative time, then, the only appropriate disabled mind/body is one cured or moving toward cure. Cure, in this context, most obviously signals the elimination of impairment but can also mean normalizing treatments that work to assimilate the disabled mind/body as much as possible. (Kafer, 2013: 28)

Instead of pushing for the critical dismantling of able-bodiedness, the frame of curative time insists on the exceptionality of disability and illness and reinforces the imperative of wellness (Cederström & Spicer, 2015). The neoliberal pressure towards bodily normalisation urges towards the hope for a solution to fix what is perceived as failing and unworthy. As Clare observes, the medical-industry complex is completely organised around the ideology that science can fix it all:

> The medical-industry complex is an overwhelming thicket. It has become the reigning authority over our body-minds from before birth with prenatal testing to after death with organ donations. [...] It diagnoses, treats, and manages the human life cycle as a series of medical events: birth, puberty, pregnancy, menopause, aging, and death, each with its own medicine. (2017: 69)

Through this perspective, chrononormativity acquires an additional nuance: it revolves around the organisation of heteronormative *and* able-bodied time to produce normalised individuals in all stages of life, from birth, through adulthood, to death. Inevitably, it is based on forms of symbolic violence that work through “changing the future by manipulating the present” (*ibid.*, 27). Echoes of this process can be found in the debate over selective abortion, which gives the possibility to abort later than usually allowed in case it is found that the future children will have disabilities (Kafer, 2013). Similarly, the forced sterilisations operated on disabled women in some countries are a reflection of the state's commitment to discourage reproduction outside the “proper” conditions (Santos *et al.*, 2019). The critique to curative time is not oriented to reject the beneficial effects of therapies and cures: it is used to highlight contradictions that cure involves. It is particularly important in the study of chronic illness, as I'll discuss further in this work, to the extent to which it unveils the centrality on diagnosis and the difficulty of embracing the chronicity of illness.

Crip temporalities are related also to the connections between disability and illness with a condition of nostalgia: the narrative of a lost or unknown state of able-bodiedness is reproduced in a wide majority of cultural representations of disability and illness. It is almost a nostalgia for a past which contains all the ideal elements that cannot be found in the present reality. The assumption that animates this view is rooted in the idea that disability cannot be a desirable location. The image of a before and an after is common especially in the typical overcoming narrative of interrupted lives, where the disabled experience is reduced to a story of personal tragedy (McRuer &Wilkerson, 2003). However, as I have discussed in the previous chapter, it is also present in the literature on chronic illness that speaks of it as a disruption (Bury, 1982). As Kafer points out, "these lost pasts are compulsory hypernormative in that they are presented as futures disabled people would give anything to inhabit" (2013: 44). The power of loss and mourning for a lost body can be seductive, even for someone that has never known able-bodiedness, because it promises an imaginary time travel that takes back to a normal condition (Clare, 2017). However, it is also tricky, because, in the end, it only reinforces the stereotype about disability and illness as obvious problems and able-bodiedness as a solution.

If the past is twisted towards the promise of able-bodiedness and the future moulded on the hope for cure, how can we crip (queer) time, then? The answer to this quest is oriented to create connections between queer temporalities as failure and crip time as "liminal temporality, a casting out of time" (Kafer, 2013: 36). The practice of imagination that goes beyond a mere critique of normalisation or an idealised state of deviation offers interesting insights on possible directions for crip time. In the first place, crip temporalities are also examples of times outside the chrononormative directions: times that run on a different pace, an alternative speed. Perhaps it is not by coincidence that "retarded" is one of the most common insults addressed to mentally disabled people. Indeed, disability and illness imply that more time is needed to do common activities, or that the time that is considered right to do something is calculated on the able-bodied standard (*ibid.*). Crip temporalities reveal the able-bodiedness that saturates all cultural definitions of time and unveil the diversity of definitions that can refer to slowness, rapidity, rest, work, success, and leisure.

Kafer also insists on the political importance of imagining crip futures as a form of responsibility towards all the disabled and ill people that are erased by mainstream time, “rendered as signs of the future no one wants” (*ibid.*: 46). Clare (2017) resounds this argument by reflecting on the difficulty of actually imagining what a restoration of body/mind would mean in terms of self-identity, especially for someone who has always lived in a disabled body. Describing the puzzlement of people that don't receive a positive answer to a question like “If there was a pill to cure you from your disability, wouldn't you take it?”, Clare affirms: “I would lose so much if that imaginary cure pill actually existed. Its absence lets me be unequivocal. It opens the door for brilliant imperfection” (*ibid.:* 88).

The notion of “brilliant imperfection” echoes directly the “queer art of failure” coined by Halberstam (2005): a figuration of failure which is actively speaking from a place of imperfection and that leaves space for imagining disability not as a disappointment but as a different form of embodiment with just the same possibility of being brilliant as the able-bodied one. Finally, a crip imagination of time cannot be unfolded as an individual mission: it requires to consider a collective effort of all those who have been excluded by chrononormative patterns. It involves a political project:

> The disability to come...will and should always belong to the time of the promise. [...] It's a crip promise that we will always comprehend disability otherwise and that we will, collectively, somehow access other worlds and futures. (McRuer, 2006: 208)

The imagination of crip times is not about refusing the promises of the future or about opting out from disability: it is about creating a collective archive of imaginaries that put disability in a different place from the victimising, passive, and unworthy role. It is about thinking disability out of (normative) time but always perfectly on time to be brilliant.

3.3 A proposal for queer-crip temporalities

Queer and crip perspectives challenge the normative understanding of time and indicate temporalities as a possible space of resistance against heteronormativity and able-bodiedness. However, how can this resistance be practiced? How can we think of time outside linearity? Are all non-linear temporalities inherently queer-crip? As discussed earlier in this chapter, queer epistemology advances that posing these questions is already part of queering the issue: hence, the aim is not necessarily to come to conclusive answers on the topic. The objective is more focused on sketching some possible connections in the designation of queer-crip temporalities to define recurrent issues and critical aspects of the debate, accepting that queer-crip signs may be found where least expected. In this section, I will present what I believe are the key elements for a queer-crip understanding of time.

If the normativity inscribed in common uses of time can be challenged, its reinvention needs to go through a queering and cripping process of the mutual links between past, present, and future. We cannot rethink the future without engaging in a critical discussion of how the past is narrated and how the present is directed to structure the future. This elaborated process of discussing all time at the same time is a queer operation in itself:

> The political task is to make the future, to invent it. And this space, and time, for invention, for the creation of the new, can come about only through a dislocation of and dissociation with the present rather than simply its critique. Only if present presents itself as fractures, cracked by the interventions of the past and the promise of the future, can the next be invented, welcomed and affirmed. (Grosz, 2004: 261)

The dislocation of the present implicates an active intervention on the past, through, for example, the recuperation of historically silenced narratives of disabled communities or the construction of LGBTQ+ archives. In doing so, we create a counter-narrative oriented to a non-linear vision of time, in which the past, the present, and the future are always simultaneous causes and consequences one of the other. However, learning to think outside linearity triggers some challenges:

> Thinking nonlinearity over and against linearity is hard enough, but figuring out the criteria by which different nonlinear temporalities might meaningfully be brought together - figuring out how to make heterogeneity analytically powerful - is exponentially harder. (Dinshaw *et al.*, 2007: 186)

Besides, not all non-linear imaginings can be considered inherently queer-crip. For example, the relevance of queer temporalities is diminished when it does not include able-bodiedness as a system of compulsion that moulds time together with heteronormativity. It is significantly irrelevant also when we consider queer experiences in their hypothetical unity and not in their intrinsic diversity. McBean, for example, underlines that:

> What seems finally significant here about queer temporality theory is its commitment to exploring the ways in which a sense of community might be felt despite or in the face of the absence of models of generation, inheritance, or futurity. (2016: 150)

Similarly, the critique of the times of disability and illness, in particular curative time, cannot dismiss *tout court* the importance that cure, therapies, and hope hold in the life of disabled and ill people nor it can disapprove their choices to invest in improvements of their condition (Clare, 2017). Together, queer-crip temporalities are about embracing multiplicity, not fostering a romanticised version of unicity which would end up being nothing but another form of normative dogma.

Finally, queer-crip temporalities activate new imaginaries directed not only to future directions but also to past and present orientations. This imaginative potential is intrinsically political and generative, for it seeks to undo current hierarchies and to propose alternative routes. It is not directed to a negative rejection of any commitment to time, as Edelman (2007) proposed; on the contrary, we can use it to imagine different scenarios, all equally valid and unstable. In this political project, failure and imperfection are points of departure, not definitive arrivals. Muñoz, for example, reminds that:

> Within straight time the queer can only fail. [...] The politics of failure are about doing something else, that is, doing something else in relation to a something that is missing in straight time's always already flawed temporal mapping practice. (2009: 174)

Queer-crip time is a collective temporal distortion: a shared responsibility that involves all those who feel out of time and out of place in the "straight time's temporal mapping". Thinking about queer-crip temporalities, hence, means most of all to accept and embrace the perspective that the time we live in is not the only possible and that there is another way to look at it and to practice it, a way which includes all the bodies and the practices that are (normatively) considered failing or imperfect. We can thus achieve a different understanding of the many forms of failure:

> Cure dismisses resilience, survival, the spider web of fractures, cracks, and seams. Its promise holds power precisely because none of us want

> to be broken. But I'm curious: what might happen if we were to accept, claim, embrace our brokenness? (Clare, 2017: 160)

Queer-crip time the time for accepting brokenness, and, within the fractures created by the supposed failures, encountering the space to thrive. It could involve recuperating the notion of aspiration, as Ahmed (2010) suggests, as a leading guide to struggle for a good life. In her proposal, aspirations are what guide queer struggle to imagine a bearable life. They need to have a form to be effective in transforming the time we live in: “We could remember that the Latin root for the word aspiration means 'to breathe'. I think the struggle for a bearable life is the struggle for queers to have a space to breathe” (*ibid.*: 120). If the struggle for queers is to find the free space to breathe, I advance that the queer-crip struggle is to find the time to breathe, or, perhaps, the freedom to choose breathing times.

Conclusions

The discussion proposed in this chapter follows a multi-layered construction. The starting point, represented by queer theories, explores how and to what extent we can adopt a queer lens to understand normativity, not only in what relates to sexuality and gender but also and foremost in what concerns the relation of sexuality and gender *with* other positionings. Queer theories offer an insightful set of theoretical tools that orient deconstruction but, at the same time, also re-assemblages. Through the discussion of the pervasiveness of heteronormativity, queer perspectives also propose how to break, undo, and fail heteronormativity in ways that undermine its very basis. The second layer outlined the notion of chrononormativity as a device that constructs time through implicit expectations generated by heteronormativity. It is a fundamental notion to understand all those existences that are out of their time: not only LGBTQ+ people, as highlighted by queer theories, but also chronically ill and disabled people. The inflexion of chrononormativity influences history, present living, and future imaginings: to some extent, just as heteronormativity and able-bodiedness, it is everywhere and hence is perceived to be nowhere. The third layer of construction is indeed constituted by the time of disability and illness as analysed by crip studies: the temporal dimensions of bodily failures are put in relation with the chrononormative expectations on reproduction, productivity, and happiness. The time of chronic illness and disability is always “out of joint”, to say it with Hamlet: they follow timelines temporalities that are counter-normative.

The interconnection of these three layers creates the foundation to formulate a proposal for queer-crip temporalities. With this proposal, I aim to provide a theoretical frame of understanding for chronic illness *and* LGBTQ+ identification under a common temporality. Provided that both chronic illness and LGBTQ+ identifications are counter-normative in their temporalities, I am interested in understanding the forms in which these multiple counter-temporalities entangle. The proposal is to intervene on a space left empty by the debate on queer temporalities: surprisingly, the authors who developed a discussion on queer temporalities focus on different nuances of the notion of failure but do not include disability and illness amongst them. To my perspective, this constitutes a significant missed opportunity and an example of the compulsory able-bodiedness that still permeates academic research. Secondarily, the notion of queer-crip temporalities elaborates on an intersectional encounter between sexuality, gender, disability, and illness through a composite fractal of entrances. Time seems to constitute a possible unifying terrain in which the intersections among these different elements can be discussed in all their surprising entanglements and unexpected outcomes.

Time is always upsetting and pushing us in a position of discomfort, from which we are forced to face expectations, difficulties, and hopes. However, it is this discomfort, with its potential failures, that encourages us to go further to investigate it as a fundamental dimension of a queer-crip way to be in the world, as an ingredient to understand sexuality and illness in all their complex entanglements. The potential failure of such investigation is part of the process itself: we may discover that queer-crip temporalities do not reflect any of the experiences collected in this study or we may be confronted with the possibility that chrononormativity is so strong that there is not space for anti-normative temporalities. However, the attempt is worth to keep on wondering why “time is always allowed to harry one”.

3. THE CONTEXT OF ITALY AND PORTUGAL. LGBTQ+ RIGHTS AND ACCESS TO HEALTHCARE

Introduction

Does Southern Europe exist? And if so, why Italy and Portugal are comparable more than other countries? What makes them Southern European and comparable between themselves? The definition of geographical is always a matter of perspectives and, depending on who is providing the definition, Southern Europe is sometimes just constituted by Portugal, Spain and Italy, sometimes it includes also Greece, or even Malta and Cyprus. Whatever definition of Southern Europe we adopt, it is evident that we point out features that serve the aim of our study: "Southern Europe is a hermeneutical device designed to highlight a series of historical facts that enhance the potential for comparative work, more so than corresponding to any strict geographical area" (Trujillo & Santos, 2014: 14).

This chapter aims at explaining the similarities and the potential for comparative work that we find in Italy and Portugal societies when we approach the matters at the core of this study. Although this is not a pure comparative work and the discussion of the following chapters will highlight continuities and contradictions that sometimes fluidly resonate between the two countries, it is important to set the context in which the narratives collected emerge.

The image of Southern Europe as a whole is much linked to common traits of familism, Catholicism, and, recently, austerity politics. The first part of the chapter will thus explore to what extent this image corresponds to present Italy and Portugal. It will thus engage in a transversal overview of these themes between the two countries.

In the second part, I will focus on the development of LGBTQ+ rights first in Italy and then in Portugal. In this regard, the history of the countries diverges in some points dramatically: thus, it is particularly interesting to focus on the specificities of each.

The last part will provide a contextualisation for the rights of chronically ill people in the access to healthcare, work, and welfare benefits. As in the previous one, this discussion will regard Italy and Portugal separately to reinforce the aspects that are particular of each country.

1. Southern Europe: God, family, and austerity

> You can't find a job / but you kiss the crucifix (in Italy)
> The monuments / the churches full of paintings (in Italy)
> People with sentiments / countryside and crimes (in Italy)
> (Fabri Fibra feat. Gianna Nannini, "In Italia", 2007)

1.1 God: Catholic power and culture

In a famous speech released to selected journalists during a flight from Armenia in 2016, Pope Francis I declared that the Church should apologise to gay people for the way it treated them and added: "They [the homosexuals] should not be discriminated against, they should be respected, accompanied pastorally"[4]. The declaration caused surprise in Portugal and Italy where it was welcomed as a long-awaited sign of change in the way the Catholic Church considers homosexuality. In both countries, the presence of Catholic morality and the pervasive power of Catholicism in institutions and politics played a key role in slowing down the advancement of LGBTQ+ rights. The official positions expressed by Catholic authorities state that homosexuality constitutes an intrinsically disordered condition and that "God created human beings in his own image, meaning that the complementary sexuality of man and woman is a gift from God and ought to be respected as such" (in Lasio *et al.*, 2020: 30). The Catholic Church acknowledges that homosexual practitioners can reconcile their "deviation" with their faith through the practice of abstinence from sexual activities that are by all means considered sinful. Catholicism founds its morality on the naturalisation of the union between men and women, the dichotomic division of

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[4] Source: https://www.bbc.com/news/world-europe-36636845. Accessed on 07 Jan 2019.

gender roles, and the sacrality of the family. Catholic representatives consistently reinstate their opposition to same-sex marriage, adoption for LGBTQ+ families, and gender diversity (Toldy & Santos, 2016). However, both the Pope and some bishops in Italy and Portugal declared the unacceptability of discrimination.

Beyond the imperatives that regulate sexuality in the official documents, the presence of Catholicism and its influence in contemporary Italy and Portugal unravels on several levels. According to a study conducted in 2017, 91,9% of Portuguese people and 83,3% of Italian define themselves Catholic[5]. Despite such overwhelming numbers, the difference between identification and practice is quite significative, since many embrace Catholicism as cultural belonging but are not involved in religious practices. In Italy, for example, only 24,9% of the population interviewed declared to actively participate in religious events regularly (ISTAT, 2018). Both Portugal and Italy host a capillary network of institutions linked to the Church, such as schools, hospitals, universities, banks, nursing homes, charities, political parties, and other institutions. The pervasiveness of Catholic culture on society spread beyond the mere religious community and became part of the cultural *milieu* in which many in Italy and Portugal grow up. The historical roots of such presence were consistently reinforced during the fascist regimes that governed Portugal from 1926 to 1974 and Italy from 1922 to 1943. Both regimes were based on the foundations of “God, Nation, Family”, which reflected the patriarchal view of a natural family and a clear gender differentiation.

In Italy, in particular, for geographical and historical reasons, the influence of the Vatican as a political actor always extended to the entire parliamentary system and is still pivotal in addressing the public debate on specific topics, such as LGBT* issues, reproduction, women's rights, and bio-ethical issues (Grigolo & Jorgens, 2010; Bellè *et al.*, 2016; Bernini, 2008). As Lasio and Serri (2019) reconstruct, while the State renounced to consider sexuality under the control of its laws, through agreements with the Vatican it delegated to the Catholic Church the authority on morality and the ethical education of the country. Such powerful influence appeared evident during recent political debates on same-sex marriage in Italy (Lasio *et al.*, 2020) and Portugal

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[5] Source: http://www.globalreligiousfutures.org/. Accessed on 07 Jan 2019.

(Santos, 2013). In the last years, the so-called “gender crusades” became instruments of reaffirmation of a Catholic vision of gender and sexuality (Santos & Pieri, 2020): the Church and right-wing parties insistently attacked the supposed presence of a “gender ideology”[6] to impede sexual education programs in public schools and the promotion of gender diversity in childhood and adolescence (Toldy & Santos, 2016; Kuhar & Paternotte, 2017). Such phenomenons reinforced the discursive power of the Church in affirming conservative politics that still retain influence on public opinion about women's issues, LGBTQ+ politics, and sexuality.

The official discourse is countervailed by a great differentiation in individual attitudes and everyday practices. As Bertone and Franchi note, for example, concerning the tension between LGBTQ+ identification and Catholic faith, people employ “different, and often seemingly contradictory, cultural repertoires in order to combine, negotiate, or integrate what public discourse constructs as incompatible positions: acceptance of gay men and lesbians and Catholic belonging” (2014: 75). The authors encountered that individuals often make a distinction between the official Church and its base and invest in personal understandings of religious practice in the everyday. Even within the Church, there is a more liberal current that embraces the changes in society and the meanings of family (Bernini, 2008). Moreover, there are several informal networks of dissident voices and organisations that work on the encounter between the LGBTQ+ community and Catholic religion (Geraci, 2007). In these contexts, the principle of unconditional love contained in the Gospel is deployed as a guiding rule to welcome LGBTQ+ people. This strategy responds to a common process in Catholic countries, in which individual self-definition crafted as a personal quest turns the mediation of the church dispensable (Bertone & Franchi, 2014).

The influence of Catholic culture extends on discourses on illness and disability which are seen as proves sent by God to test faith. They ought to be faced with courage, resilience, and acceptance. In this perspective, there is no space left for action or personal will: Catholicism exacerbates the medicalised perspectives that victimises the ill and the disabled as pitiful, passive, and

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[6] Source: https://www.vaticannews.va/en/vatican-city/news/2019-06/vatican-document-on-gender-yes-to-dialogue-no-to-ideology.html. Accessed on 07 Jan 2019.

desexualised objects of care (Santos & Santos, 2017). Insisting on the theological foundation of a certain vision of illness and disability is a key passage to understand some of the traits of contemporary Portugal and Italy concerning care. Catholic institutions occupy an overwhelming presence in the area of health, assistance, and care. In 2010, in Portugal, there were 900 centres of Catholic education (from kindergartens to universities); other institutions belonging to the Church or run by religious groups included 34 hospitals, 155 clinics, 799 homes for the elderly or disabled, 462 centres for education and social rehabilitation[7]. In Italy, as well, the presence of charities, volunteer organisations, and networks of solidarity oriented to the care of disabled and ill people is capillary. Associationism was also born within a Catholic context and a tendency to dependency culture and paternalism still pervades the work of several organisations devoted to the care of the ill and the disabled (Martins & Fontes, 2016).

1.2 Family: when blood is thicker than water

Southern European countries are generally described as governed by strong forms of familism (Calzada & Brooks, 2013; León & Migliavacca, 2013; Santos, 1995; Portugal, 2016). However, the recursive use of familism as a key explanatory feature of social relations in these countries risks to flatten the many nuances in the social meaning of families in such countries. Data collected in the last years in Italy and Portugal clearly show the meanings ascribed to the idea of the family are changing and not linear (Bertone, 2020). The rate of civil marriage overcame the percentage of religious ones in both countries: in 2018, in Portugal, 67,5 of marriages were civil unions (1,8 were same-sex marriages) (Pordata, 2020); in the same year, in Italy, 50,1 marriages were not religious (Istat, 2019). Italian and Portuguese families present higher levels of intergenerational cohabitation and spatial proximity than in other European countries (Calzada & Brooks, 2013). In both countries, young people tend to stay in cohabitation with their families until a later age than their fellows in Europe. The average age of young people leaving the parental household is 30,1 years in Italy and 29,2 in

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[7] Source: http://thecatholicnews.sg. Accessed on 06 January 2019.

Portugal (Eurostat, 2020a). They are amongst the higher average age in Europe and they reflect a significant difference from Denmark and Sweden, where the average age is 21. The same set of data showed that 87.4% of young people aged 25-29 still lived with their parents. In Portugal, 61.6% of people aged 25-29 shared the house with their parents - a lower percentage than Italy but still high if compared to other European countries (Eurostat, 2020b). Such cohabitations impact rules, intergenerational relations, and conflicts: children have full adult status and claim freedom of choice in consuming practices, relationships, and sexuality, although rarely contributing to the common income (Saraceno, 2004). This aspect is particularly important for young LGBTQ+ adults that cohabit with their parents and need to negotiate their visibility within different tensions (Pieri, 2020).

If on one side, the meaning of family is becoming more and more disjointed by the one imposed by Catholic Church (Bernini, 2008), on the other, families retain their centrality as providers of economic support, care, and welfare services. Such dual nature of economic and caregiving units (Saraceno, 2004) has been a fundamental aspect in shaping the role of families concerning Welfare states. States acknowledge the role of informal welfare provided to the point of implicitly expecting families to intervene in the failures of public services (León & Migliavacca, 2013; Santos, 1995). Their informal partnership has historical roots in the pact between the nation and the family promoted by Fascist regimes; the Catholic church encouraged it in many ways through the history of the country (Bernini, 2008). Dependency between members of the family (intended as intergenerational and extended) is a shared value (Bertone, 2020); care for the older members of the family, children, the ill, or the disabled is considerably sustained by the unpaid work of women, in a gendered division of labour which showed very little change across decades (Da Roit & Naldini, 2010). Welfare states, especially in the case of Italy, are organised around this gendered division and women receive social benefits as carers more so than as workers. Families also provide the main insurance for risks not covered by public welfare (Calzada & Brooks, 2013). Especially for what regards the care for disabled and ill people, the State relies heavily on assistance by families: personal assistance is not automatically granted as an individual right. Care is provided through everyday relationships but also a constant flux of money: as I will discuss in the next paragraph, austerity reinforced the economic importance of families as a supplier of benefits for young unemployed and precarious workers.

1.3 Austerity: crisis as a chronic state

During 2008, the world was shaken by an economic crisis of global proportions. Italy and Portugal, together with Greece and Spain, were struck by austerity politics that deeply transformed their economies and social systems for the years to come. Such politics increased the difference between the Southern European countries, also ironically called PIGS (Portugal, Italy, Greece and Spain), and the Northern countries.

The first evident consequence was the dramatic increase in unemployment rates in particular amongst young people. If in 2008, at the beginning of the crisis, 8.8% of Portuguese people and 6.7% of Italians were unemployed, in 2014, the rate reached 14.1% in Portugal and 12.7% in Italy (Eurostat, 2020c). To understand the long-term effects of such crisis, it is important to consider that in 2018, ten years after the beginning of the crisis, the rate was still higher than in almost all the other European countries (in Portugal it reached 7.1% whilst in Italy it was 10.6%). The numbers of NEET (young people not in employment, training or education), grew dramatically: in 2014, in Italy, 26,2% of Italians belonged to the category, whilst in Portugal, the percentage reached its highest peak, 16.4%, the year before (Eurostat, 2020d). With the increasing difficulties in finding regular employment, during the crisis precariousness in contracts, illegal jobs, and informal networks of mutual assistance proliferated.

In the second place, the economic crisis and a stronger centrality of governments encouraged wide cuts in social services, especially in the health sector. Such cuts took different forms in each country, but almost equally generated a reduction in public expenditure for health services (Serapioni & Hespanha, 2019). Consequently, wide sectors of the population considered vulnerable, such as disabled and chronically ill people, lower classes, numerous families, were strongly penalised by the worsening of such services.

A third important element is the rise of social inequalities that exposed a large amount of Portuguese and Italian to poverty. Moreover, many skilled workers emigrated to other countries, in particular United Kingdom, France, and Germany, with immediate effects in the demographic distribution in particular in small villages of Italy and interior regions of Portugal, such as Alentejo. According to recent data, 75% of Italians that emigrated in 2019 were young adults (Istat, 2020).

Portugal and Italy share a common model of Welfare State, based on a universalistic approach, also defined as the "Mediterranean Model" (Santos, 1995). However, the economic crisis and its consequences shattered the very foundation of such system and a torsion towards for privatisation and neoliberal models (Serapioni & Hespanha, 2019): in this aspect, austerity was "simply neoliberalism intensified" (McRuer, 2018: 16). Families as pivotal actors in providing primary care resulted overcharged instead of relieved: in particular, families of origin assumed a central role in taking care of the economic, social, and even emotional costs of precariousness amongst young adults. However, there were differences in the way the economic crisis was dealt with in Portugal and Italy. In fact, in Portugal, a strict rule of austerity imposed by the Troika[8] was enforced: the population face a severe socio-economic crisis and a stark reduction in public expenditure in all sectors due to the severe rules imposed by the EU. After 2015, the country managed to recuperate quite well despite such austerity, thanks to the investments in tourism and the mutualisation of the debt. Differently, being the third power in the EU, Italy was treated less severely, with non-binding impositions and softer sanctions. The structural problems that existed before the crisis, such as corruption, high public debt and political instability continued to be a part of the Italian scenario during the management of the crisis: in 2019 the economy was still slowly recuperating and repairing the enormous social and financial damages of the process started in 2008.

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[8] The Troika was the triadic board (composed by the International Monetary Fund, the European Central Bank and the European Commission) that controlled the economic development of the country during the crisis.

As the experiences collected in the study will analyse, the impact of austerity measures and precariousness does not concern only to the macro-economic level: they are pervasive of every aspect of life and permeate the individual narratives that each participant provides. It is worth insisting on the fact that precariousness and economic instability had devastating effects on almost every young adult in both countries: however, the impact was even more disastrous in the lives of those who belonged to vulnerable categories, such as chronically ill persons and LGBTQ+ one. The extent of such devastation is well resumed in a slogan used by the Spanish collective *La Radical Gai*: “The first revolution is survival” (Trujillo & Santos, 2014).

2. LGBTQ+ rights between tensions and surprises

> It could be said that it is uncomfortable
> not because of a sense of inferiority
> but because one does not really know
> if one is living
> before the prologue
> or after the epilogue
> and one does neither intuit
> whether it is worse or better.
> (Mario Benedetti, 2012)

2.1 Before the prologue: Italy

The story of LGBTQ+ rights in Italy in the XX and XXI century has been bumpy, with long silences interrupted by unexpected turns. Italy was the first European modern country where homosexuality was decriminalised in 1879. It was also the first Southern European country to overturn dictatorship (1943) and to extend the right to vote to women (1945). Moreover, thanks to a great work of trans activism and feminist groups in the 70s and 80s (Marcasciano, 2002), it was one of the very first countries in the world to allow legal gender reassignment surgery and allow legal gender recognition, in 1982.

Despite such important moments, the decades following the 80s did not bring the changes that many in the LGBTQ+ community hoped for: in particular, the entrance in the European Union did not produce the same effect of encouraging legal changes for LGBTQ+ people, as it happened in Spain and Portugal (Vale de Almeida, 2006; Santos, 2013). Instead, the legal frame remained stuck in a long season of substantial silence on LGBTQ+ issues. The "silence of the law" (Fabeni, 2009) is characterised by a double character. Indeed, "denial more than repression has characterised Italian public regulation of homosexuality over the last century, implying an erasure of the non-heterosexual subject rather than its public construction as a 'counter-type'" (Bertone & Gusmano, 2013: 261). Homosexuality is implicitly accepted as long as it is kept private and invisible and does not interfere with the official predominance of the natural heterosexual family model encouraged by the Church and the State. By not being formally criminalised, homosexuality was guaranteed a minimum freedom which discouraged claims for legal regulation of rights such as marriage and adoption for a long time (Lasio & Serri, 2019). However, on an opposite side, impunity is guaranteed also to those who actively discriminate on basis of homophobia or transphobia: the legal system does not include a specific law to punish hate crime and hate speech (ILGA-Europe, 2020a).

Attempts to implement laws to regulate same-sex partnership were made in 1988, 2007, and 2015: in all cases, they were boycotted not only by right-wing parties but also by left-wing politicians close to Catholic Church (Bellè & Peroni, 2016; Lasio & Serri, 2017). The interference of Catholic powers in the political debate was relevant: the discursive politics centred on the natural family, formed by a woman and a man, penetrated all levels of society and were exacerbated by the rise of the "gender crusades" (Zappino, 2016). They are also consistently deployed in the political debate by Parliament members in the attempt to depict homosexual relationships as deviations from the normalcy established by God and by nature, in particular when they involved adoption and parenting (Lasio *et al.*, 2019). It was in this atmosphere that the most recent debate on civil partnership was conducted in 2016. The proposal, named Cirinnà Law, originally included the possibility for same-sex couples to obtain the same rights given to heterosexual married couples and the stepchild adoption - the possibility to legally adopt the children of one's partner. Both in Parliament and civic society the debate was so harsh that the final version of the law, approved in May 2016, was very different from the original draft. Same-sex couples were granted the right to establish a civic partnership (named “specific social formation”) and to access basic rights such as survivor's pension or access to the hospital in case of severe illness. However, the law was stripped of all the parts on stepchild adoption and parenting, leaving hundreds of children that live with their LGBTQ+ parents without a legal frame of protection (Franchi & Selmi, 2020). Although the law was celebrated as a (late but still) important step in the institutional relationship between State and LGBTQ+ citizens, it also confirmed the implicit higher legitimacy of heterosexuality over other affective experiences (Lasio *et al.*, 2020).

The institutional reluctance in taking affirmative steps towards the improvement of LGBTQ+ lives in the country, what Pustianaz defines a “politics of indifference” (2011), is part of the reason why Italy figures as one of the worst European countries in terms of human rights protection for LGBTQ+ population. Italy still lacks important legislative instruments to tackle equality and non-discrimination, in particular in the areas of health, education, and work; it does not provide any specific measure against hate crimes and hate speech; it fails in offering legal protection to LGBTQ+ children, intersex children, and to children living in LGBTQ+ families. Unsurprisingly, Italy occupies position 35 in a total of 49 countries for LGBTQ+ rights advancement (ILGA-Europe, 2020a).

The only area that contradicts such poor performances is the civil society space: grassroots movements are active and spread over the territory, with a vast network of local and national organisations that are often able to capitalise public and private funding. In 2019, for example, 43 local Pride Marches were organised in all the 21 regions of the country. Such vitality and inner diversity of the activist community has often been more effective in local strategies than on the national level. Indeed, in the last decade, local governments, such as city councils, provinces, or regional boards showed some availability in implementing local policies for LGBTQ+ citizens, sometimes even in contrast with the national guidelines provided (Gusmano, 2017). The vivacity of local activism is countervailed by profound divisions and fragmentation on a wider scale: although this is a sign of inner diversity of the movements, where plural voices find space of expression in the public arena, it has sometimes converged LGBTQ+ communities to deep fractures. For example, in 2019, Arcilesbica, the largest national organisation of lesbian women, officially rejected medically assisted reproduction for women (including lesbian) (Santos & Pieri, 2020). In the same document, the organisation expressed their opposition to sexual assistance for people with disability and any form of sex work. The move was just the tipping point of a conflict between different areas of feminist streams started years before (Bernini, 2017). The document generated a deep fracture in the LGBTQ+ Italian movements, showing the need for a profound debate on intersectional issues which still seem unresolved. Moreover, some actors of the LGBTQ+ movements also embraced more than other the domestication and normalisation forms of what Duggan calls "the sexual politics of neoliberalism" (2004). Therefore, concepts such as respectability, good citizenship, soft entrepreneurialism are often promoted together with a national narrative on security, order, and privatisation of the sexual sphere (Acquistapace *et al.*, 2016; Di Feliciantonio, 2015; Bertone & Gusmano, 2013).

On a final note, it is important to point out that sociocultural homophobia and transphobia are still largely spread. The recent Eurobarometer report (Eurobarometer, 2020) showed that almost one-third of interviewees thought that gay, lesbian, and bisexual people should not have the same rights of heterosexual people and that 42% were against the possibility for trans people to change their civil documents according to their gender identity. The data are not much different from 2015, suggesting that civil society may still be slow in changing attitudes towards LGBTQ+ citizens. In 2019 the number of hate crimes against gay, lesbian, and trans people increased to 187, compared to the 119 recorded in 2018 (ILGA-Europe, 2020a). Although the estimate reflects just a small part of the real number, because most cases are not reported to police, it signals that homo-transphobia represents an urgent issue: the lack of legal protection in case of record to the police, together with the right-wing turn of politics in the last two years, may have contributed to a worsening of the scenario. Trans population is particularly vulnerable to violence and discrimination: to obtain the change of name in documents, the law approved in 1982 requires every trans person to undergo a psychiatric assessment and hormone treatments, while sterilisation was out ruled only in 2015 and only through jurisprudential evolvement and not by legislative actions. Non-binary persons, transgender persons, and any individual in the trans spectrum have no other options: therefore, many live with a constant mismatch between their daily performance and their legal documents, with increased exposure to discriminatory acts (Scandurra *et al.*, 2019).

For all these reasons, Italy still seems to be in a time in which it is chasing other European countries in the advancement of human rights for LGBTQ+ citizens: somehow, the prologue of what other countries already implemented.

2.2 After the epilogue: Portugal

Despite a long dictatorship that more than four decades and a strong Catholic orientation, Portugal is nowadays a democracy in which the rights to diversity are valued and protected by several laws. Such dramatic changes did not happen in one day: nonetheless, they were surprisingly fast and deep, especially when compared to the rhythms of Italian LGBTQ+ history.

Between 1926 and 1974, Portugal was ruled by a fascist regime run by Prime Minister Salazar (1936-1968) and by Marcelo Caetano (1968-1974). The orientation to “God, Family and Nation”, that the regime shared with its Italian and Spanish neighbours, implied that every deviation from the heterosexual norm was persecuted: homosexuals were objects of raids, tortures, and imprisonment (Almeida, 2010). The consequences of such a regime also dramatically targeted women, whose rights to abortion, contraception, and vote were limited (Santos & Pieri, 2020). Under the regime there was no LGBTQ+ activism, not only because it was legally impossible, but also because Portugal was only skimmed by the cultural transformations of intimacy that involved the rest of Europe in the 60s and 70s (Cascais, 2006).

After the Carnage Revolution of 1974, the country was invested by a wave of democratic reforms which aimed to recuperate the delay accumulated by the country in education, economy, and industry. The “homosexual question” was discussed in some left-wing circles but it was not a shared worry in a moment in which everything had more priority. However, in 1982, a first step was made through the decriminalisation of homosexuality. The surge of the AIDS epidemic in the 80s had the effect of bringing to the front of public debate the existence of the gay community and provided an impulse to the creation of activist communities during the following decade, like the NGO Abraço (*ibid.*). Such growth was made possible also by the hopes and discourses on human rights brought by the inclusion in the European Union (in 1986): belonging to an international community added a sense of responsibility in complying with collective standards of inclusion (Santos, 2013). In the same years, other groups emerged beyond the gay activists, giving visibility to lesbian experiences and trans lives (Cascais, 2004; de Oliveira *et al.*, 2010; Ferreira, 2014; 2015).

All the above elements constituted the prologue to an extraordinary amount of legal changes happened in the country from 2001 to nowadays. After the first Pride March held in Lisbon in 2000, in 2001 unregistered cohabitation was extended to same-sex couples (de-facto unions). In 2003, Portugal transposed a directive issued by the European Union that granted all workers protection from discrimination based on sexual orientation; the same protection was extended to all areas in 2004 with the inclusion in the Constitution of such prohibition. In 2007, following the tragic assassination of Gisberta, a trans woman, the Parliament approved the aggravation of the penal code for hate crimes based on sexual orientation and gender identity. In 2010, civil marriage was approved thanks to a massive awareness campaign conducted by activist groups and to the influence of the approval of same-sex marriage in Spain five years earlier (Vale de Almeida, 2012). In 2011, the law on gender identity was approved: it allowed for the change of name and gender identification in documents for transgender people regardless of surgery. After this, 2016 was a year full changes: the approval of the ban on blood donation for gay men; the extension of medically assisted reproduction to women of all orientation, civil status, or diagnosis of infertility; and the expansion of the right of adoption to same-sex couples. In 2018, the Parliament approved the law on self-determination of gender expression and protection of sexual characters of all individuals, prohibiting invasive non-fundamental surgeries on intersex babies.

Finally, in 2019, in compliance with the new gender identity law, the Minister of Education issued specific norms to be followed by schools of all grades in full respect of trans children in their choices of identification. This was also the year when the Health Ministry issued specific guidelines to ensure a fair treatment of gender diverse people and the Government issued the Governmental Strategy "Portugal + Igual" which included a plan for implementing equality and fighting discrimination based on sexual orientation and gender identity.

Such an extraordinary succession of changes may induce to expect that Portuguese society accompanied the progressive inclusion of LGBTQ+ individuals at the same pace. However, many authors note the existence of a considerable gap between the evolvement of the legal frame and the effective cultural and social change (de Oliveira *et al.*, 2013; Santos, 2018a). On the one side, even radical activist groups invested in the creation of trustworthy relationships with the media and the political actors (Ferreira, 2014). Such form of "syncretic activism" (Santos, 2013) oriented the agenda on multiple objectives and strategies that privileged concrete legal advancements more than ideological positioning: following a utilitarian pragmatism, activist groups operated to produce legal change together with the political actors, in a collaborative way that is opposite to the strategies adopted in the Italian case. Moreover, the language of the European Union was often deployed to claim that LGBTQ+ rights are human rights and undeniable elements of democracy itself (Sabsay, 2013). The involvement of gay and lesbian individuals in collective actions also had a positive effect on the creation of a sense of common goal and belonging (Cameiro & Menezes, 2007). On the other side, however, the societal connection with Catholic culture, familism, and patriarchy clashed with claims for change. The conflict was evident, for example, during the public debate that preceded the approval of same-sex marriage: similarly to what happened in Italy, while admitting the need to regulate same-sex partnerships, several political actors insisted in reinstating a difference between natural families and other types of family (Brandão & Machado, 2012). The naturalisation of the heterosexual family model was at the basis of the exclusion of adoption from this same law. Similarly, during the discussion of the law on medically assisted reproduction, in 2015-2016, public debate echoed the arguments employed in the "surrogacy wars" in other countries (Guerzoni & Motterle, 2018; Pérez Navarro, 2018). The opposition to the self-determination of women over their bodies has a long story in the country, if we consider that abortion was legally prohibited until 2007 (Santos & Pieri, 2020).

Therefore, the LGBTQ+ community is nowadays confronted with several new challenges, which seem to go in three main directions: the homonormative and assimilationist tendency; the persistence of homo-transphobia in society; the influence of right-wing ideologies.

The first challenge relates to an intrinsic paradox of human rights (Pieri, 2019b): the achievement of multiple rights and the speed at which such advancement was accomplished may induce the LGBTQ+ community into an illusory state of comfort. Indeed:

> Recognizing success might deprive activism of the necessary degree of dissatisfaction that stirs up protest, indignation and motivation to change things. It can also lead to a false sense of achievement, thus leading to a void in relation to demands and strategies, as well as biased assessment of the outcome. (Santos, 2013: 7)

The tendency of Portuguese activism to be nor radical nor assimilationist is seen by some as an element which will bend contemporary actions towards homonormativity (de Oliveira *et al.*, 2013). In particular, visibility still constitutes a struggle in the public space and homonormativity guarantees a sort of protection from homophobia in families and workplaces. Moreover, the insistence on a political agenda that implemented acceptance more than rupture may have created new forms of marginalisation within the LGBTQ+ mainstream community. Recent voices in this direction emerged from the black feminist collectives (such as Coletivo Zanele Munoli and INMUNE) and the experiences of asexual individuals (Alcaire, 2020). In this sense, future directions of the LGBTQ+ community may reveal a need for intersectionality and inclusion of experiences that expand the mere conceptions of sexual orientation and gender identity embracing multiple forms of belonging. The academic environment expanded its involvement in this sense and provided several examples of intersections with activism, politics, and civil society (Ferreira, 2015), despite the presence of queer studies in academic careers is still reduced.

The second challenge of contemporary Portugal is the pervasiveness of homo-transphobia in different spheres of society. As mentioned before, such presence has historic roots which can be hard to eradicate. For example, despite the ban of homosexuals as blood donors being abolished in 2016, gay men are still frequently rejected as donors (ILGA-Europe, 2020b). Similarly, the rate of cases of young LGBTQ+ persons rejected by their own families led to the creation of a safe house in Lisbon, called Casa Qui, demonstrating how coming out still presents risks especially for younger generations. As in the case of Italy, transgender, transsexual, and non-binary individuals are still a vulnerable group within the LGBTQ+ community. Despite the consistent measures and campaigns aimed at promoting increased awareness of gender diversity, transphobia is often present at all levels of society. In 2019, the suicide of Lara Crespo, one of the most prominent trans activist in the country, increased attention on the issue, revealing, amongst other issues such as difficulties in the job market and economic struggles, a discomforting high rate of mental health issues within the trans community (Hilário & Marques, 2020).

The third challenge is the global insurgence of populism and right-wing ideologies: although the actual left-wing government in charge represents an exception in contemporary Europe, Portugal has not been immune to the penetration of such ideas, in particular to the “gender crusades” previously mentioned. This influence represents a serious challenge to be considered in the contemporary context and for the next years. In fact, as in the case of Italy, right-wing movements often attacks the LGBTQ+ community through targeting the supposed existence of a “gender ideology” (Borges, 2020), promoting conversion therapies for homosexuals,[9] and opposing to LGBTQ+ parenting.

The important achievements made in the past decades turned Portugal into a safe and LGBTQ+ friendly country: however, such achievements need to be nurtured and evolved in the face of contemporary challenges.

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[9] See, for example, https://www.publico.pt/2018/07/09/impar/noticia/reino-unido-proibe-terapias-de-reorientacao-sexual-1837145. Accessed on 3 April 2020.

3. Access to healthcare

> We live in a country where
> what happens are always
> causes and never effects.
> (Italo Calvino, 1959)

3.1 Being chronically ill in Italy

According to Censis (2020), at least 39,1% of the Italian population has one or more chronic illnesses, meaning that more than 23 millions people suffer from a medical condition. The incidence of old people, one of the highest in Europe, certainly impacts on such number, if we consider that 22,8% of the Italian population is over 65 and that such number has been steadily growing in the last decade (Eurostat, 2020e).

Italy counts on a National Healthcare System (SSN - Servizio Sanitario Nazionale) which ranked amongst the best systems in the world, at least until 2008 (Falco, 2019). Founded in 1978, it is based on principles of universality, solidarity, and financial protection. Through a mixture of high public expenditure and capillary decentralisation of powers on the twenty-one regions of the territory, the SSN had the ambition of being available for free to every person resident in the country. However, the economic crisis started in 2008 and the consequent austerity politics put in place to contain costs in the public sector completely transfigured the SSN, undermining its original principles, as happened also in the other Southern European countries (Serapioni & Hespanha, 2019). Instead of easing health inequalities, the measures taken between 2008 and 2016 were oriented on cost containment and stronger centralisation and led to the escalation in the importance of the private sector (Neri, 2019). The historical gap between the North and South of the country also intensified. Considering that chronically ill patients access healthcare more often and for more prolonged periods than acute ones, the consequences of austerity measures on them were particularly harsh: issues of class, age, gender, and geography became factors of inequality in conditions of access to healthcare.

The rights of chronically ill patients are regulated by the Ministry of Health. According to the level of impairment and the gravity of the illness, the State guarantees free access to all medical appointments and exams, some forms of assistance and, in rare cases, a pension of invalidity. There are no specific regulations that guarantee personal assistance for chronically ill patients and care is implicitly considered a responsibility of families. According to the type of illness, patients have access to specific benefits in working hours and working environments (Fernández Martínez, 2015).

In 2016, the Ministry for Health launched the National Plans for Chronicity, aiming at a multi-layered intervention for the prevention, the treatment, and the assistance of chronically ill patients in the country (Ministero della Salute, 2016). It is mostly addressed to old people, confirming a general tendency to consider chronic illnesses as concerning mostly the population over 65 years. The plan proposes actions to reduce inequalities, encourage integrative approaches in the accompaniment of illness, and address the burden of chronic illness on the medical system in the long-term. However, it does not include actions specifically directed at younger patients.

Grassroots organisations, charities, and associations of patients had and still have a considerable role in mobilising resources and compensating the failures of the SSN. The history of activism on illness, as well as on disability issues, is mostly entangled with Catholic Church: the first organisations to support chronically ill and disabled people were born as an extension of Catholic institutions (Schianchi, 2014). However, it was also thanks to such relationships that organisations managed to spread in the whole national territory with great capillarity. Nowadays, there are thousands of organisations centred on activism around illness in Italy: according to Istat (2017), of the 21.000 existing associations of volunteers, 28% operate in healthcare and 27,8% in the area of social work. Most of them are organised around a specific community of patients at local levels and, in some cases, in regional sections that refer to a national level. They are particularly important in pressuring political institutions for the achievement of regulations, laws, and forms of protection for chronically ill persons, as it was the case of the regulations of care-givers in households (Tallarita, 2017).

As of today, there are no organisations, policies, or guidelines addressing specific approaches to LGBTQ+ persons with chronic illness, if we exclude the area that involves activism on HIV in the gay community. Indeed, sexuality and intimacy tend to be absent in healthcare general policies, where the accent is posed on the medical, sanitary, and therapeutic aspects of chronic illness. Such absence can be explained with different factors: the connection of many organisations with Catholic Church, which encourages a normative understanding of sexuality; the medicalised discourse which still predominates over the cultural understanding of illness; the cultural invisibility of LGBTQ+ experiences; finally, the tendency to think of illness as desexualised spheres (Arfini, 2011; Monceri, 2017).

3.2 Chronic illness in Portugal

Since 1979, Portugal counts on a National Healthcare Service named SNS (Serviço Nacional de Saúde). Access to the SNS is guaranteed to all people residing in the country and is mostly free. However, recent developments in the national economy, the impact of austerity, and the neoliberal turn that characterised most health services in Europe contributed to the growth of services provided by private companies and hospitals (Arnaut, 2019). Such changes also increased costs for the access to some services provided by the SNS and the growing dependence of the system on private services.

In this context, the regulation of chronic illnesses is in many aspects similar to what outlined in the Italian case. The definition of what is considered chronic illness is contained in a list by the General Health Service (Direção Geral da Saúde). Portugal is one of the European countries with one of the highest percentage of old people in the total population, 21,8% (Eurostat, 2020e): unsurprisingly, a great part of National plans to tackle chronic illnesses involve such population. However, there are currently a dozen of National plans that are implementing actions to prevent and control chronic illness.

As in the Italian case, the Portuguese welfare distinguishes some social and economic benefits associated with different illnesses. According to the level of incapacity and the impact illness is considered to have on everyday life patients have access to discounts in the costs of medicines, free access to all healthcare services, and lower taxation on therapies.

In terms of access to work, chronic illness is treated in the same way as disability and is regulated by the same Code. The Code affirms that workers cannot be discriminated because of their disability or illness; they have the right to access all careers, education, and formative courses; they also have the right to have a reduced working time. Moreover, the State is supposed to implement affirmative actions for the inclusion of such workers and to improve the conditions of accessibility. Recent development assigned degrees of invalidity according to the percentage of incapacity produced by disability or illness: this system, less connected to definitions of illnesses and more adequate to evaluate case by case conditions, allowed for an extension of the invalidity benefits to some more chronically ill persons. The amount of money provided is, in any case, pretty limited and in most cases not enough to sustain all the costs of living. In 2019 was approved a law that concedes certain protection on informal carers if they have to miss days of work to take care of someone in their family. The recognition of the status of “informal carer” was an important advancement in the regulation of all the relationships of care within and outside families that are the second Welfare for Portuguese chronically ill persons.

In the contemporary context, chronically ill patients in Portugal are exposed to multiple challenges. In the first place, the dismantlement of the SNS in favour of privatisation together with the effects of austerity politics employed in the country since 2008 had a harsh effect on the material conditions of life. Studies on people with disability show how they are more exposed to poverty, dependent on networks of care, and face higher difficulties in the access to work and have therefore lower incomes (Portugal *et al.*, 2010). Although there are no specific studies conducted on young adults with chronic illness in this respect, the impact of economic policies is probably similar on them. Moreover, it is important to consider that both disability and chronic illness usually imply a higher cost of life (Portugal, 2014). Another important aspect is geography: location, together with class, race, gender, may strongly impact the access to specific integrative care. Discrepancies in health literacy (Abreu *et al.*, 2018a; 2018b) have a strong impact in the way chronically ill persons manage the every day in the context of precariousness and can undermine the road to health justice: differences in class, sexual orientation, gender, race lead to major discrepancies in the way patients are treated in healthcare facilities and receive medical information.

As briefly mentioned earlier, the burden of assistance and care is assumed to be taken care of by families in most cases: the familist organisation is sustained also by forms of welfarism rooted in forms of Catholic culture, as in the case of Italy. The paradoxes of networks of care sustained by families are multiple, especially in their consequences on independence, intimacy, and self-development (Santos *et al.*, 2019).

In this context, the publication of the Health Strategy for LGBTI[10] people (Estratégia Nacional de Saúde para as pessoas lésbicas, gays, bissexuais, trans e intersexo) in 2019 is particularly important: the national project, promoted by the Ministry for Health and the SNS, aims at providing guidelines for the health promotion and health care for LGBTI people, in particular, for what regards the advancement of health literacy on LGBTI issues for healthcare professionals (Direção Geral da Saúde, 2019). The documents emerged as a necessary consequence of the several legal changes made on LGBTI issues in the last decade, which demanded the implementation of norms also within healthcare. Beyond the rights to equal access to healthcare for all people of all orientations and genders, the document reinforces the importance of positive actions that health institutions and professionals are expected to take for the specific needs of LGBTI community. The Health Strategy integrates some of the suggestions and reflections contained in the document “Health in equality” (Saúde em Igualdade) promoted in 2015 (ILGA-Portugal, 2015). Although both this document and the Health Strategy do not include any reflection on chronically ill LGBTQ+ people, they show the importance of considering LGBTQ+ population as a specific type of patients and insist on the need to promote health literacy within LGBTQ+ communities and health professionals, both fundamental issues for this research.

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[10] Lesbian, Gay, Bisexual, Trans, and Intersex people.

Conclusions

The discussion carried out in this chapter highlighted how Italy and Portugal are very different countries, in some aspects, and similar, in others. Despite the different timings and duration of their dictatorships, they were both consistently marked by the presence of Fascist regimes in their recent political history: a presence that influenced processes of liberation for minorities, women and LGBTQ+ people particularly. Their shared historical roots as countries with a strong presence of Catholicism characterises until nowadays a culture impregnated with Catholic values and, more in Italy than in Portugal, the infiltration of Catholic authorities in all public and private spheres. Moreover, the consequences of the economic crisis started in 2008 hit both countries violently, determining high levels of unemployment and the re-organisation of familiar structures through significative rates of young emigration or return to the parental household. Finally, in both countries families have a pivotal role as providers of economic support, care to the vulnerable members (mostly carried out by women), and granters of a safety net of security: in many ways, they maintain a second Welfare that completes the failures of public healthcare.

These common elements are countervailed by stark differences when it comes to LGBTQ+ rights and access to healthcare. In Italy, LGBTQ+ people are granted few basic rights: their development has been painful, divisive, and until today the state recognises only those rights that do not openly question the centrality of the procreative cis-heterosexual model. The high levels of homo-transphobia in society, the lack of political efficacy of the diverse LGBTQ+ in achieving legislative changes, and the Catholic interferences in parliamentary life are amongst the elements holding Italy back from securing the basic human rights for its LGBTQ+ population. On the contrary, in Portugal, LGBTQ+ rights developed at an extraordinary pace: the country went from putting an end to the Fascist dictatorship that did not allow women to vote in 1974 to be in 5th place for the protection of LGBTQ+ rights in Europe. The remarkable legislative evolution did not always allow the population to catch up with all the changes and, indeed, the source of preoccupation today is that LGBTQ+ people in Portugal may have the law on their side living in a society that does not.

When it comes to healthcare, Italy and Portugal present similar systems based on the Mediterranean model of welfare (Santos, 1995). The impact of austerity politics, though, changed this general organisation with a major infiltration of private sectors, cuts in public expenditure, and lower rates of benefits for disabled and chronically ill persons. In Italy, chronically ill persons face difficulties in accessing benefits destined to the categories of disability, although they can count on a capillary support of activist organisations. In Portugal, recent advancements provide benefits for conditions that are disabling and to informal care-givers, although the persistence of geographical differences and the long waiting lists in the public sector created inequalities in the access to healthcare.

Finally, it is important to highlight that in both countries activism on LGBTQ+ issues has rarely intersected with activism on chronic illness: although in Portugal some attempts have been recently made to include LGBTQ+ issues in healthcare politics, the general tendency is to maintain the two areas well separated and distant.

All these elements of context constitute a silent background for the experiences of chronically ill LGBTQ+ interviewees who are part of this study. Every interviewee, in different ways and with different perspectives, is immersed in these societies, deals with their historical legacy, struggles every day with their contradictions. It is important, though, to keep in mind that without this background their words would tell only part of the story: as in a ballet, we can better appreciate and understand the moves of dancers once we observe them on the stage, with the lights, the scenography, and the music.

4. DIVING INTO THE WRECK. THE METHODOLOGICAL JOURNEY

Introduction

In her beautiful poem *Diving into the wreck*, Adrienne Rich says: “I came to explore the wreck. / The words are purposes. / The words are maps. / I came to see the damage that was done / and the treasures that prevail” (1973). The act of researching is always a dive into some forms of wreck, especially when we engage with stories of pain, silenced identities, or uncharted experiences. While we swim and explore and lose our orientation, words help us to construct provisional maps of what is around. Words are also our purpose and our treasure, when we collect stories that were never told before. I only now recognise that what I did during fieldwork was a dive into the land where “dragons live”: when I started, I was hoping to find the wreck, and to have the words, and to rescue stories that would resist outside of the water. I knew I would find damage, because I myself experience on my role as insider what it is to live outside the secure lands of heteronormativity and able-bodiedness. However, I was not too sure I would also find treasures.

This chapter is an account of the meandering process of methodology and fieldwork. As every journey (every dive), it is not linear: the acts of packing, travelling, and learning are happening at the same time, and every day, every step, every encounter produce some new information, question previous knowledge, and give opportunities for learning. The aim of this exploration is to create a coherent connection between the theoretical frame, the empirical contexts, and the methodological choices.

In the first section, I explore the phase of packing, that is, the choice of the most suitable instruments for the purposes of this research. I discuss the interesting elements of queer methodology, what it means to queer methodology, and why I chose the method of narrative interviews. Provided that the methodology is generated also through the theoretical work, I will advance a proposal for a queer-crip methodology that takes into account the absences of the existing methods and the learnings collected in the research.

The second section will be dedicated to the description of the journey itself: in particular, the phases of recruitment, dissemination, and encounter with the sample. Although this is not a quantitative work, some important and telling information are provided on the composition of the sample, that can orientate to better understand elements of self-identification, age, and illness.

In the last section of the chapter, I will focus on the difficult exercise of self-reflexivity. As a queer, chronically ill, young adult, I reflect on my positioning as an insider in this research and the paradoxes, the challenges, and the lessons it triggered. I then focus on the encounters with participants and on the fragile but rich space of interviews as a space of shared knowledge.

1. Packing, or composing the methodology

> To carve a story that can be told
> out of those broken objects that we all are.
> From fossil to poetry, here lies a possible destiny.
> (Afonso Cruz, 2016)

1.1 Queer methodology, queering methodology

The debate on the possibility to think methodology through a queer perspective is recent. According to Browne and Nash (2010), during the 1990s, authors were more focused on the validation of queer theories and the expansion to epistemology than to the applicability on the empirical level. The attention on methodologies emerged in the last fifteen years, evidencing a general tendency to expand the definitions of queer research. It evidenced an attempt to establish a coherent frame amongst the different aspects of the research process - theory, epistemology, and methodology. We can identify two declinations in this attempt:

on one side, the definitions of queer methodology; on the other, the research to queer methodology.

An important premise is at the basis for queer methodology: the recognition that the methodologies used in social sciences are often based on a quest for neutral disembodied objectivity, the use of predetermined categories of interpretation, and a certain distance with the political implications of the research process. However, methodology (as the set of rules and procedures that constitute the design of the research) and methods (the techniques applied to collect data) can be thought as a coherent extension of queer theoretical orientations, the result of an effort to embrace a “political positioning that infuses research processes with ethical considerations” (*ibid.*: 12). Queer methodologies advance innovative instruments to challenge the limitations of the mainstream scientific knowledge, produced through hypothetical-deductive models and oriented towards a supposedly universal objectivity. Primarily, they question the origins and the effects of the categories that constitute the basis of knowledge production. Revolting against monolithic and hegemonic conceptions, queer methodologies are interested in understanding to what extent categories construct the objects of inquiry and, at the same time, how they influence the process of research (Brim *et al.*, 2016). Hence, they unveil the heteronormativity that lies behind the idea of neutrality: usually, the neutral researcher is implicitly assumed to be as a cisgender, heterosexual, white man. Secondarily, queer methodologies critically engage with failure: “if empiricism grants authority to categories that are operationalised into observable units, then queer empiricism means to embrace multiplicity, misalignments, and silences” (*ibid.*, 16). Even in qualitative research, the deductive method privileges predictability based on categorisation and explanatory models. On the contrary, queer methodology recognises that research is also made of inexplicability and chaos (Law, 2004). It prefigures research as a process based on questions more than answers (Di Feliciantonio *et al.*, 2017) and does not value much on the obsessive quest for results.

Queer methodology founds on the importance of reflexivity, intended both as openness to failure and challenges and self-reflexivity. The accent is posed on subjectivities and on the complexity of relations that constitute each subjectivity as a *unicum* who will necessarily always escape the rigid categorisations of theory:

> For the queer scholar it becomes a case of remaining alert to how subjectivities are an outcome of a relational process and to how a queer methodology must facilitate telling and interpreting narratives that do not inadvertently impose meanings rather than seeking to rework and create new meanings. (Gorman-Murray *et al.*, 2010: 101)

Provided these bases, to queer methodologies involves a critical discussion of methodologies through a queer lens: that is, the identification of the heteronormative assumptions that lie behind methods and the inflection towards fluid categories of analysis. If queer methodology can be considered a methodological approach in itself, particularly apt to capture narratives of intersectionality and silence, queering methodology is a process that can be elicited by any researcher on any topic. Treasuring perspectives offered by standpoint theory in feminist research (Crenshaw, 1991; Harding, 1991), queer methodologies value knowledge as situated, political, and socially produced. Since "critical subjectivity is the most appropriate way for dealing with subjectivity" (Dowling, 2005: 25), researching through queer methodology means to engage in an articulation of the complexity that intersects with our positioning and to bring to light the geography of silences, absences, and political implications that are usually "swept under the carpet" (Browne & Nash, 2010) in empirical analysis. It also means to embrace that "rather than fix objects in place, our methods would lead us to ask what we think we know and how we think we know it" (Morgensen, 2015: 310). Self-reflexivity constitutes a powerful source of information that does not diminish the reliability of the results collected.

As happened with queer theories, queer(ing) methodology has been criticised for its fluidity and its openness to failure, considered not enough reliable to sustain the struggles for sexual citizenship (Richardson *et al.*, 2006). However, its contribution is crucial to shed light on the way social sciences produce knowledge and reflect on the backstage of every process of research.

1.2 Telling our own stories: narrative interviews

Within the methods used in qualitative research, narrative interviews constitute an important one, in particular for the objectives of this work. Narrating history is part of the human experience in all ages and societies. Riessman resumes its centrality reminding us that nature and the world don't tell stories, individuals do (2008). In the 1980s, personal narratives began to take more centrality in the methodologies of social sciences: this “narrative turn” (Poggio, 2004) reflected increasing interest in the subjective frames of interpretation of experiences. Individual narratives were put at the center as powerful resources for research, as works by Denzin (1989), Ricouer (1981), White (1995), amongst many others, show. They reflected on how narratives create deep interactions that let unknown stories emerge and evidenced how the processes of social construction at the basis of human experience. Although forms of narratives have always been part of qualitative research, for example through methods such as life histories, narrative interviews became particularly important as methods to let stories of suffering and oppression emerge (Riessman, 1990). As Poggio asserts:

> The problem is that conventional interviewing methods often tend to silence and suffocate those stories and the meanings they convey because they are considered not pertinent to the generalisation pursued by research. A narrative interview aims instead at soliciting stories about the experience of interviewees and at giving them a voice, triggering processes of sense-making. (2004: 111)

Narrative interviews collect the stories that individuals deem most important and focus on how they integrate their experiences in a coherent sense of self (Atkinson, 1998). The narratives have a double dimension: they are ontological, since they contain the aspects through which individuals present themselves to the world; and they are epistemological, because they produce metaphors to understand the world (Poggio, 2004). Narrative interviews constitute an important source of information especially due to their relational aspect: they are an exchange centred on the choice of the interviewees to share their interpretations to a listener. However, they are also a performative linguistic act: they reflect the social repertoires of interpretation collectively constructed and historically situated. While each narrative is unique and unrepeatable, it is also a fragment of a bigger mosaic made of historical, cultural, and social signs (Atkinson, 1998).

Given these premises, there are several reasons for which narrative interviews are particularly apt for this research. Through narratives, intersectionality and positionality are brought to the front by the individual reconstruction of experiences (Poggio, 2004): what we categorise through theoretical effort comes already entangled in the stories told by those who live it. The method is appropriate particularly when the focus of research is on intersectional entanglements, such as in this work. Thanks to the flow of memories, interpretations, and connections exposed through the narrative interview, individuals find a space where multiple belongings can emerge in all their contradictory and often inextricable connections.

Moreover, narratives function as organisational tools that make sense of temporality. Through the logical reconstruction of processes in time, individuals create significant links between events of the past with a sense of continuity (Mariotti, 2002). The interview can stimulate a process of sense-making, in particular in for the invisibilised or painful experiences. Although they may appear as linear reconstructions, narratives are rarely chronologically sequential: on the contrary, they tend to reproduce the unpredictable and bumpy path so typical of queer-crip temporalities. Indeed, as Ricouer (1981) underlines, narrative identities are inherently unstable: they are constantly done and undone. Hence, they seem to perfectly fit the unstable form of LGBTQ+ identifications and experiences of chronic illness, based on blurred, often undefinable categories, constantly involved in a process of re-definition.

Finally, narrative interviews focus on each experience as valuable for the collective memory. Even when there is not a shared past, the act of collecting multiple narratives on the same topic can prefigure the constitution of an archive of experiences that brings to the front the invisible, the unknown, the forgotten. By turning explicit what is implicit, and visible what is invisible, narratives offer the opportunity to take back control of one's own story and tell it the way they believe it should be told (La Mendola, 2009). Unsurprisingly, researches showed that interviews offer several benefits to participants: they guarantee an increase in self-esteem; they provide validation to one's own experience, which is particularly important for marginalised people; they encourage a self-reflexive dimension that creates organic connections between different moments of life; they help to feel a sense of belonging to a bigger history (Atkinson, 1998; La Mendola, 2009).

1.3 A proposal for a queer-crip methodology

The queer orientation on knowledge production questions the very basis of what we do as researchers and critically engages with the inadequacies of our methodologies. However, to pursue coherence between theory, epistemology, and methodology, queer methodologies are not quite enough. If we are to discuss the normative foundations of methodology, we cannot ignore the weight of able-bodiedness as a system of compulsion that permeates methods. Some authors discuss to what extent disability *crips* methodology, forcing to understand different normativities that underscore the conceptions of how we do research (Barnes, 2002; Price, 2016; Price & Kerschbaum, 2016). Although there isn't (yet) an established *corpus* of work that reflects on crip methodologies, I believe it is important to deepen our understanding of how *to crip* methodologies. This way, we can achieve a coherent framework that connects the theoretical, the methodological, and the empirical levels of the research. The proposal for a queer-crip methodology stems from the need to expand the potential of queer methodologies towards the inclusion of critical stances related to able-bodiedness and to rethink how we do research not only on bodies but also through our bodies.

The first foundation for a queer-crip methodology is the critical identification of able-bodied (as well as heteronormative) assumptions on which methodologies are often based. If queer methodologies call for a disruption of the supposed objectivity centred on hetero-norms, queer-crip methodologies face the challenge of recognising heteronormativity *and* able-bodiedness within the instruments of social sciences. A fundamental aspect of this recognition is to examine how researchers are complicit in the reaffirmation of normalising ways of knowledge production (Nash, 2010). The literature on qualitative methodology is often based on the assumption that researchers are able-bodied and that disability or illness are conditions that only affect the objects of studies (Laurier & Parr, 2000; Liddiard, 2013; Valentine, 2003).

However, the junction of these two perspectives can help in the construction of a methodological understanding that treats able-bodiedness and heteronormativity as ever-present power structures just like gender, race, and others. In so doing, queer-crip methodologies represent an effective approach to qualitative research in general, well beyond the research topics of disability, illness, and sexuality. At the same time, a queer-crip stance on methodology contributes to the visibilisation of the struggles faced by academics that belong to underrepresented and vulnerable groups: amongst them, indeed, chronically ill and disabled academics (Brown & Leigh, 2018; Myers, 2007; Price, 2015). Emancipatory disability research insisted on the importance of involving disabled people in the process of research not just as mere objects of analysis, to promote inclusion and diversity within academia (Martins & Fontes, 2016). Resuming the contributions of the social model of disability and feminism, Valentine (2003) also highlights how every researcher should be ethically responsible for the inclusion of people with disability in every step of the research.

These reflections pave the way to consider queer-crip methodology an instrument to push the debate a bit further by taking disability outside of its usual terrain and sexuality outside queer research. Paraphrasing Binnie, we could affirm that “rather than trying to prescribe certain methods as queerer [and more crip] than others, we should pay attention to the queering [and cripping] potentialities of different types of research” (2007: 33): indeed, queer-crip methodologies expand attention to the ways different types of research can be queered *and* cripped at the same time (Patsavas, 2014).

The second foundation for queer-crip methodology is allowing vulnerability as a legitimate resource in the research process. If research aims to deconstruct the positivist notion of objectivity, it is crucial to value all those aspects that are commonly deemed misleading or even dangerous, like emotions, pain, and vulnerability. Research is often founded on the need to convince the audience about the righteousness and validity of the research process: specific “emotional regimes” (Bondi, 2007: 233) regulate how openly researchers can reflect on their emotions. For example, speaking about fears, disappointment, or frustration related to fieldwork is considered counter-productive for the reliability of the data collected. However, "not only are emotions an inherent and integral part of conducting research, but emotions can have a real and tangible impact on the research process" (Widdowfield, 2000: 201). The resistance to include emotion as part of methodological debates is rooted in a gendered understanding of knowledge production: while masculinity is related to facts, femininity is (negatively) linked to emotions. On the contrary, a theoretical framework that allows emotions (Bondi, 2007) can be useful and empowering. Therefore, the queer politics of embracing failure (Halberstam, 2011; Ahmed, 2006) and the "brilliant imperfection" of disability (Clare, 2017) can be translated into a methodology that values vulnerability and emotions: a methodology that accommodates the messiness of research (Brim *et al.*, 2016; Ryan-Flood, 2009) and illuminates the chaotic intersections between personal and political, academic and individual, empirical and theoretical.

These considerations lead to wonder if it is possible, and how, to queer and crip specific methods, namely narrative interviews. Most manuals focus on the moment of the interview as the highlight of the interview itself. However, the preparation of the interview is itself a process that involves some kind of investment of time and resources (Valentine, 2003). When disabled or ill people are involved on both sides of the process, these investments can be costly, since the physical resources may be more limited and the effort to meet the interview standards more exhausting. While a more classical approach to interviews would push towards the objective and the consistency of interviewing situations, a queer-crip method places comfort at the centre for all the parts involved. Indeed, LGBTQ+ people also benefit from an approach based on safety, especially those who are not completely out of the closet. Therefore, it is preferable to offer the possibility to choose where the interview will take place more than to pursue the replicability of conditions of interview; to ensure that timings are flexible; to include the possibility for breaks and second-rounds in case of fatigue; to guarantee that the research process is accessible in terms of spaces, materials provided, and language. This attentions protect the interviewee and the interviewer and create a general benefit perceived at all levels.

The deconstruction of the supposed able-bodiedness of researchers provides instruments to privilege comfort and self-care as guiding principles, so that the research process does create disruptions in the attempt to fit into rules but it accommodates the various body-mind abilities of all people involved. It is an approach that encourages flexibility instead of constraints (Liddiard, 2013). As I will discuss further in the chapter, in this research the same method of narrative interviews was declined in a variety of ways to navigate through the different health and living conditions of health, but also to accommodate my difficulties as a chronically ill person. These adjustments do not represent a loss of accuracy of the research nor a failure: they were critically elaborated in a constant exercise of reflexivity. The proposal for a queer-crip methodology thus emerged from the needs of the fieldwork and was moulded through the experiences of empirical research to pursue coherence and consistency between theory, epistemology, and methodology. The two foundations I put forward for a queer-crip methodology (the critical identification of able-bodiedness in methodology and its deconstruction, and the value of vulnerability) were the principles through which I grappled with the challenges of all the moments of the research.

2. Traveling, or fieldwork

> I did not look for anyone,
> I followed a light that brightened my hand.
> (Guido Ceronetti, 1988)

2.1 The preparation to fieldwork: dissemination and recruitment

Fieldwork started in early 2017 with the preparation of the call for participants in Portuguese and Italian. The first challenge of this phase was finding a way to "effectively communicating and achieving understanding across an increasingly wide range of sexual subjects, each with their own experiences, practices, relationships and subjectivities" (Gorman-Murray *et al.*, 2010: 99).

While, on one side, I aimed at encouraging the participation of people that did not necessarily identify only with the LGBT label, I struggled to find a way to make room for “queer silences” (*ibid.*): those who had non-normative understandings of their positioning, non-activists, or those who identified differently, for example as lesbian/queers, asexuals, or non-binary. I was aware that the term *queer* itself could represent a floating signifier for participants in the Italian and Portuguese contexts (Pustianaz, 2011; Santos, 2013). At the same time, I hoped that the frame used to recruit participants would convey the permeability of the term queer enough to encourage the involvement of people with various identifications and experiences.

Embracing the crip perspective on medical definitions and on illness itself implied a similar effort of communication to stress that the focus of the research was on the experience of chronic illness more than on specific medical conditions, following that:

> Different chronic illnesses are united by often very similar experiences. Considering these commonalities enables richer and deeper insights and more creative approaches to problem-solving than is possible when each illness is dealt with separately. (Dowrick *et al.*, 2005: 1)

Therefore, I opted to encourage self-definition as a guiding principle. Being conscious that the notion of chronic illness is not immediately relatable even for people that have conditions considered chronic, I stressed that the research would interest any person with an illness that caused chronic pain and/or had a considerable impact on daily activities and I included examples of the most common chronic illnesses. The strategy worked: some participants volunteered because they recognised their condition was reflected in the description of the call even if their illness was not directly mentioned. Thus, I had the opportunity to know illnesses I was not familiar with, such as adrenal insufficiency or cholinergic urticaria, and expand the spectrum of the research.

The range of 24 to 40 years old participants was chosen to reflect the age at which Italian and Portuguese young adults are expected to begin their autonomous life, by getting a paid job, living by themselves, and start a family (Roseneil *et al.*, 2016; Calzada & Brooks, 2013). As shown in the previous chapter, this range is considerably higher than in the rest of Europe. However, the age boundaries were not considered strictly and I agreed to include slightly older (aged 42) or younger (aged 23) participants.

The call for interviews was disseminated through social networks, personal contacts, and activist networks (both on LGBTQ+ issues and illness). A large majority of interviewees contacted me after seeing the call on Facebook, either posted by one of my contacts or on profile pages of activist organisations. Personal contacts with gatekeepers were also important: I met people who occupy a pivotal role in LGBTQ+ activism in Portugal and Italy or whose social circles are widespread. The meetings were crucial to disseminate the call outside the redundancy of social networks. This aspect was particularly important in Portugal, where my network is more limited than in Italy.

Surprisingly, the response by organisations was scarce. Throughout four rounds, I e-mailed 47 LGBTQ+ organisations in Italy and 40 in Portugal; plus, I contacted 56 Italian and 27 Portuguese organisations that work with chronic illness, privileging those that had a section dedicated to younger people. The messages were written in Italian or Portuguese, depending on the receiver. I strategically changed the wording of the e-mail to make it more relatable for the different audiences. In the message sent to LGBTQ+ organisations, I highlighted the importance of shedding light on the issue of illness in LGBTQ+ communities, beyond the important work done on HIV. In the e-mails sent to organisations linked to illness, I explained what “LGBTQ+” meant and spoke broadly about “sexuality and illness”. This way, I hoped to prevent possible homo-transphobic reactions, especially in the Italian context. I also made explicit that I was myself chronically ill, hence personally involved in the topic I was researching. The e-mail simply asked to collaborate in disseminating the call amongst activists and networks of contact. However, only 7% of the Italian organisations (6 out of 103) replied to my e-mail. One organisation of chronically ill people replied congratulating for the research, but also adding they “didn't have any homosexual person in their organisation”. Another replied that “these tendencies” (read: homosexuality) were not a concern within the organisation. These comments and the scarcity of replies are telling of the separation perceived between illness and sexuality within activism. They confirm the presence of the cultural tendency, discussed in chapter 3, to think that being LGBTQ+ does not have an influence on the way illness is experienced and that sexuality is irrelevant for those who focus on illness.

Another reason for the scarce response could be ascribed to the inner mechanisms through which these organisations work, especially the smallest ones. Since they often count on a reduced number of volunteers, the e-mail could have been read but left pending of some collective decision and eventually forgotten. Finally, some recipients may have acknowledged its content and even disseminated it without sending any reply. Indeed, in the Italian cultural context, it is not considered impolite not to reply to an e-mail: I assume this is also one of the reasons for which, in proportion, I received a higher number of responses from Portuguese organisations (19,4%, corresponding to 13 out of 67).

However, it is worth to note that the reaction from LGBTQ+ organisations, in both countries, was more enthusiastic than the one received from those centred on illness. The divergence is probably rooted in the type of activism previously discussed: while organisations around illness are more focused on social policies, relations with policymakers, and medical issues (Tallarita, 2017), LGBTQ+ activists tend to value collective history and appreciate studies that explore intersectionality within the LGBTQ+ community (Santos, 2013).

Besides, I conducted some interviews with experts to gather more information on the Italian and Portuguese context and to place the research within the bigger picture of Southern Europe. In Italy, I interviewed Pierluigi Lenzi, the founder of *Gruppo Jump*, the only organisation of LGBTQ+ disabled people, and Shamar Droghetti, delegate for youth issues within the national board of Arcigay. In Portugal, I interviewed Joana Vicente, the founder of APJOF - Associação Portuguesa Jovens com Fibromialgia (Portuguese Association of Young People with Fibromyalgia). During an internship in Madrid (February 2017), I conducted exploratory interviews with activists and researchers. In particular, I met with Antonio Centeno, the founder of *Yes, we fuck!*; Juana Ramos, a trans activist and the coordinator of a project on LGBTQ+ sexual health; Javier Ojeda Melian, an activist of *COGAM*; Montserrat Garcia, a researcher on women with chronic illness. Altogether, the interviews provided a strong basis to contextualize the political and cultural landscape of Southern

Europe for what concerns disability, illness, LGBTQ+ lives, and young adults, highlighting commonalities but also national differences.

2.2 The sample

Fieldwork lasted 16 months and was conducted between Italy and Portugal in recurring phases. Instead of conducting one fieldwork and then the other, I opted for a combined approach. Although it created more logistic challenges, this approach allowed me to have constant control over the process, to balance the sample, and to apply to both fieldwork the learnings I would gather on the way. I collected a total amount of 24 interviews equally divided between Italy and Portugal. Before the interview, participants were asked to fill in an information form.

In terms of sexual orientation, the sample was divided as follows.

Table 1.

Sexual orientation of participants.

Sexual orientation			
	Italy	Portugal	Total
Gay	4	3	7
Lesbian	3	4	7
Bisexual	1	2	3
Pansexual	2	3	5
Queer	4	-	2
	14	12	

Although gay and lesbian participants are prevalent, also bisexuals, pansexuals, and queer are represented. It is interesting to note how, in the Italian case, *queer* is considered an orientation while in Portugal nobody identified as such. The discrepancy is probably linked to the cultural translation that the term *queer* has met within Italian activist communities (Pustianaz, 2011), where it became used as an umbrella term to indicate an open orientation, a synonym of what in Portugal is understood as 'pansexual'[11]. Two interviewees in Portugal also self-identified as asexual and demi-sexual. As to the relational orientation, two people in Portugal and two people in Italy identified as non-monogamous or polyamorous.

The gender-identification of the sample was also diversified, as showed in Table 2.

Table 2.

Gender identification of participants.

Gender identification			
	Italy	Portugal	Total
Cis-woman	6	8	14
Gender-fluid	-	1	1
Non-binary	2	1	3
Cis-man	4	3	7
	12	13	

None of the interviewees identified as trans. During fieldwork, I made specific efforts to spread the call within the trans community and to involve key actors as gatekeepers. However, they did not produce the expected results. The absence of trans-identified people in the sample reflects the difficult compromise researchers have to make between efforts and outcomes when it comes to representation in samples (Browne & Nash, 2010). Although this absence represents a failure in the sampling process, it is somehow counterbalanced by the presence of participants self-identifying as gender-fluid and non-binary, which contribute to dilute the cis-gender prevalence. In recent years non-binary and gender-fluid identifications became more common, as a result of deconstructionist politics against gender binary, in particular amongst younger

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[11] See https://www.saberviver.pt/bem-estar/sexo/pansexualidade-atracao-sexual/. Accessed on 22.11.2019

generations (Monro, 2018; Richards *et al.*, 2017). Specific efforts were made to reach non-white communities, especially in Portugal, for example through contacts with organisations that work with non-heterosexual women of colour. However, the sample is constituted by white people, although two participants are non-European. This also constitutes one of those failures that need to be acknowledged critically and not ignored.

For what concerns age, the sample was slightly more numerous in the younger groups and more equally distributed in the Portuguese case.

Table 3.

Age distribution of participants.

Age			
	Italy	Portugal	Total
24-29 y	7	3	10
30-34 y	4	5	9
35-42 y	1	4	5
	12	12	

The information concerning illnesses is particularly rich. In most cases, interviewees reported more than one condition at the same time, some of which related to mental illness. The list of 35 illnesses showed in Table 4 reflect the diversity of conditions that fall under the definition of chronic illness.

Table 4.

Illnesses of participants.

Illness	
Adrenal insufficiency	1
Anorectal atresia	1
Anxiety	3
Non specific chronic colitis	1

Asthma	3
Cancer-related conditions	2
Cardiomyopathy	1
Carpal tunnel syndrome	1
Cholinergic urticaria	1
Chronic Fatigue Syndrome (CFS)	4
Chronic migraine	1
Coeliac disease	1
Depression	3
Epilepsy	1
Fibromyalgia	2
Hashimoto's syndrome	1
HIV	2
Hypertriglyceridemia	1
Multiple Sclerosis (MS)	1
Myasthenia gravis	1
Rheumatoid arthritis	2
Spondylosis with radiculopathy	1
Total	35

It is worth highlighting that HIV did not appear on the call for interviews on purpose since I aimed to focus on illnesses that are usually absent from the literature on LGBTQ+ people. However, when two people with HIV volunteered, I decided to include their stories because of the complexity of their profile: one of the interviewees is a self-identified bisexual woman and the other is a gay man with mental health conditions besides HIV. Their inclusion in the sample triggered important reflections over the different status that HIV holds in the LGBTQ+ community. It is also important to highlight that the sample reflects different temporalities in relation to illness: while some participants have been diagnosed several years ago, others still don't have a confirmed diagnosis or at the onset of their condition.

The participants came from all parts of Italy and Portugal, although with a slight prevalence of people from the centre-north of Italy and the main Portuguese cities. This prevalence reflects the demographic context of the two countries but, probably, also a bias related to the networks that gave visibility to the call. I will address additional information about the sample, such as level of education, living conditions, and job, in the following chapters.

2.3 Holding the reins of a running horse: the interviews

In the e-mail that preceded the encounter, I encouraged participants to suggest a quiet and comfortable place for the interview. Some people invited me to their own homes, whilst others, who lived with their parents, explicitly asked to meet somewhere else because they did feel unsafe in speaking about their story in the family home. These cases contradict the perspective suggested, for example, by Wilkens (2017), according to which home is always the safest and more adequate space to conduct an interview. In seven cases in which I could not travel or it was too demanding for the interviewee to arrange a personal meeting, the interview was conducted through video-calls on Skype. Despite my initial reluctance, Skype interviews constituted a reliable way to create meaningful conversations and, at the same time, to provide comfort on both sides (Liddiard, 2013). I did not feel that they discouraged empathic connection. Interviewees were able to speak to me while laying down in bed or on the sofa, hence minimising the bodily effects of the interview on their bodies. In one particularly telling case, the interviewee, who suffered from Chronic Fatigue Syndrome, spoke most of the time with her eyes closed to save energies and be able to focus. For the same reason, three interviews were divided into two phases: when the interviewee felt too tired to carry on, we would stop and arrange a second moment to continue.

The interviews had a duration that varied between one and three hours. Before starting, I would provide the participants with all the necessary information. I found particularly important to stress that in any moment of the interview we could stop for a break. In many cases, this was also the moment in which I would come out as chronically ill and advise that I would probably need to eat something or rest after some time. If any interview involves a performative aspect (Poggio, 2004), in the case of chronically ill people the performative pressure can result in an attempt to stretch limits of resistance, hide symptoms, and try at all costs to endure the situation. It was part of my struggle, as well, especially during face-to-face interviews and one of the moments I felt the vulnerability of the researcher (Ryan-Flood, 2009). Coming out about my condition and easing the performative pressures on both sides was a queer-crip methodological act of acknowledgement of vulnerability that made space for the interview to happen in a context that disrupted the demands of able-bodiedness to which both participants and I are constantly confronted. Indeed, some interviewees seemed relieved by this encouragement and took breaks to go to the restroom, to eat, or even to take a short nap.

During the interview, I would also become aware of the rituals of preparation that interviewees had gone through to be as fit as possible for the interview. One interviewee who suffers from Chronic Fatigue Syndrome, for example, told me he had taken an extra dose of medication in the morning that would guarantee him more resistance. Another interviewee arrived at the site of the interview one hour in advance so that the effects of the walk she took to arrive, such as itchiness and red spots in the face, would disappear before our encounter. These learnings, made step by step, contributed to the awareness that I needed to *crip* methodology to accommodate the variety of bodily conditions that constituted the centre of the research. They also showed that the interview constituted a moment of pronounced corporality, in which the material embodiment of illness would find a space to be made visible in all its aspects. Again, in a queer-crip perspective, they highlighted how the interview was just a visible peak of a larger process that began before and would last afterwards.

The outline of the interviews followed a semi-structured script. However, the first and the last question of the interview were always the same. The interview opened with the following question: “To start, I would like you to tell me how the story of your illness began as if you were telling it to someone who does not know anything about illnesses nor medicine”.

The question allowed the interviewee to begin with a specific point in time. It encouraged a personal telling of stories that patients are rarely asked to tell, as Frank underlines:

> The danger for ill people is that they are often taught how to be ill by professionals. Illness is not presented to the ill as a moral problem; people are not asked, after the shock of diagnosis has dulled sufficiently, what do you wish to become in this experience? What story do you wish to tell of yourself? How will you shape your illness, and yourself, in the stories you tell of it?. (1997: 159)

While allowing them to begin from something they knew well, the question required an effort to explain the same story with a personal language, setting the tone of the interview in a semantic universe different from the medical one.

Through the interview, questions were divided into three main blocks, which reflected the three main strands of the research: time, care, and visibility. Each block included questions specifically related to illness, LGBTQ+ identification, or their intersectional entanglement. However, I encouraged participants to speak as much as they wanted; the flow of consciousness often anticipated questions or implicitly answered some.

I often felt that my role was holding the reins of a running horse: on one hand, I managed the topics related to illness; on the other, I held those referring to LGBTQ+ identification. I needed to carefully manage the two reins to keep the horse (the interview) running as fluidly as possible: in some moments, one would make the horse turn towards topics more specifically oriented to illness; in others, LGBTQ+ narratives would prevail. It was not always easy to balance the two aspects, especially because, in most cases, participants would not feel like there was any connection between them. I learned that, in a queer-crip way, it was important to embrace imperfections and to take a definite turn towards one topic or the other without trying to keep the balance at all costs: sometimes the absence of a topic would tell much more than its presence.

The interview always ended with the same question: “I'd like you to imagine yourself in ten years (2027 or 2028). How do you see yourself? What would you like your life to be, both in terms of illness and in terms of personal relationships?”

This question required an imaginative effort and the ability of projection in the future. On one side, the aim was to understand how the multiple embodiments of illness and sexuality were imagined in the future. On the other, it aimed to conclude the interview with an open window that would encourage future reflections on the topic and trigger generative self-reflexivity (La Mendola, 2009).

After turning off the recorder, I would ask interviewees to choose a pseudonym. All interviews were transcribed in the original language, anonymised, and sent to participants for validation. The issue of anonymity is controversial in debates on methodology (Browne, 2003; Detamore, 2010). There is a certain risk that using anonymity to protect participants obscures their voice and paradoxically contributes to the reproduction of their invisibility. Indeed, a trans participant who had initially volunteered withdrew from the interview when they understood their narrative would be anonymised, explaining that they had struggled hard to have their own identity recognised and would not be comfortable in being closeted again. However, consider the fragility of some participants's conditions, the fact that some of them may still be in the closet as LGBTQ+ or as ill, and the intimacy of the narratives collected, it seemed crucial to guarantee their anonymity.

Finally, I encouraged participants to imagine the interview as the first part of a dialogue that could continue in the following months. Interviews trigger memories, reflections, and connections that were not clear before (Poggio, 2004), so I opened the possibility to contact me with further written exchanges. Several did write me, even one year after the interview, to share updates, changes in their path, but also reflections that had occurred since the interview, proving that interviews are just the initial part of a dance made of many steps (La Mendola, 2009). In March 2020, with the surge of the Coronavirus pandemic, I had close contact with some of them, an exchange based on a horizontal shared experience of isolation and vulnerability that transformed the asymmetric relations between researcher and researched into a horizontal one.

3. Returning home, or reflexivity

> Three plus three equals six,
> plus the one who counts.
> (Júlio Cortazar, 1951)

3.1 Positioning as an insider

Following feminist standpoint theory (Harding, 1993) and queer theory (Ahmed, 2006; Butler, 1993) on situated knowledge, I deem fundamental to reflect on my positioning in this research. I am a white cisgender woman; I identify as an out and proud queer person; I am a young adult and I've been struggling with a severe chronic illness for the past ten years. My condition oscillates from day to day and across the seasons: in some days I manage to conduct my life and my work at the best of my possibilities; in others, pain makes it impossible to do the smallest activities, such as walking, cooking, or reading. Most of the time my condition is invisible, although in particularly rough days I need a cane to walk or a wheelchair to move around long distances. Hence, I experience ableism in all its forms and the privilege of shifting fluidly between visibility and invisibility, able-bodiedness and disability (Samuels, 2003).

Within the parameters of methodological evaluation, my multiple embodiments would place me in as an insider in this research (Gorman-Murray *et al.*, 2010; Misgav, 2016). However, the line between insider and outsider is blurred: I'll discuss some of them in light of the experience with this research.

In the first place, the relational context of the research is the frame within which we mutually constitute our positionings as researchers, but also in which informants constitute themselves as such: our identities do not exist *a priori* (Valentine, 2003) but entangle in the moment of our encounter:

> Each time claims of rigour in qualitative research are made by privileging a particular aspect of the researcher's subjectivity as an insider, a 'credibility fallacy' is committed by ignoring how subjectivities and space are relationally co-constituted. (Gorman-Murray *et al.*, 2010: 101)

Belonging to a community, being it LGBTQ+ or of ill people, does not necessarily provide an immediate empathic understanding. Similar experiences do not imply shared identities since the signifiers, the meanings, and the multiple ways in which they are dislocated in one's life are different for each one of us (Browne, 2003; Misgav, 2016). The argument that LGBTQ+ people are better equipped to research on LGBTQ+ people has often been defended to protect research from the appropriation by an academic context still centred on heteronormativity (Nash, 2010). However, the queer rejection of essentialist identifications of sexual orientation and gender identity proved its insufficiency. Similarly, research on disability is often better received when conducted by disabled people: Liddiard (2013) notes that the tendency to occupy studies on disability by able-bodied people is so pervasive that some refuse to participate in studies not conducted by disabled researchers. After all, “experience is often the most accessible resource disabled people can leverage when it comes to knowledge production” (Patsavas, 2014: 206). Disabled and chronically ill authors (Barnes, 2002; Clare, 2003b; Kafer, 2013; Rinaldi, 2013; Salamon, 2012) insist on the importance to encourage research that responds to the claim “Nothing about us without us”, which constituted the guiding principle for much of disabled activism in the last decades (Martins & Fontes, 2016).

If it is imperative to strengthen research made by disabled, ill, and LGBTQ+ people (not necessarily on disability, illness, or LGBTQ+ issues), it is also crucial to recognise the challenges of conducting research as insiders. The presumption that because I am a queer young adult with a chronic illness I am more suitable to research this topic is not only misleading but also in contradiction with the queer understanding of identities. Through fieldwork, I learned that for a queer-crip methodology empathy is more important than identification in itself - and that it does not necessarily stem from common experiences. Indeed, Nash affirms that:

> In queering our thinking about insider/outsider status, we expect the slippery disconnections and reordering of our interactions with our 'participants' (and collaborators in knowledge production) and set out to deliberately explore that instability for what it might show about the queerness of our interactions. A queer methodology arguably seeks out and affirms the impossibility of a constant between the research, the researched and the field. (2010: 141)

The relationships between researcher and researched are inherently intimate ones (Detamore, 2010): they imply the risky abandonment and unpredictable co-construction of mutual bonding common to all close human encounters. Therefore, the position of the insider in the research is always tricky: on one side, it can create the illusion that such intimacy is pre-existent under common experiences; on the other, it generates contradictory feelings in the encounter with stories that resonate *differently* than an expected *sameness.*

Aware of these aspects, I opted not to come out as chronically ill and LGBTQ+ during the first e-mail exchanges with potential participants. This way I aimed at protecting by excessive exposure in the phase in which the call was disseminated uncontrollably on social networks. However, I also considered important that my interviewees knew where I came from. Therefore, whenever I felt it was the right moment to let the information slip, I would come out to them, either before or during the interview. In some cases, my coming out generated questions that were addressed after the interview; in most cases, it seemed to encourage the consolidation of mutual trust in the process of interview. I never had the impression that the quality of my work was put under scrutiny because I was in the position of insider: on the contrary, I mostly received positive encouragement.

Differently, in the academic environment, the position of the insider is often challenged and welcomed with suspicion. There are risks in being completely out, in my case both as LGBTQ+ and chronically ill, in a competitive and demanding environment such as the academic one, where the rules of ableism and heteronormativity are still profoundly engrained (Brown & Leigh, 2018; Myers, 2007; Price, 2016). While anonymity and privacy of participants are protected in all ways, our positioning is supposed to be declared in our writing and public presentations, over and over, to clarify from where we do what we do: this openness implies emotional and professional costs (Ryan-Flood, 2009) and often puts the researcher in a position of great vulnerability. Should my positioning change in the future, for example, should I not position myself as queer anymore, or should my chronic illness transform into a disability or a terminal illness, would my ability to engage with the research change? There is certainly a paradox in requiring explicit positioning, through a supposedly stable identification, while theoretically basing research on instability and fluidity. The reflection on the limits of this paradox and the consequences it has on researchers, both in terms of professional career and personal emotions, accompanied this work in all its phases.

3.2 The wounded researcher

Researching chronic illness through a suffering body creates a short circuit in which chronic illness constitutes at the same time the topic of research *and* the means through which research itself is made. The expectation to perform as a researcher is failed by the inability (dis-ability) to accomplish the able-bodied norm for which these expectations are designed. In other words, the process of thinking, reading, writing, and interviewing is entirely informed by strategies of management of pain. My condition dictated the time of this research and it is an inherent element of the whole process. Therefore, while my priority is to critically analyse what is the role of pain in the lives of interviewees, I cannot avoid reflecting on what pain also does to the process of research itself. Ironically, in several moments of this research, I was not able to write about the difficulties of being chronically ill because *I* was experiencing one of the typical conditions of chronic illness: unpredictability. The experience of a body in pain creates the basis for an understanding of pain through wordlessness: it becomes such a constant presence that it is transfigured into a partner, an informant, a friend, a special company (Bonino, 2009; Wilde, 2003). My body is a privileged, vulnerable informant: it translates in everyday embodied experience what emerges from the narratives of others and collaborates in the attempt to build a collective narrative based on political affinity (Arfini, 2014; Kafer, 2013). However, the constant presence of my pain and my illness also made it particularly difficult to operate a separation between work and leisure, complicating the already complex relationships between researcher and research.

I knew from the beginning that I could afford to embark on this journey because I had already done a personal path in grappling with my queerness and my illness. However, I had no way of knowing in advance what kind of emotions, memories, or even fatigue this research would trigger.

The words of Frank often resonated with me, when he solicits to learn to think with stories, which:

> Means joining with them; allowing one's own thoughts to adopt the story's immanent logic of causality, temporality, and its narrative tensions [...] The goal is empathy, not as internalizing the feelings of the other, but as what Halpern calls 'resonance' with the other. (1997: 158)

The resonance between my story, my pain, my experience, and the stories, the pain, the experiences of the interviewees required the ability to navigate emotions and to find a balance between being overwhelmed by their deepness and set up boundaries of involvement. Thinking with stories was inevitably a process of learning to think with my own story, as well: the process of fieldwork and the following analysis sometimes felt like a way to return home to my own story with a case full of what I learned through the journey.

For all these reasons, it was particularly important to engage in active practices of self-care, an aspect often overlooked in the methodological debate. Following a queer-crip approach meant primarily to consider self-care as important as care towards participants. Through the process I used some tricks to make interviews more comfortable for me, such as having food and drinks always at hand in my bag, schedule some time to rest before and after the interview, not setting any other activity in the same day of an interview. After interviews, I would often feel emotionally drained and in need of some good distraction, so I tried to watch comedies, to have delicious food, and to spend time alone. Conversations with friends and loved ones were crucial to let go of the emotional chaos triggered by fieldwork and confirmed the centrality that affects play in research (Browne, 2003). Sometimes, self-care also meant to manage frustration, when I could not do something because of pain.

Accepting that the temporality of fieldwork and writing was mostly dictated by my illness was a way to reflect, over and over, on queer-crip temporality; embracing the limits of my mobility led me to find different ways to make interviews, and to rethink queer-crip methodology. All in all, it was a process of learning: on one side, learning how to transform fate into experience and become a wounded listener and storyteller (Frank, 1997); on the other, learning to embrace all the way the queer-crip art of failure in the daily process of research.

3.3 Close encounters of the third kind: learnings and challenges from interviews

Interviews represent an encounter with otherness (Di Feliciantonio *et al.*, 2017), a dance (La Mendola, 2009), a learning process (Frank, 1997). They are an encounter between two subjectivities (Gorman-Murray *et al.*, 2010); as such, they are also the terrain where different power imbalances are at play. It was not always easy to reflect critically on the power relations involved in the interviews: being perceived in my *sameness*, as an insider, blurred the awareness of other power inequalities involved. However, being an academic in most cases put me in a position of privilege and it was clear that interviewees recognised me a superior power of explication over certain aspects of their lived experiences. For example, an interviewee asked me to explain what “gender identity” meant while filling up the information form: in the academic language this is such a common expression that it is easy to forget how it does not belong to everyday language, not even within the LGBTQ+ community. Another participant only spoke a local Italian dialect, typical of the working class, which I luckily happen to understand only thanks to my connections with the geographic area. I thus performed an unpredicted cultural translation to make the questions knowledgeable to my interviewee. In another case, an interviewee told me about her sexual experiences both with men and women and asked me whether I thought she could be bisexual, unveiling the perception of my academic privilege as the ability to name embodied experiences with the “proper” concepts.

A second important aspect worth of a reflection is the transformative potential of interviews:

> People tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others - each must create his own - but rather to witness the experience of reconstructing one's own map. (Frank, 1997: 17)

I often witnessed how connections emerged in the interviewees' accounts while they spoke, sometimes for the very first time. Interviewees would say things such as “It's the very first time I think about this”, or “You know, I had never thought of this aspect“. Their comments would confirm that they felt safe in the space of the interview and they perceived me as “a respectable companion”

(Wilkens, 2017) with no formal authority or judgement over their life. For some, I believe the transformative power of the interview was enhanced by the fact that I was the very first LGBTQ+ person with a chronic illness they met beside themselves. Isolation and loneliness that emerge so often in the narratives are also caused by the difficulty of knowing someone who lives the similar multiple embodiments. Although participants never came in contact with each other, they expressed relief just by knowing that their experience was part of a collective struggle, in “the brotherhood [sisterhood]of those who bear the mark of pain” (Schweitzer in Frank, 1997: 35).

After the recorder was turned off I often received questions about my story and my illness: in these conversations, the asymmetry between researcher and the object of research would tear down in favour of a mutual exchange. With my interviewees I confronted names of doctors, received suggestions for remedies, laughed about misadventures in the hospital; in one case we even cooked pasta and shared it before moving to the second phase of the interview. These moments of exchange of the knowledge produced by our bodies also contributed to the creation of a shared mosaic of experiences and were also part of that journey of coming home to my own story.

Language was an additional challenge. Academic work is predominantly based on words: we read, we write, we speak, we listen. I am an Italian native who moved to Portugal in 2015 and learned Portuguese from scratch. However, most of the academic work, including the PhD and this dissertation itself, is conducted in English. I daily have to adjust to a three-language translation, where Italian is the language of the soul, English is the language of the brain, and Portuguese is the language of the body. My preoccupation during the interviews was to master the language appropriately enough to understand my interviewees in all the nuances of their speaking. While it comes quite naturally in Italian, it requires an extra-effort in Portuguese. The spoken language of narratives is made of interruptions, disjunctions, and hesitations: the language of memory is made of incoherence. Hence, listening involved the ability to recognise and place words in their context whilst posing questions required skills in choosing appropriate words.

My difficulties in mastering languages were mirrored by the struggle of interviewees in telling their own stories with words that often do not even exist. Virginia Woolf, in her essay *on being ill*, reflects on the state of wordlessness that pain puts us in and affirms that:

> The merest schoolgirl, when she falls in love, has Shakespeare, Donne, Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry. There is nothing ready-made for him. He is forced to coin words himself, and, taking his pain in one hand, and a lump of pure sound in the other (as perhaps the inhabitants of Babel did in the beginning) so to crush them together that a brand new word in the end drops out. (1930: 34)

As inhabitants of Babel, participants tried to coin their own words to tell their story, a story that in most cases had never been told as such. For most of them, it was the very first time that the narratives of illness and sexuality were told together in mutual resonance, and this effort required a new vocabulary. Participants produced metaphors, images, and new words that became crucial in explains the complexities of embodying multiplicity and that constitute one of the most precious treasures found on the wreck echoed in the beginning of this chapter. This new vocabulary served as a guide through the analysis of empirical materials. It showed that, when we are short of words to express the complexity of reality, we can choose the queer-crip way of caring less about fitting in and expanding boundaries of expression.

Conclusions

As I stated at the beginning of this chapter, a journey never really ends: as I relived my visit to the wreck through this writing I still learned something and saw nuances I had not noticed during the intense phases of the dive. Embracing queer-crip methodology means also to consider everything in its inevitable instability and to admit the possibility of potential evolutions. As identities and sexualities are in constant re-definition, so chronic illness follows an unpredictable temporality. From the moment the first interviews were collected to the present moment, in which this chapter is being written, almost two years have passed. This span of time can mean a lot in a life. The experiences here collected represent a photography taken from a movie: they tell us a lot about the present moment and hint to past events; sometimes they will suggest possible futurities. However, only that present moment is what is represented in the scene.

In the chapter, I advanced that the absences of methodology and the experiences I had brought me to sketch a proposal for a queer-crip methodology. This process does not have the presumption of becoming a theory nor the ambition to create new categories for doing research. However, it is an example of how the absences we find while we do research are sometimes more telling than the presences and can lead to a closer connection between theory, methodology, and empirical work.

Some time ago, a man in the United Kingdom was cured by HIV infection through an experimental stem cell transplant[12]. It is the second case of success against an illness that, only few years ago, was mortal in 100% of cases: it is a small step in science, a giant leap for the hope of many people with HIV, including two of my interviewees, whom I immediately though about when I read the news. In the meantime, while I review the final touches of the thesis, the Coronavirus pandemic is subverting our lives with new social meanings of illness and new rules of care. The temporality of the context in which the research was conducted is important because it reflects the temporality of the content of the same research and somehow ties links between what is researched and what is happening while we research it - before and after.

If the choices we make in methodology are political and interviews can be transformative, then I should assume that what has been done in the past two years was a slow, sometimes painful, but important work of transformation. I myself evolved and changed during the writing of this dissertation, not only in my research skills, but also as a queer and as a chronically ill person. So, if methodology only allowed me to collect narratives which are represented by a frame, the queer-crip temporality that sustains this methodology leads me to remember that the movies they refer to are still going on, producing as many possible futurities as untold pasts. In other words, the journey still continues in many forms, in many other times, and the seeds of transformation created by the research may be growing: after visiting the wreck, some of us, me included, are

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[12] News retrieved from: https://www.bbc.com/news/health-47421855. Accessed on 05 february 2019.

going back to the surface, where we carry the words to speak about the damage that was done, and the treasures that prevailed.

5. INTIMACY AND SEXUALITY.WEAVING SIGNIFICANT RELATIONSHIPS

Introduction

In this chapter, the first that analyses empirical data, the aim is to look at significant bonds of affect and kinship that constitute the centre of the intimate lives of interviewees. Literature on LGBTQ+ studies usually distinguishes families of origin from families of choice, following a definition coined by Weston (1991), that ascribed to families of choice, such as friends and intimate relationships, a relevant role in networks of care and safety, often as opposed to the homo-transphobia experienced with parents and relatives. It is also important to consider that, in the context of Southern Europe, families of origin are often the main source of care and economic support and that many young adults stay in the familiar household until late (Calzada & Brooks, 2013; Saraceno, 2004).

One of the guiding questions of this chapter is thus to explore how interviewees experience their illness and their sexual orientation/gender identity in families of origin and intimate relationship. As the previous chapters anticipated, issues of visibility and time are crucial to investigate the conundrum of normative expectations, desires, and projections that constitute the core of any intimate relations.

The chapter follows an ideal circular path that begin with a discussion of the narratives relating to inherited families, continues with an exploration of chosen families, analyses of the pressures underlying them, and concludes with a reflection on imagined families. The narratives collected showed that a rigid division between inherited families and chosen relationships was not a sufficient framework for a proper reading of the complex aspects linked to LGBTQ+ identification *and* chronic illness. Therefore, the red tape that underlies the whole analysis is the double aspect of visibility and temporality: as previously discussed, the two aspects constantly intertwine in the experience of LGBTQ+ people with chronic illness and determine surprising outcomes in the negotiations of intimate relations.

In the first section, the chapter analyses the relationship with families of origin, in particular for what concerns visibility (other aspects of such relationships will be explored in the following chapters). In particular, the analysis explores how coming out as LGBTQ+ is managed and how the experience of chronic illness dislocates the meanings ascribed to sexuality, often in unexpected ways. Furthermore, it considers friendships and how the aspects of time, illness, and visibility are experienced.

The second section investigates a fragile sphere through a closer look to experiences of dating, sexuality, and intimate relationships. The narratives collected offer a fascinating perspective on the complex construction of expectations, bodily performance, fears, and suffering that contribute to pleasurable experiences of intimate bond.

In the last section, the discussion focuses on the pressures that interviewees feel in the practices, but also in the imagination, of their relationships, revealing how heteronormativity and able-bodiedness operate to mould relationships.

1. The closer ones: negotiating identities with families and friends

> People can't, unhappily, invent their mooring posts, their lovers and their friends, anymore than they can invent their parents. Life gives these and also takes them away and the great difficulty is to say Yes to life.
> (James Baldwin, 1956)

1.1 Inherited families: the struggles as LGBTQ+ and ill

Coming out to parents, brothers, sisters, and relatives is a milestone for many LGBTQ+ people and a trope in LGBTQ+ narratives (Samuels, 2003; Ward

& Winstanley, 2005). Since it never entails a once and for all performative act, but a series of strategies, coming out in families of origin results from a complex negotiation between fears, desires, and contextual elements (Bertone, 2020). It is particularly interesting, thus, to observe how such negotiation is carried out when the information about sexuality and gender identification intertwines the process of chronic illness.

The disruptive character of chronic illness, in the sense given by Bury (1991), emerges in some narratives in which illness emerges unexpectedly and contributes to the reevaluation of familiar relationships. The following excerpts offer two different examples of how coming out as gay, in these cases, is related to an overall fear of failing the expectations that families transmit on their offspring. In the first case, Lucas reflects on how hard he would want to come out to his father, especially after an aggressive form of cancer forced him to leave his job and return to the parental household: the fear of being rejected is accompanied by the fear that coming out would be a sign of ungratefulness towards the help his parents provide him. In the second case, Marco also describes how his illness added to a sense of failure that was already there since he came out as gay to both his parents:

> I can't tell him...I mean, I try but when the moment comes I just can't. (It changed after illness came), it changed, a lot. I want to tell him now but at the same time, I fear him and his reaction. It's very complicated. [...] I don't think my dad accepts people like me...he does not accept homosexuality. (Lucas, PT, 32y)

> They didn't go on holiday for months to pay for my education and made so many sacrifices for me. I'm their only son, (when I came out) my dad told me “With you our family dies”. Thus, I was charged with a burden, a sense of...failure but also of a responsibility that's bigger than me, because I didn't decide what came before me, even before my sexuality, I was born from them, not from other people. But also it's a sense of failure towards a life made of sacrifices, hardships, legitimate desires of your parents that all went in vain. (Marco, IT, 42y)

In both stories, the mere experience of illness is not, *in itself*, necessarily disruptive for the familiar relationships: it is its combination with an already complicated situation of visibility as LGBTQ+ that triggers contradictory feelings. On the one side, the vulnerability experienced through illness offers the opportunity to rethink the importance of visibility and provides a push towards a change in the choices of coming out with parents (Pieri, 2020). On the other, the same vulnerability unveils a sense of failure in being able to provide economic support to parents, but also to fulfil the implicit expectation of able-bodiedness that every heteronormative context reproduces (McRuer, 2006).

More than with disruption, illness seems to intervene in most familiar contexts as a balancing force that shuffles processes of visibility, homo-transphobia, and normative expectations. Exposed to the volatility of the privilege of able-bodiedness, families are encouraged to shift the focus on “what matters”. In many cases, the challenges posed by chronic illness overcome in weight and importance the resistances to accept LGBTQ+ members. In the stories of Maria and Andrea, for example, both faced homophobic reactions to their coming out in the family:

> It was a very...passive type of resistance, you know? Passive aggression. It's complicated. I wouldn't feel good at all with them. (Maria, PT, 39y)

> In the time of my coming out things within my family weren't easy...and this added a lot, a lot of stress, that eventually led to a strong crisis. But this crisis served as a turning point, for my parents started to accept it and understood my homosexuality was not 'just a phase'. (Andrea, IT, 34y)

Maria and Andrea dealt with families that resisted accepting them as lesbian and engaged in practices of micro-aggressions that contributed to an overall tension to the point that, in Maria's case, her family did not even participate in her wedding day. However, they both recognise that a peak in their illness was an important turning point that broke these tensions and commenced a healing process of acceptance:

> It was like that until I got severally ill and this is interesting. [...] I was very sensitive and needed to withdraw from anything that was...negative vibes, also because I couldn't bear any kind of stress, you know? I could not bear aggressivity. (Maria, PT, 39y)

> When they witnessed how worried my girlfriend was, how she would take care of me, they realised it wasn't at all something meaningless so...that crisis served to create a sort of watershed between a before and an after, for them to accept my relation. (Andrea, IT, 34y)

In these narratives of illness it is not uncommon to find the trope of “learning through suffering” (Bertone & Franchi, 2014): the pain experienced through illness is seen as an opportunity to re-prioritise what is important in life and to ascribe new meanings to affects and conflicts. The preoccupation caused by illness led both Maria's and Andrea's families to question their behaviour and to change patterns of relationship to guarantee a more peaceful environment. For Maria, together with the onset of illness, the birth of her daughter was another important factor that encouraged the distension in familiar relations: as other studies observed (Park, 2013), newborn babies often catalyse discourses of unconditional love that erase previous issues with acceptance of LGBTQ+ relations. In the case of Andrea, illness contributed in giving visibility to the strong bond between her and her girlfriend, providing Andrea's parents with a proof that it was a serious (thus, relatable) relationship.

The revision of priorities triggered by illness can take a differently nuanced route in other cases, as in the story narrated by Ellie. Born with a chronic illness, Ellie came out as pansexual to her parents, with whom she cohabits, only recently:

> My parents were cool, my father told me: “We've always known it, it's not a surprise”, my mother as well. Their typical motto is “We just want to see you happy”, because, of course, when you see your daughter suffering physically and psychologically [...] your priorities change even as a parent, so I think that for them my homosexuality or pansexuality is the least important problem. (Ellie, IT, 34y)

The excerpt shows how the unconditional love on which parental relationships are based, especially in Christian-centred cultures (Bertone, 2013), puts health (and able-bodiedness) at the top of the priorities. The particular bundle between familism and Catholic culture in the Italian context may be also encouraging this hierarchy of pain: while it may be morally acceptable to refuse support to an LGBTQ+ member of the family, it is felt that the same member needs to be accompanied through the suffering caused by illness. It is interesting to note how this double standard is felt also by interviewees, some of whom recognise how difficult it is for their families to witness their pain. In a context in which coming out as LGBTQ+ to parents is still perceived by the vast majority as a difficult step (de Oliveira *et al.*, 2013), and illness experienced as a form of failure, some feel that they need to mediate information to avoid their parents too many preoccupations. Logan, for example, came out recently as non-binary to their mum and affirms:

> I didn't mention the possibility of transitioning and all that, because I haven't got it very clear. But also because I knew it was going to be a difficult topic...I mean, I've been doing some research trying to understand what I could do, but [...] if I am worried about the impact of hormones and surgery on my health, I can imagine how worried my mum would get! (Logan, IT, 23y)

Considering that any procedure involving hormones or surgery could complicate their fragile health condition, Logan opted for a mild form of coming out with their mother: they provided her with the elementary information but spared her the details that could trigger a fearful reaction.

Almost the totality of the stories collected report difficult bundles between LGBTQ+ visibility and illness within the (already complex) system of family relations. Some are particularly striking because they reproduce narratives of rejection, shame, and guilt. In these cases, prejudices against LGBTQ+ persons interplay with ableism and impact the lives of interviewees, creating new forms of vulnerability. It is the case of Lia, who has HIV, and Lourdes, who has urticaria and whose mother reacted negatively to her coming out as lesbian:

> I decided to tell my family (about HIV) and when I told them their reaction was really bad. My mum left home for three days...when she came back she brought bleach and said I had to use it everywhere. It was...so bad. So I figured it was best to deal with it on my own and that's what happened. [...] My mum is a doctor and she hides my illness because she thinks it may affect her credibility as a psychiatrist. You see? I was brought up to give a lot of importance to what other people think. (Lia, PT, 34y)

> (After finding out that I was lesbian) my mum started to treat me in a completely different way, we never had the same relationship as before...I mean, we're still ok, but never again as it used to be. I think it started like that, because at that time I started to notice my skin would get dry. [...] But my mum, she doesn't understand the pain and the itchiness, she's more worried about the aesthetics...when I have a rash, she looks at me in agony [...] She doesn't stand to see me so red, with that appearance. (Lourdes, PT, 27y)

In both stories, interviewees are confronted with a negative reaction that comes from mothers who cannot deal with the double information about illness and sexuality. It is almost impossible to determine whether ableist conceptions triggered by the fear of illness are predominant over the aversion to non-conforming sexualities. For example, Lia's mother internalised the stigma associated with HIV, almost automatically linked to a deviant sexuality, and replicates its stereotypes. However, her fear is directed also at the possible rumours that the situation could trigger: in both excerpts emerges how important it is to keep the information about illness as invisible as possible, to avoid any negative consequence in the public sphere. As we will discuss deeper in the next chapter, the internalisation of the prejudices around illness as a punishment, especially when it is connected to a presumed deviant sexuality, often leads to disbelief, discrimination, and blame. Another interesting aspect that emerges in Lourdes' account is the direct connection she identifies between her coming out to her mother, the negative reaction triggered, and the onset of her illness. Although it is hard to argue that the rejection experienced in the familiar context is the only cause for the emergence of her condition, it is surely interesting to pinpoint how the two elements are put in connection in Lourdes' reconstruction of her life course. Through the narrative process of the interview, Lourdes seems to recuperate the organic dimension of her pace and the links between events. Her story does not only show the impact that family relations have on the well-being of LGBTQ+ members of the family: it also exemplifies the importance of narrative processes to make sense of events that seemed disjointed.

1.2 Wearing masks: visibility and coming out

Since the birth of gay and lesbian studies, friendship has constituted a trope of LGBTQ+ narratives especially for the consistent influence of the concept of “family of choice” coined by Weston (1991). During the AIDS epidemic in the 1980s, friendships constituted the safe networks of care that compensated the absence of the State and the families of origin. In later years, studies focused on the forms of activism, intimacy, and economic support that often blend within LGBTQ+ networks of friendships (Jones-Wild, 2012; Weeks *et al.*, 2001; Roseneil & Budgeon, 2004):

> Friendships particularly flourish when overarching identities are fragmented in periods of rapid social change, or at a turning point in people's lives, or when lives are lived at odds with social norms. [...] They can allow individuals who are uprooted or marginalised to feel constantly confirmed in who and what they are through changing social experiences. (Weeks *et al.*, 2001: 51)

Although friendship is a concept so broad that it can be easily romanticised or generalised, its meaningfulness is universally recognised. In the interviews, friendship constituted a red tape that emerged in the most diverse ways and as related to a vast array of topics, from visibility to precariousness, from the management of illness to the visions of the future. In this section, however, I consider it important to focus on the narratives that present how friendship is mediated by strategies of visibility both as chronically ill and as LGBTQ+.

Some interviewees confirm the importance of friendships as bonds that provide a sense of belonging and are based on a shared experience of diversity:

> In one of my groups of friends, there are few issues of neuro-diversity, so there was no need [to address my illness] because we are all in the same boat. We'd always find a way to explicit our needs and limitations, so when it was my turn I didn't face any problem. (Jasmim, PT, 35y)

> I began to make closer friends in a phase in which I would also be more open about [my homosexuality]. So, you know, it was a matter of take it or leave it. And...I would even be a little cautious in letting people get too close...so there were not many I had to come out to and...all of them reacted well. (Antonio, PT, 31y)

In these experiences, visibility has a political implication. For Jasmim, the shared experience of body-mind diversity provided the conditions for a safe coming out as chronically ill: when she was diagnosed, she knew she would not face any backlash from her friends because vulnerabilities and limitations were already part of the common experience of the group. On a similar note, for Antonio, visibility and acceptance is a non-negotiable aspect for the construction of significant friendships.

However, not all narratives are as positive as these. In some cases, participants struggle to be visible as chronically ill or as LGBTQ+ with all their friends and at all times. The stigma associated with chronic illness and the widespread homo-transphobia encourage the differentiation of practices of (in)visibility:

> The problem, the thing that is bugging me, that I don't know how to handle, is that.. I often feel to wear I mask with people, with those that don't know everything. Even with some friends at university that don't know about the whole non-binary thing, I feel like I'm leaving something big out of the picture. (Logan, IT, 23y)

> I'd go out and in the middle of it I'd start to feel an unbearable pain in my knee, so I'd endure until the end of the encounter. Then I'd go home and sometimes I'd cry...It was so complicated. [...] My friends didn't understand...they didn't know, none of them knew about it. I think that at

> the time, my girlfriend would say something to them without me knowing...but I didn't want her to do it, because...I felt I was showing them a weak side of me, an imperfect one. (Julia, PT, 35y)

The narratives show how the different layers of visibility are complicated by several elements. With friends at university, Logan were completely open about their illness but did not disclose their process of questioning gender, for fear of transphobic reactions. The feeling of wearing a mask is increased by the fact that Logan did not come out as chronically ill with their group of non-binary friends: while with them Logan feels free to express everything about their process as non-binary, they do not talk about the difficulties of being ill. Similarly, although she was out as lesbian with all her friends, Julia did not want to come out as ill because she felt it would undermine the image they had of her: at the time, she associated illness with weakness. Both stories are revelatory of the processual character of visibility and its strong influence on the way significant relationships are moulded. Similarly to what described in the previous section, where visibility profoundly changed the relationships with families of origin, here the choices of coming out are influenced by factors such as the fear of rejection, the consciousness of social expectations, and the need to feel a sense of belonging. In the cases of Logan, Julia, and others, (in)visibility is strategically performed to privilege safety to integrity: interviewees prefigure the possible consequences of falling out of the able-bodied/heteronormative order and, consciously or not, choose how to alternate between closets (Pieri, 2019).

Although this is not the focus of this section, it is worth mentioning that other participants told stories of rejection, discrimination, and verbal abuse by friends that reacted to their coming out as LGBTQ+. The threat of homo-transphobia is constantly at play in Italian and Portuguese society, so the preventive invisibility chosen by some is also justified by the social environments they are immersed in.

1.3 Friendship: a matter of time and place

The negotiation of friendships relates also to aspects of time: it is important to share activities in virtual or personal co-presence, spend actual time together, and have some experiences at the same time than friends. To a certain extent, making friendships thrive is also about following a shared rhythm (Silvestri, 2016). Interviewees often refer to the constraints that illness imposes to their timings and how they affect the possibility to enjoy their friendships. As discussed in the first chapter, chronic illness usually has an uneven pace and an unpredictable rhythm. On a basic level, some participants mention how such unpredictability makes it hard to make plans with friends or participate in common activities:

> Because of my migraines, if there is a plan I'm always the one who says “I'll catch up with you later, if I can”. I never set an appointment at a specific time in a specific place...I am the queen of bailing out! (Tove, IT, 29y)

> Sometimes they invite me out, at the last minute, to something, and I think: “I'll have to run to get there on time” and so I say: “No, I think I'm going to stay home”. [...] When I explain to people why, I feel that they snort, like “I can't believe you missed this just because you don't want to be in the sun!”, you know? It's as if they believed I was superficial. (Lourdes, PT, 27y)

In some cases, interviewees are considered unreliable because of this asynchronous timing; the sensation of unreliability is enhanced by a subtle suspicion on how justified their flexibility is. In the words of many, they feel that friends do not understand this incapacity and implicitly believe illness is used as an excuse, hence judging them negatively, as Lourdes says.

The inability to meet the rhythms of friendships is countervailed by the inability of many to adapt to the rhythms of the chronically ill persons. Especially when the onset of illness is recent, it puts a strain on friendships that already existed and make it hard to change the habits of socialisation:

> Going out as I did, I can't do it anymore...I can't go out at night anymore. Before, I used to go home at 2 am, 3 am, now I go home at 10 pm. It changed so much, I only have friends I had before [the illness], they are all from Madeira and...it's not easy. (Lucas, PT, 32y)

> I am completely aware that I lost many friendships because I was never available, since I was either working or completely exhausted in bed. When I could, I would always ask people to come over to see me, and it's not fair to put other people in this position. (Jasmim, PT, 35y)

The difficulties in meeting timings and the unpredictable pace of illness have deep consequences on the overall networks of socialisation of the interviewees. Isolation, loneliness, and even abandonment are recurrent experiences in the narratives and a shared sense of struggle emerges in many instants. The inability to take part in social activities limits also the encounter with LGBTQ+ groups, which is important especially for those who are not completely out of the closet. In these cases, the difficulty in attending social events, dinner parties, or book launches regards not only time but also space. As will be discussed in the next chapters, not only LGBTQ+ clubs are often not accessible to people with different mobilities and needs, but also they tend to be concentrated in bigger cities. For those that live outside bigger centres, the possibility of meeting with other LGBTQ+ friends is often precluded by geographical constraints. A significant example in this regard comes from Jack, an Italian interviewee with Chronic Fatigue Syndrome, who lives in a rural area in Northern Italy. Every Wednesday he tries to attend the meetings of an LGBTQ+ support group in a nearby city; however, since due to his condition he cannot drive, Jack has to either take a lift from someone or take a train. In both cases, the journey of 15km leaves him so exhausted that when he gets there he cannot interact with anyone. After the meeting, the group often goes out for drinks but Jack rarely goes:

> [I don't have many contacts with other gay men] and now with this illness even less, because I can't go out much, I can't do much. Finally, after a lot of time, after seeing this for some time, people are beginning to understand my condition, after so many times telling me "Jesus, I haven't seen you in months!". [...] But, you know, I'm free to express myself only on Wednesday, because I live in a context where they make me feel wrong all the time. (Jack, IT, 29y)

In this paradigmatic case, that reflects other narratives collected, the objective obstacles imposed by the pace of illness have a strong impact on the possibility developing significant laces with the LGBTQ+ community. If we consider that most interviewees do not have contacts with other chronically ill *and*

LGBTQ+ persons, we can understand how the feeling of isolation can be even exacerbated by differences in time and constraints in space.

Although some have a positive experience with friends who show flexibility and ability to embrace the unpredictable rhythms of illness, the majority refers to this aspect as a source of stress:

> I always had normal friendships, although I always felt misunderstood because...it happens that I have to say I'm tired and cannot go out, and I don't think they fully understand what it means to bail out at the last minute, or have to postpone because I don't feel well. (Andrea, IT, 34y)

> In some days [illness] tampers with my self-esteem, so, for example, in some days I'm more vulnerable...and I know that I'm about to have a rash and I that if I go out I'll get all itchy and red, it will only get worse! So, in those days, I'm not going out, not going anywhere. (Lourdes, PT, 27y)

Interviewees such as Andrea feel that their friends do not fully understand the reasons that are behind the choices to step out of common activities: again, as Lourdes had mentioned before, there is an implicit feeling of being judged as superficial or as exaggerated. The ignorance and the stigma still ingrained in the social ideas of illness feed these reactions and create forms of stress for which the choice to go out is a combination of rhythms of illness and its (in)visibility.

2. Spaces of intimacy

> An honourable human relationship - that is, one in which two people have the right to use the word “love” - is a process, delicate, violent, often terrifying to both persons involved, a process of refining the truths they can tell each other.
> (Adrienne Rich, 1977)

2.1 (In)visibility in the time of dating

In the manyfold world of intimacy, dating constitutes an important experience in which identifications, practices, desires, social expectations are put into play. The stories collected reflect a vast diversity in terms of the way such encounters are experienced and reveal that (in)visibility represents a considerable source of struggle. Interviewees consistently reflect on the strategies of disclosure of their illness they enact when meeting potential sexual partners. Although the practice of coming out in itself is experienced by all participants as a consistent part of their everyday life as LGBTQ+, unveiling a chronic illness in the context of a sexual encounter presents struggles and requires careful contextual evaluations. Some interviewees choose to explain to their partners only the elements of their condition that directly affect sexual performativity, such as chronic pain, the impossibility of moving a limb, or epileptic seizures connected to fatigue. Others opt to describe their condition in all its aspects to create a deeper connection with their partners. The timing of such disclosures is chosen according to personal evaluations that can change from one situation to another. For example, some interviewees do it at the beginning of the first date, even when they don't know whether the encounter will have further sexual development. Others prefer to talk right before engaging in sex to guarantee safe and consensual practices. In most cases, the way and the time of the coming out about illness determine risks, vulnerability, and potential negative outcomes.

Gay interviewees, for example, discuss how dating through apps such as Grindr[13] exposes them to episodes of direct rejection from potential sexual partners. The app offers to find partners at any time and conversations between users usually focus on basic arrangements on when, where, and how to meet. Interviewees struggle to find the right way to explain their condition:

> I use apps...but now when they ask me about sex everything stops because I can't explain to them that I have CFS [Chronic Fatigue Syndrome]. After showing pics of me in a bathing suit at the beach I can't tell them I'm not able to fuck. Nobody, no healthy person, would believe it, it's as if it was an invented excuse to tell them “I don't like you enough”. So I just say I'm looking for friends [...] with no sex...but without sex, you don't build anything, anything, in gay relationships even more so than in heterosexual ones. (Marco, IT, 42y)

> Many contact me, write me, and I tell them, obviously, not at the first message, but quite early on, and I ask: “Is it a problem?”. Most of them, almost everyone, say: “Sorry, yes, it's a problem, but we can meet to have a drink or so”. Thanks, but no, that's not what I want. (Fabian, IT, 34y)

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[13] Grindr is a popular app for dating exclusively dedicated to the gay users.

In Marco's case, the mismatch between his appearance and his actual physical status scares people away. For Fabian, instead, rejection comes from an ingrained stigma against HIV-positive status in the gay community (Hodges & Rodohan, 2004). Although Grindr allows users to show their HIV status or whether they are on PreP, few recur to this option in the Italian gay community: stereotypes and prejudices on HIV are so present that many hide into the "second closet" of illness (Di Feliciantonio, 2018). Fabian confirms that many of his friends are HIV-positive but do not disclose it, sometimes not even to their sexual partners.

Experiences of rejection or fear of rejection emerge also in the stories of others, confirming that illness triggers unexpected fears in intimate relationships and is rarely a factor with neutral impact. Interviewees are aware that keeping illness invisible can turn out to be detrimental in a further moment, because it can put at risk their well-being and the safety of their partners. Coming out as chronically ill is thus an obligatory choice and the costs of invisibility are usually not worth it:

> I usually tell them, in most cases, I talk about it, yes, also because, I must admit, I don't do it for them, I do it for myself, I mean...to advise them: "Don't go too hard on me!". But anyway...it's difficult. (Alkirk, IT, 25y)

> I speak [to my partners] right away [...] because my illness conditions my rhythms, how I can be with them, enjoy their company, and allow them to enjoy mine, so it's something that emerges right away. For me, it's important to do it right away, to let the other person decide and say: "Well, maybe I don't want to bear this all". (Maia, IT, 27y)

As Alkirk underlines, coming out is first and foremost a protection strategy: his chronic colitis affects the anal zone of his body and without the correct information it can make it hard to engage in sexual activity. However, visibility is not easy because it brings illness in a highly eroticised context and relate it to a centre of pleasure, with the risk of rejection or desexualisation. Similarly, Maia intends coming out as a way to protect the sexual encounter from misunderstandings. Her act of visibility overturns the asymmetry between her and her (able-bodied) partners and creates space for consensual encounters in which illness is constitutive of her sexuality.

Dating represents also an investment in terms of energy, time, and emotions, which can be sometimes more costly than beneficial. Interviewees with rheumatic conditions, Chronic Fatigue Syndrome, and chronic pain report being less inclined to sexual encounters in days of flares. Involvement in sexual experiences, especially when emotionally intense, is not affordable when the basic everyday tasks, such as getting out of bed, eating, showering, take up all the energies available. Chiara, a queer woman with CFS, recalls how she would feel about dating in the worst moments of her illness:

> It was also the fact of not wanting, you know, to complicate their existences, and to complicate my own, I'd tell myself: "I'm not capable, in any case, to give anything, I don't have energies to embark on something emotionally involving". So I wouldn't look for this kind of thing. (Chiara, IT, 27y)

The excerpt shows how worries that illness may complicate sexual relationships are ever-present: feelings of "being a burden" or "having nothing to give" are exacerbated by internalised ideas over the expectations occasional partners may have around sexual performativity (Santos & Santos, 2017).

Setting up encounters with potential partners constitutes a difficulty for those who have illnesses with unpredictable patterns, such as chronic pain, migraine, epilepsy, urticaria: for them, symptoms of a flare can emerge unpredictably and last for an uncertain time. Hence, the same difficulties experienced with friends in setting up appointments and respecting plans also influence the dynamics of dating. Moreover, transports and accessibility need to be taken into account in the arrangements. The following examples show some of the obstacles to accessibility:

> I can't be messaging all the time and people don't understand it. They pressure me to reply, even though I say that I can't. [...] Nobody likes to call, everything is centred on messaging, and they don't understand why I don't reply immediately and...it gets very complicated. (Lisa, PT, 27y)

> Normal people work until 7 pm and their private life begins after; my private life ends before they finish work, so I don't have anything to give in terms of time, nothing to give in terms of attention, and not even sex. (Marco, IT, 42y)

Lisa, who struggles with an illness that affects her hands, finds it hard to access dating apps only based on messaging: her example is interesting in the way it sheds a different light on the universal accessibility commonly associated with new technologies of communication (Siebler, 2016). Such universal access is guaranteed particularly in certain times of the day inscribed in the normative timeline of able-bodied and productive individuals, who work during the day and dedicate time to leisure during the night (Cederström & Spicer, 2015). Overall, interviewees encounter in dating challenges related to time, visibility, and able-bodiedness that are always potentially harmful but that also show the possibility to critically undo the implicit normative assumptions sustaining them.

2.2 Desire, communication, and sexual practices: when illness comes to bed

Chronic illness influences the experience of sexual desire as well. All interviewees admitted that their desires, not only their practices, changed together with their bodies. This process of adjustment can offer surprising turns, as in the case told by Lia. Before being diagnosed with HIV, she mostly had sexual experiences with men and sporadic sexual encounters with women. After the diagnosis, she went through a long period of sexual inactivity, which only ended when a routine appointment with her doctor changed her perspective:

> I had a doubt and was asking the doctor, I said: "I'm seeing a person and I may have sex and I just wanted to be sure about something" and he said, "Ok, but your doubt concerns a man or a woman?" and I said, "Why? Does it change anything?" and he goes, "Of course, you can't transmit the virus to a woman". I didn't know it! I got gobsmacked, I said: "What? How is it that nobody ever told me this before?" [...] I should have known for a long time, I would have loosened up much before and I'd have been only with women! (Lia, PT, 34y)

As we will see in the next chapter, it is rare for patients to receive information about sexual practices in healthcare systems (Austin, 2013). Getting to know that she could be less contagious having sex with women completely changed Lia's availability to engage in sex: as a matter of fact, it opened a space of experimentation of her bisexual drive.

The direct link between desire and practice is one of the most recurrent elements of normative sexual scripts (Siebers, 2012). Illness may interfere with their linearity and create alternative paths, in which desire retains its centrality and the importance of sexual intercourse is decentralised without causing loss of interest in sexuality at all (Santos & Santos, 2017). Thus, some interviewees find a space to undo the able-bodied scripts reproduced within normative conceptions of desire:

> I still have a sexual drive. It is almost zero...what illness changed was the practical side of it. I experience numbness, so it affects also my genitals and I don't feel pleasure. Since I don't feel pleasure, I don't want to have sex. (Momo, PT, 32y)

> Some people told me: “You've got to make do with less”, meaning “You're already ill, you've got your problems, how can you even think you get to choose beautiful partners?”. [...] This is a form of discrimination. I mean, I often feel I'm not entitled, not authorized in front of people that are too beautiful. [...] I think: “Forget, I'm out of the game, they're too beautiful for you”. (Ellie, IT, 34y)

Momo self-identifies as pansexual and demisexual. In her case, illness did not change the availability to experience desire but forced her to reconsider how desire is normatively linked to sexual practice and to explore the spaces in-between, where desire is enjoyed but not practiced. Indeed, Ellie also experiences the normative attributes ascribed to desire, which associate beauty to able-bodiedness and consider illness as a threat to sexiness and desirability (Arfini, 2011; Clare, 2003b).

Illness also influences the way bodies perceive contact and pleasure during sex. In the case of rheumatic illnesses, interviewees experience pain in the repetition of the same movement or in keeping certain positions for a long time. For those with epilepsy, it is quite common to experience hypersensitivity after a seizure, a sensation that alters the feeling of touch. Those on strong medication for pain also experience alterations in perception: lack of intensity may lead to difficulty in feeling intense pleasure. When breathing conditions or skin reactions are part of the symptoms, they tend to increase during intense sexual activity. Even within LGBTQ+ relationships, expectations on what is proper in sexual encounters are so ingrained that it is common among interviewees to express insecurity and low self-esteem concerning the possible reactions of partners. Their fears regard the ability to sustain physically intensive activity during intercourse; the possibility of not feeling pleasure; the fear of feeling too much pain; the sudden burst of symptoms such as tremors or skin rashes:

> For example, when things get hot, I'll start sweating and probably I'll experience a skin rash. I'll have to start scratching my body and...it's gonna kill the beauty of it all. (Lourdes, PT, 27y)

> I have to use hands, fingers, do oral sex...and it ends up being complicated because, while I'm trying to give pleasure to the other person, or even when I'm touching myself, I'm in pain. So, I have to say: "Sorry, I need to use the other hand", or, when we are doing a practice called "grinding[14]" [...] I have to say: "My hips hurt a lot, we need to change position". This happens frequently and I need to talk about it. (Safo, PT, 24y)

> How is it going to be? Because I won't be able to give what the person will probably want...for example, I had to give up masturbation, because vibrators are a problem, with all those vibrations. Everything is a problem, so when the time will come I'll have to say: "Listen, we'll have to figure it out somehow". (Lisa, PT, 27y)

The excerpts show how diverse and complex can be the practices of negotiations between inner desires, practices, and communication with partners. The uncontrollable manifestations of illness transform the bodies of interviewees into "leaky bodies" (Shildrick, 2009), bodies that do not contain themselves within what is expectable and proper. However, in this space of escape from the prescribed scripts, some discover new ways of exploring their sexuality. Their experiences resonate with what Wachsler defines as "one of the gifts of sudden disability - the chance to discover parts of yourself that were hidden in the flurry of 'normal' activity" (1999: 111).

In this context, communication becomes a central instrument to sexual encounters, one that can create the needed conditions of safety and consent. In most cases, interviewees have to find their way without counting on anyone's help: on one side, they rarely receive pieces of advice from healthcare professionals; on the other, they seldom talk about it with friends, due to the shame regarding sex talk still ingrained in Catholic societies, especially for those who grew up as girls.

Verbal communication is transformed into a fundamental aspect of every phase of sexual activity: the need to ask questions, direct each other's movements, and give feedbacks is harmonised into the erotic experience and transforms care into a pleasurable activity (Rainey, 2011). For some, a satisfactory sexual engagement can happen only together with verbal communication, as in the excerpts that follow.

> Sex is a form of communication, a non-verbal form of communication. It is necessary to communicate: before, after, and during, because

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[14] Grinding is a sexual practice that involves genital-on-genital touching or rubbing, similar to the better-known practice of scissoring.

> everyone involved needs to enjoy the situation and feel comfortable with it. So we need to ask “Do you like this?”, “Is there anything I can do?”, “Is there anything I'm not doing well? Would you prefer me to do something else?” (Safo, PT, 24y)

> When I have sex, my illness is there, so I don't have much resistance, I can't stay in certain positions, I need to take frequent breaks, I often get exhausted, I may need to stop early. For me it's important to clarify that it happens because I have a neuromuscular illness and not because I'm not inclined to have sex with that person, because if I'm not in the mood to have sex I've got other ways to say it. (Maia, IT, 27y)

The examples reported show how discussing before, during, and after sexual encounters is a way to construct a stronger understanding of consent. In these conversations, illness is transformed from a possible element of disturbance into a key element of sexuality: it is part of every phase of the sexual encounter and is integrated with desires and practices. As it appears evident, this is a processual learning for interviewees. In this sense, chronic illness, like disability, “can act as a radical alchemist's laboratory of relationship possibility. A place where love might be invented beyond the roles of gender, and leave behind inherited, failed mimicries of intimacy” (Lehrer, 2012: 245).

2.3 Bodies that change, relationships that change

At the moment of the interview, eleven interviewees were in one or more significant relationships: amongst them, five self-identified as polyamorous or non-monogamous. One was married and had a child with her partner, whilst only four interviewees cohabited with their partner. In the negotiation of significant relationships, chronic illness can determine a significant change in the asymmetries of power between the persons involved. In the excerpts that follow, both interviewees reflect on how the onset of illness shattered their relationships:

> I understood that my partner's issues with illnesses, with this type of fragility, were very...peculiar, quite different from mine. [...] I had to keep an eye on his anxiety and mine, because I had my anxiety issues, as well. Sometimes I feel lonely in this respect, because when you think or acknowledge that the other person has more troubles in dealing with this kind of things than you do, you have to...play it by the ear, for yourself and him, although it's you the one that has the problem and it's always a heavy burden. (Marcelo, PT, 35y)

> My partner has been impeccable, she gave me a lot of support and she told me that she needed to process the whole thing...to understand that

> the person she had married was now an ill person. However, at the beginning it was not easy because she was extremely frustrated: there were times in which I wasn't able to help at all. [...] She had to do everything and with a baby in the midst of all this it wasn't easy. But we managed. It was a tremendous test on our relationship. (Maria, PT, 39y)

The challenges experienced by the interviewees when they fall ill are reflected in the difficulties their partners face in acknowledging the changes that illness implies in aspects such as the routine arrangements, the needs of the partner, the capacity of performing tasks or working, and the bodily appearance. All these changes are not always disruptive, as Bury (1991) identified, but often impose adjustments on the expectations for the future, the ability to make plans, the sense of purpose within the relationship. Several interviewees felt a sense of loneliness, at some point in their relationship, just like Marcelo refers: the unspeakable aspects of illness and pain can become even harder when partners, on the other side, do not know how to approach all of the changes or deny them. In all cases, chronic illness puts a “tremendous test” on relationships, as Maria says. Some interviewees actively pursue strategies of compensation of the asymmetries. For example, some avoid complaining too much about pain for the concern of becoming a burden or being boring; others take more care of their partners' emotional well-being as a way to balance out the lack of material support. As I will discuss in the next chapter, the negotiation of care constitutes a significant aspect of asymmetry that implies even further challenges.

Indeed, some narratives refer to how the difficulties brought by illness represented an insuperable obstacle that put an end to significant relationships:

> He got tired of me. Anyone would have, anyone gets tired of a person that is constantly exhausted. So I can say it was my illness that caused the end. A person with no CFS performs at work, at home, but me...my illness took away even my loved ones. (Marco, IT, 42y)

> There had been problems since the beginning, because he would say: “Why don't you hang out with me at night? Don't you care about me?” and I wouldn't go out because I was exhausted. Or we would be at a party and I'd had to lie down. (Chiara, IT, 27y)

If illness puts a strain on relationships, however, also relationships have an impact on illness. Emotional well-being and significative relations of affect are considered important elements that help the day-to-day management of chronic illnesses. As such, the consequences of times of turmoil can reflect directly on bodily manifestations:

> For example, when I had those conflicts with my girlfriend, and for some time we even broke up, I got so, so much in pain. A lot, a lot, a lot, a lot of pain in my back, it got really...awful. (Julia, PT, 35y)

> As a chronically ill person, you need to think if you have energies for a relationship because it takes energy to maintain it! (laughs) It's a strategical evaluation, you know, if it's worth spending those energies, you need to consider it in the economy of energies you have. (Chiara, IT, 27y)

As it emerged in the narratives about friendships and dating, relationships also take up energies and can be very time-consuming. Hence, the pace of relationships can determine also consequences in the way the body feels: in the “economy of the (limited) energies”, one has to make a balanced choice over the well-being that a relationships create and the risks attached to emotional investment.

It would be incomplete to conclude this discussion on partnering without mentioning that not in all cases illness represents the main source of difficulty within LGBQT+ relationships narrated. For example, Logan reports how it was their path with gender-identity that put a stronger strain on their relationship:

> [My girlfriend] says that she's just concerned with my health, she keeps saying: “You already went through surgery, why do you have to do others? Why do you want to do this?”, even if these are just hypothetical interventions. [...] She also says that she doesn't know if she'd still like me in case I transitioned. So...I mean, I appreciate her honesty, but it hurts a lot. (Logan, IT, 23y)

Although the main concern for Logan's girlfriend is related to gender, it is interesting to observe how the underlying discourse on illness is deployed here to cover a form of resistance to Logan's transition. Much like for the parents that consider health a bigger worry than obscures the importance of LGBTQ+ identification, for Logan's girlfriend the desire to advance in their transition should be put on hold to avoid further physical strain on an already suffering body. The physical suffering of illness is recognised as more important than the inner suffering of a non-binary living: a significative example of how the hierarchy of pain is constructed and reproduced.

3. Able-bodied and reproductive? The pressures to normalcy

> To inherit the family is to inherit the demand to reproduce its forms.
> (Sarah Ahmed, 2006)

3.1 Being ill together

Intimate relationships are regulated by compulsory norms that permeate the individual experience, to the extent to which interviewees grapple with complying with social expectations or reproducing forms of resistance. Able-bodiedness is often referred to as a powerful form of norm that confront chronically ill individuals with standards of success, performativity, and beauty. However, by reproducing the able-bodied option as the preferable one, it also implicitly indicates that a chronically ill person would be better off with an able-bodied person (Rainey, 2011). For this reason, it is particularly interesting to analyse the narratives of the interviewees who are in a relationship with another chronically ill person. For example, Maia, who is affected by Myasthenia Gravis, a rare illness that affects muscles, describes her relationship with a transgender man who is also chronically ill (although with a different condition):

> It changed how I feel in the relationship because there is no competition between health and illness, there is no performance anxiety towards the healthy person or fear of not living up to expectations or wanting to be able to share everything the healthy person can do but you can't do. And the beautiful thing is that you are with someone that understands what you're talking about, someone who doesn't have to imagine it because he already experiences it. It makes all the difference. [...] With him, I feel allowed to be ill. (Maia, IT, 27y)

In her words, sharing a condition of illness creates a more equal relationship in which the expectations on physical performance are designed on actual possibilities: the anxiety one may feel in living up to the expectations of able-bodied people is here substituted by a sense of comfort. It is particularly striking that the combination of two situations of illness creates the condition for a more balanced relationship, where illness is not perceived as an element of differentiation but as a form of affinity: it empties the pressures related to able-bodiedness and reinforces the feeling of being allowed to be ill. Maia's words also show how strong and subtle the pressure to perform and behave as an able-bodied person can be felt. A similar sense of comfort is described by interviewees who are in a relationships with someone who has the same illness:

> It was really helpful to have a person that understood me when I'd try to explain something, that knew what I was talking about. She often reassured me, she'd tell me: “You know that when Autumn comes, it's foggy, and it hasn't been raining for some time, there's pollution and it's harder for us to breathe”. It helped me not to panic. [...] Sharing my illness with her [was helpful] also for naming certain things without fear. (Sofia, IT, 32y)

> She was able to understand when I needed to be asked how I felt and this is so important when you have asthma because there are so many situations in which you need someone...Even, like, when we are somewhere, I'm not sure I took Ventolin[15] with me and ask her: “Sarah, do you have Ventolin with you?” and she says: “Yes, I got it”, things like these. (Nina, IT, 26y)

Both Nina and Sofia highlight the importance of being with someone who perfectly understands how illness behave: the reciprocal comprehension allows space for reassurances on the small acts of care and self-care, such as bringing medication when going out or reminding how the climate changes influence, every year, the outbreak of symptoms. As Sofia describes, it creates a space of trust within the relationship, where things can be named: in this space, illness can be discussed without reticences and vulnerabilities can be dealt with care. Both challenge the idea that care providers should necessarily be able-bodied (Rainey, 2018) and undo the normative expectations on care and able-bodiedness in coupledom.

3.2 The procreative imperative

At the time of the interview, only one of the 24 interviewees was also a parent. The data is more than just a coincidence. As previously discussed, in Italy, there is still no legislative protection of LGBTQ+ parents nor specific politics that encourage adoption. Only a few LGBTQ+ people can recur to adoption or

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[15] Ventolin is a common medication used by people with chronic asthma in moments of respiratory crisis or breathing difficulties.

medically assisted reproduction in other countries (Gusmano & Motterle, 2019). On the contrary, in Portugal adoption for single or married LGBTQ+ parents, as well as medically assisted reproduction, are allowed since 2016 (Santos, 2018a). LGBTQ+ parents are usually older than the average age of people interviewed in this research, given the weight of the economic and cultural resources required for these processes. However, the topic of reproduction and parenting emerged extensively in the interviews.

Participants who are in relationships read as monogamous and heterosexual are very aware of the pressures directed towards reproduction in common discourses:

> Sometimes people say things like “Ah, we miss a child here in the village, to have some joy!” [...] An old woman, a friend of us, said “Oh, you are starting to get old”, like “If you don't have kids now, you won't have more time”. There is this pressure. [...] People in the village are not very open. It's a very conservative region and [...] obviously, expectations are completely different. This is something that worries me. (Alice, PT, 30y)

> They would be constantly like “You have to marry, you have to have children”. Or, they'd ask: “Do you have kids?”, and I'd say: “No”, and they would be surprised: “Ah! So what now?” [...] I hate kids! I don't want to have kids. One of my worst nightmares is getting pregnant one day, what the hell would I do? ((laughs)) But, of course, I couldn't explode and say it, so I'd just say: “Look, now it's not the right time”. (Momo, PT, 32y)

Being read as a monogamous and heterosexual couple leads to being subject to the pressure to reproduction, defined as “the procreative imperative” (Roseneil *et al.*, 2016: 3) or repronormativity (Franke, 2001). In Alice's view, whilst the fact that she and her partner are not officially married is socially accepted, it is also implicitly expected that the next step of their relationship after cohabitation will be having children. In the small village where they live, she is often questioned about the issue by other women. However, Alice is reluctant to consider the possibility because of the strains a pregnancy would put on her body. Momo is also resistant to the idea of having children for a double reason: her illness, multiple sclerosis, usually jeopardises fertility, but, also, she does not feel any particular mothering instinct. In the episode recalled in the excerpt, Momo was questioned on the issue by other women during a recent hospitalisation. In that circumstance, Momo strategically decided not to come out as a demisexual and pansexual person who identifies in a neutral gender and a non-monogamous relationship, since she deemed it more important to protect herself from possible negative reactions in a moment of great vulnerability. She felt that expressing her disinterest in having children would be received as equally unacceptable in a context in which mothering is often considered a natural destiny for women. It is interesting to note how both Alice and Momo are perceived as cisgender women in monogamous relationships and thus receive a strong pressure towards reproduction. They choose to pass and to maintain in the closet the elements of deviation from the norm that would make them outsiders, to protect themselves in environments in which they feel more vulnerable. In both cases, invisibility as LGBTQ+ constitutes an active strategy of resistance to discrimination (Pieri, 2019) - although it exposes them to other types of pressures.

Repronormativity also connects parenting to able-bodiedness. Disability studies and the sociology of illness explored the challenges encountered by disabled parents and on the able-bodied assumptions that set barriers to parenting based on physical aptitude (Pinto, 2011; Park, 2013; Santos *et al.*, 2019). Such assumptions are so ingrained in social discourse that several interviewees admit a recurrent fear of not being healthy enough to provide their future children all the care they need:

> (I changed my mind) when I understood my illness was genetic and that I wouldn't be able to hold a baby. Also, going through pregnancy would be awful because I wouldn't be allowed to take my medication. And if normal, healthy women feel pain in their back during pregnancy, for me it would be far worse. [...] I wouldn't be able to take care of the child, to do the most basic things. (Lisa, PT, 27y)

> I think I'd like to have children, but I don't know whether it's going to happen. [...] I think I'd be able to be a good mother, although this is a bit subjective, but I think I'd be psychologically prepared...although I'm not sure I'd be able to do it physically, I don't know if I could. (Julia, PT, 35y)

The fear of the physical struggles relates to the period of pregnancy and extends to the basic activities involved in parenting, like feeding, educating, playing. Such discourse emerges especially from interviewees who self-identify as women or non-binary persons: it is thus arguable that it comes from specific repertoires of representation that depict good mothers as able-bodied, caring, and always present.

3.3 Imaginaries on LGBTQ+ parenting

The legal and social contexts have a strong impact not only on social practices but also on the way citizens mould their desires. The different legal frameworks around parenting for LGBTQ+ persons in Portugal and Italy determine stark differences in the narratives collected. The Portuguese legislation seems to have already created an impact in the way LGBTQ+ rights of parenthood are generally perceived as legitimate human rights. When reflecting on their future as possible parents, Portuguese interviewees do not refer to being LGBTQ+ as a possible hindrance to parenting nor mention homo-transphobia as a potential problem. Some doubt illness may represent an obstacle, as previously discussed. Others highlight the importance of financial stability or the centrality of geographical location for the access to services:

> I think that even if physically I may be able, I think it would be much, much more complicated on a financial level. (Julia, PT, 35y)

> I'd like to already have the money to start thinking about adopting a child, or doing it already...an older child, eight or nine years old, one of those that the system considers already hopeless. (Jasmim, PT, 35y)

> I'd like to get married, have a family.
>
> *Do you think it would be possible here in Madeira[16]?*
>
> Yes, it may be. Otherwise, I'd go to Lisbon, adopt a child there, do it somehow. (Lucas, PT, 32y)

The main point in these narratives is the awareness that having a child requires economic and logistic resources that are difficult to find since illness strongly limits the ability to work full-time. These worries signal how illness creates side-effects on financial stability and precariousness that indirectly affect decisions over reproduction. On one side, the legal framework of LGBTQ+ rights allows interviewees to include parenting in their horizon of desire and eventually

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[16] Madeira is a Portuguese island located in the Atlantic ocean. Although the national laws were implemented there, the scarce population and the conservative orientation signals higher levels of homo-transphobia there than in the continental Portugal (Santos, 2013).

in their planning ability. On the other, the same framework is not enough to secure the actual access to those rights, because of other intersectional identifications of class, illness, age, and geographical location.

The Italian case shows starkly different narratives. When reflecting about the future, most interviewees did not even mention the possibility of being parents. This absence seems to reflect the narrowness of a legal frame that rules out parenting from the spectrum of legitimate choices for LGBTQ+ people. The political discussion that took place in 2016 before the approval of civil unions provided a strong signal in this sense: the law only passed because adoption was stripped away from the proposal (Lasio & Serri, 2019). Moreover, the fact that hundreds of children already born within LGBQT+ couples are still denied formal recognition constitutes a discouraging scenario that probably deters many to even think about parenting.

The few interviewees that refer to parenting as a desire always mention migration as well. The obstacles created by the lack of rights protection are amplified by the difficulties that illness imposes and by the necessary financial resources:

> I see it very difficult right now, things in the country are not moving fast and in any case, even if they approved gay adoption, I mean, it will depend. If I still looked like this physically, I could pass as if I was in a lesbian couple, I could take the baby and go! ((laughs)) But if I transitioned, I think it would be much harder. (Logan, IT, 23y)

> First, I'm not sure I would be a good father. Second, this is not Denmark or Sweden, unfortunately. Here in this country, as things are now, it would be unthinkable of (to have kids). (Fabian, IT, 34y)

The two excerpts show a certain underlying disenchantment towards the possibility of any change in the political scenario in the next years. Although it may be part of a cultural passivity already identified as a typical feature of Italian society (Calzada & Brooks, 2013), it also shows how the lack of recognition on the legal level transforms individual imaginaries and erases the ability to change the status quo. Interviewees seem to have resigned themselves to the impossibility of parenting. However, it is also interesting to note how much resignation comes from a combination of factors in which being LGBTQ+ is only a part.

Such skepticism about a better future is resumed ironically by another interviewee, that affirms:

> Politicians are as slow as death. I believe the Third World War will happen before they'll manage to approve a law like this in Italy! (Alkirk, IT, 25y)

The differences between narratives collected in Portugal and Italy show the actual impact that legal change can have on collective imaginaries. Once parenting is guaranteed as a basic right by legal recognition, LGBTQ+ persons can make informed choices about parenthood which are not only based on institutional homophobia or social stigma. Such recognition does not erase the other challenges represented by illness or precariousness, but it does at least offer a horizon of possibilities and social imagination.

Conclusions

Narratives collected show that the initial hypothesis of a supposed predominance of chosen relationships over families of origin in terms of safety and acceptance was not reflected in actual experiences: most interviewees, in fact, relate how every relation, including the most intimate ones, are crossed by multiple challenges of visibility and timing.

In the first place, the experiences collected show how the structural violence of able-bodiedness and heteronormativity implicate a constant negotiation in every relations, even the most intimate. Interviewees are exposed to forms of oppression related to time, visibility, physical inability, discrimination and many more: they need to operate constant choices to protect their bodily integrity, on one side, and to preserve the significant bonds of affect and love, on the other. Such negotiations can be consuming in terms of energy and time: in this sense, chronic illness diminishes the capacity to choose and increases the weight of bad choices when it comes to intimate relationships. In the micro-politics of intimacy, the pressure of heteronormative and ableist patterns towards bodily performance, reproduction, and coupledom, is particularly felt when it comes to imaginaries and projection in the future. However, as the last section highlights, the frame of legal rights also have an influence: they are important to secure access but not sufficient to provide a safe network of conditions. In a certain sense, they address to people that are *just* LGBTQ+ and leave aside all those that, besides being LGBTQ+, are also, as in this case, chronically ill and thus exposed to multiple forms of precariousness.

In the second place, however, the narratives also show a great capacity of resistance to pressures and how normative constraints create space to reinvent ableist and heteronormative patterns of relations. If all significant bonds are built on a fragile balance of (in)visibility and time, however, through such challenges each person gives rise to practices that can be even surprising and counter-normative. As the examples discussed show, the obstacles encountered with families or with sexual partners offer opportunities to undo the normative organisation of priorities and to give rise to deep connections based on a deeper understanding of intersectional suffering. When it comes to sexuality, for example, contrary to the common view that assumes illness is a synonym for passivity, interviewees show initiative in finding individual strategies to overcome initial limitations: in so doing, they give centrality to self-care, pleasure, and consent.

In the circular path from inherited families to chosen families to imagined families here explored, the pressures of heteronormativity and able-bodiedness are countervailed by the capacity of each and every interviewee to imagine and put into practice new forms of relationships that result from a careful balance between (in)visibility, time, and bodily ability: if these new forms have a name, some others need to be defined. They will not necessarily assert the superior importance of chosen families over the inherited families. As some of the stories here discussed show, the capacity of inherited families to embrace and learn through suffering is in itself an emancipatory practice that can question much literature on the theme.

6. NEGOTIATING CARE BETWEEN SILENCES, (IN)VISIBILITY, AND DISOBEDIENCE

Introduction

The previous chapter briefly signalised how care is a fundamental aspect of intimate relationships, in particular in the presence of a chronic illness. The discussion that follows aims at analysing care not only as a practice but as a politics: through the narratives collected from persons that most and primarily, but not solely, care-receivers, it questions the practices and the strategies enacted, the challenges and the influences, that relationships of care trigger. It does so intending to look at care as a relationship in which the political dimension is inescapable and necessary at the same time (Vaittinen, 2015).

The first important perspectives on care come from feminist studies. In a fundamental work, Tronto (1994) highlights the predominantly gendered characterisation of care: the author argues that care is culturally conceived as inherent to women and as a reflection of those supposedly natural characteristics of nurturing, giving life, protecting, that are associated with motherhood. As such, at a political and cultural level, the organisation of care reflects a gendered division of roles. This aspect is still relevant in Southern European countries, as previously discussed and as narratives here analysed confirm. However, when it comes to care in the context of disability and illness, relationships are not complicated only by gender but also by conceptions of passivity: in many ways, in many studies, care is the synonym of a relation of dependence between able-bodied (the care-providers) and the disabled or ill (the care-recipients). Recent literature highlighted the profoundly problematic aspect of such conceptions (Shakespeare, 2006) and proposed the concept of interdependence (Fine &

Glendinning, 2005) that blurs the dichotomy between active and passive. It suggests that there are many forms of care and we all immersed in a network in which we are always at the same time care-providers and care-receivers.

Studies on LGBTQ+ experiences recently explored how relationships of care are constructed outside normative patterns and highlighted the importance of interdependence in contexts of oppression (Santos *et al.*, 2019).

This chapter aims to explore the different forms that care assumes in interviewees' life. The first part constitutes an ideal connection with the previous chapter: it investigates how care is negotiated in personal relationships, such as with families of origin, partners, and friends. However, the complexity of interpretations is such that the discussion will gather them under four types: care as a duty, as a form of control, as a choice, and as a gift.

In the second part, the analysis will focus on the less explored sides of relationships of care in experiences of illness: the focus will be on the stories in which interviewees are not just care-recipients but also care-providers and they learn to take care of their body-mind balance. Although it is a strong element of healthist ideas (Petersen, 2015), self-care and the psychological distress are often overlooked when discussing chronic illness. The experience of LGBTQ+ people is particularly important here because it adds a layer of intersections to the embodied suffering of chronic illness.

The last part will move to the context of formal healthcare. As previously discussed, in Italy and Portugal, public health systems do not present particular strategies of engagement with young adults with chronic illness. Except for a plan launched in Portugal in 2018, they are also not receptive to address the specific conditions of LGBTQ+ in their access to healthcare. Given this context, it is important to understand how chronically ill LGBTQ+ patients navigate the power structures of medicalisation, what narrative strategies of (in)visibility they employ, and what pressures they experience.

As it is probably already evident from this introduction, the discussion that follows will deal much with issues of power inequalities, exclusion, and pain. Instead of providing a definitive categorisation for what care *is*, it will focus on analysing how care *is done*: through the stories collected, the hope is to show the manyfold aspects that compose care through time, visibility, and suffering.

1. Negotiating relationships of care

> What is important is not what people make of us but what we ourselves make of what they have made of us.
> (Didier Eribon, 2013)

1.1 Care as a duty

Care is a fundamental pillar of familiar bonds: relationships of kinship are nourished by the consistent exchange of emotional, practical, and economic care. In Southern European societies, members of a family are prone to share a moral obligation to help the others (Bertone, 2020). The naturalisation of care within families, especially amongst women, is the precondition for creating the informal welfare system that characterizes Italy and Portugal (Saraceno, 2004; Santos, 1995). Catholic culture strengthens such precondition through the celebration of family as a sacred unity and the insistence on the moral imperative to support members of the same family, particularly the vulnerable ones: ill or disabled persons, children, and old people. In this context, families provide care to their chronically ill members out of a duty to protect their community and reinforce common bonds. This type of care consistently emerges in the narratives of interviewees:

> Within a family, you take for granted that love and care will be overlapping and so it is obvious that your parents will take care of you, not because they want it or they choose it, but for the simple fact that I am their daughter, and, as parents, they have to take care of me, even if they don't feel inclined to it. (Maia, IT, 27y)

In the cases in which interviewees live with their biological families (eleven out of twenty-four), the pattern appears to be similar, with a strong relevance of women members as main care providers. Their supposedly natural inclination to care seems to not raise conflicts about the physical proximity that some activities require. The everyday routine care often involves corporeal aspects of illness: for example, spreading lotion on aching areas of the body, helping with certain movements, or spoon-feeding. Indeed, several interviewees count on such support on a daily basis.

> It takes 40 minutes to go to the hospital [...], I always go with my mum. [...] She's a housewife and she also teaches English at a night school and gives private classes. [But it has to be her] 'cause my dad is always abroad for work reasons. (Jack, IT, 29y)

> After the lidocaine treatment I do, they want me to have someone that picks me up, in case I don't feel well. It's always my sister because my parents work until late. Since she only works until midday she's more available to come with me. (Lisa, PT, 27y)

> I always go everywhere with my mum, I've got my mum always with me, in everything. It's normal. (Lucas, PT, 32y)

The excerpts unveil the temporal dimension of this kind of care. Dealing with the everyday aspects of chronic illness is extremely time-consuming: time is spent in and out of waiting rooms, dealing with bureaucracy and logistics, but also small actions within the domestic space. Providing consistent, efficient, and reliable care is an activity reserved for those that can spend actual time on it.

Care is a strongly feminised activity: mothers, sisters, grandmothers, and in-laws are in charge of caring for ill members of the family. Women are still consistently responsible for informal care in Europe, as a result of the historical gender division of labour and failure in implementing policies on work-life balance and involvement of women in the labour market (Torres *et al.*, 2007). However, this tendency is even more pronounced in Southern Europe, where historical and cultural factors always favoured the unequal participation in the job market between women and men. The precariousness following the economic crisis weighted on these pre-existing conditions and favoured higher participation of women to domestic, unpaid, or precarious work (Mínguez & Crespi, 2017). Although during the hardest years of the crisis the rates of unemployment were almost the same between women and men in Portugal (16,4% and 16% in 2013), latest data show a delay in such equal access to the job market: in 2019, 7,1% of women were still unemployed compared to 5,8% of men (Pordata, 2020b). In Italy, the difference is starkly higher, with 27% of men and 47% of women unemployed or inactive in 2019 (Eurostat, 2020f). Women tend to have more precarious jobs and more flexibility in their timetable, a factor which favours their employment in tasks related to care. In both countries, the informal welfare system constituted by the domestic work of women flanks the formal system of assistance to old people, children, ill, and disabled people. Moreover, it is not uncommon that those who take care of children are also in charge of taking care of chronically ill members:

> My parents are already a bit old, they're 75 and 73. My mother was very sick in the last years, but now she's better. At the time, though, I couldn't leave our daughter with her, she was not in good conditions. So we had to rely much on my partner's mother. [...] It was all managed through my mum and my mother-in-law. (Maria, PT, 39y)

The overlapping of care is managed through the support of female members of the family also as a way to reduce the costs of childcare and personal assistance. For example, Maria alternates peaks of crisis to moments of stability in which she can work: relying upon her mother and her mother-in-law helps her equalising the economic uncertainties that derive from such instability.

By contrast, it is particularly interesting to reflect on two excerpts that tell of the discomfort felt by two self-identified women in the relationship with their fathers:

> I had to have some stitches removed, my dad is a vet so he's got the skills to do it [...] but the stitches were all around my breast and he refused to remove them because it would mean he'd had to see my boobs. [...] At the time, I thought: “It's normal that a dad doesn't want to see his daughter's boobs”, but now I think: “How is it possible that a dad is not even able to see his daughter without sexually thinking about her body?!”. Anyway, in the end, I removed the stitches by myself. (Maia, IT, 27y)

> They said I could begin to have my therapies[17] done at home and my father was in charge of that. Poor him, I think he'll feel guilty forever [...] because I didn't want to see him. Although rationally I acknowledge all his merit, I find it extremely hard to have any physical contact with him. I hug him maybe on his birthday and Christmas, and that's it! [...] He is a very tender person, so he suffers for this distance. (Ellie, IT, 34y)

The episodes expose how the relationship of care is mediated by an unstable balance between obligatory physical proximity and the gendered meanings that this proximity assumes. Maia's father sees himself primarily as a man in close contact with a woman's body: as such, he refuses to cross the moral boundaries that distinguish a relationship of care from a sexualised one, even at the cost of compromising Maia's safety as an ill. On the other side, Ellie's father performs painful therapies on vulnerable parts of her body: her memory of the pain is so attached to the physical closeness to her father that she cannot stand having other contacts with him, nor to other men, as she admits in other instants

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[17] Ellie refers to invasive procedures such as injection and douching of the intestine.

of the interview. What is fascinating in these examples is to observe how the suffering body is placed within a framework where gender and sexuality do not disappear: instead of stripping away the meanings attached to them, illness seems to make them even more evident and complex through the relationship of care performed as a duty. In the case of these fathers, the moral obligation of providing care to a daughter clashes with the social expectations on masculinity and the gendered meanings of physical contact that destabilise the relation in different ways.

On a different note, care can also be interpreted as a duty to provide materially and economically for the well-being of the ill person. In cases in which they do not cohabit with their chronically ill offspring, parents still tend to provide through paying medical expenses:

> I believe my mother feels responsible. When she asks and doctors say my illness was triggered by emotional distress, I believe she feels a bit guilty, and...I think she doesn't want me to pay for the price of it. So when I said, for example, that I had to take antihistaminic and that I had gathered money enough to buy it, she said: “No, I'll pay”. I think she feels somewhat guilty. I don't know if she can name that guilt or not but I think she feels it. (Lourdes, PT, 27y)

> My mother...I think buying things is for her a practical way of taking care, you know? She rapidly adapted to my condition and is very well-informed and knows exactly what to buy and what to avoid. (Antonio, PT, 31y)

In these cases, the impossibility to care day-by-day is replaced by the support given through economic means. Lourdes identifies it as a way through which her mother attempts to restore a balance in their relationship, after the negative reactions she had at Lourdes's coming out triggered symptoms that degenerated into a chronic illness. Through money, both Lourdes' and Antonio's mothers continue to provide and to reinstate the centrality of families of origin as vectors of financial stability (Bertone, 2020; Saraceno, 2004). It is important to remind that care as a normative expectation is reproduced also within couples, as it was briefly discussed in the previous chapter, although the focus here was directed to families of origin for the important aspects it triggers. It is indeed not by chance that care appears in the list of marital duties: when couples exchange vows on the wedding day, they promise each other to take care of their spouse "in sickness and in health", naturally incorporating care within the expectations around coupledom.

1.2 Care as a form of control

Within the familist organisation of social structures that characterise both Italy and Portugal (Mínguez & Crespi, 2017), the role of families of origin as main care providers overlaps with a part as agents of control and regulation. The claim of disabled people's movement towards the right to personal assistance (Martins & Fontes, 2016) is based on the recognition that when the boundaries between personal relationships and care are not set clear, disabled people are limited in their self-determination. However, the totality of interviewees cannot access any form of personal care, which, in any case, would be available only through private hiring and not public funding. As previously outlined, both in Portugal and Italy, personal assistance is publicly guaranteed only to a limited range of serious cases of disability. Therefore, for many interviewees, the only possible source of continuous and reliable care is the family: in these cases, relationships turn even more complex. Some tell of specific strategies to cope with such imbalances:

> My family is overbearing. I try to tell them: "Listen, I'm still capable of doing things, ok? I'm not completely disabled!" [...] My mother makes searches, "It can be this, you should go there". And sometimes she believes in weird theories that are not very reliable [...] and I have to say: "If you want to do these things, mum, do them for you because I don't wanna know about them". (Momo, PT, 32y)

> My parents are very worried. Too much. And so I avoid the topic, not to worry them even more; otherwise, they would be constantly calling and asking: "So, are you feeling better today?", "And today, are you feeling better?". I don't want that. I prefer not to speak at all. (Julia, PT, 35y)

Momo and Julia describe how the excessive worry from their family, however well-intentioned, creates paradoxical effects of distance. For both, the reaction to such infantilising and exhausting manifestations is reducing contact and sharing little information. However, the excerpts also suggest how the interest from families stems from a genuine preoccupation and, perhaps, a will to find definitive solutions to illness. They show how difficult it can be for families to accept the unstable terminality of illness (Lerum *et al.*, 2015) and its multi-layered temporal dimension.

In other accounts, families exercise care through the regulation of lifestyles: for example, controlling smoking habits, food, weight, and activities that are deemed potentially dangerous, such as travelling. It is particularly interesting to note that these examples of excessive care are reportedly part of relationships with families of origin even when interviewees live outside the family household and are well into their 30s. Moreover, these manifestations are disjoined from the acceptance of LGBTQ+ experiences: as discussed in the previous chapter, families generally demonstrate a relentless tendency to provide the necessary care for what concerns the condition of illness, even in those cases in which they are not available to guarantee emotional support or even acceptance of LGBTQ+ identifications. Indeed, in several cases, interviewees cohabit with parents who take care of them but pretend their homosexuality does not exist:

> It hasn't been easy to deal with my homosexuality. My mum doesn't deal well with the information. I try to talk about it but she immediately changes the subject. (Lucas, PT, 32y)

> My father's reaction is...pretending he doesn't know anything. We don't talk about it, even after my boyfriend lived with us for some time! (Antonio, PT, 31y)

This contradictory attitude of hyper-care, on one side, and silent indifference, on the other, inevitably influences the relationships within families. In a paradigmatic case, Fabian, who is HIV-positive, did not share the information with his family because he wouldn't accept them to be worried for his health and, at the same time, continue to deal with his homosexuality with absolute indifference:

> At home, they all know about me but nobody talks about it, nobody ever asked me anything, if I had a boyfriend, how my life is, I mean, they never asked me anything. I know that if I told them about my illness they wouldn't go away. My fear is exactly the opposite: I'm afraid they'd become oppressive, excessively worried, and I understand that but it would make me so anxious, so I prefer not to say anything. (Fabian, IT, 34y)

The narratives analysed offer an interesting perspective on the coexistence of strategies of visibility and resistance within family dynamics. Silence and (pretended) indifference seem to be employed as active strategies of regulation concerning sexuality; they reinforce the elements of control that stem from care within families of origin. Also, they enforce a typical ableist operation that infantilises and, consequently, desexualises disabled and ill people: as Shildrick (2013) highlights, the repressive attitude of Western societies claims that the efforts of the welfare (formal and informal) should be addressed to meeting the needs of disabled and ill people, leaving the satisfaction of mere desires to the realm of the private sphere. In the cases of adult interviewees cohabiting and depending on their parents, the lines between private and non-private, care and control, are blurred and the contradictions between care and acceptance as LGBTQ+ discourage the personal exploration of LGBTQ+ identity and sexuality.

1.3 Care as a choice

Care can also be intended as part of a relational agreement in which the persons involved negotiate the practical and emotional aspects of support. In these cases, care is provided not as a direct consequence of a moral obligation but as a committed choice. It implies a certain level of awareness about the asymmetries and power relations created by illness. Such situation is common within relationships of coupledom in which the intimate bonds are agreed, discussed, and negotiated. As previously highlighted, communication is often the most important way through which interviewees undo asymmetries in their intimate relationships: the expectations related to care, the fears of being a burden, and practical arrangements on tasks are deconstructed through dialogue. Although discussing boundaries is a common practice in non-monogamous/polyamorous relationships (Gusmano, 2019), positive experiences in this sense emerge also from interviewees in monogamous relationships:

> I've got different partners, but amongst them, at this moment Alex is my main care provider. He's the only one I allow to take care of me because with him I managed to reach this kind of intimacy. (Jasmim, PT, 35y)

> During bad days, I stay in bed and Adam has to bring me the food on the bedside table. I eat in bed, I take my medication and go back to sleep. [...] Adam is also reading me this book. He already read it, but now he's reading it again for me because I can't. (Momo, PT, 32y)

The excerpts highlight two nuances of care as a choice. In the case of Jasmim, care is something that only comes with a certain intensity of the relationship, an aspect which denotes the importance and deepness of one bond compared to others. The intensity of the bond of care emerges also in Momo's experience, where the nano-practices of care more immediately related to illness come together with moments of shared pleasure, such as reading. Effective communication on care, boundaries, and needs can result in a stronger sense of “attunement” (Rainey, 2018), in which partners feel connected both emotionally and physically. The different experiences of Momo and Jasmim also highlight how such closeness is reached when all parts involved are available to open themselves: while care providers need to momentarily suspend their self-centrality to embrace their partners' needs, care-recipients have to let go of a little part of their self-autonomy to allow themselves to receive care.

As already mentioned, some interviewees are or were in a relationship with a partner who is also chronically ill. In these cases, care becomes the focal issue on which negotiations, and sometimes conflicts, are conducted daily:

> With her, this was a major source of conflict because, probably even stubbornly, I would say: “Sarah, I will not take care of you”. It was more a way to proclaim it, to reassure myself, to protect myself by saying: “I will not be there every time you're ill, I'll not be your only care provider, you”. (Nina, IT, 26y)

> In case of need, I ask help to Otto, my partner, but it's always difficult for me because he is also ill and I feel like it's not right to ask him to take care of my illness when he already has to deal with his own. Also, I don't want to create confusion between our relationship of care, related to illness, with other types of care. I mean, I don't want him to be close to me because I'm ill. I want him to choose to be with me, to spend time with me because he loves me, because he cares about me.[...] So, I'd like to be able to keep these levels separated and I believe it's important to recognise them as two different things. (Maia, IT, 27y)

Both Nina and Maia recognise how expectations on care pressure them to perform as carers within a normative conception of coupledom. Their effort is directed at keeping care as a form of help related to illness separated and identifiable from what Maia defines “other types of care”, connected to the choice of spending time and attention to the partner. Care is here turned into a multi-semantic terrain of negotiation with multiple boundaries to be discussed, established, and transformed as part of a consensual process within the relationship. Maia and Nina's accounts show how the embodied experience of illness creates a high level of attention towards the unseen costs of care (Strazdins *et al.*, 2016): they know how much time and energy care requires because they see such costs every day. The double condition of care providers and care-recipients seem to favour a deeper awareness of the challenges of care and to reinforce the intention of transforming care into a choice, not a duty.

The negotiation of practices of care is not a prerogative of intimate relationships only. In some cases, interviewees receive care by persons not related by intimate bonds. These relationships mainly respond to the concrete needs of relying on somebody's help for emergencies. In the case of epileptic seizures, peaks of pain, asthma attacks, interviewees adopt a practical approach which activates the persons who can most effectively provide such help:

> Mostly, care is on my partner Martin. Then, I have some persons I'm more intimate with, [...] three friends I'm very attached to, but I can't be with them very often so...if I need anything, it's much more likely I'll rely on someone that works with us and lives in our village. (Alice, PT, 30y)

> In Bologna, I didn't tell anyone I have asthma but to my flatmates. [...] I said: “Look, I have asthma, it's under control, I take care of myself...but in case of need, this is what you have to do”. We are five persons living here, there's always someone at home and this was something that reassured me a lot, compared to living by myself. The instability of illness makes me feel so fragile so [...] telling them reassured me a lot. (Nina, IT, 26y)

In cases of emergency, the priority is given to receive help quickly and effectively: the relationships of care is not directly linked to visibility as LGBTQ+. Alice, for example, relies on her close friends for emotional support, especially on the issues of non-monogamy. However, in moments of need, she turns to colleagues who live in the same village and to whom she never came out as non-monogamous and queer. Similarly, when Nina moved to a new city, she did not come out as queer nor as asthmatic with new colleagues or friends and she decided to tell only her flatmates about her asthma to prepare the field for possible emergencies. In these cases, care results from a strategical choice that privileges the practical aspects of illness to other aspects such as LGBTQ+ visibility.

1.4 Care as a gift

Besides more structured and negotiated practices of care, chronically ill persons can also rely on unpredictable and irregular forms of care. Interviewees mostly refer to actions that do not follow expected patterns or regulated arrangements but contribute to the general well-being: they result from emotional bonds with friends and are connected to specific instants in time. For example, these deliberate acts of care are oriented to the relief of physical obstacles that complicate the everyday management of illness:

> A friend of mine bought me this (crutch). Then she bought specific paint and we decided to paint it. (Momo, PT, 32y)

> Last semester a teacher organised a bike trip. One of my friends is a biker and I told him, as a joke: “You could take me on a tandem bike!”. He took me seriously and we found a tandem and we participated in the trip by tandem. (Logan, IT, 23y)

Although Momo would have probably end buying a crutch anyway, the fact that it was a friend who took care of it and even suggested to personalise it adds to the very materiality of illness an emotional nuance. Similarly, Logan's friend understood the symbolic importance of guaranteeing their participation to the trip, not only for a reason of accessibility but also because, before falling ill, Logan was a promising professional biker. Of course, these acts of care do not resolve the everyday issues of living with a chronic illness. However, they configure as instants in which care comes as an important plus factor, as Fabian recalls when telling about the day he collected the result of the exam that diagnosed him as HIV-positive:

> I was in the waiting room by myself, but outside there was also a colleague of mine who is almost a second mum to me. [...] I had told her: “Don't worry, I'll go collect the result by myself”, and she insisted: “No, no, I wanna come with you” and at the end she showed up there, she waited for me and when I got out of the doctor's office she was there. (Fabian, IT, 34y)

The contributions that speak about care as a gift are generally connected to the sphere of friendship, where expectations towards gratuity, spontaneity, and choice constitute the basis for emotional exchange. As Roseneil and Burgeon (2004) suggest, the way care and support flow within a network of friends are not less important nor less effective than in coupledom or families: on the contrary, they often highlight the multiple possibilities of intimacy that can be configured outside normative spaces. Moreover, they offer alternatives to the burden of the every day, easing the pain through meaningful gestures that often represent an important moment in which bonds of intimacy or friendship are cemented.

2. The unseen faces of care

> What has no choice is strong.
> Portuguese Saying

2.1 Not only care-recipients: narratives of care-providers

The concept of interdependence is crucial to understand how participants take control of their positions of vulnerability through embodied agency (McRuer & Mollow, 2012). Narratives discussed so far show how balancing between care and dependence is a constant work-in-progress: both interviewees and their care-providers need to negotiate their relationships through the power asymmetries generated by illness and (in)visibility. In this section, I will focus on cases that illustrate how such hierarchies of power are inverted or reinvented through a different understanding of agency.

For example, one of the biggest resources interviewees have as chronically ill is the amount of embodied knowledge they accumulate through their experiences. Indeed, they recurrently refer to their role as key-informants to families, partners, and friends. Through the process of illness, they become experts of their condition and possessors of precious knowledge. The cases of Lia and Fabian, both HIV-positive, particularly highlight the importance of sharing correct knowledge about an illness which is still the object of prejudices and ignorance:

> People have no idea of what it means to be in this position, emotionally and physically. I had to explain to many friends the same information I had to discover by myself. It's the same on an intimate level, I feel I am never just a girlfriend, lover, sex-partner, who is just giving a piece of information: I become a scientific informant, I have to take up this role because people don't know anything. (Lia, PT, 34y)

> My friend and his partner came to my place because he was obviously in panic and I told him: “Keep calm, I know exactly how you feel [...] Tomorrow, the day after tomorrow, when you want, call me, write me, whatever question, whatever doubt you may have”.[...] In the first months I took care of him [...] because when you receive news like this, you can feel very very sad, in just a second. (Fabian, IT, 34y)

Care is here provided through the passing of knowledge around illness: both Fabian and Lia intervene in their significant relationships in sharing all those information that others do not know. Through the experience of his friend recently diagnosed with HIV as well, Fabian he could put into practice the learning he acquired through his experience and thus make sure his friend did not panic in the very first moment of the process. Despite having different stories, both Fabian and Lia learned the importance of sharing knowledge through experience: they adopt a similar strategy of care towards friends, occasional sexual partners and significant others, making sure they enrol in safe sexual practices, and checking regularly with them about doubts on HIV.

It is interesting to note how, in the principle of “knowing is caring”, there is a reparative mechanism that restores a sense of worthiness within a fractured biography (Mazanderani *et al.*, 2012). Through the act of taking care of someone in a fragile situation or preventing that a loved one risks going through the same situation, interviewees understand how their suffering was not useless:

> One of the ways I found to manage the different conditions I have, especially psychological distress, is to take care of others, to make sure that I will do everything possible to avoid that others go through what I go or I've been through. This is extremely therapeutical for me. It's also a defence mechanism that sometimes turns against me because I end up not taking enough care of myself. (Safo, PT, 24y)

Mental health is here an equal important sphere as the one of physical well-being in the process of care and has positive implications both for the care-provider and the care-recipient. LGBTQ+ issues are also part of the exchange of care, to the extent to which several interviewees help friends in difficult moments of discrimination and provide support in coming-out processes. These examples overturn the typical depiction of LGBTQ+ persons as passive (Santos, 2018c) and offer a different perspective on how experiences of oppression can become important sources not only on an individual level but also for a collective construction of narratives. Acts of providing care are mostly oriented to the emotional sphere, also because the physical limitations and the material constraints make it difficult to provide logistic, practical, or economic support to others. The shared experiences of deviation from normative patterns can create common grounds to negotiate care as an inter-dependent network more than a dyadic process between care providers and care-recipients. The collective construction of care thus assumes a transformative importance, what McRuer and Mollow define as “a sexual-political interdependence: a politics, that is, that emphasizes our interdependence as allies and that values the potential of the sexual to enable this interdependence to flourish” (2012: 204).

2.2 Psychological distress and the body-mind balance

When designing the call for interviewees, I focused on attracting potential interviewees with physical illness. However, the crushing amount of experiences collected that involved also psychological distress convinced me of the need to examine their weight within the larger frame of chronic illness and LGBTQ+ identification. Twenty-two out of twenty-four interviewees were or had been recently following psychotherapy; eleven reported suffering forms of psychological distress, such as depression, anxiety, panic attacks; four reported having been suicidal. These numbers are too overwhelming to be ignored and they call for deeper investigations both on the psychological consequences of chronic illness and minority stress suffered as LGBTQ+ (Meyer, 2003).

The daily management of illness has a consistent impact on the psychological level:

> Having to think about what I can eat and what I cannot eat, constantly, it takes much pleasure away, you know? Because eating requires a lot of effort, I have to find a way to feed myself somehow or to prepare food myself and then carry it with me or to find a restaurant. (Antonio, PT, 31y)

> Sometimes I'd burst into tears and I had an emotional crisis because I was in pain and because I had to plan all the movements I'd do constantly, throughout the day. I mean, it has consequences, psychologically. It drains all your energies. (Julia, PT, 35y)

The temporal repetition of micro-actions of planning creates an emotional drain that has consequences on the overall well-being. The constant focus on how to communicate special needs, how to move, how to prepare food, how to control symptoms is a silent struggle most interviewees go through daily.

Chronic pain and general effects of illness on the body also cause negative effects on self-esteem, hindering self-acceptance. Some report feeling a sense of estrangement from their own body; others report difficulties in accepting their appearance; three suffered from eating disorders (anorexia and bulimia). The emotional turmoils provoked by the lived experience of chronic illness often remain invisible, either because attention from other people is focused on physical symptoms or because chronically ill persons feel discomfort in acknowledging their fragility. Jasmim, for example, explains:

> At some point I am so fed up with being ill, I'm fed up with all this, I'm fed up with feeling fragile, although I recognise we may all have our moments of vulnerability. Then I have moments in which I feel strong and deal with everything. So, for me, it's very complicated to deal with all this. (Jasmim, PT, 35y)

In parallel to the psychological toll of illness is the stress experienced as LGBTQ+. Several authors (de Oliveira *et al.*, 2013; Lingiardi & Nardelli, 2007; Meyer, 2003) agree in recognising that LGBTQ+ persons face psychological consequences for the constant exposure to hate speech, discrimination and delegitimisation, both in the public and in the private sphere. In particular, the minority stress theory developed within psychological studies by Meyer (2003), today referred as “marginalisation stress”, identifies a combination of internalised homophobia, perception of stigma, and lived experiences as triggering factors of psychological distress. Indeed, all interviewees do refer to having experienced episodes of discrimination, direct or indirect violence, or stigmatisation of their identity at least once in the last years:

> It's hard. It's very hard. There are many prejudices. Many. It happened many times in the streets, for example, people would shout “You faggot!” and things like that. This offends and also hurts. Obviously. (Lucas, PT, 32y)

> Although there are a lot of prejudices against homosexuality, bisexuality is socially invisible beyond words and it's not taken seriously. If homosexuality itself is not taken seriously but at last it's seen as a sin, as something wrong...trans and non-binary persons are not even seen as persons. (Safo, PT, 24y)

LGBTQ+ persons are the object of harassment, derision, and forms of de-humanisation, as Safo arguments. Both Safo and Lucas are deeply aware of the psychological consequences of constant pressure not only on themselves as individuals but also on LGBTQ+ community as a whole notwithstanding the deeper discrimination suffered by certain members more than others, such as non-binary and bisexual persons. However, if as LGBTQ+ people may find a form of collective notion of shared suffering, chronic illness remains mostly delimited to the individual sphere.

The combination of the pressure arising from chronic illness and the marginalisation suffered as LGBTQ+ generates a vast array of psychological consequences. Whilst homo-transphobic discrimination and the everyday management of illness both contribute to the destabilisation of psychological well-being, emotional imbalances may produce effects on the physical symptoms of illness. Healthcare professionals usually insist on the fact that emotional stability reduces negative peaks in pain or situations of crisis in the pace of illness. However, interviewees struggle to manage their body-mind balance:

> I have to deal with the psychological issues as if it was a small box, but all the boxes, at some point, intersect. In this circle, the physical condition brings in new elements that intersect but at the same time confuse the whole scenario. [...] It's as if the physical body recognised the tricks of the mind and the mind had to come up with new effects on the body. And my bodily symptoms are variable and disabling. (Marcelo, PT, 35)

> Due to my condition, I cannot suffer stress, not only physical stress, but also emotional or psychologic. I'd have a crisis every time someone was aggressive with me. Sometimes I avoid conflict with others because it immediately triggers discomfort - physical discomfort - so it's not just a matter of getting annoyed or bothered or sad. (Maria, PT, 39y)

Physical symptoms change according to emotional state but the entanglement between body and mind is hard to control. Marcelo is aware that his long history of anxiety and depression has an impact on the manifestations of his physical illness, a condition that seriously affects his heart and blood pressure. However, the symptoms he refers could always be interpreted both as psychosomatic *and* symptomatic: this aspect impacts the interpretations doctors give to his condition, often dismissing it with an “It's all in your head”. Similarly, Maria knows that any emotional stress can trigger a crisis in her condition affecting the functioning of supra-renal glands. She tries to orient the emotional environment, for example avoiding conflicts, to regulate the physical symptoms of her illness. However, the overall well-being results from a combination of multiple unpredictable factors: maintaining a satisfactory body-mind balance is part of a daily struggle and long-term learning practice.

2.3 Self-care as a learning process

An important aspect emerged from interviews is the centrality that self-care has in the management of illness and the choices of (in)visibility made as LGBTQ+. Interviewees insist on the importance of acknowledging vulnerabilities and accepting limitations as opportunities for self-improvement. They often refer to self-care as the result of a learning process initiated by the onset of illness and the experiences of exclusion lived as LGBTQ+. Although this is a different process for every individual, it is not perceived as a solitary one. Being cared by other people is often an ignition factor that change the trajectories of self-care:

> I learned how to love myself because other people taught me how to do it. Through loving me, they showed me I deserved self-care...although, of course, I don't ground my value as a person in what others believe. (Safo, PT, 24y)

> In the beginning, I wouldn't listen to my body at all. Then I began listening to it, I learned how to do it also because I got to know other ill persons. I observed their approach to their illnesses and I understood that we don't have to pretend at all cost that illness doesn't exist, we don't have to be superheroes. It's ok to acknowledge it. (Maia, IT, 27y)

The learning process for Maia and Safo involved a positive relation of care with other people. In their cases, self-care means to embrace vulnerability and accept that limitations can be also a resource: it is a literal act of “caring for one's body”, one that echoes “the care of the self” analysed by Foucault (1978). Through this process, interviewees learn how compulsory able-bodiedness (McRuer, 2003) works in sanctioning vulnerability: in a similar way to internalised homophobia, internalised ableism (Campbell, 2009) makes them feel misfits for their physical limitations and unworthy of love. Towards this form of oppression they learn to resist.

For some interviewees, dealing with vulnerability implies facing the threat of death. Although chronic illnesses are commonly distinguished from terminal or degenerative illnesses because they are not lethal (Armstrong, 2014; Bury, 1982), some illnesses can threaten life if not treated correctly or create complications that eventually may lead to death, a state defined as “unstable terminality” (Lerum *et al.*, 2015). Nina, who experienced an almost fatal attack of asthma, and Logan, who went through a heart attack, describe how getting close to death changed their relationship with illness:

> That moment was the moment of passage to an adult phase in my relationship with asthma because I thought I was dying. [...] This experience changes you, it changes completely the way you relate to illness because...you have no more alibis, no more escapes, no more excuses. [...] The act of taking medicines itself became more substantial, it became a practice of total self-care. (Nina, IT, 26y)

> The idea of re-living psychologically everything that comes after the shock is heavy. [...] It's hard to adjust mentally because...I'm always oscillating between the will to do something more, to have no limits, and the fear of exceeding the limit and having another shock, knowing that if I had another shock I'd be completely wrecked. (Logan, IT, 23y)

Their experiences taught them that self-care is not a mere option but a life-saving everyday practice, even when it is about actions as small as taking medication or walking slowly.

Each person finds their way to navigate their fears and to learn how to take care of themselves. However, there is a common path of learning through the experience of pain (Frank, 1997) that shows how vulnerability triggers a stronger attachment to life and a broader acceptance of limits:

> Through psychotherapy and a better knowledge of myself, I'm getting better. I'm still in pain but I'm getting stronger and learning to say: “Yes, I'll do this” or “No, I can't do this”, and respect myself, because I think it was this that was missing, respect for myself and the ability to say “No”. (Julia, PT, 35y)

> It's not easy. It's not easy to admit to yourself that sometimes you're not feeling ok and you can't make it. So, it was a self-training because I had to accept that this was not a failure but a part of me and that I could find a balance in it. (Andrea, IT, 34y)

Through the recognition that limitations are not a failure in the able-bodiedness compulsory system, but resources that can teach them how to better respect their bodies and minds, interviewees show micro-practices of resistance that transform the meanings ascribed to being LGBTQ+ and chronically ill. Also, they demonstrate that networks of care have the power to value the embodied knowledge that stems from experiences of suffering and turn it into a precious shared resource for self-care and shared care. The two are inherently connected by the consciousness that, in Silvestri's words, “a careless body cannot care for anyone” (2016: 76).

3. Healthcare contexts and medical power

> We are experts at hiding our shame, swallowing it, pretending it's not there. But to build anew, we can't be silent.
> (Eli Clare, 2017)

3.1 The silence on sexuality

Living with a chronic illness implies having significant relationships with the formal healthcare system: appointments with medical doctors, therapies, hospitalisation, surgeries, and exams are part of the everyday. The experience with healthcare systems still constitutes a barrier for LGBTQ+ patients: studies in the last two decades demonstrate how LGBTQ+ persons tend to access routine care services less frequently (van Dam *et al.*, 2011) and to conceal their orientation to professionals unless strictly necessary (Austin, 2013; Bjorkman & Malterud, 2007). Moreover, healthcare systems are widely moulded on the assumption that all patients are heterosexual and cisgender (Horncastle, 2017), often reinforcing sexist patterns. As explored in chapter 3, both in Italy and Portugal the healthcare systems are not structurally prepared to welcome LGBTQ+ patients, despite recent advancements in the Portuguese system (ILGA-Portugal, 2015). Sexual orientation and gender identity are generally not considered relevant information in the clinical process of a patient unless in issues related to sexual health (Koh *et al.*, 2014). However, studies demonstrate how being LGBTQ+ informs all the aspects of life and is a fundamental element to be considered within clinical processes (St.Pierre, 2012).

To understand the context in which LGBTQ+ patients move, it is important to take a step back and underline that, in general, sexuality appears to be a topic avoided by most healthcare professionals. When asked whether their doctors ever discussed the possible consequences of illness on their sexual life, interviewees answer in similar ways:

> I wish! It would have helped 50% of people's difficulties. I wish, I wish they'd talk about it, but no, it's all a discovery you make by yourself. (Andrea, IT, 34y)

> Zero, nothing. Nor sexuality nor relationships...Your life does not exist for them, you only exist for your illness, so they take care of that part and that's it. (Nina, IT, 26y)

> No, never. For doctors, we are just patients and patients don't have sex. [...] I think that for them if I can't have sex it's the least significant of my problems. (Maia, IT, 27y)

Healthcare professionals commonly avoid talking about sexuality both when dealing with symptoms of illness and providing information on treatments. In a relational context in which all sorts of graphic details about bodies are discussed, the absence of any reference to the sexual sphere cannot go unnoticed, especially if we consider that most chronic illnesses and medication have negative effects on sexual desire, can trigger dysfunctions such as vaginitis and impotence, and dramatically impact sexual activities. However, in the stark majority of cases, patients have to figure out by themselves through a process of “self-discovery” how to take care of all these aspects.

Grassroots organisations that advocate for patients tend to reproduce a discourse in which sexuality is not included in the important aspects of everyday life. In the public meetings I attended during fieldwork, both in Italy and Portugal, I noticed how the focus was mostly devoted to other aspects of patients' life, such as food, exercise, and sleep. Sexual activity was rarely mentioned and exclusively in its heterosexual declination.

Another important aspect to point out is that healthcare as a general system appears to be based not only on heteronormativity but also, as a consequence, on assumptions around monogamy and gendered ideas of respectability:

> If I go to the gynaecologist [...] or an appointment for STI[18] appointments, to do the routine test, the questions are not made for me. They ask how many persons I had sex with in the last six months, that's ridiculous! I can tell how many risky relationships I had but I'm not supposed to tell how many partners I was with! (Jasmim, PT, 35y)

> Take my brother: he's a boy, so if he experiences the loss of desire, then it's a problem, of course. But if I was the one to mention the same problem, they'd tell me I'm a bi*ch. (Tove, IT, 29y)

Multiple sexual relationships are implicitly presented as risky even in the context of an evaluation of STIs, which in principle should be more prepare to work with a vast array of sexual experiences. In the case of Tove, she discovered about the side-effects of medication by observing her body and reading the information found in the box of medicines. She is aware that the legitimacy of male desire is very different from the one given to female desire: whilst men are expected to feel sexual drive at all moments, female desire is often stigmatised and even pathologised (Rainey, 2011). Therefore, she did not feel comfortable in asking direct information to the doctor.

3.2 Being an LGBTQ+ patient

Given the invisibility of sexuality as a general matter and the pervasiveness of heteronormativity, for LGBTQ+ patients it is particularly challenging to access healthcare services and come out. According to a European survey from FRA (2013), 56% of respondents in Italy and 48% in Portugal affirmed to be open to none within the healthcare system. Only 10% in Italy and 13% in Portugal were out to most healthcare professionals, while 28% in both countries stated to be out only to a few professionals. The tendency to remain in the closet is confirmed also by a report on LGBTQ+ access to healthcare in Portugal (ILGA-Portugal, 2015): 72% of the respondents affirmed to have encountered medical doctors that implicitly assumed they were heterosexual and/or cisgender; 66% declared that the fear of discrimination influenced the decision to come out or not. Indeed, according to the FRA report (2013), almost 50% of those who are open to medical staff are likely to

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[18] “STI” stands for “Sexually Transmittable Illnesses”.

experience inappropriate curiosity, pressures to undergo medical or psychological tests, unequal treatment, and dismissal of specific needs.

The narratives collected both in Italy and Portugal confirm these data in several aspects. Most interviewees recognise they make evaluations on a case-by-case basis as to whether they should come out about their sexual orientation or gender identification in healthcare contexts. The decision-making process involves both relational and individual aspects:

> Once the doctor asked me if I had a partner and I didn't answer. So he asked: “But at least you have only one partner?”, and I said: “No”. He immediately prescribed me the HIV test. Instead, I should have told him: “I'm lesbian, I don't need the HIV test, I'm butch and I don't let anyone touch me”. [...] But since he was a super-Catholic doctor it wasn't worth even trying, he would have probably sent me to the psychiatric ward! [...] I am very uncomfortable with my body, for example when I take off my clothes in front of the doctor, I'm in such a position of unease that it's just too much to even think about telling him that I'm lesbian. (Tove, IT, 29y)

The questions regarding sexual health are biased by an assumption that heterosexuality is the norm and monogamy a safe way not to contract HIV. However, the response to the situation is rapidly elaborated through a series of micro-observations made on the profile of the doctor and the benefits or potential risks between coming out or not. Knowing the doctor was Catholic convinced Tove he would probably be homophobic; plus, the discomfort felt as a non-binary[19] person exposing her body deterred the coming out. This episode resumes how rapidly the process of decision over (in)visibility can be made and what are the assumptions, observations, and fears mobilised through selective coming out. Once again, however, it also shows the amount of pressures, stress, and evaluations it implies.

It is interesting to note that the anticipation of discrimination is sometimes more consistent than the actual episodes of homo-transphobia. In certain cases, the interactions leave spaces of doubts as to how the situations should be interpreted:

> I was at the doctor, for a routine check. She asked me if I used condoms and I said: “No, I don't need to, I have a girlfriend”. She knows about my illness, fibromyalgia...and she asked me whether the fact of being lesbian had to do with fibromyalgia! [...] She said my illness could have something to do with the fact that I had to hide it to many people...and maybe on an emotional level it had had an impact. (Julia, PT, 35y)

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[19] Tove defines herself as a non-binary lesbian/queer and goes by the pronoun “she/her”.

Julia's doctor hypothesises the burden of the closet and the difficulties related to being lesbian in a heteronormative society may have had an impact on her health to the point of triggering her illness. Although the premises of this assumption may be correct, since both minority stress (Meyer, 2003) and the emotional component of chronic pain have been demonstrated (Salamon, 2012), the episode shows how fragile is the boundary between being out as LGBTQ+ and receiving equal treatment in healthcare. The doctor seems to implicitly assume that Julia wouldn't be ill hadn't she been homosexual but she could also have, for example, assumed that Julia wouldn't be ill if society was not homophobic.

On a different note, other interviewees support the common view according to which LGBTQ+ issues are irrelevant to the matters of chronic illness:

> I believe that if I came up with the issue it would be quite unnatural, like: “Hello, good morning, I'm lesbian and I have urticaria”. I think it would be completely off-topic. (Lourdes, PT, 27y)

> I came out quite naturally and it made no difference...it didn't influence the diagnosis, I'd say. (Andrea, IT, 34y)

The most interesting aspect in this regard is the fact that the supposed irrelevance of being LGBTQ+ on the process of illness is contradicted in other moments of the same interviews. In other words, Andrea, Lourdes, (and others), on one side, believe that being LGBTQ+ does not interfere in the relationship with the healthcare system. On the other, however, they recount episodes in which the course of illness was indeed modified through coming out or in which the fact of being ill changed their path as LGBTQ+ persons. This apparent contradiction may be understood in the frame of internalised homophobia and normalisation of discourses shared also within the environment of activism that works on illness.

3.3 Sexism, fat-phobia, and discrimination in the doctor's room

Narratives consistently confirm how healthcare contexts are complicated for all persons that do not conform to expectations related to sexual orientation, gender, body shape, lifestyle, age (Austin, 2013). As well as homo-transphobia, sexism, ageism, fat-phobia, racism are constantly at play in such contexts. Interviewees report episodes of discrimination, verbal or psychological violence, offensive commentaries, and, in some cases, even physical micro-aggressions. The causes of this impressive vast array of episodes cannot be linked uniquely to homophobia, given that many don't come out as LGBTQ+. Women and persons in the trans spectrum suffer more aggressions, from the dismissal of pain to disbelief and mistreatment, an issue reflected also in the aforementioned FRA report (2013)[20]. A striking number of interviewees in the present study also reported being initially diagnosed with depression when complaining about pain or early manifestations of illness:

> During our first meeting, the doctor told me: “You have depression”. [...] And I said: “I don't think so, although I feel extremely tired and sleepy I'm still doing things, I'm willing to do things!”. But he gave his interpretation: “You're depressed as a reaction to your father's cancer or maybe to some traumatic experiences in your journey to India!”. I think he was subtly suspicious of me as a young woman who travels alone to India, you know? (Chiara, IT, 27y)

> I met doctors that made me cry, it was horrible, really horrible. They would say: “You have nothing! What is this? This is nothing! It's in your head”, things like this. A lot. So, I believe there is even more prejudice against fibromyalgia than against gay people! (Julia, PT, 35y)

Cases like the ones Chiara and Julia describe are recurrent and show how often women are discredited and disbelieved when they express pain. Depression and psychological distress are commonly used as explications for pain and led some to take medication for depression that proved even more damaging to their conditions. A deep gender bias emerges and confirms that lesbians, bisexual women, and trans+ persons encounter more difficulties in

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[20] In Italy, 8% of overall respondents declared having suffered personal discrimination; amongst lesbian, the percentage is 9% but increases to 12% amongst trans+ persons. Similarly, in Portugal, 9% is the overall percentage, 11% of lesbian and 12% of trans+ persons.

accessing healthcare, despite the different conditions they may have, for the multiple combinations of sexism and homo-transphobia (St.Pierre, 2012).

Other micro-aggressions reported refer to lifestyle and fat-phobia:

> They would ask me: “What do you do?”, and when I said I was in my first year at the Academy of Fine Arts they would grimace, I could see they thought: “She probably smokes joints”. They would ask: “Do you have a normal routine?”, “No”, “Well, then it's obvious you have migraine!” (Tove, IT, 29y)

> When they tell me something about my weight, I say: “Wait! I'm not going to accept this!”. I had a lot of symptoms I complained about and doctors told me I had to lose weight: instead, they were symptoms of Multiple Sclerosis, so no! I'm not accepting these discourses anymore, enough, I've had enough. (Momo, PT, 32y)

The assumptions generated by fat-phobia, sexism, and homo-transphobia together contribute to the underestimations of symptoms and frequent wrong diagnosis when not delayed treatment - as in the case of Momo, whose symptoms of Multiple Sclerosis were repeatedly linked to her weight. Moreover, through these assumptions, professionals reinforce what lies behind the “obligation to get well” (Cederström & Spicer, 2015): instead of recognising the possible causes of illness, professionals blame their patients for not doing enough to follow what is considered a respectable, healthy, and correct lifestyle and implicitly sanction them for being irresponsible. Illness is put down to an individual issue of insufficient self-control or self-regulation, especially when it is related to invisible and not measurable symptoms, like chronic pain. Persons with Chronic Fatigue Symptoms are made objects of recommendation to overcome their supposed laziness; chronic pain is related to a weak will to confront the complexity of life; and so on. In this context, understandably, several interviewees report medical appointments as a struggle, where they fear they may face dismissal and they know they have to deal different sources of pressure: not only as women but also as women who do not conform to the cis-heteronormative expectations on respectability.

3.4 Disobedient patients: grappling with medical power

Given the context just outlined, patients have to develop individual strategies to grapple with medical power. Besides the management of visibility as LGBTQ+, such strategies include: in-depth knowledge about illness developed independently; the concealment of specific information on behaviours that could be judged negatively, such as smoking, drinking, having multiple sexual partners; rehearsed patterns of communication that seek, for example, to exaggerate the impact of certain symptoms to be taken seriously. Interviewees perceive the healthcare system as a system of power which establishes hierarchies and delegitimates the experience of patients:

> Sometimes I think I'd like to try [...] to manage my illness by suspending medication, despite the risks it would imply: it would mean to direct responsibility on my body and my health, something we are not used to doing, for cultural reasons. We always delegate everything to medical knowledge, even if it's obscure to us: on one side, the healthcare system and medical knowledge don't give us instruments to understand, don't make an effort to be understood, but, on the other, we give them an unconditional mandate. (Sofia, IT, 32y)

> I think it's urgent to oust medical power. I think we need to bring medical powers down to earth, put them in the position to truly listen to patients. I think we need to fight this brutal medical hierarchy. (Jasmim, PT, 35y)

Obscure language and hierarchical dynamics concur to create an obstacle in the communication between patients and healthcare professionals, perceived as inaccessible: more as adversaries than allies. However, patients can sometimes actively confront such hierarchies through choices that pose at the centre their power of self-determination and that somehow echo the feminist slogan “My body, my choice”. For example, some contravene expectations and reinforce their role in the decision-making process about their health:

> I would seek medical advice only when something physical appeared, a visible symptom [...] and they would always relate it to my mental health issues. So I understood they would always put them in connection, and now I have mechanisms to face it and I don't mention anything about my mental health struggles. (Marcelo, PT, 35y)

> Of course, my gastroenterologist does not agree with me having sex as a passive gay! [...] I never asked him directly but if I were him and someone asked me: “I have chronic colitis, can I get fucked in the butt?”, my answer would be: “No! Absolutely not!”. But I don't care. (Alkirk, IT, 25y)

In the same way, some interviewees prefer not to come out as LGBTQ+ in the healthcare context, some others intentionally omit information that could deviate doctor's attention from their physical symptoms. Some other interviewees engage in more confrontational tactics that aim at exposing healthcare professionals to the need to make information clear. Posing questions, expressing doubts, but also refusing to follow certain treatments or insisting on receiving adequate answers are all strategies that demonstrate the political importance that small acts of disobedience can have in grappling with medical power and healthcare professionals.

Conclusions

It appeared clear in this discussion that whenever we investigate care we deal with multiple forms of power: both within informal relationships of care and formal contexts where healthcare is provided, power structures, inequalities, and social pressures operate as a constant. The experience of chronic illness requires to acquire a specific expertise in how to manage the multifold aspects of power. What emerges from interviews is indeed that illness and the way it informs relationships is never just about the body.

Narratives show how the negotiation of boundaries of care complicates relationships, in particular in family relationships in which issues like visibility and dependence are particularly pressing, as the previous chapter partially unveiled. Care is not always and not necessarily disjointed by forms of control or by expectations on reciprocity which are at the base of the Southern European familistic system: if the family takes care of their vulnerable members but implicitly expects something in exchange. For some interviewees, this exchange is giving away part of their freedom to be LGBTQ+ and is not the result of a choice: it is more of a forced condition.

Accessing systems of healthcare as patients is also never disentangled from the compliance with systems of cis-heteronormativity. Even when interviewees do not come out as LGBTQ+ in the contexts of healthcare, they mostly do so as a result of a strategy of costs and benefits that involve their sense of safety, their objectives, and their resources. It is important to remember that differences in health literacy create inequalities in the quality of treatments received. Factors like gender, age, and appearance also inform the experiences with healthcare systems, as the narratives of women with chronic pain diagnosed as depressed show. Therefore, all in all, the picture that emerges from these narratives is one of healthcare as a battlefield: medical doctors are mostly perceived as unable to understand what it means to be an LGBTQ+ patient and to see chronic illness in its determinants over everyday life. Moreover, the silence on sexuality and intimacy in the doctor's room reinforces the feeling that they are not important aspects in the patients' life.

However, the narratives here discussed also show multiple (sometimes unexpected) forms of resistance to pressures. In the family, in relationships, and healthcare systems, interviewees are often able to learn from their cumulative experience of vulnerability and transform it into trajectories of survival in their terms. If the lessons learned in the struggle with the cis-heterosexist system help them to forge strategies to face the challenges of ableism, similarly, the lessons learned in the struggle with ableist pressures transform their posture towards homo-transphobia and sexism. Embodied suffering thus turns into a powerful instrument through which interviewees learn to give different directions to their practices of visibility and care. It is particularly important, in this sense, to stress how such a process is not only directed at the relational context but also themselves. The pain, the discrimination, for some even the spectre of death, guide interviewees to give their bodies a different centrality, to value self-care as important, and to be themselves agents of care towards others in horizontal and consensual ways.

These different grammars of resistance are never disjointed from the stories of suffering, but it is exactly in this close entanglement that intersectionality works: multiple forms of oppression trigger multiple forms of learnings. Interviewees give different meanings to the pressures of homo-transphobia and sexism, ableism, and physical pain: however, in the way they make sense of this intersectionality they also find resources to build-up their forms of individual resistance.

On a final note, thus, it is important to stress the individual character of these processes: even when they receive adequate care in their families and by their doctors, they are often alone in choosing strategies, calculating how to proceed, making decisions about their bodies. Their loneliness is probably the most unfortunate product of the entanglement between heterosexism and ableism.

7. PRECARIOUS LIVES. NAVIGATING THROUGH WORK, PUBLIC SPACES, AND ACTIVISM

Introduction

In her discussion on vulnerability and collective grief, Butler states that “many people think that grief is privatizing, that it returns us to a solitary situation and is, in that sense, depoliticizing. But I think it furnishes a sense of political community of a complex order” (2003: 22). If we consider the pain socially produced through ableism and homo-transphobia, which already emerged consistently in this work so far, it is particularly important to analyse how it is transformed not only collectively but also into forms of political communities. This chapter aims at exploring how chronically ill LGBTQ+ interviewees perceive their struggle in a wider arena, in particular in their workplaces, in the public space, and activism.

The push to the privatisation of sexuality and the individualisation of illness has been historically encouraged by homo-transphobic and ableist institutional discourses (Kafer, 2013), and, recently, by neoliberal politics (McRuer, 2018): individuals are deemed responsible for their care, for their well-being, and for their ability to be good (re)productive citizens. Their ability to conform to the demands of productivity and their flexibility in transforming potential factors of failure into stories of success in the workplace and the collective arena is part of the construction of what is today considered the main ingredients of successful and good citizenship. For this reason, I am particularly interested to understand how interviewees experience their multiple fragilities when confronted with the entanglements of neo-liberal politics, ableism, and homo-transphobia.

In the first part, I will therefore discuss narratives around work, in which the multiple forms of precariousness inform not only the economic means of living but also aspects like autonomy from families, independence, and, once again, (in)visibility.

In the second part, I will analyse the experiences in the public space, in which the individual meanings ascribed to bodily diversity and sexual identification are confronted with issues such as safety, disability, and accessibility.

In the last part, the focus will move to activism and spaces of collective action. The analysis will explore both LGBTQ+ activism and forms of collective struggle centred on illness, highlighting the contradictions and the difficulties emerged. This section aims also at providing a deeper understanding of the forms of social ignorance that are reproduced within spaces of activism and the main obstacles that retain chronically ill LGBTQ+ persons from becoming political subjects *as such*. The many facets of precariousness, as a social, individual, economic form of vulnerability will accompany the already central concepts of care, time, and (in)visibility that have been transversally present so far.

1. Precariousness at work and because of work

> We can learn to work and speak when we are afraid in the same way we have learned to work and speak when we are tired.
> (Audre Lorde, 1984)

1.1 (In)visibility at work

According to a FRA report (2013), invisibility at work is still the preferred option for most LGBTQ+ people: 45% of respondents in Italy and 45% in Portugal declared to have been in the closet in the workplace in the last five years of employment. Moreover, 23% of Italian respondents and 25% of Portuguese participants said they had been rarely open at work. Conversely, 19% of Italian respondents admitted feeling personally attacked for being LGBT and, in Portugal, 18% had a similar experience. The mismatch between experiences of direct discrimination and the apparent majority of invisible workers can be explained with the perceived risk that many LGBTQ+ persons feel and prevents them from coming out. Indeed, recent data (Eurobarometer, 2019) confirm that the attitudes towards LGBTQ+ people in the workplace are still imbued with prejudices: 18% of Italian respondents admitted they would feel completely uncomfortable if one of their colleagues was gay, lesbian, or bisexual. In the case of trans colleagues, the percentage rises to 24%. In Portugal, the rates are slightly lower: 11% would feel “totally uncomfortable” with an LGB colleague and 14% with a trans colleague.

The general picture provided by these quantitative studies denounce that for LGBTQ+ people work is still a battlefield where success comes also as a result of a struggle with the heteronormative social organisation of most workplaces (Gusmano, 2008; Priola *et al.*, 2018). Since non-heterosexual and non-cisgender experiences are still generally perceived as a potential stigma, each person needs to develop personal strategies over (in)visibility in the workplace.

Similarly, chronic illness affects several aspects of work such as performativity, constant presence, ability to perform tasks, and availability for informal social events. Consequently, “individuals with chronic illnesses often report increased absenteeism and rates of work termination, career plateauing and redirection, lower salaries, reduced job security, restricted training opportunities, and participation in decision-making” (Vijayasingham, 2018: 43). The unpredictability of pain, the need for rest, and the impossibility to have a routine are everyday aspects of illness which radically veer from the rhythms of neoliberal working life. As discussed in chapter 3, most European countries, including Italy and Portugal, rely on legal frameworks that regulate working relations for disabled people or workers that experience sudden illness (Fernández Martínez, 2015; Portugal, 2016). However, chronic illnesses are often excluded from such regulation. Such absence increases the possibility of unlawful behaviour from companies.

Given the combination of such contextual elements, being chronically ill *and* LGBTQ+ implies a wide range of choices about (in)visibility to be played in the working context. Although in most cases it is impossible to extricate the aspect of illness from the choices linked to being LGBTQ+, interviewees show a constant state of awareness and selective practices of (in)visibility that result from conscious strategies.

Discrimination as chronically ill and as LGBTQ+ is not just a perceived risk but a part of everyday experience and many cases relate to illness:

> My boss fired me in January. It was because I was ill, she said it straightforward, she said it was because of that. (Lisa, PT, 27y)

> Coming out (as ill) did not protect me from vexatious actions and unbearable workloads that eventually led me to a nervous breakdown [...] CGIL, my trade union, did not protect me: I felt lonely and abandoned. (Marco, IT, 42y)

> My boss was angry at me, because he had employed a person with such low productivity. [...] At the end, he told me he had no choice but to fire me because I was not productive enough. (Chiara, IT, 27y)

The excerpts show how the condition of illness is incompatible with the demands of productivity and performativity. In some cases, companies dismiss the needs of chronically ill workers and take action to fire them when they are unable to comply with the productivity levels required. The sense of abandonment is increased by the fact that the political system does not protect workers from this kind of situations: as Marco recounts, recurring to trade unions nor receiving an official diagnosis is enough to countervail the rules of productivity. Although companies are not legally allowed to dismiss workers based on their health conditions[21], they easily bypass rules invoking unproductiveness as a justifiable reason for termination (Fernández Martínez, 2015). It is important to note that in the context of general precariousness, many cannot count on a regular contract: therefore, they are even more exposed to aggressive company policies and unlawful terminations.

Beside such blatant cases, interviewees narrate of countless cases of indirect discrimination:

> People hug you, they seem to accept, they acknowledge you...but that little window you opened about your illness turns into a hedgerow, so that your productivity, your ability to be efficient are immediately put into question. First, you show how you work, what you can produce, what you can offer and only after you can show a little bit of who you are. (Marcelo, PT, 35y)

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[21] In Italy, such terms are regulated by Art.15 Stat. Lav. For the Portuguese case, see Portugal (2016).

> Sometimes I feel like (my illness) is perceived as an excuse, as a way to avoid doing hard tasks so...sometimes I have the tendency to do too much, just to prove my colleagues that I don't need excuses and I do everything I can when I can. (Maia, IT, 27y)

> When I started working in this place there was a colleague that would speak openly about his sexual orientation and his partner. [...] I'd hear comments, you know, I could hear them because my colleagues didn't think it had anything to do with me. (Antonio, PT, 31y)

Indirect discrimination can be performed through comments shared with colleagues behind one's back, bad looks, delegitimisation of one's work in meetings, discredit and so on. Marcelo, for example, points out how even apparent positive reactions to coming out can hide invisible traps: productivity is constantly put into question by colleagues and superiors. Interviewees sometimes compensate such fragility investing energy and time in extra-tasks to prove their capacity. The invisible pressures towards the attunement to expectations of productivity are accompanied by the silent assumption of heteronormativity which sustains most working environments (Ward & Wistantley, 2005). The example told by Antonio clearly shows how working contexts are regulated by discursive practices that incessantly confirm heterosexuality as a universal norm. It is common practice to share jokes and comments between colleagues, which serve both to reinstate the belonging to the assumed normalcy and to strengthen the camaraderie between workers. Such dynamics implicitly discourage visibility for LGBTQ+ workers.

Given that heteronormativity and able-bodiedness constitute implicit pillars of most workplaces, interviewees have to navigate multiple pressures and find a balance between their visibility and the possible risks of disclosure about being ill and/or LGBTQ+. Both visibility and invisibility offer benefits and threats. Invisibility is a preferred choice in particular in situations of precariousness or during the search for jobs. In most cases, coming out as chronically ill is perceived as riskier than being visible as LGBTQ+:

> In the professional situation in which I was, it could have also turned into a reason to threaten me, to trigger those sneaky moves to force me to quit. It was just a hypothesis but I preferred not to give any reason for it to happen. I thought: “Ok, I'll be careful not to cut myself” and I am, indeed, extra-careful. (Fabian, IT, 34y)

> When we were looking for jobs, both me and my sister[22], we omitted our illness. Because it would be an obstacle to our employment. But then in the workplace, there are sometimes little coming outs. (Safo, PT, 24y)

> Lately, at work, I don't care about coming out as a lesbian, I just say it. But I'm more careful in saying that I have epilepsy. I've learned it to my detriment, it's not beneficial. (Andrea, IT, 34y)

The general tendency seems to be avoiding coming out as chronically ill, using the invisibility of symptoms as an advantage. It is not an easy choice: whilst it protects workers from unequal treatment, it also increases the burden on individual management of illness and the pressure on maintaining productivity despite the pain, fatigue, or other symptoms. Not disclosing his HIV-status at work, Fabian chooses to assume the burden of taking additional care in his everyday tasks at work and the consequent psychological pressure. The excerpts also provide an interesting overview of the politics of invisibility. In the first place, some opt for full invisibility, both as LGBT+ and chronically ill: as in the case of Fabian, it is a choice related to the stigma perceived about his illness and the fear that such information could be used as means to hinder his precarious working position. In a second case, Safo chooses full invisibility about her illness in the moment of highest vulnerability (when she is applying for jobs), moving across the spectrum of visibility once she is hired. Finally, Andrea chooses to be almost completely open about being lesbian but maintains herself closeted about illness because of past experiences that made her aware of the stigma still associated with epilepsy.

If the main narrative moves amongst different layers of invisibility at work, the cases in which interviewees choose for complete visibility are rarer. In such experiences, visibility is never a spontaneous choice and it results from a long process:

> There was this new colleague at work, he'd speak openly about his gay relationships and I felt the need to do the same: if he took the risk of exposing himself [...] it was unfair that I stayed comfortable in the closet. [...] It was a sense of responsibility: it doesn't make sense to contribute to more silence, [...] for me it was always very uncomfortable to be the only one, so I'll not let that person be the only one. (Antonio, PT, 31y)

The incentive to change strategies of visibility does not come from a direct experience of discrimination. On the contrary, watching vulnerability

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[22] Safo's sister also has rheumatoid arthritis.

unfolding on somebody else functions as a wake-up call to take active responsibility: visibility is imbricated in a commitment towards oneself and towards other people sharing a common experience. The individual dimension of vulnerability becomes political in the moment in which interviewees recognise there are shared struggles and collective obstacles that link them to other people around them. These narratives show an additional nuance to the visibility/invisibility paradigm, where visibility is not intrinsically a winning strategy and invisibility can offer strategic benefits in certain contexts (Pieri, 2019).

1.2 A necessary destiny: precariousness

Significantly, the experiences collected in the study confirm the impact of precarious working conditions on the everyday life, adding nuances that show the proportions of such impact on LGBTQ+ and chronically ill young adults. The narratives evidence three aspects of precariousness: the economic, the relational, and the existential aspect.

The first aspect that emerges is the economic side of precariousness: the consequences of precarious contracts, insecure income and uncertainty about career developments produce more vulnerable conditions in the job market. The cohort of age of interviewees refers to persons that, in normal conditions, would be in any case significantly affected by the structural precariousness of young adults in Southern Europe (Serapioni & Hespanha, 2019). It is significant to note that, at the time of the interview, only three out of twenty-four interviewees (12,5%) were working under a regular long-term contract and social benefits; six interviewees were unemployed; the rest were either students (eight) or employed in precarious jobs (nine)[23].

In most cases, chronic illness intervenes as a disruptive element which affects the ability to be productive, to work under regular schedules, and to perform physical tasks.

Therefore, it increases vulnerability and impacts all the other aspects of life:

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[23] The total amounts to 26 because two interviewees were both students and workers.

> The big drama is not that I am gay anymore, the big drama is my illness, because, honestly, I risk being fired even next week, next month. My position in the public sector doesn't give me enough protection, despite my certificate of invalidity. I couldn't ever go back to live with my parents, for out incompatibility...and I have a mortgage to pay, so it's impossible to live by myself, but I also can't cohabit with a partner, I wouldn't have enough energies. [...] So, my top worry right now is the illness. (Marco, IT, 42y)

Precariousness does not only refer to the uncertainty about his future but a combination of factors related to the consequences of such uncertainty. The possibility of losing his job due to his inability to be productive scares Marco, showing him grim options: either going back to live with his parents (an option he firmly discards because of his father's homophobia) or depending on someone else to pay for him without having a relationship. Such emotional distress related to the present and the future is shared by many others in their narratives.

The dependence on the economic support from others also creates a spider-web effect, where precariousness never affects just one individual but spreads in various ways in the life of those around, in particular couples:

> We have to pay for nursery school and everything related to that, so it's important to me that my wife has a more stable job. She's an engineer, she works for a multinational, but even so, she suffers from what we all women suffer from: she is paid less than men are, so we face that very common aspect of lesbian couples being poorer than other couples. We experience this aspect, even if we technically belong to the middle-class. (Maria, PT, 39y)

> Unfortunately, I am unemployed. My partner [...] works part-time. With 250 euro every month we barely have the means to buy food. [...] When I was interned in the hospital for a month, Adam lost his job: when he let them know he might miss some days because I was in the hospital, they didn't renew his contract. (Momo, PT, 32y)

Precariousness operates with a cascade-effect on partners intersecting other factors, such as the gender pay gap and the poorness of lesbian couples (Schneebaum & Lee Badgett, 2019). The two excerpts offer a significative glimpse on how an increased working vulnerability caused by illness provokes consequences also on partners. In the case of Momo, it is particularly significative how her condition of unemployment and illness shakes the working conditions of her partner, who cannot count to the benefits guaranteed to informal carers[24].

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[24] For details on the Portuguese recent legislation on informal carers see: https://www.sns.gov.pt/noticias/2019/09/06/cuidador-informal/. Accessed on 10.12.2019

A second aspect that consistently emerges in narratives is the emotional cost of precariousness and its effects on the quality of human connections with others:

> At a professional level, I have no chance of stopping. It scares me. [...] I can't refuse to work, when they pay me. [...] I stretch as much as I can and then it all falls on personal relationships, because I'm unable of being there or giving any personal energy, since I already spent all my energies to manage to pay the rent and buy food. (Jasmim, PT, 35y)

> I have two worries: not knowing if I will ever have the energy to work full time...because I work five hours every day, I come home and I go to bed, and if nobody pushes me, I sleep until the next day. I work six days a week and I feel that my social life is a bit (dead)- since most of my time is about working or resting. [...] I don't want to live to work, I work to live. (Safo, PT, 24y)

Jasmim and Safo depict examples of vicious circles created by the combination of precarious economic conditions and chronic illness: whilst the priority is to work as much as possible to gain what is needed for a decent life, the expected productive rhythms force them to a gymnastics between work and rest which consumes all their (already limited) physical energy. Hence, the availability to attend social gatherings, cultivate relationships, and see friends is reduced to the minimum. It is a perverse cycle that feeds into a sense of frustration, in particular in those cases, like in Safo's, in which the number of working hours, the money received for it, and the personal satisfaction that comes from the job are insufficient to justify so many sacrifices. It can also increase the sense of isolation, both as LGBTQ+ and chronically ill, and trigger fears for the long-term future. The demands of precariousness go in the opposite direction of care and self-care. Interviewees often tell how they push their limits to get more work done because they have “no chance of stopping”, as Jasmim states.

Precariousness emerges not as a transitional state of things or a specific condition that regards only and foremost LGBTQ+ chronically ill young adults: it merges into a broader narrative on the generation of young adults born between 1978 and 1995. This third element points to an existential aspect of general uncertainty. Through this lens we can see how the individual experiences of interviewees fit into a bigger picture:

> I don't think precariousness is a transitory state for us: it's the paradigm of our life, at least for our generation. We went to school and did

> everything knowing that life would be precarious, that it'd mean migrating, having no money, survive with poor salaries, doing shitty jobs. All this was not unexpected, it was our destiny, it was no surprise, like a necessary destiny. (Nina, IT, 26y)

Within this trajectory, traced by the macro socio-economic factors that changed the opportunities for young adults in this particular time and space, the micro-trajectories scarred by chronic illness result even more compromised, as Nina's parents seem to suggest, in a similar way as Sofia explains:

> I am sure that some of our chronic illnesses are also a product of this historical phase, not because they wouldn't exist otherwise, but because of the way they are managed, cured, and lived. (Sofia, IT, 32y)

Indeed, the stories collected do not speak only about the struggle to survive as young adults in a system organised around uncertainty and lack of resources: they also show how the conditions of precariousness double-down their perverse effects on those who are already more fragile because of illness and LGBTQ+ identification. Together with the privatisation of health systems (Arnaut, 2019) and the crisis of welfare services (Serapioni & Hespanha, 2019), precariousness disintegrates the socio-economic landscape in which young adults work and pushes for a further reinforcement of one of the main pillar of Southern European societies: family.

1.3 Don't leave to live. Family ties and cohabitation

“Health is, after all, only a matter of money!”: Alkirk, a young gay man from Italy, resumes in these words the difficulty of balancing precariousness, health, and economic independence. He is a student living with his parents, who pay for every cost associated with his illness and education. His situation is similar to the one of several other interviewees, who have no choice but to rely on the economic support of their families. Indeed, in a staggering majority of cases, the responsibility for the economic struggles created by the combination of precariousness and illness is taken up by families of origin. The role of families as fundamental economic actors is a recurrent point in the debate about Southern European societies (Bertone, 2013; Mínguez & Crespi, 2017). What makes the case of Alkirk and the other interviewees in a similar situation even more interesting is that the relationships with families are centred on multiple fractures and struggles: failure against success; dependence against autonomy; LGBTQ+ life against heteronormativity; illness against able-bodiedness.

Families intervene primarily in supporting the costs of illness, often providing means to access private healthcare and buying medicines:

> We have a long history of cancers in my family, so my mum is adamant in providing us a private insurance and she doesn't change her mind. This is wonderful. [...] I know their effort to pay me this regular insurance comes at great cost and it's already a lot. It helps me so much. (Jasmim, PT, 35y)

> The doctor in the public hospital was not helpful, hence my dad insisted to open a private insurance so that I could be checked in the private sector. (Lisa, PT, 27y)

Accessing private healthcare represents an important option particularly in case of uncertain diagnosis or unclear conditions, not only because private facilities are more equipped and modern, but also because the economic deal at the basis of the relationship between patient and doctors usually guarantees a better service. As Jasmim explains, the safety guaranteed by private health insurance is very valuable, especially if we consider that chronically ill patients need healthcare for a long time. However, help received from parents is not devoid of conflicts: Jasmim's parents have not shown support when she came out as pansexual and non-monogamous and such issue has been an important factor of distance from them. Similarly, Lisa is not in good terms with her parents and not out with them, even though they live together and they provide for her in everything.

The economic support received by families can play a tricky role in strengthening the dynamics of control by families analysed in the previous chapter. Such control becomes almost overwhelming in the cases in which families also provide housing. Ten out of twenty-four interviewees lived with at least one of their parents at the time of the interview. Such a high number is not explained barely by the general tendency of Southern European young adults to leave their households later than anywhere in Europe (Naldini, 2003). Indeed, cohabitation with families of origin represents almost an obligatory path for a combination of factors. In the first place, some interviewees are not physically able to live autonomously and cannot rely on partners or friends to cohabit with. Secondarily, the precarious economic income and difficulty to work hinder the possibility of paying a rent or mortgage. Finally, living with families of origin often implies having access to larger spaces and better accessibility conditions. Although they all are appealing factors, for most interviewees cohabitation results from the absence of other viable options:

> Right now I can't leave this house, I'd love to but I'm financially dependent on my mum. [...] I need her economic support because I'm not able to study and work. I have no emotional nor physical possibility of doing it differently. My illnesses don't let me. (Safo, PT, 24y)

> I gave myself a year, I told myself: “I'll try and see if I manage to advance in my studies but after that, I'll have to stop, to go back to my parents”, although I knew this would mean my social death! (laughs) Coming back to this village sucks but, in the end, I had to do it. (Chiara, IT, 27y)

> It scared me to think about being completely alone, without knowing anyone here and having to manage a flat and myself. So I said to myself: “Ok, let's try, temporarily”. (Me and my parents) we help each other, even because the rent is expensive and then...in the future, we'll see. (Ellie, IT, 34y)

Doubtlessly, cohabitation with families of origin solves some of the issues caused by economic difficulties. The lack of autonomy gives rise to worries for the future: as Safo highlights, leaving the parental household is possible only in the presence of another type of support, likely to be from a partner. Moreover, sharing housing provides comfort for the psychological strains provoked by illness, as it eases the sense of overbearing isolation that often comes with illness or being LGBTQ+. The language used by interviewees to explain their choices of cohabitation deserves a particular consideration: “I'd love to leave (...) but”; “I had to do it”; “Let's try temporarily”. Such expressions depict cohabitation as a forced-choice in face of no better options and highlight strong inner contradictions. Indeed, the b-side of cohabitation with families is made of compromises and renounces: it may mean “social death”; it may imply putting plans on hold; it may hinder visibility and complicate sexual life as LGBTQ+.

The literature on disability stresses how cohabitation with parents is a strong restriction to sexual freedom, not only because of the spatial limitations but also for the moral bonds that separate the space of sexual experimentation from the space of family (Santos & Santos, 2019). For example, when asked about his sexual orientation, Jack responds as such:

> It's a chapter connected to illness. Perhaps because I'm 29, almost 30, it's becoming more and more unbearable to stay here, I need to go live by myself, but now I can't, because I'm not autonomous at all. (Jack, IT, 29y)

In a few words, Jack unveils all the contradictions contained in the intersection between chronic illness, homosexuality, precariousness, and familism. The different aspects are inextricable: his desire to experiment sexual freedom with other men is bound to the possibility of living alone, not only because Jack lives with his parents but also because he is completely dependent on them to go anywhere. However, living alone is currently impossible since he is not autonomous; besides, because of his illness, he is unemployed and has no economic independence. It is probably not a coincidence that Jack asked to meet for the interview at his psychologist's office and not at home, signalling a sort of boundary of comfort between the home and the space of identification as LGBTQ+.

Similarly, as discussed before, other interviewees report how making their sexuality invisible in the familiar context is a strategy to survive through cohabitation. This gymnastics between invisibility and dependency inevitably creates a psychological burden. In the case of Jack, the preoccupation for the future is shared with other young adults with Chronic Fatigue Syndrome:

> We're thinking about the future. At the end, we're all young people that can rely on their parents now, but obviously parents die...and then we'll have to think about something, a shared facility, something...because that's what expects us in the future. (Jack, IT, 29y)

The stories collected demonstrate that families and partners constitute the main sources of support for those who lack autonomy, both in practical and economic terms. In the context of precariousness, thus, leaving the familiar household represents a privilege. The hypothesis outlined by Jack is interesting because it offers a perspective in which the care of chronically ill young adults is not left to the goodwill of those around. It shows a suggestion for a collective answer that does not (yet) exist in the Portuguese and Italian context: the possibility of creating small communities of chronically ill young adults that intervenes in the necessities of care through a collective action, that would tackle the limits of familism and precariousness whilst bolstering individual freedom, with all the benefits this could mean on the sexual side. Such line seems to go in the direction of forms of cohabitation based on friendship, which is becoming more common amongst young LGBTQ+ adults (Gusmano, 2018): in my view, it could represent an interesting queer way of undoing the constraints of precariousness, illness, and sexuality.

2. Inhabiting the public space

> Don't demand the magic word that opens worlds,
> some syllable that's distorted and dry as a stick.
> All that we can tell you today is this:
> what we aren't, and we don't wish for.
> (Eugenio Montale, 1925)

2.1 Accessibility and safety

In disability studies, accessibility is a key concept. Thanks to the reflections brought by the social model of disability (Barnes & Mercer, 2010; Davis, 2013), access to public spaces is an important element to understand disability as a collective matter. In such approach, disability in itself wouldn't be a factor of exclusion if society was not *disabling* different bodies through inaccessibility. The importance of securing accessibility to disabled bodies in the public space is also a matter of political occupation of a space of visibility that guarantees, metaphorically and practically, full participation to the public life. The struggle of the disabled movement both in Italy and Portugal affirmed basic rights of accessibility that provide access in public places, at least in principle. Thanks to this essential activist and academic works, we can better analyse what it means for chronically ill individuals to occupy public space as visible and what are the challenges they face as invisibly disabled. The relation with the public space is indeed mediated at the same time through their belonging to apparent able-bodiedness (and ability to pass) and their needs to use access facilities as disabled. However, since the very first interviews, I came to understand that questions around accessibility meant almost nothing to participants: they connected the word to disability and most of them did not identify their experience as belonging to the symbolic world of disability. The relations with the public space are thus constructed also through different relations with the cultural construction of disability.

Some of the stories, for example, refer to struggles with stairs and roads, the most typical means of inaccessibility:

> Stairs, stairs, stairs. They're always a challenge. I immediately feel my knees in pain, I can't do stairs without pain. [...] I try to avoid stairs, at all costs, and also hills, although it's hard because Lisbon is a city full of ups and downs, steep hills, and the pavement[25] is horrible. (Safo, PT, 24y)

> At the train station, I still use the elevator. Sometimes it doesn't work and in that case, I have to take the stairs, slowly: at that time, it's rush hour, everyone is running up and down, there are people all over and I need to go slowly. They make me so anxious that I go even more slowly. (Logan, IT, 23y)

Stairs represent the most iconic symbol of inaccessibility. It is interesting to stress that Safo and Logan are not completely unable to use them: although it implies a lot more of fatigue, pain, and emotional stress, they can do it. The fact that they are not 100% unable to access public spaces represents a critical point: while on the practical level, they can rely on an alternative and on personal strategies to overcome physical obstacles, on a symbolic level such privilege reduces the urgency of their claims for accessibility.

Other experiences of inaccessibility are related to food: interviewees with chronic issues linked to the intestine, such as allergies and coeliac disease, point out how difficult it is to eat out in restaurants. Despite national laws that require workers in the food industry to know about ingredients they use, many restaurants don't pay attention to the preparation of their plates nor formative actions for their workers. Another common aspect mentioned is the danger hidden in crowded places such as supermarkets, malls, and festivals. In such occasions, persons with epilepsy, chronic pain, and chronic fatigue are exposed to excessive sensory stimulations which may provoke crisis and pain. When interviewees encounter consistent obstacles to accessibility, in particular in public spaces dedicated to free time, the effort to adapt is such that in most cases they

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[25] In the original formulation in Portuguese, Safo here speaks of the “calçada portuguesa”, the typical Portuguese kind of pavement made of small tiles used to cover streets.

give up on activities like going to the movies or eating out: inaccessibility turns into a proper factor of exclusion.

Besides the obstacles in the physical space, narratives also point to factors related to time. As it already emerged evidently in many instances, the rhythm of contemporary living is set on a pace that assumes able-bodiedness and productivity. For many, being able to access public life is also a matter of having the resources to enter such symbolic temporality:

> Sometimes it's all a matter of time. In the case of illness, as in disability, time is central: while you try to do all the things of your life, you need to face limits and obstacles and so you need more time, not only more space, and this is something that many don't understand. (Sofia, IT, 32y)

> For me it is a problem to go to Lisbon and the fact that everything happens in the afternoon or the night. It's more complicated because it's not just about going by metro for two stations: it's about sitting in a bus for hours and the more I sit, the worse I feel [...] If they happened in the morning, it'd be much better. (Lisa, PT, 27y)

The actual impossibility to access symbolic and physical spaces of leisure and socialisation, in these terms, is a direct consequence of the timeframe in which such spaces work and of the different rhythms that chronic illness imposes. Since time is a constitutive part of the experiences of chronic illness, accessibility needs to be understood as an impossibility to access and inhabit not only spaces but also as time previously discussed: cripping time could thus become the way to deconstruct those forms of belonging to (re)productive citizenship linked to the rhythms of neoliberalism and the able-bodied imaginary of relationships.

2.2 The (in)visibility dilemma in the public space

Performance is another pivotal aspect in navigating the perils of accessibility. Most chronically ill persons look able-bodied. Therefore, if they want to be perceived as non-able-bodied, they need to make an explicit coming out through their performance: in such way, they make themselves intelligible to the social gaze and gain the legitimisation to occupy the symbolic space assigned to disabled people (Clare, 2003). In some countries, such as Japan or the United

Kingdom[26], public transport companies adopted policies to signal to the general public that not all disabilities look alike and that passengers who do not look like disabled may need to use the reserved seats. Besides exposing informative panels in stations and carriages, they offer the possibility of using a pin to be identified as "invisibly disabled". In Portugal and Italy, nothing similar exists and interviewees struggle to cope with the obstacles of (in)visibility:

> In public transports, I can't hold myself to the bar, imagine what it means with all the curves! [...] That's the thing, (my illness) is not visible, so I'm not allowed to use the seat reserved to disabled people. (Lisa, PT, 27y)

> Even when I use the crutch, sometimes on the bus I have to solicit someone [...] to leave me their seat. It could be the case that the person had an invisible illness as well, right?, and being in a day in which they're out without crutches. I thought about it. But...I mean, so many? And so many in student uniform and high heels? (Momo, PT, 32y)

> I have the right to sit in the seats reserved to disabled people. Many times, though, if I see someone old or with a baby, I have no problem in letting them sit because I was educated for resisting my limitations and my pain and do what it is expected to do. If I'm feeling really bad, though, I explain the situation. (Safo, PT, 24y)

As the excerpts report, the (in)visibility dilemma is multi-faceted. Interviewees may not feel entitled *a priori* to occupy the reserved seats. Such perceived absence of legitimisation originates from internal factors, such as the lack of actual identification with a disability, or external factors, such as the awareness that disability is perceived in the public discourse as something with recognisable features (a wheelchair, mainly). For example, Lisa prefers not to challenge external perceptions and struggles silently with her difficulties. On the contrary, both Safo and Momo make active efforts to make themselves visible. The miseducation of youngsters, which often occupy those seats for a lack of civic sense; the comparison with other socially vulnerable categories, such as pregnant women, persons with babies, or elders; the doubt that they may be being in front of someone who is also invisibly disabled: they are all elements that make interviewees question their entitlement to occupy the symbolic and physical space reserved to disabled people.

Considering coming out creates anxieties that lead some to stay in the closet and endure as much as they can in their performance as able-bodied:

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[26] See: https://tfl.gov.uk/transport-accessibility/please-offer-me-a-seat. Accessed on 02.01.2020.

> It bothers me. If I have an inflammation on my knee, it bothers me not being able to sit. I feel it's very hard for me to ask people to let me sit because of this reason: because people can't see it. If I had a crutch, maybe, it'd be different, but without any visible support, it's really hard to ask people. (Alice, PT, 30y)

> A concrete example is the bus. I get very tired in staying up so I need to sit but I always have qualms about it, so I am never able to ask someone to let me sit, I prefer to bear the pain and suffer. I can't legitimise myself to do it because then I'd have to tell people I have an illness. (Maia, IT, 27y)

The strategy of passing as able-bodied prevents, for anticipation, the possible negative consequences of coming out as chronically ill (Samuels, 2003). It is important to remember that these situations depicted are repeated over and over in time: both Alice and Maia, like others, use public transportation regularly and can go through these calculations many times in a day. This possibility of choice is, indeed, what constitutes a major point of difference between chronically ill people, or invisible disabled, and people with visible disabilities that cannot be hidden to the public gaze in any way. Because of the possibility of such a choice, invisibility is at the same time a privilege and a disadvantage. The choice of invisibility, also, can be at the same time a form of resistance and a way to blend into normativity: a way of passing or a path to claiming identity (Pieri, 2019).

2.3 Only for spectators: performing for the social gaze

The performative choices made in the public space have to be both credible and consistent to protect interviewees from disbelief, discrimination, or violence. The danger of being read as a fraud or not being entitled to the treatment reserved to disabled people conditions the way such choices are made. Such performative element is not just a temporary aspect of random presence in the public space: it involves also casual interactions with other people, sometimes even with known people, for example, as discussed above, in the working environment.

Both visibility and invisibility generate complications:

> People don't believe me, because they don't see a missing arm or something similar, so they don't believe me when I say I'm in pain. But if I do something today, I'll have to sleep for the next three days. [...] Once

> a person from my village told me: “Come on, it can't be that bad, you're standing on your legs!”. I replied: “I don't wish my worst enemy to go through to this...but I wish it to you, so one day you'll understand what it feels like!” (Jack, IT, 29y)

> I did many things in moments in which I just needed to sleep and people would see me and say: “Ah, then she's not sick, look, she's doing things!” They didn't see I was doing a herculean effort. (Chiara, IT, 27y)

The paradox generated by passing as able-bodied is evident in these two narratives: the social gaze catches a mismatch between the verbalised and the performative dimension of illness. The reading of such mismatch often creates even more disbelief and the difficulty to establish an empathic connection with the chronically ill person, not only from unknown people but also from family, friends, and doctors, as we've seen so far:

> I usually remove my illness until someone sees me with a Ventolin[27] in my hand and then...it's crazy: sometimes I'm embarrassed in using Ventolin in public. I try to hide myself, it's something I don't wanna do in front of other people. I don't want people to see me doing something that would immediately make them read me as vulnerable and ill. I can't bear that interaction, not even visually. So I always make selective coming out. (Nina, IT, 26y)

The social gaze forces Nina to embody a vulnerability that she does not feel comfortable with. Coming out as a person with asthma, she feels she is immediately seen as disempowered. Although in other moments of the interviews she recognises that asthma is a widespread illness to which no particular stigma is attached, Nina prefers to hide it in public contexts and choose carefully when and to whom disclose this part of her. Interestingly, the confrontation with the social gaze is the measure through which some interviewees make sense of their experience of illness. Living in a grey zone between able-bodiedness and disability, some acknowledge they are never completely fitting in either category: whilst some retain traces of internalised ableism and refuse to be associated with disability whatsoever, others see possible points of contact. The way such discourses are articulated provides an interesting insight into cultural ableism:

> At that time I had to use a wheelchair, but I could stand and walk, and sometimes I would stand just so that I wouldn't seem disabled. It was hard to be in a wheelchair. I would look down, I didn't want to meet people's eyes. For me, that was a huge shame. It was a signal of weakness, it was like a statement that I wasn't perfect. (Julia, PT, 35y)

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[27] See footnote 15.

> I think a lot of chronically ill persons are also disabled and a lot of disabled people are chronically ill. Many times you are something and you become the other, and vice versa, they are so connected. [...] I believe disability is recognised, assigned and has reason to exist only through an exterior gaze, only from the outside. Only for spectators. Otherwise, it makes no sense as a category. (Maia, IT, 27y)

The difference in the perspectives is stark, although in both excerpts unveil traces of cultural ableism. Both for Maia and Julia, the definition of their experience of illness passes through the social meaning that their performance transmits. For Julia, being in a wheelchair is the ultimate sign that state her imperfection that locates her body and her experience in the semantic universe of failure. Albeit the fact that she was in a wheelchair temporary and she was experiencing the onset of a chronic illness not classified as a disability (fibromyalgia), Julia felt that she was being read as a person with a disability and thus her whole experience was reduced to this category, with all the stigma, the shame, and the pity attached. On the contrary, for Maia, disability is not radically different from chronic illness: it exists as a need for a social categorisation which ceases to make sense once one encounters forms of making sense of their illness.

The pressure to perform for the social environment and the stigma attached by the social gaze are probably the factors that best explain a surprising data coming from the interview: most interviewees encountered more difficulties in managing visibility as chronically ill than as LGBTQ+ in the public space.

> Sometimes it is easier to say that I'm homosexual than saying that I am epileptic. Maybe because homosexuality is a more natural condition, it caused me less pain. So I feel like it will be better accepted than illness. People still attach a stigma to epilepsy, they don't know what it is. (Andrea, IT, 34y)

> They are similar processes, because the questions you make to yourself are the same: “How will people react? Will they accept me?”. Perhaps what changes is the possibility of bad reactions because...if you say you're gay, mostly there is no problem. If you say you have HIV, an illness, they may tell you: “It's not a problem that you're gay but it is a problem that you have HIV”, so what changes is that you have different reactions to same questions. (Fabian, IT, 34y)

Such reflections are particularly interesting because they confront the embodied experience of homosexuality with the one of illness: through this relation, it seems like both Andrea and Fabian manage to create a relation of priorities, benefits, and risks. Their experiences of visibility in different spaces and situations taught them to be warier of reactions to illness, because the stigma attached to it is still strong. Doubtlessly, they are speaking about illnesses that have a particular imaginary attached: whilst epilepsy was for centuries linked to mental disorders, alcoholism, sexual perversion, and drug misuse (Davis, 2013), HIV carries a history of stigma intrinsically bound to male homosexuality (Sontag, 1988). However, it is interesting that, through the challenges of visibility in public spaces (Browne & Ferreira, 2015), they came to an understanding of homophobia as a less threatening (although still present) issue than discrimination for illness. They are elaborations that resound with a crip twist, to the extent to which crip may be “describing what we might see as non-normative or non-representative disabilities - disabilities, shall we say, that would never be eligible beneath the universal access symbol for disability” (McRuer, 2018: 19).

3. The politicisation of pain in activism

> How do you throw a brick through the window of a bank if you can't get out of bed?
> (Johanna Hedva, 2016)

3.1 The epistemology of ignorance in LGBTQ+ spaces

During interviews, I asked participants to what degree they were involved in LGBTQ+ activism and/or in any kind of activism related to illness. Their reflections provided a landscape where fractures between the definition of “safe space” as LGBTQ+ clash with the needs in terms of accessibility and mutual recognition of multiple belonging in different contexts of activism is still to be reinforced.

Until recent times, the idea of safe spaces for LGBTQ+ was grounded on the need to provide spaces conditions to be protected from homophobia and make room for the expression of all genders, sexualities, and orientations (Formby, 2017). Nevertheless, this approach, based on identity politics, also reinforced a dichotomic conception of safety as an opposition between an 'us' and a 'them'. It proved itself to be insufficient to create safe spaces for people in their intersectional embodiments, such as, for example, queer people of colour, lesbian, or elders (Chin, 2017). While welcoming a certain form of queerness (white, middle-class, young, fit), LGBTQA+ spaces appeared to be less ready to undo other forms of oppression, based on race, ethnicity, class, ability, gender, age, and education: “ironically, our efforts to challenge one form of oppression often unintentionally contribute to other forms of oppression, and our efforts to embrace one form of difference exclude and silence others” (Kumashiro, 2001). This contradiction is particularly problematic in spaces of activism, where political orientation overlaps with practices involving community creation. Activists face the challenge of building inclusive spaces that are potentially safe for everyone who wants to join without (un)intentionally generating other forms of oppression.

On the front of LGBT+ activism, which is at the core of this and the next section, inaccessibility seems to represent a widespread issue. Most practices used in collective activism in the public space such as protests, Pride parades, rallies, sit-ins, public assemblies represent a struggle, since they require presence and consistent bodily engagement through walking, shouting, singing or standing, often for hours and in open-air spaces. Particular frustration emerged concerning Pride parades. Historically, organizers of Pride parades both in Portugal and Italy ignored the issue of accessibility. This absence was primarily a product of the lack of connections between LGBTQ+ movements and disabled people's movements. However, it was probably also reflected the deliberate ignorance or cultural resistance to including ableism amongst the intersectional forms of oppression that involve *also* the LGBTQ+ community.

Only in its 2018 edition the Lisbon Pride Parade, the biggest in the country, introduced measures to include people with reduced mobility. In Italy, in 2017, a long negotiation was carried out by Gruppo Jump and the organisations involved in the Bologna Pride Parade. It was the very first time that accessibility was discussed as a non-negotiable requirement. However, only a few weeks before the parade, the organising committee opted for a route that was only partially accessible but had the economic advantage of passing by some of the shops which had sponsored the event. As a consequence, Gruppo Jump dissociated itself from the organising committee and did not participate in the parade[28]. The conflict did not trigger any significant national protest.

Since organisations do not offer particular protection on this level, interviewees have to plan their participation and take personal risks. The potential factors of struggle are multiple:

> During the Pride Parade, I had a crisis, along the whole parade, because it was hot and raining, I was excited, I was too much dressed and so I was sweating. I think nobody realized what was happening, even my comrades and the people around just kept staring and thinking it was weird. (Lourdes, PT, 27y)

> Last week there was the Pride Parade here in town. Physically, it was very hard. We were all together, me and my comrades, we were super excited because the Parade lasted three hours with many things happening. We were all tired at the end, but then we rested a couple of hours, we had dinner, some drinks, and all the others were ready to go dancing, to go working the day after. Me, it's been three days, four days, and I haven't recovered yet. I spent all these days in bed. Three entire days in bed. (Maia, IT, 27y)

It is important to stress that for many Pride parades constitute one of the very few opportunities to attend an LGBTQ+ event during a year. Hence, it represents an important moment of belonging and constructing of a collective history, so important that several interviewees express strong regret disappointment for not being able to participate because of inaccessibility. Others, like Maia, choose to do it anyway, even if it implies dealing with pain and fatigue for days after.

Issues related to accessibility emerge also concerning other types of activist gatherings, such as assemblies, camps, or parties. The main source of difficulty is not the lack of accessibility in itself but the lack of awareness about accessibility. In other words, the issue is not that spaces and events are not accessible: it is that the wider culture is imbued with unconscious ableism. As Fox and Ore state, the problem in LGBTQ+ spaces is a “resistance to knowing differently in these spaces, a resistance that is circulated through an epistemology of ignorance” (2010: 640). Such culture of deliberate ignorance is reflected on rhythms that tend to be flexible, with no fixed timings; lack of respect for norms on no-smoking or heating; a resistance to change established practices:

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[28] See: https://www.gaypost.it/bologna-pride-polemiche-disabili-trans. Accessed on 15.12.2019.

> Disorganisation often comes back as a burden on those few people that have to do all the work and then, if one of them is like me, with a health problem, nobody cares. And then assemblies, as well, are hard: […] long assemblies, sometimes going for five hours! (Tove, IT, 24y).

> Last time I was at an assembly in a place [...] on the top of a mountain, with no central heating; everything was heated through chimneys and wood stoves and everyone was smoking inside. The level of smoke was a nightmare. Three of us met outside, all of us with breathing issues and I remember thinking: "Thank God, it's not just me", [...] and I said: "I'm leaving in half an hour, I can't stand it here!". Then we went back, opened windows, raised the issue, talked about it. (Sofia, IT, 32y)

The shared feeling that emerges from these narratives is both of frustration and resignation. Interviewees are aware of the difficulties they encounter: activist groups are based on volunteering work, which means that organisations are not always the top priority and everyone is expected to be flexible on the demands. However, carelessness clashes with the rigid needs imposed by illness that determine painful consequences when not respected. While both Tove and Sofia are aware of such issues, they are also implicitly accepting that it is hard to take up a claim in situations like these, for all sorts of social pressures. Illness and its needs are qualified as individual issues, hence it requires much self-confidence for an individual to reclaim the respect of rules in a collective space. For example, in the situation recalled by Sofia, the first reaction she had was to leave; she managed to speak up about her needs in the general assembly only when she found out she was not the only one experiencing discomfort with the general behaviour.

3.2 The bionic bodies of LGBTQ+ activism

The individualisation of health struggles within LGBTQ+ is a fascinating contradiction that deserves further analysis. In political contexts that struggles against invisibilisation, oppression, and normalisation, why is there no space for bodies that fail to be able? Why is the oppression of able-bodiedness considered an individual issue (or a non-issue) and not a coalitional struggle in practices of activism? What are the nuances of the "epistemology of ignorance" (Fox & Ore, 2010) on ableism in these spaces?

The first element that can lead to a recognition of what lies behind such disjuncture is the conception of the activist as functional and almost unbreakable. Perhaps such conception sees its origin in the common etymology between "activism" and "action", one that suggests that the primary task of an activist is *doing*. The pressure to be present and to be effective is countervailed by an implicit pressure to prioritise activism over other matters:

> I think that the body of the activist is a sort of bionic body. When I began to do politics [...] in a totalising way, I think I felt invincible for a long time. [...] The number of things you are required to take care of is enormous, both in terms of time and possibilities. (Nina, IT, 26y)

> A few days ago there was a protest against gender-based violence and I didn't go, because I get tired when I stand or walk a lot. [...] I feel I need to explain to people why I am not there, why I cannot make it, because people think I don't care, that I'm like that. I felt this pressure on me. At some point, I wrote on Facebook [...]I had an illness that caused me fatigue and limited me sometimes so that people knew that if I was not there much anymore, if I didn't show up, it wasn't because I didn't care: it was because I couldn't make it. (Maria, PT, 35y)

> Activism requires a permanent public persona that I can't have, I can't even think about it. It demands to be a non-stop performative and motivational machine. I've got no energy for that. (Marcelo, PT, 35y)

The *bionic body* of the activist is expected to perform in highly demanding activities which involve fatigue, hard work, multi-tasking. The complex and diverse world of activism "still assumes a consistently energetic, high-functioning body and mind, and certainly not a body and mind that are impaired by illness" (Wendell, 2001: 24). The implicit connection between able-bodiedness and good activism goes so unquestioned that Maria felt she owed an explanation to her comrades on the reasons why at some point she reduced her participation to the activities. In fact, after noticing her absence, other activists started gossiping about her detachment, until Maria felt she needed to publicly come out about her illness on Facebook. The dynamic of this coming out is surprising, coming from a place where visibilisation is celebrated as an act of liberation and not a forced justification to oppose false gossip: we can suppose the effect would not have been the same had Maria been indirectly pushed to come out as a lesbian.

Another reason for such difficult encounter is related to the cultural notion of illness as an individual struggle, a perspective often encouraged also within activist communities that work on illness, as I will analyse in the next section. The de-politicisation of illness is pervasive in LGBTQ+ contexts: even when faced with inaccessibility, some interviewees do not feel safe enough to speak about their special needs as they fear they would be delegitimised. The notion of safety and the notion of accessibility clash:

> I needed to eat but I couldn't: in those situations, first, there are six hours of workshop and then you can eat, all together, only all together. [...] Maybe it was also my problem, if I had said: “Guys, I have this problem”, for sure someone would have been more careful, but I'm uncomfortable in telling everybody. [...] There are people I don't know, I'm afraid to disturb, I don't know, I just don't like the idea. (Tove, IT, 29y).
>
> In the previous collective, the only conquest we made was to have a non-smoking space: no one ever smoked in there. It was possible because more than one had asthma. [...] However, here, people smoke inside every single space and I don't understand why! For me, they are forbidden spaces, but so far, I haven't dared to ask them to stop smoking, because [...] I've just arrived and I need to take it easy. (Nina, IT, 26y)

What the two excerpts similarly convey is the difficulty of coming out as chronically ill in environments in which there is a strong collective culture of inaccessibility. Tove and Nina could use their personal experiences to suggest an improvement of accessibility conditions within their LGBTQ+ activist spaces and their intervention could be an opportunity for a collective reflection on practices of activism. However, the absence of a shared language of accessibility discourages them to come out. Especially in contexts moulded on an ideal *bionic body*, coming out may imply too much investment. Visibility always involves an investment in terms of energy, time, and emotional distress, as interviewees know very well from their experiences in every other aspect of their life. Because illness is socially constructed as an individual issue, chronically ill activists don't feel encouraged to take the individual responsibility to talk about it as a collective issue. Their silence reinforces the invisibility of illness and the idea that it is an individual condition. This perverse dynamic even strengthens the idea that accessibility is an *ex-post* determination, an adjustment to be made when someone specifically asks for it, rather than a basic political choice that benefits the whole community *a priori.*

The difficulty of politicisation of illness is reflected in a further aspect: the detachment from narratives of multiplicity. In the last two decades, LGBTQ+ activism generally embraced intersectional practices of activism, although in

Portugal and Italy they triggered tensions between what it means being LGBTQ+ *and* black, disabled, or poor (Santos & Pieri, 2020). Interviewees report conflicts over the difficulty of being seen as intersectional beings in LGBTQ+ spaces:

> I am polyamorous but at the moment I only am with one partner. I am not less poly because of this. It's a matter of visibility. I have issues of visibility within the sphere of LGBT. I'm not seen as poly. Some from the poly community know that I'm poly, but usually I'm not seen as such. (Momo, PT, 32y)

> There is a permanent conflict and I never feel completely understood anywhere. There are two groups: people of the heart[29] and trans people. (Logan, IT, 23y)

The narratives suggest that chronic illness is not an experience which can be elaborated in an intersectional critical perspective on the multiple embodiments that interviewees inhabit: LGBTQ+ spaces seem to be quite focused on LGBTQ+ issues, so much so that Momo laments a lack of visibility even for the polyamorous orientation, which is for sure a more common issue within LGBTQ+ communities than illness is. The sense of detachment, of not being completely fitting, is a reason for discomfort for those who expect to ease their sense of isolation within LGBTQ+ activism. Maia recounts what happened when she and her partner, also chronically ill, decided to insist on issues of accessibility within the collective they were part of:

> We say we are anti-racist, anti-sexist, anti-speciesist, but we still can't deal with disabled or ill people! At the beginning it was very hard. I remember that people in the collective assembly would snort and complain, because we had a slow rhythm, they couldn't do everything they wanted, our illness was a hindrance. Everybody would say “Cool” but then they wouldn't help. [...] I think we need to work very, very hard, insist and never stop insisting (Maia, IT, 27y)

Coming out to the collective assembly and demanding certain standards to be respected was a psychologically straining experience for Maia because she did not encounter the collaborative response she expected, in particular from a group which claims to be intersectional on all levels. Changing things implied effort, strength, and energy, since the resistance in acknowledging the type of oppression exercised by ableism: the group would be resistant to self-critically analyse the dynamics of exclusion within the group was strong. The lack of accessibility in LGBTQ+ spaces can be framed as a result of a difficulty in

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[29] Logan refers as “people of the heart” to the group of activists that share their same illness affecting the heart.

intervening in the contact point between heteronormativity and able-bodiedness; the failure to acknowledge the common roots that different systems of oppression share; the inability to take on board the consequences of one system of compulsion (able-bodiedness) while fighting against others (heteronormativity and homo/bi/transphobia). Formulated this way, accessibility should not be a logistic individual issue but a conscious action of opposition to ableism which recognises it as a form of oppression linked to the others experienced by LGBTQ+ people: a collective shift in the inclusion of disability "not defined by our bodies, but rather by the material and social conditions of ableism" (Clare, 2003b).

3.3 An ensemble of atoms: activism on illness

Activism based on illness mobilises similar resources to activism on LGBTQ+ issues: it requires a certain amount of time, energy, and dedication; it offers the possibility of sharing experiences; it creates a sense of belonging; it provides means to struggle for the improvement of life conditions. However, it also presents radical differences. As outlined in chapter 3, in Italy and Portugal, organisations centre around specific conditions (e.g. fibromyalgia) or similar illnesses (e.g. cardiac illnesses). The landscape of activism on chronic illness appears rich but mostly fragmented. Contrary to what happens in LGBQTQ+ activism, chronic illness *per se* does not represent an umbrella identification for all (or most) organisations: despite the existence of several organisations that work on a specific condition, there are no nation-wide platforms that address at once the common struggles experienced by chronic ill persons as such. The chronically ill person is not a constituted political subject *per se*.

Although the social and emotional benefits of activism are known, at least in principle, interviewees express a mixture of resistance and attraction regarding involvement in this kind of activism, as it emerges reading between the lines of some excerpts:

> I need to solve a bit this situation of illness and find something more effective. I know I need to take better care of it. I've been thinking that maybe I should search for more information, more alternatives and that

> possibly one of the solutions is to meet more people that have the same thing. (Alice, PT, 30y)

> This is a time in which I'm in a bit of a search. Maybe I need more confrontation, not with homosexuality, but with organisations that work with epilepsy. (Andrea, IT, 34y)

The narratives express both hesitation and curiosity: Alice and Andrea feel that getting close to an activist organisation would be beneficial. At the same time, they seem to hesitate as if this represented a more definitive step in their relationship with illness and a formal recognition of belonging to the universe of patients - a perspective some intimately refuse to accept. As Frank argues, “whether ill people want to tell stories or not, illness calls for stories” (1997: 54): the difficulty in embracing activism may relate to a struggle to make sense of a story of illness and imagine a collective dimension for it.

Having done this step, other interviewees confess difficulties in embracing the narratives around illness shared by activists in organisations of their knowledge:

> This group I'm in is too positive for me. Too much positivity. You know, that discourse of “You have to think positive”, that you sometimes see on walls, like, “Smile even if you don't have reasons to do it”, and I say: “No! Fuck it! If I don't wanna smile, I don't smile!”. It bothers me. (Momo, PT, 32y)

> There's this group of women with HIV, it's not a self-help group, it's just about meeting every year and be together for some hours. With them I feel...you know, different ages, different backgrounds...I couldn't see one single person with whom I'd feel an affinity to say: “Let's have coffee together after this!”. (Lia, PT, 34y)

> I get so annoyed. It'd be nice if we had conversations like “Hello, good morning everyone, how are you? My day was so and so”. But they only speak about medicines, being sick, therapies. I get so depressed! All their life is centred on illness, they don't have anything else! (Jack, IT, 29y)

Within activist groups circulate various forms of information and discourses, which can fit for some but be inapplicable for others. In online groups such as forums and social media communities, in particular, it is not uncommon to find the use of religious themes or healthist rhetorics (Petersen, 2015). Such declinations represent a slippery take on illness, because they often link illness to personal responsibility (in failing to do enough for one's own body) or to divine plots (invoking a passive acceptance).

Difficulties arise also when the encounter with other persons with the same illness does not in itself provide other common grounds to share experience. However, whilst in LGBTQ+ activism the diversity of experiences is (at least in principle) celebrated as a richness and as a glue in face of common struggles against discrimination, in the case of illness, because of its social construction as an individual issue, this element of togetherness in diversity seems to be completely absent. The individual element of illness is maintained in a way that preserves the specificity of experiences but also discourages the formation of a shared conscience of belonging.

Of course, although it is the most common, this is not the only narrative that emerges. Other interviewees speak about activism as an experience that empowered them concerning their illness, provided access to precious information, and eased some of the sense of isolation:

> (Activism) was important to make me think about my needs and that all the others that have my condition also share. [...] What's your response to a situation of difference, how do you get what you need? You'll need to join with other people with the same needs. So, it's not just you anymore: if it was just you, you wouldn't have any power but together with others it's different. (Antonio, PT, 31y)

> It's positive to meet others that have the same illness or similar problems. You'll meet people that will give you hope, and sometimes you'll also meet people that are worse off than you and so you'll think that all in all you could be much worse. (Logan, IT, 23y)

Such narratives confirm the political and individual positive outcomes that activism provides. The encounter with others reminds individuals that their personal experiences are valuable and that they are not alone in the struggle. Moreover, as Logan shows, it provides terms of comparison to evaluate one's condition in an imaginary scale of gravity since the same illness can greatly vary from person to person.

Despite these differences in the approach to activism, more enthusiastic or more sceptical, there is one aspect which emerges almost univocally in all narratives: the absence of any debate on sexuality and/or LGBTQ+ issues in such contexts. As already discussed, such absence has several origins, but, in the case of activism, it is important to note that the Catholic orientation of several organisations play a fundamental role in it. The responses received by activist groups during the preparatory field of this research, discussed in chapter 4, confirm this tendency. Interviewees extensively report on the silence about sexuality:

> I'm into this group of people that have more or less the same illness that I have and even there I found scarce empathy: I took the initiative, explained my problems and talked about the impact illness had on sexuality. I felt completely...dismissed. (Ellie, IT, 34y)

> Homosexuality is a taboo, a complete, absolute taboo. You have to think this is a Catholic-oriented organisation, so...no wonder. (Marco, IT, 42y)

The absence of sexuality as a sphere that is impacted by illness and the taboo regarding LGBTQ+ issues are two aspects of a similar culture in Portugal and Italy. Unfortunately, such silence only produces more silences: indeed, many decide to stay closeted as LGBTQ+ when participating in activism around illness or to look for specific information on the impact of illness on sexual performativity by themselves. Pierluigi Lenzi, founder of *Gruppo Jump*, confirmed in our interview:

> What we try to do is not only to talk about disability and homosexuality, which is our main activity; we try to address disability and sexuality in general, because it's a huge taboo, and because in the great majority of cases, organisations that work on disability do not even contemplate the importance of sexuality and everything around it.

The experience of *Gruppo Jump*, which is in part echoed by the one of the group *Sim, nos fodemos* ("Yes, we fuck") in Portugal, is that there is a lot of work to do to introduce sexuality as a general issue in the agenda of activism on disability, and in this agenda, of course, homosexuality or LGBTQ+ experiences are one of the sub-themes. Their work has no correspondence with any other organisation in the territory that addresses a specific chronic illness and sexuality in such an explicit and militant way - if we exclude, of course, organisations centred on HIV and AIDS.

Conclusions

Decades of institutional homo-transphobia and ableism have promoted the idea that sexuality belongs to the private sphere and illness is an individual matter. The analysis here conducted had the aim to investigate how profound the public dimension of both are: the experience of chronically ill LGBTQ+ adults shows that in every moment they live. At home, at work, in public transport, and even in spaces of activism, the double entanglement of sexuality and illness, and the struggles it triggers, is always present. Therefore, it is not enough to think about them as precarious lives *just* because of their sexuality or illness or generational belonging: as Butler reminds us, “my body, socially structured in the public sphere, is mine and is not” (2003: 26).

The generation of people between 25 and 40 years, which constitutes the focus of this study, is a generation profoundly marked by discourses on precariousness: it would be thus easy to think that the interviewees experience just about the same probability of having a precarious life as all their peers. However, as the examples here discussed show, the economic precariousness they live in is both a cause and a consequence of their intersectional belonging to forms of exclusion. Therefore, in a context that offers few economic opportunities and scarce provision of welfare measures, illness and sexuality become potential factors of amplification of precariousness at work: they will thus try to blend in the normalcy of productivity and able-bodiedness required to perform well.

However, the precariousness of embodied suffering is felt also in the occupation of public space, to the extent to which it is implicitly assumed that they will perform and are not fully credited: homo-transphobia, ableism, and the persistence of a certain disbelief around invisible conditions contribute to a sense of insecurity that is also part of a general precariousness.

We could expect that activism could offer answers to contribute to the elaboration of the suffering collectively. This was, indeed, one of the initial hypothesis I outlined before entering fieldwork: if it was reasonable to expect that personal relationships, workplaces, and healthcare systems triggered challenges, it was also expectable that activism offered platforms to a sense of belonging. On the contrary, the narratives restitute mixed answers that can maybe trace a future-to-be more than a present. If being LGBTQ+ offers ways to have coalitional ways out of oppression, on the side of illness people seem more lonely, more in pain, more left to themselves.

In conclusion, the disjunction between being LGBTQ+ and chronically ill seems to be an important part of experiences for those who embody both. However, within the activist contexts centred on illness, the absence of a collectivisation of struggle emerges as a critical point: even within collective experiences, there is a sense of isolation and individualisation that stays and does not seem to open the possibility for a transformation of chronic illness into a collective identification. The experiences of inaccessibility as chronically ill in LGBTQ+ spaces are countervailed by a generalised silence around sexuality in activism on illness: interviewees find themselves navigating through different nuances of epistemologies of ignorance which are consistently reproduced.

The chronically ill subject does not exist as such as a political subject that revolts against structural ableism or demands a change in the rhythms of modernity. It does not exist *yet*: but it could become, learning from the struggles of LGBTQ+ activism, where the common factor became to tackle discrimination and hate *despite and together* the differences and where diversity was valued.

The interviews show a possible formation to come, a way to the future: whilst the present could be discouraging, the future could pave the way. The chronically ill subject as political could undo some of the current pressures of familism, precariousness, ableism, through coalitional practices that embrace the diversity of bodies and identifications. The pain produced socially from ableism and homo-transphobia could become a transformative form for a sense of political community: not only in activism, but also in public spaces, in workplaces, and all the private spaces lived every day by interviewees.

CONCLUSIONS

We are, I am, you are
by cowardice or courage
the one who find our way
back to this scene
carrying a knife, a camera
a book of myths
in which
our names do not appear.
(Adrienne Rich, 1973)

This dissertation started with the notion of “mapping the uncharted”. Since the first chapter, I aimed at locating the discussion within the empty spaces existing in debates, remaining interested in looking at the fractures more than at the surfaces. As I repeatedly affirmed, I embarked on this journey aware that the risks were as many as the possible gains. If some results did emerge, they should now be organised in a new map of that land in which *sunt dracones*, in which dragons supposedly live. With this metaphor, I do not intend to picture myself as a pioneer in any way, nor excuse mistakes I have certainly committed in the process. Also, the journey does not intend to conquer a land or to colonise an unknown branch of debate. On the contrary, it aims at understanding whether, in the end, the theoretical, methodological, and empirical propositions resist coherent analysis and whether the initial questions head to a fruitful direction. I aim to honour the need to stay in a constant state of questions (Kafer, 2013). Like any map, this will be only a translation of reality, one interpretation amongst many more that hopefully will come.

Blurring boundaries of time, care, and visibility

The discussion followed a circular pattern with recurrent elements and constant resonances. They constitute a fundamental key to understand the significance of the analysis conducted so far, in particular those that are connected to time, care, and visibility.

In the first place, the research focused on the centrality of time as a hermeneutical device to understand bodily diversity, illness, and LGBTQ+ issues. The shift from the focus on the body to the attention to temporalities unveils a different angulation in the entanglement between neoliberalism, heteronormativity, and ableism. As systems of compulsion, they produce expectations of normalcy which are deeply embedded in conceptions of time. Neoliberalism reproduces expectations on success and productivity and values the individual duty to be healthy. Heteronormativity regulates the expectations on partnering, coupledom, and monogamy. It also propagates specific gender regimes of alignment between sex and gender identification. Ableism produces norms on cure, performance, and beauty. Through the interviews, these forms of regulations became evident in the difficulty participants experience when they fail in complying with one or more of them. Interviewees repeatedly embody the queer art of failure outlined by Halberstam (2011) as the representation of non-compliance with the cis-heteronormative time. They also repeatedly do too many wrong things at the wrong time, as Kafer (2013) would suggest: the regimes of temporalities that fall upon them provide a rhythm towards which they are always asynchronous.

Temporalities are not disentangled from bodies: the analysis showed how chronic illnesses impose different rhythms of pain and relief and thus put them into a different timeframe that makes it impossible to comply with other temporal expectations, such as socialisation, working, and relationships. Therefore, temporalities are one of the many gears of the wheel of oppression: I argue that the way queer-crip times are elaborated, performed, and reproduced is a crucial lens to read anti-normativity and produce new imaginaries of intersectionality. The research confirms that time is a crucial element of the way oppression works and that every definition of normalcy is regulated also by the definition of a precise temporality. However, the experiences described offer an important proof of how time can also be used to overturn normativity and create trajectories of resistance. Some of them suggest that queer-crip time lays in recognising the expectations related to temporalities and transforming them in the every day by going against the clock. Queering and cripping time collectively, in my proposal, forces us to accept and embrace that the time we live in is not the only possible: practicing different rhythms and times, we can accept brokenness (Clare, 2017), failure (Halberstam, 2011), deviation (Ahmed, 2010) and encounter spaces to thrive within the fractures create by these supposed failings. It could involve recuperating the notion of aspiration, as Ahmed (2010) suggests, as a leading guide to struggle for a good life. If the old saying is correct when it states that even a broken clock is right twice a day, we expect queer-crip acts of asynchronicity also to be right, at least twice a day.

In the second place, the research explored the notion of care: in particular, it focused on how and to what extent the relational aspects of being LGBTQ+ and having a chronic illness intervene in easing (or aggravating) the forms of oppression experienced. Quite surprisingly, the analysis showed that families of origin retain an unmovable centrality in everything that accounts for the material care of their members. Their presence, sometimes overbearing, sometimes problematic, constitutes a phenomenal substitute for the deficits of the welfare state: when there is economic precariousness, families intervene providing financial help and housing; when there is lack of healthcare services, they offer practical support; when there is no option to establish an autonomous life, they perform all of the caregiving tasks. Although literature recognises that familism is a distinctive feature of Southern European countries, its pervasiveness still emerged as striking. In line with the queer literature on care (Gusmano, 2018; Vaittinnen, 2015), the initial expectation was to encounter more examples of networks of care provided by the LGBTQ+ community, friends, colleagues, ex-partners, multiple partners. The role of families is pervasive but not homogeneous, in particular concerning sexuality. Most families privilege the care for their ill members over the acceptance of their LGBTQ+ identification: they still provide care and can conjugate it with indirect or outspoken homo-transphobia. Many adopt the “don't ask, don't tell” rule that indirectly discourages visibility. Only a few are reportedly supportive of their LGBTQ+ kin. What appears evident is that care for economic reasons and for health reasons is considered essential and fundamentally undeniable. On the contrary, the acceptance (the care) of different sexual orientations or gender identifications is not conceived as strictly necessary: indirectly, homo-transphobia is deemed acceptable and even justified. The hierarchisation of care into separate levels of importance may be attributed to the Catholic orientation of Italian and Portuguese backgrounds. It may also have to do with generational reasons: most parents of interviewees belong to the generation of “baby-boomers”, in the case of Italy, or to the generation that grew under the dictatorship, in Portugal. The wave of commodification of private life, in the Italian case, and the control over private matters, in the Portuguese one, may have an impact on the ways intimacy and expression of feelings are managed.

The separation of care into different levels of importance is accommodated by interviewees through strategies of resistance in the everyday. For example, many rely on partners and friends for the psychological and emotional support. In particular, the relation with other LGBTQ+ people is important to process the challenges related to sexual orientation and gender identification, although not always to receive support for what regards the struggles of illness. Others carefully choose in which ways and to what extent they intend to organise their networks of care based on practical needs. A relevant aspect is that, through the process of illness, several interviewees learn how to practice self-care and to provide care for others in the same way they learn to communicate boundaries and needs when on the receiving end. In other words, in their experience, care is constantly and necessarily interdependent, although it sometimes requires significant compromises.

A very common experience denounced by interviewees in both countries refers to the lack of spaces where they feel welcomed as LGBTQ+ *and* chronically ill at the same time. Activist organisations largely reproduce a disassociated dynamic that only captures individuals in a narrow part of their intersectional belonging, producing forms of exclusions that lead to more suffering. LGBTQ+ activist groups seem to be reluctant to include accessibility in their practices and often fail to show serious commitment to tackle ableism in their spaces. Organisations working on chronic illnesses are focused on medical issues and resistant to encompass sexuality and intimacy within their sphere of action. In some cases, they are imbued with homo-transphobic ideas. Moreover, public spaces are also often inaccessible to LGBTQ+ chronically ill people: not only because of architectural barriers such as stairs, but also because of the cultural homo-transphobia that discourages, for example, signs of affection with same-sex partners. In the healthcare sector, interviewees experience several forms of struggle. As LGBTQ+, they often prefer to stay invisible for the preventive fear of being discriminated or because they do not deem important to talk about their orientation with their medical doctors. Healthcare workers seem to be generally dismissive, or ignorant, about the specificities of LGBTQ+ patients. Bias also interfere in the treatment of chronic illnesses: since they imply migrating effects, chronic pain, and symptoms invisible to the eye, they may be underestimated or misdiagnosed. Therefore, for most interviewees, the healthcare system is perceived as hostile: it is important to acknowledge that it is a place where trauma happens and oppressions are reproduced, but also work on imagining how it can be transformed to make it more welcoming for LGBTQ+ and chronically ill people.

For all of these reasons, interviewees lack forms of collective care that acknowledge them in their intersectional suffering and multiple embodied belonging. In this sense, care should be intended as a project for a political commitment to provide conditions of dignity to lives that are in most cases only bearable (Ahmed, 2010), when not dispensable. As the Portuguese case shows, a welcoming framework of legal protection is not enough to enhance this kind of change in the micro-politics of care: although the recognition of the rights of LGBTQ+ people and chronically ill people is fundamental, it is not enough to allow them to thrive and have a bearable life as LGBTQ+ *and* chronically ill. Instead, legal change must be accompanied by social policies that ensure that economic, psychological, practical care is provided taking into account the tangled relations between bodily fragility, gender, sexual orientation, class, and so on. In this way, LGBTQ+ adults would be, for example, allowed to choose whether they want to stay at their parental house in case they are unemployed because of their illness, or whether they want to access services of housing that guarantee communal spaces and activities with other LGBTQ+ or chronically ill people. They would have their illness recognised as disabling and be able to choose who they prefer as a personal assistant or receive economic support to hire someone for the task. They would have access to healthcare services that take into account the needs of trans bodies together with the needs of chronic illness, adjusting the medication but also providing all the opportunities for trans patients to work according to their possibilities. They would march in Pride parades and participate in LGBTQ+ events not made accessible because of them but despite them. These examples may outline an idealistic world, but some of these measures are already a reality in other countries in the world, for the queer-crip clock of care is already ticking.

These reflections entail a critical discussion of the kind of understanding of human rights is beneficial to people that suffer from multiple forms of oppression. Although the narratives showed how a system of rights that recognises sexual diversity as valid produces a change in the horizons and in the practices of LGBTQ+, as in the case of Portugal, they also confronted such system of rights with the lack of intersectional perspective. The stories collected thus can indicate an important aspect to take into account within the debate on human rights and within the struggles for a better system of acknowledgement of diversity. The recognition of human suffering and the validation of different experiences of embodiment do not automatically improve the life conditions of those who are intersectionally oppressed. In their inevitable normative aspects, discourses of human rights as well need to be analysed through a perspective that considers ableism and heteronormativity in their intersectional entanglement.

Finally, the research highlighted how visibility and invisibility are inherently connected to oppression, not only for LGBTQ+ but also for chronically ill people. Visibility emerged as a relational aspect that influences every space of relations, public, and private space and that defines the very experience of being LGBTQ+ and having an illness. Through the pressures and the choices on visibility, interviewees learn how to make sense of their intersectional experience. Invisibility and visibility are to be understood as opposites of a continuum of performative, multifaceted, and contextual acts that change from context to context. At the same time, the intersectional element of (in)visibility emerged in the narratives shows how oppression is not linear: interviewees themselves choose to render visible their gender identification or sexual orientation hiding their illness, or vice versa, to strategically contain the possible damages in terms of discrimination. The discrimination against LGBTQ+ people and the stigma related to illness contribute to the potentiation of each other reciprocally. In the ways (in)visibility is managed, the entanglement between compulsory able-bodiedness and heteronormativity confirms that "compulsory heterosexuality is contingent on compulsory able-bodiedness and vice versa" (McRuer, 2003: 89). Therefore, instead of a dichotomy that opposes visibility to invisibility, I argue for the use of a perspective that reads oppressions in their mutual relations and thus insert (in)visibility in the conundrum of intersections between gender, sexual orientation, age, class, ability.

Visibility implies also a temporal aspect. Narratives show that the main fatigue in the management of multiple states of visibility is not the act of visibilisation in itself or the maintenance of invisibility. The performance of both requires an investment in planning and anticipation: interviewees spend a considerable amount of time pondering choices, reading contexts, and exploring scenarios. The process of reflection constitutes a constant element of background and represents a slow, subtle, form of violence reproduced by structural ableism and heteronormativity. Most of the choices on (in)visibility are left to personal initiative and this represents a perverse effect that resonated with the neoliberal individualisation of wellbeing discussed through this dissertation (Cederström & Spicer, 2015). The way interviewees decide how and when come out is intrinsically connected with the cultural forms of ableism and homo-transphobia incorporated in their context.

As previously reinstated, the notion of visibility in itself needs to be complicated and not just celebrated. The construction of visibility reinforces the normative assumption that what is recognisable is also politically readable as either normal or deviant (Samuels, 2003; Wong, 2020). Visibility is particularly important when it breaks this assumption and provides examples of representation that can identify different narratives. In the LGBTQ+ community, visibility has long been a central issue in the struggle of activists. The groundbreaking effect of coming out by famous people in the entertainment industry, sports, journalism, demonstrated how one single act of visibilisation of diversity can produce important effects in encouraging different narratives to emerge. In the sphere of chronic illness, however, there are only a few and recent examples of this kind and it is quite rare to witness the visibilisation of pain and vulnerability. A notable exception, mentioned by some interviewees, is the coming out as chronically ill by Lady Gaga. In the documentary *Five foot two* (2017), the artist talks extensively about her struggle with chronic pain and fibromyalgia. The documentary is cutting edge because it legitimises the narrative of millions of people that have fibromyalgia and are still strongly denied recognition by the medical system (Brown, 2018; Gonzalez-Polledo & Tarr, 2018). It also renders evident how coming out as chronically ill "requires the ability to challenge the equation of appearance with ability and to deliberately withdraw from the dominant privilege connected to the possibility of passing" (Pieri, 2019: 568).

Witnessing a global celebrity withdrawing from such privilege had the positive effect to encourage many chronically ill people to talk about their conditions and be visible in the everyday. Despite this and few other examples[30], there is scarce representativity of chronic illness on a global and collective scale. Although this is not the only level of visibility on which to focus, it contributes consistently to overturn normative narratives on chronic illness. By offering means of representation to individuals with chronic illness, these stories of visibility unveil how individualised the experience of chronic illness is and how a collective identity on this basis is missed.

The lack of representation and the constant struggle with multiple choices of (in)visibility cause a sense of loneliness reported by almost all interviewees. In the narratives, the sense of isolation experienced as LGBTQ+ is exacerbated by the presence of chronic illness: interviewees feel they are "the only ones" that know what it is to live as LGBTQ+ *and* chronically ill. The scarcity of collective platforms of care contribute to reinforce the feeling of going through a solitary experience for which there are no words possible.

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[30] For example, singer Justin Bieber and singer Avril Lavigne both came out, in 2019 and 2015, as affected by Lyme disease. In 2011, tennis player Venus Williams declared she has Sjogren's syndrome.

Whilst turning to the importance of visibility in a counter-normative sense, it is also fundamental to recuperate the transformative potential of invisibility: the narratives tell of choices of invisibility that shield from violence but also defy it in a counter-intuitive manner. These strategies represent instants of micro-politics of resistance, rooted in suffering: they show that visibility is not inherently good and invisibility is not inherently bad, but they can both be navigated in a multiplicity of ways.

The unmapped

Mapping an uncharted territory is inevitably generative of new desires and new horizons: as any research, this as well could not embrace all the suggestions that fieldwork left nor deepen all the interesting connections that emerged during the process. At this point, I briefly turn to some of them because acknowledging what is yet to be explored contributes to better locate this work in the present and the future.

Some of the elements I initially hypothesised revealed to be unimportant for the majority of the interviewees. The most surprising was the centrality of Catholicism. Few interviewees mention the Catholic orientation of their families of origin as a factor that potentially contributed to a resistance concerning LGBTQ+ issues. Besides scarce examples, Catholicism did not emerge as consistently as expected. The elements gathered are not enough to establish whether this means that the description of Southern European countries as Catholic-oriented is dated or that the influence of Catholicism is not perceived strongly. Whilst Catholic practice has been declining both in Italy and Portugal at a stable rate (Istat, 2018), the influence of a cultural orientation deeply imbued with Catholic values is still capillary: its traits are probably so inextricable from other features of local cultures that it may not immediate for interviewees to identify them.

At the beginning of the research, I had doubts about including interviewees with HIV in the sample: given the extensive attention this condition has in literature, it felt more appropriate to work on less explored chronic illnesses. However, the encounter with two interviewees with HIV triggered important reflections that would need further exploration. After decades of high levels of mortality, in recent years HIV became considered a chronic illness, at least in the Global North. However, the stigma attached to its relation with sexuality and the harsh debates that accompanied it in the 1980s still resonate today. This aspect was evident in the similarities of the narratives collected by two completely different interviewees, with two different stories of life, but extremely similar stories of illness. Differently to other conditions, the long struggle of visibility and political activism that accompanied its development also from a collective point of view led to achieve important levels on awareness and healthcare response. There is a stark difference compared to other chronic illnesses that are nowadays not even univocally considered proper illnesses, as in the case of fibromyalgia or Chronic Fatigue Syndrome. Amongst the many reflections that can be summoned by this sketched comparison, the most striking is that in the case of HIV the collective mobilisations to claim the rights for patients to be treated equally made a difference. The advancements in medical research, the establishment of rigorous procedures, the agreement on protocols in the relationship with patients were reached also because this particular illness and the communities that were most affected by it mobilised around it. It makes me wonder, thus, what if for every chronic illness there was a collective mobilisation? What if there were collective mobilisations based on the “collective affinity” (Kafer, 2013) of chronic illnesses and disabilities? Would this change the paradigm in the treatment of patients, making space for more accessible, inclusive, and fair healthcare systems? After all, the great absence in this whole work is the collective dimension of chronic illness, also in comparison to LGBTQ+ experiences, the politicisation at a large level of the struggles experienced by so many in an atomised way.

Other unforeseen elements spontaneously emerged during the process as important for interviewees. Some of them were included in the analytical chapters, such as the use of online dating apps or the complex issue of mental health. Others would deserve further investigation: for example, the centrality of social media in the definition of relations and identification; the use of metaphors or invented terms to describe the experiences that seem otherwise destined to wordlessness; the specific differences in the relation with healthcare amongst lesbian, gay, bisexual, trans and non-binary, queer people. Finally, as it was affirmed in the introduction, this study does not have a comparative aim: throughout the analysis, the differences between experiences related to the Italian or the Portuguese contexts were sometimes highlighted, sometimes blurred. A deeper comparative perspective would unveil more detailed local differences, connected to contextual cultures, historical differences, and contemporary changes.

Hic sunt chroniqueers

At the beginning of this project, I wondered whether I could envision the existence of a political subjectivity that incorporated chronic illness and LGBTQ+ experiences. I called this figure “the chroniqueer”: the union between “chronic” and “queer” was the imagination of a continuum between categories. I was aware that the chroniqueer may just be an ideal figuration and took into account that it could speak to me without any connection with the actual context of the research.

I cannot affirm I encountered traces of a collective political conscience that understands chronic illness from a critical standpoint and relates it to LGBTQ+ identification. However, the interviews let emerge hints of such a process. For example, some of the narratives showed how the intersectional aspects of illness and sexual orientation and gender identification through time, care, and visibility suggested ways to imagine a new political subjectivity. The examples of resistance in the micro-practices of intimacy and the use of self-care as a guiding principle in building healthier relationships confirm that the multiple oppression suffered by interviewees contribute to pave different ways of thinking about intimacy. However, is it through enough to speak about chroniqueers as a political subjectivity? Probably, it is not. What seems consistently missing is the character of collective transformation that happens when the struggle of one become the struggle of many. As already demonstrated, activism appears to be far from making this step and the resistance to understand that the struggle against ableism is an LGBTQ+ struggle still proves to be strong. Even when they enact anti-normative strategies of politicisation, interviewees do it by their own initiative and in an isolated way: as it emerges in the research, the chroniqueer is an individualised political figure. Their struggle happens in the micro-level of intimacy, in the everyday level of dialogue with the contexts they live in. More than often, they enact queer and crip practices out of a need for survival, not as part of a bigger political project in which they feel backed by others. The solitary character of chroniqueers should be intended as a temporary and fluid state. In other contexts or in other times, there are reasons to believe the chroniqueers could emerge as a political subjectivity. For example, the recent development of the global pandemic of Covid-19 could change the face of the debate on chronic illness, in the same way it is already overturning some ideas over accessibility and time that seemed hard to be challenged (Gupta & Chadd, 2020). The development of studies both in other contexts and in other times will be necessary to explore more about how chronically ill adult who do not conform to cis-heteronormativity live.

In her exploration of the queer politics of happiness, Ahmed suggests that a “bearable life is a life that can hold up, which can keep its shape or direction, in the face of what it is asked to endure. [...] A bearable life suggests that the conditions of liveability involve a relationship to suffering, to 'what' a life must endure” (2010: 97). Chroniqueers embody a strong relationship to suffering: they know, because they experience in their every day, that what is asked them to endure is a lot. The pressures of cis-heteronormativity and ableism are strong and involve any aspect of their time. The chroniqueers could be just a subject who attempts to achieve a bearable life, who keeps their direction, even when it points to deviation from expectations. They are inevitably failing in many aspects. The chronic state of their illnesses denounces they will always fail at achieving health. Their LGBTQ+ identification reveals they will fail, somehow and at some point, in following the direction of happiness defined by the linearity of coupledom, monogamy, reproduction. Chroniqueers do not fail after attempting: queer and crip failure is already inscribed in their definition and this element could become powerful once it is transferred to a political level.

In providing a sketched image of chroniqueers I do not intend to romanticise the concept: however, the power of imagining political figuration reveals as fundamental when we want to transform the learnings built through research into political change. Although the research only shows hints of the chroniqueers, it suggests what they could become, in a different time and place. Furthermore, it suggests where intervention can be made to turn their lives more bearable. It leads the way for imagining the future through a queer-crip perspective. In fact, from the empirical work conducted, the suggestion is that the acts of queering and cripping are not just mere theoretical orientation. To queer and to crip mean more than orientations towards concepts: they point to practices that confront normalcy and enact strategies against normalcy. These queer-crip act may not be deliberately political in the intentions but assume a strong political meaning in the way they overturn expectations and claim different ways to be in the world. In the dissertation, I employed a queer-crip reading of theoretical framework, of the methodology, and in the empirical analysis. Bending the perspective towards a queer-crip lens reinforced the conviction that a queer-crip epistemology is an interesting lens to analyse dynamics of power, oppression, and resistance. As such, it can be imagined as a fruitful perspective to look beyond sexuality and illness, encompassing other forms of normalcy that are produced also through the heteronormative and able-bodiedness compulsory systems. Through *queering* and *cripping* not only the object of research but also how we do research, we pave the way to multiple ways to unveil the comedy that lies behind normativity (McRuer, 2006) and thus make space for invisible and silent experiences to emerge.

The journey conducted in this work aimed at mapping an unexplored territory. In old maps, such territories were marked by the sentence *hic sunt dracones*, here be dragons. The research aimed at recuperating and unveiling the monster (the dragons) as the embodiment of abjection and vulnerability at the same time (Shildrick, 2002). The monster, the abject, the misfit is a discursive figuration that lives in each of us, both attractive and repulsing: a reminder of the instability of social and biological bodies and a link to the abject state of constant becoming. In this sense, this work had the objective of charting out where dragons live, and how. However, through the process of research it became clear that the real issue at stake was not so much a mere description of a largely unknown population, but the question itself. The necessity to define a part of a map where dragons live implicitly confines the monsters to a specific territory: it reassures the observer about the line that divides humanity from monstrosity and, again, from normalcy to abnormalcy. In so doing, it provides the observer with the certainty that the monsters live in one specific area and thus they can be observed, analysed, and othered through the privileged gaze of those who live in mapped territories.

As the research tried to show, the chroniqueer as an unknown figuration interrogates all of us in considering vulnerability, precariousness, and interdependence as part of our condition within the social world. It forces us to ask ourselves what are the performances of (in)visibility we need and we choose to employ to protect our vulnerabilities and our privileges. It reminds us of our bodily instability and that the body we live in today is the product of floundering between social categories of heteronormativity and able-bodiedness. To this extent, thinking about the chroniqueer has not the intention of creating another category of embodied difference just for the sake of depicting one (more) encounter with a stranger other. On the contrary, it is a way to undo the category of normalcy and the single categories of LGBTQ+ and chronically ill, showing how they speak directly to the grey zones in which such embodiments happen. In other words, through the perils and dangers of entering an unmapped territory, the suffering encountered unveiled that there are no dragons there: they already live amongst us, they are us. They transform our understanding of vulnerability through the everyday transformation of time, care, and visibility.

“I came to explore the wreck”, says Adrienne Rich (1973) in the poem that guided this work, “to see the damage that was done, and the treasures that prevail”. After exploring the painful damages that were done, the many treasures that prevail after all, I come back to the surface, “by courage or cowardice”, to tell a story of monsters: a story where the names of chroniqueers, our names, will finally appear.

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