

Title: Understanding the problem of long-term treatment adherence: a phenomenological framework

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Abstract:

In light of the large burden of chronic disease and the low rates of long-term treatment adherence contributing to high rates of morbidity and mortality worldwide, this paper contributes to better understanding the particular kind of challenge that living with chronic illness and adhering to long-term treatment can imply. Both literature on the concept of chronic disease and the experience of illness suggest going outside specific diagnostic categories to better understand the problem of adherence. After introducing the distinction of a thin understanding of chronicity—merely as long duration—and a thick one—chronicity in a phenomenological sense, this paper analyses academic literature on the experience of illness and specifies it to the case of chronic diseases, introducing an original conceptual framework describing some main challenges arising from the experience of chronic disease. The framework is organised in three dimensions: Failing to recover as a failure to belong; Being at a loss; and Breaking-up with oneself. This work suggest a particular subjective state in which struggling to follow long-term treatment may seem understandable and reasonable, offering a phenomenological perspective that feeds into the ethical problems arising in chronic diseases, and shedding light on how to increase adherence without reproducing patterns of disadvantage.

Keywords: chronic disease; illness experience; psychological adjustment; self-management; adherence; long-term treatment; ethics.

I. Introduction:

Non-communicable chronic diseases are the main disease burden worldwide,¹ and adherence to long-term treatment for all chronic conditions is around 50% globally, which contributes to high rates of premature death and poor individual and population health outcomes.²

Conceptualising adherence to treatment is difficult because it refers to a process comprising the initiation, implementation (daily self-management) and/or persistence of treatment.³ Although most research focuses on implementation, many studies lack a definition of adherence, leaving the results open to interpretation.⁴ Beyond this issue, there is broad agreement that adherence is highly complex, being affected by a large number of factors. Research shows that there are at least five dimensions that play a significant role in adherence' rates: social and economic factors, therapy-related factors, patient-related factors, condition-related factors, and healthcare team and system-related factors.⁵ However, these do not clearly differentiate between the determinants of short-term adherence for acute conditions and those of long-term adherence for chronic diseases.⁶

Most of the contextual elements affecting adherence require multi-level complex interventions, but most efforts to increase adherence focus on patient-related factors (e.g. self-management education)—despite one-dimensional approaches have been argued to have limited effects.⁷ Chronic diseases are considered a major life stressor and require

adaptation in multiple life domains. It is well known that poor psychological adjustment to illness leads to difficulties in self-management,⁸ but it is not clear which strategies and dispositions are most effective for adjustment to and acceptance of chronic disease, so it is difficult to know how to support those living with chronic diseases.⁹ In this sense, although people living with chronic conditions are often considered their own principal caregivers,¹⁰ medical care for chronic disease fails to meet the needs of individuals and facilitate them becoming effective self-managers of their disease.¹¹

This paper aims to make progress on this problem by better understanding the experience of chronic diseases and providing useful conceptual tools for healthcare services and professionals to support patients in the individual process of adjusting to chronic disease and long-term treatment.

Research on personal transformation or growth achieved through chronic illness is an important angle in the literature on psychological adjustment. Since illness experiences, symptoms and treatments are heterogeneous, for methodological reasons most studies on the experience of chronic illness focus on the transformation associated with specific diseases—which are clustered under the broad and poorly defined category of chronic diseases, and generalise their findings to the whole category of chronic illnesses.¹² However, these studies do not address the fundamental question of what chronic diseases may have in common that is relevant for adjustment and self-management.

In line with the importance of thinking outside specific diagnostic categories when it comes to chronic diseases and adjustment, Dubouloz and colleagues'¹³ model of the process of personal transformation in a primary care context for people living with chronic illness builds on two diagnostic groups, HIV and diabetes. In short, it describes that after the turning point associated with the diagnosis, people reflect on what changes need to be made in order to respond to the new state of illness and face the challenges of adjusting future perspectives and discerning the self from the body. Once this is achieved, people enjoy a more intense sensitivity to life, better understanding and acceptance of the self, and an increased appreciation for significant others¹⁴.

Chronic illness is not a normative developmental milestone, but Dubouloz and colleagues'¹⁵ three-stage model is an example of a prescriptive or normative process of transformation marked by a positive or restitutive view, driven by a narrative of success and acceptance in which people are expected to achieve personal growth from the experience of illness. This does not seem to say much about the experience of those in the 50% of people who do not follow this successful path and arguably struggle with adjustment and adherence. Models like this encourage self-management support interventions that focus on adaptive behaviours and psycho-education, overlooking the psycho-emotional impact of chronic illness¹⁶, and failing to acknowledge and support the skills that people need in order to make sense of their disease and the impact the disease has on their sense of self or identity.¹⁷

Illness experiences are different in many ways and require specific and contextual approaches. But at a different level of analysis, people living with chronic illness face a common set of challenges that is fundamental for a comprehensive understanding of disease and the support needed from healthcare interventions.¹⁸ These two levels of analysis suggest that experiences of illness are always unique and at the same time clustered into groups or conceptual categories. Both literature on the experience of

illness, and consistent low rates of treatment adherence for all chronic diseases suggest the importance of thinking outside specific diagnostic categories to achieve an in-depth understanding of this issue. So this paper will argue for the idea of temporality of disease, in this case, chronicity in a phenomenological sense, as a far-reaching conceptual category to learn more about the experience of chronic illness. This approach offers a specific read on the problems of adjustment and adherence in chronic illness that can account for the category of chronic disease as a whole without suggesting a prescriptive model of the experience of illness, and the ethical problems arising from chronic disease and long-term care.

Section II of this paper briefly reflects on the concept of chronic disease from the perspective of traditional conceptual analysis and, building on an understanding of chronic diseases as bodily properties, it introduces a distinction between a thin sense of chronicity—merely as long duration of disease—and a phenomenological sense of chronicity, which is argued to be a distinguishing feature of this category. This leads to argue that the experience of illness requires special attention in the study of chronic disease, so building mostly on phenomenological literature, section III of the paper develops the argument of a common core in the experience of chronic disease. This gives rise to the main original contribution of this paper, namely, a conceptual framework comprising three dimensions or emotional spaces, which describe the experiences of *Failing to recover as a failure to belong*, *Being at a loss*, and *Breaking-up with oneself*. The framework traces the idea of chronicity in academic literature on the experience of illness more broadly, offering a nuanced understanding of the potential struggles of living with a chronic disease. Finally, in light of this framework, section IV of this paper discusses the ethical problems raised by chronic diseases and long-term treatment. These particularly highlight a cumulative effect of disadvantage in the chronically ill, which might be operating in reproducing disadvantages in this group, specifically through a social gradient in long-term treatment adherence that suggests a shift in perspective with regards to how adherence is understood and measures, and calls for action in clinical practice.

II. Chronicity as a core feature of the experience of illness:

Despite the term chronic disease is widespread, there is no clear-cut definition of the concept.¹⁹ The World Health Organization recently changed its definition of chronic diseases, making it more flexible by losing its previous focus on non-communicability and progression. This definition states that chronic diseases “tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behaviours factors”.²⁰ But since the World Health Organisation uses Non-communicable disease and chronic disease as interchangeable concepts, strictly this definition does not allow for the inclusion of infectious chronic disease—such as HIV and others, so it does not contribute to addressing the complexity underlying the current state of chronic disease epidemiology and leaves the door open to significant confusion in research and policy.²¹

This problem, however, is not new or unique to chronic disease. It follows from the long-standing and still unresolved problem of the conceptualisation of health and disease, and the place of mental disorders and medically unexplained conditions in that discussion. It is not the purpose of this paper to engage in this discussion, but to

acknowledge the ambiguity of the whole reference class to which chronic diseases belong to, and adopt an open perspective towards possible contextual definitions.²² This means that any working definition that might be taken on is likely to change in light of further insights and reflection.

The idea of chronicity generally refers to long duration. The word “chronic” is an adjective making reference to something of or relating to time, and alongside the word disease—“chronic disease”, it is used to give a certain disease the attribute of long-lasting, constant or continuous.²³ This thin understanding of chronicity is a core element in most definitions of chronic disease. Examples of this are the WHO²⁴ definition presented before, and in the UK context, the definitions used by the Department of Health,²⁵ The National Health Services,²⁶ and The King’s Fund.²⁷ All these use “chronic disease” as interchangeable with “long-term condition”, although what counts as “long-term” varies.

By the means of traditional conceptual analysis, Jonathan Fuller²⁸ offers a definition of chronic disease that presumes this idea of long duration, but also contributes to advance reflection on its specificity. Fuller²⁹ states that all chronic diseases are bodily properties. This means that, although there are biological processes involved in the emergence of the properties of any chronic disease, once these properties arise, they become the disease, and even if there are further changes in the pathogenic process, such properties endure.³⁰ From this view, chronic diseases are described as mostly dispositional or realizable properties, such as asthma, but can sometimes also be manifest properties, such as in the case of HIV infection. Either way, chronic diseases cannot be conceived as independent from the body, nor can they be removed from the body, becoming a part of it and, in this sense, a part of the person.³¹

Phenomenological research stresses that chronic diseases comprise the bodily dysfunction, the disruption of the self, and the disruption of the surrounding world. This suggests a bodily metamorphosis in which the bodily disruption becomes the norm.³² From this perspective, time and space are the fundamental structures or conditions of possibility for human experience. Therefore, human subjectivity is understood in time—the present is constantly being shaped by the past and the future—and imbedded in the world with the body acting as mediator. Hence, human beings are a body-subject unity in which the body and perception are the centre of personhood, the body is both an organ of perception and a lived physical body that is central in the study of illness³³. Substantial bodily changes modify the contents of experience, its structure, and conditions of possibility, representing changes at the core of the self and broadly disrupting the individual’s experience of being in time and in the world³⁴. Such changes need to be long-lasting in order to modify the self, since acute substantial bodily changes—when known to be curable—only transitorily modify experience and the self may preserve a sense of continuity with the previous and forthcoming healthy body. So changes in the body and their temporality are crucial to understand how illness disrupts the body, experience, and the self.

Building on this perspective and the conceptual analysis offered by Fuller,³⁵ insofar chronicity in illness comprises the long duration of dispositional and manifest bodily properties, chronic diseases might be considered paradoxical and, in this sense, imply a specific kind of problem at the level of experience. Symptoms may be cyclical, but still somehow static, this is, still present in absence, as likely to recur. In this way,

chronic diseases would have the quality of being always present even in the absence of their manifestation.

So, beyond a thin understanding of chronicity merely as long-duration, it might be argued that chronic diseases also imply an understanding of chronicity in a phenomenological sense. This would be characterised by a paradoxical experience of long-duration of disease, which implies significant abstraction or awareness of its presence in the absence of its manifestation, as likely to recur. Thus, chronicity in a phenomenological sense implies a positioning of the individual in relation to this long duration of disease, which can transfer the quality of continuous and irreversible to an experience that might be thought of as discontinuous in terms of how it is expressed in the body.

Although Fuller's³⁶ analysis focuses heavily on somatic pathogenic processes potentially drawing a strong line separating chronic physical illness and mental disorders, or medically unexplained conditions, it also stresses the continuity between the body and personhood. As already mentioned, drawing clear conceptual lines in the realm of disease and illness is not easy, and there doesn't seem to be academic agreement to support a clear cut distinction between mental and physical chronic diseases.³⁷ Settling this problem certainly exceeds the scope of this work, but this analysis leaves the door open for further reflection on the comprehensiveness of chronicity in its phenomenological sense, and its potential to also apply for the cases of chronic mental illness and medically unexplained symptoms.

The next section explores how chronicity in the phenomenological sense may be argued to affect the body, experience and the self, leading to the introduction of a novel phenomenological framework describing some of the main challenges arising from the experience of chronic disease.

III. Towards a phenomenology of chronic disease:

Building mainly on the work of Susan Sontag, Arthur Kleinman, S. Kay Toombs, Michel Bury, Arthur Frank, and Havi Carel, this section presents a framework that specifies academic literature on the experience of illness in general, to chronic diseases in particular by underlining the role of chronicity in a phenomenological sense.

Although these authors' works aim at rather abstract conceptualisations about illness, and only some of them make direct reference to chronic diseases—as a broad, unspecific category, their work is highly valuable as it emerges in the context of first-person experience of chronic diseases. Susan Sontag and Arthur Frank lived and wrote about their experience of cancer; S. Kay Toombs about multiple sclerosis, and Havi Carel about lymphangiomyomatosis (LAM lung disease). Michael Bury and Arthur Kleinman's work is slightly different, as it arose from qualitative research with rheumatoid arthritis patients, and clinical experience with people living with mental health conditions, respectively. So it is the epistemic conviction that first-person accounts of illness are central for the study of illness what brings them all together in this original work.

The phenomenological framework presented in this section is structured around three dimensions: *failing to recover as a failure to belong, being at a loss, and breaking-up with oneself*. The word dimension makes reference to the emotional space within which the experience of chronic illness takes place, proposing a particular lens to

conceptually organise the complex and multi-layered struggles of living with a chronic condition. So the dimensions in this framework are neither stages nor necessary conditions of experience.

By proposing relevant nuances and specifications to current understandings of chronicity, and highlighting the importance of experience and its emotional spaces, this work offers a novel and unifying perspective on the category of chronic disease. It is worth reaffirming that this framework stands out in its effort to embrace the complexity and variability inherent to human phenomena, instead of risking oversimplifying the matter by suggesting a prescriptive guideline for normalcy.

Failing to recover as a failure to belong:

“Social structure is an integral part of the inner experience”.³⁸ People are immersed in a world already inhabited, shaped, and made familiar to them by others, and it is this familiar world which gives the person the capacity to be oriented.³⁹ Chronicity in illness implies that cure or full recovery is off boundaries, so chronic illness may anticipate the subject’s departure from the world of the living, and its forced reallocation to what Frank⁴⁰ calls the remission society and Carel⁴¹ describes as an experience of unreality, estrangement, and detachment.

Diseases that have an unclear cause and non-curative treatment, just like chronic diseases, tend to be considered capricious and unacknowledged, therefore challenging the current biomedical premise that the body can be fixed.⁴² The military metaphor of illness implies regarding illness as a fight, attributing agency to disease processes that need to be countered by the person with the disease, often with the help of medicine. However, when it comes to chronic illness there is no winning, killing the enemy or eradicating the disease. Chronic diseases become one with the body, and thus one with person, regardless of treatment. Although Sontag⁴³ wrote about illness metaphors reflecting on tuberculosis, cancer and HIV in the late 1970’s and 1980’s, when illness and medicine might be argued to have been somewhat different, her insights continue to shed light on current understandings of illness.

Insofar medicine works on the assumption that the body is other than the self, it works on the assumption that treatment attacks the ill body, and not the self. However, from the ill person’s perspective these are not two independent things. Fighting the disease means fighting the body, and hence, the person living with the disease. At present, people living with chronic diseases often suffer more from the side effects from treatment, than the disease itself. People diagnosed with HIV before showing any symptoms, for example, may never have symptoms of the disease itself, but still struggle with the consequences of treatment on a daily basis—such as osteoporosis, lipodystrophy, diarrhoea and headaches. So although the disease might be controlled, fighting the virus can significantly affect a persons’ life. Furthermore, when people decide to stop treatment for this reason, they might be harshly judged, facing comments such as “oh, so you just want to die”, or “you are just giving up”, or “don’t you want to protect those around you?” Comments like these, not only lack empathy, but also blame the ill person for being ill and demand her to fight regardless of the consequences.

As highlighted in the previous example, because the boundaries between the disease and the person who has it are particularly blurry in the case of chronic diseases, by associating the disease with evil, the military metaphor of illness very easily turns

against and blames those who are ill. This process has been described to contribute to the stigmatisation of the disease and the person, rushing a social death in anticipation to biological death.⁴⁴ This seems particularly relevant for the case of chronic diseases, for which the military metaphor can only imply living in struggle, failing to recover. It could be argued that fighting chronic illness could also be seen as heroic or noble, like soldiers are usually portrayed especially once wars are over, but chronicity implies that there is no ending to the fight, no big moment. So this fight is often taken for granted, merely seen as what needs to be done in order to continue living or to live the best life possible. Life with chronic illness often implies a significant invisible burden of what could be called, the logistics of care. The chronically ill often organise their schedules around treatment, tests, appointments, having to follow up on tests results and prescriptions to make sure to have their medication available on time, for example. This is often invisible because it can surely sound ungrateful to complain about this relatively small price to pay, even from the perspective of the chronically ill.

Furthermore, chronic illnesses are often referred to as self-inflicted illnesses mainly because, despite their multifactorial cause, their main risk factors are related to lifestyle.⁴⁵ This conceptualisation clearly invites for personal responsibility, although health risk factors associated with chronic diseases are socially determined, burdening those who live in disadvantage the most.⁴⁶ Putting together the ideas of blame, failure, effort taken for granted, imperative of gratitude, and personal responsibility developed in the last few paragraphs, it might be thought that the experience of chronic disease could actually have more in common with the experience of poverty in capitalist societies, than with the experience of soldiers at war.

Among other, this process of stigmatisation of chronic disease contributes to the disruption of the sense of belonging to the world, breaking the normal rules of reciprocity and mutual support.⁴⁷ The fundamental re-thinking of the person's self-concept brought by chronic illness implies changes in personal and community involvement, social roles, and activities, which often lead to significant withdrawal and isolation.⁴⁸ On the one hand, there might be physical difficulties to engage with social contexts, but also potential embarrassment, frustration, or other emotions arising from the limitations associated with the disease,⁴⁹ and from being confronted, through the gaze of others, with common fantasies and meanings associated with chronic illness. Some people may be embarrassed to be in public with an asthmatic wheezy chest, for example, and worry that others may think they have something contagious. Furthermore, in the spirit of being considered, healthy people may stop asking for support from the chronically ill, arguing that they already have so much going on because of their disease, and do not wish to extra burden them with their problems. Chronically ill people may also find themselves, receiving sympathy, and thus being othered, for symptoms people believe they suffer from, but that actually do not match their illness experience, among many more.

Healthy bodies belong to the culturally shared and corporally enacted beliefs and norms reinforcing youth and independence in western societies,⁵⁰ so chronically ill bodies that can only anticipate further disability and dependency, specially from treatment and healthcare, may result in painful intersubjective experiences of excorporation or loss of transparency.⁵¹ This is particularly relevant considering that the social world plays a meaningful role in limiting or facilitating bodily becoming. As described by Zeiler,⁵² Merleau-Ponty's concept of sedimentation refers to the strong process through which a

particular way of being acquires a favoured status after receiving frequent confirmation. Thus, some culturally shared and corporally enacted beliefs and norms can become part of peoples' taken-for-granted being-in-the-world and shape embodied agency,⁵³ suggesting that in rejecting chronic illness as a way of being, the social world has the potential to significantly interfere with someone's process of sedimenting chronic illness as a new way of being. This evidences the power dynamics involved in certain bodies being more transparent than others.

Being at a loss:

Although the individual meaning of illness has a very personal form, the idea of loss has been identified as a recurrent and common content in this experience.⁵⁴ Some of the losses associated to chronic illness are more concrete and some are more abstract. Toombs⁵⁵ offers a detailed description of five sequential losses in which chronicity has an amplifying effect. These five losses include loss of wholeness, certainty, control, freedom to act, and the familiar world. Loss of wholeness refers to the rupture in the body-self unity that is described in terms of experiencing the ill body as other-than-me, which leads to a loss of certainty in terms of abandoning the assumption of personal endurance, experiencing vulnerability and anxiety. This then leads to the loss of control understood as control over the body, breaking the spell that medical science can protect people from illness and cure disease, thus leading to the loss of freedom to act specifically regarding medical treatment, precisely because of the serious lack of knowledge about which might be the best course of action. All these losses together lead to an overall experience of loss described as the loss of the familiar world. This is characterised by the new and distinctive way of being that is imposed by illness, isolating the ill person from her everyday familiar world.⁵⁶

These losses are intensified in chronic illness because of its paradoxical presence even in the absence of its manifestation, leading to a close monitoring of bodily processes to regain some control, but also learning to live in contingency because of the loss of trust in the body.⁵⁷ In the case of chronic gastrointestinal diseases for example, disease symptoms may be experienced as periods of illness in which the body is not acting normally, needing to take time off work or not being able to live their normal life until the flare-up is under control. During this time people may be in significant pain and discomfort. Furthermore, chronic gastrointestinal conditions can be affected by so many variables that flare-ups can be difficult or impossible to anticipate and prevent, even if people are following treatment and broader life-style recommendations, understandably leaving some with little certainty about how much the treatment actually helps. Treatment for such diseases requires constant action, even when people may go through long asymptomatic periods. This example highlights chronicity in its phenomenological sense, contributing to realise in which way living with a chronic disease may lead to a particular new way of being.

Building partially on Toombs⁵⁸ work, Carel⁵⁹ describes the experience of illness as an overall state of bodily doubt that invades the normal sense of things, making the ill person feel incapable, exposed and threatened, and revealing the extent of human vulnerability. This state is composed by the loss of continuity of experience and purposeful actions, the loss of transparency of the body and the loss of faith in one's body.⁶⁰ Closely linked to the idea of body monitoring,⁶¹ loss of transparency reflects on

how the body becomes explicitly thematised by the self as a problem, leading to an explicit attitude of concern, anxiety, and fear.⁶²

The idea of loss of transparency, briefly introduced in the previous dimension, has to do with Carel's⁶³ reflections on Sartre's work regarding the idea that as long as the body does what it is expected to do—in the way healthy bodies are regarded to do, it remains transparent in the sense that the body's orders as object and subject are experienced as harmonious. Thus, in a rather paradoxical manner, the body's key feature as the fundamental medium for encountering the world implies it remaining in the background. It is worth noting that this has been argued to imply that loss of transparency of the body is necessarily limited to the angle of perception while other profiles remain in the background, and thus transparency is never completely lost.⁶⁴ Keeping this in mind, transparency of the body, or the transparent unity of self, might be frequently disturbed by the encounter with others and non-disease features of the body—someone commenting on a new haircut, or simply stating how tall someone might be. Drawing on Sally Gadow's work, Young⁶⁵ suggests that although loss of transparency is often described in this negative way, as a painful experience in which the body imprisons the self limiting its possibility to be, transparency might also be lost in experiencing the body being in an aesthetic mode—that is, people may be aware of themselves “as body and take an interest in its sensations and limitations for their own sake, experiencing them as a fullness rather than as a lack”.⁶⁶ This argument might be stretched even further to include body practices that focus precisely on becoming aware of the body, such as in the case of practicing yoga or meditating. Thus, it might be argued that whether transparency of the body is lost in a positive or negative way will follow from complex evaluation processes largely founded on cultural and historical contexts shaping the experience of embodiment. In this way, and acknowledging that this argument might be contentious, transparency might be regarded as something that is achieved—rather than a natural condition, probably in adulthood as the stage in which the body reaches a rather stable state, and it can be disturbed in many ways having different outcomes.

Still, building on the ideas presented in the previous dimension, *failing to recover as a failure to belong*, adjusting to a chronically ill body implies giving up a previous favoured status—healthy—and adopting a new way of being that has been argued to be rejected, rather than frequently confirmed by the social world, so this must be regarded as a difficult change.⁶⁷ This emphasises how particularly challenging it may be to transit from a healthy body-self to a chronically ill body-self, suggesting a corrosive interaction between chronic illness and power, contrary to what is implied in restitutive processes of personal transformation through the experience of chronic illness. Even if someone's experience of chronic disease includes elements of personal growth from illness, these will most likely involve very intimate features, not easily attributed by other to the disease. An example of this might be that even if people experience a positive subjective change in their appreciation of relatively simple activities, such as being able to take a walk in the park, this is unlikely to capture others' attention and receive frequent confirmation for the chronically ill to sediment their new way of being as a chronically ill body-self. For someone who going for a walk in the park has little value, it is likely that this will go unnoticed, highlighting instead how difficult it must be not being able to play any sports or needing help to shower.

Breaking-up with oneself:

Rather than an independent dimension, it offers a different perspective on the previous dimensions, reflecting on what these imply at an inner subjective level. Closely linked to the last argument about the difficulties involved in adjusting to a chronically ill body as this implies giving up a previous favoured status, losses associated to chronic illness introduce the idea of mourning.⁶⁸

The experience of loss associated with chronic illness implies consecutive and cumulative losses, requiring a particular kind of mourning, which, from Kleinman's⁶⁹ perspective, constitutes the key psychological feature of chronicity. Chronic illness patients grieve "for the loss of a body part, physical function, body—and self—image, and way of life"⁷⁰

As a psychiatrist, it might be thought that when Kleinman makes reference to the concept of mourning he is somehow referring to the Kübler-Ross model of grief—denial, anger, bargaining, depression, and acceptance. From this perspective, reaching a state of acceptance is considered normal and healthy. Denial is only justified while it serves a protective purpose in psychological terms, but if prolonged, it is argued to lead to complicated or pathological grief.⁷¹ In fact, Kleinman⁷² suggests a model of caring for the chronically ill that mirrors this model, but adds specifications for the kind of losses associated with chronic illness, which include grieving one's own death and anticipated losses. Although this view contributes to specify the struggles of living with chronic diseases, this model is also—as Kübler-Ross'—founded on a medical understanding of health and disease, and emotions arising from this experience, such as anger and fear, are seen as potential interference with normal grief processes in which acceptance and restitution is achieved.⁷³ Problems arising from such prescriptive models and success narratives were already discussed when reflecting on the model of personal transformation in a primary care context for people living with chronic illness, and were argued to be inconsistent with the experience of chronic illness.

This idea of mourning for the body as it was before and the process of changing sedimented ways of being might be argued to be even more difficult if the idea of chronicity developed in this article is taken into account. In practice, chronic diseases lead to an absolute loss of wholeness, introducing the marked experience of a "before and after illness", and are always present even in the absence of their manifestation (as likely to recur). But this cyclical manifestation also implies that the body becomes an unstable or disorienting (sometimes healthy, sometimes ill) mediator to encounter the world, prompting an ambivalent experience of the body-self. If so, the losses described in the previous dimension, *Being at a loss*, would have the quality of being, at least to some extent, re-experienced alongside the cyclic manifestation of symptoms, so grief and mourning in the context of chronic illness would be, at least to some extent, re-experienced alongside the cyclic manifestation of symptoms, eliciting an overall far-reaching experience of being at a loss regarding how to continue living both with others and oneself. In the case of people living with a chronic gastrointestinal disease, for example, after a long period of feeling stable symptoms-wise, they might start trusting the body more and more, and start doing more sports. Eventually, they may decide to start training for a big cycling tour and, even if they knew all along that flare-ups are always a possibility, it would be understandable if they felt devastated for having to cancel the tour because of the illness. This could trigger strong emotions of frustration

and anger towards the disease, the body and even themselves, potentially having to go through the process of recuperating both physically and emotionally from this experience, once again. Depending on how often this happens and how difficult it may be to recover, among other things, this way of living may become a big deterrent for doing things they enjoy, with little clarity towards what they can actually do or be, both intimately and with others.

Many times chronic illnesses have an insidious onset that often leads to a rather late involvement of others, so the process of realising that there is something wrong with the body is generally lived intimately.⁷⁴ This insidious onset may contribute to resist bodily becoming and prolong the favoured status of being healthy. But once the disease is established the body appears as an object other than the self, requiring the subject's attention⁷⁵ and special treatment. Thematising the body as a problem implies that the attitude of the ill person towards her own body is negative, largely focused on deviation and dysfunction, constituting a reminder of bodily incapacity.⁷⁶ From this perspective, it does not seem surprising that specifically in the context of chronic disease, the ill may cease to consider themselves as desirable to themselves, fearing that they are no longer worthy of the most simple and daily objects and actions, such as buying new shoes or brushing their teeth.⁷⁷ This may be argued to mirror the previously argued social death hastened by chronic illness, showing how, in the intimacy of the relationship with oneself, the ill person experiences herself as somehow no longer worthy of living. Frank⁷⁸ describes four ways of being—or normative stereotypical bodies—that attempt to compensate for the embodiment problems of desire and body-relatedness in illness, but they all struggle to accept the contingency of illness, suggesting that the disruption in the intimacy of the body-self is an unavoidable element in the experience of illness. These may be considered rather extreme considerations in the experience of chronic disease, mostly referring to those whose life and possibility to live as they would like to is significantly disrupted by illness, even if only at times. People experiencing low energy and high pain levels—either permanently or at times—due to endocrine chronic conditions or chronic rheumatic diseases for example, may find it hard to achieve most of their goals, losing their motivation and possibility to engage not only with others, but also with their own lives. In such circumstances, it may be understandable for people to lose their willingness to live, and for some to experience suicidal thoughts.

If the ill person is ambivalently or cyclically identified with being healthy, and also with her previous sense of belonging to the society of the healthy and capable, she might strongly reject the new body and its new demands, adopting a hostile attitude towards herself as a body that mainly carries negative meanings, potentially trying as hard as possible to hold on to her healthy sense of self to continue living. Long-term treatment including, dietary requirements, regular tests and health check-ups, overscheduling, constant chasing of prescriptions and medication delivery, to mention a few, may impose a sense of always present to mostly cyclical manifestations of illness, crashing the hope of preserving the identity built around being healthy. In a world split between those who are healthy and those who are sick, the chronically ill might be argued to be in the position of lacking a role, from which they could somehow cohere the ambivalent experience of chronicity. To exemplify this, the chronically ill usually depend on the flexibility their employers want to or can give them, to have time available during working hours to deal with the logistics of their care, which, as mentioned before, can be

very demanding. If they are not strictly ill, they cannot ask for sick leave to go to the regular procedures, tests, or treatments they usually need in order to prevent periods of illness. The chronically ill are in this sense expected to function the way healthy people do, having to excel at managing the extra burden of treatment and periods of sickness, so others notice it as little as possible, and they can keep their jobs and career prospective. This partial way of relating to others can also become a way of relating to oneself.

Drawing from the three dimensions, the next section will discuss the implications of the experiences described as *Failing to recover as a failure to belong*, *Being at a loss*, and *Breaking-up with oneself* for the delivery of long-term treatment, whilst also acknowledging the ethical issues raised by chronic disease and long-term treatment.

IV. The ethics of chronic disease and long-term treatment:

Taking on the perspective offered by chronicity in its phenomenological sense, and the framework just presented, means that chronic illness must be regarded not only as a difficult and potentially painful individual experience, but also as a red flag signalling further hurdles.

It is largely known that the distribution of chronic diseases follows Marmot's⁷⁹ description of the social gradient of health, and the burden of disease for chronic conditions tends to cluster amongst those who live in disadvantage.⁸⁰ Furthermore, the disadvantaged are likely to either lack the functionings that could allow them to successfully self-manage their illness, or have to risk other central functionings in order to make use of available healthcare services.⁸¹ This double inequity and cumulative effect of disadvantage in the chronically ill suggest a social gradient in treatment adherence.

This is highly consistent with extensive research showing that low socioeconomic level, lack of social support, and low educational levels have a negative impact on adherence to long-term treatment.⁸² Social networks and an overall sense of belonging to the social world have been identified as one of the most important fertile functionings contributing to overcome a broad range of difficulties, showing that being well-supported by friends and/or family correlates with greater agency to implement desired health behaviour changes, such as adhering to long-term treatment.⁸³ So considering the isolating effects of chronic diseases as described in the dimension *Failure to recover as a failure to belong*, people living with chronic diseases may be at greater risk of lacking the functionings that would help them adjust and manage chronic illness. Furthermore, anxiety and depression are strongly associated with non-adherence to treatment in medical patients (not being diagnosed or treated for psychological or psychiatric conditions),⁸⁴ so the emotions and subjective state described in the dimensions *Being at a loss and Breaking-up with oneself*, only add to the rationale that having a detailed and nuanced phenomenology of chronic diseases contributes to better understanding what might be underlying the persistent results of low rates of long-term treatment adherence.

Building on this, it could be thought that people who experience *Failing to recover as a failure to belong*, *Being at a loss*, and *Breaking-up with oneself* at some point and to some extent in their illness trajectory, will either fail, struggle or be inconsistent when attempting to follow life-long treatment recommendations and self-care tasks, which would be reflected into the measurements of long-term treatment adherence as "non-adherent" at the time of measurement. On the one hand, this helps makes sense of the experience of those within the 50% of non-adherent people and,

according to the double inequity described before, understand the challenges of changing this experience and behaviour, breaking the vicious circle of disadvantage associated with chronic disease.⁸⁵ On the other hand, this perspective also feeds back into the long-standing and complex discussion on how to conceptualise, measure, and interpret results of adherence (see Kardas, Lewek, and Matyjaszczyk 2013; Vrijens et al. 2012; Osterberg and Blaschke 2005), specifically for the case of chronic diseases and long-term treatment.

Although non-adherence is often blamed on people living with the chronic illness, largely because self-management plays such a relevant role in long-term care, there is evidence that healthcare system factors, such as the relationship between healthcare professionals and the ill person, also have an important effect on adherence.⁸⁶ From the healthcare professional's perspective, building on the original ideas developed in this article, it would seem particularly interesting to consider treatment adherence specifically in the context of chronic disease as a life-time adjusted process, which requires acknowledging the likelihood of periods of non-adherence, instead of setting the goal on constant optimal adherence. This would imply seeing adherence as a rather fragile process, closely intertwined with the individual's life, and illness experience and trajectory, instead of a discrete and stable outcome. In this way, having an awareness of the on-going challenges of living with chronic illness and long-term treatment, would in turn point to continued support in terms of recognition of the process and its frailty, focusing on compensating for the corrosive effects of chronic illness on health outcomes inequalities for chronic conditions. Although these ideas would require further analysis and empirical research, they show how this work and line of research has the potential to orient future ethically driven practice innovations in the delivery of long-term care.

From this perspective, there are good reasons to think that both the phenomenological framework describing some of the main challenges arising from the experience of chronic disease and the ethical issues raised in this section are central elements in how healthcare professionals might better support those living with chronic disease. This does not mean to undermine the negative effects of the larger context of inequalities—beyond healthcare systems—that constantly affects health outcomes inequalities, or the importance of making progress on this,⁸⁷ but to highlight the potential of contributing to the goal of tackling health outcomes inequalities from the highly resourceful individuals and structures delivering long-term care.

V. Conclusion:

This paper presented the problem of low rates of adherence to long-term treatment by reflecting on the association between psychological adjustment to illness and self-management of chronic disease, evidencing the need for further research on this area. After building a persuasive argument in section II about chronicity—both in a thin sense and a phenomenological sense—being a central feature in the experience of chronic diseases, this paper presented an original framework specifying some of the main potential struggles of living with chronic disease. The novelty of the framework presented in section III contributes to specify and better understand the challenges of living with chronic illness, whilst also raising important ethical issues. These are discussed in section IV in terms of a double inequity affecting the chronically ill, which suggests a social gradient in treatment adherence.

Building on theoretical developments based on first-person accounts of illness, the

framework described a particular subjective state in which struggling to follow long-term treatment may not only seem understandable, but also reasonable. The rationale behind this is the complete opposite to the predominant biomedical discourse on adherence, in which following treatment is the rational thing to do. Power dynamics affecting the experience of illness have been highlighted throughout the paper, and now it also becomes evident how these play a significant role in current understandings of treatment adherence and “patient” agency. In this way, the overarching question of this paper focused on addressing how the experience of chronic illness helps us understand the difficulties in adherence in long-term conditions.

Finally, it is important to highlight that empirical research aiming at exploring the experience of chronicity and long-term treatment in cross-category cohorts of chronically ill individuals is needed to further specify, challenge, or complement the phenomenological framework specifying some main challenges arising from the experience of chronic disease, and so increase its chances of informing ethically driven innovations in the delivery of long-term care.

Notes:

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- ¹ WHO, 'World Health Organization Noncommunicable Diseases Facts Sheet'.
 - ² Sabaté, 'Adherence to Long-Term Therapies: Evidence for Action'.
 - ³ Vrijens et al., 'A New Taxonomy for Describing and Defining Adherence to Medications'.
 - ⁴ Kardas, Lewek, and Matyjaszczyk, 'Determinants of Patient Adherence: A Review of Systematic Reviews'.
 - ⁵ Sabaté, 'Adherence to Long-Term Therapies: Evidence for Action'.
 - ⁶ Kardas, Lewek, and Matyjaszczyk, 'Determinants of Patient Adherence: A Review of Systematic Reviews'.
 - ⁷ Kardas, Lewek, and Matyjaszczyk; Sabaté, 'Adherence to Long-Term Therapies: Evidence for Action'.
 - ⁸ Chronister and Chan, 'Hierarchical Coping: A Conceptual Framework for Understanding Coping within the Context of Chronic Illness and Disability'; Ridder et al., 'Psychological Adjustment to Chronic Disease'; Stanton, Revenson T., and Tennen, 'Health Psychology: Psychological Adjustment to Chronic Disease'.
 - ⁹ Chronister and Chan, 'Hierarchical Coping: A Conceptual Framework for Understanding Coping within the Context of Chronic Illness and Disability'.
 - ¹⁰ Bodenheimer, Wagner, and Grumbach, 'Improving Primary Care for Patients with Chronic Illness. The Chronic Care Model, Part 2'.
 - ¹¹ Bodenheimer et al., 'Patient Self-Management of Chronic Disease in Primary Care'; Bodenheimer, Wagner, and Grumbach, 'Improving Primary Care for Patients with Chronic Illness. The Chronic Care Model, Part 2'; McDonald et al., 'Chronic Disease Self-Management by People With HIV'; Wagner et al., 'Improving Chronic Illness Care: Translating Evidence into Action'.
 - ¹² Asbring, 'Chronic Illness – a Disruption in Life: Identity - transformation among Women with Chronic Fatigue Syndrome and Fibromyalgia'; Kalitzkus and Matthiessen, 'Personal Growth in Chronic Illness – a Biographical Case Study of Living with Fibromyalgia'; Karademas, 'The Psychological Well-Being of Couples Experiencing a Chronic Illness: A Matter of Personal and Partner Illness Cognitions and the Role of Marital Quality'; Prodingler and Stamm, 'Self-Reflection as a Means for Personal Transformation: An Analysis of Women's Life Stories Living with a Chronic Disease'.
 - ¹³ Dubouloz et al., 'A Model of the Process of Transformation in Primary Care for People Living with Chronic Illnesses.'
 - ¹⁴ Idem.
 - ¹⁵ Idem.
 - ¹⁶ Furler et al., 'The Emotional Context of Self-Management in Chronic Illness: A Qualitative Study of the Role of Health Professional Support in the Self-Management of Type 2 Diabetes'; Kendall et al., 'Social Processes That Can Facilitate and Sustain Individual Self-Management for People with Chronic Conditions'.
 - ¹⁷ Edgar, 'The Expert Patient: Illness as Practice'.

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- ¹⁸ Swendeman, Ingram, and Rotheram-Borus, 'Common Elements in Self-Management of HIV and Other Chronic Illnesses: An Integrative Framework'; Wagner et al., 'Improving Chronic Illness Care: Translating Evidence into Action'.
- ¹⁹ Bernell and Howard, 'Use Your Words Carefully: What Is a Chronic Disease?'
- ²⁰ WHO, 'World Health Organization Noncommunicable Diseases Facts Sheet'.
- ²¹ Choi et al., 'Bringing Chronic Disease Epidemiology and Infectious Disease Epidemiology Back Together'.
- ²² Rogers and Walker, 'The Line-Drawing Problem in Disease Definition'.
- ²³ OED, 'Chronic'.
- ²⁴ 'World Health Organization Noncommunicable Diseases Facts Sheet'.
- ²⁵ Department of Health, 'Long-Term Conditions Compendium of Information: Third Edition'.
- ²⁶ NHS, 'Long-Term Physical Health Condition. NHS Dictionary'.
- ²⁷ The King's Fund, 'Long-Term Conditions and Multi-Morbidity'.
- ²⁸ Fuller, 'What Are Chronic Diseases?'
- ²⁹ Fuller.
- ³⁰ Fuller.
- ³¹ Fuller.
- ³² Kleinman, *The Illness Narratives. Suffering, Healing and the Human Condition.*; Toombs, 'The Metamorphosis: The Nature of Chronic Illness and Its Challenge to Medicine'.
- ³³ Carel, *Phenomenology of Illness*.
- ³⁴ Carel.
- ³⁵ 'What Are Chronic Diseases?'
- ³⁶ Fuller.
- ³⁷ Rogers and Walker, 'The Line-Drawing Problem in Disease Definition'.
- ³⁸ Kleinman, *The Illness Narratives. Suffering, Healing and the Human Condition.*, 39–40.
- ³⁹ Zeiler, 'A Phenomenology of Excorporation, Bodily Alienation, and Resistance: Rethinking Sexed and Racialized Embodiment'.
- ⁴⁰ Frank, *The Wounded Storyteller. Body, Illness and Ethics*.
- ⁴¹ Carel, *Phenomenology of Illness*.
- ⁴² Sontag, *Illness as Metaphor ; and, AIDs and Its Metaphors*.
- ⁴³ Sontag, *Illness as Metaphor ; and, AIDs and Its Metaphors*.
- ⁴⁴ Sontag.
- ⁴⁵ Busse et al., 'Tackling Chronic Disease in Europe. Strategies, Interventions and Challenges'.
- ⁴⁶ Wardle and Steptoe, 'Socioeconomic Differences in Attitudes and Beliefs about Healthy Lifestyles'.
- ⁴⁷ Bury, 'Chronic Illness as Biographical Disruption'; Carel, *Phenomenology of Illness*.
- ⁴⁸ Bury, 'Chronic Illness as Biographical Disruption'.
- ⁴⁹ Bury.
- ⁵⁰ Gawande, *Being Mortal. Ageing, Illness, Medicine and What Matters in the End*.
- ⁵¹ Zeiler, 'A Phenomenology of Excorporation, Bodily Alienation, and Resistance: Rethinking Sexed and Racialized Embodiment'.

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- ⁵² Zeiler.
- ⁵³ Zeiler.
- ⁵⁴ Kleinman, *The Illness Narratives. Suffering, Healing and the Human Condition*.
- ⁵⁵ Toombs, 'The Meaning of Illness: A Phenomenological Approach to the Patient-Physician Relationship'.
- ⁵⁶ Toombs.
- ⁵⁷ Carel, *Phenomenology of Illness*; Frank, *The Wounded Storyteller. Body, Illness and Ethics*; Kleinman, *The Illness Narratives. Suffering, Healing and the Human Condition*.
- ⁵⁸ Toombs, 'The Meaning of Illness: A Phenomenological Approach to the Patient-Physician Relationship'.
- ⁵⁹ Carel, *Phenomenology of Illness*.
- ⁶⁰ Carel.
- ⁶¹ Kleinman, *The Illness Narratives. Suffering, Healing and the Human Condition*.
- ⁶² Carel, *Phenomenology of Illness*.
- ⁶³ Carel.
- ⁶⁴ Leder, *The Absent Body*.
- ⁶⁵ Young, 'Pregnant Embodiment'.
- ⁶⁶ Young, 51.
- ⁶⁷ Zeiler, 'A Phenomenology of Excorporation, Bodily Alienation, and Resistance: Rethinking Sexed and Racialized Embodiment'.
- ⁶⁸ Carel, *Phenomenology of Illness*.
- ⁶⁹ *The Illness Narratives. Suffering, Healing and the Human Condition*.
- ⁷⁰ Kleinman, 39.
- ⁷¹ Kübler-Ross, *On Death and Dying*.
- ⁷² *The Illness Narratives. Suffering, Healing and the Human Condition*.
- ⁷³ Kleinman.
- ⁷⁴ Bury, 'Chronic Illness as Biographical Disruption'.
- ⁷⁵ Frank, *The Wounded Storyteller. Body, Illness and Ethics*.
- ⁷⁶ Carel, *Phenomenology of Illness*.
- ⁷⁷ Frank, *The Wounded Storyteller. Body, Illness and Ethics*.
- ⁷⁸ Idem.
- ⁷⁹ Marmot, *Status Syndrome: How Your Social Standing Directly Affects Your Health*.
- ⁸⁰ WHO, 'Preventing Chronic Diseases. A Vital Investment: WHO Global Report'.
- ⁸¹ Stutzin Donoso, 'Chronic Disease as Risk Multiplier for Disadvantage'; Wolff and de-Shalit, *Disadvantage*.
- ⁸² Kardas, Lewek, and Matyjaszczyk, 'Determinants of Patient Adherence: A Review of Systematic Reviews'.
- ⁸³ Bury, 'Chronic Illness as Biographical Disruption'; McDonald et al., 'Chronic Disease Self-Management by People With HIV'; Vassilev et al., 'The Influence of Social Networks on Self-Management Support: A Metasynthesis'; Wolff and de-Shalit, *Disadvantage*.
- ⁸⁴ DiMatteo, Lepper, and Croghan, 'Depression Is a Risk Factor for Noncompliance with Medical Treatment: Meta-Analysis of the Effects of Anxiety and Depression on Patient Adherence.'
- ⁸⁵ Stutzin Donoso, 'Chronic Disease as Risk Multiplier for Disadvantage'.

⁸⁶ Kardas, Lewek, and Matyjaszczyk, 'Determinants of Patient Adherence: A Review of Systematic Reviews'.

⁸⁷ Marmot, 'Fair Society Healthy Lives'.

Patient and public involvement statement: Patients and/or the public were not involved in this research.

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