How people with chronic illnesses express their self:

A thematic analysis of past and desired future narratives

Master Thesis Positive Clinical Psychology and Technology

by

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Abstract

Being diagnosed with a chronic illness can cause significant disruptions in life, as it challenges one's habitual and taken for granted ways of thinking, feeling and acting. Besides, adjusting to living with a chronic illness can have a significant impact on how individuals experience their self. The different types of selves people with chronic illnesses may express have been summarised into a new theoretical framework that is based on foundational research by Kathy Charmaz, who described common experiences of people with chronic illnesses and their possible influence on their self. The aim of this study was to explore how people with chronic illnesses express their self in written past and desired future narratives. The two types of narratives written by people with chronic illnesses were analysed by means of thematic analysis. The narratives consisted of past illness narratives about participants' experiences living with a chronic illness and the Letters from the Future writing exercise, in which participants expressed their desired future. Two thematic analyses were performed, one exploring the different types of selves expressed by participants and one investigating the (temporal) patterns in selves throughout the narratives. Based on a sample of 68 narratives by 34 participants, which were collected among Dutch adults with various chronic illnesses, 11 types of selves were identified. Further, multiple different journeys could be identified regarding the patterns in selves throughout the narratives. The current study contributes to scientific knowledge by providing new insights to Charmaz' work and adding the desired future dimension, providing deeper insights into patterns in participants' selves and their desires and wishes for the future.

Keywords: chronic illness, self, illness narrative, letters from the future, thematic analysis

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This research investigates how people with chronic illnesses express their self in written narratives of their past and desired future lives. Chronic illnesses are the main cause of death worldwide and have serious consequences, as they do not only affect individual's physical and mental wellbeing, but also how they experience their self. The basis for this study is the work by Kathy Charmaz, who extensively researched the topic of chronic illness and the self. Based on her findings, a new theoretical framework, which summarises the different types of selves people with chronic illnesses might experience, was constructed and applied to written narratives for the first time. This research explores two time dimensions, namely the past in the form of illness narratives and the desired future in the form of Letters from the Future. Adding the relatively new and unexplored desired future perspective of people with chronic illnesses provides insights into their wishes and desires for their future selves and allows for temporal patterns to be investigated. Thus, the aim of this study was to explore which selves people with chronic illnesses express and which patterns of self can be identified when comparing participants' past and desired future narratives.

Chronic illnesses: definition, prevalence, examples

Nowadays, chronic illnesses are the largest cause of death and disease burden worldwide as well as the main reason for individuals in high-income countries to seek healthcare (Dowrick et al., 2005). In January 2022, about 10.3 million people in the Netherlands had at least one chronic illness. This constitutes 59% of the Dutch population (Volksgezondheid en Zorg, 2022). According to the Center for Disease Control (2022), chronic illnesses can be defined as “health conditions that last one year or more, require ongoing medical attention or limit activities of daily living or both". They are characterised by being prolonged, not resolving spontaneously, and rarely being completely cured (Dowrick et al., 2005) and have been found to result from an interplay of environmental, physiological, genetic and behavioural factors (World Health Organisation, 2022). Main risk factors include tobacco use, physical inactivity, obesity, excessive alcohol consumption and poor nutrition (Busse et al., 2010; Centre for Disease Control, 2022; World Health Organisation, 2022).

Worldwide, the most common chronic illnesses are cardiovascular diseases, different forms of arthritis, respiratory problems, diabetes and epilepsy. Chronic illnesses have traditionally solely entailed physical conditions. However, over the years this definition has been changed to include chronic mental illnesses, such as depression or schizophrenia, and other disabilities, such as sight impairment (Busse et al., 2010; Dowrick et al., 2005). This study focuses solely on chronic physical illnesses, as all participants reported a chronic physical illness as their main diagnosis. One commonality of all chronic diseases is their need for long-term and complex treatment, including coordination by various healthcare professionals and access to needed medication and equipment (Busse et al., 2010; Dowrick et al., 2005).

Consequences of chronic illnesses

People with chronic physical illnesses are affected by their condition in various ways. They must deal with not only physical aspects of the disease such as pain, discomfort and effects of treatment procedures, but also emotional and social consequences (Petrie & Moss-Morris, 1997; Portillo et al., 2012; Royer, 1998). They often experience impaired health-related quality of life (Sprangers et al., 2000) and have found to be more prone to mental health problems, for instance depression and anxiety (De Ridder et al., 2008; Huurre, 2002; Petrie & Jones, 2019).

Furthermore, people with chronic illnesses must confront a wide spectrum of needs including having to alter their behaviours, dealing with the social and emotional impacts of symptoms, disabilities and interacting with medical care professionals (Dowrick et al., 2005). They must learn acceptance, self-management and adjusting to the disease, which can come with complications such as denial or failing to cope. This makes living with a chronic illness a process that is complex, cyclical, dynamic contextual and multi-dimensional (Ambrosio & Portillo, 2018). Being diagnosed and living with a chronic illness also frequently affects one's experience of self, as it can lead to experiences of self-growth or self-loss (Charmaz, 1983; Golub et al., 2015).

Defining the construct of self

There have been debates among researchers what exactly self is - and is not. Thus, difficulties arise in clearly distinguishing multiple related terms such as self, self-concept, and identity, and there are differing opinions about whether they are inherently different, or all fall under the same umbrella term of identity. While some researchers have argued that there is no real difference between the term self and identity (Breakwell, 1987; Roeser et al., 2009), others identified several ways in which they can be differentiated (e.g., Côté & Levine, 2002; Soenens & Vansteenkiste, 2011). Differing opinions stem from the fact that the terms, specifically self, have been used with various meanings depending on the author and discipline (Vignoles et al., 2011). To arrive at a working definition for this study, research by Kathy Charmaz will be used to conceptualise self. Charmaz is a foundational researcher in the field of self and chronic illnesses and has done extensive qualitative research on these topics, making her insights especially fitted for this study's topic of self in people with chronic illnesses.

Charmaz supports the notion that there are differences between the concept of self and identity or, as she calls it, self-concept. According to Vann-Ward, Morse and Charmaz (2017), the self is actively constructed through a person's social interactions. The authors derive this definition from symbolic interactionism, which assumes that individuals actively construct the worldviews they hold through interaction with others (Blumer, 1969; Mead, 1934). Interactions with their social environment can lead people to sustaining, altering or even transforming how they experience self. Charmaz (2011) describes this as an "unfolding social and subjective process" (p.170), also referring to the self as an experienced self.

Charmaz contrasts the self with the term self-concept, which refers to a more stable and structured way of seeing the self. While the self-concept consists of organised sets of consistent definitions, the self is more fluid, multi-faceted and emerging through the individuals' experiences (Charmaz, 2011). Thus, according to her, an individual can inhabit multiple different selves that are continuously evolving and changing with their experiences and social interactions. Her view of self that is subjective, actively constructed, evolving and shaped through social interactions, dynamic and "multiple" will be adopted for this research. Charmaz' understanding of self has not been used to understand chronic illness experience before, nor been applied to written narratives. However, her qualitative work on self is extensive and deals with the same target group as this study, namely people with chronic illnesses, making her notion of self the best fitted for the current research.

Types of selves based on research by Kathy Charmaz

With her foundational research on people with chronic illnesses, Kathy Charmaz provided important insights into how people with chronic illnesses experience and form their self depending on the experienced changes to their lives and habits, their adjustment to and acceptance of their illness, and the reactions and treatment of others around them (Charmaz, 1983, 1994, 2002, 2008, 2019; Charmaz & Rosenfeld, 2006). Different types of self can be inferred from her work, namely the habitual, disrupted, lost, stigmatised/marginalised, reconstructed/transformed, and enduring selves, which I will summarise in the following paragraphs.

According to Charmaz (2002), people see themselves in terms of their habitual ways of thinking, feeling and acting towards others, themselves and the world as a whole. These habits are social by nature, as they are formed through cultural norms and values and affected by the relationships with others and, thus, connect the self to the social world. When people are diagnosed with a chronic illness, this disrupts their taken-for-granted *habitual* self, as they are often faced with having to change their daily habits that might have been an integral part of their self (Charmaz, 2002).

The experienced changes in habits may lead to reflection and reassessment of one's life and notion of self, which can come with negative emotions or the feeling of a shrinking and sinking of self (Charmaz, 2002). People with chronic illnesses experience challenges to their self not only due to physical discomfort but also because they might have to quit work, limit their social interactions and avoid activity, leading to a perceived *disrupted* self. These disruptions can go as far as making them feel as if their former self is crumbling away and they are unable to establish new perceptions of self that are equally valued (Charmaz, 1983). They might start to perceive parts of their former self to be *lost*. For people with chronic illnesses, consequences of losing parts of their selves and the feeling of control over their present and future lives can be a loss of self-esteem or their whole experience of self (Charmaz, 1983).

People with chronic illnesses are frequently confronted with social expectations that assume being healthy and able-bodied as the norm and prescribed standard. They themselves tend to share these expectations, which can lead them to self-stigmatise and feel that they "should" be healthy (Charmaz, 2008; Charmaz & Rosenfeld, 2006). Individuals who cannot meet these expected standards can be confronted with a self that feels *stigmatised* or even *marginalised* by others, which can range from experiences of being ignored to degradation or deprivation. Besides, whether a person's illness or disability is visible to others around them plays an important role in the responses they receive. As somebody with a chronic illness that is invisible to those around them, trying to match societal expectations, they often experience further impairment and marginalisation. Those who have visible differences that distinguish them from the norm tend to experience marginalisation more immediately. However, marginalisation is not a solely negative experience, as an outside view enables new interpretations of society and can offer opportunities for change and transformation (Charmaz, 2008; Charmaz & Rosenfeld, 2006).

People with chronic illnesses who experience disruptions or even losses of self are often confronted with a need to change their habits of feeling, thinking and acting and develop new selves. This requires at least some extent of reconstruction and can lead to regaining a sense of control and a *reconstructed* or *transformed* self (Charmaz, 1994, 2002). Reconstructions of self happen through reflection of perceived weaknesses and valued strengths. This can lead to setting new priorities. However, the reconstructions people may undertake do not necessarily imply that the new emerging selves must be better. Instead, reconstructions imply the modification, revision and potentially the re-envisioning of self (Charmaz, 2002). Some people with chronic illnesses made their experienced transformation of self a central focus of their lives. Transformation does not have to imply a victory over one’s illness but can also be felt in terms of a better understanding of and coping with it (Charmaz, 1994).

However, not all people with chronic illnesses feel their self is lost or in need of changing due to their illness. Instead, some have a relatively *enduring* self (Charmaz, 2002). On one hand, people with chronic illnesses may have such deeply ingrained habitual selves that they are unable to have them altered. They are in denial of being chronically ill and resist reconstruction until alternative explanations for their condition are exhausted and their experiences proof that they have, indeed, changed. On the other hand, when people with chronic illnesses remain resilient despite bodily changes caused by their illness, they may also experience an endurance of self. Their self uses of both inner resources, which constitute a consistent foundation to act from, and outer resources, which support that foundation further, to endure. In these cases, continued relationships and daily activities lead to an enduring self, which stays stable in its core while also being open to new opportunities and reconstructions (Charmaz, 2002). To really understand how people with chronic illnesses express their selves, their personal experiences and stories need to be listened to.

Illness narratives, the self and the relevance of time

Narrative psychology can help deepen one’s understanding of the illness experience of people with chronic illnesses and how they express their self. The field's focus lies on personal stories and narratives, and it strives to reveal how people give meaning to themselves and their lives (Murray & Sools, 2015). Through illness narratives, people with chronic illnesses tell stories that help them find coherence and meaning in otherwise distinctive events as well as in their long-term course of suffering (Kleinmann, 1988). Looking at different illness narratives informs about a multitude of factors influencing people's illness experience, for instance the impact of their illness on their personal daily lives and relationships, how the outside world treats them, the ways they cope and make meaning, and their wishes and aspirations for the future (Franits, 2005; Gucciardi et al., 2016; Lucius-Hoene, Holmberg & Meyer, 2018).

A crucial aspect of illness narratives is time. As Ricoeur (1980) emphasised, temporality and narratives are closely related, as the experiences we narrate cannot be separated from the time they take place in. Through narratives, people create a sense of coherence throughout time. Previous research has paid significant attention to the past. It has been found that one's self is closely tied to past autobiographical memories (Addis & Tippett, 2004; Bluck & Habermas, 2000; Conway, 2005; McAdams, 2001; Wilson & Ross, 2003), specifically vivid and frequently accessed memories, so-called "self-defining" memories (SDMs) (Blagov & Singer, 2004; Lardi et al., 2010; Singer & Moffitt, 1991-1992; Sutin & Robins, 2005; Thorne et al., 2004). These serve as an anchor of self in remembered reality and represent the most dominant themes and concerns of an individual.

Further, several studies suggest that the imagination of meaningful or desired future events can foster one's self even more than memories of the past (Addis et al., 2008; Berntsen & Bohn, 2010; D’Argembeau & Van der Linden, 2004, 2006). However, narrative research has frequently neglected the future, making it an underresearched dimension of time (Sools & Mooren, 2012; Squire, 2012). To address this issue, D'Argembeau et al. (2012) introduced the concept of self-defining future projections (SDFPs) and showed with two studies that people can name future events that are significant to them and that convey important information of who they are. The style participants constructed SDMs was found to be similar for SDFPs, showing that the self is grounded in both types of events. Overall, their studies were able to support the notion that the imagination of future events is partly nourishing one's self (D'Argembeau et al., 2012). These findings suggest that further research with a focus on the future dimension specifically is needed, which could be achieved by letting people with chronic illnesses imagine their desired future.

The current study

The previously discussed literature makes two important claims regarding people with chronic illnesses and their self. Firstly, being diagnosed and adjusting to living with a chronic illness can seriously influence one's self. Not all individuals endure in their self, meaning that their perception of self stays stable over time. Instead, they often experience disruptions or even losses of self that require them to transform their old habitual selves into new ones. It, thus, seems that a lot of people with chronic illnesses can be viewed as being on a journey to constructing new valued selves that integrate their illness. Secondly, people with chronic illnesses can express and form their self through illness narratives. This can give them a feeling of meaning and coherence. Temporality plays an important role in this process of understanding and contributing to the self throughout time. The central question of this research is therefore how exactly people with chronic illnesses express their self in narratives of different time dimensions.

This study addresses the topics of self and temporality in an innovative way. Work on people with chronic illnesses and their self by the foundational researcher Kathy Charmaz is summarised into a new theoretical framework (see Appendix A) and applied to written narratives for the first time. This serves the purpose of investigating whether her previously discussed types of selves can be identified in this study's sample of people with chronic illnesses. Charmaz' research is based on people with chronic illnesses' life and experiences with their condition in the past until now. Adding the future dimension in form of desired future narratives fills a research gap and provides the opportunity to get important insights into people with chronic illnesses' desires and wishes for the future. Besides, including both the past and desired future time dimensions creates the possibility to identify (temporal) patterns in how people with chronic illnesses express their self throughout time.

Thus, this research aims to answer the following research question: *“How do people with chronic illnesses express their self through narratives about their past and desired future lives?”*. For this, the first sub-question concerns the different selves: *"Can different types of selves be identified in the participants' past and desired future narratives?"*. To answer this first sub-question, an adaptation of Charmaz’ conceptualisation of selves, will be the basis. The second sub-question deals with possible patterns throughout time: *"Which patterns of self can be identified when comparing participants' past and desired future narratives?"*. For this, the two types of narratives will be compared in terms of the selves expressed within them. They will be analysed regarding whether the participants express their selves in a continuous way, meaning that the selves remain relatively the same throughout the narratives, or in a discontinuous way, meaning that the selves expressed change throughout the narratives.

Methods

Study design

The current study is based on a research project from the Netherlands by Anneke Sools and Jacqueline Coppers (2021) called ‘Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst’ (‘How people with chronic health conditions story their past and future lives’). They combined qualitative and quantitative data collection methods. As a qualitative method, writing exercises about participants’ past and present experiences being diagnosed and living with chronic illness and their desired futures by means of the Letters to the future method were applied (Sools & Mooren, 2012; Sools et al., 2015; Sools, 2020). As a quantitative method, the Dutch version of the Mental Health Continuum-Short Form (MHC-SF), a questionnaire measuring mental health by assessing emotional, social and psychological well-being, was used. Besides, demographic data including gender, age, occupation and living situation was collected. The online survey tool Qualtrics was used to collect data.

Participants

To partake in the research, participants had to fulfil several inclusion criteria. They had to perceive themselves as living with at least one chronic illness, be at least 18 years old, understand Dutch and be able to write in Dutch, and possess the digital skills to fill in the survey and the cognitive skills to sufficiently reflect on their past and imagine their desired future. The participants were recruited by means of purposive sampling, as the survey was distributed through the researchers' network (including social media platforms like LinkedIn), as well as through the network of various patient organisations in the Netherlands. Individuals with different types of physical or mental chronic illnesses were asked to fill in the survey.

The final analysed sample of the current study (N=34) consisted of 33 women (97%) and one man (3%) with an age range from 24 to 70 years (M= 45.74). The sample was selected based on the narratives' characteristics, namely the length of the narratives as well as how extensive participants talked about self; Longer narratives that entailed frequent and detailed expressions of selves were favoured. This was done to get the most detailed insights into how participants expressed their selves and avoid including narratives that do not contribute to answering this study's research questions. Participant demographics such as age, gender or chronic illness, were not considered in the selection process.

The participants reported various chronic physical illnesses such as migraine, Hodgkin lymphoma (which led to an amputation of an arm), persistent postural perceptual dizziness (PPPD), Ehlers-Danlos syndromes, cerebrovascular accident, rheumatic arthritis, postprandial distress syndrome, hypermobility, chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), post-exertional malaise, spondyloarthropathy, multiple sclerosis (MS), lichen sclerosus (LS), traumatic brain injury, diabetes, astma, chronic astmatic bronchitis, fibromyalgia, endometriosis, and long-covid.

Procedure

This study used the data collected by the larger study by Sools and Coppers (2021), and the procedure of the larger study is as follows. The participants received a leaflet with information about the study, including a QR-code or address to the Qualtrics questionnaire. First, they were asked to read the information letter in Qualtrics, and if they wanted to partake in the survey, they had to give their active consent (Appendix B). If consent was given, participants were asked to write a story about their past to present experience being diagnosed and living with a chronic illness (Appendix C). Afterwards, they were given an introduction on and questions to answer in their ‘Letter from the Future’ (Appendix D). They were then asked to fill out the Dutch version of the Mental Health Continuum Short-Form (MHC-SF) and to answer several demographic questions (e.g., gender, age, education, employment, living situation), and questions about their chronic illness. The survey took participants on average 45 minutes to complete. The participants were able to contact the researchers via email or phone in case they needed help or had any questions regarding technical difficulties or information about the research while completing the survey. Besides, they were given the option to withdraw from the study at any time without consequences or the need to provide a reason for their withdrawal. At the end of the survey, participants were asked whether they wanted to take part in the second phase of the study, consisting of in-depth interviews about their survey responses. There was no reimbursement or compensation of participants for their participation in the research. However, as some participants expressed in their narratives, knowing they are contributing to research in this field, might feel like a way to help raise awareness and inform professionals about their personal experiences.

Materials

The current study is only using the qualitative data collected in the original study by Sools and Coppers (2021), namely (1) the past and present illness narratives and (2) the 'Letters from the Future'.

Illness narratives and 'Letters from the Future'

With the illness narrative (Appendix C), participants were asked to write about their experience being diagnosed and living with a chronic illness, including as much detail and elaboration on their feelings as they liked. The story had to be about their own personal experience, but participants had the freedom to decide which areas of their lives they wanted to share information about, namely their personal or social life, living situation, occupation or how they view themselves.

The Letters from the Future exercise was originally used as a creative writing exercise in health promotion for older people with mild depressive symptoms (Bohlmeijer, 2007), but has been adapted by Sools (2020) for research purposes. The participants were instructed to imagine they were travelling forward in time and writing a letter back to the present (Appendix D). They could freely decide the addressee of their letter (e.g., themselves, a loved one, a person of authority etc.) and the exact time in the future they wanted to write from. Besides, they were encouraged to imagine their desired future as if it had already been realised and include information about various aspects of their lives such as their desired occupation, social contacts, living situation, perception of themselves, and which message their wanted to share with the addressee. In addition to the original exercise, a question was included for the specific research by Sools and Copper (2021) asking participants about their chronic illness in the future, i.e., if it still plays a role in their desired future and how.

Data Analysis

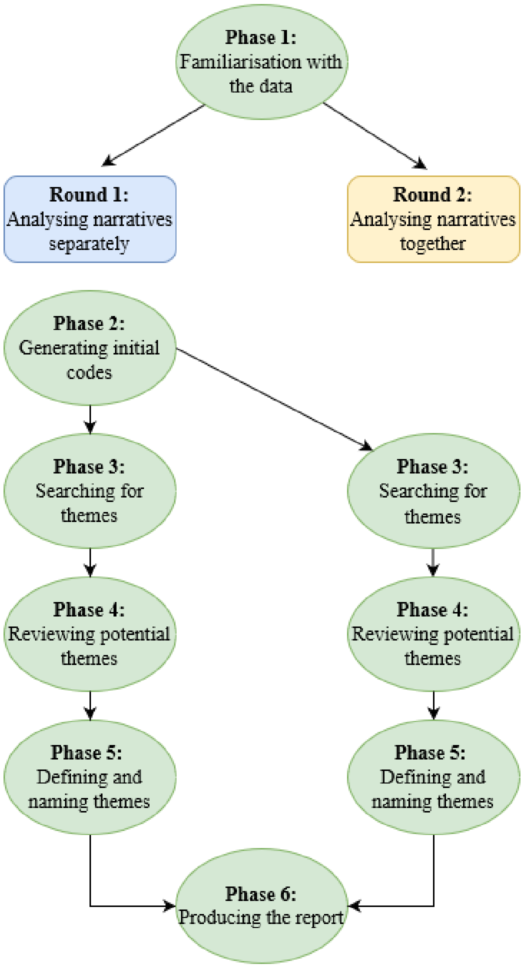
The collected data was analysed with the qualitative research tool Atlas.ti (version 23.0.8), which was used as an organisation tool for coding the data for themes. The data analysis method chosen for the current study is thematic analysis, a method within qualitative data analysis that is used to identify, analyse and report patterns or so-called themes within data. In contrast to other qualitative methods, thematic analysis is not bound to a specific pre-existing theoretical framework or epistemology and can, thus, be used across a range of different theories and epistemological approaches, making it a very flexible approach.

The flexibility of thematic analysis calls for a clear positioning of researchers regarding the theoretical position they base their analysis on (Braun & Clarke, 2006). In this research, an experiential orientation is adopted, as the focus lies on the subjective experiences and feelings of the participants. Not only semantic but also latent coding is used, which means that the participant’s data is interpreted beyond what is explicitly stated. The analysis was done both deductively and inductively. In a deductive manner, the analysis was based on the research on self by Kathy Charmaz (Charmaz, 1983, 1994, 2002, 2006, 2008, 2019; Charmaz & Rosenfeld, 2006). From her work, different selves were inferred and summarised into a new theoretical framework, which were used as initial ideas for codes. In an inductive manner, the data informed the creation of codes for additional relevant selves that were expressed by participants.

For the current research, Braun and Clarke's (2006) six-phase guide for conducting thematic analysis was followed. However, the analysis was performed in two overall rounds, which is an adjustment of Braun and Clarke’s phases. An overview of the analysis process can be seen in figure 1. In the first round, the two types of narratives were coded separately, starting with all illness narratives and continuing with all Letters from the Future. In the second round, each participant's narratives were analysed together. Continuity and discontinuity were investigated regarding the selves expressed by participants and (temporal) patterns were identified. A detailed description of the six phases as proposed by Braun and Clarke (2006) can be found in the paragraphs below.

Figure 1

Overview of the analysis process including two analysis rounds and Braun and Clarke's (2006 six-phases



Before starting the analysis, it needed to be determined which parts of the narratives were considered expressions of self and which were not. As Charmaz’ insights on self in people with chronic illnesses had not been summarised and applied to written narratives before, there were no pre-existing guidelines for the coding process. Thus, it was decided to base the coding on Charmaz' conceptualisation of the self as subjective, actively constructed, social, dynamic and "multiple" (Charmaz, 2011; Van Ward et al., 2017). This was reflected in the coding choices in the following ways: Multiple selves were coded per narrative, the coding was based on participants' subjective experiences and active construction rather than facts, participants' interpersonal experiences (e.g. support, stigmatisation) were considered in the coding, and the selves were seen as changing over time rather than static. Further, not only explicit self-statements such as "I am an optimistic person" were used to derive codes, but also more implicit expressions of self such as the participant's thoughts, feelings, and behaviours.

During the first phase "familiarization with the data", all 196 past and desired future narratives of the 98 participants of the larger study were read, starting with the illness narratives followed by the Letters from the Future. The initial codes were not tried to be identified in the narratives and no notes were taken yet, to ensure an unbiased first view of the data. Next, all narratives were read again and 68 narratives by 34 participants were selected for further analysis. The narratives were chosen based on their length, meaning that longer narratives were preferred, as well as based on how extensively participants talked about their selves, meaning that narratives which included frequent and extensive expressions of self were preferred. During this second round of reading, notes were taken about the emotions experienced while reading through participants' stories.

After the first phase of Braun and Clarke (2006), the analysis was split into two rounds. For the first analysis round, the phases were followed analysing past and desired future narratives separately. The second phase "generating initial codes" started with reading through the selected 68 narratives systematically, beginning the coding process of all the illness narratives followed by coding the Letters from the Future. Deductively, it was tested whether the initial codes could be applied to the data. Excerpts were found, which fit the theoretical framework that was constructed from Charmaz’ work, consisting of the habitual (Charmaz, 2002), disrupted (Charmaz, 1983), stigmatised/marginalised (Charmaz, 2008, 2019; Charmaz & Rosenfeld, 2006), lost (Charmaz, 1983), enduring (Charmaz, 2002), and reconstructed/transformed (Charmaz, 2002, 1994) selves. These selves were chosen as initial codes. However, an inductive approach was also applied by letting the data inspire the coding.

Next to the six initial codes, six additional codes were identified, namely the fighting/resisting, guilty/burdening, supported, supporting, recovering, and healed self. These were codes that seemed of importance but were not captured by the original six selves described by Charmaz.

In the third phase "searching for themes", initial themes were decided on. As explained by Braun and Clarke (2019), there are two ways of identifying initial themes; (1) codes with similar meaning can be combined into one theme with the name being the overarching theme or (2) codes that seem significant can be promoted to a theme. In this phase, several codes were combined to form themes. For instance, the codes recovering self and healed self were combined into one theme that was named recovering self, as these two codes had significant overlap. Further, the codes habitual physical self, habitual psychological self, habitual relational self and habitual occupational self were combined into the theme with the name habitual self.

The goal for the fourth phase "reviewing potential themes" was to further refine the themes. For each narrative, the codes were reviewed again, and it was checked if the quotes were applicable to their corresponding themes. Several theme names were revised, namely changing the stigmatised/marginalised self to stigmatised self, the guilty/burdening self to guilty/failing self, and the supporting/inspiring self to supporting self, as these theme names reflected the quotes belonging to the theme more accurately.

In the fifth phase "defining and naming themes", the themes were named and definitions that clearly described the themes' meanings were written down. Besides, potential sub-themes within the eleven main themes were explored. Sub-themes were identified for three of the main themes, namely the reconstructed/transformed, stigmatised, and supported self (see table 1 in results section). A thematic map was used to visualise and track the thought processes throughout step four and five (Appendix E). In this map it was also visualised which selves appeared to be contrasting to each other, for instance the stigmatised and supported selves.

After phase five, the second round of analysis started. In this round, the narratives were analysed together, always looking at both narratives of one participant to identify patterns over time. For this, phases three to five of Braun and Clarke (2006) were performed again. Phase two was skipped because the selves expressed by participants, had already been coded in phase two of the first round and were used in the second round again. For phase three "searching for themes", the narratives were explored based on whether the story told by the participant was continuous, meaning that the selves expressed stayed relatively the same over time, or discontinuous, meaning that the selves were changing throughout or between the narratives. Discontinuity and continuity were, thus, identified as themes, whereas the selves expressed by participants were the codes. In phase four "reviewing themes", the themes were reviewed again with the same criteria as in the previous round and in phase five "defining and naming themes" the theme of discontinuity was divided into sub-themes; Change of selves between past and desired future narrative and change of selves starting in past illness narratives.

The sixth and final phase "producing the report" brought together the two analysis rounds in the results section, which is separated into two sub-questions addressing each analysis round's findings. In this phase, the results were written up with the goal of creating a "concise, coherent, logical, non-repetitive and interesting account of the story the data tell" (Braun and Clarke, 2006, p.93).

During the analysis, challenges arose that had to be dealt with. For instance, in the second phase of the first round, it became apparent that several quotes seemed to entail multiple different codes, making it difficult to decide on the best fitted code for each excerpt. This showed that certain selves, for instance the enduring and fighting/resisting selves, had an overlap in meaning or were closely related. This was dealt with by first assigning multiple potential selves to the quotes. In the following third phase, it was then decided whether the codes belonged to one theme or separate themes. Regarding the enduring and fighting/resisting selves, it became apparent that they did not share the same meaning but belonged to separate themes. In phase five when the themes were named and defined, it was decided which theme each quote best fit into by comparing the content of the quote with the theme definitions.

Results

Sub-question 1: Types of selves identified in illness narratives and Letters from the Future

An overview of all themes and sub-themes with their meanings in past illness narratives and desired future narratives can be found in table 1. In total, 11 themes were identified from the illness narratives and the Letters from the Future, which represent the different types of selves expressed by the participants. They included the six selves inferred from Charmaz' research (i.e., the habitual, disrupted, lost, stigmatised, reconstructed/transformed, and enduring self) as well as five additional selves (i.e., the fighting/resisting, guilty/failing, supported, supporting, and recovering self), which were identified during the thematic analysis of the data. The selves of participants were expressed not only explicitly (e.g., in self-statements such as "I am a social person"), but mainly implicitly, through statements about their thoughts, feelings, and actions that their selves are interwoven in.

In general, almost 7 times more excerpts expressing self were found in the illness narratives (N=421) compared to the Letters from the Future (N=63). This may be a function of the number of words of the writing exercises themselves; Generally, the illness narratives were much more detailed and had on average more than twice the word count (M= 718.79; SD = 341.84) as the Letters from the Future (M= 306.76; SD= 248.35). The length of the narratives could be related to the instructions participants received for the writing exercise; they were supposed to write a maximum of one A4 page for the illness narrative and a minimum of half a A4 page for the Letter from the Future. Further, all 11 themes could be found in the illness narratives, whereas only seven were found in the Letters from the Future, namely the enduring, reconstructed/transformed, recovering, fighting/resisting, guilty/failing, supported, and supporting selves. Sub-themes were identified for three of the themes. The four themes that could solely be found in the illness narratives were the habitual, disrupted, lost, stigmatised, and fighting/resisting selves. The themes had partially the same and partially different meanings in past and desired future narratives, as I will elaborate on later on.

Table 1

Overview of themes and sub-themes of self in past and desired future narratives with descriptions and frequencies

Theme of self	Sub-themes	Description/meaning		Frequency	
		In Illness narrative	In Letter from the Future	Past	Future
Habitual*		Habitual ways of thinking, feeling and acting towards others, themselves and the world as a whole	/	49	/

Disrupted*		Experiences of disruptions related to different parts of their self	/	120	/
Lost*		Experiences of loss of self, including grief, hopelessness or letting go of dreams	/	20	/
Stigmatised*	Invalidated, invisible, lonely, misadvised, misunderstood	Feelings of stigmatisation in one or different forms	/	56	/
Enduring*		Stable self that endures through the course of illness	Desired stable self that endures through the course of illness	20	6
Reconstructed/transformed	Reconstructions of habits, reconstructions of thinking	Different reconstructions/ transformations of self they experienced	Different desired reconstructions/ transformations of self	52	15
Recovering		Self that is partially recovered	Wishes predominantly about a fully recovered self	7	9
Resisting/fighting		Self that resists/fights	Self that used to resist and fight their	27	1

		against their illness, including denial, negative emotions and disregard for own boundaries	illness		
Guilty/failing		Self that feels guilty towards others and like they are failing in different roles (e.g. parent)	Self that used to feel guilty and like a failure	12	1
Supported	By professionals, by loved ones, by fellow sufferers, by people with power and authority	Feelings of support by loved ones, professionals and fellow sufferers	Feelings of support by people with power and authority	43	18
Supporting		Self that supports others in different ways	Self that wishes to support and inspire others	17	14

Note. Themes marked with an * are the selves inferred from Charmaz' work.

Illness narrative-specific selves

Participants talked about how their life had been prior to the diagnosis with a chronic illness until now. They expressed *habitual selves*, i.e. their habitual ways of thinking, feeling and acting towards themselves, others and the world through their narratives. These related to different aspects of their lives, for instance their relational habits. It stood out that different participants were emphasising different habits as important to them, describing them as integral parts of their self. Some participants talked more in depth about their occupation or hobbies and which habits they had established in these areas of life, whereas others emphasised how integral to their self their relational habits, such as seeing friends and family and going out frequently, had been prior to their diagnosis.

To illustrate, Participant 13 (female, 27 years old, Ehlers-Danlos syndromes, past) highlighted her occupation and the associated occupational habits: *"I played professional table tennis 6 times a week. Table tennis was my life, I prioritized it over everything including my social life, maybe I would have time for that [social life] later on.”.* In this quote, she expresses how important her profession as a table tennis player was to her, she even states it was her life. She seemed to be used to spending a significant amount of time for it and prioritising it above other aspects of her life.

Further, participants described how they experienced disruptions of their habitual selves, leading to *disrupted selves*. These disruptions took place in different areas of their lives, for instance in their occupation. Several participants felt that they lost crucial parts of or even their whole self due to their experienced disruptions, resulting in *lost selves*. This often came with a variety of feelings and processes; grief and mourning for their perceived losses, having to let go of one’s old self and the dreams they had, and accepting their feelings of frustration and helplessness, uncertainty about whether they could get back to their old self, and even hopelessness in some cases. Participant 97 (female, 39 years old, long covid, past) describes this in the following excerpt:

> *I can't imagine that I will be able to fully resume my work, that I will be as strong physically as I was before I took the Covid. I've actually kind of given up on that hope. I don't want to think about it too much because then I get discouraged and very sad. And I*

> *don't know how to continue. I still have the feeling that I have to let go of my "old" life before the Covid and that feels like I am constantly in mourning for the loss of my job, the fulfillment of my life, etc.*

In this quote, the participant describes feeling hopeless about getting back into work and uncertain about how to progress with her life. She expresses feeling the need to let go of different parts of her self, such as her job and physical strength; it seems she perceives these parts as lost or unlikely to be gained back. This leads her to feel that she is in a grieving process of the life she used to have, which she does not think she is able to get back, signifying a perceived loss of parts of her self.

Due to their chronic illnesses, participants frequently felt that they were stigmatised by others, including their loved ones, healthcare professionals, employers, and other social contacts. This elicited different feelings in them, namely feeling invalidated, invisible, lonely, misadvised and misunderstood, which were chosen as sub-themes. Participants expressed in their narratives that feeling stigmatised by others had a great impact on them; many experienced unpleasant emotions, such as loneliness, as a result. Several participants started to see themselves as they thought those around them do, which led them to self-stigmatise, such as in the case of participant 38 (female, 24 years old, rheumatic arthritis and hypermobility, past). She expressed feeling invalidated and judged by healthcare professionals who were not able to find any medical causes of her complaints, which led them to thinking that their patient was not physically ill but ill on a psychological level:

> *(...) someone turned the whole thing around. Is it physical? Maybe we should look at the psychological level. It can be a form of attention seeking in a negative way. As soon as I*

> *heard the above sentence, I felt like I lost my mind. Am I really sick? The pain I feel is there, isn't it? Or am I assuming? It's not between my ears, is it? Or is it? Could my mind have invented this consciousness? Am I crazy?*

This quote illustrates the impact of other people's opinions on one's self. In this case, the participant was led to question her own judgement and sanity, seemingly shaken in her self. It seems like she was not certain whether she could trust her own experiences anymore, possibly leading to self-stigma and believing she is "crazy", as she phrased it.

Several participants reported feeling “invisible”, as for many their condition cannot be seen from the outside, leading people around them to assume they are healthy and well. This leads people with chronic illnesses to feel like they need to hide their condition, making them limited in their authentic expression of self, perhaps even trying to change their self for others, except their close relationships: *"(...) only with people, who are very close to me, do I allow them into my life and do I let them know, what and how is going on with me."* (participant 27, female, 51 years old, traumatic brain injury, past). This feeling of invisibility can lead to difficulties such as misunderstandings and invalidations, as participant 42 (female, 59 years old, endometriosis, past) explains:

> *People don't see anything about me, because the disease is inside. Which also doesn't make it easy. The outside world prefers to 'see' your condition, so that more understanding can be shown by the outside world. After all, what one does not see is not there, right?????*

She expresses that because her chronic illness is not visible from the outside, there is a lack of understanding and validation from others because they assume that something that cannot be seen does not exist.

Selves in illness narratives and Letters from the Future

In contrast to the participants who experienced disruptions to or even losses of their self, there were also participants who were able to *endure* in their self. Participant 121 (female, 45 years old, long covid, past), for instance, described that her self remained stable, emphasising that her chronic illness has not changed how she feels about and sees herself: *"I don't feel like I'm anyone else now, even though I can do far fewer things. My worth is not in the things I do."*. It becomes clear that she does not think her self-worth is dependent on her ability to do things, although she does not make clear how she derives her feeling of self-worth. For individuals like participant 97 (female, 39 years old, long covid, future), the endurance seemed to be related to resilience, a will to keep going and the belief that they can get through the challenges they are faced with:

> *It was hard work and a big fight against your long-covid syndrome. You had to do a lot, and it was immensely hard, especially when a heavy depression entered your head. You went through many therapies, had to endure a lot and often wanted to give up, but you persevered and finally all your fighting was rewarded.*

This quote illustrates how interrelated some of the selves are, as there are expressions of both enduring but also fighting in it. However, as the fighting/resisting self is more linked to negative outcomes, such as a worsening of one's symptoms, as many other participants stated, and this participant talks about rewards and perseverance, this quote was coded as an expression of the enduring self instead.

Inspired by the disruptions participants experienced in several aspects of their lives, they felt the need or even forced to make changes to their current habitual ways of acting but also to their thinking and feeling. They went through *reconstructions* and *transformations* of their selves, as their old habits were not possible to be continued or did not serve them anymore in their recovery and wellbeing, as expressed by participant 94 (female, 55 years old, long covid, future): *"It took quite a while when I realized that speed would not help me. Rest would. Lots and lots of rest. Dear impatient you. You made it. By being grateful for new life and rest."*. In this quote, she expresses how her realisation that she needed more rest and her decision to act accordingly made her succeed in the end. She expresses that this was not an easy change but took time and patience. Other participants talked more about wanting to be more accepting of their chronic illness, as they did not think recovery would happen for them:

> *The chance that your disease will remain stable is nil, but that does not matter. This is just part of you. A part that is completely accepted. We have no need to grow healthy and very old. We have the desire to live a happy life with not too many inconveniences for as long as that may last. I'm proud of you.* (participant 38, female, 24 years old, rheumatic arthritis and hypermobility, future).

This participant shows acceptance and self-compassion despite predicting that her physical state will not improve. It seems that this participant wishes to change her outlook on life or perhaps already did, hoping for happiness in the moment more than recovery or a long life, as she expresses in the quote.

Participants frequently talked about the topic of recovery, either in regards to if and in which aspects they already experienced (partial) recovery or in regards to their specific wishes for recovery, for example things they dreamt about being able to do again such as visiting family. In the illness narratives, there were participants that did not see great or even any progress in their health yet, but there were also some that did experience a *recovering self*. This was not a fully, but partially recovered self, which made them feel grateful for how far they had come and hopeful for potential future progress, giving them a feeling of having (part of) their ‘normal’ self back, thus, impacting their self. Thus, the recovering self does not solely imply a physical recovery but also a recovering of parts of their 'old' self, which had been believed by participants to be lost, but was now recovered. A good example of this is the following excerpt: "*Now, six months later, I feel like living again, but I still can't do everything, but I'm super grateful for what I can do."* (participant 114, female, 41 years old, long covid, past). In the Letters from the Future, most participants were talking about experiencing full recovery in the future, for example participant 97 (female, 39 years old, long covid, future) who wrote the following: *"The therapies had a good effect and to the amazement of everyone and especially of yourself you recovered completely."*.

Several participants described in their illness narratives that they were trying to *fight against or resist* their diagnosis and the accompanying symptoms and disruptions. They described that this fighting and resisting was often related to a desire to stay as they were and continue their habits and life as before. Realising that this might not be possible often went hand in hand with disbelief, denial, and intense negative emotions. Participant 104 (female, 48 years old, long covid, past), for instance, went over her own limits in hope to get back to her ‘normal’ self, as she expressed in her illness narrative: *"I tried, because I wanted to and ignored all my* *physical, mental and emotional alarm bells. I wanted so badly to be a participant in life again".* Other participants seemed to be in disbelief about their diagnosis, not wanting to accept it and therefore denying it, which led to emotional reactions like frustration or anger: *"Get me tested for rheumatism???" I almost yelled at the doctor. That's only for old people."* (participant 38, female, 24 years old, rheumatic arthritis and hypermobility, past). In this case, the participant's reaction also seems to be influenced by stereotypes and prejudices about the illness, in this case that rheumatism is an illness that older people get, leading the participant to a misconception that she is protected from it through her young age. Thus, in her case the resisting and fighting seemed to be a result of self-stigma that originated from the stigma of healthcare professionals.

Participants reported being limited in various aspects of their lives, for example work, relationships and daily activities, which resulted in a need of extra support, less resources for parenting, cutting down work hours or even drop out of the workforce completely, and many more adjustments. As they described, this led a lot of participants to experience *guilt*, as they felt like a burden to those around them or like they were *failing* in their role as a parent, husband or wife, employee or friend. This can stand in contrast to what other people think about them.

> *A sense of failure and a feeling of guilt are coming up more and more often. Failure in my recovery process, failure as a wife/mother/daughter/sister/friend. No one thinks I'm failing, but that's how I feel about it myself. I know intellectually that I am not, but my feelings say otherwise. Same with my guilt.* (participant 105, female, 48 years old, long covid, past).

This participant expresses how she feels like she is failing in multiple different roles in her life. Although she recognises that others do not think of her in this way and that her thoughts might not be rational, the feeling of failing and guilt stay, as she seems to judge herself.

Motivated by these feelings of guilt and failure, participants reported trying to compensate by hiding their true emotions or minimizing their difficulties, as participant 9 (female, 54 years old, migraine, past) shared: *"I also overcompensate a lot. Put my smile and kindness on the forefront to make up for it. Make up for something I can't do anything about".* As illustrated by these two quotes, it stands out is that often the participants seemed to be aware that their thoughts, feelings and behaviours were not helpful and that there was nobody expecting them to 'make up' for anything, but they still felt that way.

Despite the many negative feelings, several participants talked about the positive experiences that came with their diagnosis, specifically the support they received. Many expressed feeling a deep gratitude for the *support* by those around them, including professionals, loved ones, and "fellow sufferers", as they called them. Regarding their experiences with healthcare professionals, some participants described feeling validated and noticing growing knowledge and recognition of their chronic illness. This led them to feeling validated and less alone, as illustrated by participant 108's (female, 25 years old, long covid, past) experience:

> *I have met all of these professionals who take my symptoms seriously and seem to understand what I am going through. As the months go by I notice that there is more and more knowledge about Long Covid and I really like that. It turns out I am not the only one with these symptoms and I am not "going crazy".*

In this quote, the participant expresses receiving support in different ways, including by professionals who have the necessary knowledge about long-covid, as well as increasing general knowledge and awareness in society. This seems to support her in knowing that her symptoms are indeed present and not something she is imagining, as there are other people who go through similar experiences has her.

Being in contact with other people with a chronic illness seems to be another support for participants. They talked about attending self-help groups or rehabilitations programs, but also online support in forums or Facebook groups was mentioned. With them they feel especially understood and less alone, and they can share their stories without fear of being judged or misunderstood, as participants stated. This can help them feeling validated and seen in their experience, as participant 39 (female, 29 years old, persistent perceptual postural dizziness, past) describes: *"Here I found recognition from the practitioners and recognition from the other patients in my group."*.

Desired support by people with power and authority such as politicians, was something that the participants talked about predominantly in their Letters from the Future. Participants also stated that there had not been enough support and consideration for them in the past by people in leading positions and society, which is probably why some of them addressed their letters to ministers of Health such as Hugo de Jonge or Ernst Kuipers:

> *Dear Minister Hugo de Jonge, I am so proud of you that you have listened to a delegation of people who have to live with unexplained complaints, such as fibromyalgia and CFS/ME [chronic fatigue syndrome/myalgic encephalomyelitis], etc. Thanks to your efforts you have been able to realize that everyone in the Netherlands now has a basic*

> *income. Because of this you have lifted the (financial) sword of Damocles from above the heads of so many people.* (participant 28, female, 56 years old, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis, future).

In this excerpt the participant expresses her gratitude towards the minister for establishing a basic income for people with chronic illnesses and, thus, helping them with their financial difficulties, which seems to be one of the worries most prominent for her.

Next to receiving support from others, participants also talked about wanting to or already helping others, expressing their *supporting self*. This included different ways, in which they were trying to help or inspire those around them, especially other people with chronic illnesses. They did this in multiple ways, such as by supporting organisations:

> *I had only heard of [organisation for patients suffering from acquired brain injury and their support network] since last October, when I signed up for a course. I thought it would be a great idea to donate to this patient association, so they can give more courses and get more exposure. To give information, which I and my family missed terribly immediately after the CVA.* (participant 20, female, 65 years old, cerebrovascular accident, past).

This participant talks about signing up for a course by an organisation that supports people with acquired brain injury and donating, as she wanted to support them financially to raise awareness and share knowledge on this illness. This seemed to be motivated by her own experiences of lacking helpful information when she and her close ones would have benefited from it.

What stood out in the Letters from the Future was that some participants expressed an inspiring self in terms of an uplifting and hopeful message to the addressee of their letter or stated what they wished from their behaviour. To illustrate, one letter was addressed to coming generation, stating the participant's wish for them: *"My message for the next generation is: have more understanding for people with a condition. The medical world does not stand still. Help fight pppd [Persistent perceptual postural dizziness] together."* (participant 39, female, 29 years old, persistent perceptual postural dizziness, future).

Sub-question 2: Patterns in selves throughout the narratives

To answer the second sub-question, the patterns of self throughout the narratives were explored. An overview of the findings can be found in table 2. The narratives were analysed together, looking at both narratives of one participant. It was investigated if and how participants express their self differently throughout the narratives, i.e. whether the story participants told was mainly characterised by continuity, meaning that the selves expressed stayed relatively the same over time, or discontinuity, meaning that the selves were changing throughout or between the narratives.

Table 2

Patterns regarding continuity and discontinuity in past and desired future narratives with descriptions

Pattern	Description	Selves in past narratives	Selves in desired future narratives
Continuity (n=3)			

Positive self (n=2)	Participant expresses positive selves throughout both narratives	Habitual, enduring, reconstructed/transformed, supported, supporting, recovering	Enduring, reconstructed/transformed, supported, supporting, recovering
Negative self (n=1)	Participant expresses negative selves throughout both narratives	Habitual, disrupted, lost	Disrupted, lost
Discontinuity (n=31)			
Between narratives (n=7)	Participant expresses negative selves in the illness narrative, followed by more positive selves in the desired future narrative	Habitual, disrupted, lost, resisting/fighting, guilty/failing, stigmatised	Reconstructed/transformed, supported, recovering, supporting
Starting in illness narrative (n=24)	Participant expresses negative selves in the illness narrative, followed by positive selves starting in the illness narrative and continuing in	Habitual, disrupted, lost, guilty/failing, resisting/fighting, stigmatised Reconstructed/transformed, enduring, supporting	Recovering, enduring, supported, supporting, reconstructed/transformed, guilty/failing, resisting/fighting

	the desired future narrative

Continuity

Only few of the participants narrated their past and desired future narratives in a continuous way (N=3), creating either a positive and hopeful story throughout the narratives (N=2; enduring self, reconstructed self, supported self, supporting self, recovering self) or one characterised by hopelessness (N=1; disrupted self, lost self, uncertainty). Some participants expressed a rather enduring self in both narratives, meaning that their self remained relatively stable instead of getting disrupted or lost. They described different things that helped them endure in their self; they talked about persevering throughout difficulties even if it was challenging not to give up, staying optimistic about the future and being grateful for every small step in their recovery even if they might wish to recover more or faster.

They also emphasised the transformations in their thinking and things they had learnt throughout the course of their illness, such as respecting their own limits and being able to experience their life as beautiful despite certain restrictions. These stories were also highlighting the topic of support. On one hand, the participants talked about feeling supported by their environment, including loved ones and professionals. On the other hand, they expressed a wish to support or inspire others by sharing their own story and listening to those of others. Overall, their stories were characterised by endurance, happiness and hope in both past and desired future narrative.

This is illustrated by the narratives of participant 11 (female, 54 years old, Hodgkin lymphoma), who seems to use her chronic illness as an inspiration to see the good things in life and use this as an inspiration to inspire others. When she talks about her life in her illness narrative, she mentions solely positive things she experienced:

> *My husband and I have remained childless but have been able to take many wonderful trips because of this and lead a nice life together with dear family, friends and neighbors. I am positive in life partly because of these experiences, I can greatly enjoy what is.*

She seems to see things that could be interpreted as something negative, for instance not having children, in positive ways, seeing the benefits it gave her, such as traveling.

In her illness narrative, she also talks about the support she receives and her wish to inspire and support others:

> *I experience much love and friendship in my life. Especially in the past year. Because I am now thinking again about my future plans in terms of work, I got the idea to share my story. Maybe it can inspire others to take control of their lives, never give up, to want.... possibilities. Possibly it can inspire students to become good at what you do, you can save lives or help people find their lives again.*

Despite an amputated arm and shoulder, she describes her life as *"miraculously beautiful"*. She expresses gratitude for the things that are possible thanks to physiotherapy stating that she can *"live very independently and enjoy a walk, going out, vacations, although a little adapted, but wonderful. Also at home I can pick up things like cooking, washing, which is* *also very pleasant."* Overall, in her illness narrative, she expresses feeling "*powerful and strong*" and wishing to share her happiness with others.

Participant 11's Letter from the Future has the same themes of hope, feeling supported and wishing to support others. Addressing her letter to people who are facing challenges in life, she gives them a positive message:

> *There may be difficulties on your path but you can overcome them and then it will make you stronger. I see me having faith in life, overcoming my fears, taking leaps and discovering new routes. These routes are endless and along the way there is always help. So much love and friendship that make you silent. In the silence there are answers. This is how I find my next destination.*

In her letter she talks about hope, resilience and finding new routes to continue on, while also expressing that others can overcome their difficulties as well. She encourages the reader to see the endless possibilities and ask for help. Her wish for others reading her letter she describes in the following: *"Everyone visible, taking each other into account, looking out for each other.......... That is the good news, that is the change I wish for everyone."* She, again, expresses her wish to be a support for others: *"Because I get inspired, maybe I can inspire others. We can learn from each other and get connected."*.

However, one participant's story had continuous themes of loss and uncertainty, creating a rather hopeless story. In his illness narrative, participant 102 (male, 55 years old, long covid) described all the disruptions in his life affecting his work, family and personal life. He also talked about feeling like he is nothing more than a patient, and like his life has been ruined and doubting recovery in the future:

> *Personally: I see no progress in the recovery, and I think that it goes towards the wia [Wet werk en inkomen naar arbeidsvermogen], whether I can ever (normally) work again I do not know. Let alone, my normal life again pick up, this is not there anymore. I have now become a 'Long Covid' patient and can tell you that this virus has ruined my entire life. I can do little or nothing because I have insufficient energy, insufficient concentration and I am easily over-stimulated. (...) There is little left of my life before the COVID infection. The amount of symptoms I experience on a daily basis hinders me in my family life, my working life and has a great impact on my mental state.*

Talking about his life, he mentions solely negative experiences he has had due to his chronic illness. He expresses that he is feeling hopeless about being able to recover and work again and that he thinks there is not much left of him other than being a patient.

In his Letter from the Future he expressed similar concerns, stating that the course of his illness would be uncertain and that his symptoms would most likely remain. He seems to have a negative view of his future, expressing all the things that are not possible and uncertain:

> *You can no longer depend on your other family members. You will be dependent on this droid to heal you and you cannot claim a refund or any form that things are not going well. In short, we do not know if you can be cured of a virus and what you will be left with. It may be that you will continue to suffer much or little in daily life, work is*

> *uncertain, and your mobility is not allowed because of your constant problems with nerves, concentration and cognitive symptoms.*

He talks about not being able to depend on his family anymore but being dependent on a robot and not being free in his mobility. He seems to critical and uncertain of his ability to recover and he seems to see himself as likely to "suffer" more in the future.

Discontinuity

Most participants narrated their stories in a discontinuous way with changes from generally negative (disrupted, lost, resisting/fighting, failing, and stigmatised selves) to more positive experiences of self (reconstructed, supported, recovering, and supporting selves) (N=31). The discontinuous narratives were of two main kinds; one kind showed discontinuity between past and desired future narrative (N=7), whereas the other showed discontinuity already starting within the illness narrative and continuing in the future one (N=24). The former seems to express that positive changes of selves have not occurred yet but are hoped to happen in the future, whereas the latter shows changes to a more positive self that have already started happening.

Change between illness narrative and Letter from the Future

There were a few narratives that showed discontinuity when comparing past and desired future narratives (N=7). These all contained mainly negative descriptions of self in the illness narratives (disrupted, lost, fighting/resisting, guilty/burdening, and stigmatised self) and more positive ones in the desired future narratives (reconstructed, supported, recovering, and supporting self). An example of this is participant 28 (female, 56 years old, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis, past), whose quotes will be used in the following paragraphs as an illustration of this pattern.

In their illness narratives, participants mentioned disruptions of self in their occupation, physical health, social life, or ability to plan their daily lives. There were also many who experienced a loss of self, which sometimes happened relatively unexpectedly and suddenly. They talked about nothing being possible anymore and not having a perspective of things changing in the future, creating a rather hopeless perception of their circumstances, as expressed by participant 28 in the following excerpt:

> *And it's frustrating and sad that you can't do what you think you should be able to at 56! I've lost myself! It's hard to say what I want because now I'm more afraid that it won't be possible again.*

Dreams participants had seemed to be lost, something also mentioned by participant 28, their social life was non-existent or at a minimum, and they saw themselves as only a shadow of who they once were. Often, the participants reported fighting and resisting against their chronic illness and the according changes, expressing that they could not accept their illness or even were in denial about it.

Participants reported feeling as if they were failing in life; they felt guilt towards their families and partners and saw themselves as a burden for those around them, such as participant 28 as she describes: "*It also affects my family! Especially my husband, who fell in love with a cheerful woman who could do everything... well she is no longer there that way... and then my sons... they both received complaints from me.*". According to her, her children seem to have inherited some of her condition's symptoms. Many participants talked about the stigma they were experiencing, feeling excluded and lonely, misunderstood by or invisible to the healthy people around them, as expressed in this quote:

> *When you are in a wheelchair or have an arm or leg in a cast, people see something about you. As soon as that is not there, people quickly find that it is between your ears and you should continue, then it will pass.* (participant 28, female, 56 years old, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis, past).

For her, all these things resulted in her feeling as if she had to "*fight against the evil outside world.*".

In contrast, these participant's desired future narratives consisted of different wishes for a better future. Many participants expressed the desire for a transformed thinking that would help them cope with their illness in a more productive way. In these ideal futures, they talked about being able to accept their limitations and experiencing gratitude for the things that are still possible. They also expressed feeling at peace with the uncertainty that their illness comes with. They wished to be kinder to themselves, take their own energy level more into account and let go of feelings of guilt about not meeting other's and their own expectations. In the case of participant 28, it seems that she has gained an understanding of her own occupational limits and tries to follow these: "*I now work the 12 hours that are the maximum for me with an employer.*".

Regarding the support from those around them, the most prevalent wishes were the one for a society that is more aware and considerate of people with chronic illnesses, improved working conditions and understanding from their employers, doctors being more knowledgeable about chronic illnesses, and people with power, such as politicians, who take their struggles into account and create regulations that support them. The latter is illustrated by participant 28's letter to the future, which she addressed to a Dutch minister:

> *So thank you Minister Hugo de Jonge that through your intervention in the financial system I can make myself useful again for myself, my family and for others, without my financial situation having become so bad that I would have ended up in debt relief myself.*

Further, the theme of recovery, i.e. experiencing decreased or no symptoms of their illness, played a big role in many participants' desired future narratives, as most of them seemed to wish to feel better physically and be less restricted by their condition. They expressed that in an ideal future, they would be able to work again, make plans without having to cancel them, get a degree despite their illness, or generally experience fewer or less severe symptoms and needing less check-ups. Lastly, participants expressed an inspiring self in their desired future narratives, often in the form of positive messages they were giving to the addressee of the letter, namely their past self or other people with chronic illnesses. These messages encouraged the reader to be kind to themselves and others and be perseverant through difficult times, wishing them all the best. In the case of participant 28, her supportive self was expressed in this excerpt: "*Besides that, when things are going well, I can offer a listening ear as a coach for people who need it.*".

Change starting in illness narrative and continuing in Letter from the Future

Most participants told their stories in a discontinuous way, with the changes in selves already starting in the illness narratives and further progressing in the desired future narratives (N=24). For some, it seemed as if the changes in self were already relatively big throughout their illness narrative, whereas for others they were smaller, followed by more significant changes in the desired future narrative. To illustrate, some participants showing relatively big changes in the illness narratives talked about for instance feeling like they were almost back to “normal”, were working again or had changed their thinking about their illness entirely and had accepted it as part of themselves. Participants who showed smaller changes in the illness narratives expressed for instance that they were still far from being back to “normal”, were not able to work again or only very few hours, or were trying to accept their illness more, but still experienced a lot of inner resistance and fighting against it. In general, the developments expressed by participants entailed changes from more negatively evaluated selves (disrupted, lost, resisting/fighting, guilty/failing, stigmatised selves) to more positively evaluated selves in the later parts of the illness narratives and all throughout the desired future narratives (reconstructed, enduring, supported, supporting, recovering selves).

The changes in selves seemed to have different reasons of origin. For many participants, they stemmed from support of healthcare professionals, including psychotherapists, occupational therapists, physiotherapists, doctors, and internists, and their specific advice, medication prescribed, or programs attended. To illustrate, participant 104 (female, 48 years old, long covid), who expressed different types of negatively evaluated selves in her illness narrative, including the disrupted, guilty/failing, fighting/resisting, and stigmatised self, experienced a great shift in self after getting in touch with an occupational therapist:

> *And from that moment on things are different. From that moment on, I am no longer sitting next to Covid in the passenger seat driving around recklessly, but I am behind the wheel myself and the speed goes down, way down. Because by means of a points system with which I weigh and scale all my activities, I slowly gain insight into my energy possibilities and limitations.*

Participant 104 started transforming in both her habits and thinking, and slowly started to see improvements in her health through this. In her Letter from the Future, she reflects back on her difficult journey, expressing how she was able to endure and comfort herself in times of doubt:

> *Do you remember all those moments when you thought; I won't get there, I'll never succeed. Do you remember me telling you: hang in there, you are doing well. Your wishes will come true, really, trust the process. At those moments that you were so broken up, that you didn't see life for what it was, I carried you with me. I comforted you and held you.*

She talks about experiencing many moments in which she was hopeless about getting better but encouraging and motivating herself to trust and keep on going and comforting herself, seemingly practicing self-compassion. This ultimately, she expresses in her desired future narrative, led to her dreams coming true, which included finding love, transformations of thinking and recovery:

> *You learned to love yourself again and how heavy it was, not to do at times. But it was necessary, the difficult process has helped you to get where you want to be. You regained confidence, things got lighter and lighter and the new love relationship you longed for has come, as has your full recovery. Everything you wanted is there. You deserve it too. Now enjoy and relax.*

She emphasises that she learnt to love herself and gained confidence and a new relationship, seeing the difficulties on her journey as necessary for her to get to where she always wanted to be. It appears she really wants to believe in these dreams being realised in the future, writing herself this letter from a better future. The way she expresses herself makes it seem as if she is trying to give herself a positive and hopeful message.

Some participants mentioned the support from their family or even their employer being a driver of change. Besides, it was reported that for some, the changes experienced, especially the reconstructions of habits, were forced through circumstances, as they had no other choice than to adjust their day-to-day life. This is what participant 107 (female, 45 years old, chronic asthmatic bronchitis, ADD and long covid) seemed to experience due to the various restrictions she experienced, including physical and cognitive complaints, problems with food intake and inability to work: *"I had to reinvent myself. Everything that was normal for me now works differently."*.

Others seemed to have experienced developments in self with time, either because they got to know themselves better and had an easier time accepting their illness, or due to recovery and progress in their health. For participant 108 (female, 25 years old, long covid), the change in thinking seemed to have come from the lessons she learnt throughout the course of her illness:

> *Because I don't know what the future holds. What I do know is that I have learned a lot about myself through Long Covid. And that my need for control is not going to help me further in my recovery. I have learned to let go and that is one of the most important lessons of this period of illness. I don't know if I'm ever going to be that energetic nurse again who could always be there for everyone, but that's (literally) worry for later. For now, I enjoy the small steps, the beautiful things and the life lessons I encounter along the way.*

In this quote, she reflects on her realisation that she does not have control over her recovery and her future, which she is learning to accept and, instead, see the good things in life.

Changes from negatively perceived selves to positive contrasts

During the analysis of the discontinuous narratives, clear differences between the expressed selves stood out; The selves perceived as negative by participants and the following positively perceived selves, seemed to be contrary of each other. For instance, participants who were experiencing a stigmatised self in the past, expressed a supported self in the future. Both the stigmatised and supported selves are related the participants interpersonal experiences, but they are strongly contrasting each other. Participant 39 (female, 29 years old, persistent postural perceptual dizziness, past), for instance, reported a lack of understanding from her environment and difficulties in public places:

> *The most difficult thing for me is that both strangers and people you know do not understand and underestimate the condition. Have often heard: oh, I also get dizzy sometimes. Public areas (such as the hospital) are often decorated in a very stimulating way. Think of bright colours, patterns on the floor or wall, stripes or dots. Those places are very difficult for me to visit, because they make me dizzy, nauseous and overstimulated.*

In her desired future narrative, however, she talked about a future that was more considerate of her and her needs in terms of knowledge of professionals but also public places:

> *Fortunately, nowadays there is more understanding for people with a balance disorder. The doctor has more knowledge than before. I can go there with my questions about the treatment.* (…) *Nowadays, all public facilities take into account people who cannot*

> *tolerate many stimuli. I also hear more and more understanding from the environment. This is because more information is being shared about balance disorders.*

She expresses that doctors have more knowledge about her illness and able and open to supporting her. Besides, she talks about public places being more inclusive for people with balance disorders and more general awareness being raised. The support, thus, seems to come from different sources.

Participants who were supported after past disruptions and loss, seemed to have found a drive to support and inspire others in the present and future. Both selves centre around the topic of support, but they seem to have contrary directions, as the supported self entails receiving support and the supporting self entails giving support to others. Participant 36 (female, 25 years old, chronic fatigue syndrome/myalgic encephalomyelitis) reported in her illness narrative that her internist prescribed her an off-label medication that helped with remission of her symptoms: *"I was in both a physical and mental crisis and I would not have come out of it alive if I hadn't ended up with an observant internist after two years."*. This support led to her feeling inspired to research this medication further and find out if it might help others as it did her. She called this having found her "calling". "*For this I network a lot so that my story gets known among researchers. In this way I hope to alleviate the suffering of others, who are still in bed with my suffering."*. In her desired future narrative, she writes having completed her mission: *"The professor I finally got hold of wanted to try it, to test whether my method also works for others."*. She seems to be hoping to give back this support she received to others around her by making professionals aware and helping them spread awareness and information:

> *Soon I will have a presentation at an international conference on ME/CFS [chronic fatigue syndrome/myalgic encephalomyelitis]. I'm going to give a live demonstration*

> *where I have myself attached to the equipment on site so that they can follow the measurements.*

Further, participants who talked about fighting against or resisting their illness in the past, talked about reconstructions of thinking related to accepting themselves. In this context, both selves are highlighting how the participants evaluate their illness, but they express contrasting evaluations; The fighting/resisting self emphasises a rejection of the illness, whereas the reconstructed self shows acceptance of it. In her illness narrative, participant 108 (female, 25 years old, long covid) reported fighting against her chronic illness by going over her physical limits by exercising a lot, which she reported "*seemed to be completely killing my body.*" and this eventually led to her having to use a wheelchair again. In contrast, in her desired future narrative that she addressed to her past self, she expresses accepting and loving herself again despite times of struggle:

> *First of all I want to let you know that you have finally learned to deal with yourself a little better and have learned to love yourself. You definitely have moments when it's mentally tough for a while, but by now you know very well how to deal with it, that you can handle the struggle and that allowing it doesn't make you crazy.*

Instead of resisting accepting her diagnosis by overexercising and making her health deteriorate more, she expresses that she learnt to love herself and cope better. She can now allow the difficulties she experiences, instead of fight against them.

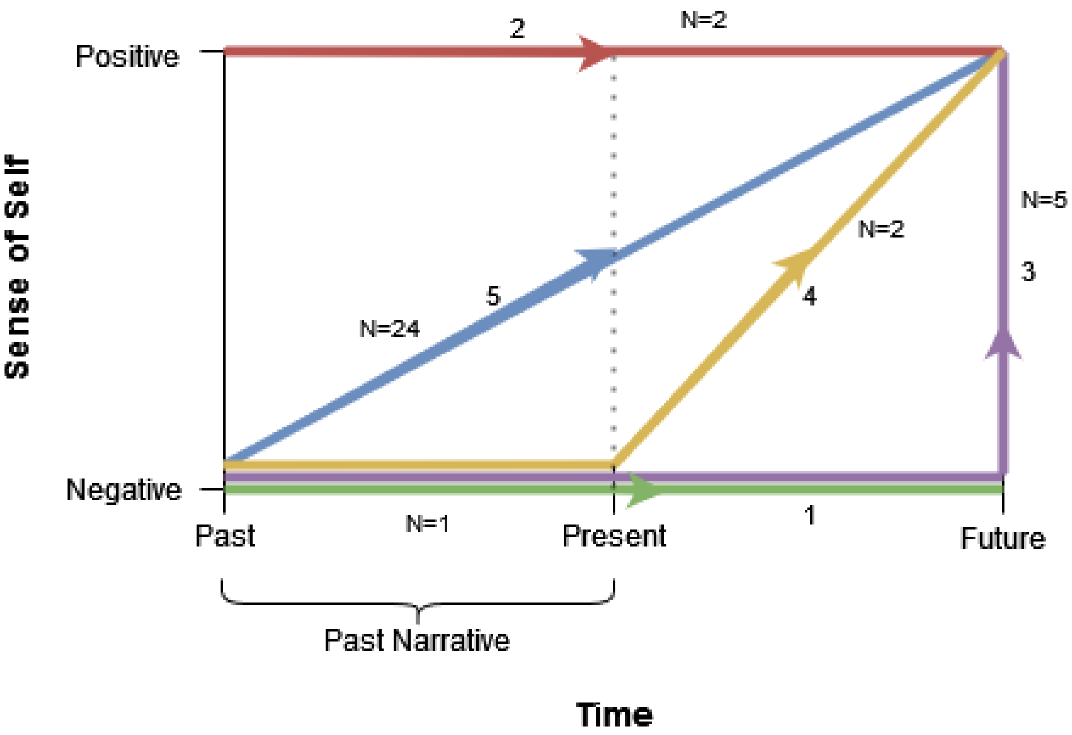
Participant's journeys with their chronic illnesses

Taking all results into account, namely the identified selves and the differences in patterns throughout the narratives, it can be concluded that participants seem to be on different journeys with their chronic illness (see Figure 2). There were two types of continuous journeys narrated by people with chronic illnesses (line 1 and 2). Some participants seemed to express their self rather negatively in both narratives, not showing any hope to reach or capacity to imagine their desired future (line 1, N=1). Others seemed to have endured in their self and feel positive about both their present and future self (line 2, N=2). These participants seem to be stuck in present and past issues and do not seem to be able to imagine a future (line 1) or have already reached their desired futures (line 2), perhaps leading them to talk more about the present moment or evaluate the past.

Besides, three types of discontinuous journeys of people with chronic illnesses were identified (line 3, 4 and 5). There were participants experiencing a change in self when comparing past to desired future narrative, but who gave no insight into the path between past and future, making it seem as if their positive future self will suddenly be there (line 3, N=5). Other participants experienced a change in self when comparing the two narratives, with a negative self in the illness narrative and a positive self in the desired future narrative, who gave insight into their path and how the change came about (line 4, N=2). And lastly, a majority of participants seemed to have experienced a development in self that already started in the past and continued in the future, while also giving insight into how these changes came about and their path (line 5, N=24).

Figure 2

The different journeys participants go through with their illness regarding their expression of self in past, present and future



Discussion

The current study investigated how people with chronic illnesses express their self in narratives of past and future. The basis was a new theoretical framework inferred from Kathy Charmaz research on people with chronic illnesses and self. Two thematic analyses were conducted to answer the two sub-questions exploring (1) the different selves expressed by participants in their illness narratives and Letters from the Future and (2) the (temporal) patterns in selves throughout the narratives.

Summary and interpretation of findings

To answer the first sub-question that dealt with the types of selves expressed by participants, the narratives were analysed separately for the different selves expressed by participants. In total, 11 selves were identified. Overall, all the six selves inferred from previous research by Charmaz were identified in the narratives, supporting her findings. Additionally, five more selves were identified, expanding scientific knowledge about people with chronic illnesses' expressions of self. A majority of the selves were identified in both narratives, whereas others were expressed solely in the illness narratives, namely the habitual, disrupted, lost and stigmatised selves.

Reflecting on how participants perceived or judged the selves they expressed, differences between the two types of narratives became apparent. Several of the selves identified in the illness narratives were perceived by participants as rather negative or undesirable, for instance the disrupted or lost self, which caused them to feel emotions such as grief. Some of these selves were either not expressed by participants in the Letters from the Future or expressed in a retrospective manner, as they were looking back on a self that in their desired future was no longer present. Participants seem to be hoping to have left these selves behind in their desired futures, showing that they evaluated them as negatively affecting them. However, participants also seemed to perceive other selves expressed in their illness narratives as more positive or desirable, for instance the supported self, which came with a lot of gratitude for the people in their lives that were supporting them. In a great majority of the Letters from the Future, participants expressed solely more positively evaluated selves, namely the selves they desired. For instance, they expressed a wish to experience reconstructions of self for instance by changing their ways of thinking about their illness and being able to accept it. As stated above, the selves that came with more personal challenges, such as the fighting/resisting self, were rarely mentioned and expressed as something that they had overcome.

Further, it stood out that several of the selves expressed in both narratives had different meanings depending on the type of narrative they were expressed in, including the recovering, fighting/resisting, guilty/failing, and supported selves. When participants expressed a recovering self in the illness narratives, they were mostly talking about partial recovery that they had experienced, whereas in the Letters from the Future, it became apparent that most participants desired a fully recovered self. This, to them, entailed not being negatively influenced by their chronic illness anymore for example due to limited concentration. Regarding the fighting/resisting and guilty/failing selves, participants were talking about the ways in which they had been or still were fighting against their illness or ways in which they felt guilty or like they were failing. In contrast, in their Letters to the Future, participants expressed these selves in a retrospective manner, emphasising that these are past selves they left behind in their desired future. The supported self expressed by participants in the illness narratives was solely focused on support they were already receiving from their loved ones, healthcare professionals or other people with chronic illnesses. In the Letters from the Future, however, participants emphasised that the support they were desiring was mainly support by people with power and authority, such as politicians. They were expressing the wish for new regulations that support them, for instance financially.

When comparing the work of Charmaz to the current research's findings, it stands out that the addition this research made by including the desired futures of participants did not lead to new selves being identified, as none of the additional selves were solely expressed in the participants' Letters to the Future. Thus, the question arises why new selves were identified in the current research. This could be related to the nature of narrative engagement itself, which is a highly individual process that, according to Martinez (2014), depends on the reader's storyworld possible selves (SPSs). SPSs can be defined as "imagings of the self in storyworlds" (p.119), which consist of two different inputs, namely the mental representation the reader develops for the focal character of the story and the mental representation the reader holds for themselves, also called self-concept. These two inputs can vary greatly between readers, resulting in varying interpretations of narratives (Martinez, 2014). In the context of coding written or audio narratives of people with chronic illnesses, differences in identified themes might originate from differences in the readers' SPSs and their diverging engagement with the narratives.

For the second sub-question regarding patterns of selves throughout the narratives, the selves expressed in the illness narratives and the Letters from the Future of each participant were analysed together. It was investigated whether participants told a continuous or discontinuous story of self throughout the narratives. Different journeys that participants are on regarding their chronic illness could be identified. Two types of journeys were continuous, not showing any change in the selves expressed by participants. Only three narratives were written in a continuous way, meaning that the selves expressed were either solely positive (N=2) or solely negative (N=1) throughout both narratives.

Three types of identified journeys were discontinuous, showing a change of selves. A large majority of participants wrote their narratives in a discontinuous way (N= 31). Some of the stories told by participants were characterised by discontinuity between the two narratives (N=7), with the illness narratives expressing negative selves, and the Letters from the Future expressing positive selves. The stories differed regarding whether they contained a description of the path between past and future, in which participants explain how the changes in selves came about (N=2), or not (N=5). Thus, they were categorised into different discontinuous journeys.

Most of the discontinuous stories, however, showed a change in selves in the illness narrative already, with the change progressing further in the Letters from the future (N=24). What stood out was that the selves expressed often seemed to be strongly contrasting each other. Depending on which negative self the participant expressed in their illness narrative, the positive self they focussed on later in their illness narrative or in their Letter from the future was a contrast to the former self expressed. To illustrate, participants who talked about experiencing a disrupted or lost self in the illness narrative, seemed to desire a reconstructed/transformed self, as expressed in their Letters from the Future. These stories told provided an insight into the path between past and future, constituting the third type of discontinuous journey.

Strengths, limitations and recommendations for future research

The current research provides an in-dept view on how people with chronic illnesses express their current and desired future selves. Work on chronic illnesses and self by the foundational researcher Kathy Charmaz was used to construct a new framework, summarising her insights on self and applying them to written narratives for the first time. Her proposed selves were identified in the narratives of this research's participants, further supporting her findings. Besides, several additional selves were identified, which adds new insights to the scientific knowledge on people with chronic illnesses' experience and expression of selves. By analysing the desired future perspectives in form of the Letters from the Future, a relatively new and previously neglected but important aspect of illness experience was highlighted. This enabled the investigation of patterns in selves over time. Five different journeys people with chronic illnesses can go through were identified with most narratives showing a change from a more negative perception of selves in the past to a more positive one in the desired future. By investigating participant's desired futures, insights into the wishes of people with chronic illnesses for their future selves were gained, which can inform health care professionals and the growing body of future-oriented therapies on how to support people with chronic illnesses best on their journeys to reaching their desired futures.

However, when interpreting this study's findings, several limitations need to be considered. First, the stories told by participants were mostly characterised by changes in selves throughout the narratives, from more negative perceptions of self to positive ones. Almost all narratives showed a growth plot that is centred around "personal growth and fruitful dialogue with the outside world leading to a meaningful whole" (Moenandar, 2017, p.1). This is the dominant way of narrating stories in Western popular culture and has become widely accepted. However, there are other plots to be explored, such as the Picaresque plot, in which the main character does not change, nor strive to find coherence in their story and a place in society. Instead, episodic fragmentation and a hostile relation to one's surroundings are valued (Moenandar, 2017). Thus, the question arises, if most personal narratives follow the growth plot or if this way of interpreting their life story is forced onto people due to its dominance in Western countries. Solely relying on the growth-plot in personal narratives might be rather one-dimensional, suggesting that the only story worthy to be told is one of personal growth. Therefore, future research should investigate different countries and cultures' narratives to explore other plots, such as the Picaresque one.

Second, many participants either did not write a Letter from the Future or kept their text relatively short, especially in comparison to the illness narratives. This might have to do with the instructions for the two narratives; Participants were instructed to write a maximum of one A4 page for their illness narrative and a minimum of half a A4 page for their Letters from the Future. Future research could alter the instructions to achieve longer future letters by suggesting the same length for both exercises. This difficulty was dealt with in the selection process of narratives by excluding the participants with narratives, specifically Letters from the Future, which were only a few sentences long or did not provide any or limited information on participant's selves. However, this came with the cost of excluding a large majority of the male participant's narratives, as the men represented in this research generally wrote shorter texts.

This led to a large majority of the chosen sample being women (97.06%) with only one man (2.94%) represented, resulting in a mostly female perspective on illness experience and self. However, research suggests that there are gender differences in the illness experience of men and women. Especially in social, economic and physical determinants and consequences of illness, there seem to be crucial differences between the genders, for instance women experiencing more marginalisation by society than men (Vlassoff, 2007). Regarding their symptom perception and evaluation, women tend to report more symptoms, more chronic illnesses and poorer perception of physical health than men (Artinian & Duggan 1995; Conn et al., 1991; Sharpe et al., 1991), and in terms of symptom management, they tend to use different coping strategies (O'Neill & Morrow, 2008). Charmaz (1994) proposed that men experience different dilemmas regarding their identity than women, as men generally contracting more life-threatening and severe chronic illnesses than women. These mentioned gender differences suggest that there could also be differences in how chronically ill men and women construct their self, a topic that should be further investigated in future research.

Lastly, before and during the analysis of the narratives, several difficulties regarding the conceptualisation and operationalisation of self were encountered. Regarding its conceptualisation, it was difficult to come to a clear working definition for this study, as the topic of self seems to be a conceptual minefield. Baumeister (2011) summarised several difficulties in clearly defining the self. First, researchers have been unable to assign the self to a specific part or process in the brain (Metzinger, 2009). Instead of defined by brain processes, the self seems to emerge through several aspects, for instance one's experiences, interpersonal relations, and the culture and society one is born into. Further, there has not been a consensus among researchers regarding whether people possess one or multiple selves. While Baumeister (2011) believes people have only one self, which can change over time, but remains continuous to some extent through the enforcement of our social system, other researchers support the stance of multiple selves (Bloom, 2008; Markus & Nurius, 1986).

To deal with these conceptual difficulties, it was necessary to develop a clear stance on how self is conceptualised in this study and how it can be distinguished from related concepts such as self-concept or identity. As the developed theoretical framework of selves is based on work by Charmaz, an in-depth understanding of her definition of self was established first by reading various of her papers on the topic. It was decided to adopt her view of a subjective, actively constructed, dynamic and "multiple" self that is evolving and shaped through social interactions. The strength of this study that the work by Charmaz was summarised into a new framework and applied to written narratives for the first time came with the trade-off that there were no guidelines on how to code self. Thus, it was tried to reflect Charmaz' view on selves in the way self was operationalised with the following choices; Multiple different selves were coded in one narrative, the coded selves were based on the subjective experience and active construction of participants rather than factual information, participants' social interactions were considered by focusing on their interpersonal experiences such as stigmatisation or support by others, and the selves were considered to be dynamic, as changes in selves throughout the narratives were anticipated and investigated.

Conclusion

The current study makes an important contribution by adding to scientific knowledge about the illness experience and present and desired future selves of people with chronic illnesses. A new framework was constructed, summarising different papers by Kathy Charmaz, who is a foundational researcher in the field of chronic illness and self. Her insights on people with chronic illnesses selves that was derived from past narratives in the form of interviews was implemented on written past and desired future narratives of people with chronic illnesses for the first time. The previously neglected but crucial desired future dimension was investigated, thus, shedding light on the participants' wishes and intentions for their desired future selves. By analysing both the past and desired future narratives, patterns in how people with chronic illnesses express their selves over time could be identified. The most important finding was that participants seem to be on different journeys with their chronic illnesses, differing in how they think about and describe their desired future selves, as well as how close they are to and hopeful about being able to reach it. A majority of the journeys represented a growth-plot, which raises the question if this tendency reflects reality or is forced onto people due to its popularity in Western culture. Thus, future research should investigate different countries and types of plots, such as the Picaresque plot.

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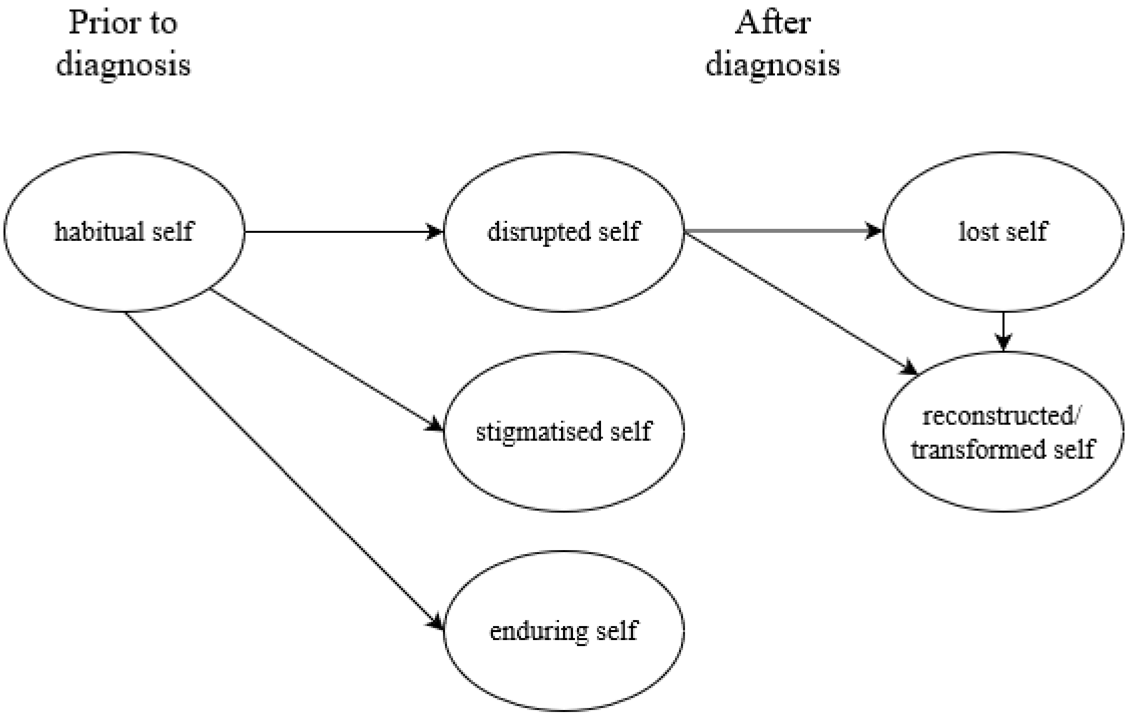
Appendix A

New theoretical framework of selves based on research by Kathy Charmaz



Appendix B

Information Letter and Informed Consent

Onderzoek: “Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst”

Welkom bij het onderzoek "Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst". Wat fijn dat u mee wilt doen aan dit onderzoek!

Het onderzoek bestaat uit de volgende onderdelen:
1. uw verhaal schrijven over uw leven met een chronische aandoening (maximaal 1 A4), 2. een brief schrijven over uw gewenste toekomst (minimaal 1/2 A4, mag ook meer)
3. een vragenlijst invullen.

Het onderzoek duurt ongeveer 45 minuten.
U kunt tussendoor stoppen en op een later moment verder gaan, uw antwoorden worden tussendoor opgeslagen.

Heeft u nog vragen? Dan kunt u contact opnemen met Jacqueline Coppers, door te mailen naar: j.p.m.a.coppers@utwente.nl of te bellen of te sms-en (06-51541796).

Door op onderstaande knop te klikken verklaar ik dat

- ik 18 jaar of ouder ben

- ik weloverwogen heb besloten om deel te nemen aan het onderzoek “hoe mensen met chronische aandoeningen verhalen over hun verleden en toekomst”
- ik de informatiebrief voor deelnemers heb gelezen (zie Informatiebrief verlenging verhalen chronische aandoening universiteit twente)
- ik begrijp dat ik mijn deelname op ieder moment en zonder opgave van reden kan stoppen
- ik begrijp dat mijn persoonlijke informatie (naam en contactgegevens) vertrouwelijk wordt behandeld, beveiligd wordt bewaard en geanonimiseerd wordt voorafgaande aan de data-analyse mijn deelname aan het onderzoek vrijwillig is.

o Ik ga hiermee akkoord en ik wil starten met het onderzoek

o Ik ga niet akkoord, ik wil niet deelnemen aan het onderzoek en ik stop

Appendix C

Writing a story about the illness experience

Wilt u in het lege veld hieronder uw verhaal schrijven over uw leven met een chronische aandoening (verleden)?

Wilt u uw verhaal vertellen hoe het met u is gegaan sinds bekend werd dat u een chronische aandoening heeft? Beschrijf met zoveel mogelijk details wat u tot nu toe heeft meegemaakt en hoe u zich daarbij voelt. Misschien heeft het uw leven veranderd. Bijvoorbeeld op het gebied van gezondheid, wonen, werk of andere activiteiten, sociale relaties, andere levensgebieden of het beeld over uzelf. Of misschien ook niet.

We zijn geïnteresseerd in uw eigen persoonlijke ervaring. Het gaat dus om uw eigen beleving.

Het schrijven van een verhaal over uw leven met een chronische aandoening zal ongeveer 15 minuten kosten. Sommige mensen hebben meer tijd nodig en sommigen minder. Neem alle tijd die u nodig heeft. Het gaat om een verhaal van maximaal 1 A4.

Appendix D

Letters from the Future method

Brief over uw gewenste toekomst.

Stel u voor dat u in een tijdmachine stapt en reist naar een door u gewenste toekomst. U kunt uit de tijdmachine stappen op één moment in de toekomst of op meerdere momenten.

Gebruik uw verbeeldingskracht: bedenk dat het gaat om iets wat nog niet gebeurd is en dat het een kans is om te verzinnen wat er zou kunnen gaan gebeuren: stel u voor dat u de toekomst kunt ontwerpen!

Probeer met zo veel mogelijk details uw brief te schrijven, bijvoorbeeld over wat u belangrijk vindt op verschillende levensgebieden zoals wonen, werk, sociale relaties, of uw karakter of zelfbeeld.

Schrijf wat er spontaan in u opkomt over de gewenste toekomst, probeer niet te veel na te denken. We zijn geïnteresseerd in uw eigen, persoonlijke ervaring.

U sluit de brief af met een boodschap vanuit de toekomst aan uzelf of aan anderen in de huidige tijd.

U heeft nu een globaal idee van de opdracht om een brief vanuit de toekomst te schrijven.

Hierna volgen stapsgewijs enkele vragen die u helpen om straks de brief te schrijven. Voel u vrij om vanuit deze suggesties de brief op uw eigen wijze te schrijven.

Het schrijven van een brief vanuit de toekomst duurt ongeveer 15 minuten (sommige mensen hebben meer tijd nodig en anderen minder). Neem alle tijd die u nodig heeft voor het schrijven van een brief van minimaal 1/2 A4.

Prompts:

(1) Wanneer speelt uw gewenste toekomst zich af? Hoe ver in de tijd reist u in de toekomst? Het tijdstip in de gewenste toekomst bepaalt u zelf. Dit kan 1 uur, dag, een week, of jaren later zijn. Misschien ziet u uzelf op een bepaalde leeftijd? Of in een bepaalde levensfase? Of waaraan merkt u dat uw gewenste toekomst zich op dat moment in de toekomst afspeelt?

(2) Waar bent u in de gewenste toekomst? Beschrijf hieronder bijvoorbeeld de omgeving of de plek van uw dromen, met zoveel mogelijk details die voor u belangrijk zijn. Of wat ziet of hoort u? Wat ruikt u? Of hoe voelt de toekomstige omgeving?

(3) Speelt de chronische aandoening een rol in uw leven in de gewenste toekomst? Op welke manier wel of niet? En welke rol? Op welke levensgebieden?

(4) Aan wie schrijft u de brief?

Bedenk aan wie u de brief wil schrijven: aan uw huidige ik of aan iemand anders (bijvoorbeeld uw kind of kleinkind, leeftijdgenoten, of de volgende generatie, etc.). En hoe spreekt u deze persoon aan? (lieve, beste, geachte, etc.).

U kunt nu de brief gaan schrijven. Het gaat dus om uw gewenste toekomst.

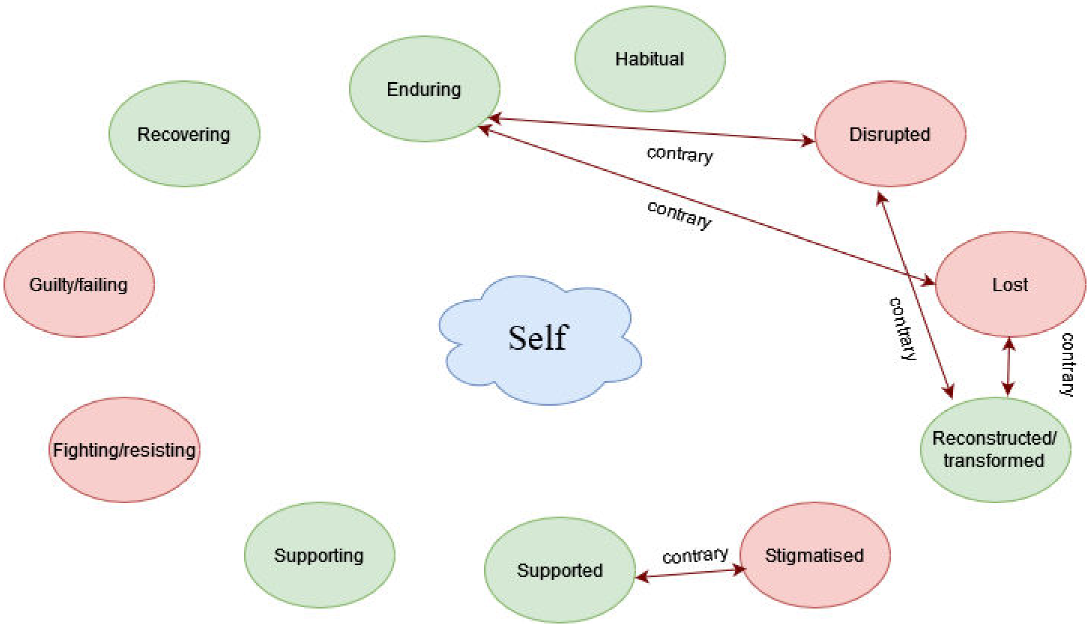
Stel u een gewenst toekomstig leven voor, waarin (met of ondanks uw chronische aandoening) een wens, verandering of droom is uitgekomen. Misschien heeft u iets bereikt wat u graag wilde. Of u leidt het leven zoals u dat wilt leven. Of u heeft een bepaald probleem opgelost. Of u heeft een goede manier gevonden om hiermee om te gaan.

Vertel uw verhaal over een concrete dag, of een specifiek moment, of een concrete gebeurtenis. Geef bijvoorbeeld details over wie, wat, waar, of hoe de gewenste toekomst eruit ziet of over hoe u zich daarbij voelt. Vertel bijvoorbeeld hoe u daar gekomen bent, of wat u heeft gedaan om dit te bereiken, of wat u achteraf het meest heeft geholpen, of hoe u op het leven van nu terugkijkt.

Met welke bedoeling schrijft u aan de ontvanger van deze brief? Of welke boodschap heeft u voor deze persoon?

Appendix E

Thematic map of themes of self



Note. Selves that are perceived as negative or undesirable by participants are presented in red circles and selves that are perceived as positive or desirable by participants are presented in green circles.