

Master thesis Psychology

Well-being in the perspective of chronic illness.

A thematic analysis of well-being in narratives of the chronically ill.

Denise Fingal (s2112205)

University of Twente, Enschede, The Netherlands

First supervisor Dr Kevin Pijpers

Second supervisor Dr Heidi Toivonen

02-09-2022

Abstract

Chronic illness brings about a biographical disruption. Being diagnosed creates a divide between a person's past and future aspirations. Through narratives of the past, participants construct well-being based on questions concerning living with a chronic illness and adapting to this biographical disruption. As well-being is an essential factor in living with a high quality of life, this study aims to answer *how well-being is constructed in the past and future narratives of chronically ill individuals*. Thirty narratives were analysed based on the content of the narratives regarding the concepts of well-being and the mention of chronic illness. Participants were asked to write a letter about their illness experience and a letter of the future. Thematic analysis was used to analyse how well-being is constructed in illness experience and future letters. Codes were formulated both deductively using theories of well-being and inductively by reading the data. The past narratives included themes of pain and dependence, losing sense of self, invisibility and diagnosis and clarity. These themes contain expressions of change and the difficulties in dealing with becoming ill. The future narratives included themes such as social understanding and acceptance, ability to do more and pursue dreams, acceptance of illness and living better, cure and returning to normal and loss of hope and letting go. The overarching theme here is hope. Hope for better well-being, hope for a positive future, unrealistic hope and loss of hope. To conclude, well-being in the past narratives was constructed more negatively than in the future letters. Future studies should look at how hope, illness type, onset and duration influence well-being. It would also be interesting to research how a person's personality, identity, background and perception of illness, and perception of work performance might influence their well-being and adjustment to the biographical disruption due to chronic illness.

Introduction

Being diagnosed with a chronic illness can throw a wrench in future plans and can hinder a person's well-being. Bury (1982) describes chronic illness as an experience that disrupts daily activities and refers to chronic illness as biographical disruption or a biographical disagreement. It creates an interruption between past life and future aspirations and thus alters how an individual thinks and sees themselves and the world (Lim, 2020; Zautra & Hempel, 1984; Öhman, Söderberg & Lundman, 2003). Those who experience this disruption due to chronic illness often change the way they view themselves and the world to adapt to their illness and the changes it brings. Through narratives of illness experience, it is possible to construct well-being based on questions concerning living with a chronic illness and adapting to this biographical disruption.

Chronic illnesses are responsible for 71% of all deaths globally (World Health Organization, 2021). They are defined as “health conditions that last one year or more, require ongoing medical attention or limit activities of daily living or both” and result from a “combination of genetic, physiological, environmental and behavioural factors” (Center for Disease Control, 2021; World Health Organization, 2021). In 2019, 57% of the population in the Netherlands had at least one chronic illness (Volksgezondheid en Zorg, 2019). About 95% of people 75 years or older had at least one chronic illness whereas 40% of people 40 years or older had at least one chronic illness. Living with chronic illness requires individuals to be adaptable as it can impact their lives in many ways. Dobbie and Mellor (2008) describe both short-term and long-term impacts of living with chronic illness. In the short term, they argue that chronic illness invokes psychological, physical and social changes where the individual might feel different from others without an illness. This could lead to individuals feeling lonely and alienated which could reduce their self-esteem. Long-term effects of chronic illness might present a threat to the individual's social and work life as the physical and psychological condition might hinder this area of life even if they can cope and manage their illness. All of these stressors have an impact on the individual's psychological well-being as they might feel increasingly stressed, gain an increasingly negative outlook on themselves and experience a change in their meaning of life. In the long run, individuals with chronic illness are more likely to seek professional help for their mental health and well-being (Dobbie & Mellor, 2008). As well-being is an important factor in living with a high quality of life, this study aims to look at how people with chronic illnesses express well-being in stories about their illness experience and letters to the future. This study aims to answer *how well-being is constructed in the past and future narratives of chronically ill individuals*.

Definition of well-being

Well-being is understood as an individual's optimal functioning and experience which affects one's quality of life. It involves feelings of positive emotion, realising one's potential, becoming a better person and finding ways to prosper socially (Westerhof, 2013). It is conceptualised in two approaches, hedonic well-being and eudaimonic well-being. Hedonic well-being, also known as subjective or emotional well-being, encompasses how the individual evaluates their life and consists of "frequent pleasant feelings [positive affect], infrequent unpleasant feelings and an overall judgement that life is satisfying [an avowed quality of life]" (Keyes, 2007; Tov, 2018, p. 2). Thus, emotional well-being encompasses the experience of positive emotions and satisfaction with life (Westerhof, 2013).

Eudaimonic well-being encompasses psychological and social well-being (Keyes, 2007). This approach takes into account that to reach a person's full potential one needs to meet and fulfil certain qualities or needs that are crucial for personal development and growth. Psychological well-being reflects an individual's view on life and their functioning in life (Lamers et al., 2011). It consists of six dimensions namely autonomy, positive relations, environmental mastery, self-acceptance, personal growth and purpose in life, which are crucial for a person to function well (Tov, 2018). Social well-being focuses on how an individual evaluates their functioning in societal contexts (Keyes, 1998). For positive social well-being, a person should be able to experience social acceptance, social actualization, social contribution, social coherence and social integration (Keyes, 2007).

Keyes' (2002) mental health continuum, combines these concepts of well-being. Keyes (2002) argues that if a person is high in one hedonic aspect and six aspects of eudaimonic well-being they could be considered flourishing. Thus, positive well-being incorporates all three components of well-being namely emotional, psychological and social well-being. The concepts are further defined in the coding table (Table 1) in the data analysis section.

Relation between chronic illness and well-being

Well-being is an important concept in chronic illness research as it has been found that "higher levels of (mental) well-being may promote recovery and reduce the risk of mortality in people with physical disease" (Bohlmeijer & Westerhof, 2020, p. 2). Tov (2018, p. 4) argues that emotional well-being is "experienced in reaction to specific events" and looks at positive affect versus negative affect. Negative affect triggers the body's stress response and

when negative emotions are chronic, it could lead to impairment in the immune system functioning which results in an elevated risk for health problems. Positive affect, on the other hand, might be associated with better social support, greater immune functioning and healthier behaviour which could help in the recovery of illnesses and reduce the risk of health problems (Tov, 2018). Cognitive well-being looks at the satisfaction of life as a whole but also in different areas of life such as work, health and family. Individuals have their own goals, standards and values in life which, when reached, could bring about positive emotions. However, when these are not fulfilled, or if there is a disruption, it could have negative effects on affective and cognitive well-being.

As mentioned before, chronic illness brings biographical disruption and changes the way a person views themselves and the world around them. A change in health status could influence life satisfaction because of limitations due to the illness as it could lessen the enjoyment and performance of previous activities and it could create a gap between their current life situation and aspirations for their standard of living (Lim, 2020; Zautra & Hempel, 1984). Lim (2020) argues that big gaps between current life and aspirations induced by chronic illness often lead to frustration and dissatisfaction which can thus lead to a decrease in well-being. Zautra and Hempel (1984) argue that experiencing dissatisfaction and negative emotions could change how they view themselves and the world around them as their expectations for their own life are not being met or cannot be met due to chronic illness. Some individuals have a more optimistic or resilient outlook on illness and illness management (Dobbie & Mellor, 2008; Wang et al., 2021). Lim (2020, p. 1775) argues that “individuals with chronic conditions may negatively alter their treasured life goals or plans that bring meaning to life” while others “may cope with their illness by engaging in positive thinking or wish-fulfilling fantasies”. Wang et al. (2021) argue that high subjective well-being is often associated with positive emotions such as anticipation, hope, happiness and joy which are a basis of resilience and can play a protective role against chronic illness. Resilience factors such as optimism, locus of control, understanding of the illness, self-esteem and social support could contribute to positive adjustment to chronic health conditions and an increase in well-being (Dobbie & Mellor, 2008).

Narratives, chronic illness and well-being

Narratives can help understand how well-being is represented in the experiences of those with chronic illnesses. Of interest is how people describe their experiences with change, in this case experiencing chronic illness, and how they make sense of their own experience,

growth and development (Adler, 2012). Individuals using a narrative form to make meaning and sense of purpose of experience provide them with the opportunity to assimilate the self across situations and time. Chronic illness poses a challenge and changes the meaning-making of their narrative after onset to connect past to present and future self (Adler, 2012; Synnes et al., 2020; Öhman, Söderberg & Lundman, 2003). Therefore, past narratives, or written illness experiences, of those with chronic illness could illustrate how they try to organise the events of the onset, diagnosis and treatment of illness as it unfolds and how they express the changes in the relationship between the self, body, society and aspirations (Synnes et al, 2020; Lim, 2020). Various studies have analysed recurrent themes in illness narratives as well as well-being (Adler et al., 2016; Bauer, McAdams & Pals, 2008; McLean et al., 2020; Öhman, Söderberg & Lundman, 2003). They have looked at recurrent narrative themes such as agency, communion, redemption and growth as well as broader themes connected to illness such as “experiencing the body as a hindrance, being alone in illness, struggling for normalcy” (Öhman, Söderberg & Lundman, 2003, p. 538). It is important to understand how “imagining possible and preferred future guides and motivates present thought and action” and how these imagined futures could influence social, personal and societal change (Sools, 2020, p. 451-452). In this study, future letters are significant as they provide insight into how well-being is constructed in a person’s desired future. Thus, the goal of this study is to look at how well-being is constructed in the past and future narratives of chronically ill individuals.

Method

Design

The present study is part of the larger study “Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst”. Ethical approval was granted by the ethical committee of the Faculty of Behavioural Sciences at the University of Twente under number 2111138. The study used the Mental Health-Continuum Short Form (MHC-SF) questionnaire in Dutch to collect quantitative data regarding emotional, psychological and social well-being. To collect qualitative data on the participants' experience of living with chronic illness and their desired future, the *Letters from the future* exercise were used (Sools et al., 2015; Sools, 2020).

The current study is a qualitative study that aims to construct well-being in the past and future narratives of those with chronic illness. The data used in this study originate from the larger and ongoing study.

Participants

The sample size used in the current study contains data obtained from the larger study collected up to the 16th of February, 2022. 99 participants took part in the study. 30 narratives were analysed in this study based on the content of the narratives regarding the concepts of well-being and the mention of chronic illness. The participants' age varied from 28 and 70 years ($M=50$, $SD=10.05$). There were a total of 28 female participants and 2 male participants. The chronic illnesses reported by the patients were long COVID, asthma, q-fever, cancer, hypermobility syndrome, Pompeii's disease, migraine, multiple sclerosis, lichen sclerosis, brain injury, fibromyalgia, Ehlers-Danlos syndrome (EDS), dizziness, spondylopathy and thyroid disease. Some participants also had additional psychological, physical or neurological diagnoses.

Participants were recruited through purposive sampling among the researchers' professional and personal networks, Dutch patient- and healthcare organisations and social platforms such as LinkedIn and Facebook. Participants had to be at least 18 years of age and had to perceive themselves as living with a chronic illness. Other inclusion criteria included understanding and writing in the Dutch language, having sufficient digital skills to fill in an online survey and cognitive skills to reflect upon the past and imagine the future. Exclusion criteria included missing values for the chronic illness or failure to fill in a past or future narrative.

Materials

To collect narratives of individuals with chronic illness, the *Letters from the future* exercise were used (Appendix C). This exercise was originally a health promotion instrument used by a group of older people with mild depressive symptoms (Bohlmeijer, 2007; Sools, 2020). The letters provide an insight into how people respond to current situations in their daily life through a narrative form (Sools, Tromp & Mooren, 2015). Most importantly, using these letters could provide insight into patterns of imagining the future and how these could relate to health and well-being, which is the aim of this study.

Participants were instructed to imagine travelling to the future and writing a letter to an audience in the present about the depicted future and describing the path they took to get there. The participants had the freedom to choose their audience as well as their desired future and were given a prompt to help them with visualising and writing about this future. They were asked to visualise when in the future they would be writing the letter, to describe

the environment they travelled to and to explain this in terms of sensations, if and how their chronic illness played a role, the receiver of the letter and the message they wished to convey to the receiver. The third point, how their chronic illness played a role, was added to this particular study.

Procedure

Participants were contacted via the above-mentioned method and were given a flyer with information regarding the background and aim of the study, benefits and burdens of participating in the study, eligibility criteria, confidentiality, information about the team of researchers and the content of the survey. Participants were asked to read the information on the flyer and upon deciding to participate, they could give consent to take part in the survey (Appendix A). The data was collected via Qualtrics which is an online survey tool. When participants gave their consent, they were asked to write a past and future narrative.

For their past narrative, the participants had to write about their experience with receiving a diagnosis for their chronic illness (Appendix B). The participants were instructed to write about how they have been doing since it became known that they have a chronic condition. They had to write about this in detail describing their experience, how it made them feel and if they also experienced any changes in their life. Afterwards, the participants received an introduction regarding the letter to the future and were given a few prompts to help them with the writing process. Participants were instructed to use their imagination and describe as detailed as possible what the future looked like, especially in areas of life that were important to them. They had to indicate when and where in the future this scenario took place and how their illness played a role in their desired future. The last instruction was to end the letter with a message from their future self to themselves or the person they are dedicating the future letter to.

Upon completing their story, they were asked to fill in the MHC-SF and other questions regarding their chronic illness and demographic data such as age, education, gender, employment and marital status. When the participants had filled everything in, they were asked if they wanted to be invited to the second phase of the study which involved interviews based on the data collected in phase one. The whole process took about 45 minutes. Participants were able to contact the researchers in case of any questions or concerns and they were also able to withdraw from the study at any point. The participants were not reimbursed nor given incentives for their participation in the first phase of the study.

Data analysis

To analyse the narratives a qualitative thematic analysis was conducted. Thematic analysis is a flexible method for “systematically identifying, organising and offering insight into patterns of meaning (themes) across a data set” (Braun & Clark, 2012, pp. 57). This method makes it possible to identify collective experience and meaning. It also allows for identifying and giving meaning to commonalities in collective experience and shared meaning (Braun & Clark, 2012). Patterns of meaning found in commonalities are important to the topic and research question being explored. In this case, thematic analysis was used to explore how well-being is constructed in the past and future narratives of participants with chronic illness. This is done, as mentioned before, by analysing past narratives and future letters of participants with chronic illness. For this analysis, a combination of inductive and deductive approaches was used to analyse the data using well-being concepts from existing literature. The themes are constructed from engagement with the data, while also being theoretically informed based on the definition of well-being based in the literature. The coding scheme is based on a previous thesis by Kuhn (2017) and the definitions found in the literature can be seen in Table 1.

The data analysis follows the 6 phases of thematic analysis as described by Braun and Clarke (2006). Firstly, the narratives were translated from Dutch to English using DeepL and manually checked for grammar, spelling and content accuracy. Then, the narratives were printed out and read through thoroughly without the coding scheme to get acquainted with the data. Initial thoughts and ideas about the narratives and codes were written down as well. Secondly, after having gone through the narratives once, the coding scheme was printed. The narratives were read through again this time with the coding scheme alongside them. Hereby, the related codes in the narratives were organised into meaningful groups. During this process, pen and paper were used to mark the unit of analysis, namely sentences or parts of sentences, that corresponded to certain codes. In a separate notebook initial ideas, topics and themes were noted down.

Thirdly, after all the data was coded they were sorted into different potential themes. When the different themes were identified, a mind map was created to clarify how the codes related to each theme and how the themes might relate to each other. Some codes are used in multiple themes. These were organised based on the context of the sentence or paragraph they were coded in. Fourthly, the themes were reviewed. The extracts were read for each theme to see if they are coherent with the theme. Then the individual themes were reviewed to see if they are an accurate representation of the data, well-being and the research question.

Fifthly, the themes were defined and refined. The themes were given a definition that describes what they are about. The most interesting aspects of the themes were noted down as well as aspects of the narratives that capture the theme. Lastly, the themes were put in a table with the definition, recurring codes and frequency of the themes and the result section were written.

Table 1.
Coding scheme and descriptions.

Well-being	Description
Emotional well-being	
<i>Positive emotion</i>	Happiness, interest and pleasure in your life, balance between experience of positive and negative emotions
<i>Life satisfaction</i>	Feeling of satisfaction, peace and contentment, wishes and need differ little from accomplishment and achievements, long term view of one's life
Psychological well-being	
<i>Self-acceptance</i>	A positive attitude towards self, recognizing and accepting the different aspects of yourself; a positive feeling about your own life until now; feeling good about self despite limitations
<i>Purpose in life</i>	Having goals and direction in life; experiencing past as meaningful; finding meaning in effort and challenges
<i>Autonomy</i>	Self-determining, being independent; being resistant against social pressure; evaluating oneself based on own personal standards; personal authority
<i>Positive relations to others</i>	Satisfying personal relationships; developing and maintain warm and trusting relationships; being interested in well-being of others; being capable to feel strong empathy, affection and intimacy; understanding reciprocal components in human relations
<i>Environmental mastery</i>	Control in life; feeling capable to handle difficult surroundings; choosing a surrounding or creating a surrounding which suits oneself, meeting one's needs and desires
<i>Personal growth</i>	The feeling of continuous development and opportunities; being open for new experiences; making the most of one's capacities and talents; Insight into one's own potential for self-development
Social well-being	
<i>Social coherence</i>	Being able to make sense of what is happening in society; caring and being interested in living together in a community and the environment; maintaining or promoting the desire to make sense of life.
<i>Social acceptance</i>	Positive attitude towards others while acknowledging their difficulties; feeling comfortable with others, favourable views of human nature; recognizing and accepting other people as they are, despite sometimes troublesome and difficult behaviours
<i>Social actualization</i>	Contributing and believing that community has potential and can evolve positively; hope for future society; ideas for growth and development; believing society realizes existing possibilities
<i>Social contribution</i>	Feeling that one's activities contribute to and are valued by society; belief one is a vital member of society; thinking daily activities are appreciated by the community.
<i>Social integration</i>	Sense of belonging to a community; believing to be a part of the community and being supported; having things in common with others

Note. Definitions of the components are derived from Keyes, 1998; Keyes, 2002; Keyes, Shmotkin & Ryff, 2002; Lamers et al., 2011 and Westerhof, 2013) and the existing coding scheme in Kuhn (2017).

Results

Table 2.
Main themes.

Theme	Definition	Code(s)	Frequency N(Nn)*
<i>Past narratives</i>			
Pain and dependence	Dependence is influenced by the symptoms of chronic illness, especially pain.	Positive emotions, life satisfaction, positive relation to others, autonomy, environmental mastery, self-acceptance, personal growth	26 (15)
Invisibility of illness	Many illnesses are not visible to others which brings misunderstandings and feelings of loneliness	Social acceptance, positive relations to others, positive emotion	16 (10)
Losing sense of self	Due to the change from healthy to ill one loses their sense of self while coming to terms with their illness and “new” life	Self-acceptance, positive emotions, life satisfaction, purpose in life, positive relation to others, environmental mastery	27 (15)
Diagnosis and clarity	Diagnosis of illness brings with it clarity and understanding	Positive emotions, self-acceptance, personal growth, autonomy, environmental mastery	15 (11)
<i>Future narratives</i>			
Social understanding and acceptance	Hope that society gains more understanding for those with chronic illness and accept them as they are	Positive emotions, life satisfaction, positive relations to others, social acceptance, social actualization, social integration, social cohesion	10 (06)
Pursuing dreams and ability to do more	Hope for the ability to do more and pursue (new) dreams despite limitations due to illness	Purpose in life, self-acceptance, personal growth, life satisfaction, positive emotion, autonomy, environmental mastery, positive relations to others	09 (07)
Illness acceptance and living better	Hope to learn to accept the illness and adapt to it in order to live a better life	Self-acceptance, positive emotion, life satisfaction, autonomy, environmental mastery, personal growth, positive relations to others, purpose in life	14 (08)
Cure: returning back to normal	Hope for a miracle cure to be rid of the illness and return back to “normal life” before the illness	Positive emotion, purpose in life, autonomy, environmental mastery, self-acceptance,	09 (06)
Loss of hope and letting go	Losing hope of becoming better and learning to let go of the past	Self-acceptance, positive emotions, life satisfaction,	06 (03)

**Note: N refers to frequency of codes and Nn refers to frequency of narratives the codes were mentioned in.*

The themes identified are all related to well-being. A brief definition, corresponding codes and the frequency of the codes can be seen in Table 2. There are a total of nine themes. These themes will be further discussed in this section. This section is divided into two narratives, past and future. Each section is further divided into themes and gives a brief definition of the themes, an explanation of what the theme entails, examples from the narratives and the corresponding codes.

Past narratives

Pain and dependence

Pain, for many participants, is a major factor in how they lead their life. They express how the pain associated with their illness leads to them losing a lot of their independence as they are increasingly dependent on others to perform daily tasks. When writing about pain with regards to their energy levels, daily tasks and other aspects of life they often use strong wording. For example, Dianne describes how their life is “dominated by the[ir] migraine”. They express how their life “comes to a standstill” when they have a migraine and “can’t do anything”. Others use expressions such as “living in a prison” or “no longer having a life” because of the pain and illness. A common worry for a majority of the participants was the inability to work. Many of them express how losing their job or losing hours of work because of the pain was devastating as their income decreased or they felt like they lost their purpose in life. Some expressed negative thoughts and emotions towards their pain as it made them more dependent on others. This theme largely consists of the codes autonomy, environmental mastery, self-acceptance, personal growth, positive relations to others, life satisfaction and positive emotions.

Invisibility of illness

Many of the participants had chronic illnesses that were not externally visible to others. This invisibility of the illness was expressed in the narratives as well. Participants often expressed frustration with others because of this, for example, Patty wrote how “understanding from the outside world is difficult”. They also write about how this affects social relationships and/or social situations as people do not see why they are struggling to do normal daily activities. Many participants express how they often prefer to lie about how they are feeling to not have to go through the trouble of having to justify and defend themselves. Keith explains how as soon as they do not have a leg in a cast “people are quick to find that it is between your ears” showing how if it is not visible people do not take the illness seriously and make it difficult to

feel understood and have positive relationships with others. Others simply could not express what they were going through due to the lack of information they have about their illness. Participants who had chronic illnesses that were less common or less researched expressed more feelings of loneliness. The main codes in this theme are social acceptance, positive relations to others and positive emotion.

Losing sense of self

Because of the change in daily life activities due to the impact of illness, participants expressed losing a part of who they were. While some of them do not particularly use the words “losing my sense of self” they do express how there is a change compared to who they were before. Clichés and strongly worded sentences are common when writing about this change. For example, Kim wrote that she is “a shadow of the woman” she once was while Mike wrote that they have become “a person I never wanted to be”. Others write about how their life progressed in a different way than they imagined. This expression of a change in expectation was common in many of the narratives. They write how the illness made them “mourn” what is no longer possible, how dreams fall apart and how their body and mind don’t cooperate anymore. What is also striking was the references they made to their role in society and how this has changed because of their illness. Kim writes how they feel like a “failure as a wife/mother/daughter/sister/friend” while others write about how they are not able to be the parent they want to be. Others write how they could not contribute to society in their work anymore. Expressing negative thoughts and emotions about their change in role and change in themselves. This theme largely consists of the codes self-acceptance, positive emotions, life satisfaction, purpose in life, positive relation to others and environmental mastery.

Diagnosis and clarity.

Some participants described receiving a diagnosis as a sigh of relief. Many narratives included expressions of fear of the unknown, confusion and denial regarding the symptoms of their chronic illness. Participants wrote about the struggle of knowing that something is “not right” with their health but not knowing what is happening to their bodies. When finally receiving a diagnosis from a health care worker, many participants expressed positive emotions and used words such as peace, insight, relief and acceptance to describe their immediate reaction to their diagnosis. Maggie wrote how the diagnosis was a relief and “not between my ears”. In contrast to those who expressed the invisibility of an illness because of

the lack of external characteristics, those who received a diagnosis, even if the chronic illness is not externally visible, expressed more positive emotions. However, while a majority of participants expressed more positive emotions after receiving a diagnosis, others expressed anger, fear and denial. Keith expresses this by writing “initially you are happy that what you have has a name and then, then nothing, there is nothing for it”. Similarly, others express their frustration with receiving a diagnosis of a chronic condition by explaining how it becomes overwhelming. There is too much information at once that they have to process and the mourning process they have to go through before coming to terms with the diagnosis is difficult. Nevertheless, like the majority of the participants, they also express how getting a diagnosis gives them clarity and information to gain back their independence by learning how to cope and manage their illness. Participants also express how receiving a diagnosis has helped them mend social relationships by being better able to explain their illness and their needs. This theme includes the codes positive emotions, self-acceptance, personal growth, autonomy and environmental mastery.

Future narratives

The prominent theme in the future narratives is hope. All of the narratives in one way or another expressed hope whether it was hope for a cure, hope for a better life, hope for social understanding, loss of hope or hope for pursuing new and old dreams. At times, the future narratives were written more poetically compared to the past narratives seeing as participants tend to idealise their future and use this type of language to express deeper feelings.

Social understanding and acceptance

In the future narratives, some participants write a letter dedicated to other people in society. The letters contained words of gratitude and were addressed to relatives, friends, other sufferers, doctors and people in government. The letters addressed to the government and doctors contained gratitude for tangible things such as medicine and financial efforts. They also contained gratitude towards doctors for working together with patients to help them gain more information about their illnesses. Keith expresses how with their newfound financial freedom they are less burdened by debt and can feel useful again for themselves and those around them. Others express gratitude to the whole of society for becoming more understanding and accepting of those with chronic illnesses. While some of the narratives express this gratitude as something that has already happened, thanking people for already having accepted and having empathy for those with chronic illnesses using the past tense,

others still use the future tense. Nikki, for example, wishes for a future for herself where everyone “accepts limits and wishes in a respectful way”. Aside from acceptance and understanding participants also expressed a wish for more tolerance and inclusivity in society. Overall, the participants used positive language to express their gratitude to society. The main codes in this theme include positive emotions, life satisfaction, positive relations to others, social acceptance, social actualization, social integration and social cohesion.

Pursuing dreams and the ability to do more

The hope to pursue new (and old) dreams as well as the ability to do more despite their illness was expressed by some of the participants as of utmost importance. The narratives are written in different tenses but they all express the same thing. A majority of the narratives are in the present tense, telling a story of how their day was, what they have achieved and using phrases such as “being proud” of themselves for doing something. Some of these narratives finish with the participant addressing themselves by writing, like Patty, “hopefully [this] can be achieved”. One narrative was written in the future tense. In this narrative, they express what they want for themselves in the future, unlike the other narratives where they envision that their dream has already happened. Dianne writes in you form and also ends the letter addressing themselves writing “I am writing this letter to myself because I grant myself to take another step, even with migraine”. Many of the narratives explain in detail what they see for themselves in the future after they have achieved their goals. They discuss their feelings regarding their progress and also the feelings of those close to them. Most of the participants also write in detail about what their life looks like with their existing (or desired) family. Most of these narratives include small victories such as having a garden, cooking breakfast and enjoying a day with their family swimming pool. This theme largely consists of the codes of purpose in life, self-acceptance, personal growth, life satisfaction, positive emotion, autonomy, environmental mastery and positive relations to others.

Illness acceptance and living better

Some participants envisioned a future where they have accepted their illness and have learned to manage it. These narratives, just like the ones in the previous theme, express wanting to accept their illness despite the limitations it comes with. In this theme, the participants write about having accepted their illness, having learned how to live with their limitations and having learned how to create a desirable life for themselves and their circumstances. Many of the participants start by writing about the struggles they experienced with their illness in the

past and as the letter progresses they start describing how they live with their illness after having accepted it and learned how to live a good life with it. Some, as in other themes, write about this acceptance as if it has already happened. For example, Kim writes “I have learned to deal with my limitations, learned to build a different life and still be able to enjoy myself despite my limitations”. Others write about acceptance as something that is yet to happen. Chrissy, for example, writes “for me, complete acceptance of rheumatism with its limitations, being able to live in the now and being happy with what I can do”. Common words or phrases used in these narratives are enjoying life, adapting, learning to embrace, peace and wish. Just like in the previous theme, participants acknowledge that they will still go through difficulties because of their illness but describe being open to making a good life for themselves despite this. The main codes in the theme are self-acceptance, positive emotion, life satisfaction, autonomy, environmental mastery, personal growth, positive relations to others and purpose in life.

Cure, returning to normal

Cure and returning to normal is a wish some of the participants wrote about. These narratives contained futures where the illness no longer exists and there was no more suffering. There were two ways participants expressed the hope for a cure in their narratives. Two of the participants described having dreams and learning to live with the illness. Mary described having a dream come true and living with the illness despite hesitation but closes her letter by writing “when I heard LS no longer existed I was very relieved and super happy”. While Chrissy writes that she secretly “hopes of course for a miracle drug so that the pain and fatigue disappear”. Thus, while they still express wanting to accept their illness and achieve other dreams despite their illness, they still wish or hope for a cure or elimination of their illness. The other four participants on the other hand write about a future where the illness no longer exists in their bodies. They express gratitude and excitement for having been cured. The participants address the letters to their family and friends and express how excited they are that they can do everything they used to do again, with no worries. Harley writes how she is “completely free of [long COVID]” and how she lives “day to day and don’t worry about tomorrow”. Similarly, Cathy writes how she is no longer dependent on her mobility scooter. Words and phrases such as enjoying life, living life to the fullest, being able to decide and do normal things again and no more limitations were common in this theme. This theme includes the codes of positive emotion, purpose in life, autonomy, environmental mastery and self-acceptance.

Loss of hope and letting go

Some participants did not see a hopeful future like the rest. These participants expressed this in their dedication to themselves or their family members. The language used in the narratives is more sombre compared to the rest of the narratives and they are also shorter and straightforward. Jim wrote, “my message is to say that I love them, but I cannot be who I want”. Betty on the other hand wrote a poem to herself, reassuring herself that “it won’t be a long journey anymore” and to enjoy the time she has left. She expresses gratitude for the past and hopes to develop the strength to let go of the children. In both of the narratives, family is central. However, unlike in the other themes, the hope of becoming better or even for a cure is absent. The theme largely consists of the codes self-acceptance, positive emotions and life satisfaction.

Discussion

This study aimed to answer *how well-being is constructed in the past and future narratives of chronically ill individuals*. To answer this question, past narratives and future narratives of those with chronic illness were analysed based on the well-being concepts. Common themes of well-being in the past narratives were pain and dependence, losing a sense of self, the invisibility of illness and diagnosis and clarity. For future narratives, the overarching theme was hope. It had five sub-themes namely social understanding and acceptance, ability to do more and pursue dreams, acceptance of illness and living better, cure and returning to normal and loss of hope and letting go. When coding the unit of analysis, it became clear that the different dimensions of well-being influence each other. This corresponds to Keyes’ (2002) mental health continuum where he argues that all three components, psychological, social and emotional, contribute to a person’s overall well-being. In these narratives, when a person expresses low emotional well-being they also express a decrease in aspects of social and/or psychological well-being. They also express how when they experience an increase in aspects of psychological well-being, for example, it also increases aspects of emotional and/or social well-being. Even in themes where one well-being component is not explicitly mentioned there are underlying connections to them. Based on the analysis, it could be argued that compared to the past narratives, the content and construct of well-being in future narratives were more positive. In the past narratives, a lot of the participants express their struggle with their illness and the change it brings. They also use more negative language compared to

future narratives to describe their illness experience. The future narratives contain more positive language, and different tenses depending on how they describe their desired future.

Work or being able to work was a prominent topic in the past narratives. The ability to work and having stability in job and income was a common topic in three out of four themes in the past narratives. Participants wrote how the most difficult part of accepting the illness or managing the illness came when they had to cut down the amount of time at work or even had to quit their job as they were no longer able to work anymore. Some used words such as disappointment and expressed frustration when writing about this topic. Vickers (1997) argues that capitalism is the core of success in Western countries and people, like those who are chronically ill and who cannot find success through the workforce, might experience disappointment and have a negative self-perception and self-esteem. Safillios-Rothschild (1970, p. 194, in Vickers, 1997) explains that work is not only an important instrument in capitalism but also for its “psychological side effects”. Being able to work is important for a person’s moral and psychological makeup and plays a crucial role in forming a person’s core identity in life, self-esteem and mental and physical health (Safillios-Rothschild, 1970 in Vickers, 1977). A study by Munir et al. (2007) found that both the impact of work performance on illness and how the illness interferes with work performance affect health-related distress and psychological well-being. Thus, psychological well-being may be closely connected to work as evident in the narratives of the participants in this study.

As mentioned in the result section, hope and different variations of hope were prominent themes in future narratives. Compared to the past narratives, the future narratives come across as more positive due to this theme of hope. The ideal future is described using more poetic language and depicts positive experiences that participants hope to encounter in the future. The participants express the ability to do more with family and pursue dreams that seem less possible in their current state. These ideal scenarios are then followed by expressions of positive emotions which are not as present in the past narratives. Hope is indicative of a person's sense of well-being and enables trust in the future and helps individuals anticipate a better future which is evident in the letters to the future of this study (Davis, 2005). For participants that view themselves as being cured, concepts of positive emotion, life satisfaction, positive relation to others and purpose in life were prominent. These were also the participants who had more negative illness experiences. The concept of self-acceptance and personal growth is also evident in more realistic future narratives where participants express having overcome the difficulties, having learned how to live with their illness and being able to do things they enjoyed doing because they have learned to manage

their illness. This more active expression of hope might be more positively connected to well-being than the “cure” narrative which comes across as more passive. For two participants, hope played a role in their narrative but had the opposite message. While the hopeful narratives express being able to enjoy a better life, these narratives do not contain any future scenario. The narratives were short and sombre and read more like “goodbye” letters compared to the others.

A red line that runs throughout the past narratives and connects to the future narratives is social well-being. While not actively present in the past narratives, underlying connections to dimensions of social well-being come to the foreground. In the past narratives, participants explicitly express their dependency on others and how this (negatively) affects their relationship to others. In the other themes, such as invisibility and diagnosis, being understood by others is important. Participants express “not being seen” by others or actively hiding their illness from others which negatively impacts their social and emotional well-being. Being diagnosed comes with both relief and negative emotions and discomfort but it might also have a positive effect on social well-being. When the disease is recognized, by others and the participants, it becomes easier for participants to express their needs and gain more understanding for themselves and from others which might increase social well-being. Instead of participants solely depending on others, a form of mutual relationship or interdependency is restored. Participants can depend on others for physical and emotional support while also being able to tend to others’ needs (again). This is also evident in the future narratives where participants describe a future where social acceptance and interdependency are prominent. They express feeling useful again for themselves and others. When comparing the future and past narratives along the lines of social well-being it becomes more apparent that while it is not explicitly mentioned, there is an underlying social dimension in the narratives.

A constant topic throughout all of the narratives was this disruption in “normal life”. A description of how people’s lives have completely changed due to their illness is present in most of the narratives. Bury (1982) called this biographical disruption or a biographical disagreement. Bury (1982) describes how chronic illness is an experience that changes the structure of everyday life and a person’s sense of self. It disrupts an individual’s social relationships and plans and expectations for the future which have to be re-examined. Bury presents three aspects of disruption that occur at the onset of a chronic illness. The first is that chronic illness breaches common-sense boundaries. This is evident in the past narratives where participants express how they slowly start noticing pain and bodily states they might

not usually pay attention to. The second aspect is the disruption in a person's biography and self-concept. In the past narratives, this is evident when participants start to question the meaning of the illness and start to question why this is happening to them (Williams, 2000). Williams (2002) argues that in this aspect when individuals start questioning the illness and the changes happening to them, individuals start working on processing the disruption and start to repair the rupture between self, body and society. The last aspect concerns the response to the biographical disruption or rather the mobilisation of resources when facing a change in life circumstances. This last aspect is seen in some of the more positive past narratives when participants start to learn how to manage their illness, experience social support and express self-acceptance and positive growth. This aspect is also evident in a lot of the more realistic hopeful future narratives where people express hope for being able to manage their illness and becoming more active despite their limitations due to their illness.

Lastly, while there are various types of illnesses analysed in this study, participants with long COVID expressed their well-being more negatively in their past narrative and had more hope for a cure and going back to normal. This raised a few questions about the reason behind the common negative past narratives and a more hopeful outlook on the future where most express having been cured and/or returning to normal. A reason might be the uncertainty that long COVID brings with it. Long COVID is a fairly new diagnosis; therefore, the symptoms and treatment of the illness are not yet certain. Because of this, it might be more difficult to adapt to the illness and what it comes with. In a study done by Treharne et al. (2005) on rheumatoid arthritis patients, they found that perception of the illness affected well-being, particularly for those that were newly diagnosed and perceived their illness to have severe consequences for their health. These patients experienced a decrease in well-being, especially in life satisfaction and positive emotions. Thus, the uncertainty and the new diagnosis of long COVID might be the reason for more hopeful future narratives hoping for a cure and more negative past narratives. Most of the long COVID patients described their life before COVID in their past narratives before mentioning how the illness has completely changed their life. This was striking as none of the other participants described their life before their illness.

Strengths, limitations and recommendations

More research is needed on how hope might influence well-being after having written letters to the future. It would be interesting to dive deeper into the nuance behind this theme of hope. Questions that arose when thinking about hope are whether or not this is true hope. By this, it

is meant whether the hope portrayed in the narratives is realistic, a form of wishful thinking or a way to balance out their negative experience with a hopeful view of the future. Another interesting topic in the theme of hope would be to analyse which aspects of well-being are more tied to hope. In this study, there were a few concepts that were prominent in these narratives of hope but more research would be needed to concretely identify if these are truly connected to well-being.

It would also be interesting to look at how the duration of an illness or the time of onset of an illness as well as the type of illness might influence a person's well-being but also how they story their illness. In this study, it became clear that the duration of an illness might affect how a person view's their illness experience but also how and when they start to accept this "new way of life" they are confronted with. This could also answer a previous question asked in the discussion of why long COVID patients described a more negative past narrative and a more positive/hopeful future. What might also be fruitful to analyse is the person's personality and background and how this might affect their representation of well-being. An interesting question to ask might be how a person's identity, personality, background or environment influences their past narrative, their future narratives and their well-being concerning the chronic illness.

Lastly, how work impacts the well-being of those with disabilities might also be important to research. There is much research on how a person's well-being is influenced by work conditions or working with a disability. As is noticeable in past narratives, this is an important topic for many participants in this study. Therefore, it would be interesting to get a deeper understanding of how work is linked to their well-being, specifically their purpose in life, life satisfaction, autonomy and positive emotions.

There were some strengths and limitations in the current study. One of the strengths of this study was having a clear theory with well-defined concepts on which the analysis was based. There was also a variety of narratives to work with. From shorter to longer narratives but also narratives that varied in positive and negative expressions of well-being that gave different perspectives to the concepts of well-being. Having the past narratives and the future narratives also gave different views and contexts on how people view their journey with their illness and how they look at themselves living with their illness in the future. Some limitations in this study were missing values for the past narratives and/or future narratives. Some participants had interesting past narratives but did not fill in their future narratives which made it difficult to gain a broader perspective on their view of their illness in the future and how they express their well-being in the future. Some participants also did not seem to

completely understand the exercises and skipped the questions about their past narrative and/or future narrative. This seemed to happen to older participants which might be a point of improvement for the larger and/or future study.

Conclusion

In conclusion, this study looked at how well-being is constructed in the past and future narratives of chronically ill individuals. Based on the analysis it could be concluded that well-being is not just the narrow definition found in the literature. As analysed, well-being involves other aspects such as hope. This should be taken into consideration when doing research and in (clinical) practice, particularly with those who are chronically ill. Dimensions of well-being are also intertwined and should not be seen as “separate” from each other as they often influence each other. Future studies should look at how hope, illness type, onset and duration influence well-being as well as how a person’s personality, identity, background and view on the importance of work performance might influence their well-being and adjustment to chronic illness.

References

- Adler, J. M. (2012). Living into the story: Agency and coherence in a longitudinal study of narrative identity development and mental health over the course of psychotherapy. *Journal of personality and social psychology, 102*(2), 367. doi: 10.1037/a0025289
- Adler, J. M., Lodi-Smith, J., Philippe, F. L., & Houle, I. (2016). The incremental validity of narrative identity in predicting well-being: A review of the field and recommendations for the future. *Personality and Social Psychology Review, 20*(2), 142-175. doi: 10.1177/1088868315585068
- Bauer, J. J., McAdams, D. P., & Pals, J. L. (2008). Narrative identity and eudaimonic well-being. *Journal of happiness studies, 9*(1), 81-104. doi: 10.1007/s10902-006-9021-6
- Bohlmeijer, E. (2007). *De verhalen die we leven: Narratieve psychologie als methode*. Amsterdam: Boom.
- Bohlmeijer, E. T., & Westerhof, G. J. (2020). A new model for sustainable mental health: Integrating well-being into psychological treatment. In *Making an impact on mental health* (pp. 153-188). Routledge.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101. doi: 10.1191/1478088706qp063oa
- Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 57–71). American Psychological Association. doi: 10.1037/13620-004
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness, 4*(2), 167-182. doi: 0141-9889/82/0402-0167 \$1.50/1
- Center for Disease Control. (2021). *About Chronic Diseases*. <https://www.cdc.gov/chronicdisease/about/index.htm#:~:text=Chronic%20diseases%20are%20defined%20broadly,disability%20in%20the%20United%20States>.
- Davis, B. (2005). Mediators of the relationship between hope and well-being in older adults. *Clinical nursing research, 14*(3). pp. 253-272. doi: 10.1177/1054773805275520
- Dobbie, M., & Mellor, D. (2008). Chronic illness and its impact: considerations for psychologists. *Psychology, health & medicine, 13*(5), 583-590. doi: 10.1080/13548500801983041

- Höhne, H. (2022). *The Temporality of Illness Experience: How People with Chronic Illness Narrate their Past and Future*. [Master's thesis]. The University of Twente.
- Keyes, C. L. M. (1998). Social well-being. *Social psychology quarterly*, 121-140.
<http://www.jstor.org/stable/2787065>
- Keyes, C. L. (2002). The mental health continuum: From languishing to flourishing in life. *Journal of health and social behavior*, 207-222. doi: 82.75.119.37.
- Keyes, C. L. (2007). Promoting and protecting mental health as flourishing: a complementary strategy for improving national mental health. *American psychologist*, 62(2), 95. doi: 10.1037/0003-066X.62.2.95
- Keyes, C. L., Shmotkin, D., & Ryff, C. D. (2002). Optimizing well-being: the empirical encounter of two traditions. *Journal of personality and social psychology*, 82(6), 1007. doi: 10.1037//0022-3514.82.6.1007
- Kuhn, A. (2017). *Flourishing with Basic Income: Age differences in Imaginations of Flourishing Futures with a Basic Income*. [Bachelor's thesis]. The University of Twente.
- Lamers, S. M., Westerhof, G. J., Bohlmeijer, E. T., ten Klooster, P. M., & Keyes, C. L. (2011). Evaluating the psychometric properties of the mental health continuum-short form (MHC-SF). *Journal of clinical psychology*, 67(1), 99-110. Doi: 10.1002/jclp.20741
- Lim, S. S. (2020). The effects of chronic illness on aspirations and subjective wellbeing. *Journal of Happiness Studies*, 21(5), 1771-1793. doi: <https://doi.org/10.1007/s10902-019-00156-0>
- McLean, K. C., Syed, M., Pasupathi, M., Adler, J. M., Dunlop, W. L., Drustrup, D., ... & McCoy, T. P. (2020). The empirical structure of narrative identity: The initial Big Three. *Journal of Personality and Social Psychology*, 119(4), 920. doi: <https://doi.org/10.1037/pspp0000247>
- Munir, F., Yarker, J., Haslam, C., Long, H., Leka, S., Griffiths, A. & Cox, S. (2007). Work Factors Related to Psychological and Health-Related Distress Among Employees with Chronic Illnesses. *J Occup Rehabil* 17. pp. 259–277. doi: <https://doi.org/10.1007/s10926-007-9074-3>
- Sools, A. (2020). Back from the future: A narrative approach to study the imagination of personal futures. *International Journal of Social Research Methodology*, 23(4), 451-465. doi: <https://doi.org/10.1080/13645579.2020.1719617>

- Sools, A. M., Tromp, T., & Mooren, J. H. (2015). Mapping letters from the future: Exploring narrative processes of imagining the future. *Journal of Health Psychology, 20*(3), 350-364. doi: <https://doi.org/10.1177/1359105314566607>
- Synnes, O., Orøy, A. J., Råheim, M., Bachmann, L., Ekra, E. M. R., Gjengedal, E., ... & Lykkeslet, E. (2020). Finding ways to carry on: stories of vulnerability in chronic illness. *International Journal of Qualitative Studies on Health and Well-being, 15*(1), 1819635. doi: 10.1080/17482631.2020.1819635
- Tov, W. (2018). Well-being concepts and components. In *Handbook of subjective well-being* (pp. 1-15). Salt Lake City, UT: Noba Scholar.
https://ink.library.smu.edu.sg/soss_research/2836
- Treharne, G. J., Kitas, G. D., Lyons, A. C., & Booth, D. A. (2005). Well-being in rheumatoid arthritis: the effects of disease duration and psychosocial factors. *Journal of health psychology, 10*(3). pp. 457-474. doi: 10.1177/1359105305051416
- Vickers, M.H. (1997). Life at work with “invisible” chronic illness (ICI): the “unseen”, unspoken, unrecognized dilemma of disclosure". *Journal of Workplace Learning 9*(7). pp. 240-252. doi: <https://doi.org/10.1108/13665629710190040>
- Volksgezondheid en Zorg. (2019). *Chronische aandoeningen en multimorbiditeit*.
<https://www.vzinfo.nl/chronische-aandoeningen-en-multimorbiditeit/leeftijd-en-geslacht>
- Wang, S., Liu, Y., Lam, J., & Gao, Z. (2021). Chronic Illness, Subjective Wellbeing, and Health Services Availability: A Study of Older Adults in Australia. *International Journal of Environmental Research and Public Health, 18*(15), 7718. doi: <https://doi.org/10.3390/ijerph18157718>
- Westerhof, G. J. (2013). The complete mental health model: The social distribution of mental health and mental illness in the Dutch population. In *Mental Well-Being* (pp. 51-70). Springer, Dordrecht.
- Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of health & illness, 22*(1), 40-67.
- World Health Organization. (2021). *Non communicable diseases*.
[https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases#:~:text=Noncommunicable%20diseases%20\(NCDs\)%20kill%2041,%2D%20and%20middle%2Dincome%20countries.](https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases#:~:text=Noncommunicable%20diseases%20(NCDs)%20kill%2041,%2D%20and%20middle%2Dincome%20countries.)

Zautra, A., & Hempel, A. (1984). Subjective well-being and physical health: A narrative literature review with suggestions for future research. *The International Journal of Aging and Human Development*, 19(2), 95-110. doi:

10.2190/A9RB-7D02-G77K-M3N6

Öhman, M., Söderberg, S., & Lundman, B. (2003). Hovering between suffering and enduring: The meaning of living with serious chronic illness. *Qualitative health research*, 13(4), 528-542. doi: 10.1177/1049732302250720

Appendices

Appendix A: 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 B: 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 C: 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?