

HOW PEOPLE LIVING WITH A CHRONIC ILLNESS STORY THEIR PAST AND FUTURE

How People Living with A Chronic Illness Story Their Past and Future.

How Can Connectedness, Hope and Optimism, Identity, Meaning in Life, and Empowerment (CHIME) Be Recognized in the Narratives about Past and Future Lives?

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Abstract

Introduction. Being diagnosed with a chronic illness can disrupt one's life continuity. Narratives, such as past and future narratives are useful in reobtaining a continuity of life. An example to study narratives is recovery narratives that were previously analysed with the five components of the CHIME model created by Leamy et al. (2011). These recovery narratives and the CHIME model have been applied exclusively to people living with mental illnesses. However, people living with chronic illnesses and people living with mental illnesses face similar challenges, which might indicate that the CHIME model applies to chronic illness narratives. Studying past and future narratives can help to learn more about the recovery process of people with chronic illnesses.

Method. The narratives of 30 participants were analysed. To analyse past and future narratives of people living with chronic illnesses, the thematic analysis with a deductive-inductive approach was used. Illness narratives of the past and the desired future narratives in the form of *Letters from the Future* were collected as part of a larger study. The narratives were analysed under the lens of the five components of the CHIME model.

Results. 5 themes and 15 subthemes could be established. All five components of the CHIME model could be recognized in the past and future narratives, whereby the definition of the components for people living with chronic illnesses partly deviates from the initial definitions for the components.

Discussion and conclusion. The components of the CHIME model imply to be relevant for people living with chronic illnesses. Future studies might consider the expansion or an adapted version of the CHIME model which considers people living with chronic illness. Future narratives could be relevant and valuable for chronic patients.

Keywords. Chronic illness, narratives, CHIME, past, future

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Introduction

People living with chronic diseases often must face physical and psychological complaints (Bouwens et al., 2009; Diener et al., 2019; Nilsson et al., 2016). Being diagnosed with a chronic illness provide those affected with a break in their continuity of life and previous beliefs about them and the world changed (Bury, 1982). Narratives are useful for people with chronic illnesses as they can help them to change their ways of looking at the illness experience and perhaps find meaning in it (Charmaz, 1983; Kirkpatrick et al., 1997). Recovery narratives are a specific type of narrative that help people with psychological disorders to promote personal recovery, a concept that characterizes the well-being of a person (Bejerholm & Roe, 2018; Hurst et al., 2022). For people living with chronic illnesses, personal recovery describes the arrival at a state of well-being (Heggdal et al., 2018). There is a need for promoting more personal recovery interventions for people living with chronic illnesses, because there are only a few interventions available and mostly focus on people with mental health concerns (Heggdal et al., 2018). This study aims to investigate what personal recovery means for people living with chronic illnesses by analysing past and desired future narratives to get an understanding of what they are missing and need for their personal recovery.

Chronic Illnesses and Their Challenges

Chronic illnesses, such as cardiovascular diseases, chronic respiratory diseases, diabetes, and cancer, account for the most deaths worldwide (Yach et al., 2004). According to Hajat & Stein (2018), every third adult lives with multiple chronic conditions (MCC), meaning more than one chronic condition. As reported by the World Health Organisation (WHO), chronic conditions “are not passed from person to person. They are of long duration.” and are not curable through medication (Bernell & Howard, 2016, p.2). It was

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established that by the year 2021, more than half of the Dutch population (59%) have been diagnosed with at least one chronic illness, which concerns 10.3 million people (VZinfo, 2022).

Being diagnosed with a chronic illness involve somatic and psychological challenges. The first great challenge represents being physically limited due to their condition. For instance, a person with an acquired brain injury struggles with forgetfulness or a person with chronic migraine suffers from severe headaches (Bouwens et al., 2009; Diener et al., 2019). All these diverse challenges can influence their daily functioning (Muscari, 1998). Therefore, some people with a chronic illness are (partially) dependent on or in need of the support of others to manage their daily lives (Nilsson et al., 2016). Next to physical challenges, studies describe that being physically restricted leaves people affected with feelings of anxiousness, fear, and insecurity (Nilsson et al., 2016). Those psychological challenges arise for several reasons. For example, being confronted with those physical limitations might evoke fearing the unknown and what the future might hold, as well as a possible threat of death (Lebel et al., 2020). Severe pain experienced by people with chronic illnesses might produce stress or the psychopathology of some chronic illnesses might produce mental health complaints (Katon, 2003).

Chronic Illness and Narratives

It is often difficult for people to maintain continuity of life when they are diagnosed with a chronic illness or live with it. This implies that beliefs and explanations about the world and oneself are undermined. This phenomenon is called *biographical disruption* (Bury, 1982). Narratives can be helpful in re-establish their life's continuity (Ricoeur, 1980). Additionally, people who suffer from chronic conditions may find meaning in narratives while discovering their ability to persevere through the pain or their need to re-learn skills

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(Charmaz, 1983). Furthermore, establishing such new meanings can help affected people, but also their loved ones to experience and perceive the chronic illness from a different perspective, which conveys more purpose (Kirkpatrick et al., 1997).

Narratives can also function as an intervention. An example of narratives to study could be narratives of a desired future in which a person shares at what point in life they imagine themselves to be in the future and how they got there (Sools, 2020). Being able to imagine the future can serve people in becoming more mentally flexible which could help them to view more possibilities for them in the future (Sools & Mooren, 2012). Possible positive outcomes might be that the person becomes more resilient, a resource that could be helpful when facing difficult situations (Sools & Mooren, 2012). This might be relevant to overcome anxiety and helplessness in people with chronic illnesses facing these difficulties.

Recovery Narratives and Personal Recovery

Another specific type of narrative used in research is the recovery narrative. Recovery narratives are viewed as contributing to mental health promotion (Hurst et al., 2022). The method was shown to be useful for people, as they found a way to be paid attention to by other people. In those narratives, people with mental health complaints share stories of their journey toward personal recovery (Hurst et al., 2022). The concept of personal recovery refers to enhancing the well-being of a person (Bejerholm & Roe, 2018). This includes aspects such as overcoming stigma, promoting self-confidence, and building hope (Macpherson et al., 2016). However, Macpherson et al (2016) stress the individuality of personal recovery, which can be established through narratives. For people living with chronic illnesses, the concept of personal recovery does not describe the phenomenon of curing the illness but rather the arrival at a state of well-being (Heggdal et al., 2018). Gucciardi et al. (2016) stated some needs of people living with chronic illnesses, including obtaining more knowledge about the illness itself and acquiring coping skills to overcome their pessimism and negative feelings

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about their future. Furthermore, people living with a chronic illness wish that health professionals take their complaints seriously and for being involved in important social functions, such as decision-making processes (Nilsson et al., 2016). In their paper, Heggdal et al. (2018) stress the limited research on personal recovery interventions in people with chronic conditions. A way to get a better understanding of personal recovery in people with chronic illnesses and to promote their well-being might be through analysing their narratives.

CHIME Model

A way that recovery narratives have been analysed in the past was through using the CHIME model. Leamy et al. (2011) identified elements that constitute personal recovery and as a result, generated the CHIME model. The acronym stands for five components, namely *Connectedness, Hope and Optimism, Identity, Meaning in Life, and Empowerment* (Leamy et al., 2011). The CHIME model was created through qualitative studies on mental health issues (Piat et al., 2017). The purpose of this model is to be able to assess people's recovery process regarding mental health issues and to obtain a better understanding of the concept of personal recovery (Hurst et al., 2022; Piat et al., 2017). The *Connectedness* component comprises aspects such as to what extent the person perceives themselves as having valuable relationships with others, feelings of belongingness, or being part of a community, but also receiving support from others (Leamy et al., 2011). *Hope and Optimism* are about whether the person sees recovery as a possible outcome. This includes that the person is willing to change, and the ability to think in optimistic ways. The *Identity* component considers that the person in the recovery process can overcome stigmas but also be able to redefine one's identity positively. *Meaning in Life* considers whether the person can see meaning in the illness experience. Moreover, the person can live a qualitatively good life, also regarding social aspects and having goals. The person can reconstruct his or her life. *Empowerment* is the last component of the CHIME model and is about to what extent the person can recognize and appreciate

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their strengths. Also important in this part is that the person can take responsibility but also have control over their life. If a person can fulfill all five components, that person is considered to be personally recovered (Leamy et al., 2011).

Summarising, the CHIME model is a useful tool to assess the recovery process of people with mental health issues. Through research, parallels between mental health and chronic health issues can be assumed, for example, in their non-linear recovery process where it is unclear whether a full recovery can be expected (Helliwell et al., 2022; Ng et al., 2019). This can be seen also in the effect that many mental health issues are considered to be chronic conditions (Williams et al., 2019). Therefore, as the components of the CHIME model enable an individual to manage their lives despite their mental illness, it is likely that those components can be useful for people with chronic illnesses as well, as people with mental health and chronic health issues face similar challenges. For instance, people with mental health issues have the need to be able to be involved in social functions, which is also a need found for people living with chronic illnesses (Leamy et al., 2011; Nilsson et al., 2016). Using the CHIME model to analyse chronic illness narratives could perhaps set building blocks for a potential expansion of the model to personal recovery in chronic illness patients.

Current Study

Connecting the previous parts, people living with chronic illnesses suffer from physical symptoms as well as psychological symptoms (Bouwens et al., 2009; Diener et al., 2019; Nilsson et al., 2016). Being diagnosed with a chronic illness can disrupt a person's life continuity (Bury, 1982). However, reconstructing the past through narratives, as well as formulating desired future narratives can help the person to regain their life continuity (Ricoeur, 1980; Sools & Mooren, 2012). The purpose of looking at past and future narratives in this study is to investigate what people that live with chronic illnesses are missing and what they need to personally recover. The aim is to investigate past as well as future narratives

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under the lens of the CHIME components, to identify how the components can be recognized in their narratives. This is because the personal recovery process of people living with chronic illnesses might be similar to those of people who suffer from mental illnesses (Heggdal et al., 2018). This could open the possibility to expand the CHIME model to chronic illness recovery. Both approaches of future and past narratives can help to learn more about the recovery of people living with chronic illness. A wide range of chronic illnesses is included to gain a detailed idea of the needs of various chronic illness patients.

Research Questions

RQ1: How can the components of the CHIME model be recognized in the past life narratives of people living with a chronic illness?

RQ2: How can the components of the CHIME model be recognized in the desired future narratives of people living with a chronic illness?

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Method

Describing the Original Study

This current study is based on an original study 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”) and was conducted by Sools and Coppers (2021). In this original study, among others, qualitative research data was used to gather 1) participants' illness experiences from the past and 2) their desired future perceptions using the *Letters from the Future* method (Sools, 2020; Sools & Mooren, 2012). Qualtrics was used as an online tool to collect all the data. Participants were recruited via social media platforms including *Facebook* and *LinkedIn* but also through Dutch patient organisations. The researchers also reached out to their network to look for participants, using the convenience sampling approach. Ethical approval was given by the Ethics Committee of the Faculty of Behavioural Science at the University of Twente with request number 211138.

Procedure of the Original Study

At the beginning of the study, participants were provided with general information about the procedure and purposes of the study and were invited to give their consent to participate in the study. They were informed about the possibility to withdraw from the study at any point in time. For the completion of the task, a duration of 45 min was estimated. As a first task, participants were invited to write about their experiences of living with a chronic illness. Afterward, participants were introduced to the letter from the future exercise (Bohlmeijer, 2007; Sools, 2009). For that task, the participants received guided questions (e.g., when, where) which allowed them to give detailed descriptions of their desired future. Next, participants were invited to fill out the Dutch version of the MHC-SF and were also asked to give information about their chronic illnesses and demographics.

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Participants

Participants had to perceive themselves as having a chronic illness, have fluent proficiency in the Dutch language, and be at least 18 years old to participate in this study. Sufficient digital and cognitive skills were necessary to be able to fill out the surveys and to give proper answers to the questions and assignments. The larger study consisted of 99 participants in total. To assure a thorough analysis of the narratives, a subsample of 30 participants of the total sample was selected. The narratives that provided the most detailed description of their past life narratives and desired future letters were chosen to allow for the most insightful analysis possible.

The final sample consisted of 28 women and two men, who were between 24 and 81 years old. Types of chronic illnesses of the sample included Chronic Obstructive Pulmonary Disease (COPD), Lichen Sclerosis, rheumatoid arthritis, asthma, migraine, and endometriosis, to name a few.

Materials

Narratives of the Past Life

The participants of the study were asked to share their personal experiences of how they perceive their life since the diagnosis of a chronic illness until now. In that regard, they were invited to give a detailed depiction of how this experience made them feel, how it perhaps changed them or aspects of their life, including their social or work life or engaging in free time activities.

Letters from the Future

This exercise was initially introduced as a creative writing task for people suffering a mild depression (Bohlmeijer, 2007). During this exercise, participants are invited to imagine themselves in their desired, already-realized future (Sools, 2020). They are asked to write a

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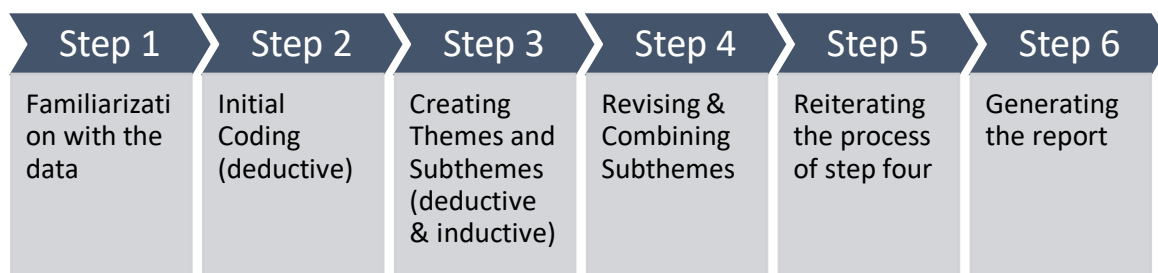
letter from the perspective of their desired future selves. In this letter, participants were invited to 1) indicate the time and 2) the location of where their future selves are, 3) to what extent their chronic illness plays a role in their future selves, and 4) to whom the letter is addressed and what message they want to send. Point three was added for the purposes of the original study.

Data Analysis

For this current study, the thematic analysis by Braun and Clarke (2012) with an inductive-deductive approach was used to analyse the data. Thematic analysis is originally an inductive approach created to search for clusters in data (Braun & Clarke, 2012). In total, the thematic analysis follows their recommended six steps. The approach is fitting for this study as this study aims to find clusters in the participant's data too. However, since this study aims to discover to what extent the CHIME components can be recognized in the narratives, the approach was adapted, starting with a deductive approach first. In Figure 1, an adapted version of the thematic analysis procedure that was used is displayed. The procedure of the adapted version of the thematic analysis was conducted two times, separately for past and future narratives, to answer both research questions independently.

Figure 1.

Adapted Version of the Analysis Steps of the Thematic Analysis by Braun & Clarke (2012).



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1. **Familiarization with the Data.** The first step involved familiarisation with the data by reading through the narratives multiple times and taking notes (Braun & Clarke, 2012).
2. **Initial Coding (deductive).** In the second step, the initial coding phase started by coding the narratives in consideration of the five components of the CHIME model, namely Connectedness, Hope & Optimism, Identity, Meaning in Life, and Empowerment. Hereby, aspects that fit into one of the components were coded, using a deductive approach. To do this, the definitions formulated by Leamy et al. (2011) for the CHIME components were used as a coding scheme. To decide on definitions for the codes, it was looked at what patterns there are within the narratives of the participants. One pattern equalled one code. Aspects mentioned by the participants that differed from the original definitions or were very specific led to the adaption of the definitions of the CHIME components according to the experiences shared by the participants. This was a challenging part since some aspects were not mentioned by everyone. This made it difficult to decide when the adaption of the scheme was necessary. Here, an adaption of the scheme was only made if an aspect was mentioned by multiple participants. The following quote serves as an example of where an adaption of the Connectedness definition was made for a past narrative:

“Precisely because my healthcare professionals were able to see me, the person instead of the patient or the condition, they were also able to give me the tools to shape my new life.” (Participant 46, woman, 51 years old, diagnosed with Guillain barre syndrome).

In this example, the definition of the Connectedness component was made more specific to receiving support from healthcare professionals.

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The application of the coding scheme looked different for past and future narratives because of the different foci in both narratives. The coding scheme for past narratives was more concerning what aspects of the components are met and which are lacking, while in the future narratives, the coding scheme had to be adapted to capture the wishes for components to be fulfilled.

3. **Creating Themes and Subthemes (deductive and inductive).** As a third step, themes were created that are the same as the CHIME components. Subthemes for each of the five CHIME components were created inductively that illustrate what a CHIME component looks like for a person living with a chronic illness. This was done by merging fitting codes into one subtheme which was generated in the second step. The challenging part was to decide which codes fit together to form a theme and subtheme. Step four and five helped to avoid any codes not to be forgotten during the process.
4. **Revising and Combining Subthemes.** In the fourth step, the focus was on revising the subthemes by going through the initially generated subthemes and revising those by merging subthemes that fit together and separating a subtheme into different themes (Braun & Clarke, 2012). Attention was closely paid to what the participants wrote when deciding on names for the subthemes.
5. **Reiterating the Process of Step Four.** As a fifth step, the process of revising subthemes was repeated several times until a final set of subthemes could be established. A final subtheme was established when there was no additional information left that indicated another subtheme. The chosen names for the subthemes relate to what participants described in their narratives.
6. **Generating the Report.** In the last step, the report of the findings was generated. For both past and future narratives, the themes equaled the CHIME components.

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The subthemes that could be established were reported per CHIME theme, starting with subthemes found for the Connectedness theme and then moving forward with the following themes. For each variation of how a subtheme could be established, one quotation was used to visualize the participant's experiences. Hereby, a quote that represented best what all participants have mentioned was used to represent the variations of a subtheme as clearly as possible. This occasionally led to selecting quotes from the same participants more often than quotes from other participants.

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Results

From the analysis, 5 themes and 15 subthemes emerged in total. The reported quotes serve as examples to exemplify the findings and are a selection of all established quotes. First, the eight established subthemes of the CHIME components for the first research question will be presented. Subsequently, the seven subthemes identified for the second research question will be presented. In the entire results section, it is referred to Leamy et al. (2011) when discussing how the CHIME components are originally defined.

Research Question 1: How can the components of the CHIME model be recognized in the past life narratives of people living with a chronic illness

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Table 1.

Results of the Analysis of the First Research Question

RQ 1: How can the components of the CHIME model be recognized in the past life narratives of people living with a chronic illness?

Theme 1: Connectedness

Subtheme 1.1: Experienced Support

Subtheme 1.2: Changed Social Life

Theme 2: Hope and Optimism

Subtheme 2.1: Optimistic Thinking

Theme 3: Identity

Subtheme 3.1: Grieving the Loss of My Old Self/ Learning to Accept My New Self

Theme 4: Meaning in Life

Subtheme 4.1: Enjoying Adapted Life

Subtheme 4.2: Feeling Useful Again by Helping Peers and Educating Health Care Workers

Subtheme 4.3: Adjusting Life to the Chronic Illness

Theme 5: Empowerment

Subtheme 5.1: (Unable to) Having Control over One's Life.

Theme 1: Connectedness

For the construct of *Connectedness*, two subthemes could be established: *Experienced Support* and *Changed Social Life*.

Subtheme 1.1 Experienced Support. Connectedness is, among other aspects, defined as receiving support from others. In the narratives, participants shared how they received (no) support. *Experienced support* could be broken down into two domains: *experienced social*

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support and experienced support from health professionals. (For each domain, different aspects of how support was experienced became apparent.)

(Lack of) Experienced Social Support. Many participants reported a lack of emotional support from other people, meaning that people did not show understanding or took the participants seriously.

"And besides having to deal with your own emotions and those of your family, you also fight against the evil outside world. It's a condition that you don't pass on to anyone, at least not as long as you can walk... so why can't you do something? Why are you sick? 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, woman, 56 years old, diagnosed with fibromyalgia and chronic fatigue syndrome)

Furthermore, another participant mentioned how other people compare their symptoms with the ones of the chronic patient. In the example provided below it seemed that this participant evaluates the comparison as if her symptom experience is not perceived as valid. This might produce feelings of their symptom experience being devalued by others, making the participants feel even less understood and, therefore, also less supported emotionally.

"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." (Participant 39, woman, 29 years old, diagnosed with persistent postural-perceptual dizziness)

Besides the lack of support experienced by some participants, several participants also wrote about how they experienced support from others. This participant provides an example of emotional support from her husband by showing understanding regarding her chronic illness.

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"Apparently there is little research on the relationship between cholesterol-lowering drugs and women's libido. So that already put quite a strain on my sexual activities. Fortunately I have the most understanding husband on earth" (Participant 24, woman, 70 years old, diagnosed with Lichen Sclerosis)

In the narratives, not only emotional support was observable. The following participant explains how her partner and friend actively help her with daily tasks, which she cannot deal with alone.

"My partner is my backup for ideas, solutions, pep talk, motivation, but is also my guide to the appointments in the hospital, with conversations at work because I can't remember it yet." [...] *"My friend picks me up, takes me to work (because I don't know the way anymore, or because of the stimuli it is difficult to go home independently)"* (Participant 125, woman, 53 years old, diagnosed with asthma and Long Covid)

Both quotes are examples of what support for chronic patients looks like. There is the observation of emotional support by showing understanding of the person's condition and active support by receiving help from friends and family.

Contrasting the stories about receiving support to the ones where support was lacking, it is noticeable that it is rather the family and friends who show more understanding for the chronic illness of a participant and rather 'the evil outside world' who do not take the participants seriously.

(Lack of) Experienced Support from Healthcare Professionals. For the following domain, two different aspects could be analysed of how patients (have not) received support from health professionals: they either received a lot of support or were not taken seriously. Starting with the support participants received, this participant provides an example of receiving active and emotional support from the healthcare professional:

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"Precisely because my healthcare professionals were able to see me, the person instead of the patient or the condition, they were also able to give me the tools to shape my new life." (Participant 46, woman, 51 years old, diagnosed with Guillain barre syndrome)

It seems important for participants that they feel seen, taken seriously, and understood. Furthermore, participants appreciated if they got an adequate amount of information about the illness and its treatment, but also guidance on how to shape their new lives as well as possible.

However, a lot of participants reported a lack of support from their health professionals. The participants have been left alone with their illness and healthcare workers did not believe patients when they were told about the symptoms. Furthermore, patients seem to not always get immediate help, but they must fight for attention to finally get some treatment. Both, emotional and active support seemed to be lacking as one participant describes:

"I have asked several agencies for help and either I don't hear back or they can't help me so it really feels like yet another battle I have to fight alone. Medically I always have to fight alone too doctors never believe things when it happens to my body and that is incredibly exhausting. A pneumothorax was not believed and it took two days before I got help"

(Participant 13, woman, 27 years old, diagnosed with Q-fever)

Subtheme 1.2: Changed Social Life. Connectedness, by its original definition, means having close relationships and being part of a community. In the narratives, participants shared how their condition influenced and changed their social life.

Due to severe symptoms, some participants experience a decrease in their social life. It is difficult for them to maintain their social life as it has been in the past because the symptoms are often too severe, and participants must cancel plans.

My social life changed. I had no energy at all and slept a lot, could not tolerate any stimuli. A party or a trip has not happened for a long time. And to this day I have to plan this

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well and often have to say no. For a social person, who likes to be everywhere, that is really difficult." (Participant 46, woman, 51 years old, diagnosed with Guillain barre syndrome)

Participants reported that their social life extinguished completely or decreased to a great extent. Participant 46 provided a clear idea of how her illness influences her social life. People often do not have the energy to engage in social activities, even though they would like to join after all. Consequently, friends of the participants react not always with compassion. A participant wrote about her experiences with friends' reactions the following:

"So many times, I felt the disappointment but also the disappointment of others to have to cancel an appointment." (Participant 9, woman, 54 years old, diagnosed with migraine)

Summing up, not being able to attend social activities and the subsequent disappointment of friends make it difficult to maintain a social life.

On the contrary, some participants mentioned that they have a pleasing social life.

"I experience much love and friendship in my life. Especially in the past year."
(Participant 11, woman, 54 years old, diagnosed with Hodgkin lymphoma)

Apart from that, participants manage to maintain a social life by connecting with people who share the same fate.

"Fortunately, the patients' association with a closed Facebook group for women turned out to be there. They have information there and a lot of fellow sufferers! Then you notice that you are not alone with this condition, and you can ask anything!" (Participant 40, woman, 62 years old, diagnosed with Lichen Sclerosus)

Connecting with other patients through Facebook groups seemed to be an important aspect for participants. Since they often feel alone in their suffering, connecting, and sharing experiences with people who suffer the same, appears to provide them with more feelings of belonging and make them feel less alone.

Theme 2: Hope and Optimism

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For the construct of *Hope and Optimism*, one subtheme could be established:

Optimistic thinking.

Subtheme 2.1 Optimistic Thinking. The construct of *Hope and Optimism* is defined as having the ability to think optimistically in life and acting toward personal recovery.

Participants mentioned in their past narratives to what extent they can think positively in life.

"Fortunately, I am an optimistic person and I can accept and experience when things are not going well, there have to be those days too" (Participant 60, woman, 49 years old, diagnosed with hypermobility)

Some participants hold an optimistic view regarding their life and future. What makes it possible for them to be optimistic is to focus on what is still working or what participants are still able to do and not directly giving up but also accepting that there will be bad days too.

A different aspect of thinking optimistically is displayed in the following example:

"Followed a rehabilitation program in [place] to learn to deal with the condition. This was not a curative treatment, but to get the best out of yourself with the condition."

(Participant 39, woman, 29 years old, diagnosed with persistent postural-perceptual dizziness)

Some participants are motivated and have the chance to get better and therefore participate in a therapeutic setting or acquire coping strategies for example. An interesting aspect Participant 39 mentions is that her goal is not to achieve a full recovery. A full recovery is not a requirement for her but the ability to become the best possible self with her illness. The optimistic angle of the participant appears to be that the chronic illness is accepted and that it is ok not to be able to fully recover because there seems to be the possibility of living a valuable life with a condition.

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Although participants seem to have the ability to think optimistically to a great extent, some participant also mentioned their concerns about the future and do not know when or how significantly the illness might progress.

"My future doesn't look good, my health/mobility will deteriorate, and I don't really expect my NAH (niet aangeboren hersenletsel) to recover any further, although I do hold out hope that it will." (Participant 86, woman, 63 years old, diagnosed with Hypermobility and acquired brain injury)

For Participant 86 and other participants, it might be uncertain when their illness might progress and to what extent. Consequently, this implies providing them with doubts about a pleasant future. Despite those uncertainties, this participant holds out hope that there may be a possibility of recovery in the future.

Theme 3: Identity

For the construct of *Identity*, one subtheme could be established: *Grieving the loss of my old self/ Learning to accept my new self*.

Subtheme 3.1 Grieving the Loss of My Old Self/ Learning to Accept My New Self.

According to the original definition, the identity construct is about being able to positively redefine one's identity. Living with a chronic disease means for some participants that the self has changed due to the illness. One participant shared the difficult part of defining her identity positively, wanting back her old and healthy self.

"I've lost myself!" [...] "I feel like I'm in a constant stream of grief. Saying goodbye more and more to what you used to be able to do and now you can't." (Participant 28, women, 56 years old, diagnosed with fibromyalgia and chronic fatigue syndrome)

However, participants also found ways to accept their new self and view it in a more positive light, as this participant demonstrates:

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"I gradually became more familiar with potholes and obstacles and learned to put my feet down better. I had learned my limits, acquired a new rhythm of life, learned to stand up for myself and accepted my new self." (Participant 20, woman, 65 years old, diagnosed with acquired brain injury)

Theme 4: Meaning in Life

For the construct *Meaning in Life*, three subthemes could be established: *Enjoying adapted life*, *Feeling useful again by helping peers and educating health care workers*, and *Adjusting life to the chronic illness*.

Subtheme 4.1 Enjoying Adapted Life. The component *Meaning in Life* entails that the person can live a life that is of quality. Participants reported that, besides their chronic condition, they can be independent and do joyful activities in life, including going on vacation.

"My life now, with an amputated left arm, is miraculously beautiful. I can, thanks to intensive physiotherapy, live very independently and enjoy a walk, going out, vacations, although a little adapted, but wonderful." (Participant 11 woman, 54 years old, diagnosed with Hodgkin lymphoma)

However, for some participants, the symptoms do not allow them to work or engage in social activities, which implies that they experience a loss in quality of life.

"Working is no longer possible, social activities are sparing, not being tired is rare and having no pain is a memory of the past. In short, it's not really living the way you imagined your life when you were young." (Participant 31, woman, 36 years old, diagnosed with rheumatism and endometriosis)

Subtheme 4.2 Feeling Useful Again by Helping Peers and Educating Health Care Workers. Originally, the definition of meaning in life also included, among other aspects, the

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ability to fulfill an important societal function. Some participants shared that they seem to lack this because they are restricted by their symptoms. In their narratives, participants explained how they were able to take on an important social function by sharing their stories to inspire others and help them overcome difficult times. The following example demonstrates how this participant was able to make herself feel useful again:

"And the best thing: I now use everything I have gained during my illness and care process to help make care more people-oriented. In addition to being a volunteer for the [name Foundation], I am also an experience sharer at the [name Foundation]. The dream of this Foundation is to make care more people-oriented by starting with care-oriented education. I tell my story and what it has done to me to, among others, (future) doctors, physiotherapists, occupational therapists, speech therapists and nurses. In these conversations we will look together at what human-centered care is and how cooperation in care works. Students can take these experiences with them in their further studies and in their professional lives. That's nice and the side effect? I feel useful again. Despite my limitations (or because of?), I have added value. And I'm happy about that." (Participant 46, woman, 51 years old, diagnosed with Guillain barre syndrome)

Subtheme 4.3 Adjusting Life to the Chronic Illness. Another aspect of Meaning in Life includes the ability to reconstruct one's life. Completely reconstructing their lives seems to be difficult for chronic patients, as their condition can impair certain skills they were once able to do. For the participants, it appeared to be more about adjusting to the condition to be able to engage in their daily tasks and hobbies as adequately as possible.

"Adjustments were made: a walking stick, I had to stop doing folk dance and started doing yoga, I started cycling more instead of walking and because I could no longer wriggle my way around, I got domestic help." [...] "I found wheelchair dancing and went along to a folk dance evening for the first time to watch and see people again. There was sadness

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afterwards that I cannot do that anymore, but also gratitude that I have danced for 20 years and now can experience the joy of dancing again, even if it is in a wheelchair." (Participant 74, woman, 49 years old, diagnosed with rheumatism)

Theme 5: Empowerment

For the construct *Empowerment*, one subtheme could be established: *(unable to) Having control over one's life.*

(Unable to) Having Control over One's Life. Having control over one's life is part of the definition of Empowerment. Participants described in their narratives how their illness controls their lives and impairs their daily functioning and responsibilities, such as managing the household:

"Physically I made good progress, but as an optimist, I had seriously underestimated the consequences of my illness. I couldn't help with the household at home, that came down entirely to my husband. The caregiving for my father also went to my husband." (Participant 46, woman, 51 years old, diagnosed with Guillain barre syndrome)

In some cases, chronic illness also influences participants' ability to work or follow their education.

"I had to admit to myself that I could no longer do my job. This took a lot of time, because I kept thinking to myself tomorrow it will be okay again. In addition to my work, I followed an education. I also had to stop doing this because I couldn't concentrate, couldn't read long texts and couldn't handle the stress of exams." (Participant 39, woman, 29 years old, diagnosed with Persistent Postural-Perceptual Dizziness)

Even though some participants experience a loss of control, other participants shared how they were able to regain some control over their lives by using medication to limit the symptoms, for example.

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"My asthma started to play a smaller and smaller role in my life and now, at the age of 27, I dare say that I have it under control with just a few medications. I do a lot of sport and work full-time." (Participant 77, woman, 27 years old, diagnosed with asthma)

RQ 2: How can the components of the CHIME model be recognized in the desired future narratives of people living with a chronic illness?

The subthemes summarized in Table 2 illustrate the participant's wishes for their desired future.

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Table 2.

Results of the Analysis of the second research question

RQ 2: How can the components of the CHIME model be recognized in the desired future narratives of people living with a chronic illness?

Theme 1: Connectedness

Subtheme 1.1: The Wish for Being Understood

Theme 2: Hope and Optimism

Subtheme 2.1: Faith in Life

Theme 3: Identity

Subtheme 3.1: A Part That Is Completely Accepted

Theme 4: Meaning in Life

Subtheme 4.1: Inspiring Peers

Subtheme 4.2: Realizing Plans

Theme 5: Empowerment

Subtheme 5.1: The Wish for Work and Education

Subtheme 5.2: I Can Do This!

Theme 1: Connectedness

For the *Connectedness* component, one subtheme could be established: *The wish for being understood.*

Subtheme 1.1 The Wish for Being Understood. Getting support from others is part of the definition of the connectedness component. In the future narratives, it became apparent that the kind of support participants wish for manifested itself in receiving care from others, including social contacts as well as health professionals.

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"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. He/she is also 100% behind that I will follow this treatment." (Participant 39, woman, 29 years old, diagnosed with persistent postural-perceptual dizziness)

Additionally, receiving care was observable as a consideration that some people with a chronic condition cannot tolerate many stimuli. In the future, the wish is that this will be considered when, for instance, public facilities are designed.

"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." (Participant 39, woman, 29 years old, persistent postural-perceptual dizziness)

Receiving care also includes people raising awareness on conditions where there is attention lacking. For the participants that means educating people about the existence of different illnesses but also researching on discovering possible treatments for those.

"Thank you all so much for expanding your knowledge and expertise about Lichen Sclerosus. Because of this, the quality of life for thousands of people, women, men and children has demonstrably improved!" (Participant 15, woman, 64 years, diagnosed with Lichen Sclerosis)

Theme 2: Hope and Optimism

For *Hope and Optimism*, one subtheme could be established: *Faith in life*

Subtheme 2.1 Faith in Life. One way people show hope and optimism is that they, besides their condition, believe that life still is valuable for them. One participant makes this explicit and says she can overcome difficult times.

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"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."

(participant 11, woman, 54 years old, diagnosed with Hodgkin lymphoma)

Nonetheless, there is also a slightly different perspective on faith in life. The following participant mentions that she on the one hand appreciates the beauty of life and takes a very positive stand towards life. On the other hand, she also takes a realistic point of view and emphasizes the possible progression of her illness.

"Do not forget that the future can bring a lot of beautiful things. Think of an adapted house/apartment with a garden in a quiet neighbourhood. Your husband running around chasing your baby. Animals that bring all the love together in the house. We have to stay realistic. 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, woman, 24 years old, diagnosed with rheumatoid arthritis and hypermobility)

Theme 3: Identity

For *Identity*, one subtheme could be established: *A part that is completely accepted.*

Subtheme 3.1 A Part That Is Completely Accepted. In their future narratives, participants considered their self has changed due to their chronic illness, as illustrated by this participant:

"I can finally slowly get used to my new, other me." (Participant 125, woman, 53 years old, diagnosed with asthma and Long Covid)

Additionally, to this quote, other participants mentioned that their illness is part of their identity, which is fully accepted.

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"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." (Participant 38, woman, 24 years old, diagnosed with rheumatoid arthritis)

The ability to accept their new selves also seems to be a result of other people accepting the 'new person' as well.

"I feel more accepted again and get a more positive self-image. Very nice that the team accept me as I am. Together you achieve more than alone." (Participant 27, woman, 51 years old, diagnosed with acquired brain injury)

Theme 4: Meaning in Life

Two subthemes could be established for the *Meaning in Life* component: *Inspiring peers* and *realizing plans*.

Subtheme 4.1 Inspiring Peers. One way how people experience a meaningful life is by embracing their illness and sharing their experiences with people who share the same fate. The following participant demonstrates that sharing experience is important. It appeared to help others to feel understood and not alone. On the other hand, the participant feels important and useful by inspiring others and helping them to deal with the illness.

"I would like to be an example for people with MS or another chronic disease. I want to inspire people and give them back their confidence in their own bodies. Staying positive is sometimes difficult but very important." [...] *"I have been writing a blog about my life with MS for a while now and I do this mainly to write about certain situations or events but I also hope to inspire other people in the future."* (Participant 21, woman, 40 years, diagnosed with multiple sclerosis and asthma)

Subtheme 4.2 Realizing Plans. Meaning in life, according to the original definition, also means that people can realize their goals, besides their condition. This was also observable in the future narratives of the participants. Making plans, in the case of the

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following participant, means that she can enjoy life again by joining activities, like going on trips.

"I am now sitting on the couch, enjoying a cup of herbal tea. I dare to make plans again, for example for holidays and weekends away. Soon we will go to Disneyland Paris. I look forward to a whole day of walking and seeing and experiencing. I'm sure it will work without attacks this time. I am so happy and grateful for that, for myself and for you too."

(Participant 30, woman, 40 years old, diagnosed with i.a. asthma, chronic migraine, and autoimmune disease)

Theme 5: Empowerment

For Empowerment, two subthemes could be established: *The wish for work and education* and *I can do this!*

Subtheme 5.1 The Wish for Work and Education. Empowerment means having control over their lives and being able to take over responsibility. In the future narratives, participants aim for this by wishing to be able to follow education or work in the future.

"My wish for you is that, in spite of your migraines, you will have the opportunity to obtain a certificate so that you can teach at an MBO school." [...] "It would be great if you could work one or two days at a college and spend time studying. Ideally you would like to work around 24 or 28 hours at the school." (Participant 9, woman, 54 years old, diagnosed with migraine)

Subtheme 5.2 I Can Do This! A different aspect of empowerment is the focus on what a person's strengths, and not on what they cannot do anymore. In future narratives, participants share how they are able to focus on what they can do.

"Last week I had the opportunity to organize a fantastic wedding with my team. We have arranged everything for the bride and groom down to the last detail. I myself helped to take beautiful pictures of the bride and groom in the park. My creativity came out well and I

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am looking forward to making a beautiful photo album for them, so they will never forget their day. Until late in the evening, our team took care of them. How proud I am of myself, that I can do this. Never thought I could work with people again, show my creativity. This makes me very happy." (Participant 27, woman, 51 years, diagnosed with whiplash)

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Discussion

The first research question was: *How can the CHIME components be recognized in the narratives about past lives?* In the past narratives, all components of the CHIME model could be recognized. For the component *Connectedness* in their past narratives, participants specifically mentioned whether they receive or do not receive support from others. This was mainly about emotional and active support. Furthermore, participants shared to what extent they were still able to keep valuable relationships and stay part of a community. *Hope and Optimism* were found in ways that participants shared the optimistic thinking they have in life, but also that they work towards recovery. Despite knowing that complete recovery is not possible, participants still hold hope that they can recover at some point. Regarding *Identity*, participants discussed how they perceive their new selves and that some people struggle with accepting and viewing themselves in a positive light, while others mention that they can see themselves in a positive light. For participants, *Meaning in Life* included the aspect of being able to live a life that is of quality. Additionally, participants shared how they have been able to make themselves feel useful again by taking on an important social role. Reconstructing life, as part of the component, was less about getting back to the exact structures of how their life looked like before receiving the diagnosis, but about being able to successfully adjust their lives to their chronic illness. Regarding *Empowerment*, it became apparent that some participants can have control over their symptoms and therefore, also control over their lives, whereas other participants are controlled by their symptoms and have less control over their lives.

The second research question is: *How can the CHIME components be recognized in the narratives about future lives?* In the narratives about future lives, aspects of all five components could be recognized. *Connectedness* was found to be about receiving care from others. This included that participants feel understood and seen and that outside people raise more awareness about certain illnesses. The *Hope and Optimism* component was about positive thinking as well.

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Participants share an optimistic perspective about their future lives, including the ability to overcome challenges. Despite their knowledge that their illness will progress, they hold a positive perspective on how to enjoy life, nevertheless. Regarding *Identity*, participants in their future selves consider their illness as part of themselves, which is fully accepted. Because other people accept the new version of the participants, it makes it easier for participants to also accept their new selves. *Meaning in Life* was found as means of taking on an important social role and inspiring people by advising them on how to go on with life. Additionally, enjoying life was also a finding in which participants mention their ability to engage in valuable activities. *Empowerment* in the future narratives means for participants their ability to take on responsibility and be able to work or follow education. Another point mentioned in the future narratives was that participants focus on what they still can do.

To conclude, both research questions could be fully answered, and all components of the CHIME model were able to be identified in the past and desired future narratives. Some aspects are similar to those who live with psychological disorders, while some aspects differed from the original definition of the components.

Differences and Similarities to Psychological Disorders

The CHIME model was initially created to examine the personal recovery of people living with a psychological disorder. For the possibility of expanding the model by including chronic illnesses, this excerpt aims to compare similarities and differences in the important aspects of recovery for psychological and chronic illnesses. In Table 3, a summary of the comparison can be found.

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Table 3.

Meaning of the CHIME components for people living with a mental illness and people living with a chronic illness in comparison.

Component	People living with mental illness	People living with chronic illness
Connectedness	Need for active and emotional support Not necessarily a need for physical Do not want to be labelled as a 'sick person'	Need for active and emotional support Need for physical support Want their condition to be acknowledged
Hope and Optimism	Achieving life goals	Achieving life goals
Identity	Re-establish a positive self-image Overcome stigma	Re-establish a positive self-image Overcoming stigma is not discussed in narratives
Meaning in life	Sharing stories of their recovery process Rebuild their lives	Helping others to deal with their illness Adjusting life to their illness
Empowerment	How to use their strengths to work toward recovery	Appreciating what they are still able to do

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Connectedness

The connectedness component seems to look very similar for people with mental and chronic illnesses. Especially the support aspect seems to be very similar. People with chronic illnesses were found to need active but also emotional support from others. In a study conducted by Piat et al (2017), participants with mental illnesses were also found to benefit from the active and emotional support of others, enabling an easier recovery. A slight difference here includes that due to their limitations, people with chronic illnesses are more in need of physical support. This is plausible as their symptoms manifest themselves as bodily symptoms, whilst people with mental illnesses are not necessarily physically impaired. Another difference could be found in the way the people want to be looked at. While in a study conducted by Hurst et al. (2022), people living with a mental disorder wish to not be seen as a person that is sick, participants of this study stressed the necessity of acknowledging their condition and want more awareness to be raised. These participants wish that there is more education about the existence of such illnesses and that there is more research done on the treatment possibilities of those. This might be because of the still-existing stigmatization and, therefore, potential discrimination of people with severe mental illnesses, which could lead to negative self-images in those affected (Ross et al., 2019).

Hope and Optimism

Leamy et al (2011) defined hope and optimism as the possibility to view recovery as a realistic outcome. However, the findings of this study and the study by Hurst et al. (2022) both imply that for both, people living with a mental and chronic illness, different aspects of hope and optimism can be encountered than simply the possibility of recovery. Examples include achieving life goals or engaging in valuable activities (Hurst et al., 2022).

Identity

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For people living with a mental disorder, part of the recovery is the ability to re-establish a positive self-image (Jagfeld et al., 2021). Just as people living with psychological disorders, participants in this study also demonstrated in their narratives the value of accepting their new selves and the ability to obtain a positive self-perception. Being able to overcome stigma did not seem to be of great importance for the participants. This might be because there are not as many stigmas as with mental illnesses (Ross et al. 2019).

Meaning in Life

Aspects that contribute to the ability to recover from a mental disorder are the ability to take on an important social function and see a meaning in their illness (Leamy et al., 2011). Being an inspiration for others and helping them how to deal with a chronic illness was a reoccurring aspect found in the narratives of the participants. This gives them a sense of feeling useful again. While for people living with chronic illnesses feeling useful again means helping other people dealing with their illnesses, for people living with mental illnesses it means sharing their stories of how they recovered (Hurst et al., 2021). Leamy et al. (2011) found that another aspect of meaning in life included the ability to rebuild one's life. The findings in the narratives yield that for people living with a chronic illness, it is not about completely being able to rebuild their lives, since this is sometimes simply not possible due to physical restrictions. In the narratives, it became apparent that for them it is more about adjusting to their illness than being able to get back to their lives as it was before their diagnosis.

Empowerment

Regarding empowerment, a noticeable difference in the recovery process of people with psychological and chronic illnesses is the way people focus on their strengths. For people with a psychological illness, the focus is on how they can use their strengths to recover from their illness (Hurst et al., 2011). On the contrary, for people with a chronic illness, it is more about appreciating what one is still able to do or is again able to do, considering their condition. Again,

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this might be because chronic illnesses come along with physical restrictions, while psychological disorders do not necessarily.

Comparison of the Meaning of Recovery in Past and Future Narratives

This section addresses the similarities and differences in the meaning of recovery in the past and future narratives.

In the past narratives, it became apparent that the process of personal recovery is different for some participants. For all CHIME components, some participants are far in the process of personal recovery, while other participants have difficulties working towards it. The reason for this might be the severity of symptoms for some participants. Especially in the Connectedness, Hope and Optimism, and Empowerment components, reaching personal recovery is partially linked to clinical recovery. To give an example, some participants mentioned that they need more rest and cannot engage in social events the way they used to due to the severity of their symptoms. The consequences partially lead to a decrease in social belongingness. This means that personal recovery sometimes seems to be out of the participants' control to some extent, due to their symptoms. In the future narratives, on the other hand, participants view themselves as reaching personal recovery in all of the components and are less focused on the clinical recovery aspect. This became especially observable in the Hope and Optimism component, where positive thinking is less linked to symptom reduction like it is a focus in past narratives, but rather focused on other positive outlooks in life, such as enjoying family.

Reflecting on the questions used to elicit past and future narratives, the future narratives have helped obtain an idea of what the participants wishes and needs for their future lives are. The past narratives helped to understand what is missing in their lives. Together, both past and future narratives supplement each other well as they provided a comprehensive understanding of what is missing and what is needed for a potential personal recovery in people living with a

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chronic illness. Additionally, the future narratives illustrate that there is a possible mindset for reaching personal recovery. Especially for the Hope and Optimism component, the comparison yields that people are indeed able to alter their minds to achieve personal recovery.

Strengths and Limitations

Several strengths and limitations in the methods used and analysis conducted could be established.

A first strength of this study was the great number of findings considering the CHIME components. This leads to the assumption that the components of the CHIME model seem indeed relevant for people living with a chronic condition. Moreover, the thematic analysis approach of Braun & Clarke (2012) was a good choice for this research as it allowed for a structured analysis of the narratives considering the CHIME components. Especially the steps of creating initial themes and revising themes made it possible to get a structured overview of the findings. Furthermore, the deductive-inductive approach allowed for a guided analysis by focusing on the CHIME components. Specifically, the inductive approach allowed for deviating from fixed definitions of the CHIME components. This was especially helpful while coding aspects of narratives that indicated specific meanings of the components for people with chronic illnesses and that did not exactly meet the definitions of the CHIME component. This flexible approach made it possible to also consider other important findings in the narratives that did not fully fit with the initial definitions of the CHIME components. Nevertheless, a difficulty arose while applying the thematic analysis with the CHIME model. The thematic analysis approach provides a detailed and structured guideline for how to analyse data inductively (Braun & Clarke, 2012). Since this study started with a deductive approach, it was difficult to apply this as there are no clear guidelines on how to do the analysis deductively. This could have possibly resulted in an irregular coding approach. Another difficulty that resulted from the deductive approach is that everything that was analysed was a matter of interpretation and does

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not guarantee a completely reliable result. To counteract the risk of unreliable results, it was tried to stick to the same patterns of how the written passages of the participants were interpreted by specifying which aspects belong to which CHIME component. Furthermore, the definitions for the CHIME components formulated by Leamy et al. (2011) helped as a guide to make the results as reliable as possible. Another difficulty was the decision-making of when to use a deductive and inductive approach because there were not any guidelines either. This was a problem when deciding on the themes and subthemes. Besides, since the analysis started with using a deductive approach, other important information, that does not directly fit into the components of the CHIME model might have been overlooked.

Reflecting on the sampling methods, it was noticeable that the sample almost exists of women only. This is an important aspect to consider, as the findings only represent the experiences of the woman. Consequently, it is not possible to say something about the experiences and needs of men that live with a chronic illness. Furthermore, while deciding on narratives, attention was mainly paid to how detailed the description of the narratives was. This is valuable as it allows for an insightful analysis of the experiences of the participants. However, narratives that were not that detailed but could have contained valuable information were neglected.

Implications for Future Research and Health Care

A first piece of advice for future studies would be to conduct a thorough analysis of the comparison of past and future narratives, which were missing in this study. This could help in obtaining a more detailed picture of the recovery process. Next, more studies should investigate how the CHIME components can be recognized in past and future narratives, as was done in this study, to potentially validate the findings made in this study and to possibly obtain more insights that might have been overlooked in this study. This would be also necessary to evaluate if more aspects need to be included in case future studies plan on expanding the CHIME model

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to chronic illnesses. It might be valuable to also include the male population, to receive a clearer and more distributed idea of the needs of people living with chronic illnesses. Healthcare systems could pay attention to the wishes addressed in this study when treating people with chronic illnesses.

Conclusion

This study contributed to the research on people living with chronic illnesses. It provided insight and understanding of the recovery process and progress of people living with chronic illnesses by studying past and future narratives. Future narratives helped obtain an overview of the participants' outlooks on their personal recovery process. The components of the CHIME model imply to be relevant to the target population. However, the definition of the components within the context of chronic illness partly differs from the initially established definitions. Future studies might consider further research on the expansion or an adaption of the CHIME model, which includes people living with chronic illnesses.

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Appendix A

Instructions for the narratives of the original study

Illness narratives

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

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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.

Letters from the Future

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.

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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?