



**The Temporality of Illness Experience:**  
How People with Chronic Illness Narrate their Past and  
Future

**UNIVERSITY OF TWENTE.**

Master Thesis Positive Clinical Psychology and Technology

by

Henriette Höhne

s2604132

Department of Psychology, Health and Technology

Faculty Behavioural, Management and Social Sciences

---

*First Supervisor* Dr. A.M. Sools

*Second Supervisor* Dr. H. Toivonen

*External advisor* Jacqueline Coppens (MSc)

*1<sup>st</sup> February 2022, Enschede*



## **Acknowledgement**

I want to express my gratitude towards all people involved, who made an important contribution in the completion of my Master Thesis. First and foremost, I want to thank my thesis supervisors Dr. Anneke M. Sools, Dr. Heidi Toivonen and Jacqueline Coppers for their valuable feedback, assistance in data collection and analysis, inspiration and dedication of time and thought. I wish to express my sincere thanks to all the participants, who shared their stories and gave insight into their journey of living with a chronic illness. These stories form the centrepiece of this research.

## Abstract

Life stories can suddenly be disrupted by events that challenge one's understanding about the self, others and the world. Being diagnosed with a chronic illness can be regarded as such a disruptive life event. Living with a chronic illness affects how people look back to their past and construct meaning around their illness. The various ways how people with severe illness tell their stories has been outlined by Arthur Frank's three typologies of illness narratives (restitution, chaos and quest). However, as chronic disease implies the permanence of illness, a prospective narrative approach is needed to account for the human capacity to imagine a future, when the previous plans and hopes for the future might no longer be feasible. Following a narrative approach, the purpose of this study is to better understand how personal stories about the past and the future as well as the perception of time can be disrupted and reconstructed as a result of chronic illness experience. To develop a clearer understanding of this interrelation, we make use of narrative life-review as well as prospective methodology, called *Letters from the Future*. On the basis of a total sample of 32 narratives, collected online among Dutch people with diverse chronic illnesses, we identified variations in *(dis)continuity in narrative genre* as well as in *future time perception* (immediate, distant, nostalgic). A combination of both types of (dis)continuity revealed five different categories, with distinct themes and functionalities of future imagery. This study makes an important contribution in rethinking Frank's illness narratives by acknowledging the relational and communal aspect of living with a chronic disease. The findings call for greater attendance to the subjective experience of people with chronic illness in health-care and collaborative work of researchers and policy-makers in addressing the needs, burdens and wishes of those people accordingly.

*Keywords:* Chronic illness, narrative, future imagery, temporality, letters from the future

## 1. Introduction

“I hope to give readers understanding and recognition through my story. I hope to motivate those affected. Keep fighting, never give up and still try to push your limits a little bit every time. I want to share my story with care workers and care workers in training. To give a glimpse behind the emotional scenes of someone with brain damage.”

- Irene (participant, 75-years old)

Chronic illnesses, such as cardiovascular diseases, diabetes and cancer are responsible for approximately 70% of all deaths worldwide (World Health Organization [WHO], 2019). In the Netherlands, around 32% of the population lives with a chronic illness and the percentage is expected to increase up to 40% in 2030 (Public Health Forecasting Report, 2014).

According to the Centers for Disease Control (CDC, 2021), chronic diseases are defined as “conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both”. Besides representing a global health burden, they also imply a major disability burden for people living with a chronic condition, affecting physical, mental, emotional, social and occupational aspects of people’s lives (Hwu, 1995; Megari, 2013; Charmaz, 1983)

Living with a chronic illness or getting diagnosed often resembles a major break of the continuity of life and undermines previously held beliefs and explanations about the self and the world. This has been conceptualized as *biographical disruption* by Bury (1982). He is the first sociologist who began research into the various ways in which chronic illness can disrupt one’s assumptions, beliefs and plans. One way in which people process a disruption of daily structures and knowledge, is by using narratives (Ricoeur, 1980). Narratives help to create a sense of coherence, unity and purpose from otherwise disparate events. Moreover, Ricoeur (1980) emphasizes the interrelatedness of narrative and time, in the sense that human experience cannot be separated from a temporal framework in which it is situated. Still,

narrative research is mostly focused upon past experiences, reminiscence and meaning-making (Sools & Mooren, 2012) leaving the future as a relatively under-researched area of narrative investigations. Especially with respect to chronic illness, which has a long-term or life-long impact on people's life, anticipating a future when people's life story is disrupted by illness, would be an important topic of research. As life stories tend to include beginnings, middles and endings, the way people make sense of their past might affect their vision of the future. Likewise, having a changed future perspective requires a new sense-making and interpretation of the past in the light of present and future concerns. A better understanding of how people living with chronic illness narrate their past, present, and future can help improving health care services and better quality of life for those concerned.

### **1.1 Chronic Illness as Threat to Self and Meaning**

Chronic illness is not limited to physical distress, including coping with bodily symptoms or attending medical appointments. It also has a profound impact on the persons' identity, social relationships, working lives, plans, and expectations for the future, mental health, and every-day routines (Van Bulck et al., 2019; Prefontaine & Rochette, 2013; Turner, 2000). People might be more dependent on the help of others, adjust their daily structure to their physical needs, encounter suffering or even be confronted with the finiteness of life. Especially the growing dependency on family, friends, or societal networks can be experienced as threatening and deeply disrupting in a society, which values autonomy and reciprocity (Williams et al., 2019; Bury, 1982). In addition, chronic illness also entails a rethinking of plans and expectations previously held for the future (Brown & de Graaf, 2013; Ezzy, 2000). Another critical construct in research on the psychological impact of chronic illness is the sense of self or identity (Golub et al., 2015). Foundational research in this field was done by Kathy Charmaz (1983), who found that as a result of the chronic illness, people might encounter social isolation, stigma, and daily restrictions. Thereby, people can

experience low self-esteem and a *loss of self*, which she described as ‘former self-images crumbling away without a simultaneous development of equally valued new ones’ (Charmaz, 1983). Both, Bury (1982) and Charmaz (1983) got their insights through lay experiences of patients with chronic illness. The study of subjective insights of illness experience forms an alternative to the objective or ‘outsider’ perspective dominant in the medical system, through understanding and informing decision-making processes in health care practices and establishing new guidelines in research practice (Dohan et al., 2016).

Together, these accounts make two relevant claims. First, the notion of a disruption of biography and self presupposes a sense of global meaning (Lee, 2008). This refers to an incorporated life schema, which is meant to provide purpose and meaning in life, such planning ahead based on the expectation that there will be a tomorrow. This set of assumptions remains intact and unquestioned until moments of profound change happen, such as being diagnosed or having to live with a chronic illness. It represents a break in the expected continuity of life. Second, not the illness itself, but how individuals perceive and interpret it, defines their illness experience and coping style. Narrative research invites individuals to share their stories and personal experiences in their own words and it helps to uncover themes that might emerge within the relationship of participant and researcher. This method allows for understanding how individual knowledge generated and how experience is processed.

## **1.2 Illness Narratives**

If chronic illness disrupts the sense of temporal continuity of life, narratives can be seen as one possibility to create a meaningful whole from the fragmented pieces. An illness narrative is “a story the patients tell, and significant others retell, to give coherence to the distinctive events and long-term course of suffering” (Kleinman, 1988). Telling stories and being listened to gives the patient an active role in health care, gives insight into their coping

style, helps to derive meaning from their experiences, and enter relationships (Gucciardi et al., 2016).

With respect to chronic illness, a similar account has been proposed by Arthur Frank (1998). To understand the lived experiences of individuals with chronic illness, Frank (1998) differentiates between three narrative story types, namely *restitution*, *chaos*, and *quest narrative*. He suggests them be understood as ‘useable pathways’, as means to find a way through one’s current situation.

The basic plot of a restitution story centres on the diagnosis and treatment: everything that has been done, that is currently being done and will be done, if treatment fails. The illness is deemed negatively and as something to be ‘conquered’ (Frank, 1998). This form of recovery narrative dominates our western cultural narrative, which holds that for each disease, there is a cure (Frank, 1995; Lupton, 2003). Among chronically ill, restitution stories are rarely evidenced (Frank, 1995), as they “no longer work” when illness is chronic. Especially, because a chronic condition undermines the possibility to overcome illness, people might feel intimidated or marginalized if they fail to satisfy the restitution narrative (Frank, 1998).

The chaos story, so Frank (1998), is told by the ‘deepest ill’. This narrative is characterized by lacking a sense of control and perceiving none of their actions as having an effect on the course of the disease. This also becomes apparent in a rather fragmented narrative or how Frank (1998) put it: “Seriously ill people are wounded not just in body but in voice”. Chaos narratives among chronically ill persons are found when they experience severe symptoms and sudden and intense relapses setting them back into a state of debilitation, frustration, and uncertainty (Whitehead, 2006).

Finally, unlike the first two story types, illness and suffering is accepted and given a sense of meaning in the quest story. Without denying the burden or chaos of the chronic condition, it acknowledges the valuable change the illness brought about in people’s life. People telling a quest story express a high sense of agency, a sense of ‘reclaiming one’s life’,

gratefulness and unconditional acceptance of life conditions as they are. It often includes ‘giving up the old self’, finding meaning in suffering and appreciating remaining or new opportunities. In terms of chronic illness, Synnes et al. (2020) illustrated how patients with chronic illness sustain their stories in vulnerable situations. Across four patient groups with different medical backgrounds, it was shown that despite the experienced burden and fragility, their stories also visualized means of carrying on and a sense of agency to living well with the disease. It supports Frank’s notion about the possibility to gain new insight about the self and what can be reclaimed, bearing the potential for growth and development (Carel, 2007).

### **1.3 Relevance of Time**

Taken the previous findings and theories together, it becomes clear that time is inherently related to the experience of chronic illness. The biographical disruption does not only challenge past beliefs about ‘who I was’, but also imply the question about ‘who I am’ and ‘who I will be’. This subdivision seems to occur naturally for people with chronic illness, as a consequence of making this burden more manageable (Hannum & Rubinstein, 2017). The subjective experience of illness becomes fragmented into smaller pieces, indicated by time, such as time before being diagnosed, illness onset, treatment phase, resolution, and expectations for the future (Hannum & Rubinstein, 2017). Illness narratives offer an opportunity to tie these pieces together within a temporal framework.

In this context, the future takes on a central significance. Constructing meaning around an illness experience, presupposes a revision of past and future concerns in the present. Now that the expected life story is disrupted and can no longer take place, a more direct focus on how people with chronic illness make sense of this newly confined future life is needed. Getting diagnosed or having to live with a chronic illness that encompasses giving up or reducing former activities, social or working life can come with a wealth of uncertainties. Especially in situations of uncertainty or where people have a high need for certainty,



explicitly inviting them to tell a story about their future can be helpful for enhancing resilience and guiding “current thought and action” (Sools & Morren, 2012). Imagining a desired future allows taking a step back from the current situation and getting an overview of where we are and where we want or imagine us to be. Hopes, dreams and expectations about the future can provide useful insights into how people with chronic illness make sense of their past and present. Thus, one might even venture to say that the experience of chronic illness cannot be fully understood without the consideration of time and especially of the future.

#### **1.4 The Current Study**

So far, two main conclusions can be drawn from the collected evidence and lines of reasoning. First, how people cope with chronic illness can be viewed as a personal journey or story. The way people narrate their illness experience can be understood in terms of their ‘valued ending’ (Gergen, 1994, p. 190) as well as a ‘useable pathway’ in the search for meaning (Frank, 1998). Narratives can create a meaningful whole from what would otherwise be disparate events. Second, human experience is about living in time and as chronic illness implies a long-term condition that often demands life-long adjustments to new situations, disabilities, and restrictions in the light of uncertainty and unpredictability, the future becomes a highly relevant topic to investigate. The central question is therefore, how past and future narratives of people living with chronic illness are related, with regard to narrative genre and temporality of the future imagery. Bringing together the empirical and narrative study of past and future might broaden the scientific understanding of how chronically ill people make sense of their lives. Moreover, understanding people’s illness experience in terms of their imagined future might support health care practitioners to identify possible needs, capacities, and resources of patients with chronic illness.

## **2. Methods**

This was an empirical web-based study, using past and future narrative methodologies for data collection and qualitative comparative data analysis methods for the written narratives. The data collection took place between the 19<sup>th</sup> October 2021 and 9<sup>th</sup> November 2021.

## **2.1. Description of the Larger Study**

The current study was part of a larger 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’). It was composed of qualitative forms of data collection, involving writing exercises about the illness experience living with a chronic illness and the desired future using the *Letters from the Future* method (Sools & Mooren, 2012; Sools et al., 2015; Sools, 2020); as well as quantitative forms of data collection by means of a questionnaire measuring mental health in terms of emotional, social, and psychological well-being (Mental Health Continuum-Short Form in Dutch, MHC-SF) and general data about their chronic illness, age, gender, occupation and living situation.

The data was collected via the online Survey tool Qualtrics, which was distributed by means of purposive sampling among the personal and professional networks of the researchers, social media platforms like Facebook and LinkedIn, and Dutch patient- and health care organizations. A short flyer and an information letter offered further details about the background and purpose of the study, eligibility criteria, and content of the survey, benefits and burdens of participation, confidentiality, and information on the research team. Ethical approval has been granted by the Ethics Committee of the Faculty of Behavioural Sciences at the University of Twente with the ethical request number 211138.

## **2.2 Participants**

The inclusion criteria were that the participants perceived themselves as living with a chronic health condition, were able to comprehend and write in Dutch language, had sufficient digital skills to fill in an online survey as well as cognitive skills to reflect upon the

past and imagining the future. Participants needed to be at least 18 years old. As some chronic illnesses, such as acquired brain injury might come with severe cognitive impairments and thus participants with such diseases would not be eligible for this study, participants were asked if they meet the inclusion criteria prior to the survey. Two narratives have been excluded from the analysis, because they did not provide sufficient material to be analysed; one did not mention anything about a chronic condition, whereas the other did neither contain a narrative about the past nor about the future.

The total sample to be analysed (N=31) consisted of 28 women and three men with the age ranging from 24 to 81 years. The chronic illnesses included a variety of physical chronic conditions, such as migraine, cancer, multiple sclerosis, lichen sclerosus, Q-fever, cerebrovascular accident, fibromyalgia, endometriosis, and chronic pain and two mental chronic conditions, namely schizophrenia and bipolar disorder.

### **2.3 Procedure**

Participants were asked to read the information letter and give active consent to take part in the survey (Appendix A). If consent was obtained, participants were asked to compose a story about their personal experience of being diagnosed with a chronic illness (Appendix B). Subsequently, participants could indicate with which of the three illness narratives by Frank (1998) they identify most. Thereafter, participants were given a short introduction about writing a letter from the future and were provided with several questions (when, where, to whom, with which message) to help them compose the letter in the end. They were then asked to fill in the Mental Health Continuum Short Form (MHC-SF, Dutch version) and to answer several questions about their chronic illness and general data (e.g. age, gender, education, employment, relationship status). At the end of the survey, participants were asked to indicate whether they wish to be invited for the second phase of the research project, which involves in-depth interviews, based on their responses in phase one. The completion of the

whole survey took the participant approximately 45 minutes. In case participants wanted further information about the study, experienced difficulty or needed help at any time during the survey, they could contact the researchers via email or telephone. If participants wished to withdraw from the survey, they could do so at any time without providing a reason. Participants were not reimbursed and did not receive incentives for taking part in the first phase of this research project. Nevertheless, the possibility exists that being heard or listened to could have beneficial effects for the person telling the story (Frank, 1998).

## **2.4 Materials**

### ***2.4.1 Letters from the Future***

The *Letters from the Future* (LF) exercise has its origin in health promotion as creative writing exercise among older people with mild depressive symptoms (Bohlmeijer, 2007). The task was to imagine travelling into the future with a time machine and write a letter back from the future to the present (Appendix C). The moment of time in the future as well as the addressee of the letter was self-chosen. Participants were asked to creatively imagine a desired future as if it has already been realized. To help them visualizing and writing the letter, they were given five prompts, which were 1) the time in the future from which they write the letter, 2) the place or environment they travel to and how they describe it in terms of sensations, 3) if their chronic illness plays a role and if so how, 4) the receiver of the letter and 5) which message they wish to convey to the receiver. For the purpose of this study on chronic illness, the third prompt was added to the original instruction of the LF exercise.

## **2.5 Data Analysis**

The qualitative analysis was conducted in a three-step procedure. First, continuity and discontinuity were investigated by referring to Frank's three genres of illness narratives (restitution, chaos, and quest) and investigated on two levels of analysis. On a holistic level,

the narratives were looked at as a whole narrative, thus combining past and future narrative, to identify (dis)continuity in terms of the three illness narratives by Frank (1998). However, this strategy was not applicable throughout all narratives, because in case of discontinuity, a closer look on how the discontinuity is expressed was necessary. This required a second level of analysis focussing on past and future narrative separately. Both levels had to be applied in order to determine (dis)continuity of narrative genre(s). For the past narratives, participants' self-reported answer to the question about their illness narrative was used as an orientation and carefully examined. In case of differences between self-reported and analysis of the genre, it was investigated whether a mixture of narrative genres could be applied or whether the indicated genre becomes more explicit in the future narrative. When applying Frank's illness narratives to the concept of continuity and discontinuity, special attention was paid to Frank's caveat that the narrative types intertwine and rarely occur in their pure form. Moreover, each illness narrative is honoured in its own right and understood as a "story they need to tell in order to work through the situation in which they find themselves" (Frank, 1998).

Taken together, *Continuity* in narrative genre has been identified, if the narrative genre of the past was maintained in the future narrative. In some cases these were pure forms of e.g. quest or restitution narratives. In other cases, a mixture of two or more genres reappeared as such in the future narrative. *Discontinuity in narrative genre* was observed, if the narrative genre of the past differed from the narrative genre of the future, e.g. moving from a chaos story in the past to a quest story in the future.

In a second step, the focus lied on the *future time perception*. Hereby, direct use was made of the participants' response to the prompt about *when* their dreamed future takes place. Future time perception refers to the timespan between the moment the story is told (present) and the moment in time when the desired future takes place. In most cases, the future time was explicitly mentioned by the participant (e.g. "in 10 years"). In cases where no information

was given or was not specified (e.g. “when I’m out of hormones”), further information about the time could be deferred from the broader context of the future imagery as well as the tense used. Taken together, future time perception is not confined by temporal distance per se, but also involves how the participant perceives his or her future enacted and the temporal orientation of the future narrative.

Finally, (dis)continuity in terms of the three genres and future time perception were plotted against each other and main themes for each category have been identified. An overview of the distribution of (dis)continuity in narrative genre and future time perception is presented in Table 1.

The data analysis was performed using the software ATLAS.ti 9.0 as an organizational tool for the coding process. Further, as the data was collected in the Netherlands, the original language was Dutch, which is not the mother tongue of the researcher, although familiarity with the language exists. As a support, the online translator machine DeepL was used for translation into English language. In addition, any inconsistencies in translation were corrected by the external advisor, who is proficient in Dutch and English.

### **3. Results**

An overview of the distribution of narratives according to (dis)continuity of narrative genre and future time perception is presented in Table 1. The main finding constitutes that narratives differ with regard to continuation of (1) narrative genre and (2) future time perception, e.g., when the future is perceived to take place.

First, a difference has been found as to whether participants maintained the same narrative genre throughout the past and future narrative (*continuity*) or whether there was a break in narrative genre between the past and future narrative (*discontinuity*). Although many narratives did not show a pure form of Frank’s narrative genre, a dominant narrative genre or a mixture of narrative genres, could be identified. For nearly half of the discontinuous

narratives (n=5), none of Frank's illness narratives could be applied to the future narrative, but required other definitions of categorization. These will be explained more in detail in the following sections. In four narratives, no letter from the future was given, but they were included in the analysis, because it contained valuable information about the future in the past narrative or in the prompts about the future.

Second, three different kinds of future time perception could be inferred from the question about when the preferred future takes place: 1) Fifteen participants envisioned their future in the here-and-now or in close temporal proximity (*immediate*), e.g. looking prospectively towards the future or equalizing the present with the future ("now is my future with a positive outlook on life"); 2) A sample of fourteen participants envisioned their future temporally *distant* from the present, ranging from a couple of months to 10-20 years; 3) Two participants imagined their future in the past, meaning that they wished to return to a prior state of being and living their future in the way they envisioned it before the chronic illness or treatment occurred. In line with previous research by Bradbury (2012), this has been termed *nostalgia*. Importantly, this term does not mean to return to the past, but to imagine a future that has not been enacted or could not unfold due to unexpected life events.

In the following, a short description about the main characteristics of each category will be given and substantiated by one narrative, representative for each category.

**Table 1**

*Summary of the Distribution of (Dis)continuous Narratives according to Frank's Narrative Genres and Future Time Perception*

	Future Time Perception			N
	Immediate	Distant	Nostalgia	
				19
Continuous	Quest - Gratitude and acceptance of the present moment (n=8)	Restitution - Call for social action (n=9)	Chaos - Empty future and longing for the past/ Nostalgia (n=2)	
Discontinuous	Becoming an agent and envisioning a path (n=7)	Connectedness and envisioning a goal (n=5)	(n=0)	12
	15	14	2	31

### **Continuous narratives**

#### *Category 1: Quest - Gratitude and acceptance of the present moment*

The majority of the narratives (n=5) belonging to this category have a quest narrative as dominant genre, whereas the other narratives (n=3) constitute a mixture of quest and restitution narrative. Commonly, these narratives display a high sense of purpose, acceptance of the illness, gratitude, appreciation of life and a transformation of personal values and qualities. Moreover, it was found that these narratives mostly involve phases of restitution and chaos throughout the storyline, thus reading as a journey of losing and finding coherence. This includes initial denial or struggle waiting for a diagnosis, dealing with uncertainty and loss, undergoing several treatments and experiencing suffering and loneliness. In contrast to



other narratives, however, participants seem to have gained something from the illness and the overall tone was accepting, thankful and positive. Examples of insights include the importance of friendship as resource, deepening of relationships, discovering strength and resilience to overcome difficulties and the value of enjoying the present moment.

The future is perceived as taking place in the present moment, often using present tense or future tense to express hopes and dreams for the future. Indeed, many wish that in the future there will be more understanding for and awareness of living with a chronic condition, that medication will be helpful in stabilising the course of illness or that they will maintain good relationships with other people. Nevertheless, these goals are rather abstract and welcomed as making life more pleasant, but are secondary to what they consider most important in life.

Additionally, in six letters from the future, the participants share a high concern for others. They wish to encourage others, who share a similar fate or want to increase the knowledge and attention by caregivers. The participants wish to be an example and inspiration for others, by telling their own story. These letters are characterized by high empathy and solidarity for fellow sufferers, encouragement to become aware of one's resilience and optimism for new opportunities. Two participants did not write a letter from the future, but the appreciation and importance of a social environment were visible throughout the narrative.

Representative of this category of narratives is a story told by Marian, a 54-year-old woman, who underwent several operations and chemotherapies due to a malignant tumour underneath her collarbone. As a last resort to prevent further growth of the tumour, she got her left arm amputated. After sharing her medical story, she describes her personal experience as follows:

- 1 *“This experience has certainly affected my life. My husband and I have remained childless,*
- 2 *but because of this we have been able to make many wonderful trips and live a nice life*

3 *together with dear family, friends and neighbours. I have a positive outlook on life, partly due*  
4 *to these experiences, and I can enjoy life to the full. I experience a lot of love and friendship in*  
5 *my life. Especially in the past year. Because I am now thinking again about my future plans in*  
6 *terms of work, I came up with the idea of sharing my story. Perhaps it can inspire others to*  
7 *take control of their own lives, never give up, to want to find .... opportunities. Maybe it can*  
8 *inspire students to become good at what they do, save lives or help people find their lives*  
9 *again. My life now, with an amputated left arm, is miraculously beautiful. Partly thanks to*  
10 *intensive physiotherapy, I can live very independently and enjoy walks, outings, holidays –*  
11 *still a little adapted, but wonderful. I can also pick up things at home such as cooking and*  
12 *washing, which is also very pleasant. Apart from the fact that I have felt enormously*  
13 *supported by my surroundings, I had to go through some moments on my own. But somehow*  
14 *I felt and feel powerful and strong. I am happy and I want to share my happiness!*

Together with her medical story, the presentation of her illness experience incorporates elements of restitution as well as of quest narrative. Due to the various treatments and therapy, she seems to have recovered from cancer and was able to restore a sense of feeling good and capable, despite her amputated arm (9-11). The quest becomes especially apparent in the appreciation of life and optimism, to which her illness experience contributed to some extent (3-4), in calling her life beautiful despite her condition (9), in enjoying activities although done differently than before (9-12), and in giving her occupational life a new direction and purpose which is dedicated to her illness (5-6). In that sense, she becomes the agent of her story. Instead of letting the illness take over her life or fighting against the boundaries that the illness might set, she seems to own her illness. A high degree of agency in terms of finding ways to create a life, in which the illness is integrated and accepted, is a common feature of this category of narratives. The agency also becomes apparent in terms of doing something for others, such as being an inspiration, providing information, encouraging others and highlighting a sense of community with fellow sufferers.

The notion of connectedness, support and love she experiences by friends and family is very salient throughout her story (4-5, 12-13). Moreover, Marian comes to think about the future by herself and in optimistic ways (3, 5-6), in which she wants to share her story to

encourage others (6-9). The importance that is attributed to living in the present moment is highlighted by the fact that the future is taking place in the now or as Marian put it: “*As of today, by writing this letter and sharing my story, I have taken a step into the future.*”

Marian addresses her letter to others who suffer and don't know how to proceed:

15 *I am writing this letter to all those who need/want to overcome difficulties. My future started*  
16 *again with the beautiful words of the doctor who was going to perform the amputation of my*  
17 *left arm: I HAVE GOOD NEWS. Dear person, I see this good future before me. There may be*  
18 *difficulties on your path but you can overcome them and it will make you stronger. I see me*  
19 *having faith in life, overcoming my fears, making jumps and discovering new routes. These*  
20 *paths are endless and there is always help along the way. So much love and friendship that*  
21 *makes you silent. In the silence are the answers. That is how I find my next destination. Giving*  
22 *life, my life, form and content, moving, standing still doesn't exist..... Everything moves*  
23 *towards a better future. Everyone visible, taking account of each other, looking out for each*  
24 *other ..... That is the good news, that is the change I wish for everyone. Difficulties or*  
25 *sadnesses sometimes accompany you through life like a shadow; letting go doesn't always*  
26 *work.....and holding on to something else might. Because I get inspired, maybe I can inspire*  
27 *others. We can learn from each other and get connected. Good news, sweetheart, today 26*  
28 *October 2021*

The letter is characterized by solidarity with others who struggle and who might not see a future yet (21-22). There is also wisdom displayed in her words about finding solutions (24-25). The silence that she describes could be interpreted as contemplation about the truly important things in life that she seems to have found through support and community and which gave her life a new direction (25). The quest is also displayed in meeting suffering head on, the acceptance that loss is difficult, but something new can be gained from it (28-30). Interestingly, she mentions the break between her old and new future (15-16). One way of interpreting is that her old narrative and imagery of the future did not hold and had to be abandoned in order for a new narrative that emerged when she had been operated. It reflects that the end of something old can be the beginning of something new.

This narrative paints a very peaceful and optimistic picture, but not all quest narratives

do so. Although there too, illness is accepted, considered valuable and they found ways to live with the illness, they also make you feel the effort and struggle to deal with the limitations on a daily basis. Nevertheless, these stories too share an appreciation for their life and urgency to live in and enjoy the present moment.

### *Category 2: Restitution - Call for social action*

The dominant narrative in this category is a combination of quest and restitution narrative or restitution narrative only. As such, they expressed high hopes for complete or partial cure or stabilization of the course of chronic illness and confidence in the achievements in medical science. Four participants hoped for a cure or remission of the chronic illness, whereas the other five participants mentioned that they wish to have their illness under control by means of treatment and medication or prevent reoccurrence of additional chronic illnesses, such as cancer. Importantly, the subjectivity of the person appears absent and instead, the story is told by clinicians or therapists, who are the agents of the narrative and set the course of action. This externalized agency is a strong characteristic of this category. Still, the participants declare the wish for more recognition of their chronic illness and its impact on daily living by society, healthcare and insurances. The lack of recognition, medical knowledge and social understanding, and the incompetence health care practitioners are common themes in the past narratives.

The future takes place in the distant future. Two participants did not explicitly mention a timespan, but the broader context and tense indicate temporal distance between now and the future. The letters are characterised by a vividly described future using present tense, where the wish of living a life without or reduced burden of the illness thanks to medical progress has been realized. Moreover, participants who describe their illness experience as relying mostly on treatments and are more inclined to also envision a future in which quality of life can be restored by use of medical treatment.

One representative of this category of narratives stems from Helen, a 64-year-old woman living with lichen sclerosus. Here she describes her past illness experience:

1 *Initially, I had problems with my skin, including around my anus, diagnosed as*  
2 *psoriasis. I was given various ointments to treat this. I was not always satisfied with*  
3 *the treatment, like the time a dermatologist did not look at my skin, prescribed a*  
4 *repeat prescription and said I had to make a check-up appointment. Another*  
5 *dermatologist doubted the diagnosis of psoriasis and took a biopsy. The diagnosis of*  
6 *psoriasis was confirmed. The pain and itching increased. In addition to the*  
7 *dermatologist and the family doctor, I was now being treated by a gynaecologist. The*  
8 *gynaecologist operated on me and the cut he had to make in my perineum closed up.*  
9 *This was followed by a repair operation, during which he laughingly said that I*  
10 *shouldn't take a mirror and check every day to see if my vulva was growing closed.*  
11 *The pain and itching around my anus and vulva increased, to the point where it drove*  
12 *me crazy! I went to see an acting GP, who thought it was Lichen Sclerosus. After some*  
13 *ointments, I was referred to a gynaecologist. My gynaecologist denied that I had*  
14 *Lichen Sclerosus and did not want to take a biopsy. My vulva closed up again. An*  
15 *acting gynaecologist operated on my vulva, and I asked again for a biopsy. The*  
16 *conclusion: Lichen Sclerosus. My gynaecologist "wasn't supposed to believe that". I*  
17 *had had enough of the incompetence of so many doctors and wanted to go to the vulva*  
18 *clinic, which, according to a hospital website, was supposed to be there, but it turned*  
19 *out not to be. I complained again and asked for a referral to a vulva clinic in a*  
20 *university hospital. There I received the correct treatment on a scientific basis. Lichen*  
21 *sclerosus requires specialist treatment to prevent further suffering and a small risk of*  
22 *vulvar cancer!*

The desperate wandering from one practitioner to the next without getting help or getting a diagnosis becomes clearly visible throughout Helens' story. It also becomes apparent that she wasn't really seen or understood by the practitioners (3-4, 9-10), which left her frustrated (16-17). This struggle could be interpreted as characteristic for a chaos narrative. When she finally got the diagnosis, it could be argued that it provides her with some hope again in form of finding a "correct treatment" (20), which is indicative for a restitution narrative. The future she describes takes place in 2026 and is described as such:

23 *I am in Holland. The Lichen Sclerosus Foundation is disbanded. The people who care*  
24 *for me have known for a long time that I have Lichen Sclerosus, know how to care for*  
25 *it and how to deal with it. There is no shame, everyone now knows what Lichen*  
26 *Sclerosus is and how you can recognise it. Men with LS also speak openly about their*  
27 *illness and, very remarkably, even children who have LS know about it. No one would*  
28 *have thought that in 2021! Thanks to scientifically proven treatment, there is no longer*

29 *any vulvar cancer. What a joy that caring for LS is as normal for everyone as*  
30 *brushing their teeth!*

The future shows a clear connection to her past. The quick recognition, treatment and awareness that she found lacking in her past is now common practice (23-24). Moreover, as vulvar cancer could be prevented in the future (28-29), future imagery might function as a way to reduce her fear of getting cancer and giving some certainty about the future. This can be seen as indicative for a restitution narrative. Likewise, the role of her chronic illness will become less interfering and thereby providing new opportunities:

31 *Lichen Sclerosus has disappeared into the background. Sex is no longer a painful*  
32 *problem and finding new life partners with LS is easy for everyone.*

The letter from the future is clearly addressed to practitioners of various fields, with the call for social action that deepening knowledge and research into treatments are worth it, reducing further suffering:

33 *Dear carers, nurses, practice assistants, general practitioners, dermatologists,*  
34 *gynaecologists, urologists, paediatricians, sexologists, pelvic floor therapists and*  
35 *scientists,*  
36 *Thank you all for expanding your knowledge and expertise on Lichen Sclerosus.*  
37 *Because of this, the quality of life for thousands of people, women, men and children*  
38 *has demonstrably improved! Not only physically, but also psychologically and*  
39 *socially. With a relatively small intervention, vulvar cancer has been prevented in all*  
40 *cases. Through this intervention, for the first time in history, the suffering caused by*  
41 *Lichen Sclerosus is being openly discussed. A great burden has been lifted from their*  
42 *shoulders. Those who were professionally involved experience more honour from the*  
43 *work they were trained for. In short, we all benefit!*

Taken together, the future narrative displays elements of restitution as well as quest narrative.

The restitution can be found in the strong emphasis on medical treatment, reliance on professional agency and hoping for prevention of cancer thanks to medical progress.

Although it could be considered characteristic for a quest narrative, that due to the illness the insight into the need for more social action has been learned, it adds something new to

Frank's definition of a quest narrative, because it goes beyond the individual.

### *Category 3: Chaos - Empty future and longing for the past*

Two narratives could be identified as continuous in genre and as envisioning a future that is oriented towards the past. In this case, the dominant genre was a chaos narrative, with the future looking empty and returning to the past instead. The chaos depicted in both narratives is less about living with the illness, but more about the consequences of treatment and powerlessness to change something about the situation. The narratives were found chaotic in structure as well as in content, displaying a high sense of frustration and despair.

One case representative of this category is the story written by Mark (57) who suffers from acquired brain injury and chronic pain.

1 *Hard to see 1 a4 in a window on your smartphone but I am trying to tell it. Dec 2016*  
2 *drilled into my hand and walked for years at hand wrist centrum. 3 surgeries and now*  
3 *at pain clinic. Hypersensitive nerve and also dead spots remains difficult especially*  
4 *with explaining to work and its authorities. In August 2017, I had an accident on a*  
5 *normal bicycle. The pole of the municipality was crooked and therefore out of balance*  
6 *and fell on a hill. Lying in ICU. Fractured skull with blood and lightheadedness.*  
7 *Fractured jaw and damaged balance organ. 7 broken ribs in several places and*  
8 *shoulder blade in several pieces. Lung contusion etc. The ribs have grown wrong for*  
9 *years and there is chronic pain. Unfortunately, surgery is too difficult. I also suffered*  
10 *brain damage from the skull base fracture. And so together with my hand I drama.*  
11 *But still busy with the UWV because they always think differently. After waiting for a*  
12 *long time on a waiting list in 2019, finally revalidation but there was not much left to*  
13 *get. Some solutions as to how to continue living. Only getting help.... That is another*  
14 *story.*

The language that he uses to describe his illness experience seems rather stoic, as it resembles an enumeration of his accidents, operations and physical symptoms. This makes the abstract impersonal, leaving the place of the 1<sup>st</sup> person narrator empty and instead resembles the listing of medical history by a professional. The chaos becomes apparent in his struggle for recognition by the insurance company (UWV, 11) and a sense of emptiness about the future

as “*how to continue living*” (13).

The despair is visible in the tone of his future narrative:

15 *I am writing this because you asked me to. But I don't even know who you are apart from a*  
16 *student. My daughter also has a master's degree in psychology. I want to send a letter to the*  
17 *authorities who still know very little about NAH. And I also have a combination of physical*  
18 *problems. While I used to run a half marathon and even a marathon every month. I also ran a*  
19 *lot of 10 km races. But make it "best dear student".*

20 *The future is up to me and I don't want to think about it. Now I need help and prefer to*  
21 *go back to the past. Institutions are systematically working against each other. And*  
22 *thinking about what you would like has nothing to do with the future. So this piece will*  
23 *be of no use to you.*

(NAH = niet aangeboren hersenletsel, engl. acquired brain injury)

The future narrative is more chaotic in structure, switching between different topics, without connections in between (15-19). He refuses to think about the future (20), which might indicate the hopelessness, characteristic for a chaos narrative. The resisting attitude and supposed uselessness of his contribution to the research project stay in contrast to his participation. Thus, it seems that he puts faith into the unknown researcher, by making an imaginative connection to his daughter. It could thus be argued that despite the lack of hope described in the letter, he might expect or hope for some help by participating. Interestingly, as Mark sees no use in imagining the future, he rather wishes to “*go back to the past*” (20-21), which is also underlined by his memories of his capabilities in the past (18-19). The letter from the future that Mark writes demonstrates reluctance to engage in an exercise to imagine a better future, but prefers to stay realistic, coming to terms with his current situation:

24 *Little story. You are being lived. You have to obey all kinds of rules. You are*  
25 *confronted with inaccuracies that you have to fight against. But everything is as it is.*  
26 *If things don't go your way.... then it has to be the way it is.*

The passiveness in this abstract, which is expressed in the use of 2<sup>nd</sup> person narration and in the statement of ‘*being lived*’ by life (24) indicate the non-agency and powerlessness of the



participant in changing or steering his course. As such, the future is not described as being in his own hands and thus he remains sceptic about a future that might be more positive. In consideration of how future imagery might function to help an individual, this representative letter shows that instead of imagining a better future that might create false hopes or disappointments, it can make sense to stay realistic and to deal with the present.

### **Discontinuous Narratives**

#### *Category 4: Becoming an agent and envisioning a path*

Seven narratives displayed a break in their storyline, moving from a chaos or restitution narrative to a quest narrative in the future. Importantly, the future was not seen as equivalent to the present such as the narratives of the first category, but depicted a future that is very close to the present (e.g., next week) or looked prospectively into the future. The participants already had a clear idea of how to proceed and can be seen as agents, who decide to take a different path in their course of illness. Although the narrative genre differs from the one of the future, the participants seem to be able to envision a path of how to reach their desired future. For instance, they know about their strengths and interest, their capabilities in creating a future they desire or which support they need to realize their dreams. The shift in agency and tone constitutes additional characteristics of the discontinuity between the past and the present. One exception is a narrative that is discontinuous in the sense that no future imagery is presented, but described as being on the search for realistic goals.

The following example of this category is a narrative told by Henk (73):

- 1 *[...]Thus began in 2010 my Q story, sometimes I call it my Qut story. Investigations,*
- 2 *strange symptoms, difficult because sometimes they are very present and sometimes*
- 3 *almost not. And now, more than 10 years ago, I don't know anymore what has to do*
- 4 *with my age and what with qvs. Doctors visits, therapy, q patient contact and many*
- 5 *question marks. In short, a vague state with also strange and vague complaints. The*
- 6 *worst is the confusion in my head and the neuropathic symptoms in my hands.*
- 7 *Disabling and unsettling. Every day you ask yourself: can I do this, can I not do this*

8 *and do I have an overview of everything? I work on staying healthy every day,*  
 9 *sometimes with unusual methods (e.g. winter swimming to increase my resistance*  
 10 *(before, I had pneumonia every six months). I'm glad we got that letter in the mail and*  
 11 *knew right away that it was a fever, because that way I could tell, otherwise I would*  
 12 *have gone crazy. Sad that I had to give up so much, glad that I'm older so that I'm not*  
 13 *plagued with benefit hassles and my son says very sweetly; ah, you're finally becoming*  
 14 *age-appropriate because before I got ill I was super active and fit.*  
 (qvs = Q-koorts vermoeidheidssyndroom, engl. fatigue related to Q-fever)

The story about his illness experience shows the confusion, limitation and uncertainty that encompass living with the chronic condition, that resembles a chaos narrative (1-8). The frustration also becomes apparent in calling his illness experience a “Qut story”. Throughout the lines the regret about what he has lost due to the illness shows up, comparing himself to his earlier and more active self (12-14). It reads as a struggle of coming to accept his limitations, although an accepting attitude shines through, when he cites his son in the end (13-14). The desired future is described as follows:

15 *It is tomorrow, in a year's time or was it 10 years later, I don't know just that it is a*  
 16 *morning of clarity. My fog that I have been carrying in my head since the qvs is gone.*  
 17 *I have found a solution. After all these years, I've decided that I love the fog, that it*  
 18 *belongs to me. As a result, I no longer experience the fog as an enemy but as*  
 19 *something that belongs to me, and sometimes I'm even glad. Glad that I don't overlook*  
 20 *and see everything, glad that I can live with it and glad that the people around me*  
 21 *know that I don't overlook everything in the fog, that I can explain it clearly, that*  
 22 *there's nothing else wrong with me, but that sometimes I don't understand something*  
 23 *or forget something or just don't know anymore. I am almost at that point. It makes me*  
 24 *happy, there is nothing more annoying than blaming yourself for that, unsure the fog*  
 25 *is closing. Tomorrow and further on I learn to say better and better: " wait a moment,*  
 26 *sometimes the fog dissipates then I am there again, sometimes the fog is there for a*  
 27 *long time but it belongs to me".*

The future narrative can be considered as a quest narrative, including acceptance of the chronic illness (17-19, 25-27) and emphasis on the positive sides of living with the fog (19-21). The conversational tone towards his future self is understanding, patient and gentle, e.g. taking himself time to evolve a friendlier attitude towards his condition and not judging him on his limitations (24-25), which is in contrast to the regretful and struggling tone of the past narrative. The agency becomes apparent in his decision to accept the fog and integrating it

into his self-image and daily life (17-18). Interestingly, the time when his future takes place seems irrelevant (15-16), but he also mentions to already follow this path of acceptance (23). The unspecific or even irrelevant time frame could be interpreted as allowing himself to take the necessary time that it takes to integrate the chronic illness and to acquire a more gentle and understanding attitude. He is not there yet, but seems to know the path he wants to take.

*Category 5: Connectedness and envisioning a goal*

Five participants wrote narratives that were discontinuous in narrative genre and imagined their future to take place in the distant future, mostly between 5-10 years. The past narrative could be classified as chaos or restitution narrative, making visible the struggle and frustration of living with the chronic illness, feeling alone and not recognized in their pain, seeing plans for the future falling apart and being confronted with obstacles on their way forward. The future imagery was difficult to describe using Frank's illness narratives, because the participants only scarcely described the role of their chronic illness in the future. Instead, common themes were finding themselves in an appreciative environment, being part of a community, being recognized and useful. In contrast to the struggle in the past, the future was often described very peacefully, affectionate, very vividly, with many sensory details and written in the present tense. One participant did not write a letter from the future, but in one of the prompts, she described a future scenario, in which she finds herself in an appreciative working place. The letters from the future conveyed the message of creating hope, encouragement and perseverance. The perspective is thus often retrospective in advising and encouraging the present self, by describing a future that is worth fighting for. This is often accompanied by the emphasis of the future and present self working as a team, which expresses itself in formulations like "we" or a switch between speaking in the first or second person. This observation might underline the communal aspect of this category, which goes beyond the characteristics of Frank's illness narratives.

Finally, whereas the past is often characterized by powerlessness or hopelessness, the participants turn into an agent of creating a life that they desire, but described as a goal rather than a path. That means, that the future is describes as a desired state of being, but the means how to reach this goal are not mentioned.

Representative of this category is the story told by Thea (25):

1 *I played table tennis 6 times a week. Table tennis was my life and I did everything for*  
2 *it. I also did a lot of social work, but that might have come later. However, I was also*  
3 *often injured and it was not very clear why. I got a q fever infection when I was 15, so*  
4 *I was still very young. And then I went from a fit top athlete to someone who couldn't*  
5 *even walk 200 metres. And at the time, there was no understanding whatsoever, either*  
6 *medically or socially. I was attacked by school officials for leaving school*  
7 *unauthorised and I was bullied for not attending. From a medical point of view,*  
8 *nobody knew what to do with it either q fever was not very well known back then.[...]*  
9 *Socially, I am now in a complete low for years and that makes me very sad if I think about it*  
10 *too long I see nobody of my age and that's just not nice. I can't have fun with anyone just for*  
11 *once. [...]*From a medical point of view, I always have to fight alone, too; doctors never  
12 *believe things when they happen to my body, and that is extremely tiresome. A pneumothorax*  
13 *was not believed and it took two days before I got any help. That was it. And I always have to*  
14 *go through my life like that, it feels like a big fight and I don't really want that anymore.[...] I*  
15 *also try to have a hobby because otherwise I have nothing to challenge myself with so I started*  
16 *singing lessons. [...]*And I started to train table tennis again, which is a bit between work and  
17 *hobby. It remains difficult to play table tennis because I can't do that any more and my body*  
18 *collapses, but I am glad that I have found another way to keep busy. Only the association pulls*  
19 *at me a lot and I find that difficult because I already have so little energy and if they let me do*  
20 *even more then my whole week consists of table tennis and I can't do anything for myself. I've*  
21 *been wanting to draw for months now, but I can't. So it's always a struggle. So it's always a*  
22 *struggle and a fight either with the outside world or an internal tug-of-war with my own*  
23 *energy.*

The past narrative is dominated by the internal and external struggle of living with the illness, characteristic of a chaos narrative. She mentions the disruption and loss of her former self (4-5), the loneliness (9-10) and lack of social and medical recognition (11-13). Throughout the story, her attempts and perseverance to change something about her situation seem to fail, receiving no support and leaving her as a lone fighter (14). She seems to be caught in a struggle of wanting but not being able or allowed to. Although she wishes to resume some hobbies and interests, the perceived incapability to change something about her situation displays a lack agency in her story. Overall this story elicits a great compassion with her

situation. When she is asked to write about when she envisions her desired future, she describes it as such:

24 *First of all I always avoid this for specific reasons of not wanting to think about the*  
25 *future but I am going to try. In 10 years time I hope I will have found a balance in my*  
26 *life and that the fucking housing market will finally be normal so I can buy a house. It*  
27 *doesn't have to be much, but a small house with a bathtub, which is very important. In*  
28 *addition, there must of course be a nice table tennis club in the area where I can meet*  
29 *a range of new people. I also sincerely hope that I am allowed to have a relationship*  
30 *one day, but if not, I can be happy too. I would like to have children later on, but I*  
31 *don't think that I am allowed to have them, maybe through other means, but not*  
32 *through the usual way. I'm guessing my body won't take it and I don't want to pass this*  
33 *drama on to my children (also the reason why I find it so difficult to talk about the*  
34 *future). In terms of work and study, I don't think it's that important. Realistically, I*  
35 *know that I can't do much. Ideally, I would like to do a lot, but I know I won't be able*  
36 *to, so it's not good to want it. So the most important thing for me is that I have a nice*  
37 *place to live because I don't have that now and a nice environment with people around*  
38 *me and that I have peace in the internal struggle and who knows, maybe I'll be*  
39 *granted the chance to finally share some love in all that.*

The resistance to think about her future stays in stark contrast about the many ideas she has about her future. It could be argued that because she describes her current situation as a state of fighting and finding a way to live with the chronic illness, she does not see a path yet how to realize the goals and wishes for her future. It is interesting to see how much she hopes for a future characterized by a loving relationship, family, study, work, sports, a nice place to live and peace. At the same time, she appears to create distance to these hopes. This is underlined by the passive and admonitory tone of e.g. "*being allowed to have a relationship*" or "*I have to give myself realistic dreams*", reminding her to stay realistic. The contrast between agentic (e.g. "*I would like to have children*") and non-agentic (e.g. "*but I don't think that I'm allowed to have them*") formulations really stand out in her story. She also explains that being realistic in her dreams is important because she knows about her capabilities and limitations (35-36). This also becomes apparent in her response about which role the chronic illness might play in the future:

40 *Yes, because I am a realistic person and although I dream I remain realistic. So*  
41 *they have to be achievable goals. If I have dreams that are not achievable, I've noticed*

42 *that it makes me very unhappy, and with my type of illness it's quite necessary to be*  
43 *realistic because you know that it's not going to get better at any point. So in every*  
44 *area of life my condition comes back because my condition is part of me it's not me but*  
45 *I have to live with it and I have to give myself realistic dreams within those limitations*  
46 *and I did learn that you can be very happy with very small things and that you don't*  
47 *need to travel the world to see beautiful things.*

In this section multiple elements of a quest narrative can be found. She seems to accept her illness and wants to find ways to live with it within its boundaries (44-46). Moreover, it becomes apparent in the learning that took place in form of appreciation of the beauty of life (46-47). In the following, she writes a letter from the future, addressed to herself:

48 *Hi, Today I took a beautiful walk with my boyfriend near our house. It was such*  
49 *spooky weather. The mist hung over the woods and you could hardly hear anything,*  
50 *even the birds were silent as we walked through the woods (who knows, maybe they*  
51 *found the mist scary). It was a pity I did not have my camera with me, as you know I*  
52 *always forget it. I always say I should take it with me to capture the beautiful moments*  
53 *but I always forget it. Oh well, we fell back on the mobile phone cameras which are*  
54 *just as good actually but nothing beats a heavy camera in your hands. It was great*  
55 *that I wasn't alone like before but together. Thea, you really have to make sure and go*  
56 *out there that you don't stay alone. Just keep going. It is so nice to share these*  
57 *moments with someone, even if they are as small as a walk. You go well yourself but*  
58 *from a tardis, Thea*

The letter describes a beautifully written future scenario, completely free of the frustration and struggle as found in her illness story. The tone is encouraging and gentle (56-58). The place in the future is highlighted by connectedness and paints a picture of peace, which very much contrasts with the struggle beforehand. Her words of advice are kind and affectionate and might function to give hope to overcome her struggle and seek connectedness. The letter from the future cannot be placed in any of Frank's genres, but depicts a different situation of time space. Whereas the past was characterized by loneliness and internal and external struggle, the future is a time of togetherness and peace. Metaphorically speaking, the situation that Thea describes can be seen as being representative of her internal state. Being in the woods, surrounded by mist and silence, might express a situation of not knowing where to place the feet next or what the destination will be. She also imagines herself to be with someone in the woods, thus that she does not need to take this path alone. In addition, the

notion of quest is also apparent in reminding her to be attentive to the beautiful things in life. She mentions twice that she happens to forget her camera, which might indicate that she might not always be able to appreciate the small things, but she tries and is patient and gentle with herself.

All in all, this category distinguishes itself from the previous category in describing a vivid future that is yet distant and described as a desired state of being with the intention to increase hope and encouragement, even if the means and the path how to reach it are not tangible (yet).

## **4. Discussion**

The purpose of this study was to explore how past and future narratives of people living with a chronic illness are related with a focus on narrative genre and future time perception. The combined narrative approach about past and future narratives contributes to our understanding of illness experience and provides new scientific and practical insights into the use and functionality of future imagery among the chronically ill.

### **4.1 Summary of Findings**

The main finding constitutes that narratives differ with regard to continuation of (1) narrative genre and (2) future time perception. First, a difference has been found as to whether participants maintained the same narrative genre throughout the past and future narrative (*continuity*) or whether there was a break in narrative genre between the past and future narrative (*discontinuity*). Second, three different kinds of future time perception could be inferred from the future narratives. Participants either envisioned their future in the here-and-now or in close temporal proximity (*immediate*), in a few years' time (*distant*) or in the past (*nostalgic*).

Through the combination of both types of (dis)continuation (genre and time perception), five different categories could be identified. First, *continuous quest narratives*

display a high focus on the here-and-now, looking prospectively into the future and expressing gratitude and a high concern for others. Second, people telling *continuous restitution narratives*, imagine their future in a few years' time, hoping for the medical progress to cure or stabilize the disease and imagining a future in which their condition is more socially accepted, seen and understood. Third, for *continuous chaos narratives*, the future could be understood as a continuation of a previously held future, before the illness occurred, with no imagery for a future living with the chronic illness. Fourth and fifth, for *discontinuous narratives*, a difference has been found in the degree to which the participants envision a *path* or a *goal* as a function of time. Whereas participants seeing a path towards the future were more inclined to imagine their future temporarily close to the present, participants who wrote about their future in terms of goals, imagined their future in temporal distance from the present. Moreover, whereas both groups told a past narrative that could be classified as chaos and/ or restitution narrative, the future narrative of the fourth group could be understood as becoming an agent in the search for meaning (quest), whereas the future narratives of the fifth group could not be defined using Frank's narrative genres, but expressed a strong wish for *connectedness* and togetherness instead.

#### **4.2 Interpretation of Findings**

The focus on temporality, i.e. life-review and letter from the future, provided valuable insights into the meaning-making of chronically ill people that go beyond the description of Franks' narrative genres. A key finding of this research is the emphasis on the relational and societal aspect of living with a chronic illness. Frank's narrative genres centre on the individual journey of living with a serious disease, but appear to disregard the social and societal context of the individual. Although this theme was addressed differently across the narratives, it appeared to be of central significance. For instance, most people holding a quest narrative mentioned their social environment as important resource along their path and



formulated a strong wish to encourage others through their stories. Likewise, the letters from the future exercise revealed peoples' request for better medical recognition and social action, besides the hope for a cure or treatment. The most striking finding was that one category of future narrative could not be placed into one of Franks' genres. This category distinguishes itself from the other categories by its high emphasis on connectedness and relationship with little or no concern for the illness at all. From a clinical perspective it could be argued that this kind of exercise can be used to cope with illness, stress or anxiety by visualizing a psychological safe space to create distance from their current complaints (Rancour, 2009).

Together, these findings challenge the underlying assumptions of Frank's typology. The genres might be implicitly based on the classical romantic genre of the Greek mythology, which pictures an individual hero who succeeds in overcoming adversity and "is able to transcend the world of experience as a result of the quest for good" (Murray, 1985, p.177). The classical genre of comedy, which places more importance on the collective group to overcome difficulty and conflicts, might have featured less in Franks' investigations of personal stories. Moreover, from a gender perspective, Franks' typologies reflect rather masculine attributes of independence and control. In contrast to the focus on individual agency and masculinity, the findings make visible that agency can also be understood as being communal or relational.

The findings stress the importance of societal support in dealing with chronic illness. It could be argued that sharing and caring for each other are a vital part of being human, of surviving, and meaning-making. Drawing upon Burys' (1982) and Charmaz' (1983) notions on *biographical disruption* and *loss of self*, chronic illness can be considered a threat to one's identity and social relationships, e.g. incapacity to work, not fulfilling social roles, and limited access to cultural activities. The stress, resentment or marginalization involved in this process might possibly increase the need for belonging and being part of society (Lehardy & Fowers, 2018). Especially because chronic conditions imply a long-term management that mainly

takes place outside the clinic, community and finding a world of advocacy is an important resource (Leys, 2010). On the societal level, the need for social action is reflected in patient right movements that aim for greater visibility, involvement in medical and political decision-making, and social awareness (Chronic Illness Inclusion, 2021). These movements as well as support groups could be helpful in creating a collective identity and social narrative on chronic illness that promote social reforms. With regard to this study, it seems reasonable that due to the purposive sampling method, people who are already very committed about this issue might have felt more inclined to participate in this research to give a voice to their community.

The societal aspect of individual's narratives on chronic illness might also help to understand the high percentage of restitution narratives in this study. Although restitution narratives were expected to be scarce among people with chronic illness, more than half of the narratives expressed hope for a future that promises a cure or treatment. This observation might display the societal prominence of this narrative in western culture, in which the future is narrated to be in the hands of scientist and modern medicine (Frank, 1995; Camarck, 2006). The preference for a restitution story might be based on the underlying conception of health and illness in western society, which guides clinical practice in important ways. The naturalistic approach of medical philosophy tends to use health as a synonym for normality, whereas illness denotes a deviation from that norm (Boorse, 1997). A common critique of this conceptualization is that people might consider themselves abnormal if they suffer from a chronic condition, possibly leaving them helpless, passive, and awaiting for a cure or treatment by scientists or medical professionals (Catita et al., 2020). More holistic approaches consider health as capability to manage one's life according to one's values and goals and adapting to changing life circumstances (Nordenfeldt, 2007; Rudnick, 2000). Understanding health as a process that allows for transformation and growth could increase the autonomy and self-determination in coping with a chronic illness. Thereby, people might discover

alternatives to narrate their stories that better align with their experience creating a ‘corpus of stories’ that are polyphonic, i.e. explicitly involving different narrative genres and contradictory elements (Stuij et al., 2016; Ezzy, 2000).

Furthermore, the differences in temporal distance of the future imagery might function as an indication to which extent the individual perceives himself as capable of constructing his future as well as how the future is framed in terms of the desired outcome. Participants who live their illness as quest, appear to have a high appreciation for the present, with an optimistic and open attitude towards the future. Through the experienced unpredictability of the future, they might have come to embrace the uncertainty of the future, acknowledge the limited control over the course of life and become aware of what matters most for them now. In the paper by Ezzy (2000) this type of narrative is characterized by “living with a philosophy of the present” (Davies, 1997) in which the uncertainty of the future bears higher appreciation and intensity to the present moment. In contrast, for individuals holding a chaos narrative, it might be less helpful to engage in an exercise about the future, but to focus on what can be preserved and is still possible to realize in the present. Thus the ‘management of disappointment and loss’(Crow & Andrews, 2019, p. 567) might be a prerequisite before moving to think about the future. It is also the insight, that some things cannot be changed by the individual and acceptance might be the better option than constant fighting. It could be argued that holding a chaos narrative displays the divergence between the current experience and the narrative that was held in the past (Ezzy, 2000). With the current situation and limitations due to the chronic illness, no future might be imagined and in order to maintain a sense of coherence, in which the narrative from the past is depicted as the expected future.

The functionality of the future imagery for individuals holding a restitution narrative is less straightforward and linked to a difference in agency. It seems conceivable that the future was envisioned with greater temporal distance and less agency for those, who wish for new medicines and treatments, which are not tangible yet, or who might not see means and

possibilities how to reach the desired future. However, it could also be argued that the concurrent wish for connectedness, peace and an appreciative environment, displays an important step in realizing the desired future. The support by external sources in forms of encouragement and appreciation constitute a critical factor in feeling capable to attain personal goals among people with chronic illness (Franklin et al., 2019). In contrast, the future was imagined in close temporal distance and characterized by the search for meaning, for those, who tend to be more aware of personal and social resources and turned into an agent in pursuing their goal. This is in line with goal-setting theory, in which short-term goals include plans as opposed to long-term goals which are rather expressed as hopes or wishes (Cook 2016; Nilsen, 1999).

As stories are told in relationship to someone listening, these findings could be helpful in guiding clinical practice and social interaction. For example, people holding a quest narrative might benefit from a community, e.g. patient organizations or online forums to share their stories and encourage others. In turn, people with a restitution story might be helped by feeling recognized and involved in a community and become aware of their capabilities and resources in coping with the illness. Individuals narrating a chaos story could be supported by feeling acknowledged in their suffering, working on the current situation and opening alternatives for the future.

#### **4.3 Limitations and Recommendations**

The findings of this study have to be interpreted in the light of several limitations. First, the sample consisted of predominantly western, Dutch-speaking participants. As illness narratives are sensitive to narratives that dominate a society or culture, it would be interesting to investigate how differently individuals might reflect upon their past and future in other cultural or societal contexts. For instance, cultures that share a high emphasis on collectivism

and in which communality, family and friendship are highly valued, might deal differently with illness experience, such as feeling more supported, accepted and recognized (Goodwin & Plaza, 2000). Likewise, attendance towards the cultural influence on illness narratives, could give insight into spiritual or religious accounts that individuals might see as resource of hope and perseverance in times of hardship (Lima et al., 2020). In fact, some respondents expressed notions of spiritual wisdom or religious belief, especially if they hold quest as dominant narrative. As this was not the focus of this research, future research could explore the role of cultural or spiritual/religious beliefs in future imagery among chronically ill people.

Second, the research was carried out online and consisted of writing exercises that required some degree of cognitive and linguistic skills from the participants. One argument why some participants did not write a letter from the future or gave very brief responses could be that this form of expression is not suitable for everyone. Future research can discover different creative formats, such as artistic ways of future imagery that better fit the capabilities and interests of people involved in this exercise (Zittoun & Gillespie, 2018).

Third, the findings of this study have to be interpreted with caution, given the explorative nature of applying Frank's illness narratives to the future imagery of chronically ill people. This becomes apparent in the different distribution of narrative genres, e.g. only two narratives have been identified as chaos narratives and the combination of nostalgic and discontinuous narratives was not represented. To substantiate or extend the results and implications, it is recommended to replicate the study in a larger sample, potentially with a specific focus on the social and societal role of living with a chronic disease. Although collaborative work on the analysis of (dis)continuity of narratives was present, inter-rater reliability could be enhanced in follow-up studies.

Moreover, the findings can be understood as a snapshot of human experience. Stories are constructed differently depending on specific time and place, the purpose and the audience. They evolve over time and narrative genres might vary in its dominance at different

moments of time (Frank, 1998). In this study, participants might have been at different ‘stages’ of their illness trajectory, e.g. with the illness onset being in the early or more recent past. In this study, this factor has not been part of the analysis. In addition, this study included a collection of different chronic diseases that might vary in its severity and prognosis, that might influence how people tell their story and see their future. Thus, follow-up studies could look more specifically at the potential role of illness onset and kind of chronic illness.

Qualitative analysis that accompanies patients over a larger timespan might provide valuable insights into the individual processes and inter-subjective differences of meaning-making and future imagery among the chronically ill. In this endeavour, additional knowledge about other factors, such as hope, agency, social-economic status, values or social support can be gained.

Finally, although the focus of this study lies on people with chronic illness, the findings might be equally important and necessary to be extended to people without a chronic illness. The findings highlight the personal and social meaning of illness, especially of chronic illness, as well as the importance of communal and relational views on recovery. These views might challenge the social norms associated with living with a disease. Future research can actively contribute in reframing these conceptions by having a mediating role between individuals’ needs and experience on the one hand, and medical practice and policy-making on the other hand. Crossing these boundaries could help to revise the continuous co-construction of social norms and conceptions of normality or wellness that legitimates limited rights and possibilities of people with chronic illness (Bertilsdotter Rosqvist et al., 2016). This requires research practices and values, policies and a form of social cohesion that is able to dis-locate people with chronic illness from being problematic or abnormal to being in need of relational support and social reform (Bertilsdotter Rosqvist et al., 2016). Curiosity and openness for narratives that might be controversial or contradict the medical or social narrative are deemed necessary for future research practice. Future research can actively

contribute to this process by spreading people's stories and show alternative ways of narrating about living with illness.

#### **4.4 Conclusion and Final Remark**

This study makes a small, yet valuable contribution to the fields of social sciences, health care practice and policy-making that are concerned with the lived experience of people with chronic illness. The narrative approach and the focus on future imagery provide insight into meaning-making, personal wishes and needs of people living with a chronic disease, respecting the individual history of each person. The most interesting finding constitutes the importance of thinking about chronic illness not only from the individual perspective, but in relation to the larger social and societal surrounding and narrative. This could inform health care practice in providing more patient-centred care and shared decision-making that is in line with the patients' needs, capabilities, values, goals, and conception of living a good and worthy life. Given the resentment and activism for social reforms among people with chronic illness, the findings stress the need for collaborative work between researchers, health care practitioners, policy-makers, and patients in increasing social awareness, reducing the financial and occupational burden of living with a chronic condition and fostering a social dialogue that allows for a variety of illness narratives to be told and listened to.

In this sense, I want to conclude with the words of Arthur Frank: "The professional's task is *not* to tell people what stories ought to be significant for them. People have to *find their own stories*; the stories they find for themselves [...] are those that can take care of them best. But what clinicians and researchers can do is to *amplify and spread* people's stories. Professionals can *connect* people through their stories. Researchers and clinicians can spread good stories, which can show people how they might tell their own stories." (Frank, 1995, p. 82)

## References

- About chronic diseases*. (2021, April 28). Centers for Disease Control and Prevention.  
<https://www.cdc.gov/chronicdisease/about/index.htm>
- Bertilsdotter Rosqvist, H., Katsui, H., & McLaughlin, J. (2016). (Dis)abling practices and theories?: Exploring chronic illness in disability studies. *Scandinavian Journal of Disability Research*, 19(1), 1-6. <https://doi.org/10.1080/15017419.2016.1269535>
- Bohlmeijer, E. (2007). *De verhalen die we leven. Narratieve psychologie als methode*. Amsterdam: Boom.
- Boorse, C. (1997). A rebuttal on health. In J.M. Humber & R.F. Almeder (Eds.), *What is disease?* (pp.1-134). Humana Press. [https://doi.org/10.1007/978-1-59259-451-1\\_1](https://doi.org/10.1007/978-1-59259-451-1_1)
- Bradbury, J. (2012). Narrative possibilities of the past for the future: Nostalgia and hope. *Peace and Conflict: Journal of Peace Psychology*, 18(3), 341-350.  
<https://doi.org/10.1037/a0029069>
- Brown, P., & De Graaf, S. (2013). Considering a future which may not exist: The construction of time and expectations amidst advanced-stage cancer. *Health, Risk & Society*, 15(6-07), 543-560. <https://doi.org/10.1080/13698575.2013.830081>
- Bury, M. (1982). Chronic illness as biographical disruption. *Adult lives*, 4(2), 48-55.  
<https://doi.org/10.2307/j.ctt1t895q0.11>
- Carel, H. (2007). Can I be ill and happy? *Philosophia*, 35(2), 95-110.  
<https://doi.org/10.1007/s11406-007-9085-5>
- Carmack, H. J. (2006). Medicine as culture: Illness, disease, and the body in western Societies: Medicine as culture: Illness, disease, and the body in western societies. *Medical Anthropology Quarterly*, 20(2), 257-259.  
<https://doi.org/10.1525/maq.2006.20.2.257>
- Catita, M., Águas, A., & Morgado, P. (2020). Normality in medicine: A critical review. *Philosophy, Ethics, and Humanities in Medicine*, 15(1).  
<https://doi.org/10.1186/s13010-020-00087-2>



- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168-195. <https://doi.org/10.1111/1467-9566.ep10491512>
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168-195. <https://doi.org/10.1111/1467-9566.ep10491512>
- Chronic Illness Inclusion. (2021, July 19). *Vision, mission & values*. <https://chronicillnessinclusion.org.uk/about/vision-mission-values/>
- Cook, J. (2016). Young adults' hopes for the long-term future: From re-enchantment with technology to faith in humanity. *Journal of Youth Studies*, 19(4), 517-532. <https://doi.org/10.1080/13676261.2015.1083959>
- Crow, G., & Andrews, M. (2019). Biographical interviews and imagined futures essay writing: Users of two methods in conversation. *International Journal of Social Research Methodology*, 22(6), 557-569. <https://doi.org/10.1080/13645579.2019.1610597>
- Cunliffe, A. L., Luhman, J. T., & Boje, D. M. (2004). Narrative temporality: Implications for organizational research. *Organization Studies*, 25(2), 261-286. <https://doi.org/10.1177/0170840604040038>
- Davies, M. L. (1997). Shattered assumptions: Time and the experience of long-term HIV positivity. *Social Science & Medicine*, 44(5), 561-571. [https://doi.org/10.1016/s0277-9536\(96\)00177-3](https://doi.org/10.1016/s0277-9536(96)00177-3)
- Dohan, D., Garrett, S. B., Rendle, K. A., Halley, M., & Abramson, C. (2016). The importance of integrating narrative into health care decision making. *Health Affairs*, 35(4), 720-725. <https://doi.org/10.1377/hlthaff.2015.1373>
- Ezzy, D. (2000). Illness narratives: Time, hope and HIV. *Social Science & Medicine*, 50(5), 605-617. [https://doi.org/10.1016/s0277-9536\(99\)00306-8](https://doi.org/10.1016/s0277-9536(99)00306-8)
- Frank, A. W. (1998). Just Listening : Narrative and Deep Illness Just Listening : Narrative and Deep Illness, 16, 21–40. <https://doi.org/10.1037/h0089849>

- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press.
- Franklin, M., Lewis, S., Willis, K., Rogers, A., Venville, A., & Smith, L. (2019). Goals for living with a chronic condition: The relevance of temporalities, dispositions, and resources. *Social Science & Medicine*, *233*, 13-20.  
<https://doi.org/10.1016/j.socscimed.2019.05.031>
- Gergen, K. J. (1994). *Realities and relationships. Soundings in social construction*. Cambridge, MA: Harvard University Press
- Golub, S. A., Gamarel, K. E., & Rendina, H. J. (2015). Loss and growth: Identity processes with distinct and complementary impacts on well-being among those living with chronic illness. *Psychology, Health & Medicine*, *19*(5), 572-579.  
<https://doi.org/10.1080/13548506.2013.855318>
- Goodwin, R., & Hernandez Plaza, S. (2000). Perceived and received social support in two cultures: Collectivism and support among British and Spanish students. *Journal of Social and Personal Relationships*, *17*(2), 282-291.  
<https://doi.org/10.1177/0265407500172007>
- Gucciardi, E., Jean-Pierre, N., Karam, G., & Sidani, S. (2016). Designing and delivering facilitated storytelling interventions for chronic disease self-management: A scoping review. *BMC Health Services Research*, *16*(1). <https://doi.org/10.1186/s12913-016-1474-7>
- Hannum, S. M., & Rubinstein, R. L. (2017). The meaningfulness of time; Narratives of cancer among chronically ill older adults. *Journal of Aging Studies*, *36*, 17-25.  
<https://doi.org/10.1016/j.jaging.2015.12.006>
- Hwu, Y. (1995). The impact of chronic illness on patients. *Rehabilitation Nursing*, *20*(4), 221-225. <https://doi.org/10.1002/j.2048-7940.1995.tb01632.x>
- Kleinman, Arthur. (1988). *The Illness Narratives: Suffering, Healing and the Human Condition*, Kindle ed. New York: Basic Books.
- Lee, V. (2008). The existential plight of cancer: Meaning making as a concrete approach to the intangible search for meaning. *Supportive Care in Cancer*, *16*(7), 779-785.  
<https://doi.org/10.1007/s00520-007-0396-7>

- Lehardy, E. N., & Fowers, B. J. (2018). Ultimate (evolutionary) explanations for the attraction and benefits of chronic illness support groups: Attachment, belonging, and collective identity. *Current Psychology*, 39(4), 1405-1415. <https://doi.org/10.1007/s12144-018-9841-7>
- Leys, M. (2010). *A social science perspective on care for chronically ill people: Relevance for public health and healthcare policy making*. (Policy brief). Department of health sciences and medical sociology (MESO), Brüssel
- Lima, S., Teixeira, L., Esteves, R., Ribeiro, F., Teixeira, A., Pereira, F., & Magalhães, C. (2020). Spirituality and quality of life in older adults: Path analyse model. <https://doi.org/10.21203/rs.2.18813/v2>
- Megari, K. (2013). Quality of life in chronic disease patients. *Health Psychology Research*, 1(3), 27. <https://doi.org/10.4081/hpr.2013.e27>
- Murray, K. (1985). Life as fiction. *Journal for The Theory Of Social Behaviour*, 15(2), 173–188.
- Nilsen, A. (1999). Where is the future? Time and space as categories in analyses of young people's images of the future. *Innovation: The European Journal of Social Science Research*, 12(2), 175-194. <https://doi.org/10.1080/13511610.1999.9968596>
- Noncommunicable diseases*. (2019, June 12). WHO | World Health Organization. [https://www.who.int/health-topics/noncommunicable-diseases#tab=tab\\_1](https://www.who.int/health-topics/noncommunicable-diseases#tab=tab_1)
- Nordenfelt, L. (2007). The concepts of health and illness revisited. *Medicine, Health Care and Philosophy*, 10(1), 5-10. <https://doi.org/10.1007/s11019-006-9017-3>
- Prefontaine, K., & Rochette, A. (2013). A literature review on chronic pain: The Daily overcoming of a complex problem. *British Journal of Occupational Therapy*, 76(6), 280-286. <https://doi.org/10.4276/030802213x13706169932905>
- Rancour, P. (2009). Guided imagery: Healing when curing is out of the question. *Perspectives in Psychiatric Care*, 27(4), 30-33. <https://doi.org/10.1111/j.1744-6163.1991.tb00348.x>
- Ricoeur, P. (1980). Narrative time. *Critical Inquiry*, 7(1), 169-190. <https://doi.org/10.1086/448093>

- Rudnick, A. (2000). The ends of medical intervention and the demarcation of the normal from the pathological. *The Journal of Medicine and Philosophy*, 25(5), 569-580.  
[https://doi.org/10.1076/0360-5310\(200010\)25:5;1-w;ft569](https://doi.org/10.1076/0360-5310(200010)25:5;1-w;ft569)
- 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. <https://doi.org/10.1080/13645579.2020.1719617>
- Sools, A.M., & Mooren, J. H. (2012). Towards Narrative Futuring in Psychology. *Graduate Journal of Social Science*, 9(2), 206.
- 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. <https://doi.org/10.1177/1359105314566607>
- Souza, S. P., & Lima, R. A. (2007). Chronic condition and normality: Towards the movement that broadens the power of acting and being happy. *Revista Latino-Americana de Enfermagem*, 15(1), 156-164. <https://doi.org/10.1590/s0104-11692007000100023>
- Stuij, M., Elling, A., & Abma, T.A. (2016, March). 'Starting All Over Again.' *Living with Diabetes and the Quest for Restitution* [Paper presentation]. The 11th Global Meeting of the Health Project: Storytelling, Illness and Medicine. Inter-Disciplinary.Net, Budapest. <https://www.researchgate.net/publication/318393505>
- Synnes, O., Orøy, A. J., Råheim, M., Bachmann, L., Ekra, E. M., Gjengedal, E., Høie, M., Jørgensen, E., Michaelsen, R. K., Sundal, H., Vatne, S., & 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.  
<https://doi.org/10.1080/17482631.2020.1819635>
- Turner, J. (2000). Emotional dimensions of chronic disease. *Western Journal of Medicine*, 172(2), 124-128. <https://doi.org/10.1136/ewjm.172.2.124>
- Van Bulck, L., Luyckx, K., Goossens, E., Oris, L., & Moons, P. (2018). Illness identity: Capturing the influence of illness on the person's sense of self. *European Journal of Cardiovascular Nursing*, 18(1), 4-6. <https://doi.org/10.1177/1474515118811960>

- Whitehead, L. C. (2006). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science & Medicine*, 62(9), 2236-2245.  
<https://doi.org/10.1016/j.socscimed.2005.09.008>
- Williams, A. M., Christopher, G., & Jenkinson, E. (2019). The psychological impact of dependency in adults with chronic fatigue syndrome/myalgic encephalomyelitis: A qualitative exploration. *Journal of Health Psychology*, 24(2), 264-275.  
<https://doi.org/10.1177/1359105316643376>
- Zittoun, T., & Gillespie, A. (2018). *Imagination in human and cultural development*.  
Routledge.

## 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](mailto: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.
- **Ik ga hiermee akkoord en ik wil starten met het onderzoek**
- **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?