

*"I never thought that I could do this again!":* How people with chronic  
illnesses construct their past and future - A narrative study on the ASCS model

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### Abstract

**Background.** Chronic illnesses (CI) have a substantial impact on the lives of affected individuals. They alternate the living conditions of people with CI as well as the perspective on their past and future. Narratives about the past illness experience and wishes for the future can help to provide a sense of continuity to the life story of people with CI. Studying and contrasting such narratives can provide valuable insights. A narrative model by Lieblich et al. (2008) could be a good fit for CI narratives. However, it has never been applied to such data.

**Method.** As part of a larger research project, a mixed inductive-deductive thematic analysis of the narratives of a subsample of 30 participants was performed. The main constructs of the ASCS model were applied to written illness narratives and *Letters from the Future* from people with chronic illnesses. In multiple phases, past and future narratives were analysed separately and contrasted with each other within each participant.

**Results.** A total of eight themes and 16 subthemes were created. The ASCS model was found to be very applicable to the data regarding the relevance of the four main constructs, but not regarding its internal structure. Agency was found to be a central concept with relationship to all other constructs of the model. The comparison approach proved useful, the combination of past and future narratives painted a clear picture of the subjective experience of the participants.

**Conclusion.** Despite some methodological limitations, the current study was successful in applying the ASCS model while exploring and contrasting past and future narratives of people with chronic illnesses. It has important implications for future research. A possible adaption of the ASCS model specifically for chronic illness narratives could prove useful. Contrasting past and future narratives could be beneficial and insightful as well.

**Keywords:** Chronic illness, Agency, Structure, Communion, Serendipity, Illness narratives, *Letters from the Future*

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***"I never thought that I could do this again!": How people with chronic illnesses construct their past and future - A narrative study on the ASCS model***

Chronic illness (CI) often presents significant health burdens for people that are affected by them (WHO, 2022). It often restricts the autonomy of people with CI and change their perspective on their life and future (Årestedt et al., 2014; Bury, 1982; Venning et al., 2008). The drastic changes in living conditions and forced alteration of plans for the future are often experienced as biographical disruption, meaning a significant shift in the perception of one's past, present and future life (Bury, 1982). Narratives help people with CI to find new meaning in their changed lives and give their life story a kind of coherence (Good et al., 1994). Studies indicate that people with CI have perceptions on their past that differ from the perception of the future (Bury, 1982; Gullickson, 1993; Jowsey, 2016; Venning et al., 2008). However, so far no study focused specifically on contrasting future and past narratives of people with CI. The current study aimed to examine similarities and differences between past illness narratives and desired future narratives of people with CI. Further, it applied the narrative agency, structure, communion, serendipity (ASCS) model to examine its functionality as a tool for the analysis of narratives from people with CI.

**Chronic illness and its impact on affected individuals**

Chronic illness can be considered one of the biggest global health issues, causing 74% of all deaths worldwide. CI tend to be permanent burdens for affected individuals and thus require lifelong adjustment (WHO, 2022). Common symptoms include pain, fatigue, and the loss of abilities related to activities of daily living. While many chronic conditions are primarily physical in nature, they have a significant impact on the psychological well-being of people with CI as well (Prefontaine & Rochette, 2013). CI frequently impairs the autonomy of people with CI, since it makes them dependent on the support of others (Årestedt et al., 2014). This typically presents a significant lifestyle shift for people with CI themselves, but also their families.

Further, CI has a psychological impact by changing the individuals' perspective on

their own life (Bury, 1982; Venning et al., 2008). More specifically, plans and expectations for the future will be disrupted by the condition and the adaptation it requires. For example, people with CI might have to bear more significant monetary costs or experience strong feelings of uncertainty and anxiety regarding their future (Bury, 1982). Additionally, CI leads to a higher awareness of one's own mortality (Gullickson, 1993). For some, this might lead to more anxiety and lowered mood as they realize that they will not be able to live their life as they planned it (Bury, 1982). Others, however, gain more appreciation for their life, and especially for the little pleasures it offers (Gullickson, 1993; Jowsey, 2016). Some people with CI state that their increased awareness of their own death led to a shift of attitude where they started to "embrace the fruit of their lives" as part of their journey, rather than waiting until their retirement to enjoy their lives more intensively (Gullickson, 1993, p.1390).

These findings underline that for people with CI their perception of their future is integral to their interpretation of their life (Bury, 1982; Gullickson, 1993). It provides rich information about both the attitude to and the management of their illness. Further, it appears as if people with CI often expect their situation to change in the future in comparison to their past illness experience (Bury, 1982; Gullickson, 1993; Jowsey, 2016; Venning et al., 2008). They tend to be either optimistic about their self-management and functioning in the future, or expect their situation to worsen (Bury, 1982; Gullickson, 1993; Jowsey, 2016; Venning et al., 2008). Studying this perspective on the future on its own could already be valuable, but contrasting it with the perspective on their past illness experience could paint a more complete picture of their needs and what aspects they would like to change. This is because elements of the past will likely contextualize visions for the future and vice versa. Differences between perspectives on the past and the future could reveal central conflicts within an individual. Therefore, it might be valuable to examine in what way those differences present themselves in the experience of people with CI. This could also assist health care professionals in the future to gain a better understanding of

the subjective experience of people with CI. One of the ways to examine these perspectives is through the use of narrative methods.

### **Narratives and their use to study the experience of chronic illness**

Narratives often play an important role in the lives of people with chronic illness. As Good et al. (1994) claims, narratives enable individuals to make sense of and give meaning to experiences that would otherwise be considered solely aversive. People can integrate their perspective on their past with their understanding of the present and their perception of the future into one more or less coherent life story. Thus, aversive events can be contextualized and reevaluated. This is critical for people with CI, as they are confronted with a problem to which no solution can reasonably be expected (Good et al., 1994; Tang & Anderson, 1999). The importance of narratives to people with CI also makes narratives a useful research tool in the study of their subjective experience. Narratives can be collected through a variety of research methods and are very suitable for qualitative analysis methods (Lieblich et al., 2008; Sools & Mooren, 2012; Tang & Anderson, 1999). They have a unique advantage as they allow for an assessment of perspectives on different times than the present. For example, they are often used to study the past illness experience and general life story of people with CI (Good et al., 1994; Jowsey, 2016). This unique advantage applies also to future perceptions since there are tasks that instruct participants to narrate about their vision of the future (Sools, 2020; Sools & Mooren, 2012). One example is the *Letters from the Future* task that can be used to gain insight into how participants imagine their ideal future (Sools, 2020; Sools & Mooren, 2012). Thus, narrative methods could be a useful tool for a comparison between how people with CI construct their past and (desired) future perceptions.

### **Agency, Structure, Communion, and Serendipity**

One narrative model that may be very fitting for the analysis of the past and future construction of people with CI was proposed by Lieblich et al. (2008). They integrate *agency* and *structure*, as well as the concepts *serendipity* and *communion*, into a model

that serves as a framework for the narrative analysis of an individuals' subjective experience that can be studied through the lens of these concepts. A graphic illustration of this model can be found in Figure A1. *Agency* can be defined as individuals' ability to act independently and autonomously, without being majorly restricted in the way in which one choose to live one's life. It contrasts with *structure*, describing an individuals' adherence to certain structures like medication schedules imposed by social actors like care takers and medical professionals (Lieblich et al., 2008; Tang & Anderson, 1999). *Serendipity* refers to forces outside the control of an actor, that appear to be random but are ultimately beneficial (Lieblich et al., 2008). It differs from luck, since it also implies that the individual is able to take advantage of the opportunity it offers. It opposes *agency* differently than *structure*, since it does not imply helplessness or inactivity, but rather the ability to improvise without prior planning. Communion can here be defined as "the tendency to merge or unite with others", thus also opposing agency, which is more associated with a separation from others (Lieblich et al., 2008, p. 616). In the model, *agency*, *structure*, and *serendipity* form a single continuum where *structure* and *serendipity* are proposed to oppose *agency*. The model also proposes another level that encompasses the duality between *agency* and *communion*. For the purposes of this study it will be referred to as the Agency, Structure, Communion, Serendipity (ASCS) model.

The main elements of the ASCS model in many ways resemble parts of the experience of people with CI. Multiple qualitative studies indicate that people with CI often experience a partial or complete loss of agency due to their dependence on the support of others (Årestedt et al., 2014; Tang & Anderson, 1999; Williams et al., 2019). This loss of agency is sometimes partly attributed to an adherence to structures of the health care system (Tang & Anderson, 1999). Specifically, in a past study on women with CI they described conformity (e.g., to treatment schedules, medication plans and the advice of medical professionals) without questioning the authority or becoming active themselves. Similarly, in a narrative study by Lucherini (2020) CI has been proposed to

reduce serendipity, due to the physical demands it brings and the routines people with CI have to follow. Finally, the duality between agency and communion is frequently in narrative accounts of people with CI (Årestedt et al., 2014). As they become more dependent on their loved ones, they are drawn closer to them, often reducing their agency. However, the resulting communion in romantic couples and families, is often perceived as fostering the relationship as indicated by qualitative data as well as systematic reviews (Årestedt et al., 2014; Dalteg et al., 2011). While agency and communion lie on opposite ends of a continuum on the motivational level of the ASCS model, Lieblich et al. (2008) acknowledge the existence of agency-in-communion. This is nicely illustrated by the experiences of couples affected by CI that managed to find new meaning and creative solutions for their problems (Årestedt et al., 2014; Dalteg et al., 2011).

Additionally, the principles of the ASCS model are also relevant for the future perception of people with CI (Årestedt et al., 2014; Dalteg et al., 2011; Lucherini, 2020; Williams et al., 2019). Over the course of the illness, their experience related to these concepts changes, and they can have certain expectations of their future management of their illness that are related to the ASCS principles (Årestedt et al., 2014; Dalteg et al., 2011; Lucherini, 2020; Williams et al., 2019). To illustrate, some people with CI express an expectation of a future dependence on certain structures like health care systems that will impede their mobility and thus their agency to an extent (Lucherini, 2020). An expectation of reduced mobility also often means a reduction of serendipity, as it becomes harder to use opportunities when they arise. Future expectations of people with CI regarding communion are relatively diverse. While some people with CI expect the aforementioned fostered partner or family relationship to continue improving, others expressed worry about whether they will be able to function in case the support from important others is omitted (Årestedt et al., 2014; Dalteg et al., 2011; Tang & Anderson, 1999; Williams et al., 2019). As these findings show, the principles of the ASCS model are suitable for an analysis of the experience of people with CI regarding their perception of



past and desired future experience. However, in the discussed narrative or qualitative studies, expectations for the future were discussed mostly parenthetically, without being the center of attention. Studies on the subject that focus specifically on future perspectives of people with chronic illness, and contrast them with their past experience are lacking.

### **Current study**

People with chronic illness can have differing perceptions between their past illness experience and their future illness experience and life in general (Bury, 1982; Gullickson, 1993). Concepts like agency, structure, communion, and serendipity are relevant in this context and related perceptions differ as well regarding past and future (Årestedt et al., 2014; Lieblich et al., 2008; Lucherini, 2020; Tang & Anderson, 1999). The way people with CI construct their illness experience, in relation to the concepts of the ASCS model, can be studied using written narratives (Lieblich et al., 2008; Sools, 2020). This can assist in providing a better understanding of their experience. Additionally, comparisons of past and future perceptions of people with CI can help to identify their needs, regarding support and autonomy. Further, the ASCS model could be a promising theoretical framework for an analysis of narratives from people with CI. Still, such an analysis has not been performed yet. Therefore, the aim of the current study is twofold. On the one hand, it seeks to contrast narratives of past illness experiences of people with CI with narratives on their desired future. Further, it attempts to apply the ASCS model to those narratives to assess to what extent it is applicable to CI narratives. To achieve those two goals in combination, the current study used the ASCS model as an analytical framework for the analysis of illness narratives, desired future narratives and a comparison between them. This results in the following main research question, with three subsequent subquestions.

**RQ:** To what extent is the ASCS model applicable for an analysis of narratives of people with CI?

**SQ1:** How do people with CI construct agency, structure, serendipity, and communion

in past narratives?

**SQ2:** How do people with CI construct agency, structure, serendipity, and communion in future narratives?

**SQ3:** What are differences and similarities in how people with CI construct agency, structure, serendipity, and communion in past and future narratives?

## Methods

### Design and procedure of the larger study

The current study was part of a larger research project named “Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst” (“How people with chronic health conditions story their past and future lives”). Besides collections of quantitative data that are not relevant for the current study and demographical questions, two methods for collecting qualitative data were used. Participants were asked to provide a narrative of their illness experience up to that point. Further, the desired future perception of participants was assessed using the *Letters from the Future* method (Sools, 2020; Sools & Mooren, 2012). Data was collected using the online tool *Qualtrics*. Social media platforms like *Facebook* and *LinkedIn*, as well as Dutch patient organizations, were used to reach participants. Further, through a convenience sampling procedure, the main researchers Dr. Anneke Sools and Jacqueline Coppens (MSc) reached out to people in their personal network and asked them to participate. Ethical approval for the study was granted by the Ethics Committee of the Faculty of Behavioural Science at the University of Twente (request number 211138).

After giving their informed consent, participants were instructed to write a story about their personal experience of living with a chronic illness. Next, they received a short introduction to the letter from the future task, including guiding questions that prompted them to provide specific information about time, location, setting, and context of the letter. Afterwards, they were asked to provide general information about demographics and their CI. The completion of the survey took approximately 45 minutes. The participants were allowed to cease participation at any point in the study, and they were provided with an email address to contact the researchers in case they had any questions. All aspects of the data collection, including the surveys and the answers of the participants, were originally in Dutch. The answers of the participants were later translated into English using the translation tool *DeepL* (<https://www.deepl.com/translator>).

## **Participants**

To be eligible for the study, participants had to suffer from a chronic health condition, be fluent in Dutch, and at least 18 years old. Further, they had to possess sufficient digital and cognitive skills to be able to answer the online survey and live independently in their community. The sample of the larger study was comprised of 60 participants overall. To be able to perform an in depth analysis of the data, I selected 60 narratives from 30 participants out of the larger sample. The decision-making on which participants to include was based on my subjective impression on the richness of the narratives but also the length of the written letter from the future, since many participants only wrote a very short or no letter at all. Overall, the analysed sample was composed of 30 people (27 women and 3 men) aged between 25 and 70 years. The CI's of the participants included Migraine, Asthma, Multiple sclerosis, Lichen sclerosis, Q-fever, Fibromyalgia, Rheumatoid arthritis, Endometriosis, Chronic pain, and Bipolar disorder.

## **Materials**

### ***Instructions for illness narratives***

For the first task, participants were asked to describe in as much detail as possible what they have experienced so far since they became aware of their chronic condition. Additionally, they were supposed to indicate how those experiences made them feel. Specifically, they were prompted to tell about experiences regarding work, housing, social relationships, and their self-image. The exact instructions can be found in Appendix B

### ***Letter from the Future***

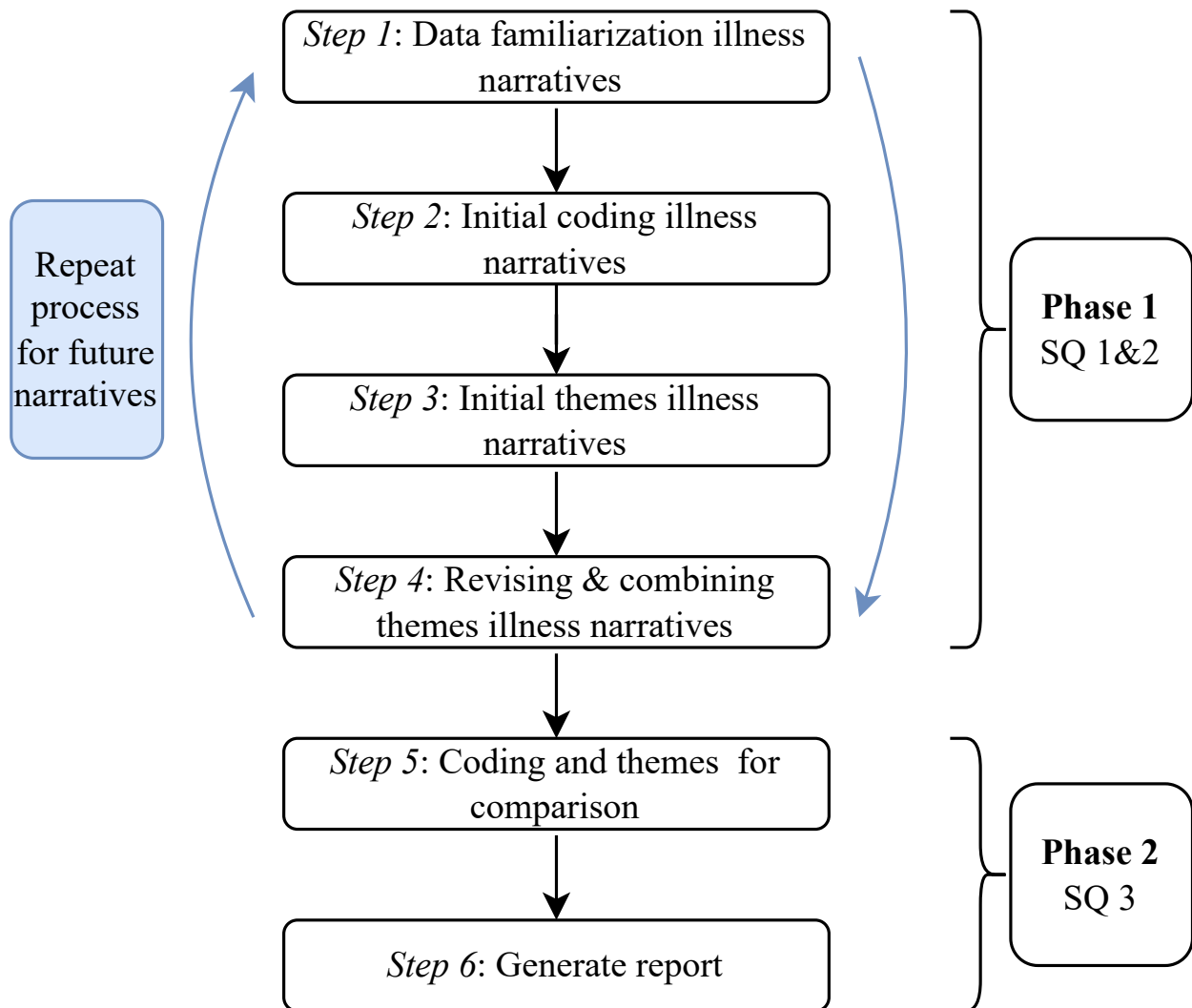
The *Letters from the Future* exercise was originally proposed as a creative writing exercise for elderly people with mild depression (Bohlmeijer, 2007). It involves imagining oneself in a very desired future setting and writing a letter back to the present. In the current study, the participants could choose the time, setting, and addressee of the letter themselves. They were presented with five prompts: 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. The third prompt was added to the original task to make it more applicable to the current target group. The exact instructions of the larger study can be found under Appendix B.

**Data analysis**

**Figure 1**

*Analysis phases of the current study adapted from Braun and Clarke (2012).*



For the data analysis, I chose an inductive-deductive thematic analysis approach, broadly derived from Braun and Clarke (2012). In principle, my analysis followed the six steps of Braun and Clarke (2012). However, as my analysis was conducted in light of the principles of the ASCS model, the initial codes were originally not generated inductively, but following the 4 main constructs of the model. The six steps of Braun and Clarke were adapted to fit that approach. An overview of my adapted analysis phases and steps can be found in Figure 1. During the first step of the analysis, I familiarized myself with the data, reading it repeatedly and making notes (Braun & Clarke, 2012). Next, I started the first coding round while using the four constructs of the ASCS model as starting codes and gradually splitting them up into more specific subcodes. While this approach was deductive in the sense that initial codes were defined by the underlying theory, I did not adhere strictly to the structure provided by the ASCS model. More specifically, the ASCS model proposes that its four main constructs lie on two different levels and relate to each other in a specific way. I did not attempt to replicate this structure or check for its existence in the data. Instead, the four constructs and resulting codes were applied independently of each other. In that sense, the resulting subcodes and themes were generated more bottom-up from the data.

At first, I worked on the past and future narratives separately to be able to answer each research question separately as well. According to Braun and Clarke (2012), the third and fourth steps of analysis comprise the generation and reviewing of preliminary themes. I generated initial theme ideas already during the first coding rounds by combining related codes that share the same core idea. In the end, I had a list of candidate themes that I then checked by going through all the coded data again. Here, I specifically checked whether there was enough support for each theme, but I also combined themes. Themes were usually tied to a specific construct of the ASCS model or the relationship between two constructs. Again, I went through this phase for past and future narratives separately. At this point in the analysis it became clear, that while most of the themes were fitting for

either the past or the future sections respectively, there were also exceptions. To illustrate, the construction of serendipity did not differ significantly between the past and future narratives. Therefore, it was not applicable to generate two different themes for the past and future section of the report. To solve this issue, I ultimately decided to discuss the construct during the comparison section, covering both the past and future narratives as well as drawing the comparison between them.

After I concluded the original analysis phase for the two narrative parts separately, I started the second phase in which I contrasted the past and future narratives of each participant separately. Specifically, I investigated whether constructions of the constructs of the ASCS model differed within a given participant's past and future narratives. In this phase, I also did another round of coding to gather important quotes and see if new themes arise. Additionally, I made notes for each participant regarding their within-person comparison. The resulting themes were then revised in a similar manner as for the previous two research questions.

The final step of the analysis was the generation of the report. The structure of the report is informed by the sequence of the subquestions of the main research question. The themes are discussed in separate subsections within the sections of the subquestions that they were associated with. I often created the title of the themes by combining a quote of one of the participants that I considered illustrative with a description of the basic observation underlying the theme. First, I started with a list of different subthemes of the relevant construct in the data to present sufficient evidence to answer the research question. In case it was applicable, I highlighted contrasting constructions between the participants. I supported the findings by repeatedly providing quotes from participants to illustrate arguments. Some quotes were chosen because they appeared to be relatively representative of either multiple other participants or the larger point I was trying to convey. However, some quotes were also chosen as a transitioning device when they were exemplary of two content points. All names of participants used in the report are pseudonyms.

## **Results**

As a result of the above described analysis, eight themes and 16 subthemes emerged in total. In the following, the results will be presented according to the structure implied by the three sub questions of the main research question. Hence, first the three themes that emerged through the analysis of the past narratives will be discussed, before focusing on the two themes of the future narratives. Finally, a separate section will address the three themes that were found regarding the comparison between past and future narratives. Interestingly, constructions of serendipity were found to be very similar in the past and future narratives. Therefore, serendipity will be discussed exclusively in the last section of the results. An overview of all themes and subthemes of their respective research questions can be found in Table 1.



**Table 1**

*Results table 1*

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SQ1: How do people with CI construct agency, structure, serendipity, and communion in written past narratives?

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Theme 1: "Many very things I could not do" – experiencing a (partial) loss of agency as a result of living with a CI

*Subtheme 1.1: Losing one's work*

*Subtheme 1.2: Changed plans for the future*

*Subtheme 1.3: Being unable to engage in one's hobby*

Theme 2: Structure as a threat to agency, - or its biggest enabler?

*Subtheme 2.1: Lifestyle changes and physical changes*

*Subtheme 2.2: Medication and other treatments*

*Subtheme 2.3: Different approaches in dealing with structure*

Theme 3: Agency in communion – connecting with others as fundamental coping strategy for people with CI

*Subtheme 3.1: Communion in family- partner-, and friend relationships*

*Subtheme 3.2: Loneliness and isolation*

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SQ 2: How do people with CI construct agency, structure, serendipity, and communion in written future narratives?

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Theme 4: Hoping for external factors to regain one's agency

*Subtheme 4.1: Regaining agency through medical interventions*

*Subtheme 4.2: Regaining agency through change of structure*

Theme 5: "Together we are strong" - The desire for more communion in the future narratives

*Subtheme 5.1: Connecting with others*

*Subtheme 5.2: Finding joy through others*

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SQ3: What are differences and similarities in how people with CI construct agency, structure, serendipity, and communion in written past and future narratives?

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Theme 6: "I have found a calling" – making the best out of one's situation as a construction of serendipity

*Subtheme 6.1: Using additional time for things one enjoys*

*Subtheme 6.2: Finding an opportunity for work in the new situation*

Theme 7: Wishing for what was lacking or sharing one's success with others

*Subtheme 7.1: Wishing to gain the things in the future that were lacking in the past*

*Subtheme 7.2: Sharing one's success with others*

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Theme 8: Regaining one's agency through external or internal factors?

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**SQ 1: How do people with CI construct agency, structure, serendipity, and communion in written past narratives?**

***Theme 1: "Many very things I could not do" – experiencing a (partial) loss of agency as a result of living with a CI***

**1.1 Losing one's work.** Constructions of agency, or lack there of, occurred in a variety of ways in the past narratives of people with CI. One major way concerned the impact CI had on the career and ability to work of many participants. People described having to reduce their working hours drastically or completely refraining from doing any kind of (paid) work. "Anne" (40):

*"With this diagnosis, it was no longer possible for me to work with people, something I had enjoyed doing for 18 years. Processing this loss will take some time"*

This quote from Anne, diagnosed with a selective antibody deficiency, illustrates that for people who have previously enjoyed their work quite a bit, having to give up that work could impair their agency. The fact that she described this change as a "loss" implies that the work has been a substantial part of her life. Additionally, a reduction of agency as a result of dropping out of the workforce also was constructed in a more practical way, where people described being more dependent on financial help from others than before. The psychological impact of these changes are illustrated by a statement made by "Emma" (27), suffering from severe migraine:

*"Grief, fear and mourning for what is no longer possible. Grief because my life is so dominated by the migraine. Difficulty keeping up my work. I work less now too. My work that I love so much. Plans for the future to possibly teach at the MBO to pass on the love for my profession. Want to follow a study for this. How then?? Seeing dreams fall apart."*

**1.2 Changed plans for the future.** In addition to the above-mentioned points, Emma's quote demonstrates another commonly addressed form of loss of agency. For many people with CI, the diagnosis and its consequences for their daily life had fundamentally changed their plans and hopes for the future, which restricted their agency in the sense

that they felt no longer able to plan their future the way they wanted to. Participants described how uncertainty about their future influenced their decision-making in the present. “Johanna” (25):

*"The drug works now, but will it still be the case in 10 years? Nobody knows that. This attitude influences my choices on several levels. For example, I don't feel like starting a 6-year study, because will I still be there?"*

**1.3 Being unable to engage in one's hobby** A restriction in agency was also apparent for many participants in other areas of life. Many described being unable to engage in hobbies such as music, art, or sports due to their physical or mental limitations. For some, this resulted in a situation where they were neither able to work nor perform other interesting or challenging behaviours, thus leading them to become mostly inactive. An example of this process can be seen in the following example by “Linda” (29) suffering from pppd:

*Before my pppd I played trumpet with several associations. This was a great passion of mine. I stopped doing this too, because I get sick of looking at sheet music (because of the lines). Pppd has therefore had a lot of impact for me on work, study and hobbies*

### ***Theme 2: Structure as a threat to agency, - or its biggest enabler?***

**2.1 Lifestyle changes and physical changes.** Since structure as a construct is not tightly defined in the literature, constructions of it in the data were diverse. People primarily mentioned significant lifestyle changes that became necessary as a result of their CI. Some participants described their dependence on certain structures quite literally in the sense that they, for example, had constructions within their homes to make it less difficult for them to perform their activities of daily living. Additionally, physical aids like walking sticks, wheelchairs or electric bicycles were commonly mentioned. They can also be considered structures since they become entangled into the daily life of people with CI and influence it. “Isabelle” (39):

*"I am glad and grateful that I have some aids that make life a little easier. Braces in*

*the bathroom, a walker and mobility scooter, silversplints for all fingers, thumbs and wrists and more braces for elbow, knee and ankle in case something goes wrong with them again. And a walking bike. And that I have an assistance dog who helps me so much."*

Further, Participants wrote about following specific and complicated schedules that include thorough planning of any given day's activities and regular periods of rest. This is illustrated nicely by these two quotes from "Maria" (51) and "Johanna" (25):

*"I became a manager of my own, in order to get through the day as well as possible, to be able to distribute all the activities in a day as well as possible."*

*"I am only allowed to eat specific foods at specific times and need 40 minutes of total rest every 5 to 6 hours to allow the pills to dissolve properly in my stomach"*

**2.2 Medication and other Treatments.** Medication and other treatment methods were described to strongly influence the lives of people with CI due to the aforementioned scheduling issues, but also due to side effects that for example impair the sexual activities of people with CI. Similarly, participants described regular check-ups and meeting with health professionals becoming a substantial part of their life. "Tess" (50), diagnosed with Q-fever:

*I got terrible complaints about my joints which results in monthly check-ups with the rheumatologist and neurologist, scans, etc*

**2.3 Different approaches in dealing with structures.** Being influenced by external structures in one's life appeared to be a very common experience for most participants. However, the way in which they dealt with this structure and their general attitude towards it, differed quite a bit between different participants. For some, the structure and lifestyle changes that resulted from their condition were hard to accept. They tried to keep working or taking care of their family to the same extent as before. They resisted the need to change their routines and behaviours and forcefully tried to stay agentic. Sometimes they even put up a facade in front of others. This is illustrated by the following quote by Tess (50), diagnosed with Q-fever:

*"Every given moment that our children and husband are out the door I SECRETLY take my chance to sleep and still fall into a very deep sleep within a few seconds. I tell NO ONE about my complaints and my extreme fatigue because WHAT MUST I BE TIRED OF as a mother who does not work and stays at home"*

The fact that she tried to hide her tiredness in front of her husband and children in addition to everyone else implies that she was not yet able to admit her limitations openly. Further, her statement, "WHAT MUST I BE TIRED OF as a mother who does not work and stays at home" implies that her thinking and behaviour are very much influenced by social norms, which can also be seen as a construction of structure in this context. Further, Tess's attempt to stay agentic by force, ultimately restricted her agency more as is forced her to sleep at unusual times, disabling her from doing other things.

For other participants, the negotiation with structures occurred more regarding adherence to medication and other treatments. While this non-adherence to medication structures was sometimes motivated by a lack of trust in medical professionals or pharmacology, others decided to refuse medication to maintain more of their agency. "Elisabeth" (49):

*"I hardly ever use painkillers. In my opinion, it's a choice without end, with painkillers I cross more borders and cause more damage, because of the progressiveness of my illness I also want to keep something in reserve."*

At this point, it is important to stress that not all participants perceived structures of any kind, or even their condition itself, as very limiting to their agency. For multiple participants, it seemed as if their resistance to their condition and its structural consequences was an earlier reaction to the condition when the diagnosis was still more fresh. Many of them first went through a process of grief before slowly moving more towards an acceptance of the condition. Around that time, for many, the structures described earlier started to be considered from a different perspective. For example, the sophisticated scheduling that became a routine for some participants was sometimes

considered more of a blessing than a curse. “Johanna” (25):

*"I am only allowed to eat specific foods at specific times and need 40 minutes of total rest every 5 to 6 hours to allow the pills to dissolve properly in my stomach [...] To outsiders this sounds heavy, I think it's a gift from heaven. In this way I am able to exercise, with some adjustments in terms of times I can work again in outdoor sports and I have even started studying again since this year"*

This quote from Johanna (25), diagnosed with Chronic Fatigue Syndrome is exemplary of a common experience among the participants in this study. Some forms of structure can enable people to actually regain some of their autonomy and become more active again. For others, the consequences of their condition or structural changes were never considered particularly limiting to begin with. Some participants even described a decelerating effect that they perceived after experiencing their first symptoms. Sophie (50):

*"I experienced a kind of peace when I was not faced with tasks such as housework. Could fully enjoy, laugh and relax and took my rest in time. All within my limits."*

### ***Theme 3: Agency in communion – connecting with others as fundamental coping strategy for people with CI***

The ASCS model suggests that communion can sometimes impede agency, since the more one is connecting with another person, the less independent one will grow automatically. This assumption was not confirmed in the context of living with CI in this study. Communion, as in receiving support from others and maintaining social and romantic relationships, was almost exclusively discussed as being beneficial for one's agency and general well-being in the past narratives. Again, communion was constructed in different ways for the people in this study. Some explained that they found support by connecting with other people with CI online through social media platforms. This can be seen as a form of communion, as participants described a feeling of connectedness and recognition by realizing that they are not alone with their disease. Others valued a close relationship with medical professionals that was built on trust and a complete

understanding of the participants' situation. "Elisabeth" (49):

*"My rehabilitation doctor really looks for the healthcare providers that he knows are a good match. The man knows me inside out and knows exactly what is and isn't a waste of time."*

**3.1 Communion in family-, partner-, and friend relationships.** Still, the most common construction of communion in this sample can be found in reflection about family-, partner-, and friend relationships. These close others were stated to provide support both in direct physical as well as psychological ways by raising the mood in times of despair and enabling affected individuals to enjoy their lives more. In that regard, communion has a very interesting, reciprocal relationship with agency. Having a supportive social circle helps some people with CI to retain some agency by enabling them to pursue activities that they would not be able to pursue on their own. Additionally, being autonomous and flexible appears to be a necessary condition to build and maintain social relationships at times, as it requires one to be able to travel freely. This point is supported by the following statement from "Mila" (27), diagnosed with EDS (Ehlers-Danlos-Syndrome):

*I can't have fun with anyone just for once. Because I have no one to do anything with. I have tried everything to find people, but it just doesn't work [...] I am stuck doing things in the neighbourhood because I am too limited to do things that are further away and in the neighbourhood there are only old people so that doesn't work*

**3.2 Loneliness and isolation.** Many participants described a significant reduction in social contacts that had a negative psychological impact on them. For others, their condition has negatively affected their sexual relationships. One participant, suffering from endometriosis, a condition that made vaginal penetration very painful for her, reflected on multiple failed relationships that resulted from this issue. She explained that multiple men in her past were put off by her condition or did not accept her limitations with regard to intercourse. "Adriana" (63):

*"You mainly hear about understanding, support of your partner, but if you are single? It has an enormous impact on your life. I don't dare to start a new relationship anymore, I miss the touch, the arm around me and I become more and more lonely. It is a lonely disease."*

The expression "lonely disease" implies that Adriana draws a direct causal connection between her condition and the loneliness she experiences. This quote underlines that a lack of communion can have a substantial negative psychological impact.

## **SQ 2: How do people with CI construct agency, structure, serendipity, and communion in written future narratives?**

### ***Theme 4: Hoping for external factors to regain one's agency***

In the future narratives, there was an almost universal wish that was expressed by most participants: regaining some of their previous agency. This can be seen by the fact that many participants portray future scenarios in which they are able to be more active than they currently are. They described how they will be able to work more, and be more active in doing things they enjoy. While this wish is very similar for most participants, the ways in which they envision themselves reaching that goal vary a lot. Some people with CI in this study imagined internal factors as the most important factor in regaining their agency to a degree. They had a very pragmatic view on their situation and relied on pacing and other self-management techniques that they wished to become more effective over time. Others however, hoped more for external influences that will ultimately alleviate or reduce their limitations. These external factors can broadly be divided into two categories.

**4.1 Regaining agency through medical interventions.** The first is related to the hope for a medical intervention of some kind that will be invented in the future and grant full or partial recovery from the symptoms. This is illustrated nicely by the following two quotes from "Sara" (67), diagnosed with Lichen Sclerosis

*"It used to hurt 15 years ago, but now they have good drugs for it."*

*And I've been super lucky that they found something for my lungs too"*



It is important to mention here that these wishes are not only expressed by participants who had not (yet) reached a state of acceptance at the time of participating in this research. For example, “Maaike” (49), who has been diagnosed with Rheumatoid arthritis, acknowledged that she is expecting her condition to worsen further over the course of the next 15 years. Still, in her future narrative, she admits that she still hopes for a miracle drug that will alleviate her symptoms and make her more agent again:

*"Secretly, deep down, I hope of course for a miracle drug, so that the pain and fatigue disappear. So that I can walk again, climb the Errisbeg and the Diamond Hill in Connemara/Ireland with the children."*

**4.2 Regaining agency through change of structure.** Similar interpretations can be made regarding the other category of external factors that people hope for to regain some of their agency. It concerns major changes of structure on the societal level. Multiple participants described a future in which governmental or private powerful organizations have reacted in some way to the needs of people with chronic illness and thus enabled them to become more agent again. Commonly mentioned examples of such structural changes are measures to reduce air pollution, organic farming, or providing a universal income and thus helping financially. However, the most commonly stated wish for the future was related to an increased societal awareness for the needs and limitations of people with chronic illness. This awareness was often seen as the foundation on which other societal changes can rest. This point is nicely illustrated by the following quote by “Maaike” (49), diagnosed with Rheumatoid arthritis:

*"I do wish that by 2036 we had reached the point where there is much more understanding and inclusiveness of chronically ill people in society. For example, a basic wage for everyone would be very nice, but also physiotherapy for everyone who needs it, which is currently unattainable for many people"*

Within this theme, many participants displayed hope for structural changes on a societal level, reflecting their sense that the society lacks understanding and awareness of

CI. While some structures are beneficial for the agency of people with CI, others are perceived as being rather limiting.

***Theme 5: "Together we are strong" - The desire for more communion in the future narratives***

**5.1 Connecting with others.** Constructions of communion in the future narratives were in many ways similar to the ones in the past narratives. People expressed wishes for supportive partner and family relationships. Generally, most future narratives reflected a wish for more connectedness. In addition to those similar aspects, there were also some constructions that were more exclusive to the future narratives. Multiple participants described how they connected with others through joined work endeavours. This can be seen as a construction of both agency and communion, as people described being able to do new work and meeting new friends as a consequence of it. Similarly, others described finding opportunities to work through a social contact. "Maaike" (47):

*[Name of husband] is still active as a self-employed ecologist, especially in his favourite field - mushrooms. Every now and then, he does a little vegetation mapping. But by that time, we'll take some space together to regularly go out for a day, into nature. Sometimes combined with assignments that he does where I can help/cooperate a bit. And in the office work too, I may be able to help/cooperate a bit by then."*

**5.2 Finding joy through others.** Another construction of communion in the future narrative is related to the newfound possibility of some sufferers to enjoy their life with others again. In the previous theme discussing communion, it was already addressed that lack of agency can sometimes be very restricting for one's communion. This is also reflected by the future narratives, where many participants stated that they hope for many social contacts, and being able to do nice activities with their friends or family that bring them joy. They also expressed that their connection with others will give them a new perspective on life and a more positive attitude. One example of such a wish can be seen here. "Joanna" (63):

*"Next month Yvonne is coming for a few weeks and in two months Peter and Margriet are coming, also for a few weeks. Cosy, and nice to show them around. It's great that I now have a rich social life"*

**SQ 3: What are differences and similarities in how people with CI construct agency, structure, serendipity, and communion in written past and future narratives?**

***Theme 6: "I have found a calling" – Turning something good out of what happened to me***

The definition of serendipity in the ASCS model characterizes it as the ability to make use of lucky coincidences. As the subject of the narratives was the illness experience of people with CI, the random forces they encountered and reflected upon would not inherently be considered "lucky". Illnesses and limitations are usually not initially considered something positive. Still, there are numerous examples in the data, where people were able to draw something positive out of their changed living situation that resulted from their condition. Therefore, this will be the primary construction of serendipity that will be discussed in the following section. Further, as mentioned before, constructions of serendipity did not differ enough from each other between the past and future narratives to justify discussing it in separate themes. Therefore, the following section will summarize all constructions of serendipity throughout the narratives, while also contrasting statements related to it in the illness narratives and the *Letters from the Future* within one person.

**6.1 Using additional time for things one enjoys.** The primary way in which serendipity emerged in the data was that for some participants, their condition, or the limitations that resulted from it, opened up new opportunities for them. This effect came up in multiple ways. For some, being less active regarding work and physical activities enabled them to pursue other activities for which they previously would not have had enough time. A few of the participants were even able to combine joyful hobbies with activities that are also medically beneficial. A prime example of this can be seen in "Mila"

(27), diagnosed with asthma:

*"I started singing lessons I have always loved music and never dared to take singing lessons and well at one point I just did it especially after that pneumothorax. The lung specialist also thought it was a good way to rehabilitate my lung, otherwise I would have to do a lot of lung exercises because of my very bad asthma"*

**6.2 Finding an opportunity for work in the new situation.** Others were able to use the wisdom and experience they had gathered after their diagnosis to generate creative or informative output in the form of writing books or leading support groups for other affected individuals. For example, "Mandy" (59) diagnosed with endometriosis, describes how she tries to raise awareness about her condition to help other individuals who suffer from it:

*I dedicate myself to helping women with endometriosis in their search for a remedy that works for the woman in question. Do my best to raise awareness of endometriosis, which is so desperately needed.*

While the previous examples were mostly drawn from the past narratives, in the future narratives' serendipity was constructed mostly in a similar way. Even participants, that had not yet found a way to use their changed living situation, described scenarios for the future where they find new hobbies and use the additional time they have. Other participants, who already made experiences related to serendipity, envisioned themselves expanding upon their current activities in the future. They described becoming inspiring and supportive personas for other people with CI or even assisting in scientific work related to their condition. "Johanna" (25):

*"Soon I will have a presentation at an international conference on ME/CFS. I'm going to give a live demonstration where I have myself attached to the equipment on site so that they can follow the measurements"*

With these findings in mind, serendipity can be seen more as a complementary factor to agency rather than opposing it. This is because those people who were able to use

the negative things that happened to them for something good, in most cases became more agentic in the process as they were able to do things that they were not able to do before.

***Theme 7: Wishing for what was lacking or sharing one's success with others***

**7.1 Wishing to gain the things in the future that were lacking in the past.** While contrasting the past narratives and *Letters from the Future* of each participant, one very central observation was made regarding their construction of the four of the ASCS model. Those participants who described something that they have been missing in their past and current illness experience tended to envision themselves achieving that thing in the *Letters from the Future*. There are multiple constructions of that pattern that will be discussed in the following. The construction of that pattern for serendipity was already alluded to in the previous theme. Participants, who expressed feeling as if they had lost their purpose in their past narrative, often described a desired future scenario in which they were able to draw something positive out of their condition, for example by providing support to other sufferers. Similarly, as pointed out in previous themes, people who described a lack of agency in the past narrative envisioned themselves regaining that agency in different ways in the *Letters from the Future*.

For communion, there are different ways in which the above described pattern emerged. For example, "Mila" (27), diagnosed with EDS, described severe loneliness in her past narrative:

*"Socially I am now in a complete low for years and that makes me very sad if I think about it too long I really see no one my age and that's just not fun"*

In her letter from the future, she then described how she was able to find someone to spend time with and how that has positively impacted her:

*"It was great that I was not alone like before but together [...] It is so nice to share these moments with someone namely even if they are as small as a walk."*

This quote illustrates that her need for communion is likely very high at present. Another participant, diagnosed with lichen sclerosis, also expressed a strong sense of

loneliness in her past narrative, although more in regard to physical intimacy. However, even though her need for communion in that sense appears to be quite strong, she stated in the letter from the future that she wishes for a romantic partner but will accept the situation nonetheless:

*Who knows, maybe the little house at the edge of the woods will be there one day, with or without a friend and you will accept the situation as it is.*

**7.2 Sharing one's success with others.** The pattern of wishing in the future for what was lacking in the past occurs consistently throughout the narratives. However, as mentioned before, there are also participants who are already relatively satisfied with their situation at present and did not express a significant lack of agency, communion, or serendipity in the past narrative. For those participants, another very interesting pattern emerged, where those participants often envisioned themselves trying to spread their success and enable other people with similar issues to cope better in the future. As established earlier, some sufferers mentioned for example building support groups, writing books or working with other affected individuals. "Johanna" (25), who developed a self-management technique revolving around pacing, described in her future vision how she would like to introduce her technique to others to help them with their self-management as well:

*The professor I finally got hold of wanted to try it, to test whether my method also works for others. We received part of the subsidy from ZonMW*

While the constructions of this pattern are diverse, they all have something in common. Through their projects, participants wanted to raise more awareness for the needs of people with CI and those to enable more agency for all affected individuals. This recurring vision can be seen as another type of agency, since the will to assist others in their journey could be indicative of sufficient self-management skills and autonomy.

***Theme 8: Regaining one's agency through external or internal factors?***

This theme can partly be seen as a continuation of themes two (*Structure as a threat to agency, - or its biggest enabler?*) and four (*Hoping for external factors to regain one's agency*) that were discussed in the previous sections. For the past narratives it was found that some participants considered structures as rather constricting to their agency while for others it was an important factor in regaining their agency. In the *Letters from the Future*, it was described how some participants hoped to regain their agency in the future by relying on external factors. Prominent examples of those were new, more effective treatments or structural changes on a societal level. During the comparison phase of the analysis, it became clear that there might be a relationship between those two findings. A general trend could be observed where those participants who mentioned struggling with the acceptance and self-management of their CI in the past narratives, more often envisioned a future where their symptoms get reduced drastically by new treatments or their self-management is facilitated by structural changes. Consequentially, those participants who expressed a sense of acceptance and successful self-management already in their past narrative, tended to also rely on these aspects more in their vision for the future. While there are noticeable exceptions to this observation, as for example described in theme four, a clear pattern could be observed. To illustrate this point, examples from two participants that have been quoted before, will now be discussed in detail.

Tess (50), diagnosed with Q-fever, was quoted to illustrate a point in theme two. She struggled to accept and admit her limitations, and thus slept secretly when no one was around her. Similar statements that illustrate this point were made all throughout her extensive past narrative. She vividly described the psychological impact her limitations had on her and the behaviour and emotions that it led to:

*Inside I cry and feel weak limp and worthless a nothing and nothing left of the vibrant woman I have always been [...] I do pep up every private event to still present myself in this way and nobody around me will really know how I'm really doing. I have become*

*really good at that and do exactly what I don't want to do and if not I am ACTING..... In the meantime I am fighting against myself, I am MAD ANGRY DISAPPOINTED*

This section also showcases the inner conflict Tess finds herself in ("I am fighting against myself"). Throughout her past narrative, she also described a process of adapting to the new situation and ultimately at the end of her past narrative, she acknowledged the need to pace herself, be open about her situation and seek support from a local group. Still, her inner conflict is quite apparent up until the end of the past narrative.

This impression is then confirmed when contrasting her past narrative to her letter from the future, which is comparatively short. Here she basically stated that her condition has disappeared entirely, without describing how that was possible:

*You won't believe it but I am cured and there is no more Q fever in my body [...] I am very grateful that you were always there. Now we go full speed ahead"*

This example underlines that the process of adaptation to the new living situation is not a linear one. Further, it supports the pattern described earlier.

The second participant, "Maaike" (49) who was diagnosed with rheumatoid arthritis, was quoted as an example of someone who managed quite well already and had a very pragmatic view of her own future in the sense of not expecting her problems to miraculously resolve. Still, she was also an example of someone who, despite her pragmatism, secretly hoped for such a miracle cure. In her past narrative, she made numerous statements illustrating her adaptation process and how she learned to use structures to her advantage regarding agency. Her letter from the future was consistent with this observation. She described how she does not expect her condition to improve significantly and thus simply hopes for a slow progression of the disease and that she will be able to retain some of her agency through her self-managing techniques:

*"I assume that in 15 years time there will be no progress, only regression (after all, I am getting older) and therefore perhaps some more limitations, but hopefully not too quickly and not too much [...] Walking will still not be possible for long, so my wheelchair*



*will probably stay."*

Later in her letter she stated, that she hopes to be able to accept her condition one day and also provides a rationale on how this acceptance could be achieved:

*I wish that in 15 years' time I can really accept rheumatism (and old age), that I know that everything is always changing and that there is no other way than to feel that deep inside and therefore to be able to move along with what is happening.*

The two discussed examples illustrate two very differing illness experiences and visions for the future. From Tess's statements, she could be interpreted as someone who struggles to accept her limitations in her illness narratives and thus relies on external factors to regain her agency in her desired future. Maaïke on the other hand, appears to manage already quite well in her illness narrative and thus constructs a more pragmatic vision for her future in which she manages according to her limitations. Still, they also both make statements that are exceptions to the observed pattern. Tess acknowledges her need to accept her condition in the illness narrative, and Maaïke admits that she secretly still hopes for a miracle drug that will reduce her limitations.

## Discussion

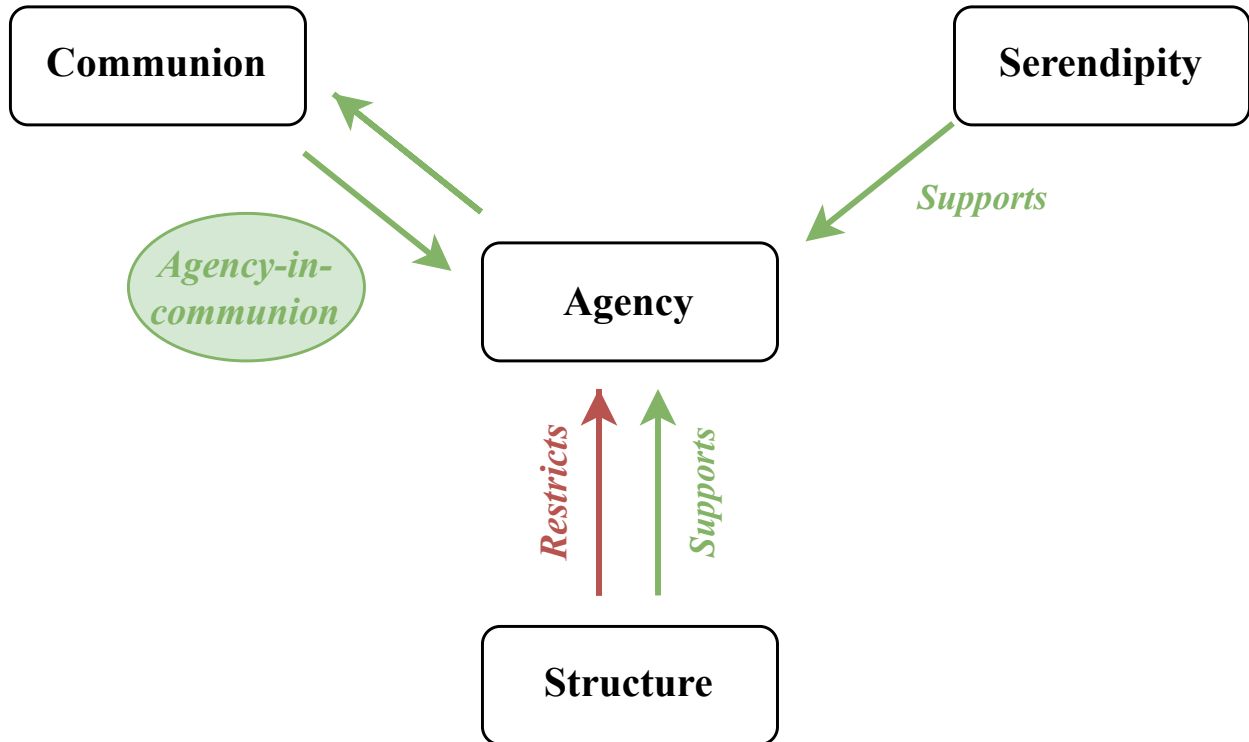
The purpose of this research was to investigate to what extent the principles of the ASCS model can be applied to written illness narratives and *Letters from the Future* from people with CI while contrasting the two narrative types within participants. Specifically, the study aimed to answer one large research question with 3 subquestions concerning the construction of agency, structure, communion, and serendipity in those narratives. In the following, the main research question will be answered together with its subquestions. Afterwards, the implications of those findings will be discussed.

The main research question was: *To what extent is the ASCS model applicable for an analysis of narratives of people with CI?* The subquestions were: *How do people with CI construct agency, structure, serendipity, and communion in written past narratives?*, *How do people with CI construct agency, structure, serendipity, and communion in written future narratives?*, and *What are differences and similarities in how people with CI construct agency, structure, serendipity, and communion in written past and future narratives?* Overall, the model appeared to be a good fit for the data, even if its structure was not replicated. The four constructs of the ASCS model were all found in both the illness narrative as well as the *Letters from the Future*. The concepts appeared to be highly relevant to the subjective experience of the participants. Agency appeared to be the most relevant construct, as it appeared to have interesting relationships with structure, communion and serendipity. However, those relationships were sometimes different than how the ASCS model suggested them. For example, structure was not necessarily perceived as being a limitation to agency, and at times even perceived as complementary to it. Therefore, the main elements of the ASCS model appear to be applicable for an analysis of CI narratives, while its structure does not. A summary of the interrelations between the constructs, as found in the current study, can be found in Figure 2. Regarding the contrasting between past and future narratives, the main finding was that the narratives were often complementary to each other. To explain, often negative aspects that were

discussed in the illness narratives were envisioned to change in the future while positive aspects would be expanded upon.

**Figure 2**

*Adapted version of the ASCS model based on the findings of the current study*



*Note.* Green arrow means support of the other variable; the red arrow means a restriction of the other variable. Relationship between agency and communion is reciprocally beneficial

**Interpretation of findings**

One of the most substantial findings of the current study was that the structure of the ASCS model was not always found in the data. More specifically, the ASCS model suggests, that structure, communion, and serendipity can all be limiting in one way or another to an individuals’ agency (Lieblich et al., 2008). When considering structure, for example, this assumption is partly accurate. There were a number of ways in which participants described certain structures as limiting to their agency. This effect is also touched upon in the scientific literature. Larger societal structures such as social norms are

often perceived as limiting by people with CI as they dictate a set of behaviours that is often difficult to perform for those individuals (Townsend, 2012). For example, it is generally expected of women to take care of their family and perform household chores. A Woman like Tess from the current study feels forced to function according to those societal norms despite her physical limitations, thus limiting her agency. However, this study also highlighted the potential opposite relationship where structure can be beneficial for one's agency. A good example for this were activity schedules that participants of this study use to enable themselves to engage in more activities. Scheduling and pacing are also strategies that are often cited in the literature as being beneficial for one's agency, despite being structures (Danoff-Burg et al., 2004).

How can this paradoxical nature of the agency-structure relationship be explained? First of all, it really depends on the definition of structure that one is using. While in the literature structure is sometimes tightly defined as having a larger societal or institutional nature, this study, and the ASCS model treat it in a broader sense as any set of rules that influence the behaviour of an individual. Therefore, in this study, the aforementioned scheduling and pacing was considered structure as well. The biggest difference between such structures and the larger societal ones is that they are often created out of the individual's own endeavour, and thus include the individual's needs and preferences. A person with CI that adheres to a strictly timed schedule has likely generated that schedule because it works for them specifically. Therefore, they perceived it as more natural and beneficial. On the other hand, social norms or medical interventions tend to be imposed on individuals regardless of their personal preferences. It might be, that whether a structure is perceived as beneficial for one's agency is dependent on whether it is internally motivated or externally forced upon the individual.

Regarding the relationship between agency and communion, the principle finding is also not entirely in line with the suggestions of the ASCS model. The model proposes that communion can be restricting to agency, based on the assumption that the tendency to

connect with others automatically disables individuals from acting entirely autonomously (Lieblich et al., 2008). However, it also acknowledges the reversed relationship, termed agency in communion, where the connection with others benefits agency, as close others provide support that enables more activities. Both of these relationships are supported by scientific literature (Årestedt et al., 2014; Danoff-Burg et al., 2004). Still, in the current study only agency in communion was found. This bares the question of why this potential negative effect of communion on agency was not apparent in the data, even though it is commonly reported in the scientific literature. As laid out before, many of the participants reported being severely impaired due to their symptoms. For them, it was not really a question whether they would lose some of their agency when getting close to others, as they had significantly reduced agency to begin with. Therefore, if anything, connecting with others primarily helped them to become more agentic. In fact, loneliness was a far more common complaint than lack of agency due to dependence on others. While the scientific literature acknowledges the potential negative effect of communion on agency also in the context of CI (Dalteg et al., 2011), it is usually based on the assumption that individuals have some agency that they could potentially lose by become dependent on others. However, for individuals who are impaired to a degree that makes them dependent on support from others anyway, it is likely beneficial if those others are people with whom the individual shares a meaningful connection. At this point, it is important to remember that the ASCS model was not specifically created to analyse narratives from chronically ill people. Therefore, it could be that investigations of the agency-communion relationship show a more diverse picture in other populations.

A similar observation was made regarding the duality between agency and serendipity. In the data of the current study, serendipity emerged almost exclusively as a factor that appeared rather valuable for the agency of the participants. In the ASCS model, it is also proposed as a potential limiting factor to agency. However, as already mentioned in the results section, the definition of serendipity was slightly adapted for the

purposes of this research. While the ASCS model describes serendipity as the ability to draw something positive out of random coincidences that are “lucky”, in the current study, that lucky characteristic was not considered necessary to call something serendipity. This alteration was done since in illness narratives, luck or positive coincidences are not very commonly mentioned. This way, it was possible to discuss the core of the serendipity construct in detail, which is the ability to deal with random forces in one’s life. Here might also lie the reason why the findings of the current study differ from the suggestions of the ASCS model. It is noticeable that serendipity appears to unite two separate constructs into one. For one, there are the random forces that influence the lives of people and over which they have no control. It is those random forces that Lieblich et al. (2008) propose to oppose agency, since anything that lies beyond the control of individuals is naturally restricting their agency in a way. Secondly, there is the other aspect of serendipity, the individuals’ ability to handle these random forces and draw benefits from them. And this ability is inherently beneficial for agency, as it showcases adaptivity and the ability to act effectively. It is this aspect of serendipity that was primarily present in the data. Therefore, again the nature of the duality between serendipity and agency is dependent on the definition of serendipity one employs.

Regarding the comparison approach of the current study, a big coherence between the illness narratives and *Letters from the Future* was found, in the sense of having recurring elements and subjects within one person. This might be since they are constructed by the same person, and experiences in the past have a strong influence on expectations and desires for the future. As noted by Sools (2020), the *Letters from the Future* provide information about how desires for the future guide the behaviour in the present. The illness narratives do a similar thing where through examining experiences from the past it becomes far easier to understand behaviours in the present. Combining those two analytical approaches was successful in the current study, as it provided a more holistic picture of the experiences of any given participant. The fact that in the current

study, the picture that emerged was often so coherent could in part be due to the nature of the tasks themselves. The illness narratives automatically imply to narrate about something negative in the past, as illness experiences tend to be perceived as negative originally. The *Letters from the Future* automatically ask for a positive narrative, as they specifically instruct to imagine the best possible future. Therefore, it is logical to assume that if one is to first narrate about something very negative in their life, that they will then continue with imaging that negative aspect to change into something positive in the future.

### **Strengths and limitations**

One of the biggest strengths of the current study can be seen in the fact that the application of the ASCS model allowed for a rich analysis of the data. The major constructs appeared to be relevant for the subjective experience of the participants, and for the most part they were easily apparent without forcing the analysis to deviate much from the original text. This is particularly notable since the ASCS model was originally not created to be fitting for the analysis of narratives of people with CI. Further, thematic analysis allowed for an easy and structured analysis of the data in light of the concepts at hand. Especially with regard to the comparison phase of the analysis, the approach was useful since the coding from the previous phases made it easier to get an overview. Similarly, the mixed deductive-inductive approach was effective since it enabled the analysis to be flexible yet structured simultaneously. However, the fact that it did not follow the structure of the model strictly, made it harder to compare the findings of the current study to previous findings.

Another strength of the current study is the uniqueness of its research question and analytical approach, especially regarding the comparison between illness narratives and desired future narratives. The comparison phase of the analysis led to findings that could not have been generated otherwise. Examining the differences between each pair of narratives individually provided a more exhaustive picture of the discussed themes and revealed interconnections between them. While the comparison approach is one of the

major strengths of the current study, it is also the first of its potential limitations. Comparing the two narratives for each participant meant examining the differences between them. There is a gap between the "*what has happened to me so far*" nature of the illness narratives and the "*what do I wish will happen in the future*" nature of the desired future narratives, that is not necessarily touched upon in the narratives. To explore the differences between them and drawing conclusions out of it, automatically meant to fill that gap with interpretation. Within this interpretation lies a potential for bias, especially since thematic analysis does not provide a framework for such analyses.

A related issue with the comparison approach concerns the nature of the *Letters from the Future* task. As the task instructs participants to describe the most desirable possible future, their answers are naturally prone to be rather extreme and not necessarily very likely to become reality. Therefore, some conclusions made in this study about the apparent difference between the narratives have to be taken with caution. For example, the finding that some participants envision a miracle medical intervention that eradicated their symptoms despite being already sufficient in their self-managing, could be affected by this. It is understandable, after all, that no matter how good one is at managing one's disease, being completely cured is still more desirable. Still, the *Letters from the Future* task also had significant benefits for the current study since narratives about the desires of participants makes it easier to identify their needs.

Another potential limitation of the current study related to the possibility of bias that results out of the fact that the data was coded and analysed by only one researcher. While the steps of thematic analysis were used as a broad framework and the analysis was informed by theory, it is still important to mention that the interpretation and entire structure of the analysis was subjective to a degree. As an individual, I cannot exclude the possibility that my cultural and demographic background might have influenced my interpretation and thus the findings of this study. For example, the fact that I have a background in nursing and thus have interacted a lot with people with CI might have



biased me to consider some aspects like self-management more important than others. However, these personal characteristics could have just as well had a positive effect on the analysis and can be considered a resource. It is possible that my practical experience enabled me to have more empathy and understanding for the experiences of people with CI, which could have improved the accuracy of my interpretations. Additionally, the steps of thematic analysis from Braun and Clarke (2012) were adapted to include the comparison analysis. This adapted approach was therefore novel and not validated by any previous study or researcher.

### **Implications for the future**

**Theoretical implications.** There are two basic lessons that were learned from attempting to apply the ASCS model to narratives from people with CI. Firstly, it became clear that for the current sample the model is not applicable in the sense that its structure was not replicated and that some constructs needed to be redefined. However, the second lesson was that the once those changes were made, the model was actually very applicable, and the constructs appeared to be very relevant for the subjective experience of the participants, judging from their narratives. From this, one can conclude that an adapted version of the ASCS model, specifically designed to analyse narratives from people with CI, could be a very beneficial tool. Such a model could have altered definitions of the four main constructs that are more applicable to chronic illness narratives. For example, serendipity could be divided into two separate constructs, as implied by the previous sections. That model could also suggest a different interrelation structure between the constructs, where agency can both be restricted as well as facilitated by the other factors. Future research could generate test such a model and use it in narrative studies with a more diverse sample regarding gender and age and multiple researchers coding and analysing the data.

Another theoretical implication relates to the comparison approach that was employed in the current study. In the previous section, a number of advantages and disadvantages of this approach were listed. The most important resulting implication for

future research is that it could be valuable to a comparison analysis between past and future narratives of people with CI, while using a different research tool than the *Letters from the Future*. Future narratives that cover a more “realistic” future scenario, rather than one that described the most positive possible outcome, could add an additional value. Such a comparison could provide a more realistic picture of the gap between past and future narratives. Additionally, core findings and implications of the current study could be checked regarding their validity.

**Practical implications.** The current study also has some practical implications, mostly related to the promotion of agency for people with CI. As laid out extensively, structure, communion, and serendipity all have the potential to be beneficial for an individual’s agency. Therefore, it could be valuable for health care professionals to try to promote those elements for people with CI. For example, for structures it could be beneficial to include people with CI as much as possible in the creation and management of structures, since the current study implied that structures that generated more internally are better received than the one’s that are forced upon the individual externally. More concretely, medical professionals could, for example, try to engage in a more collaborative process with their clients while creating medication routines or treatment schedules. This way, it might become easier for people with CI to accept such structures and perceive them as beneficial to their agency.

## **Conclusion**

The findings of the current study present a small but valuable addition to contemporary research on the subject. The ASCS model proved to be mostly applicable to the data regarding the relevance of the constructs. A total of eight themes and 16 subthemes arose out of the analysis that painted a good picture of the subjective experience of the participants of the study. Despite some methodological limitations, the current study has some important implications for future research. An adapted version of the ASCS model, specifically designed for narratives from people with CI could prove a

useful tool for future studies. Some of the theoretical and practical insights of the current study could be used in the future to inform interventions aimed at improving the well-being and self-management of people with CI.

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**Appendix A**

**Original ASCS model by Lieblich et al. (2008)**

**Figure A1**

*Agency Structure, Communion, and Serendipity (ASCS) model by Lieblich et al., (2008).*

**Agency, Structure, Communion, and Serendipity:  
A Drama of Voices**

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**Agency, Structure, Communion and Serendipity—A Drama of Voices**

*First level—Existential: Structure—Agency—Serendipity*



*Second level—Motivational: Agency -Communion*

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## **Appendix B**

### **Tasks and instructions of the original study**

#### **Illness narratives - original Dutch version**

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.

#### **Illness narratives - translated into English by DeepL**

In the blank field below, would you like to write your story about your life with a chronic condition (past)?

Would you like to tell your story of how things have been going for you since it became known that you have a chronic condition? Describe with as much detail as possible what you have experienced so far and how you feel about it. Perhaps it has changed your life. For example, in health, living, work or other activities, social relationships, other areas of life, or how you view yourself. Or maybe not. We are interested in your own personal experience. In other words, it is about your own experience. Writing a story about your life with a chronic condition will take about 15 minutes. Some people need more time and some need less. Take all the time you need. The story should be no more than 1 A4.

#### **Letters from the Future - original Dutch version**

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.

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?

### **Letters from the Future - translated into English by DeepL**

Letter about your desired future

Imagine stepping into a time machine and traveling to a future you desire. You can step out of the time machine at one point in the future or at several points in time. Use your imagination: remember that it is about something that has not yet happened and that it is an opportunity to invent what might happen: imagine that you can design the

future! Try to write your letter with as much detail as possible, for example about what you think is important in different areas of life such as living, work, social relationships, or your character or self-image. Write what spontaneously comes to mind about your desired future, try not to think too much. We are interested in your own, personal experience. You will conclude the letter with a message from the future to yourself or others in the present time.

You now have a rough idea of the task of writing a letter from the future. Following are step-by-step questions that will help you write the letter later. From these suggestions, feel free to write the letter in your own way.

Writing a letter from the future takes about 15 minutes (some people need more time and others less). Take all the time you need to write a letter of at least 1/2 A4.

When does your desired future take place? How far in time do you travel in the future? The time in your desired future is up to you. This can be 1 hour, day, a week, or years later. Perhaps you see yourself at a certain age? Or at a certain stage of life? Or what do you notice that your desired future is taking place at that time in the future?