A Qualitative Analysis of how Individuals with Long COVID construct their Resilience through Narratives

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Abstract

Long COVID has affected many people in the past two years. Since Long COVID is a chronic illness, the symptoms are long-lasting. This can be a disruption in the life of those affected. Therefore, analyzing how people suffering from Long COVID construct their resilience is vital, given the lack of research in this regard. Two modes of storytelling, narratives, and letters from the future, have been used in this thesis to understand comprehensively how people with Long COVID experience their condition. A qualitative approach, thematic analysis, has been used to analyze the data. Based on this data analysis, the following main themes regarding resilience have been constructed from the narratives and future letters: "Maintaining a positive attitude", "Decelerate life”, "Acceptance and Adaptability", "Visualization of the future”, "Connecting to other people", "Perseverance" and "Initiative behavior". These insights could be helpful for providers of health services to develop individual, holistic, caring plans based on the patient's unique needs to maintain or improve their resilience and, therefore, the ability to deal with health problems in a more adaptive way. The thesis makes a small contribution to narrative research as it analyzes how participants construct resilience not only in their past and present but also in their future lives.

Keywords: Chronic Illness, Long COVID, Resilience, Qualitative Studies, Thematic Analysis, Health Care

Introduction

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) was first identified in Wuhan, China, in December 2019 (Cheng et al., 2020). Since then, the virus has spread rapidly worldwide and has been declared a pandemic by the World Health Organization (WHO, 2020). According to Raveendran and colleagues (2021), around 80 % of those affected by COVID-19 have experienced mild to moderate symptoms, and approximately 5 % developed a critical illness. However, few people who recovered from COVID-19 developed long-lasting symptoms. In literature, this is referred to as “Long COVID”, “Long Haulers,” or “Post COVID syndrome” (Raveendran et al., 2021). Interestingly, patients themselves collectively made the persistence of the COVID-19 symptoms visible during the first months of the pandemic. Callard and Perego (2021) described how those affected found one another on Twitter, where they exchanged their experiences. They made their voices heard over social media, printed media, and policy channels within a few months. Responding to Callard and Perego (2021), who addressed why patients were that effective in making Long COVID visible and igniting action to improve its care, this thesis uses narrative inquiry, a field of research that investigates the power of storytelling, to analyze *how individuals with Long COVID construct their resilience through narratives*. This is of great importance as the patient’s perception needs to be incorporated more intensively into the conceptualization, research, and treatment of the disease (Callard & Perego, 2021). This thesis gives the participants a voice for articulating the illness experience.

Chronic diseases are long-lasting conditions - mostly three months or more prolonged - or can even be persistent in their effects (Bernell & Howard, 2016) and typically require continuous medical attention (CDC, 2021a). In contrast, acute diseases typically have a relatively clear determinable starting point, develop suddenly, are usually of short duration, and are generally medically treatable (BZgA, 2022). Since Long COVID symptoms can last weeks (post-acute-

COVID) or even months (chronic-COVID) (Greenhalgh et al., 2020; Raveendran et al., 2021), it can be seen as a chronic illness. Common Long COVID symptoms include extreme tiredness, shortness of breath, problems with memory and concentration, chest pain, loss of appetite, the inability to do routine activities, and mental health issues such as depression, anxiety, post-traumatic stress disorder, and many more (Carfi et al., 2020). The Centers for Disease Control and Prevention (CDC) currently defines Long COVID as occurring when someone does not return to their usual health within four or more weeks after their initial infection. Still, there is no official diagnosis of Long COVID yet (CDC, 2021b). This thesis, however, includes all people that see themselves as living with Long COVID. Chronic illness, such as Long COVID, can be a physical or mental health condition that causes functional restrictions or requires ongoing monitoring and/or treatment (Buttorff et al., 2017) and display a significant impairment for those affected on a physical, mental, emotional, social, and occupational level (Megari, 2013). Therefore, it is important to hear what people affected with the chronic illness Long COVID state about their chronic illness experiences and give a voice to those affected. It is still unknown who is at the greatest risk of developing Long COVID. Some research has found a correlation between the severity of the acute illness and the likelihood of developing Long COVID (Sykes et al., 2021). Other research has shown that Long COVID was more likely with increased age, body mass index, and female gender (Sudre et al., 2021). Moreover, there is not yet a single effective treatment for Long COVID (RIVM, n.d.; Yong, 2021). The newness of the disease and therefore the low level of information regarding the best healing methods can cause the patient additional stress. Thus, the diagnosis of Long COVID can be seen as a disruptive life event that significantly impacts one’s expectations and view of the future. Interestingly though, research has also shown that some psychological factors, such as hope, optimism, gratitude, and faith, can help adapt to chronic illnesses (Rybarczyk et al., 2012). Hence, this thesis analyzes how resilience, which is connected to the above-mentioned positively focused constructs (Cohn et al., 2009; Tugade & Fredrickson, 2007), is shown in Long COVID patients.

Resilience can be seen as a complex and multidimensional construct and as an essential concept in learning to adapt to life with a chronic disease. Research suggests that resilience influences the treatment of various chronic diseases, including, among others, diabetes, rheumatoid arthritis, and systemic lupus erythematosus (Cal & Santiago, 2013; DeNisco, 2011; Girtler et al., 2010). More precisely, the protective factors that come with resilience, including "optimism and positive mood, self-esteem, self-care, independence, social support, and reduced anxiety," are related to biological processes such as neuroendocrine and immune function. Again, these factors are associated with a progression of the disease through a higher level of well-being and response to treatment (Cal et al., 2015). Resilience comes with several benefits. It can, for instance, give the patient a higher expectation of life and general well-being (Diener & Chan, 2011), positive mental health (Abiola & Udofia, 2011), and positive emotions (Cohn et al., 2009; Tugade & Fredrickson, 2007). Hence, resilience seems to buffer against mental health problems. It is, therefore, essential to address resilience in individuals affected with Long COVID, as this can affect their mental health (Raveendran et al., 2021). As Ungar (2018) has stated, resilience can be broadly understood as “the capacity of a system to anticipate, adapt, and reorganize itself under conditions of adversity in ways that promote and sustain its successful functioning (in human terms, its well-being)" (Ungar, 2003, p. 33). Additionally, resilience can be seen as the capacity to navigate resources towards well-being, not only individually but also in a collective capacity, such as the family environment (Ungar, 2010). Some literature defines resilience as a personality characteristic (Stewart et al., 1997). However, in this thesis, resilience is neither seen as an individual trait, a static process, nor a quantifiable construct. It is more understood as a dynamic process, as it is referred to in qualitative research, a “dynamic process through which people develop a sense of regaining well-being despite all challenges" (Hassani et al., 2017). It is seen as an adaptation during or following significant disturbances, such as Long COVID can be. Here, being resilient means that an individual narrates themselves as adapting to the adverse conditions in which a chronic illness can result in.

According to Bannink (2012, p.78), "people who cope resiliently, tend to construe events positively, including objectively challenging events”. Consequently, resilience and positive psychology are connected. Although studies on how individuals generally suffering from chronic illnesses construct resilience already exist, there hasn’t been any work published yet, which investigates this matter, focusing specifically and exclusively on the construction of resilience when suffering from Long COVID. Taking this into account, it appears to be even more vital and valuable to precisely do this within this thesis.

As mentioned, to analyze the experiences of individuals with Long COVID, narratives were investigated. Narratives help us define our identity and social life; to be more precise, as Murray (2003) stated, "Through narrative, we not only shape the world and ourselves but they are shaped for us through narrative". Narratives are unique and significant since people make sense of their lives through storytelling (Murray, 2003; Wong & Breheny, 2018). Moreover, storytelling gives insights into how people cope with different situations and how they derive meaning from their experiences. Constructing meaning after the diagnosis of a chronic illness goes along with redefining the previous view of life. The expectation towards the current life and future might change through this disruptive life event that a Long COVID diagnosis can be. For this thesis, two ways of storytelling have been considered: describing your past and future life. These two modes of storytelling are essential to understand comprehensively how people with chronic illness experience their condition. In moments when people are suddenly confronted with disruptions to their lives, uncertainty might arise. Inviting people with chronic illnesses to tell a story about their life and future might help improve resilience and guide their current thought and action (Sools & Mooren, 2012). Therefore, a sense of certainty can be regained since the desired future's imagination allows us to better understand the current situation and redefine new life goals. In sum, narratives can help people process a disruption of daily life structures (Ricoeur, 1980) which can be influenced by chronic conditions, such as Long COVID. Moreover, narratives can help transform illness events and construct a world of illness, reconstruct one’s life history in the event of a chronic illness, and explain and understand the illness (Hydén, 1997).

To conclude, this thesis aims at investigating *how individuals with Long COVID construct their resilience through narratives*. More precisely, through analyzing the meaning of resilience described by Long COVID patients through narratives, themes of resilience can be identified. The results generated from this thesis can contribute to a wider research field regarding the relatively new matter of Long COVID. Moreover, it can raise the awareness for the suffering patients so that their perception does not fall into oblivion by the sinking COVID-19 numbers at date (WHO, 2022).

Methods

Design of the Study

The data analyzed in this thesis stems from a Dutch empirical web-based 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'). The data used for this thesis was collected between the 19th of October 2021 and the 16th of February 2022 and is an ongoing study. The data was collected through Qualtrics. The ethical approval was granted by the Ethics Committee of the Faculty of Behavioural Sciences of the University of Twente (211138). The survey was spread through different social media platforms such as Facebook or LinkedIn and various patient organizations. A brief information letter that provided all necessary further information on the background, the purpose, the eligibility criteria and the survey content, the benefits but also the possible burdens of participation, the confidentiality, and the information about the research team was permanently attached. The inclusion criteria for this study were that the participants see themselves as living with a chronic illness, were proficient in the Dutch language, had enough technical knowledge to participate in an online survey, and had reached the minimum age of 18. The participants were then asked to give consent to participate in the survey. It took approximately 45 minutes to complete the whole survey. Researchers were available via telephone and email if a participant had questions concerning the study. Withdrawal from participation without giving a reason was possible at any point of the study. No reimbursements or incentives for participation were offered. The dataset (*N* = 98) consists of 78 women and 20 men aged between 24 and 76.

In this study, narratives of people with chronic diseases have been collected. More explicitly, people with chronic illnesses were first asked to write about their experiences living with their condition. Using an illness narrative, they were asked to label their story according to Frank (1998), and afterwards write about their desired future using the method "Letters from the Future" (Sools, 2020). "Letters from the Future" is a creative writing exercise where people imagine traveling into the future and writing a letter from the future to the present. With this instrument, "the human capacity of imagining the future", and insights into how humans construct their future selves (Sools et al., 2015) can be explored. Participants can choose to whom the letters will be written and from which future moment they are writing. Moreover, a questionnaire that measures mental health (Mental Health Continuum-Short Form in Dutch, MHC-SF (Keyes et al., 2008), a well-being scale, and general demographic data (age, gender, occupational situation, living situation, other diagnoses) were included to generate a comprehensive overview of the sample. Participants were also asked how the illness has affected their lives; they could choose between "positively", "negatively", "both positively and negatively," or "hardly not affected". Participants were also asked about their relationship status and whether they had a second or third diagnosis.

Data Analysis

To analyze the data and identify the main themes regarding resilience, thematic analysis (Braun & Clarke, 2012), a common method used in qualitative data analysis, was used. Thematic analysis is a method of data analysis for understanding experiences, thoughts, or behaviors across an entire data set (Braun & Clarke, 2012). In this thesis, resilience is seen as a dynamic process through which people develop a sense of regaining well-being despite all challenges (Hassani et al., 2017) and an adaptation during or following significant disturbances. Additionally, resilience is seen as navigating resources towards well-being. As a flexible analytical approach, thematic analysis focuses on key themes relevant to the research question of *how individuals with Long COVID construct their resilience through narratives* while maintaining an openness to new constructions in the data. To analyze the data more thoroughly, it was first dissected to be worked on step by step.

According to the six steps of thematic analysis (Braun & Clarke, 2012), research started with (1) *familiarization with the data*. Since this study explicitly focuses on Long COVID patients, only the participants' narratives, future letters, and diagnoses of people with this diagnosis were translated from Dutch into English by the author using the translation program "DeepL". A native Dutch speaker proofread the translations. Afterward, one file was created for each of those participants, and the data was re-read to get more familiar with it. For the second step of (2) *generating initial codes*, all narratives were uploaded into the program "ATLAS.ti" (Version 22.0.2). Then, all documents were coded on a half-sentence level to multiple sentences by the researcher, which was the unit of analysis in this thesis; the unit of observation is resilience, and the themes are the level of analysis. The narratives and future letters were analyzed regarding the question on how people describe their experiences on living with Long COVID. Data relevant to this was coded from meaningful data fragments with descriptive and interpretative codes, which were modified throughout the analysis (Braun & Clarke, 2012). For instance, the following quote is considered as meaningful as it contains several codes, shown through the brackets in the quote, on how "Lieke", a 54-year-old woman, constructs resilience while describing her experiences with Long COVID.

> *I can only call for half an hour on good days. I can't stand stimuli and have nowhere to go. I take a walk with my dog, mess in the garden, and read a bit [Self-Care]. Luckily, I can still do that [Gratefulness]. On good days. But I am also sick for days and sometimes weeks in a row. Sometimes because I've done too much. Then all I can do is lie in bed [Rest]. I feel very limited, I am a shadow of who I once was, and I have lost my sparkle. Yet I am courageous [Self-Confidence]. The confidence that this phase will one day lead to something good [Optimism, Hope, Faith].*

After coding, the third step of (3*) searching for themes* was completed by grouping codes meaningfully into overarching themes regarding the research question, how individuals with Long COVID construct their resilience. The coded data got reviewed, and similarities were identified. For (4) *reviewing potential themes,* codes were reviewed again for each transcript, and corresponding quotes were checked for applicability to the themes. Two additional rounds of reviewing codes and themes were completed to make further refinements. These iterative cycles of coding verification, feedback, and thematic grouping ensured data immersion. To ensure intercoder reliability, the coding scheme was co-coded by another psychology master's student from the University of Twente.

Thematic analysis depends on whether one works with a prior research question (deductive approach) or first creates themes from the material, which can later become research questions (inductive approach). In this work, a hybrid approach was chosen, i.e., a mixture of both techniques (Fereday & Muir-Cochrane, 2006). The first categorization was conducted inductively. Thus, the analysis was open-ended, and all possible themes found in the material were categorized. The research questions of this thesis guided the second pass (from step 3), and from the themes found, those that could provide concrete clues to answer the research questions were further pursued and coded. Accordingly, this followed a deductive approach.

Description of Data

Since people with all different chronic diseases could participate in the survey, only the 37 participants who self-reported suffering from Long COVID were considered for this thesis. One participant of these 37 was omitted due to incomplete and unusable responses. The final sample that this paper is therefore going to analyze (*N* = 36) narratives, which consist of 31 women (86 %) and 5 men (14 %), in the age range from 25 to 63 (*M* = 48.75; *SD* = 10.32). The participants consider themselves to be a person who is suffering from Long COVID. In total, 17 participants (47 %) stated that their lives had been only negatively influenced, 17 participants (47 %) said that their lives had been positively and negatively influenced, and 2 participants (6 %) said that their lives had been hardly or not at all affected by Long COVID. In total, 23 participants (64 %) stated that they are married, or in a registered partnership, 8 participants (22 %) stated that they are single, and 3 participants (8 %) stated that they are divorced. Two participants (6 %) stated that their relationship status differs from the given answers. Twenty participants (56 %) claimed they have at least one other diagnosis next to Long COVID, and 16 participants (44 %) do not have an additional diagnosis.

Results

Based on thematic analysis, I found seven main themes addressing the construction of resilience by the participants, where they illustrated in their narratives how they adapted to Long COVID or regained a sense of their well-being (resilience) throughout the course of the disease or illustrated a desire or wish to do so in their future letters. The themes that I found are the following: "Maintaining a positive attitude", "Decelerate life", "Acceptance and Adaptability", "Visualization of the future", "Connecting to other people", "Perseverance," and "Initiative behavior" (*Table 1*).

Table 1: Themes and Codes from Thematic Analysis regarding Resilience.

Themes	**Codes**	**Frequency of the Themes**
Maintaining a positive attitude	Optimism, Hope, Faith Gratefulness Living in the here and now Finding meaning in helping others	96
Decelerate life	Avoiding stimuli Setting boundaries to restore energy Rest Searching for professional support	70
Acceptance and Adaptability	Acceptance of the illness Adapting to the disruptive life event Revision of your own self-concept Growth after the disruptive life event	65
Visualization of the future	Making plans for the future Restore normality Visualizing a new meaningful job	48
Connecting to other people	Importance of the family Support, Love, Connectedness Felt heard and taken seriously	44
Perseverance	Not giving up after long courses of illness and setbacks Patience Self-Confidence to fight illness	38
Initiative behavior	Self-Control Taking care of oneself Starting new activities	23

Note. Frequencies display the number of occurrences in narratives and future letters.

Theme 1: Maintaining a Positive Attitude

Participants wrote about the importance of maintaining a positive attitude. As an aspect of maintaining a positive attitude, optimism, hope, and faith were mentioned. “Julia”, a 51-year-old woman, described at the end of her narrative, where she wrote in detail how hard the course of the disease was for her after nine months of ups and downs where she even spent time in the emergency room, optimistically: "*Stay Positive is my life motto, I am currently sticking to it*". Her optimistic life motto seems to help her throughout the nine months of ups and downs that she experiences with Long COVID. “*Staying positive*” is commonly described by the participants. “Lieke”, a 54-year-old woman, described vividly in her narrative: "*I feel very limited, I am a shadow of who I once was, and I have lost my sparkle. Yet I am courageous. The confidence that this phase will one day lead to something good*.”. Lieke maintains her optimistic thinking even though she is “*a shadow of who* [she] *once was*” and even “*lost her sparkle*”. Furthermore, she even states how she has the confidence that the phase of Long COVID “*will one day lead to something good*”. It seems as if this hopeful thinking helps her adjust to the chronic illness. As “Thomas”, a 63-year-old man, described, he relapsed three times. Nevertheless, he has hope that the third time will be the time it will all change for the better:

> *Looking back on this period of 15 months: I have gone through a rough time, I was on the verge of collapse in the ICU… I am a true optimist by nature, and that did help me through.*

Thomas has stated how being an optimist has helped him cope with the disrupting life event, as many other participants described in their narratives and future letters. As seen in his future letter, he wrote an optimistic thought at the end to probably cheer himself up: "*Hang in there, keep your head up, and know that you can do this*". Further, participants seemed to maintain their positive attitude by writing about being grateful or “*thankful for* [her] *health*” (Lotte). “Kim”, a 55-year-old woman, described her gratefulness after she was in a coma as the following:

> *From the moment you opened your eyes you had one goal in mind: to be grateful for your body that survived the virus. Very grateful also for the nurses and doctors. Grateful for my husband and children.*

And she later explains that she "*made it by being grateful for [her] new life"*. Being grateful for surviving and for the family members was narrated commonly in the narratives and future letters.

Theme 2: Decelerate life

The participants describe throughout their narratives how they try to slow down in their lives, rest more, cancel visits from friends to restore their energy that can be used for recovery and avoid stimuli in general. Moreover, some of the participants wrote about their desire or wish in their letter from the future, how they want to cut back their lives in the future (which is closely connected to the theme "visualization of the future").

As a means to decelerate life, avoiding stimuli was mentioned. Julia described in her narrative how it helped her to avoid stimuli and "*plan the day and especially make the rest moments stimulus-free, so lie in bed, and take recovery time*". It seems that having "*stimulus-free moments*" are "*especially*" helpful for her. Later she described how this helped her with "*getting some grip*" on her life. As Isa described, "*avoiding messages*" has helped her since she gets "*completely overstimulated by the music, the light, my list, other customers, sounds, etc*.". Avoiding stimuli and, therefore, decelerating life has helped the participants to adapt to the new life circumstances and increase their sense of well-being. As shown in the future letter from Kim, she described to herself how rest would help her when dealing with Long COVID:

> *My goal was to get back on that train as soon as possible. It took quite a while when I realized that speed would not help me. Rest would. Lots and lots of rest. Dear impatient you. You made it. By being grateful for new life and rest.*

It seems as if to "*get back on that train as soon as possible*", here meaning living a healthy life again, would be manageable through "*lots and lots of rest*". As "Fiene", a 38-year-old woman, described vividly, she “*stopped all the treatments except for a few more times of occupational therapy*” and “f*inally choose what all the therapists kept saying but didn't feel any room for: REST*”. She even described how her headaches “*decreased from 'continuous' to 'regular*'” through resting. The extracts illustrate how the participants need rest during their illness and how this helped them to get better and adjust to the new situation in a more adaptive way.

Many participants described how setting boundaries and saying no to visitors has helped them to restore their energy and decelerate their life. As “Livina”, a 28-year-old woman, wrote in her narrative:

> *I have learned to say no, to choose for myself, and not always be ready for someone else. I notice that some people are not always there for me. That's why I choose myself. I no longer put energy into people who weren't there for me now. I desperately need that energy to get through the day well, and to grab the moments that give me energy!*

She even described how she “*learned to say no*”, “*choose herself,*” and “*no longer put energy into people who weren’t there for her”.* It seems as if the illness has taught her to set boundaries for herself and how this gives her new energy “*to get through the day well*”. “Lotte”, a 45-year-old woman, even stated how she “*started to pay more attention to [her] limits*” to “*become less anxious*”. Setting boundaries and paying attention to her limits helped her to regain a sense of her well-being through becoming less anxious. Listening to oneself and one’s limitations and then setting boundaries to restore energy has helped the participants deal with Long COVID and regain a sense of their well-being.

Some participants wrote how professional help helped them with slowing down in life. Livina wrote about something similar, how she was also going to see a psychologist and how “*the psychologist has helped sort the chaos in the head and link causes/effects. This gave peace and overview*”. Here, the help of the psychologist seemed to help her reduce the chaos in her head, which can be seen as more calmness and recreation. This seemed to help the participants decelerate their life and restore their energy, which appears helpful for adjusting to the new life circumstances and regaining a sense of well-being.

Theme 3: Acceptance and Adaptability

In the theme “Acceptance and Adaptability,” the participants wrote about a process of adapting to what is supposed to be a new phase in their lives, dealing with the processing (acceptance) of the illness. Here, the participants describe their new stage of life as inevitable, which should be met with acceptance and adaptation. A forced change on the part of the participant is described as impossible. Ultimately, some participants learn that they grow by dealing with the effects of the disease and how they revise their self-concept.

Firstly, acceptance was shown as a means of dealing with Long COVID. Julia described how acceptance of how Long COVID is now a part of her life and will be a part of her life in the future and how this even helped her become more aware of making choices that are good for her:

> *Long Covid is a struggle in your life right now. However, know that that has brought you to very good decisions in your life. Long Covid will continue to play a role in your life, but that is precisely why you are more and more aware of making choices that are good for you. You needed this hard lesson… My message is; accept life as it comes. You cannot already know what the course of your illness will be. Really a waste of your energy.*"

She described how acceptance could help not waste the energy to find out how the course of the illness might be. If acceptance helps maintain one’s energy, this energy might be better used for recovery. By saying that Long COVID “*has brought her to very good decisions*” in her life, she illustrates how this disruption in her life has led to something positive, which can be seen as growth. Throughout the narratives, many participants described their illness as a “*lesson*” that they “*needed*” and constructed its influence in terms of, for example, an increase in consciousness. Advice on how to “*accept life as it comes*” was not uncommon in the narratives. “Tjarda”, a 48-year-old woman, described how she was “*struggling to recover*” for a long time and how “*after a lot of tears,* [she] *learned to deal with the limitations*”. She stated that she has "*learned to build a different life and still be able to enjoy* [herself] *despite the limitations*". "*Dealing with limitations*" was commonly described by the participants as a way of accepting the new life circumstances.

Moreover, adaptation was mentioned as a means of dealing with long COVID. Thomas described how he made an important decision "*as of August 2022, I will no longer work in education: I will bring my retirement forward about 2 years and enjoy the free time that will be given to me then"*. He adapted his life after falling ill from Long COVID and described how he would "*enjoy his free time*" then. He seems to regain his well-being through taking active steps in his life and adjusting to it. Moreover, participants wrote about how they had to revise their self-concept.

Furthermore, growth was also mentioned. As the following example shows, Kim described how the new life circumstances have led to something positive:

> *My life takes place between the triangle of couch, bed, and a little exercise. And from that triangle, I watch my husband and four children participate in life. I stand on the sidelines. It's not always an annoying triangle, by the way. My life has never been more mindful, simple, and regular. The clock ticks slowly, the dishwasher is no longer an in-between chore. Having coffee together with my husband can even be called very enjoyable.*

Here, the participant described how her life has changed after adapting to it and how something good evolved through the forced change by the illness. She described her life that she has now as something positive, even more positive and "*more mindful*" than it was before. Describing the new life as "*more mindful*" in the future letters was not uncommon. Kim described how having coffee with her husband can "*even be called very enjoyable*". This illustrates that having coffee before with her husband might not have been as enjoyable because her life has not been as mindful and slow as it is now. She seems to have a higher sense of well-being than she had before. These experiences can even be seen as more than the dynamic process of adapting and regaining well-being despite all challenges. The participants seem to adapt to the new life through the acceptance of the illness as well as adapting to, for instance, through revising their self-concept. In some participants, growth can even be an outcome of dealing with Long COVID.

Theme 4: Visualization of the future

The participants wrote about a desired future; some wanted to restore their normality and others wanted to start a new meaningful job. As a means of visualizing the future, making plans for the future was mentioned. Thomas wrote in his future letter how he desires to make plans for "*bringing forward his retirement*", which other participants also described in their future letters.

> *I have made an important decision: as of August 2022, I will no longer work in education: I will bring my retirement forward about 2 years and enjoy the free time that will be given to me then. (...) I see my future bright when I no longer have any headaches about teaching. In any case, I'm going to enjoy it to the fullest: our beautiful apartment, cycling, shopping, and cooking, having a good time with my husband (name) working on my old jeans and then wearing them with pride and showing them to the outside world, reading thrillers when I can, watching detectives idem.".*

He seems excited about his future and his new plans. It is the opposite of resignation within the illness. He is visualizing a bright future and lists many things that bring him joy. This description of a "*bright future*" and "*enjoying life to the fullest*" was not uncommon in the future letters of the participants. This visualization of the future gives the participants a sense of well-being. As "Neeltje", a 62-year-old woman wrote in her letter to the future that she wrote to herself: "*I have my humor, happiness, and my life with fulfillment. The decision to retire early was a good one, but also to spend half of those last two years doing something else that gave me energy".* Here, she illustrates the desire to fill her life with something that gives her energy by retiring earlier, which seems to provide her with a sense of well-being, as she described how she now has "*humor, happiness and life with fulfillment*". Livina described how she wants a more meaningful job and change something after the Long COVID experience: "*I am also thinking about making a switch in work. I notice that the regularity that I now have is very good for me."* Moreover, she even realized how her “*current job with irregular shifts has given [her] stomach complaints*” and how these complaints “*have disappeared since I got home”* after falling ill with Long COVID. Visualizing a new, more meaningful job gave the participants a sense of well-being.

Other participants did not seem to want to change their future after dealing with Long COVID; it seems as if they wanted to restore their normality again. As “Saskia”, a 41-year-old woman, described in her letter to the future how she has the desire to “*go back to the way we* (she and her husband) *used to be, traveling around with the tent again and doing normal things again*”. Being able to go back to life as it has been before the illness or visualizing this in the future letters seems to give the participants a sense of well-being despite the challenges that come with Long COVID. Both aspects, visualizing a more meaningful job and making new plans for the future as well as restoring the normality seem to be a part of adapting to the new life and regaining a sense of well-being. This theme is closely connected to acceptance and adaptability, as it is necessary to accept the new life circumstances to consider an adaptation of one’s life in the future.

Theme 5: Connecting to other people

In people’s extracts, they write about hopeless times through their need to connect to others which is problematized by their disease. The importance of family was mentioned. “Tess”, a 53-year-old woman wrote in her narrative: "*My partner is my backup for ideas, solutions, pep talk, motivation, but is also my guide to the appointments in the hospital, with conversations at work because I can't remember it yet.".* Tess describes her partner as her backup and guide, which were common metaphors for family members in this theme. Participants did not describe their partners or family members as being unsupportive. This underlines the idealized impression management which occurs in this data. Moreover, aspects that can be seen as support, love, and connectedness (beyond the family) are mentioned often regarding the recovery process. “Isa”, a

40-year-old woman, has noted how she is “*now in contact with fellow sufferers*” and how she has “*underestimated how valuable that is*”. She writes: “*I don't have to explain anything there, I feel appreciated and not judged*”. The support of fellow sufferers seems to be especially helpful when dealing with Long COVID, as it is commonly mentioned in the participants' narratives. Similarly, Tjarda claimed in her future letter how it is necessary to go through times like the Long COVID experience together and show cohesion:

> *But in the end, we had to do it together, solve it together, get out of that crisis together. Because everyone was fed up. Commenting, criticizing, and grumbling from the sidelines is what happened instead of putting our shoulders to the wheel together and biting the bullet. Support each other, respect each other, be creative, then we all come out stronger in the end.*

Also, in visualizing your own future, connectedness and cohesion are important aspects to “*get out of that crisis together*”. On the other hand, some participants wrote about their limits and how they had to set boundaries with friends or visitors to restore their energy level. These two different perceptions will be explained in depth in the seventh theme and discussion. Isa wrote in her letter from the future to her children: “*Never forget girls, that you have to take care of yourself. Now I help other people with this process, and it is so valuable. As far as I'm concerned*”. She gives her children the knowledge to take with them on their way that they “*have to take care of [them]selves*” but at the same time that “*life is all about connecting people*”. It seems as if a balance of both is important when dealing with Long COVID.

Further, feeling heard and taken seriously was mentioned as a form of connecting to other people. “Sophie”, a 55-year-old woman, even described in her letter from the future to herself that “*people who feel heard don't have to feel anger and don't have to hunt for "the guilty". And this gives peace*”. Feeling heard from others is important to participants when dealing with Long COVID; this helps them feel less anger or even more peaceful. Participants seem to adapt to the new life and regain a sense of well-being through connecting to other people, receiving support and love through their families, partners or friends, and feeling heard and taken seriously by doctors.

Theme 6: Perseverance

During the rehabilitation process, the participants describe that they encounter obstacles. Naturally the obstacles set them back in a multitude of ways. However, the participants are willing to find ways to overcome them. Many participants know that the rehabilitation process can be long, requiring perseverance and patience. The stories were complex: participants lost members of their families while being incurably ill themselves. Most of them lost the ability to work again or exercise. However, many mentioned not giving up after long courses of illness and setbacks. Lotte wrote about her experience with Long COVID: "*I was sick for nine months, and I was back to square one".* Even though Lotte had repeated relapses throughout her illness, and even had to start over after nine months of trying to get better, she kept fighting and trying until she was able again to "*get out of bed about half of the time*" after six weeks. Hans, a 62-year-old man, described vividly how he kept fighting despite repeated relapses: "*So, almost one and a half years after the beginning of my illness. I'm only progressing in very small steps. Like 20 forwards and 19 backwards".* But as he continues in his story, he does not give up and "*keeps going*". Juliea wrote in her narrative, "*on bad days it feels like a curse... And yet, I don't give up, giving up is not an option. I am in fact on the right track".* Here, the endurance can be seen clearly as she is not giving up, even though the chronic illness feels like a curse to her. The following quote comes from the participant's letter from the future, and it shows how perseverance is, in retrospect, essential for "Hendrikje", a 39-year-old woman:

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

The participant illustrates how showing endurance is worth it, even when suffering from Long COVID and from “*a heavy depression*” at the same time and fighting and enduring can even be rewarded in the end.

Furthermore, patience was mentioned as a form of perseverance. Hendrikje wrote how enduring and having patience is essential in adapting and regaining well-being, which is in the thesis at hand, defined as resilience. In addition, self-confidence was also mentioned as a form of perseverance. In their experience with Long COVID, the participants mentioned phrases that illustrate their self-confidence while enduring the course of the disease. The participants had self-belief in themselves and in the ability to get better. After describing how hard Long COVID is on her life, Julia makes powerful statements, for instance, “*this won't happen to me, I'm going to fight, and I'm going faster than anyone thinks*!” which seem to help her in enduring during the Long COVID experience. The participants adapt to the new life and regain a sense of well-being through persevering and believing in themselves.

Theme 7: Initiative behavior

The participants described initiative behavior in their stories by expressing doing things that bring them pleasure and by talking about starting new activities. Firstly, as a form of initiative behavior, the desire for self-control is expressed by the subjects by describing a high level of activism after being bedridden for a long time due to the disease. They strive to be able to shape their own lives again rather than just having to follow the course of the disease.

Self-control as initiative behavior was expressed in different ways by the participants. “Juliea”, a 48-year-old woman, described it as the following:

> *And from that moment on things are different. From that moment on, I am no longer sitting next to Covid in the passenger seat driving around recklessly, but I am behind the wheel myself and the speed goes down, way down.*

She described how gaining back control of her life, and the disease has helped her take the speed out of the course of the disease, which is helpful with the process of adapting and regaining well-being. She is “*behind the wheel*” and takes the initiative to deal with the challenging situation. Before the extract, she described how she was tired of the uncertainty, the symptoms, and the ups and downs that came with the disease. In the shown quote, she seems to structure herself and the uncertainty through being “*behind the wheel*” and trying to decide by herself what comes next. This highlights how regaining self-control can be seen as another aspect of taking the initiative to deal with the disease and participate in life again. “Maaika”, a 25-year-old woman, on the other hand, described how one of the most important lessons of the period of illness was that her “*need for control is not going to help further in the recovery*” and how she “*learned to let go*”. Both, taking control as well as letting go can be seen as part of the dynamic process of developing a sense of regaining well-being and adapting to the adverse conditions that Long COVID can be.

Further, self-care was described as a form of initiative behavior. Lotte described her experience in the narrative as the following, which illustrates how she positions herself as someone taking the initiative to participate in life again:

> *I've learned to watch out for my limits and take good care of myself, so I do that at times like that. I go to church again and I play the flute again in church, as I used to. Every now and then I go to the sauna with my husband for a day. Every now and then I meet up with a friend for an afternoon of shopping.*

The participant presents herself as someone who has learned to take care of herself, described as an act of “*watching her limits*”. Listing different activities that the participant does „*again*“ after having to quit them for a period after falling ill with Long COVID was a common phenomenon in this theme. Lastly, starting new activities was shown as a form of initiative behavior. Lieke stated in her narrative, after vividly describing how hard the Long COVID disease was on her, how she “*started volunteering at a market garden*” and how this “*gave her energy*”. Lieke, therefore, expresses how taking the initiative and starting new activities seem to help her adapt to the new life and regain a sense of well-being.

Discussion

Summary and Interpretation of Findings, including Practical Implications

Overall, I found seven themes throughout the narratives, as well as the letters from the future of the participants.

A theme that occurred often was how the participants maintained a positive attitude and stayed hopeful during the hard times. This finding of a narrative where an ill person is to be positive and self-confident in Western society stands in alignment with other research (Couser, 2016). In Western society, being healthy is considered normal and illness refers to a deviation from that norm (Boorse, 1997), which might explain this clichéd positive and self-confident narrative. An important aspect of resilience appears not to be the absence of difficult life experiences but rather the ability to determine a positive perspective within the experiences, which stands in alignment with earlier studies (Olsson et al., 2003). Optimism, hope, faith, and gratitude were often mentioned throughout the narratives and future letters. The results I found stand in alignment with other research: the above-mentioned positive constructs such as hope and optimism can bring relevant results for general health and physical well-being (Snyder et al., 1991). Some research claims that positive expectations are considered one of the main determinants to see whether people will continue to pursue their life objectives when living with a chronic disease (Hart et al., 2008). The positive psychological factors of hope, optimism, gratitude, and faith can help adapt to chronic illnesses (Rybarczyk et al., 2012). Therefore, it makes sense how this theme occurred as often throughout the narratives. As shown in the results of this thesis, a positive attitude was mentioned many times, also in the sense of cheering oneself. Thus, it might be necessary for families and nurses to maintain and promote this positive attitude of Long COVID patients to increase their resilience. The positive psychological exercise "Three good things" might be helpful for this. Humor, sometimes mentioned in the narratives, might be beneficial as well. Therefore, keeping a positive attitude as a healthcare provider might help the patients to maintain theirs.

Almost all the participants wrote about was how they decelerate their life after falling ill with Long COVID. They wrote about avoiding stimuli, resting, and setting boundaries to restore their energy, which is in alignment with earlier studies (Opsomer et al., 2019). This contrasts with other qualitative research, where the participants describe physical activity and exercise as helpful when living with chronic illness (Hunt & Papathomas, 2020). It seems to depend on the illness and the individual, which way they describe as being helpful. In this thesis, however, one participant described how she learned that her need for control was not helping her recover and that learning to let go was one of the most important lessons in her period of illness. This contrasts with how many other participants described that being in control is helpful for them in dealing with chronic disease. Resting and letting go seem to be meaningful for the participants to construct both aspects in this thesis, which aligns with other qualitative chronic illness research (Lerdal, 1998; Najafi Ghezeljeh & Emami, 2014). The findings in this thesis show how patients deal with chronic illness differently and how unique individual treatment is crucial for the patients.

Furthermore, the participants wrote how accepting the new life that is caused by Long COVID, for instance, through revising their self-concept has helped them to adapt and regain a sense of well-being. One of the most important dimension of meaning that contributed to resilience was that of acceptance. Being able to accept a new life chapter of living with a chronic illness as well as adapting to this are important aspects for the participants and to deal with Long COVID. Recent research has stated that acceptance and commitment therapy (ACT) helps foster resilience in pediatric chronic illness by promoting psychological flexibility (Ernst & Mellon, 2016). By accepting the new reality, adjustments for adaptation can be made. For nurses and families, this insight might help avoid raising false hope with the course of the disease. If a patient is young and healthy, not to tell them that they will be better soon but instead to make sure that for now, the patient accepts the diagnosis and the change in life. Promoting acceptance of the chronic illness might increase the will to adapt to the new life (Walker et al., 2004). The findings are in alignment with the findings of Hassani and colleagues (2017), as they have found in their qualitative analysis of resilience in the elderly with chronic illness following themes: "accepting life with chronic disease" and "adapting to health problems".

I found in the future letters how the participants visualized their future and how they either wrote about restoring their normality or finding a new, more meaningful job. This brings new information to narrative research, as the method of imagining one’s future was first used in analyzing how people with Long COVID construct their resilience. The participants present plan-making in their narratives or future letters to give them a sense of well-being and a positive mindset. Especially in the future letters, the positive visions came clear; the participants wanted to change their lives for the better or restore their normality. It seems as if this is an individual and subjective desire that varies between the participants. Health care providers or families could assist the participant in visualizing their future as this was constructed by the participants in this thesis in a very positive way.

The theme of connecting to other people and giving and receiving support often occurred throughout the narratives and future letters. The participants often wrote about how the love and support of others helped them to keep going. Some people reported that without this, they would not be able to continue their "journey" with Long COVID. Some research has shown that social connectedness can be seen as a source as well as a consequence of meaning in life (Stavrova &

Luhmann, 2015). Moreover, some research has shown that a sense of meaning in life can increase resilience to stressors (Ostafin & Proulx, 2020). The insights from the thesis at hand on how Long COVID patients narrate about connectedness and the support of others might help nurses and families in dealing with the disease. For a healthcare worker, looking out for support for the patient within their family system or friends is essential. If none of this is applicable, it might be helpful to suggest support groups for people with chronic illnesses. Then, people can receive the support and understanding that they might need. Health care workers could additionally focus on telling patients about the ability to grow from this chronic disease since many fellow sufferers reported that this is possible in the narratives and future letters and that they now have a more meaningful life than before falling ill with Long COVID. Therefore, resilience in patients might be maintained or increased.

Additionally, the participants narrated how perseverance, not giving up after several relapses through being patient and believing in themselves, has helped them to adapt and regain a sense of well-being which is seen as resilience in the thesis. The ability to keep going despite major setbacks, here called perseverance, can be seen as one part of resilience, which aligns with how Wagnild & Young (1993) define resilience. In this thesis, the participants described how they kept going despite setbacks or relapses of Long COVID, how this endurance is worth it and might be rewarded in the end. This reflects the common “warrior metaphor”, a common narrative in Western society that describes how illness is a war and the individual goes through it fighting like a soldier (Chin, 2020). This stands in alignment with findings of other research, as they have found how "being strong" and "bearing pain" are essential to maintaining endurance in life with chronic illness; moreover, living with chronic disease could be seen as "hovering between suffering and enduring" (Öhman et al., 2003). In the thesis at hand, the aspects were reflected in the experiences of the Long COVID patients. Having endurance and being persistent are personal strengths reported by patients in another qualitative study of people with chronic illnesses (Kristjansdottir et al., 2018), which aligns with the results found in this thesis. This insight given in this thesis into how perseverance is mentioned as a prominent theme in the narratives and future letters can inform families about the importance of promoting the perseverance of those affected. Moreover, the self-confidence of the patients could be increased through psychologists, as participants described how having professional help has supported them.

The participants describe how showing initiative behavior through starting new activities or regaining a sense of control in their lives has helped them to adapt to their new lives and regain a sense of their well-being. This stands in alignment with another qualitative study on resilience in chronic illnesses (Opsomer et al., 2019). Keeping the results in mind, it might be necessary for the families and healthcare providers to foster the initiative behavior of the participant and increase the sense of control or motivate them to start new activities. As other research has also stated, promoting the autonomy of the chronically ill patient, is vital for managing the condition best (Heaton et al., 2015).

Most of the discoveries in this thesis are in alignment with the PERMA-model (Seligman, 2018) of well-being, for instance, having positive emotions (optimism, hope, faith), showing engagement in activities that give you a higher sense of well-being (initiative behavior), having positive relationships (connecting to other people), and accomplishment (visualization of one's future).

Strengths, Limitations, and Recommendations

One strength of this thesis is that, to my knowledge, this is the first qualitative study that analyzes how people with Long COVID construct their resilience. Furthermore, it is a small contribution to chronic illness experiences and narrative studies with the strength that this thesis at hand does not only look at how participants construct their resilience in their past or present but also how they write about a desire or wish in the future on how to adjust to the illness and regain a sense of well-being. This thesis used datasets of 36 participants with Long COVID; the saturation was achieved in that themes were repeated across the sample. Another strength of this study is that a qualitative method has been used for analyzing resilience. As Ungar (2003) has stated, qualitative methods are well suited to discovering processes relevant to the lived experiences of the research participants in resilience.

Additionally, one strength of this thesis is that I coded the transcripts being chronically ill myself. Therefore, knowing many things about chronic illness already, I believe I can identify with the topic and reflect especially well on it. This subjectivity and personal reflection are seen as a resource in reflexive thematic analysis (Braun & Clarke, 2019).

One limitation of this study is that because of the high number of participants with several chronic illnesses, the results cannot be explicitly attributed to Long COVID. It might be the case that the participants constructed their resilience differently due to other experiences with other chronic diseases. Another limitation of this thesis is that the dataset is limited to participants from the Netherlands, and the results cannot be generalized to other cultures. Mainly since illness narratives depend on different values of a society, the narratives might look different in other cultures. As Ungar (2006) has found out, youth that faced similar adversities coped in a great variation across cultures. For example: Perceived and received support looks different in British and Spanish students (Goodwin & Plaza, 2000). Moreover, resilience in itself is seen differently in other cultures. As Ungar (2006) has stated, most resilience research has focused on western populations and their definitions of healthy functioning. Aspects of healthy functioning, such as self-efficacy, hopefulness, or attachment, might be relevant globally, but “the relative importance of each is far from consistent in the literature when cultural variation is taken into account” (Ungar, 2006, p.222). Future research could therefore gather data regarding the construction of resilience in Long COVID patients from different cultures, especially since this chronic illness affects people around the entire world.

Another limitation is that for the data gathering, writing exercises were needed; therefore, the participants required some degree of cognitive skills. Future research could use different tools so that people with less cognitive skills can participate. Moreover, the participants were in various stages of their chronic illness course, and therefore the mindset of the patients might differ due to that. Additionally, the severity of the disease was not surveyed. Consequently, it is unclear whether resilience was found more in people with more severe disease courses or the opposite. Future research could elaborate on this issue. One other limitation is that the dataset consisted of 80 % women; therefore, the experiences of men are underrepresented in this thesis; however, since women are twice as likely to develop Long COVID as men (CDCb, 2021), the underrepresentation of men in the data is not that high. Nevertheless, future research could include more experiences of men living with Long COVID.

The data was coded, and the themes were identified by one person; multiple perspectives from various people with different expertise could not be provided. Future research could involve several individuals with themes being developed using discussions with other researchers, a panel of experts, or the participants themselves.

Conclusion

Examining the personal experiences of Long COVID patients is currently of great importance. The high level of impairment of those affected is alarming; thus, research should focus on what is buffering against the high impairment and what those being affected see as helpful for their resilience. Understanding how people with Long COVID construct their resilience, which was examined in this thesis, helps with that. Therefore, this thesis makes a small but valuable contribution to the field of narrative research in chronically ill people by analyzing not only the past or present experience of people with chronic illness but also the desires and wishes expressed in the future letters. For the first time, narratives of Long COVID patients regarding resilience were analyzed. Moreover, this thesis amplifies previous findings on resilience in people living with a chronic illness. The importance of nurses and families in the role of resilience in chronically ill people should not be underestimated. Therefore, the practical implications might help the surrounding of those being affected to adjust to their chronic illness in a more adaptive way and regain a sense of their well-being. Health care providers and families could profit from the results gained in this thesis to develop, for instance, holistic caring plans for Long COVID patients as supporting patients in mobilizing their strengths is essential in providing empowering, person-centered care for people with chronic illnesses. Moreover, this thesis gives a voice to Long COVID patients and a better understanding of the chronic illness to others, which is vital given the fact that the patient's perspective needs to be more incorporated into the research of this chronic illness. Moreover, this thesis can raise the awareness for the suffering patients so that their perception does not fall into oblivion by the sinking COVID-19 numbers at date.

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