

Exploring the Complexities of Long Covid: An Analysis of Illness Narratives through Antonovsky's Sense of Coherence Theory

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Abstract

Long Covid is a chronic illness resulting from Covid-19 infection, characterized by persistent symptoms over an extended period. Given the significant impact on affected individuals' lives, it is crucial to understand and interpret their experiences. Therefore, comprehending how affected individuals understand, manage, and derive meaning from their lives becomes essential. Antonovsky's Sense of Coherence (SOC) theory (1987), comprising Comprehensibility, Manageability, and Meaningfulness, can serve as a foundation for this exploration. SOC is shaped by life experiences and aids in finding effective coping strategies. However, the expression of SOC among people with long Covid has not yet been studied. Therefore, this study examines how people with long Covid negotiate the three SOC components in illness narratives. Thematic analysis of 34 online collected illness narratives from Dutch individuals with long Covid revealed 13 themes interpreted in relation to SOC components. The findings include three themes that were interpreted as reflecting the Comprehensibility component, displaying an understanding of long Covid and its' impact, and experiences of social support. Three themes fall under Manageability by describing maintaining control and normality through seeking professional help and adapting to the new state of health. Meaningfulness was characterized by two themes, expressing recognition of values and a sense of direction for maintaining motivation in recovery. Five themes were interpreted as barriers to SOC components, as participants mentioned experiencing misunderstanding and invalidations, medical and public uncertainty, relinquishing enjoyable activities, and struggles in progress and illness acceptance. These results can enhance understanding of long Covid among individuals and assist healthcare practitioners tailor interventions to their specific needs.

Keywords: Long Covid, Sense of Coherence, Illness narratives, Thematic analysis

Exploring the Complexities of Long Covid: An Analysis of Illness Narratives through Antonovsky's Sense of Coherence Theory

Long Covid is a chronic illness that can emerge following a Covid-19 infection. It is characterized by persistent symptoms such as cough, fatigue, or cognitive impairments that can significantly influence an affected person's ability to function in everyday life (World Health Organization, 2022). It has a major impact on the life of an affected person due to emotional and physical consequences. These include, for example, feeling misunderstood or experiencing health declines, including cognitive symptoms. This can potentially lead to an inability to work and subsequent financial implications (Macpherson, 2022). Furthermore, it was observed that people living with long Covid experienced ongoing issues disclosing psychiatric symptoms like depression, or anxiety (Houben-Wilke et al., 2022). Living with these impacts requires resilience and functional coping strategies.

Applying appropriate coping strategies can be easier if one views one's life as comprehensible, manageable, and meaningful because it motivates one to find meaning and an acceptable way to deal with an illness such as long Covid (Lambert et al., 2009). These three components – Comprehensibility, Manageability, and Meaningfulness – are the basis of the Sense Of Coherence (SOC), a theoretical construct that is shaped by individuals' perceptions of life events, including illness experiences (Antonovsky, 1984).

There appears to be a research gap regarding the role of SOC in people suffering from long Covid. However, previous research focused on SOC in the general population during the pandemic. In this regard, it was shown that SOC can predict mental health (Super et al., 2020), and acts as a coping strategy (Mana et al., 2021b). Moreover, research has suggested that SOC may be associated with better physical and mental health outcomes in individuals with chronic illnesses (Norekvål et al., 2008; Veenstra et al., 2005). However, previous literature does not specifically examine how Comprehensibility, Manageability, and

Meaningfulness of SOC support people who are suffering from long Covid. Therefore, the objective of this study is to thematically analyze expressions of SOC in illness narratives from individuals with long Covid. The aim is to obtain a comprehensive understanding of the impact of this illness by delving into the nuanced experiences of individuals affected by this illness. Through immersion in their stories and perspectives, valuable insights into the multifaceted nature of their experiences will be revealed, with underlying themes, patterns, and challenges being disclosed. This qualitative investigation will shed light on the strategies expressed by individuals with long Covid to deal with the illness, while also identifying areas necessitating further support. Illuminating how the experiences of individuals with long Covid can be interpreted in terms of Comprehensibility, Manageability, and Meaningfulness aids in enhancing the provision of support, resources, and coping strategies dedicated to their well-being.

Long Covid

The emergence of the coronavirus pandemic in December 2019 has significantly impacted the global population with over 654 million people infected at least once (Radtko, 2022). Being infected with the coronavirus lead to symptoms such as fever, cough, tiredness, and loss of taste or smell (World Health Organization, 2020). It could potentially result in long Covid, a chronic illness. Long Covid is characterized by the continuation or emergence of new symptoms three months after the initial Covid infection, lasting at least two months without another cause (World Health Organization, 2022). How often long Covid occurs remains unknown. However, a Dutch study (Ballering et al., 2022) found that approximately 12.5% of patients experience persistent symptoms after a Covid infection, while the Rijksinstituut voor Volksgezondheid en Milieu (RIVM) reports that up to 20% of individuals have symptoms 4-5 weeks after infection, gradually decreasing three months later (RIVM, 2022).

Research has highlighted that people suffering from long Covid face various physical, cognitive, psychological, and emotional challenges. These challenges are characterized by the fact that long Covid is reported by over 200 different symptoms affecting daily life (World Health Organization, 2022). The most common physical symptoms, as summarized by a Dutch study, encompass cardiopulmonary symptoms such as breathing difficulties and pain, sensory symptoms including hot/cold sensations, musculoskeletal symptoms, as well as general symptoms like aching limbs (Ballering, 2022). According to Humphreys et al. (2021), individuals with long Covid experience significantly reduced physical functions, compounded by cognitive and psychological effects such as extreme fatigue, brain fog, and stress. They also face emotional challenges in finding and interpreting tailored advice about physical activity, struggle to accept temporarily reduced function, and fear a lasting physical and cognitive decline. Furthermore, Pearson et al. (2022) state that emotional consequences include experiencing a new sense or loss of self, requiring adjustment reactions. Moreover, individuals with long Covid seek understanding from family, friends, and healthcare professionals due to encountered invalidations. They were faced with a lack of medical knowledge, empathy, and understanding, which led to anxiety and confusion (Macpherson, 2022). These challenges might also contribute to relevant symptoms of anxiety, depression, and Post Traumatic Stress Disorder, reported by 35 to 47% of long Covid sufferers in the Netherlands and Belgium (Houben-Wilke et al., 2022).

Additionally, financial worries arise because many sufferers can no longer work. In a study by Brehon et al. (2022), only 53% of people with long Covid returned to work since they are confronted with emotional, cognitive, and physical consequences while lacking sufficient workplace support. This can increase their psychological problems, which may jeopardize their prospects in the professional world (Kohn et al., 2022).

To summarize, current research emphasizes the challenges faced by people suffering from long Covid. These include public and medical uncertainty surrounding the illness, the impact of chronic symptoms on daily life, and the need for adjustment. Overcoming and dealing with these described consequences requires resilience and adequate coping mechanisms.

Coping with Long Covid

It is relevant to study the notion of coping in the context of long Covid because it helps to face and navigate the challenges arising from this chronic illness. Various authors have provided definitions of coping which can be summarized as coping being the cognitive assessment of threats and resources and the active selection of coping strategies. Strategies include behavioral changes to reduce physiological arousal and effectively manage stressors (Lazarus, 1984; Levine and Weinberg, 1978). This may look like applying mindfulness or physical exercise to reduce anxiety and start relaxing (Bjerg et al., 2020). This in turn can help to navigate and adapt to challenging situations.

A recent qualitative study (Aghaei et al., 2022) highlights the significant role of social, individual, and health system resources in coping with long Covid. Related coping strategies encompass emotional, material, and informational support, as well as physical activity, emotional management, knowledge acquisition about long Covid, and dietary improvements. Related to informational support and knowledge acquisition, mental health practitioners play an important role in coping with long Covid. In this regard, Goldberg et al. (2022) suggested that mental health practitioners should support people living with long Covid by providing useful coping skills to structure life with the illness and to manage symptoms. Furthermore, they should educate the medical community about the complexity of long Covid to prevent misunderstandings and to facilitate coping.

Consequently, to better support people with long Covid, understanding the illness experience is crucial. While analyzing coping strategies helps understanding the specific

stressors associated with long Covid, it may not capture the broader orientation including cognitive, emotional, behavioral, and existential aspects as well as the individual's outlook on life. These aspects help to examine the understanding of the illness and what meaning those affected draw from it. To achieve this broader view, it is worth taking a closer look at the theory of Sense Of Coherence (SOC; Antonovsky, 1987), which combines aspects of Comprehensibility, Manageability, and Meaningfulness.

Sense of Coherence and long Covid

SOC finds its origin in the salutogenic theory, which focuses on the factors that contribute to people's health instead of looking at why people get sick. It concentrates on available resources to stabilize health (Antonovsky, 1979). The approach was developed by Aaron Antonovsky, a stress researcher, while establishing a primary care-oriented faculty in Israel, aiming to teach preventive measures rather than reactive treatment. Therefore, he established the concept of SOC to explain how the perception and feedback of experiences in life results in an attitude toward life. This feedback is characterized by the recognition and utilization of so-called 'general resistance resources' that provide a person with experiential feedback and help them cope with a situation. These general resistance resources include, for example, material resources, knowledge, confidence, as well as consistent belief and value systems, which influence the development of SOC. Positive experiences and constructive feedback contribute to the development of an effective SOC, while conflicting, confusing, or negative feedback can undermine it (Antonovsky, 1991). Because these experiences are individual, the effectiveness of SOC may vary from person to person (Antonovsky, 1987).

The concept of SOC describes a comprehensible, manageable, and meaningful view of the world. Antonovsky (1987) defined it as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence" (p.19) to see the world as coherent. The three components, Comprehensibility, Manageability, and

Meaningfulness, contribute individually to SOC but are connected to each other and equally relevant to form it. *Comprehensibility* determines the degree to which a stimulus makes cognitive sense. It contributes to whether an individual perceives information as orderly and consistent, and therefore as predictable. If this is the case, the likelihood of facing unplanned, open-ended situations increases because one is convinced that one can structure and make meaning of them and can predict the outcome. *Manageability* refers to the aspect that one is convinced that the available capabilities are sufficient to successfully accomplish the situation. It is irrelevant whether the resources come from one's own efforts or those of others. *Meaningfulness* describes the amount to which one can give meaning to one's life with its challenges and on this basis is convinced that it is worth investing in and committing oneself to (Antonovsky, 1987). In addition to these definitions, Antonovsky (1993) developed the SOC scale (Appendix A) to better measure an individual's SOC. The scale explains more detailed aspects of the theory. Therefore, for the purposes of this study of SOC in individuals suffering from long Covid, a summary of the statements of the SOC scale was created in order to understand and apply all facets of the three components. An overview based on the scale can be seen in Table 1. How SOC and its components are expressed in empirical research is presented afterward.

Table 1

SOC Components

| Component | Description |
|-------------------|---|
| Comprehensibility | The individual can understand and make sense of the demands, events, and situations that they encounter in life. The individual: <ul style="list-style-type: none"> - feels understood by and has a connection with others - has an awareness of the cause and effect of their actions and arising feelings - can interpret and makes sense of their environment in the right proportion |
| Manageability | The individual has confidence in their ability to meet the demands and challenges of life. The individual: |

| | |
|----------------|--|
| | <ul style="list-style-type: none"> - has a sense of self-efficacy - believes that they can successfully deal with the difficulties that life presents and find solutions - has good feelings about themselves and others |
| Meaningfulness | <p>The individual has a belief that life is worth living and that it has a purpose. The individual:</p> <ul style="list-style-type: none"> - has a sense of purpose and direction - believes that life and the future are interesting, have meaning, and value |

Note. The definitions of the components are based on the SOC-scale (SOC-29) developed by Antonovsky (1993). The scale can be seen organized by component in Appendix A.

Antonovsky (1987) emphasizes that SOC stabilizes by the age of 30. This means that it becomes less influenced by later events. However, research (Antonovsky & Sagy, 1990; Eriksson, 2017) indicates that major life changes like a decline in health or traumatic events prompt a re-evaluation of SOC to incorporate these new experiences into their worldview. Nevertheless, this re-evaluation does not necessarily alter the fundamental perception of the world as more or less coherent; rather, it represents a reassessment. In contrast, Volanen et al. (2007) find that SOC is not stable but dynamic. It seems to be dependent on negative life events, i.e. it is unstable after critical life events, especially if these have occurred recently.

Even so, an effective SOC can help to find appropriate coping strategies during challenging times since it is related to one's ability to identify and make use of available resources and perceive threats as comprehensible, manageable, and meaningful (Antonovsky, 1987; Delgado, 2007). This attitude also facilitates acceptance of a chronic illness diagnosis because it helps apply effective coping strategies, such as embracing the consequences of a chronic illness (Chittem et al., 2015).

Additionally, SOC proves valuable in navigating the challenges of the Covid-19 pandemic. A Dutch study showed that SOC, among other factors, can predict mental health during the pandemic (Super et al., 2020). It acts as a crucial determinant in identifying and utilizing coping strategies to deal with challenges and various stressors posed by the

pandemic (Mana et al., 2021a). Furthermore, across diverse national and social contexts, individuals' capacity to perceive life as comprehensive, manageable, and meaningful emerges as a fundamental coping resource during the pandemic (Mana et al., 2021b). In a study examining managers' SOC during the pandemic (Hansson et al., 2022), it was observed that they showed a heightened sense of Comprehensibility, Manageability, and Meaningfulness. Comprehensibility helped to identify how they obtained structured information and social support. Manageability discovered the extent of their adaptation to the new situation by noticing and resolving problems. Meaningfulness referred to their identification of meaning and knowledge of the pandemic to face future challenges. These findings highlight the role of SOC in helping individuals effectively cope with the demands of the pandemic.

In conclusion, SOC helps people deal with challenges during a pandemic and chronic illness. Referring back to the research gap, this raises the question of what characterizes SOC in people with long Covid, what sustains it, and if the described emotional, cognitive, and physical consequences influence SOC of affected people. Therefore, the research question of this study is: How do people with long Covid negotiate Comprehensibility, Manageability, and Meaningfulness in their illness narratives?

Methods

Study design

This study is based on a larger Dutch 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) by Anneke Sools and Jacqueline Coppers. It is registered by the Ethics Committee of the Faculty of Behavioural Sciences at the University of Twente at the ethical request number 211138.

It consisted of qualitative data collection in which two illness stories were collected, one related to past experiences and the other to visions of the future (see 'Materials'). In addition,

demographic data was collected, and a questionnaire was used that measured the well-being including emotional, social, and psychological well-being.

Chronically ill people were recruited with flyers (Appendix B) shared within the personal and professional networks of the researchers, Dutch patient organizations, and social media channels. The Flyer contained a basic description of the study, a link, and a QR code that could be used to get to the informed consent and information letter. This entailed more detailed information about the purpose, eligibility criteria, content, benefits, and burdens of participation, information on the research team, and the goals of the study. If participants were interested, they were directed to an informational letter (Appendix C) within Qualtrics at the end of which they could give or refuse their consent (Appendix D).

After giving consent, they were asked to write an illness narrative about their past and present experiences of living with their chronic illness (Appendix E). Afterwards, they were introduced to the 'Letters from the Future' exercise (Sools & Mooren, 2012) and were asked to write their vision for the future. In the end, they were requested to fill in the Mental Health Continuum Short Form (MHC-SF) questionnaire about their well-being and to answer general questions related to their illness and their demographic information. The procedure lasted about 45 minutes.

The researchers were available through email or telephone if someone needed help or wanted further information about the study. Participation had no risks or disadvantages and could be terminated at any time without giving any reason. There was no remuneration and participation was voluntary.

The current study focused on illness narratives from participants who self-identified as having long Covid. The MHC-SF questionnaire and the Letters from the Future were not used for further analysis. Data from Dutch participants suffering from long Covid was collected from the 9th to the 16th of February 2022.

Participants

In general, the study could be attended by people who were at least 18 years old and comprehend and write in proper Dutch. Due to the web-based design and cognitive component of reflecting on their past and future, sufficient digital and cognitive skills were necessary. This study concentrated on a sub-group of the participants, namely people that perceive themselves as living with long Covid. This was the case for 37 people, of which 34 narratives were used for the following analysis. Two narratives had to be excluded because the narrative only consisted of a few sentences about their current condition and consequently did not provide sufficient analysis material. One narrative was excluded because the narrated long Covid experiences interfered too much with another chronic illness. Of the remaining 34 participants, four were men, 29 were women and one person did not specify their gender. The age varied between 25 and 63. Education levels were mainly MBO, which represents secondary vocational education, and HBO, which refers to tertiary vocational education at the level of university of applied science. 68% of the participants lived together with their partners and/or children, 23% lived alone, and 9% lived in other circumstances.

Materials

Data was collected with the survey tool Qualtrics. The data consisted of illness narratives. Illness narratives are stories that ill people, in this case people who self-identify as long Covid sufferers, write about their experiences with the illness. They had the freedom to describe their experiences from their own point of view, without being influenced by external circumstances and people (Kannaley et al., 2019). Hence, illness narratives provide qualitative insights into the subjective aspects of illness, including symptoms, treatment journeys, emotional impacts, and personal experiences (Kleinman, 1988). In the current study, the participants were asked to describe how long Covid has affected and changed their lives in terms of their health, housing, work, social relationships, other activities, and/or self-

image. Because the study was conducted in the Netherlands, the data was translated from Dutch into English for research purposes via the online translator machine DeepL and was checked by a native Dutch student from the University of Twente. The length of the illness narratives varied in the English language between 171 to 1633 words. These narratives represent secondary data whose themes were interpreted in terms of SOC theory.

A questionnaire to request demographic information was used. This information included the query of their chronic illness, age, gender, profession, and living situation.

Data Analysis

In this study, SOC in illness narratives of people suffering from long Covid were analyzed thematically. The SOC scale and theory developed by Antonovsky (1979, 1993) was taken as a point of departure for a six-phase thematic analysis (see Braun & Clarke, 2006), aimed at discovering, analyzing, and describing patterns within qualitative data. A thematic analysis allows for a rich description of meaning-making patterns, further than content analysis, by using a flexible coding process. This makes it distinctive in comparison to other qualitative methods of analysis and makes it accessible, especially for beginners, which suits the current researcher (Braun & Clarke, 2006). Furthermore, thematic analysis was selected because it can be used with most theoretical frameworks in a deductive approach (Terry et al., 2017), which allows integration of the SOC theory. The six phases according to Braun & Clarke (2006) were used as an orientation, but in order not to interrupt the flow of the analysis and to integrate the deductive approach, they were not strictly followed but adapted. To aid the analysis, the qualitative analysis tool 'atlas.ti' was used. Antonovsky's SOC theory (1979) provided a lens to understand the data, revealing that the constructs of the theory were consistent with how individuals with long Covid expressed their experiences with the illness. The analysis and interpretation highlighted the impact of Comprehensibility, Manageability, and Meaningfulness on the perceptions of those affected

by long Covid. An overview of the analysis steps can be seen in Table 2 and are explained in detail below.

Table 2

Description of analysis steps

| | | |
|---|------------------------------------|--|
| 1 | Familiarizing with data and theory | <ul style="list-style-type: none"> - Reading and summarizing SOC theory and scale - Reading and marking illness narratives - Exclusion of narratives |
| 2 | Generating initial codes | <ul style="list-style-type: none"> - Transferring data into atlas.ti - Set the unit of analysis - Code data regarding comprehension, manageability, and meaning |
| 3 | Grouping themes | <ul style="list-style-type: none"> - Group codes into themes based on the definitions of the SOC components - Name themes |
| 4 | Checking codes | <ul style="list-style-type: none"> - Check quotes to code allocations and reallocate if necessary - Create new codes if necessary - Second coding cycle |
| 5 | Reviewing themes | <ul style="list-style-type: none"> - Rename themes if necessary - Check the assignment of codes to themes |
| 6 | Verification of SOC components | <ul style="list-style-type: none"> - Compare themes with definitions of SOC components - Create new themes if necessary |

The analysis started with *familiarizing* the theory by reading the theory and the associated SOC-scale, and generating an according table (see Table 1). Furthermore, familiarization with the data was done by printing out and reading the narratives. In addition, different colors were used to mark initial ideas about which statements refer to each SOC

component. Meanwhile, the narratives were filtered with a focus on identifying those that were useful for the analysis and excluding those that were not relevant. Those that were found to be useful were those that provided sufficient analysis material to long Covid.

Second, the data was transferred to the software “atlas.ti” as a tool to *generate initial codes*. The smallest basic unit of analysis that could be coded was set as a group of words consisting of a subject and a verb, while the largest basic unit of analysis was set as a whole paragraph which consisted of about 15 sentences. This was done to ensure that different aspects of the various components were not lost. The first sentence of a narrative was read and given a code. Then the next sentence was read, and it was seen if the generated code seemed to fit. If it did not, a new code was generated. This is how the entire narrative was coded. After that, the next narrative was read to see which existing codes fit or which contents required new codes. Given the familiarity with the theory, the coding process was conducted with a nuanced approach. The coding process focused on how participants expressed their comprehension, management, and meaning in their narratives. This focus led to the exclusion of the following types of information from coding: statements that did not relate to the participants' personal experience with long Covid (e.g., unrelated injuries or unaffected relatives), temporal classifications that were irrelevant to the narratives, greetings, farewells, poetic sayings, and descriptions of pre-illness characteristics that did not pertain to changes experienced through long Covid. One notable challenge encountered during coding was that some statements expressed, for example, both comprehension and meaning, requiring the use of multiple codes for the same statement. Consequently, the same quote could later be interpreted as reflecting both Comprehensibility and Meaningfulness.

In the third step, the *themes were grouped* by examining the codes. Within this step, the focus was on identifying which codes fit Comprehensibility, which fit Manageability, and which fit Meaningfulness. Within these divisions, codes representing similar themes were

examined. To aid in this process, the definitions of the SOC components were referenced, and the data was interpreted in terms of individual aspects of the theory. For example, by referring to the definition of Comprehensibility, which emphasizes achieving predictability through perceiving information as orderly and consistent (see Introduction), codes like ‘my experienced symptoms’, ‘where/when I got infected’, and ‘why it got worse’ could be grouped under the theme of ‘Recognizing the origin and course of the illness’ to reflect an aspect of predictability. The result section elaborates on how theory influenced the definition of these themes, with all other information derived from the data itself. The influence of theory in this step also revealed that some codes expressed themes that did not precisely align with the definitions of the SOC components, instead, the participants’ meaning-making process could be interpreted as expressions of barriers to SOC components. Therefore, codes were grouped into themes expressing facilitators and barriers of SOC. To get a better overview of this process, a three-column table was used to search and name the themes by noting each code and the assigned theme.

The fourth step consisted of *checking the codes* to ensure the accurate assignment of quotes to codes and the codes’ significance. This was done by revisiting each code in atlas.ti and re-reading the associated quotes. It became evident that certain codes were too general and did not properly capture the illness experience. For example, the code ‘painful consequences’ was not specific enough as this code encompassed both unpleasant emotions and adjustments like giving up certain activities, changes in identity, or realization of no improvement. As a result, the quotes under ‘painful consequences’ were split, and new codes were created. Thus, these quotes could then be assigned to the codes ‘my self changed’ or to new codes such as ‘my condition is still bad’ and ‘negative emotions’. This necessitated a second coding cycle to incorporate these new codes into all illness narratives.

After that, *the themes were reviewed* and adjusted based on the coding changes in the fifth step. The more accurate codes revealed more fundamental aspects of the themes. For example, the theme 'Adjustment reactions' was renamed as 'Adapting to the new state of health through new strategies' because it became apparent what they were adapting to. The more specific names were then also used to check whether the assigned codes all matched the theme. If this was not the case, they were rearranged or new themes were created.

In the last step, *the three SOC components were verified* since they are in the highest order and are needed to make a final assessment of whether the themes express the SOC components or require adjustment. This step consisted of revisiting the themes and comparing them to the SOC component's definitions. As a result, new themes were generated once again, as it became clear, for example, how uncertainty is not only part of the Comprehensibility component but also expresses that there was no possibility to manage the illness (see theme 'Medical uncertainty making managing long Covid impossible') and thus belongs to the Manageability component as well.

Results

The qualitative analysis of 34 long Covid narratives led to the identification of 13 themes in total. Five themes are interpreted as belonging to the Comprehensibility component, five to the Manageability component, and three to the Meaningfulness component. Among these 13 themes, five are classified as barriers to the respective SOC component. The number of themes that facilitate SOC and those of barriers already show that not every theme that facilitates SOC has a counteracting barrier theme. The assignment of facilitators and barriers to each SOC component is further explained below and an overview can be found in Table 3 including underlying codes and frequencies. It is worth noting that not all themes were present in every narrative, as the frequencies suggest. However, in 32 out of 34 narratives, all three SOC components were present with at least one theme. Tables 4,5

and 6 provide explanations of the themes within each component, along with exemplary quotes. The themes are explained in more detail below.

Table 3

Overview of the division of codes, themes, and components including related frequencies.

| Component | Theme | Code | Frequency |
|--------------------------------|---|------------------------------------|------------------|
| Comprehensibility (n=300) | Recognizing the origin and course of the illness | Where/when I got infected | 15 |
| | | My experienced symptoms | 93 |
| | | Why it got worse | 25 |
| | Uncertainty and lack of knowledge* | Uncertainty | 20 |
| | | Medical uncertainty | 9 |
| | Understanding what impact long Covid has on one's life including one's social environment | My self changed | 40 |
| | | What I (have to) forgo | 26 |
| | | The effect of my illness on others | 8 |
| | Encountering understanding and support | Feeling understood by others | 25 |
| | Experiencing misunderstanding and invalidations* | I'm feeling alone | 36 |
| Unsatisfaction with government | | 3 | |
| Manageability (n=360) | Referring to professionals and research to manage the illness | Doing my own research | 6 |
| | | Seeking professional help | 77 |
| | Managing daily tasks | I can manage to go to work | 24 |
| | | I'm feeling better | 37 |

| | | | |
|--|--|---------------------------------------|----|
| Adapting to the new state of health through new strategies | Improving in (slow) steps | 25 | |
| | My self changed | 40 | |
| | Giving the body the needed rest | 31 | |
| | Applying new strategies | 34 | |
| Giving up something enjoyable* | Negative emotions while being sick | 51 | |
| | What I (have to) forgo | 26 | |
| Medical uncertainty making managing long Covid impossible* | Medical uncertainty | 9 | |
| Meaningfulness (n=192) | Recognizing values in one's life | I can see the positive things in life | 33 |
| | | My wishes | 18 |
| | Sense of direction through an improvement of the state of health | I'm feeling better | 37 |
| Positive feelings because of my diagnosis | | 3 | |
| I am hopeful | | 22 | |
| Struggles with progress and illness acceptance* | My condition is still bad | 28 | |
| | Negative emotions while being sick | 51 | |

Note. The table provides an overview of different themes emerging from long Covid narratives. n shows how often codes belonging to each component were coded. A * indicates that the theme is interpreted as a barrier to a certain component, while a theme without a * expresses the component. It can also be seen that the same code can belong to different themes and thus different components. This salience will be explained in more detail in the second result section 'Within-narrative interaction between SOC components'.

Comprehensibility

According to Antonovsky (1979), the Comprehensibility component refers to the extent that an individual can understand and make sense of their life experiences. In this study, five themes described understanding and making sense of long Covid, which is why they were

interpreted as belonging to the Comprehensibility component. These themes include the participants' utterances of recognizing the course and impact of the illness, which was illustrated as helping to accept limitations, understand and live with long Covid. Furthermore, they displayed receiving understanding from peers and medicals, which supported their interpretation of long Covid. However, two themes reflected uncertainty and misunderstandings with other people, and are classified as barriers to the Comprehensibility component because they were rendered as limiting the participants' access to necessary resources and information. Further explanations on these issues and an overview can be found below and in Table 4. The text explains how the quotes in the table specifically relate to the themes and Comprehensibility. The links in the table help to get to the respective text.

Table 4

Definitions of themes related to the Comprehensibility component

| Comprehensibility | | |
|--|---|--|
| Themes | Explanation | Exemplary quotes |
| Recognizing the origin and course of the illness | The participants demonstrated recognizing where and when they became infected, what symptoms are part of the illness, and that relapses can occur, or certain incidents can promote relapses. | <p>(1) <i>My body reacted very alertly to overstimulation, that leads me to experience ringing in both ears, headaches, nausea and fatigue daily. This taught me to respect my own limits. Something I didn't always do before. If I didn't respect those boundaries, I immediately had a relapse, this still helps me to properly monitor and respect my boundaries.</i> (Participant 28, female, age 55).</p> <p>(2) <i>"On 14 January 2021, a colleague reported a fever in the afternoon. She had been to a small private party at the weekend where everyone was given covid. She went to work and infected almost everyone at work. So did I."</i> (Participant 1, female, age 54)</p> |

| | | |
|---|--|---|
| Uncertainty and lack of knowledge* | <p>The participants discussed that they are confronted with a lot of uncertainty in different aspects. These aspects include medical treatment, progression of the illness due to sudden relapses, or the future regarding improvement and the financial situation.</p> | <p>(3) <i>“But I’m also worried about the future. If I can count again. And about how it will go financially. Would I be able to continue living in my house?”</i> (Participant 31, female, age 54)</p> <p>(4) <i>“I was especially confused during this time because I didn’t understand why I was suddenly getting so much worse. ... From December 2021 I managed to cycle to work and spend half an hour, and then an hour, doing something with the residents. Unfortunately, in mid-January 2022, it suddenly stopped working. From one day to the next I felt much worse and I became short of breath much faster.”</i> (Participant 29, female, age 45)</p> |
| Understanding what impact long Covid has on one’s life including one’s social environment | <p>The participants expressed that the illness has affected them and led to a change in identity. This refers to describing reduced functional level or not feeling the way they did before the illness.</p> <p>The participants narrated that the illness has forced them to forgo things like hobbies, strong stimuli, work, social contacts, or driving. In addition, they spoke about noticing the impact of the illness on those around them, who perceive that the ill person is unwell, and missing from family gatherings and everyday life.</p> | <p>(5) <i>“I still have many symptoms that prevent me from doing sports; shortness of breath and lightheadedness. I really miss sports, but I have to be patient for a while.”</i> (Participant 20, female, age 32)</p> <p>(6) <i>“My boyfriend and I don’t live together at the moment I am very happy with that ... so that he doesn’t always see how I am and I can withdraw because I don’t want anyone around me because the stimuli are too high.”</i> (Participant 18, female, age 52)</p> |
| Encountering understanding and support | <p>The participants explained that feeling understood by other people (including family, friends, colleagues, fellow sufferers, and healthcare professionals) and having a beneficial</p> | <p>(7) <i>“After that, the company doctor was followed by another company doctor who did make a physical appointment. I immediately felt heard and taken seriously. He even protected me because I wanted too much. He is open and honest and</i></p> |

connection to them, helped to comprehend the situation.

looks what is good and feasible for me. I feel supported by him.”
(Participant 25, female, age 28)

(8) “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.” (Participant 33, female, age 53)

Experiencing misunderstanding and invalidations*

The participants conveyed not feeling understood by others, who do not take the complaints and illness seriously, give inappropriate advice, or make them feel like a burden. Additionally, they described dissatisfaction with the government, which does not see or take them seriously.

(9) “Through fellow sufferers, I understand that there is still much misunderstanding among professionals, where there are people who do not believe in it, or do not take it seriously as a chronic disease. Where ‘just keep going and go beyond your limits’ is recommended, but has the opposite effect. Building up as quickly as possible and exercising hard caused me to end up back in a wheelchair and be able to walk a maximum of 500 meters without collapsing through my legs.”
(Participant 16, female, age 25)

(10) “And I am already so tired. And I become silent, I don’t share much about my complaints anymore. Everyone is tired of it, including me. Everyone is tired from time to time, I hear, everyone forgets, everyone... You look good, everyone says. I feel alone in this.” (Participant 13, female, age 48)

(11) “Unfortunately, I have little faith in the government authorities. Corona has been and is being given sufficient attention. The ever-growing group of long Covid patients is not taken

seriously. At least so it seems.”
(Participant 4, male, age 62)

Note. A * indicates that the theme is interpreted as a barrier to the Comprehensibility component, while a theme without a * is classified as an expression of the Comprehensibility component.

Recognizing the origin and course of the illness

The participants recognized the origin and, to some extent, the course of long Covid by telling about the infection source, symptoms, and triggers for relapse. By presenting this knowledge about the progression of the illness, and in this regard, the understanding of the forthcoming events, the participants indicated gaining a certain degree of predictability. This can be seen in quote (1) in Table 4. Here, Participant 28 described what effect overstimulation had on her symptoms, which shows that she could predict how her body would respond. Furthermore, she expressed how not respecting her boundaries led to a relapse. This demonstrates that she understood the progression of the illness and could predict what will happen. By writing about this, she displayed consistency in an otherwise unpredictable illness. As Antonovsky (1987) stated that a certain degree of predictability is necessary to comprehend and understand life, this theme can be considered part of the Comprehensibility component. Furthermore, some participants mentioned that knowing where and when they contracted long Covid helped them understanding their life. This shows that understanding the origin of the illness brought retrospective consistency to their lives, as seen in the example quote (2). Here the participant talked about the exact day and place where she contracted Covid and thus tracked exactly when her life changed to regain that consistency. The core point of this theme is that the participants seek to comprehend and find predictability and consistency in their illness by describing how they gained knowledge about long Covid, which aligns with the Comprehensibility component.

Uncertainty and lack of knowledge

In contrast to the previous theme, participants' narratives also highlighted the uncertainty regarding the treatment and the sudden deterioration in the course. This is recounted as impacting their understanding of long Covid, resulting in an unpredictable future. Quote (3) illustrated this when Participant 31 conveyed worries because she could not predict the course of her illness, her improvements, and therefore, the rest of her life. Due to this incoherent perception of the future, this theme could be interpreted as a barrier to the Comprehensibility component. Furthermore, in quote (4), Participant 29 explained how a relapse had suddenly limited her performance again, which confused her a lot. She conveyed how the uncertainty of when the next relapse will occur, made it hard to understand the progression of the illness. This can be interpreted as challenging her understanding of the illness by disrupting her coherence and Comprehensibility of her life. Moreover, participants mentioned the difficulty of overcoming this uncertainty, as even professionals were confronted with medical uncertainty and a lack of knowledge due to the novelty of the illness (see 'Medical uncertainty making managing long Covid impossible'). In summary, the participants' narratives reflected uncertainty as causing difficulties in creating a coherent narrative of their experiences, thereby impacting the Comprehensibility component.

Understanding what impact long Covid has on one's life including one's social environment

The participants shared how their illness experiences significantly impacted their lives in terms of self-perception, feasible activities, and social interactions. By narrating these things, the participants illustrated their understanding of the situation, which is why this theme is interpreted as a facilitator for the Comprehensibility component. The narratives showed this understanding through the participants' recognition of identity change and the need for adaptation considering their current condition. Participant 20 (quote (5)) expressed this understanding by explaining her limited capacity to engage in sports, demonstrating that

she recognized the need to forgo certain activities. This uttered acceptance is a way to articulate comprehension of the causes and effects of her behavior and perceptions.

Furthermore, the participants recognized the changes resulting from long Covid as a new part of their life. For instance, in quote (6), the participant recognized that she changed and that it is therefore in the best interest of both herself and her boyfriend to live separately for the moment. This decision reflected her comprehension of the situation which prompted her decision to align her behavior with this newfound understanding. Therefore, the participants communicated how an understanding of the impact of their illness can bring order and consistency back into their lives. However, it is worth noticing that the full extent of the illness's impact may only become fully realized after adapting to the new circumstances (see 'Manageability component'). In conclusion, the participants disclosed an understanding of the impact of long Covid on their lives and social environment. This is reflected as enabling them to make decisions and take actions aligned with their comprehension of the situation, ultimately facilitating their management of the illness.

Encountering understanding and support

The participants talked about receiving support and understanding in social interactions with fellow humans. They mentioned encountering these as beneficial, as they recognized being seen, taken seriously, and feeling understood. These interactions were displayed as getting the possibility to confirm their own assessment of the situation. This is reflected in the exemplary quote (7) in Table 4, where Participant 25 explained how her company doctor helped her realize what is best for her. Thus, she stated how her company doctor supported her by giving her the opportunity to talk about her illness-related behavior and thoughts, providing feedback, and offering guidance. Since this allowed for a better understanding of long Covid, this theme can be classified as part of the Comprehensibility component. Additionally, the participants expressed the importance of having people around

them who comprehended their struggles, as it provided them with a resource to understand and handle the changes brought about by long Covid. This is shown in quote (8), in which Participant 33 got supported by her husband. In summary, writing about receiving support and understanding falls under the Comprehensibility component by providing the participants with the opportunity to obtain appropriate feedback about their experiences and new perspectives on how to handle long Covid and new circumstances.

Experiencing misunderstanding and invalidations

The importance of feeling understood was highlighted in the previous theme, yet it was observed that not all participants shared this experience. Many narrated encountering misunderstandings or a lack of trust in their interactions. The participants talked about feeling understood and supported by one person but not by others. This became clear when participants wrote about professionals that do not take their complaints seriously or do not know enough about the illness, but still give advice that, in retrospect, even led to the worsening of their condition. Participant 16 in quote (9) explained how she lost control to the point where she could barely walk due to counterproductive recommendations from professionals. This lack of understanding is interpreted as a barrier to the Comprehensibility component as it attributed to the challenges she faced in accessing accurate information about long Covid and comprehending its nature. Additionally, participants discussed how the lack of understanding from family and friends hindered them from properly interpreting and understanding their long Covid experiences, which are the core aspects of the Comprehensibility component. This is stated by Participant 13 in quote (10) who declared trivialization of her symptoms which represented an impediment to communicating and making meaning from long Covid. Similarly, the mentioned lack of recognition by the government, as expressed in quote (11), described an absence of trust and limited access to resources and information necessary for understanding long Covid. To sum up, it becomes

clear how a presented lack of support and understanding of one's fellow human beings can be classified as hindering the Comprehensibility component since it is narrated as making it more difficult to understand and make sense of long Covid.

Manageability

According to Antonovsky (1987), Manageability refers to people's ability to meet the demands and challenges of their life. Therefore, a person may understand stressors but cannot manage them due to limited resources available. In this study, Manageability is classified through narrated active and adaptive approaches participants took to manage and cope with the challenges posed by long Covid. These were displayed in their description of developing strategies, adjusting to daily routines, searching for fitting information and treatment to maintain functioning, a sense of control, and normalcy. However, not all participants disclosed handling the new circumstances successfully, as they articulated difficulties in relinquishing certain activities, triggering a sense of incompetence and loss of control. Table 5 shows an overview of these themes. A more detailed description of these themes is explained further below.

Table 5

Definitions of themes related to the Manageability component

| Manageability | | |
|---|--|---|
| Themes | Explanation | Exemplary quotes |
| Referring to professionals and research to manage the illness | The participants described performing actions to help them improve their condition. These measures included reading research about long Covid and seeking professional help in the form of doctors, occupational and physical therapists, psychologists, neurologists, or pneumologists. | (1) <i>"I phoned the GP again and insisted that we had to do something. I was allowed to go to the physio (some people said that maybe that would help). The physio immediately said: 'What? You must first go to the occupational therapist, otherwise you will have a relapse because of me.' I immediately called the family doctor, and that was okay or so ... sigh. She also gave me a youtube video of the lung foundation about</i> |

long Covid. Very informative. Finally, I got some kind of help from the occupational therapist and physio.” (Participant 2, male, age 35)

Medical uncertainty making managing long Covid impossible*

The participants expressed being faced with medical uncertainty, that resulted in them not receiving adequate treatment, so they had no way to manage their symptoms in terms of medication or a cure.

(2) “I have Long-Covid. A still relatively unknown syndrome where nobody actually knows exactly how to be treated. My physiotherapist from the covid rehabilitation and my occupational therapist mention ‘that I have to learn to deal with it’. Are you kidding me? ... I already have to plan it when I want to wash my hair, ridiculous.” (Participant 27, female, age 51)

Managing daily tasks

The participants mentioned managing everyday tasks such as household chores, cooking, gardening, or going to work.

(3) “I pass the time with a lot of reading, occasionally watch a quiet program or a film in pieces. I also do the laundry and the dishwasher myself, I take care of myself and my cat.” (Participant 26, female, age 38)

Adapting to the new state of health through new strategies

The participants displayed adapting to the new circumstances by resting more often, working through tasks gradually, or using new strategies such as seeking help around the house or using walking aids, to use energy reserves more wisely.

(4) “Then I decided to take a different approach. Instead of therapy after therapy I decided to finally choose what all the therapists kept saying but I didn’t feel any room for: REST I stopped all the treatments except for a few more times of occupational therapy. Almost every week I went to a camp site by myself for a few days to really relax. Slowly my headaches decreased from ‘continuous’ to ‘regular’ and sometimes even not for a day.” (Participant 17, female, age 38)

(5) “My private life is completely disrupted by my illness. Larger household tasks are taken over, like vacuuming, mopping, washing windows, gardening, big shopping

trips. ... I cannot stand or walk for a long time, for example on a day out I make use of a mobility scooter.”
(Participant 21, female, age 42)

Giving up something enjoyable *

The participants uttered that they could not maintain everything in their life as it was before the illness. They had to give up hobbies, leisure activities, sports, jobs, or social contacts. This giving up is displayed in association with negative emotions such as sadness, disappointment, stress, hopelessness, or difficulty in acceptance.

[\(6\)](#) *“I went from working 50/60 hours a week as a self-employed person to being dependent on help, I still find that the worst, no control over your own life, always dependent on someone else, I had to make the choice to give up my company which I had worked hard for, after a year it was clear that that was not going to work now and maybe never again.”* (Participant 19, female, age 45)

Note. A * indicates that the theme is a barrier to the Manageability component, while a theme without a * expresses the Manageability component.

Referring to professionals and research to manage the illness

The participants wrote about consulting medicals and academic research to help them improve their condition. By doing this, they represented their active search for information and appropriate treatment to manage long Covid. Therefore, this theme is viewed as a facilitator for the Manageability component. This active approach became explicit in quote [\(1\)](#) in Table 5. Here, Participant 2 recounted his willingness to actively gather information to improve his condition, showing his way of finding a solution to manage long Covid by insisting on receiving treatment. He described that the therapists provided him with valuable information by giving him video material. Furthermore, he conveyed that they gave him guidance in managing symptoms effectively by preventing him from relapsing through the correct sequence of treatment. This demonstrated that healthcare professionals and research are helpful to treat long Covid, and contacting them is a way to manage the illness. The core point of this theme reflects how crucial the active search for information and appropriate

treatment is in managing long Covid, as the participants vocalized how this valuable guidance for symptom control is necessary to deal with the illness.

Medical uncertainty making managing long Covid impossible

In contrast to the previous theme, the participants also discussed that the availability of professionals who can provide guidance on dealing with the illness was not always given. Instead, they presented that medicals told them that there is no cure and no advice to learn how to manage their symptoms. This came from the lack of medical knowledge, which may be a problem in terms of Comprehensibility. Nevertheless, the participants displayed how this medical uncertainty led to a lack of guidance and handleability of symptoms, and therefore can be classified as a barrier to the Manageability component. This is evident in quote (2), where the participant got no actionable guidance on treating her symptoms, which limited her possibilities for Manageability. This signaled how the lack of Manageability frustrated her and left her unsure of how to proceed further and control the situation. In addition, she narrated that she succumbed to her symptoms, which subsequently impacted how she carried out everyday tasks. In conclusion, the participants outlined that they faced a lack of medical guidance and knowledge in managing their long Covid symptoms, which is written about as hindering them to control and cope with their illness. This is deemed to be a Manageability barrier. Nevertheless, this theme highlighted the connection to the Comprehensibility component since a cure and medication are only available if medicals and participants understand the illness. This interaction will be further explained in the second result section and the discussion.

Managing daily tasks

In the narratives, some participants talked about fulfilling everyday tasks such as household chores, going to work, or going for a walk. This presented how they handled the demands of daily life despite facing challenges from long Covid, which can be viewed as part

of the Manageability component. Participant 26 (quote [\(3\)](#)), for example, listed her daily actions and wrote about how she can take care of herself and her household despite being confronted with long Covid. This revealed how important it is for her to preserve a sense of normalcy and structure in her daily life. Furthermore, she talked about her sense of responsibility and independence as she does not depend on help and took care of herself, the household, and the cat on her own. This also emphasized that this cannot be taken for granted, as also highlighted by the fact that not all participants were able to do these kinds of activities, which is explicit in the theme 'Giving up something enjoyable'. Nevertheless, the participants also expressed applying strategies such as asking for help to fulfill everyday tasks. The following theme 'Adapting to the new state of health through new strategies' explains this in more detail. In summary, the theme 'Managing daily tasks' shows that some participants talked about handling the demands of daily life despite the challenges of long Covid experiences, which is interpreted as increasing their Manageability through a heightened sense of normalcy and coping.

Adapting to the new state of health through new strategies

The participants described that they adjusted to their new state of health by developing new strategies such as doing more breaks to maintain functioning. This adjustment represented an active approach to manage long Covid because the participants outlined finding ways to independently manage the challenges they face. Participant 17 from quote [\(4\)](#) stated this by describing how she changed her daily routines by taking more resting moments. Thereby, she portrayed how this strategy helped her to reduce her symptoms and gain control over her illness. Moreover, the participants discussed how these strategies helped them to find ways to continue to function instead of foregoing ventures, such as Participant 21 in quote [\(5\)](#) who used a mobility scooter. By recounting this active role, the participants communicated better coping responses to manage long Covid, displayed controlling the

challenges, and maintained their personal proficiency. Based on these examples, the participants wrote about recognizing the need to adjust to their circumstances by developing new strategies to manage the challenges they face. This can be classified as enhancing their functionality and sense of control which is classified under the Manageability component.

Giving up something enjoyable

However, not all participants expressed handling the new circumstances successfully, most of the participants also reported difficult situations. They talked about forgoing things that once were part of their life such as reducing or quitting social contacts, physical activity, watching TV, or their jobs. In most cases, giving up these activities was described as difficult, indicating it was not an adaption strategy within this context but can be interpreted as a barrier to the Manageability component. This was evident in participants' descriptions of struggles to manage their current condition and associated negative feelings. Participant 19 stated this (see quote [\(6\)](#)) by explaining that she had to give up her self-employment, and felt dependent on others, which suggests frustration and disappointment. Moreover, this relinquishment is stated as a loss of control of the situation, as she articulated the impossibility of autonomously deciding what she wants to do and to care for herself. This can thus be regarded as an overall barrier to the Manageability component. The core point of this theme is that the participants reported difficulties to handle the new circumstances because they were forced to give up activities that they enjoyed, leading to presented struggles, negative feelings, and a loss of control. This is classified as impeding their Manageability.

Meaningfulness

Meaningfulness is defined as a belief that life is worth living and that it has a purpose. It is known as the motivational element of SOC, providing people with emotional aspects of living such as caring and concern (Antonovsky, 1987). In the narratives of this study, the Meaningfulness component was characterized by whether the participants described living

according to their values and see improvement despite the challenges and adversities they face. This is displayed as a motivation to continue working further on their condition and signals to find meaning in recovery from long Covid. Nevertheless, some participants recounted struggles with their progress and illness acceptance, which made it hard to find meaning during this challenging time. These themes are examined in more detail in the following and an overview can be seen in Table 6.

Table 6

Definitions of themes related to the Meaningfulness component

| Meaningfulness | | |
|--|---|--|
| Themes | Explanation | Quote |
| Recognizing values in one's life | The participants described a feeling that life is worth living while suffering from long Covid as one can still express one's (new) values in life or can recognize them again. These values are characterized by the awareness of the importance of health and recovery, social support, faith, relaxation, rest and regularity, independence, or the little things in life such as enjoying coffee. | (1) <i>"I don't feel like I'm anyone else now, even though I can do far fewer things. My worth is not in the things I do. I have learned to take better care of myself and to set my boundaries. Worrying less about things, because that costs energy, which I can better spend on my recovery. I feel supported by my faith. It has touched me that so many people sympathize with me. Lots of phone calls, texts, cards, flowers."</i> (Participant 29, female, age 45) |
| Sense of direction through an improvement of the state of health | The participants wrote about plans for the future, being confident, and recognizing what the future holds. This is characterized by uttering hope that their condition will improve. | (2) <i>"So I keep looking at new developments and therapies that are being developed as more knowledge comes in about long Covid and hopefully in time I can then say that I am (somewhat) better."</i> (Participant 19, female, age 45) |
| Struggles with progress and illness acceptance* | Participants recounted many unpleasant emotions such as pain, frustration, sadness, or despair that come from not making enough progress or | (3) <i>"In good spirits I followed a rehabilitation program for another 3 months (physiotherapy, occupational therapy, treatments with a psychologist). With very small steps I</i> |

not being able to accept their illness.

made progress. But many complaints did not seem to improve any further. Now after fifteen months and two weeks after my rehabilitation I still have a lot of complaints. ... I see no progress in the recovery, and I think that it goes towards the WIA¹, whether I can ever (normally) work again I do not know. Let alone, my normal life again pick up, this is not there anymore. I have now become a 'Long Covid' patient and can tell you that this virus has ruined my entire life. I can do little or nothing because I have insufficient energy."
(Participant 11, male, age 55)

Note. A * indicates that the theme is a barrier to the Meaningfulness component, while a theme without a * expresses the Meaningfulness component. 1: WIA is the Dutch disability pension.

Recognizing values in one's life

The participants recognized and manifested personal values like their health or relaxation in the face of long Covid. This is classified as a signal of the Meaningfulness component because they displayed their meaning in life despite being confronted with challenges and adversities. Participant 29 in quote (1) of Table 6 showed this by emphasizing that she is confronted with challenges in the form of not being able to manage everything as before, but she still saw the positive things and holds on to her values, namely her health, faith, and social contacts. By doing that, she disclosed that she still perceived life as interesting, which is regarded as a reflection of the Meaningfulness component. Participant 29 (quote (1)) also outlined that her values signaled her what to use her leftover energy for and to stay motivated. This represented significance in her daily experiences, as she focused on what truly mattered to her. Furthermore, she revealed the importance of maintaining a sense of identity and meaning by naming her challenges but stating that they do not define her. Instead, she focused on her values. To sum up, recognizing and expressing personal

values is interpreted as a signal for the participants' Meaningfulness component, as it discloses how they find meaning, stay motivated, and maintain a sense of identity.

Sense of direction through an improvement of the state of health

The participants talked about being hopeful for improvement in the future. As Antonovsky (1987) said that the Meaningfulness component is about signaling one's sense of direction by indicating that the future is worth investing in, this theme is classified as belonging to the Meaningfulness component. As an example, Participant 19 (quote (2)) communicated her sense of direction by seeing beyond the current situation and being hopeful that her condition will improve. At the same time, she narrated her motivation as she informed herself about new treatment options instead of just waiting. This signaled that recognizes what she wants for the future. Consequently, the core point of this theme is that the participants recounted how staying hopeful and feeling better motivates them to actively pursue recovery and stay positive, which can be considered to represent their Meaningfulness component.

Struggles with progress and illness acceptance

Some participants manifested about not making progress in their recovery which was associated with negative feelings. By conveying this, the participants outlined the significant challenges they faced while dealing with long Covid and how hard it is to overcome these. They uttered a lot of dissatisfaction during their progress, which is interpreted as a barrier to the Meaningfulness component. Quote (3) illustrated this sentiment as Participant 11 conveyed that he started with an optimistic and positive mindset, but all his efforts and time invested did not lead to an improvement. Moreover, he outlined frustration and a loss of hope as well as his doubts about his ability to return to work. These descriptions are read as a barrier to the Meaningfulness component as his normal life is no longer attainable, emphasizing a loss of direction. Participant 11 also uttered how his illness prevents him from

engaging in meaningful activities, as he said that he has no energy to do anything. In summary, this theme demonstrates that the participants narrated a lack of progress in their recovery from long Covid, which is described as enhancing feelings of despair and restriction in engaging in meaningful activities.

Intermediate summary

In conclusion, the SOC of people with long Covid depended on many factors. Participants showed that they could understand long Covid with its extent, they could manage their condition and daily life with the help of health professionals and new strategies, and they gave hope to their life through their values despite this difficulty. Despite all this, these experiences were not consistent, because they were also surrounded by a lot of uncertainty and misunderstanding, an inability to manage usual activities, and difficulties with accepting the illness and not making progress, which made it difficult to recognize meaning in life. This emphasized the complexity of capturing long Covid experiences and handling the illness. Furthermore, this interaction between and within components and barriers will be explained in detail in the following.

Within-narrative interaction between SOC components

To show how these themes (see ‘Comprehensibility’, ‘Manageability’, ‘Meaningfulness’) have been expressed and how SOC components interact with each other, the analysis of one narrative is explained in detail below. This narrative encompasses 10 out of the 13 presented themes, highlighting the reflection of all three SOC components and some of their barriers. What the interactions between the SOC components could look like, is made especially clear in the following analysis. Chosen for its representation of the majority of the explained themes and their interaction, the narrative of Emma¹ is shown. It provides valuable insights into the experience of long Covid illness and patterns within and between the SOC components and their barriers. The narrative can be seen in Figure 1.

1: Emma is a fictional name to preserve the anonymity of Participant 31.

Figure 1

Illness Narrative of Emma

1 Until I got infected with Covid-19 in March 2021, I was someone who was passionate
2 about life. Always full of energy to tackle everything and learn new things. Sports every
3 day. Active in nature a lot. Interest in film, cultural events and museums. Enjoying tasty
4 healthy food. Being busy in the garden. Reading a lot. Often social contacts. I had my
5 own company for sixteen years and had myself hired as a freelancer within the Social
6 Domain for the last six years. For twenty-one years I worked with difficult target groups.
7 In recent years I have been conducting fraud investigations. Every day, sometimes on
8 weekends, at five o'clock in the morning next to my bed. Eager to get to work. I was also
9 available on weekends and evenings. I never turned off. Until I got Covid-19. I had a
10 mild form, I thought to myself. A week of flu, of which a few bad days with a bad
11 headache. On better days I worked from home. Because I just had a new assignment,
12 with a lot of responsibility, also towards others. But it stopped soon. After fifteen
13 minutes of calling my head turned off, nothing came in anymore and I went back to
14 bed with a terrible headache. I kept this going until mid-May, solely on willpower.
15 After that I agreed to take a time-out of one month. Now, almost eleven months after the
16 infection, I am still unable to go to work. As a freelancer, I don't have an employer to start
17 reintegration for a few hours. Although that wouldn't even work. And a new employer
18 wants someone in my profession who can go for it full-time right away. The first half year
19 I did my best to recover. Exercise as much as possible and go outside and always with one
20 goal: looking around and networking to see if I could find an entry into another
21 profession. Because I have the feeling that my head is not going to turn out all right. Not
22 good enough to handle the stress that comes with my job. I started volunteering at a
23 market garden in October. In the beginning it gave me energy. But it took too much
24 physical effort. My muscles no longer work the way I used to. So, I had to stop again. I
25 haven't seen anyone since December. I text with my friends. Fortunately, they now
26 support me, although they did not understand it at the beginning. I can only call for
27 half an hour on good days. I can't stand stimuli and have nowhere to go. I take a walk
28 with my dog, mess in the garden and read a bit. Luckily, I can still do that. On good days.
29 But I am also sick for days and sometimes weeks in a row. Sometimes because I've
30 done too much, sometimes for nothing. Then all I can do is lie in bed. I feel very
31 limited. I am a shadow of who I once was, and I have lost my sparkle. Yet I am
32 courageous. The confidence that this phase will one day lead to something good. But I'm
33 also worried about the future. If I can count again. And about how it will go
34 financially. Would I be able to continue living in my house?

– Emma, female, age 54

Comprehensibility Manageability Meaningfulness
Barrier to Comprehensibility Barrier to Manageability Barrier to Meaningfulness

The structure of Emma's narrative highlights the foregrounding of the Comprehensibility and Manageability components. This can be seen in the fact that the first 27 lines, except lines 15-18, deal with themes that belong to either one of the components or both at the same time. Towards the end of Emma's narrative, the Meaningfulness component also shows up, but in contrast to the other components rather scarcely. These frequency patterns are consistent with the narratives of many participants, which can be viewed in Table 3. The structure of Emma's narrative also represents recurring barriers of SOC components,

which are surrounded by statements supporting SOC. They particularly occur towards the end. This indicates that Emma, representative for the participants, was primarily focused on understanding and managing the illness and its impact on her life. The barriers demonstrate that she experienced practical and emotional challenges while dealing with long Covid. That suggests that participants faced challenges in finding meaning. However, the presence of the Meaningfulness component, even briefly, suggests a growing recognition of the broader context and some sense of purpose in her experience.

In Emma's narrative, the Comprehensibility component is evident through the theme 'Understanding what impact long Covid has on one's life including one's social environment' (lines 1-9, 31) by sharing how her life was before long Covid and how it has changed. The theme 'Recognizing the origin and course of the illness' (lines 9-14, 26-27, 29-30) signaled Comprehensibility by explaining her symptoms and what causes a relapse. Furthermore, the Comprehensibility component was reflected through the theme 'Encountering understanding and support' (lines 24-26) by stating that she gets support from her friends. The Manageability component showed up in the theme 'Adapting to the new state of health through new strategies' (lines 1-9, 15, 18-24) in Emma's adaptation to her new condition, employing new strategies to cope with long Covid. The Meaningfulness component was present through the theme 'Recognizing values in one's life' (lines 27-28) by finding positive experiences despite her illness and 'Sense of direction through an improvement of the state of health' (lines 31-32) by signaling that she can see beyond her current situation and stays hopeful for the future. These themes show that, despite long Covid, it is possible to maintain or redevelop one's SOC and be motivated to find a way to live with the illness.

The interplay of these themes in the narrative reveals the contribution of various experiences to SOC. It also illustrates the interconnectedness of components and their influence on each other because the same statement can reflect different components

simultaneously. For instance, lines 1 to 9, exemplify the Comprehensibility component with the theme ‘Understanding what impact long Covid has on one’s life including one’s social environment’ as the participant can consciously name and understand that she has changed. Concurrently, the Manageability component is present with the theme ‘Adapting to the new state of health through new strategies’ since this change can only come about because the participant has adapted to the situation. On the other hand, this adaptation can only be possible if she comprehends the illness and recognizes that adaptation is necessary. This shows that the components influence each other and that the experience of long Covid is complex.

However, Emma’s narrative includes difficulties within the illness experience such as ‘Experiencing misunderstanding and invalidations’ (line 26), ‘Uncertainty and lack of knowledge (lines 29-30, 32-34), ‘Giving up something enjoyable’ (lines 15-18) and ‘Struggles with progress and illness acceptance’ (line 15-18, 30-31). These issues are interpreted as barriers to SOC, as explained in the first half of the result section. All other 33 participants reported barriers as well. Furthermore, a single statement can manifest multiple barrier themes too. For example, in lines 15 to 18, it is evident that her struggles with progress due to her health issues can be classified as a barrier to the Meaningfulness component. Additionally, the same expression becomes a barrier to the Manageability component, as she gave up her work and cannot continue her typical life. Following this logic, the barriers to SOC may also interact.

It should also be noted that the same statements can be interpreted as demonstrating both barriers and components of SOC. In Emma’s narrative, for example in lines 30 to 31, she outlines unhappiness with the situation because she feels restricted and not like herself. However, this is also an exposition that she understands the impact long Covid has on herself and her life. According to this, not only do the components themselves interact with each

other but they are also weighed with difficulties. In the example of Emma, this is an expression that the circumstances can be understood in terms of the Comprehensibility component, but she does not know how to counteract them. This results in struggles with progress and illness acceptance, which is interpreted as a barrier to the Meaningfulness component.

Discussion

This study provides a foundation for understanding the experience of being ill with long Covid through the lens of Antonovsky's SOC theory (1979). This theoretical basis provided insights into what it is like to live with long Covid and how these experiences can be interpreted in terms of Comprehensibility, Manageability, and Meaningfulness. Overall, these insights highlighted how complex and varied the long Covid experience is, and how mentioned experiences can be interpreted as facilitating and hindering SOC simultaneously.

The findings of the current study shed light on what themes characterize Comprehensibility, Manageability, and Meaningfulness in long Covid experiences. In total, 13 themes were found. The Comprehensibility component was found in themes expressing understanding over the course of long Covid, realizing how it has impacted life, and support from the participant's social environment. The Manageability component was described in themes displaying how the participants referred to professionals, managed daily tasks, and adapted to the new state of health by developing new strategies to maintain control and normality. The Meaningfulness component was illustrated in themes where participants talked about their values, found life interesting, retrieved purpose and motivation, and worked toward their recovery, signaling to look beyond their current situation.

The present themes correspond with prior research on long Covid experiences. Specifically, the importance of interpersonal connections (Rushforth et al., 2021) is present like in the current theme 'Encountering understanding and support' in which participants

highlighted the opportunities to obtain feedback. Furthermore, Macpherson et al. (2022) underline the perceived impact of long Covid on individuals' identity, captured within the present theme 'Understanding what impact long Covid has on one's life including one's social environment'. Moreover, Kingstone et al. (2020) emphasize the importance of adapting to the new life situation, which is echoed in the present theme 'Adapting to the new state of health through new strategies' where participants expressed strategies to maintain functionality. In addition, Rushforth et al. (2020) recognized that people with long Covid tend to acquire medical knowledge, which is also found in the present theme of 'Referring to professionals and research to manage the illness' in which participants describe how expert guidance helped them. The similarities between this study and previous research validate the current understanding of long Covid experiences. However previous research did not expose how individuals with long Covid find meaning in their lives and maintain motivation. Therefore, this study introduces new themes such as 'Recognizing values in one's life' and 'Sense of direction through an improvement in the state of health'. Hence, by employing the SOC theory, this study reveals how participants interpret, give meaning, and navigate life using these experiences.

However, the current study identified five themes that can be interpreted as barriers to the SOC components. These themes were 'Experiencing misunderstanding and invalidations' and 'Uncertainty and a lack of control' as barriers to the Comprehensibility component, the Manageability component was hindered by the themes 'Giving up something enjoyable' and 'Medical uncertainty making managing long Covid impossible', while 'Struggles with progress and illness acceptance' was a barrier to the Meaningfulness component. These barriers are classified to hinder the participants to understand or make sense of long Covid, or to view life as coherent and predictable (Comprehensibility), to feel competent and self-determined (Manageability), or to view life as meaningful (Meaningfulness). Similar

struggles have been noted in other studies, such as the uncertainty of the illness course and misunderstanding with practitioners (Russell et al., 2022). Concerns about work, and lack of improvement (Macpherson et al., 2022), threats to identity and frightening symptoms (Kingstone et al., 2020), and difficulties accessing services and facing an uncertain prognosis (Ladds et al., 2020) have also been reported. The presence of such discomfort during long Covid experiences underscores the challenge of maintaining one's SOC and the need for adequate support for affected individuals.

To date, no other studies have examined how SOC can be used to understand long Covid narratives. Nevertheless, comparable SOC studies in related illnesses, where sufferers experience similar symptoms, reveal the potential of overcoming barriers. For instance, a study about post-haematopoietic stem cell transplant survivors (Sharin et al., 2020) demonstrated symptom similarities to long Covid, such as fatigue, cognitive decline, depression, anxiety, and financial worries. The themes characterizing SOC observed in both groups included themes expressing an understanding of the experience to adapt to a new identity as encompassing Comprehensibility. Manageability was described by themes describing maintaining control through self-management strategies and engaging in daily activities while Meaningfulness was expressed through themes concerning seeking meaning in personal values such as relationships. These shared experiences suggest that SOC is influenced by common factors in response to adversity, not exclusive to long Covid. However, a difference lies in the ability of transplant survivors to let go of the past and accept uncertainty as they are in an intermediate stage between illness and health. This ability may also emerge in long Covid sufferers as stress factors diminish, allowing for a reinterpretation of barriers. Additionally, the illness stage of long Covid may explain why understanding the origin and progression of the illness holds significance for their Comprehensibility

component, unlike that of transplant survivors who are less concerned with the course of the illness due to their familiarity with it.

Furthermore, the findings of this study suggest that Comprehensibility and Manageability play prominent roles for individuals with long Covid as they just begin to perceive meaning within a broader context. This fits partly with Bergman et al.'s (2012) research that emphasizes the significance of Comprehensibility with myocardial infarction, as understanding the illness enhances Manageability and Meaningfulness. The fact that experiences in terms of Comprehensibility and Manageability were the most recounted components in the current study and that these statements interacted strongly with each other, underlines the aspect that Comprehensibility is necessary to manage long Covid. However, the results also reveal the importance of Manageability in understanding the illness's impact on life, indicating that for people with long Covid Comprehensibility and Manageability are equally important. Furthermore, unlike the findings of Bergman et al. (2012), the prominence of Comprehensibility was not observed as increasing themes in the sensation of Meaningfulness. This shows that it can be difficult to retain a sense of Meaningfulness during long Covid and that solidifying Comprehensibility and Manageability, potentially without experiencing barriers, may be necessary before meaning can be found.

Overall, it is worth noting the complexity of long Covid and SOC. This comes from the participants making indications that they were able to maintain or redevelop their SOC but also reported barriers at the same time. The simultaneous presence of barriers and facilitators to SOC corroborates Volanen et al.'s (2007) study that SOC is a dynamic orientation but contradicts Antonovsky's (1979) original definition of SOC as a global orientation and as something that is just reevaluated through great changes in life. Therefore, negative life events such as suffering from long Covid, seem to have an impact on SOC. Accordingly, a dynamic orientation suggests that is not a fixed and stable psychological

construct and could also be strengthened again by eliminating certain barriers. However, present results suggest that the entanglement of expressions and barriers to SOC may also indicate the difficulty of overcoming them because if one prevents these, one also prevents experiences that contribute to SOC. Therefore, it is not only important to eliminate barriers but also to reinforce strengths.

The results of this study discussed so far lead to several implications to strengthen SOC and help sufferers get out of the stressful phase of the illness. To address barriers in the Comprehensibility component, educating relatives about long Covid could promote better understanding and empathy. This would benefit the Comprehensibility component as they would be able to better understand their illness through increased communication. In relation to this, one implication is for practitioners and the government to provide targeted counseling and education about long Covid to reduce uncertainty. However, this presupposes the necessity for improved medical understanding and practitioner empathy, as already suggested by Goldberg et al. (2022). Accordingly, this study underscores the importance of further research on long Covid and ongoing education for practitioners. Given the interconnectedness of SOC components, such implications would also enhance Manageability by improving treatment options. Multidisciplinary care from various healthcare practitioners is recommended to further strengthen Comprehensibility and Manageability and provide strategies for understanding and dealing with long Covid, as many of the current participants recounted the benefits of encountering medical support. In addition, one implication is to facilitate timely access to psychological and reintegration support to encourage progress, help manage worries and negative emotions, and promote satisfaction and a sense of direction. However, it is important to recognize that individual experiences with long Covid vary, and the proposed implications may not universally apply. Nonetheless, integrating appropriate

interventions early on can help strengthen the Meaningfulness component, considering its relative scarcity in the narratives.

Nevertheless, this study also has limitations. The data is already over a year old and may not reflect current advancements in long Covid research or medical and public education. Therefore, the relevance and applicability in the current context is questionable. Moreover, the deductive approach used in this study to address SOC components may have introduced bias and overlooking or interpreting information differently. For example, by focusing on the SOC theory, the influence of the cultural context might have been overlooked. Therefore, cultural norms surrounding the illness and help-seeking behaviors can impact individuals' illness narratives and coping strategies, but this study may not fully reflect this. In addition, the study also lacks information about participants' lives before their long Covid illness, preventing the examination of whether the described identity really changed or only the participants' perception of life before the illness.

Based on these limitations, it would make sense to repeat the study. In this sense, a long-term study is advisable to enable an improved comparison of how perceived barriers and changes come about and are told retrospectively. Future research could accordingly investigate in more detail what influence long Covid has on the retelling of one's illness story and the perception of one's life to date in terms of the SOC to better examine the influence of long Covid on one's SOC.

Conclusion

In summary, this study explored the experience of living with long Covid through the lens of Antonovsky's SOC. Using this lens, insight into what helps people living with long Covid to understand, manage and find meaning in their illness was gained. The findings emphasize that SOC of people with long Covid is characterized by various themes presenting either facilitators or barriers. Comprehensibility and Manageability were most prominent, and

it seemed more difficult to maintain Meaningfulness during a long Covid illness. Therefore, this study suggests that interventions that focus on enhancing meaning and purpose in life should be easier accessible.

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Appendices

Appendix A: Items of the SOC-29 (Antonovsky, 1993) listed per component

Comprehensibility

1. When you talk to people, do you have the feeling that they don't understand you?
Never - Always have this feeling
3. Think of the people with whom you come into contact daily, aside from the ones to whom you feel closest. How well do you know most of them?
You feel that they're strangers - You know them very well
5. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well?
Never happened - Always happened
10. In the past ten years your life has been:
Full of changes without your knowing what will happen next - Completely consistent and clear
12. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?
Very often - Very seldom or never
15. When you face a difficult problem, the choice of a solution is:
Always confusing and hard to find - Always completely clear
17. Your life in the future will probably be:
Full of changes without knowing what will happen next – Completely consistent and clear
19. Do you have very mixed-up feelings and ideas?
Very often - Very seldom or never
21. Does it happen that you have feelings inside you would rather not feel?
Very often - Very seldom or never
24. Does it happen that you have the feeling that you don't know exactly what's about to happen?
Very often - Very seldom or never
26. When something happened, have you generally found that:
You overestimated or underestimated its importance - You saw things in the right proportion

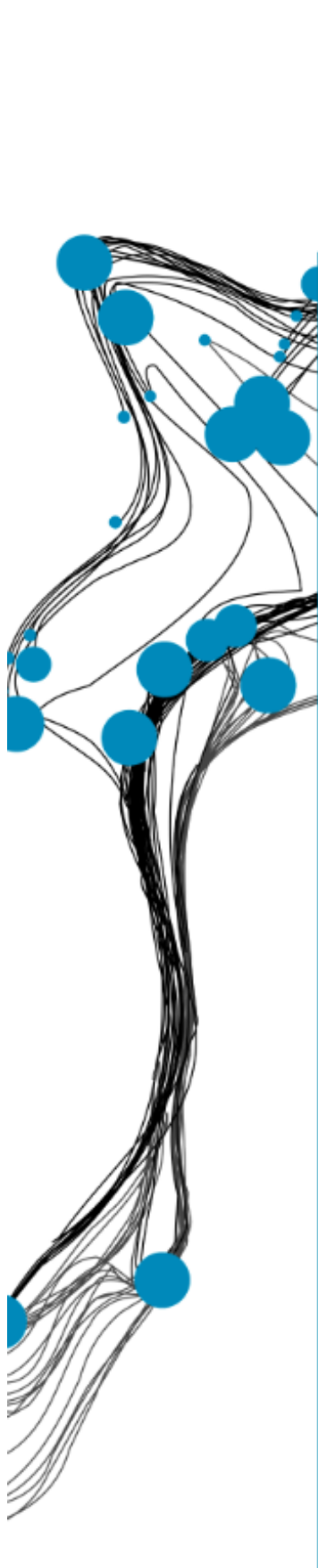
Manageability

2. In the past, when you had to do something, which depended upon cooperation with others, did you have the feeling that it:
Surely wouldn't get done - Surely would get done
6. Has it happened that people whom you counted on disappointed you?
Never happened - Always happened
9. Do you have the feeling that you're being treated unfairly?
Very often - Very seldom or never
13. What best describes how you see life:
One can always find a solution to painful things in life - There is no solution to painful things in life
18. When something unpleasant happened in the past your tendency was:
"To eat yourself up" about - To say "ok that's that, I have to live with it" and go on
20. When you do something that gives you a good feeling:
It's certain that you'll go on feeling good - It's certain that something will happen to spoil the feeling
23. Do you think that there will always be people whom you'll be able to count on in the future?
You're certain there will be - You doubt there will be
25. Many people – even those with a strong character – sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?
Never - Very often
27. When you think of the difficulties you are likely to face in important aspects of your life, do you have the feeling that:
You will always succeed in overcoming the difficulties - You won't succeed in overcoming the difficulties
29. How often do you have feelings that you're not sure you can keep under control?
Very often - Very seldom or never

Meaningfulness

4. Do you have the feeling that you don't really care about what goes on around you?
Very seldom - often or never
7. Life is:
Full of interest - Completely routine
8. Until now your life has had:
No clear goals or purpose at all - Very clear goals and purpose
11. Most of the things you do in the future will probably be:
Completely fascinating - Deadly boring
14. When you think about your life, you very often:
Feel how good it is to be alive - Ask yourself why you exist at all
16. Doing the things you do every day is:
A source of deep pleasure and satisfaction - A source of pain and boredom
22. You anticipate that your personal life in the future will be:
Totally without meaning or purpose - Full of meaning and purpose
28. How often do you have the feeling that there's little meaning in the things you do in your daily life?
Very often - Very seldom or never

Appendix B: Flyer



**Bent u
iemand die ervaringsverhalen en
toekomstwensen wil delen,
over leven met een chronische
aandoening?**

Dan zijn we op zoek naar u!

Voor ons onderzoek zijn we op zoek naar mensen die ervaringsverhalen willen delen:

- hoe het is om te leven met een chronische aandoening
- over hun toekomstwensen
- door hierover te schrijven (mag kort!)
- op deze manier mensen met een chronische aandoening een stem willen geven
- en dit perspectief onder de aandacht willen brengen bij zorgprofessionals


Voor deze uitbreiding van een langlopend onderzoek zijn we ook op zoek naar mensen met Long COVID / klachten na COVID-19.

Scan de QR-code of klik op de link voor meer informatie!
https://utwentebz.eu.qualtrics.com/jfe/form/SV_eE6AAihR3CwUAlu

Maar wees er snel bij! Want half maart 2022 gaan we aan de slag met de verhalen.

Kent u iemand met een chronische aandoening?
 Of met Long COVID / klachten na COVID-19?
 Verspreid dit bericht dan graag verder!

Hartelijk dank namens het onderzoeksteam van de Universiteit Twente (afdeling Psychologie, Gezondheid en Technologie): Anneke Sools en Heidi Toivonen: onderzoeker en universiteit docent, en Kevin Pijpers: postdoctoraal onderzoeker, Jacqueline Coppers, onderzoeksassistent, Lianne Joling, Luca Schlieper, Marco Richter, Katharina Walzik en Denise Fingal, master-studenten psychologie.



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Appendix C: Information letter

Informatiebrief voor deelnemers aan het onderzoek “Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst” Fase 1: een verhaal en brief schrijven

Welkom!

Welkom bij ons onderzoek naar uw verhalen over het verleden en de toekomst! Dit onderzoek is bedoeld voor volwassenen met een **chronische aandoening**. Dat is een aandoening die langer dan een jaar duurt en medische aandacht vraagt of het dagelijks leven beperkt. Herkent u zich daarin? Dan nodigen we u uit om deel te nemen aan het onderzoek.

Kent u iemand met een chronische aandoening? **Stuur** deze informatiebrief dan **gerust door**.

Voor deze uitbreiding van het langlopend onderzoek zijn we specifiek ook op zoek naar mensen met Long COVID / klachten na COVID-19 (ook al zijn die klachten minder dan een jaar aanwezig).

Wie doen het onderzoek?

Het onderzoeksteam van de Universiteit Twente (afdeling Psychologie, Gezondheid en Technologie) bestaat uit:

- Anneke Sools en Heidi Toivonen: beiden onderzoeker en universiteit docent, en Kevin Pijpers: postdoctoraal onderzoeker.
- Jacqueline Coppers: onderzoeksassistent en ergotherapeut.
- Lisanne Joling, Luca Schlieper, Marco Richter, Katharina Walzik en Denise Fingal: allen master-studenten psychologie.

Wat is het doel van het onderzoek?

Wij zijn geïnteresseerd in hoe mensen verhalen vertellen over hun **ervaringen** met een chronische aandoening. Ook zijn we benieuwd naar de **toekomstwensen** van mensen met een chronische aandoening.

We willen weten hoe hun ervaringen en toekomstwensen samenhangen. Deze kennis kan helpen om meer inzicht te krijgen in ervaringen van mensen met chronische aandoeningen. Door hun hoop en dromen voor de toekomst te leren kennen hopen we mensen met een chronische aandoening een stem te kunnen geven. Om daarmee uiteindelijk verbeteringen voor te stellen voor de zorg aan mensen met een chronische aandoening.

Wat verwachten we van de deelnemers?

We verwachten van u als deelnemer dat u:

1. een **verhaal** schrijft over uw leven met een chronische aandoening.
2. een **brief** schrijft over uw wensen voor de toekomst.
3. enkele **vragen** beantwoordt over uzelf, over uw verhaal en over uw chronische aandoening.

En verder:

U kunt op elk moment stoppen met het onderzoek, zonder een reden te geven. U bepaalt zelf hoeveel **tijd** het u kost. We verwachten dat het ongeveer **45 minuten** kost. Maar u kunt zoveel tijd nemen en zoveel **pauses** nemen als u

wilt. U kunt ook tussendoor stoppen en later weer doorgaan, want de antwoorden worden tussendoor bewaard.
U beantwoordt de vragen in uw eigen tempo, liefst voor **half maart 2022**.

Wat zijn de voors en tegens van deelname aan het onderzoek?

Voors:

- Sommige mensen vinden het fijn om hun verhaal te delen met anderen. Ze vinden het fijn dat er naar hun verhaal geluisterd wordt.
- De ethische commissie van de Universiteit Twente heeft het onderzoek goedgekeurd.

Tegens:

- Niet iedereen vindt het fijn om zijn verhaal te vertellen.
- Het kost u tijd en inzet om uw verhaal en brief te schrijven en om de vragen te beantwoorden.

Wat doen we met uw antwoorden?

Wij, het onderzoeksteam, verwerken de antwoorden **anoniem**, dus zonder uw naam of andere persoonlijke informatie te gebruiken. Want we willen dat niemand weet dat de informatie over u gaat. We gebruiken de anonieme informatie voor een artikel in een wetenschappelijk tijdschrift, of voor een presentatie op een congres.

Hoe bewaren we uw persoonlijke informatie?

We bewaren uw persoonlijke informatie op een **veilige plek**, apart van de gegevens van het onderzoek. Alleen het onderzoeksteam heeft toegang tot de onderzoeksgegevens en uw persoonlijke informatie.

We moeten de anonieme onderzoeksgegevens 10 jaar bewaren.

Want als het nodig is, dan moeten andere onderzoekers de anonieme resultaten van het onderzoek kunnen controleren.

Wilt u meedoen?

Dan kunt u terugkeren naar het onderzoek. De link naar het onderzoek is: https://utwentebbs.eu.qualtrics.com/jfe/form/SV_eE6AAihR3CwUAIu

Wilt u ons verder helpen?

Dan kunt u (andere) mensen die leven met een chronische aandoening uitnodigen om deel te nemen aan dit onderzoek.

Heeft u nog vragen?

Mail, bel of sms dan gerust met Jacqueline Coppers via emailadres: j.p.m.a.coppers@utwente.nl of telefoonnummer: 06-51541796.



Appendix D: Informed Consent

Onderzoek: "Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst"

Welkom bij het onderzoek "Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst". Wat fijn dat u mee wilt doen aan dit onderzoek!

Het onderzoek bestaat uit de volgende onderdelen:

1. uw **verhaal** schrijven over uw **leven met een chronische aandoening** (maximaal 1 A4), 2. een **brief** schrijven over uw **gewenste toekomst** (minimaal 1/2 A4, mag ook meer)
3. een **vragenlijst** invullen.

Het onderzoek duurt **ongeveer 45 minuten**.

U kunt tussendoor stoppen en op een later moment verder gaan, uw antwoorden worden tussendoor opgeslagen.

Heeft u nog vragen? Dan kunt u contact opnemen met Jacqueline Coppers, door te mailen naar: j.p.m.a.coppers@utwente.nl of te bellen of te sms-en (06-51541796).

Door op onderstaande knop te klikken verklaar ik dat

- ik 18 jaar of ouder ben
 - ik weloverwogen heb besloten om deel te nemen aan het onderzoek "hoe mensen met chronische aandoeningen verhalen over hun verleden en toekomst"
 - ik de informatiebrief voor deelnemers heb gelezen (zie Informatiebrief verlenging verhalen chronische aandoening universiteit twente)
 - ik begrijp dat ik mijn deelname op ieder moment en zonder opgave van reden kan stoppen
 - ik begrijp dat mijn persoonlijke informatie (naam en contactgegevens) vertrouwelijk wordt behandeld, beveiligd wordt bewaard en geanonimiseerd wordt voorafgaande aan de data-analyse mijn deelname aan het onderzoek vrijwillig is.
- **Ik ga hiermee akkoord en ik wil starten met het onderzoek**
- **Ik ga niet akkoord, ik wil niet deelnemen aan het onderzoek en ik stop**

Appendix E: Writing a story about the illness experience

Wilt u in het lege veld hieronder uw verhaal schrijven over uw leven met een chronische aandoening (verleden)?

Wilt u uw verhaal vertellen hoe het met u is gegaan sinds bekend werd dat u een chronische aandoening heeft? Beschrijf met zoveel mogelijk details wat u tot nu toe heeft meegemaakt en hoe u zich daarbij voelt. Misschien heeft het uw leven veranderd. Bijvoorbeeld op het gebied van gezondheid, wonen, werk of andere activiteiten, sociale relaties, andere levensgebieden of het beeld over uzelf. Of misschien ook niet.

We zijn geïnteresseerd in uw eigen persoonlijke ervaring. Het gaat dus om uw eigen beleving.

Het schrijven van een verhaal over uw leven met een chronische aandoening zal ongeveer 15 minuten kosten. Sommige mensen hebben meer tijd nodig en sommigen minder. Neem alle tijd die u nodig heeft. Het gaat om een verhaal van maximaal 1 A4.