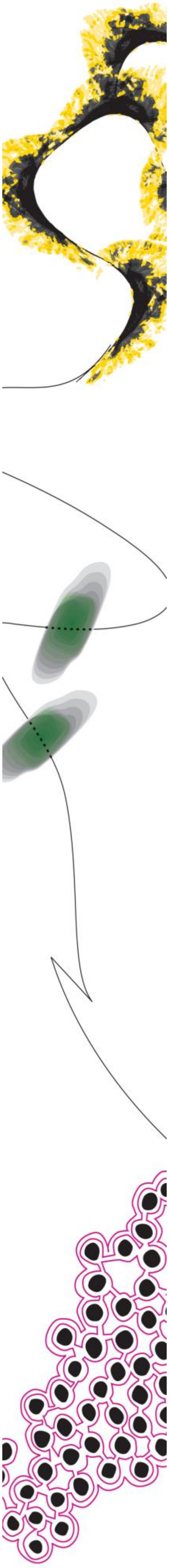

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The concepts of disease, illness, and sickness in Post COVID:

A thematic analysis on patient narratives

Master Thesis Positive Clinical Psychology and Technology

by

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Abstract

Post COVID is a novel and contemporary health condition which is characterized by prolonged symptoms after a COVID-19 infection. Due to the novelty of the condition, its uncertain prognosis and the absence of treatment options, the illness trajectory of Post COVID sufferers may be met with conflicts related to themes on (inter)personal and societal dimensions. Research on the exploration of these various 'points of tension' related to Post COVID, based on the personal illness experience of its sufferers, seems to be lacking in scientific literature. The 'disease-illness-sickness' triad is a theory to that can be utilized to conceptualize various societal perspectives of the Post COVID illness experience, namely its personal (illness), biomedical (disease), and social (sickness) perspectives. Narratives can be used to be able to gain a deeper understanding of a person's experiences and explore various themes on the triad as told from the personal experiences of Post COVID sufferers. Therefore, the current study aims at exploring the illness narratives and 'Letters from the Future' written by persons suffering from Post COVID, to answer the question where Post COVID sufferers perceive the placements and interactions of various illness-related conflicts on the 'disease-illness-sickness' triad. Thematic analysis on the illness narratives and 'Letters from the Future' found that there are ten different themes that can be considered to be tension points between various in the triad: eight themes of dyadic nature (illness-disease and illness-sickness) and two themes related to the complete interaction of the triad (illness-disease-sickness). These themes seem to be primarily caused by the novelty and unfamiliarity of Post COVID as a human health condition on biomedical and societal structures, including its (perceived lack of) developments (e.g. of medical, economic, legislative or societal resources), having a negative effect on the personal Post COVID illness experience. The findings of the current study aim to call for greater awareness to the personal illness experience of individuals suffering from Post COVID for governmental policy-makers, healthcare professionals, and society at large.

1. Introduction

In late December 2019, at the dawn of the current decade, a novel SARS virus was discovered in Wuhan, China. This virus was named SARS-CoV-2 and it causes an illness most commonly known as coronavirus disease 2019 (COVID-19). The majority of COVID-19 infections follow the typical pathway of an acute disease, namely with an onset, an illness period, and a distinct ending – either recovery or death. Through time, a growing number of persons has emerged who suffer from long-term symptoms after the onset of a COVID-19 infection. This phenomenon is referred to as ‘Long-Haul COVID’, ‘Long-Tail COVID’, ‘PASC’ (Post-Acute Sequelae of SARS-CoV-2), and recently officially named ‘Post COVID’ by the World Health Organization (Nath, 2020; Nehme, Braillard, Chappius, & Courvoisier, 2021; World Health Organization [WHO], 2021). Research from the Dutch National Institute for Public Health and Environment on Post COVID showed that sufferers can experience a wide variety of illness symptoms, the most recurring symptoms being fatigue, shortness of breath, chest pain, muscle strains, headaches, heart palpitations, persistent fever, forgetfulness – often called ‘brain fog’, and loss of taste and/or smell (RIVM, 2021). These symptoms may persist for several weeks but can also last for several months, and may vary in severity and extent from person to person.

Post COVID fits the description of a chronic illness, which are illnesses that continue indefinitely and have no distinct, clear ending (Larsen, 2006). Specifically, chronic diseases are defined as “a human health condition or disease that is persistent or otherwise long-lasting in its effects”, including when the course of the disease lasts for more than three months (Bernell & Howard, 2016, p. 2). Chronic illnesses mostly develop at older age, but can also begin at a young age or even at birth. In the Netherlands, the most common chronic illnesses are cardiovascular diseases (CVD), diabetes, cancer, and chronic obstructive pulmonary disease (COPD) (RIVM, n.d.). Due to its indefinite nature, a chronic illness may imply a major burden for the individual that impacts all aspects of the individual’s life, including physical, mental, emotional, social and occupational aspects (Hwu, 1995; Megari, 2013; Charmaz, 1983).

Post COVID is also characterized by prolonged illness symptoms after onset of the COVID-19 infection without a definitive ending, fitting the description of a chronic illness. As the Post COVID phenomenon is still relatively novel, much is still unknown about the condition. Both persons with a previously severe COVID-19 infection requiring hospitalization, as well as persons who experienced a mild infection, can contract the illness and suffer from the Post COVID (RIVM, 2021). Research published by the University Medical Center Groningen (UMCG) has shown that approximately one in eight persons who contract COVID-19 may develop Post COVID (Ballering, van Zon, Olde Hartman & Rosmalen, 2022). There is an absence of detectable body abnormalities in Post COVID sufferers despite thorough diagnostic investigation, making it difficult to medically grasp the illness (Ballering, Olde Hartman, & Rosmalen, 2021). Furthermore, it remains unknown why some persons recover from a COVID-19 infection while others do not fully recover from the symptoms and develop Post COVID as a result. Research has shown that it most often occurs in – but is not limited to – women, persons with higher BMI, asthmatic patients, and persons with pre-existing hypertension (Pazukhina et al., 2022; RIVM, 2021). However, even otherwise young and healthy populations are at risk for developing Post COVID and make up a significant portion of Post COVID sufferers (Nehme et al., 2021).

For Post COVID patients, the return to their former health trajectory is slow and painful (Yelin et al., 2020). Persons suffering from Post COVID continue to suffer for weeks, months or even years after onset of the infection. Post COVID sufferers have already sought and found refuge and support with fellow sufferers and have made great steps to increase the visibility of their illness. Yong (2020a) described how the symptoms of Post COVID patients are often misunderstood by medical professionals, reducing their symptoms to merely being an experience of ‘illness anxiety’. Furthermore, the causes, determinants and trajectory of Post COVID have proven to be difficult to establish by medical professionals due to its novelty, which makes the prognosis for Post COVID patients uncertain (Ballering, Olde Hartman, & Rosmalen, 2021). As Post COVID is a novel and contemporary phenomenon, it would be valuable to gain deeper insights into the personal, subjective experiences from the perspective of persons who have suffered, or are currently suffering, from the condition. However, to be able to investigate aspects of a certain human health condition, it is important to take a step back and to consider the complexity of the concept of human health.

1.1 The triad disease, illness, and sickness

The human condition is a complex phenomenon that can be described in various ways – however, one way to define it is according to the following literature by Hofmann (2017). According to Hofmann, there are three prominent perspectives on human health which make up a triad, namely *disease*, *illness*, and *sickness*. He argues that the distinction between the concepts of disease, illness, and sickness has been a topic in the sociology, anthropology, and philosophy of healthcare literature since the 1950s. The three concepts represent different perspectives of health – namely the professional, personal, and societal perspective – and may be utilized to investigate differences related to a health condition. In this paragraph, the concepts are further elaborated on based on Hofmann’s (2017) work.

The definition of *disease* is rooted in the perspective of medical professionals and has a mainly objective component; a disease can be observed, examined, mediated, and measured, e.g. by means of science and technologies. For example, diseases are defined according to e.g., detectable physiological abnormalities, biochemical defects, and genetic abnormalities. As a result, a disease calls for action by health professionals with the aim to identify, treat, and take care of the person; overall, it aims for a cure. On the other hand, the definition of *illness* is based on the first-person perspective of the experience, which is based on subjective components related to emotions and personal experiences, e.g. anxiety, fear, pain, and suffering. Illness can be further characterized in terms of bodily and/or mental awareness related to the condition, including feelings of estrangement, unpleasantness, or uncanniness. The illness experience may affect the self-concept, relationships, and activities of the individual. We may gain access to a persons' illness experience by means of interaction with the person and gaining deeper insights into the phenomena, language, and mental states of the person. The role of healthcare professionals in the treatment of an illness is to provide comfort, care, and/or relief of suffering.

Lastly, the phenomena related to the concept of *sickness* is rooted in a broader, social perspective; namely the expectations, conventions, policies, and social norms and roles, which are discovered through social interaction and participation between individuals. As sickness is a societal construct, both the patient, the medical professional, and societal structures are agents in influencing the concept of sickness and how it is treated. The common understanding of a sickness determines whether a person suffering from a condition is entitled to treatment, economic rights, exemption from social duties, such as work (e.g., benefits or sick leave), but also whether a person is legally accountable for his or her actions. The social nature of the construction of sickness suggests that societal differences may influence the understanding of a sickness and how it is treated by societal structures.

According to Hofmann (2002, p. 7) the paradigm case in healthcare is "when a person feels *ill*, the medical profession is able to detect and treat *disease*, and society attributes to him the status of being *sick*". All, several, or none of the triad's concepts may apply at the same time and the interplay between the concepts may change over time as well (Twaddle, 1994). Furthermore, the concepts of disease, illness, and sickness are not independent – on the contrary, according to Hofmann (2017), they have a dynamic relationship in which they may directly or indirectly influence each other. For example, a disease may influence the sickness perspective due to scientific and medical evidence about the disease, and a sickness may influence the disease perspective by means of societal interest. Furthermore, a sickness may influence the illness perspective when society is socially accepting of the sickness, which may facilitate personal identification with the illness; vice versa, an illness may influence the sickness perspective due to patients' suffering pressure by patient organisations. Lastly, a disease may influence the illness perspective due to the health professionals' conception and scientific knowledge of the disease, which may validate or invalidate the illness perspective of an individual; on the other hand, an illness may influence the disease perspective due to patients' suffering pressure from their symptoms, encouraging scientific research on their illness.

Different combinations of the triad may impose positive or negative effects on the individual suffering from the condition. As Hofmann (2017) has observed, conditions like fibromyalgia and chronic fatigue syndrome are considered sicknesses by society, but initially they were not considered diseases by medical professionals due to a lack of scientific/medical evidence for the condition. Furthermore, conditions like hypertension and pollen allergies are considered to be medically-proven diseases but do not warrant a sick role, meaning that persons suffering from such conditions are not entitled to certain rights or benefits. Moreover, before the 1970s, homosexuality was considered to be a sickness due to its deviance of heterosexuality, in other words 'normality', but where the person has not felt ill, and the medical profession has not recognized any disease notion (Hofmann, 2002). A negatively imposed sickness perception, such as the aforementioned example of homosexuality, may result in stigma or discrimination by society at large (Biordi, 2006; Hofmann, 2017; Mann & Stuenkel, 2006). Furthermore, a lack of consensus about a condition being a sickness or a disease, may adversely affect the health of individuals suffering from the condition and may deny them opportunities to meet their needs (Hofmann, 2017; Levy & Sidel, 2006).

1.2 Patient activism in relation to the triad and the case of Post COVID

Disease, illness, and sickness are often perceived as perspectives on human health with a negative connotation, as they are related to states of the human condition characterized by ailment and suffering. However, developments or shifts in the perception of the condition may also give way to a reduction of suffering. For example, according to Hofmann (2017), increased awareness of a certain human health condition in societal structures, such as medical professionals or legislative organisations, may for example encourage the development of medical resources for the treatment of the condition, create laws for justified work absence, or give way to economic support. Furthermore, how scientists engage with knowledge about a condition affects how its meaning is constructed, including what evidence about the illness is considered a priority (Callard & Perego, 2021). The results of this scientific research are then integrated into the healthcare system, which directly influences how patients' condition is treated in a healthcare setting. Therefore, it has been shown that patients and their illness experience play a crucial factor in the creation of awareness about their illness (Callard & Perego, 2021).

Social activism among patients – otherwise called *patient activism* – can be described as persons creating awareness for their medical condition and to help and/or empower others to do the same thing (Moss, 2016). They may engage in groups and communities that aim to change the narrative around their illness, to provide support for fellow sufferers, and educate patients and caregivers alike on their experiences with the illness and how they prefer to be treated by the healthcare system and society at large. Historically, the disability movement has always been quite activist – "nothing about us without us" is a slogan that is rooted within the disability rights community which is used to communicate the idea that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy (Carlton, 2000). An example of an illness that has gathered awareness by great social activism of its sufferers are mental health survivors (Sweeney et al., 2009). In the past, mental illnesses have been heavily stigmatized by society at large, but have made great leaps by means of their activism. The mental health movement emerged around the 1970s and framed their ideologies – namely the protection, support, and acceptance of this disadvantaged, discriminated, and stigmatized group – around the idea that "mental health is a government responsibility" (Bodenheimer, 2016).

According to Callard & Perego (2021), Post COVID is the most recent example of an illness that is also being made visible by its sufferers, even considering it to be a 'patient-made illness'. Early Post COVID activism emerged in March 2020, when COVID-19 patients started sharing their experiences on social media, including patients whose illness symptoms did not fit the initially understood symptoms of COVID-19 – which, at the time, was understood to be an acute illness. In April 2020, newspapers started writing about personal accounts from patients documenting how they experienced a challenging recovery from their COVID-19 infection. In June and August of 2020, Yong published the articles "COVID-19 can last for several months" (Yong, 2020b), and "Long-haulers are redefining COVID-19" (Yong, 2020a), where the term 'long-hauler' quickly moved into general circulation. These events in the early history of the COVID-19 pandemic demonstrate how the growing publicity of patients' illness experiences has led to the awareness, and therefore the creation, of the concept of Post COVID. According to McClymont (2021), Post COVID is unique because patients have defined, researched and raised awareness on Post COVID on their own by means of both the Internet and social activism. Furthermore, the use of prominent individuals, social media and online support groups – one example being the "Corona Square" on the website of the Dutch Lung Fund (Longfonds, n.d.) – have been influential factors in this development. This social activism from sufferers has provided support for fellow sufferers, and doctors and researchers began to take the illness seriously (McClymont, 2021). Connecting this development in Post COVID history to the triad disease-illness-sickbess by Hofmann (2017), it may suggest that a shift or an expansion has occurred of the position of Post COVID on the triad. Over time, these attempts at activism and awareness creation gradually shifts Post COVID from solely being an illness to also gain a sickness perception by society at large. This newly developed sickness status might have encouraged scientific research at attempting to medically understand the condition, implying a gradual development of a disease status for Post COVID as well. It would therefore be interesting to explore the personal experiences of Post COVID patients with regard to their condition, to gather information about their perception of their illness in light of the triad, and to examine on what kind of societal matters they experience conflicts and/or developments.

Previously, the individual illness experience of Post COVID sufferers has already been researched with various aims. For example, Rushford et al. (2021) have focused their research on the illness narratives of Post COVID sufferers, and especially explored how the structure and content of their storytelling via social media channels have created pervasive accounts of a novel illness journey – which was often full of setbacks and dismission by health professionals – and concluded that these stories have been effective in the growth of the visibility of Post COVID, and therefore developed an increased sickness perception about their health condition. Furthermore, Ladds et al. (2020; 2021) used illness narratives of Post COVID sufferers to develop patient-generated quality principles for Post COVID services, with the aim of providing insights and advising healthcare professionals for the improvement of clinical Post COVID care based on the patient's perspective. This may reflect an attempt at the development of a disease perception of Post COVID and its consequences, namely the improvement of clinical care for the condition. However, there have yet to be studies specifically focused on investigating the Post COVID illness experience while also exploring the underlying interactions of the disease-illness-sickness triad, meaning to simultaneously take both the personal (illness), medical (disease) and societal (sickness) perspective into account to put their perceived points of tension in a larger, multidisciplinary perspective. This is especially valuable as the novelty of the condition and the lack of medical detectability of Post COVID might impact the kind of societal attribution of a sickness and/or disease notion (Ballering et al., 2021; Hofmann, 2017). The personal illness experience of Post COVID sufferers about perceived conflicts may provide insights about the impact the condition has on their lives, what their attempts have been at relieving (parts of) their suffering, what internal or external factors they consider to have positively or negatively influenced their illness experience, and how they perceive the future of their condition.

1.3 The personal perspective: illness narratives

One method to get acquainted with the way in which individuals perceive the world, including their personal experiences, wishes and desires for the future, is to listen to their life story. According to Ricoeur (1980), personal narratives help to create a sense of coherence, unity and purpose from life events. Language and stories play a central role in the process of self-construction. Narratives are susceptible to various impactful life events. According to the *shattered assumptions theory* by Janoff-Bulman (1992), experiencing traumatic events can change how one perceives themselves and the world. Crossley (2002) mentions that an example of an experience that might influence, change or even disrupt one's personal narrative is the emergence of a chronic or serious illness.

Being diagnosed and living with a chronic illness can resemble a major disruption of the continuity of life, where previously held beliefs about the self and the world are undermined or even shattered. An individual diagnosed with a chronic illness may experience "a shift in their perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging" (Bury, 1982, p. 171). In other words, individuals with a chronic illness might have to re-examine the plans, wishes and hopes that they have held for the future, which can be a painful and debilitating realization for the individual.

According to Kleinman (1988, p. 49), an *illness narrative* is “a story an illness sufferer tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering”. Patients’ stories about their illness experience – including diagnostic procedures and treatments, encounters with healthcare institutions, and the impact the illness has on their social and private life – are an important perspective into their meaning-making and coping endeavours (Lucius-Hoene, Holmberg & Meyer, 2018). Persons without a disability are automatically outsiders to the experience of disability and therefore cannot have the same level of insight about issues that impact individuals with disability (Smart, 2001). Thus, illness narratives may help to deepen the understanding of the illness experience, e.g. how the illness impacts their daily life (i.e. the illness experience), how the outside world perceives and treats their illness and its suffering (i.e. the perceived attribution of a sickness and/or a disease status), and what their wishes and desires are for the future that might represent developments, shifts or change of the position of the triad (Franits, 2005). To resume, the current research may provide insights in the illness experiences of Post COVID sufferers, what they perceive to be societal conflicts and/or tension points with regard to their illness experience, and what positions on the disease-illness-sickness triad are reflected by these personal experiences. The novel and puzzling nature of Post COVID makes it especially valuable to gather more insights into the health condition and to explore its (inter)personal and societal complications.

2. Methods

2.1. Description of the larger study

This study is based on a larger Dutch study introduced by Sools and Coppers (2021) called ‘Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst’ (‘How people with chronic health conditions story their past and future lives’). The research involved writing exercises for chronically ill individuals about (1) their illness experience of living with a chronic illness and (2) their desired future by means of the *Letters from the future* method (which will be explained in 2.4.1). Quantitative data collection was included by means of the Mental Health Continuum Short Form (MHC-SF), which is a self-report questionnaire that measures mental health in terms of social, emotional, and psychological well-being. Furthermore, items about general demographic data (gender, age, occupational situation, and living situation) were included as well. Ethical approval has been granted by the Ethics Committee of the Faculty of Behavioural Sciences at the University of Twente with the ethical request number 211138.

2.2 Participants

Data collection of the greater study by Sools & Coppers is ongoing, however, the current research utilizes the narratives published by the participants between February 9th, 2022 and February 16th 2022. Inclusion criteria of the larger study were that participants had to perceive themselves as living with one chronic illness or more. Moreover, to be eligible to partake in the study, participants had to be at least 18 years of age, able to comprehend and write in the Dutch language, have sufficient digital skills to fill in the survey, and have sufficient cognitive skills to be able to reflect upon the past and imagine the future. Persons with all different types of chronic illnesses could respond to the survey, thus only the 37 participants who self-reported to suffer from Post COVID were considered for the current research. Of these 37 narratives, one narrative was omitted due to incomplete information on the open questions. The final selection of 36 narratives consisted of 5 male participants (13.9%) and 31 female participants (86.1%) with an age range between 25 and 63 (M = 48.75; SD = 10,32).

2.3 Procedure

The procedure for the current study is identical to the larger study by Sools and Coppers (2021). The larger study made use of purposive sampling to recruit participants, of which the current study specifically selected the participants who self-reported to suffer from Post COVID. A flyer (Appendix A) was shared on personal and professional networks of the researchers, various social media channels, and Dutch patient organizations. This flyer included both a link and a QR code which referred to further information about the purpose, content, and goal of the study (Appendix B). Participants who wanted to join the study were asked to read the information letter and to consequently give consent or to withdraw to take part in the survey (Appendix C). In case consent was given, participants started with writing a story about their history with their chronic illness (Appendix D), and afterwards were encouraged to write their ‘Letter from the Future’ (Appendix E). Then, they proceeded to fill in the items on the MHC-SF and to answer the questions related to their demographic information. Completion of the entire survey took approximately 45 minutes per participant. In case participants requested help, experienced (technical) issues during the survey, or wanted more information about the research, they were able to contact the researchers via email or telephone. Participants were granted the option to withdraw from the study without any consequences if they wished to do so. At the end of the survey, participants were asked whether they would like to take part in the second phase of the study, involving in-depth interviews about their responses on the survey. Participants were not compensated or reimbursed for their participation in the current research.

2.4 Materials

The online survey tool Qualtrics was used for primary data collection. The Qualtrics output was then further analysed by means of the qualitative research tool Atlas.ti, version 22.0.1, which was used as an organizational tool for the coding process of the narratives. The current study only makes use of the outcomes of the qualitative data measure of the survey, namely the illness narratives and letters from the future submitted by the participants suffering from Post COVID.

2.4.1 Illness narratives & Letters from the Future

With the illness narrative (Appendix D), participants are instructed to write about their experiences of living with a chronic illness. They are encouraged to write about their experiences and how they feel about it in as much detail as possible. For example, they were granted the freedom to write about how the illness has impacted or changed their personal lives, health, living situation, occupation, social relations, or the view they hold of themselves. The story had to be based on their own personal experience.

Letters from the Future part (Appendix E) is a creative writing prompt that stems from a health promotion program for older people with depressive symptoms (Bohlmeijer, 2007) and has been adapted for research purposes (Sools, 2020). In this writing prompt, the task is to write a letter as if one was able to time-travel to the future where they are able send a letter back to the present day. The writer of the story has the freedom to choose the how, where, and when of their desired future and to whom they want to send it to. Participants are encouraged to be as specific as possible and to write about e.g., their desired living situation, occupation, social relations, personality, perception of themselves, and how this desired future makes them feel. They end their Letter from the Future with a message to the recipient.

2.5 Data analysis

As the responses on the survey were written in Dutch by the participants, they were translated to English to match the language of the current research. ‘DeepL’, an online translation tool, was used to translate the narratives into English. The responses were anonymised by omitting sensitive information that could be traced back to the participant, e.g. names and locations. Only gender, age, and participant number have been included to be able to differentiate the responses.

Thematic analysis was the main data analysis method to be able to explore the content of the narratives. It is an appropriate method of analysis for qualitative data for the aim of seeking to understand experiences, thoughts, or behaviours and to construct certain themes from a dataset (Kiger & Varpio, 2020). The illness narratives and the Letters from the Future from the participants were considered as a whole and were read as one, with the illness narratives reflecting the past and the present and the Letter from the Future representing a hypothetical (ideal or desired) future. The narratives were then analysed using disease, illness, and sickness (Hofmann, 2017) as sensitising concepts.

Specifically, the data was analysed in three phases (Soratto, de Pires, & Friese, 2019): (1) pre-analysis, (2) material exploration, and (3) interpretation. The *pre-analysis phase* consisted of individually structuring, anonymising, and translating the narratives, and importing them into the Atlas.ti software. The documents were then read globally to become familiar with the content of the data. Next, the *material exploration phase* consisted of thoroughly reading every narrative document. The material exploration phase was an iterative process which involved re-reading the documents and coding relevant paragraphs, sentences or phrases considered to be related to specific conflicts or interactions between the personal, biomedical, and social perspective of the Post COVID illness experience. The end product of the material exploration then gave way to a large set of codes with various specific, unidimensional topics. The aim of the *interpretation phase* was then to infer connections between these unidimensional topics to be able to create comprehensive themes, each representing an overarching conflict or point of tension between the illness experience and the biomedical or social dimension. These themes were then able to facilitate interpretation of specific interactions and positions based on the literature of the disease-illness-sickness triad.

3. Results

Results of the data analysis showed the following. In total, ten different themes were discovered among the illness narratives and Letters from the Future of the participants. Each theme is representative of an overarching interaction within the triad; two interactions being of dyadic nature (illness and sickness; illness and disease) and one interaction being a combination of an interplay between the three perspectives (illness, disease, and sickness). An overview of the interactions within the triad and its corresponding themes can be found in Table 1.

Table 1. *Interactions within the triad and the themes related to the interaction.*

Interactions within the triad	Themes related to the interaction
Illness and disease	Uncertainty and anxiety with regard to healthcare resources and treatment
	Discrepancies between the personal illness experience and the perception of healthcare professionals
	Denial of the illness experience by the participant
	Becoming activist in the development of Post COVID as a disease
Illness and sickness	The social dimension of the illness experience
	The effects of societal conflicts related to the COVID-19 pandemic on the illness experience
	Uncertainty about employment and reintegration abilities
	Taking steps to bridge the gap between illness and sickness
Illness, disease, and sickness	Perceived justification of the illness experience
	Issues regarding governmental health-related policy-making and legislation

3.1 Illness and disease

In the narratives, several themes were discovered that could be related to a reciprocal influence between the personal illness experience of the participants and the lack of medical evidence for the treatment and trajectory for Post COVID. These themes are ‘uncertainty and anxiety with regard to healthcare resources and treatment’, ‘discrepancies between the personal illness experience and the perception of healthcare professionals’, ‘denial of the illness experience by the participant’, and lastly ‘becoming activist in the development of Post COVID as a disease’.

3.1.1 Uncertainty and anxiety with regard to healthcare resources and treatment

Several participants mentioned issues with a lack of healthcare resources, for example options for treatment or a lack of consensus about the best fitting treatment for Post COVID symptoms, that were directly related to the novelty of, and the resulting lack of biomedical knowledge about, Post COVID. For example, Participant 15 (male, age 66), who presumably contracted COVID-19 in March 2020, when the virus was a novel occurrence in the Netherlands and was increasingly infecting the Dutch population. In the case of Participant 15, he was not aware yet that his symptoms were caused by COVID-19, but he wanted to consult his GP about these symptoms. Social distancing was one of the first measures aiming at controlling the infection spread, which worked against Participant 15 with regard to his search for medical help: “*I could not see any doctor at that time, it was a new disease and even doctors were afraid of infection*”. Only after multiple weeks of suffering from prolonged illness symptoms, he was able to see his GP, who referred him to a lung specialist:

> *“Finally, in May, I was able to see a lung specialist. He diagnosed pneumonia. He also had my blood tested, which showed that it contained antibodies. Thus, I had contracted Corona. Actually, from the first infection until now I have never been the same again. I have had many ups and especially many downs. Treatment was slow in coming, and I had to find out for myself what was best for a Corona patient. There was no form of treatment yet.”*

Only after two months, he finally received closure about his prolonged symptoms being caused by a former COVID-19 infection, together with a pneumonia diagnosis from the lung specialist. Then he mentions how he has struggled with prolonged symptoms since the start of the infection, that he had “*many ups and especially many downs*”, and that “*I had to find out for* *myself what was best for a Corona patient*". This part of his narrative also reflects how his inner battle with the illness experience, accompanied with the mourning of his former self ("*I have never been the same again*"), was negatively influenced by the fact that there are no treatment options available yet, and that he was not able to find relief for his symptoms as a result.

The sentiment of Participant 15 was similar to what Participant 4 (female, age 55) had experienced. In her illness narrative, she wrote about her ups and downs throughout her Post COVID experience, and her unsuccessful attempts at finding the right treatment for her symptoms. She wrote the following in her illness narrative: "*Searching for the right care provider, and that everyone received help in different ways, gave me the impression that the medical world had to invent the wheel in treatment as well*." The fact that other Post COVID sufferers were treated differently for their symptoms did not only relate to her own experiences in her search for treatment, she also reflects on idea that treatment providers are in a similar situation as well; attempting at finding what works best for their patients in terms of symptom alleviation. The fact that she writes "*invent the wheel*" can be interpreted as a reflection of the lack of knowledge and scientific evidence for treatment contributing to the disease perception of Post COVID.

3.1.2 Discrepancies between the personal illness experience and the perception of healthcare professionals

Some participants mentioned how their illness symptoms or their illness experiences were often dismissed, trivialized, or overlooked by healthcare professionals. This was due to various reasons: a lack of knowledge, insights, or treatment options for the illness, especially during the beginning of the pandemic; a lack of serious consideration from medical professionals; referrals to medical specialists without positive results; or a combination of two or all three. The latter option is described in the illness narrative participant 13 (male, age 35), who contracted COVID-19 in January 2021 and contacted his GP 6 weeks after infection due to persisting illness symptoms:

> *"I went to see my GP: "Well, covid can cause residual symptoms for a long time, as we now know." Acting on findings was the motto, nothing further. Symptoms in the first 6 months were mainly: Brain fog, fatigue, burning lungs and a peanut taste in my mouth. I called the family doctor several times, but the same advice: "Can you just walk up the stairs? No physio needed then. Just take it easy"."*

The situation described by Participant 13 took place in the first half of 2021, meaning that the responses of the GP partially fit within the perception, understanding and evidence of Post COVID and the way it was treated at the time. However, even after contacting his GP multiple times, the health concerns of Participant 13 were met with superficial health advice from his GP ("*just take it easy*") and, as a result, he felt left without adequate consideration for his Post COVID related symptoms. In his narrative, he further expresses his dissatisfaction with receiving unhelpful medical advice including his frustration with the illness itself and his wish for treatment:

> "*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... sigh.*".

This part of his narrative shows how his referrals to various specialists left him in the run-around for a fitting treatment. His last sentence, which he concludes with a token of disappointment ("*sigh*"), supports this sentiment and suggests that the experience was tedious and lengthy for him.

3.1.3 Denial of the illness experience within the patient

The aforementioned themes were based on a limited disease knowledge about Post COVID that was projected by healthcare professionals onto the participants. However, denial within the individual can be considered to be connected to both illness and disease as well, due to the following. Denial was often a response in participants who experienced a discrepancy between their physical functioning before and after the COVID-19 infection. The perceived discrepancy between former and current physical health and functioning often negatively impacted the perception of themselves and their capabilities, which increased feelings of frustration, confusion, and mourning of their previous self. Feelings of denial were often amplified due to the fact that the prognosis of Post COVID is still uncertain, and that treatment aiming at full recovery of Post COVID is currently non-existent, resulting from the lack of clinical evidence for Post COVID as a disease and about its treatment. To illustrate, Participant 3 (female, age 51) provides an example of this denial experience. She contracted COVID-19 in March 2021 and noticed that her symptoms were not decreasing after several months. She writes about this in her illness narrative:

> *“Slowly it dawns on me, I have Long-Covid. A still relatively unknown syndrome of which nobody actually knows exactly how it is 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? In March I was a sporty, slim, healthy eating and fit fifty-something. And now? I already have to plan it when I want to wash my hair, ridiculous. I nod yes and politely say what I should do, but all fibers in my body and head resist this. This won't happen to me, I'm going to fight, and I'm going faster than anyone thinks! Unfortunately this is exactly the wrong thing and I fall from kickback to kickback. Why doesn't my body and especially my mind want to cooperate?”*

Here, she described a conflict between her and her therapists, who were unable to help her recover from her symptoms due to their inability to treat her Post COVID symptoms. She was left perplexed by their remark to “*just deal with it*”, revealing feelings of frustration and denial of her current illness situation as it is in stark contrast with her identity and her capabilities before the infection: “*This won’t happen to me, I’m going to fight, and I’m going faster than anyone thinks!*”. Attempts at recovering unfortunately were not successful for her, leading to the realisation that her will and her bodily capabilities were no longer aligned. In her Letter from the Future, in which she took the perspective of her four-year older self from the future and addressed the letter to her current self, she wrote the following:

> *"Long-Covid is a struggle in your life right now. However, know that it has brought you to very good decisions in your life. Long-Covid will continue to play a role in your life, but that is precisely why you are more and more aware of making choices that are good for you. You needed this hard lesson. We now know everything about the origin and treatment of Long-covid. As a result, I can now lead a carefree life, I know what I can and cannot do better and I am flexible in my daily schedule. I feel very calm under this fact, it has become a part of my life."*

In this letter, she expresses a wish for a shift from her current negative illness experience to the acceptance of the situation, while also hoping that an increased disease status for Post COVID might provide relief as well: "*We now know everything about the origin and treatment of Long-covid. As a result, I can now lead a carefree life*". Notably, in this letter, she does not express a desire for full recovery of Post COVID. On the contrary, her sentiment emphasises a wish for coming to terms with Post COVID being a part of her daily life, now and in the future, possibly indicating that she perceives this as a realistic version of the future. This might reflect the current lack of disease knowledge about Post COVID including its uncertain prognosis.

3.1.4 Becoming activist in the development of Post COVID as a disease

One narrative, which was written by Participant 32 (female, age 45), mentioned how her personal experiences with Post COVID evoked an interest in following the latest information about Post COVID and sparked the urge to partake in scientific research about Post COVID. In her illness narrative, writes the following: "*I keep looking at new developments and therapies that are being developed as more knowledge comes in about long covid*", implying an active interest in the developments concerning the Post COVID, and therefore an interest in the development in the disease status of Post COVID. Additionally, Participant 32 also shared her interest to partake in Post COVID studies to be able to mean something concerning the future of the illness: *"I also participate in every study they ask me for, if not for myself then maybe for someone in the future, because I don't want this for anyone."*. In light of both her interest and her activism, she then writes that "*hopefully in time I can then say that I am (somewhat) better*", further supporting her desire for development in research by providing a personal wish to recover from the illness; specifically, her illness experience. Though she does not specify the types of studies she partakes in, the fact that she keeps up-to-date with developments and partakes in studies regarding the illness expresses a certain wish for improvement about the medical knowledge about Post COVID and, therefore, its disease status. Moreover, her activism seems to also be rooted in targeting the collective interest of Post COVID sufferers, "*if not for myself then maybe for someone in the future*", not solely from personal interest, further supporting the impact Post COVID has had on her and how she wants to make a difference in the alleviation of the illness experiences for future Post COVID sufferers – probably highlighting the discrepancy between the illness experience and the perception of Post COVID as a disease.

3.2 Illness and sickness

The interplay between illness and sickness among the participants became evident in topics rooted in interpersonal and societal aspects, considered to be caused by a perceived discrepancy between the illness experience of the participant and the sickness understanding of Post COVID by persons close to them or by society at large. Furthermore, participants often also mentioned issues related to the uncertainty about their employment and reintegration abilities, often resulting from a discrepancy between the sickness perception of Post COVID and the illness experience of the participant. Lastly, some participants took an active stance in bridging the gap between the illness experience and the sickness perception of Post COVID.

3.2.1 The social dimension of the illness experience

The current theme is mainly representative of the personal illness experience of the participants in relation to their social environment; however, it may have subtle connections with sickness due to the following. Social isolation was a recurring topic among the narratives which consisted of mentions of a decrease in social contacts and/or feelings of loneliness.

Participants who mentioned this topic often felt unable to maintain or be involved with their social lives due to their impaired health and, as a result, they noticed a decrease in their social network. On the other hand, at times participants were under the impression that social isolation was caused by a lack of understanding about the participants' illness situation by their social network, or due to the illness experience deviating from what is deemed 'normal' by them. Thus, social isolation be considered to be a result from a discrepancy between the personal illness experience and sickness attribution from the social environment of the participant. Experiences of social isolation were related to feelings of loneliness, sadness, and frustration in the participants, especially when their social networks were highly valued or important for them. To illustrate, Participant 7 (female, age 54), who fell ill from COVID-19 in March 2021 and suffers from prolonged symptoms ever since, wrote in her illness narrative about her impaired ability to socialize due to her illness symptoms: *"I haven't seen anyone since December. I text with my friends. Fortunately, they now support me, although they did not understand it at the beginning."*, in which she implies that not only her symptoms prohibited her from seeing her friends, but also the opinions and lack of understanding of her friends about her illness was a cause for her social isolation experience. However, she also mentions that her friends "*now support me*", implying that there was a temporal element involved in the shift of perception about the illness – possibly due to newly acquired understanding about the illness experience over time, creating a common ground for the illness experience of the participant and sickness perception of her surroundings.

Furthermore, Participant 12 (female, age 54), who fell ill from COVID-19 in January 2021 and still suffers from prolonged symptoms, expressed how her limited physical capabilities led to a withdrawal from social activities: *"Socially, I don't see many people. Can't go out. Need a lot of rest. Can often only do something for 30 minutes. If I really have to think, it takes a lot of energy. Listening and doing are hardly possible"*. In her Letter from the Future, which she addresses to the reader, she writes "*Don't forget to visit people, ask how things are going that day. Because I can live with the limitations pretty well. But the fact that people don't visit you any more or ask how you're doing... I find social loneliness the most difficult."* Participant 12 might have experienced a reciprocal process of social withdrawal due to her illness which was followed by a decrease of her social network, "*people don't visit you anymore or ask how you're doing*" resulting in loneliness. Her Letter from the Future implies that she wants to create awareness about how loneliness greatly impacts a chronically ill person, especially when their illness symptoms hinder them from partaking in social activities, thus encourages the reader to be mindful of others and to keep in contact with them. This possibly reflects that she perceived her loneliness to both have an internal and external cause, namely her own physical incapability and lack of attentiveness from her surroundings.

On the other hand, Participant 25 (female, age 48), who fell ill from COVID-19 in November 2020 and suffers from Post COVID, highlights a different dynamic that caused her loneliness. Her loneliness experience seems to be mostly caused by internalizing what in other instances might be blamed on others but is now done by herself, namely the minimisation or denial of complaints: "*To the outside world I trivialized everything. I didn't want to bother people, everyone suffered from the suffering called Covid."* Here, she implies that the pandemic has had a great impact on society and was therefore reluctant to be open about her own illness experience to her surroundings. This possibly further implies that Participant 25 assumes that the general mentality or opinions surrounding the malady about the pandemic has influenced the sickness perception of Post COVID, which may have influenced this reluctance to speak honestly about her own illness experience to others. "*To friends and family who visited me, I held my ground. I smiled kindly, "feeling better all the time". I never told them I hated it when they left again. "Please take me with you" I wanted to shout after them"*. Here, she explains how she minimises her illness experience herself to not bother her surroundings with it. As a result, she feels lonely in both her illness experience as well as in her social life. She then tragically mentions the effect this had on her: *"Behind closed doors I allowed my emotions to flow; never before had I felt so intensely alone"*. The case of Participant 25 shows how the limited reciprocity between herself and her environment, due to her own assumption of the sickness perception by others and the forthcoming reluctance of her own illness experience, resulted in an internal vicious cycle which led to intense feelings of loneliness.

3.2.2 The effects of societal conflicts related to the COVID-19 pandemic on the illness experience

Some participants mentioned how they felt disappointed, at times discouraged, with the way in which society at large has handled the pandemic, and that this had greatly impacted their own illness experience. Post COVID is a unique phenomenon in this regard, as it is related to a virus that caused a global pandemic that governments worldwide endeavoured to battle by means of measures that impacted societal freedoms, e.g. social distancing, travel bans, and vaccination certificates, which were often a topic of conflict. For example, a few participants mentioned frustration with the nonchalant attitude that some groups held against COVID-19 measures, scepticism from certain groups in society or complot-theorists, as well as the division that had emerged between the believers and non-believers of COVID-19. Especially Participant 26 (female, age 61) seems to be representative of this specific topic as she takes a stance against it in her Letter from the Future. She explains that the most difficult part of coming to terms with her new life with Post COVID was caused by the way society at large had handled the illness and the pandemic in general. She wrote:

> "*Covid-19 caused a polarization in society. People who followed the measures neatly, who recognized Covid-19 and people who made up conspiracy theories and didn't believe in them, did not adhere to the measures etc. It became an endless and despondent discussion between those two parties. Because everyone was fed up. Commenting, criticizing and grumbling from the sidelines is what happened instead of putting our shoulders to the wheel together and biting the bullet."*

Without placing herself in one or either side of the discussion, she makes a genuine, wholehearted statement about how the polarizing behaviour of society had disappointed her, and how she had wanted to see this differently, namely "*putting our shoulders to the wheel together and biting the bullet*". Further in her letter, she elaborates on this perspective by turning her frustration around and expressing a wish for a better approach in the future in a hopeful, collaborative tone:

> *"I hope that now, looking back on that pandemic, we have learned from it. And that if, God forbid, there is ever another pandemic or crisis, we will do things differently. Together. Not condemning, not spreading negativity or sensationalism, not stirring things up, but together putting our shoulders to the wheel. Support each other and be there for each other."*

The narrative of Participant 26 is an example of how societal opinions and behaviours may impact the illness experience to a great extent. As aforementioned, she mentioned that her struggle with the illness itself and the mourning of her old life was difficult for her, but this experience was aggravated due to this polarization in society. This is made especially clear due to her hope that "*we have learned from it*" and that society will "*do things differently*" if there is ever another similar crisis. The fact that she wrote about this issue extensively in her Letter from the Future is a notable point of attention as it suggests the magnitude of the impact it had on her, as well as that it might reflect her values and what she considered lacking.

Furthermore, similarly to Participant 26, Participant 4 (female, age 55), mentioned how coming to terms with her new life after Post COVID involved a slow and tedious process of which she felt was impacted by interpersonal conflicts, opinions, and behaviours. She further elaborates on this in her Letter from the Future:

> "*Dear fellow people, I wish for you a future in which you can be yourself and where you feel heard. The reason I wish you this is because people who feel heard don't have to feel anger and don't have to hunt for "the guilty". And this gives peace. And if I wish you to be yourself, may I too? If I cancel a visit after an hour, it's not because I don't want to see you, but because an hour's visit to me is what I can give you. If we accept each other as each is, then we also accept everyone's limits and wishes in a respectful way. We receive respect and get it. Then, a patient does not feel abandoned. Then, a person who is already struggling with himself,*

> *still feels seen and heard, and feels no less than the other. This is what I would like to see in my future for each of us."*

This letter implies that she believes that mutual respect and attentiveness toward each other might have facilitated her own journey towards acceptance of her current situation, both on an interpersonal, societal level ("*People who feel heard don't have to feel anger and don't have to hunt for "the guilty*"; "*If we accept each other as each is, then we also accept everyone's limits and wishes in a respectful way*"), as well as on the individual level ("*If I wish you to be yourself, may I too?*"; "*Then, a person who is already struggling with himself, still feels seen and heard*"). Participant 26 makes the point that mutual respect might yield better understanding of the illness experience, both by the illness sufferer and their surroundings, and then influence the sickness perception of society at large as a result as well.

3.2.3 Uncertainty about employment and reintegration abilities

In the narratives, a large number of participants mentioned that they experienced issues with regard to their employment or their impaired ability to work, with some of them enduring accompanying financial trouble due to being physically unable to fulfil their working hours. For example, Participant 9 (female, age 53), who wrote in her illness narrative about her own insecurities about the ability to rehabilitate, which is in contrast with the expectancy of her employer: "*After a rehabilitation of almost a year I found out that I still have a job ... and that my work wants something, read expects, that I come again and go back to work .... How, I think?*". This part of her narrative implies that her own illness experience does not correspond with the perceived sickness role the employer thinks she is entitled to – which, presumably, is different from her own illness experience, indicative by the phrase "*how, I think?*" – which may lead to a disagreement in labour expectations. Further in her narrative, she writes "*The work gives me pleasure but especially complete chaos in my head, which I cannot filter*", further highlighting the conflicting situation between pleasure related to her job and capabilities related to her illness experience.

Reintegration problems were oftentimes accompanied by feelings of regret about being unable to resume their job, especially if they previously had an occupation they greatly enjoyed and were passionate about. Some of them also expressed how their inability to work due to their illness felt like a force majeure; they felt there was no other option besides reintegration to overcome their impaired ability to work, however, this often worked to their disadvantage when reintegration attempts exceeded their physical capabilities. This can be viewed as a denial of both the illness symptoms as well as rejection of the sickness role, where great efforts to reintegrate might work to their own disadvantage. Participant 15 (male, age 62) mentioned the following about this in his illness narrative:

> *"Since March 2020, I have not been able to work. I am a teacher and special education. I did try a few times, but each time I relapsed considerably, which made my health deteriorate even more. At the moment, I have had to apply for the WIA at the UWV. [...] I would like to work and teaching is my passion. I hope that the UWV will give me the opportunity to slowly reintegrate."*

The illness narrative from Participant 15 is an example of how, even after multiple reintegration attempts, a Post COVID sufferer may fail to resume working his job as usual. For Participant 15, this was an especially regretful experience as he mentions how "*I would like to work and teaching is my passion*", implying a great motivation and longing for a return to his job but regretfully not being able to do so. In accordance with many other fellow sufferers, he mentions how he had to apply for government benefits, but he also included an aspect of insecurity about his future: "*I hope that the UWV will give me the opportunity to slowly reintegrate*", implying that the return to his former occupation is still uncertain for him, but that he hopes it will be a future possibility.

3.2.4 Taking steps to bridge the gap between illness and sickness

A few narratives expressed that they had shared, or have a desired future ambition to share their personal Post COVID illness experience with fellow sufferers or society at large. Their motives were related to a desire to provide society with a personal look inside the challenges related to their Post COVID experience to create awareness or challenge the sickness perception, or to mean something for others or inspire them. These actions shared a common motive, namely to make an impact on persons or society at large – therefore, to influence the societally imposed sickness perception. For example, Participant 20 (male, age 48) is quite activist about his own illness experience with Post COVID and has shared his story on social media, TV, and radio. A snippet from his Letter from the Future reads:

> *"I would like to refer you to my facebook page. [link]. And click on the item from [regional public broadcaster]. In it I tell on TV, internet and radio about my experience of now 2 years of living with long-covid and the challenges that I may experience every day. And also in this a positive explanation ... how I think about the future as in our family and me."*

Not only does he mention how Post COVID has impacted his life for over two years, he also incorporates a positive perspective about himself, his family and the future. The latter implies that he wishes to share positivity with the world as well, as opposed to only providing insights and awareness on the issues he has endured throughout the past two years. He shared his story on various media outlets such as television, internet, and radio, showing how passionate he is about making an impact and inspiring others.

Furthermore, Participant 6 (female, age 40) mentioned the following in her illness narrative about the value and importance of connecting with fellow sufferers: *"I am now in contact with fellow sufferers and have underestimated how valuable that is: I don't have to explain anything there, I feel appreciated and not judged"*. From this part of her narrative, it becomes clear that she greatly values the connections she has made with fellow sufferers, with an undertone of pleasant surprise and solace. Most notably, she mentions how she feels "*appreciated and not judged*", indicating that her involvement with fellow sufferers has worked the opposite way for her in terms of a perceived judgemental attitude from outsiders – namely, a lack thereof. In her Letter from the Future, Participant 6 further elaborates on her decision to become involved with fellow sufferers, including a social commentary perspective: *"In this* *society in which everything is so fast and demanding, we pay too little attention to how it actually feels. Whether our body still likes it, or whether we can still get it organized in our head*". Here, Participant 6 provides a context in which is described what may be at stake in case someone refuses to accept the fatigue caused by the illness, all while trying to keep up with the fast-paced tempo of the environment – an attempt at creating awareness about the importance of listening to the body. She further elaborates: "*Now I help other people with this process and it is so valuable. As far as I'm concerned, life is all about connecting with people. And you only make that connection, when you listen, feel, experience".* Important to consider in the case of Participant 6 is how she describes her activist experience from the inside out – firstly, she elaborates on her positive personal experience due to connecting with fellow sufferers, and afterwards describes the value and importance of sharing this connection with others to the reader of her letter. The sentiment of Participant 6 is important to consider as part of the interplay between illness and sickness – sharing each other's illness experiences as a means of alleviating the societal pressure and effects on the illness experience, while simultaneously putting an emphasis on the importance of social contribution.

In her Letter from the Future, Participant 29 (female, age 25) writes about her wishes and ideals for her future. In this letter, she describes that she wants to write a book about her personal experiences with Post COVID. This desire indicates an activist motive with regard to her illness experience and to share her story with the world. Furthermore, she writes about her desire to write a "*self-help book*", possibly implying another motive, namely to not only share her own story but also to help or support others who are facing similar illness-related issues. This wish to make a difference for others is also further implied in her wish to finding "*a job where you can mean something to other people*". Notably, in the last sentence of her Letter from the Future, she states "*indeed, there are a lot of people who seem to have forgotten about the pandemic again*", which implies that she has felt a decline in the collective attention towards the pandemic and, due to this, feels a need to re-educate society by creating awareness about the effects that Post COVID may have on a human being – the reattribution of awareness for the illness by influencing the sickness perception of society at large.

3.3 Illness, disease, and sickness

A combination between the three concepts of the triad was found among the following themes: 'perceived justification of the illness experience' and 'issues regarding governmental health-related policy-making and legislation'. Some narratives expressed a general dissatisfaction with the way the COVID-19 pandemic has been regulated, including how Post COVID has been treated, by the government, medical professionals, and society at large. Topics that were highlighted in these narratives were accompanied by frustration, sadness or anger about a lack of consideration for the interests and/or perspective of Post COVID sufferers or persons with fragile health, both on government-level (e.g. policy-making or protection of public health) as well as by public opinion (e.g. the general perception of the severity of the illness, sensationalism, or even complot theorists). To illustrate, Participant 11 (female, age 38), who is representative of both topics, wrote the following in her illness narrative:

> *"I am especially angry about a lack of recognition that I have sometimes experienced due to the lack of a positive PCR test. About people who think it's only in your head, who are also people close to me. About health and safety service whose attitude actually helped my health deteriorate. About the lack of recognition by the Ministry of Health, Welfare and Sport. About the government's neglect of the duty to protect public health. About the fact that too little account is taken of single-person households."*

The above section of her illness narrative provides examples of the various issues that Post COVID sufferers might face in light of the fair treatment of their illness. In the case of Participant 11, her experiences seem to have been partially influenced by a lack of 'proof' for the disease (the positive PCR test), leading to a lack of consideration of her symptoms possibly being related to Post COVID. She also addresses her anger towards "*people who think it's only* *in your head*", indicating that her illness experience was often met with scepticism or marginalisation from outsiders. She also expresses her frustration with the lack of responsibility, action, and fair treatment by the government to Post COVID sufferers. She also mentions how these events "*actually helped my health deteriorate*", which implies the magnitude of effect it may have on a Post COVID sufferers' already impaired health.

3.3.1 Perceived justification of the illness experience

A perceived justification of the illness experience from the perspective of the illness sufferer can also be considered to lie between all three concepts of the triad, due to the following. Participants often mentioned that their social environment – consisting of friends, family, colleagues, healthcare professionals or even society at large – often disregarded their suffering and/or impaired health. During the beginning of the pandemic, this lack of understanding for prolonged symptoms after a COVID-19 infection was often due to its novelty and limited scientific evidence about it; the lack of a disease status. However, even after the concept of Post COVID attained more attention and moved more into general circulation, and the group suffering from Post COVID related symptoms increased, many participants expressed that they had to explain or even justify their impaired health to their surroundings. A perceived need for justification was especially prevalent when they suffered from invisible illness symptoms (e.g. fatigue or impaired cognitive abilities). The environment's lack of understanding was often related to marginalisation of the symptoms or a negative perception of the participant themselves, e.g. perceiving the participant as a 'pretender'. Participants who mentioned that they felt misunderstood or unacknowledged by their environment often felt the urge to stand up for themselves and to justify their illness, which was often accompanied by frustration, sadness, and fatigue. To illustrate, Participant 14 (female, age 58), who fell ill from COVID-19 at the beginning of the pandemic and struggles with prolonged symptoms for nearly two years, mentioned the following in her illness narrative:

> *“Since 2020, I have been in a serious physical decline, which has led to a very unpleasant period of depression. It's very hard to accept that you won't be the same as you were before the infection. And also the total lack of understanding in the beginning of the infection. Always having to explain and being seen as a poser is also very unpleasant. When finally, after many tests, it turned out that a long covid infection had been diagnosed in those infected early in 2020, a whole new world opened up for me. Finally, clarity and recognition for so many people”*

Participant 14 especially expressed how, initially, her symptoms were not taken seriously and she suffered from allegations of pretending to be ill. Only after various medical tests provided an answer (proof for disease attribution), it appeared that she did not have to justify her symptoms anymore, which led to recognition and clarity for her surroundings (sickness attribution), but notably also for herself (acceptance of the illness experience). The fact that the proof of a COVID test was necessary for Participant 14 to finally be able to convince her surroundings of her illness, implies that her own illness experience did not suffice to gain the same. Moreover, she also mentions that “*finally after many tests”* it became clear what caused her illness symptoms, possibly indicating the extensive efforts needed to finally receive recognition and closure. However, the attribution of the disease status by means of a medical ‘proof’ for the symptoms evoked a process of acceptance for both Participant 14 and her surroundings, showing how a development related to one of the three concepts of the triad may yield positive effects for the other concepts as well.

However, for some participants, the attribution of the disease status was not enough. months and sometimes years later, when scientific developments and knowledge about Post COVID had already increased to a great extent, a lack of acknowledgement or understanding by the general public was still prevalent. For example, Participant 10 (female, age 43), who fell ill from COVID-19 in January 2021 and suffers from Post COVID for over a year, mentioned in her illness narrative that “*I don't always feel like explaining everything or even having to defend myself. I think the worst thing about it is that it’s invisible to others”*. Further in her narrative she mentions that she is “*fighting a lonely battle”*, implying how the lack of understanding and recognition by her environment for over a year has created an isolating illness experience for her where she does not feel supported. Furthermore, Participant 34 (female, age 42), who fell ill from COVID-19 in March 2021, mentioned in her illness narrative that "*During my illness process many nasty things have been said, I don't feel seen and heard. The communication is very difficult, I constantly have to guard my limits. I find this very difficult and I feel very guilty".* Participant 34 expresses an internal battle here with regard to how she acts toward her environment. The criticizing comments from her environment makes her feel victimized to the point that she feels the need to defend herself, but she also mentions that defending herself makes her feel *guilty* – implying that she does not want to accept her illness experience nor wants to have to guard her limits to other persons, but still feels the need to do this for her own wellbeing, even if this is very difficult for her.

3.3.2 Issues regarding governmental health-related policy-making and legislation

Issues regarding governmental policy-making and legislation was found to be topic with various points of tension. This theme is related to all aspects of the triad in varying degrees, which will be elaborated on. Due to the social nature of sickness, behaviours or decisions stemming from societal structures, such as the government, may impact the development and the attribution of the sickness perception of a condition, which may have positive or negative effects on both the illness experience as well as the development of Post COVID as a disease. For example, Participant 15 (male, age 62) mentioned in his illness narrative that he has "*little faith in the government authorities*". According to him, "*Corona has been and is being given insufficient attention*", expressing his disdain with the regulation of the pandemic by the Dutch government. He also mentions that, according to him, "*The ever-growing group of long COVID patients is not taken seriously*", which was a common theme among participants who expressed their disappointment in the government and their policy-making; namely the lack of serious consideration by the government for the interests of Post COVID sufferers.

Another perspective to the same issue was mentioned by Participant 1 (female, age 63). Her narrative is an example of the interplay between both illness, sickness, and disease in the interests of Post COVID. She addressed her Letter from the Future to Dutch citizens, in which she wrote: "*Dear fellow countrymen, it is now a year after there were hopes and eases in the whole corona thing in February 2022. Fortunately, that hope has not become despair. The government has finally realised that prevention (exercise, healthy eating, vaccination programme) and investment in healthcare (more ICU capacity, more well-trained and rewarded staff) is the key to solving any pandemic.*" In this segment, she does not actively express criticism about specific actions that the Dutch government has made with regard to the regulation of the COVID-19 pandemic. Instead, she puts a constructive emphasis on how the government can handle and prevent a future pandemic from her point of view. Moreover, the sentence "*the government has finally realised*" hints that she feels generally dissatisfied with the way the government is currently regulating the pandemic, and that she believes that the government needs to focus on different problem areas in this regard, e.g. prevention and investment in healthcare. Furthermore, she then writes about a wanting to see a positive development in light of Post COVID treatment: "*We have also succeeded in developing a programme to do something about the disruption to the autonomic nervous system and the disrupted stimulus processing caused by long covid.*", which implies a wish for scientific development in the treatment of Post COVID. This can be seen as a wish for an increase in the disease status for Post COVID which might lead to the decrease in the illness symptoms. As a result of this development, she hopes that "*I (and many others with me) can live as usual again*", implying that her experiences of living with Post COVID deviate from what she defines as 'living as usual', specifying the difference between her current illness experience and her former life.

Lastly, Participant 18 (female, age 61) addresses a different legislative issue. In her Letter from the Future, which she addresses to a successor of the Dutch minister, she describes a hypothetical, positive future where great leaps have been achieved regarding the management of the COVID-19 pandemic and the treatment of Post COVID. In this letter, she writes about the "Gatekeeper Improvement Act" (Wet Verbetering Poortwachter), a current Dutch law aiming to return employees who are on sick leave to work as soon as possible (Ministerie van Sociale Zaken en Werkgelegenheid, n.d.). For the first year of illness, employers are legally obliged to continue to pay at least minimum wage. However, this currently does not apply for the second year of illness. This means that some Post COVID patients who have suffered from their symptoms for over a year and are still unable to reintegrate will have to apply for government benefits, depending on wage. As the current prognosis of Post COVID patients is uncertain, and there is no effective treatment available which might grant Post COVID sufferers enough symptom relief to be able to successfully reintegrate, the current issue also contains a disease-related element. In her Letter from the Future, Participant 18 writes: "*The important change in the "Wet Poortwachter", which at the time was the prolongation of the sick leave period to 3 years, in Aug. '22, has become the salvation of most long covid patients*". This part from her letter implies her current dissatisfaction with the Gatekeeper Improvement Act and how it does not adequately take the uncertain prognosis of Post COVID sufferers into account, which can sometimes span a long time, for a better chance at reintegration at their workplace. For Participant 18, this is an especially important topic as she mentioned in her illness narrative that "*I am worried about my job, because reintegration is not going very well*", which supports her wish for a change in the reintegration law together with valid concerns regarding her own reintegration attempts. This perspective shows the difficulties Post COVID sufferers may have to face to be able to sufficiently manage their illness symptoms and its uncertain prognosis together with an uncertain trajectory to employment reintegration.

4. Discussion

The purpose of this study was to explore the narratives of individuals who self-reported to live with Post COVID on their perceived position of Post COVID using Hofmann's (2017) triad of illness, disease, and sickness.

4.1 Summary and interpretation of findings

The content of the narratives shows that Post COVID is a condition that, as described and experienced by the participants, includes various themes that can be placed on various positions on the triad disease, illness, and sickness. These positions can be perceived as certain 'points of tension' or discrepancies between two or all three components of the triad. Oftentimes, these discrepancies had a negative impact on the participant. Firstly, four themes were found to be related to an interaction between illness and disease. These were identified as 'uncertainty and anxiety with regard to healthcare resources and treatment', 'discrepancies between the personal illness experience and the perception of healthcare professionals', 'denial of the illness experience by the participant', and lastly 'becoming activist in the development of Post COVID as a disease'. These aforementioned themes may be considered to be the immediate result of the novelty of the condition and lack of evidence of Post COVID being a detectable, treatable disease. This created a perceived discrepancy between the biomedical world, including healthcare professionals, and the individual illness experience, which led to negatively experienced consequences for the participants accompanied by anxiety, fatigue, and stress about their current health and their perception of the future.

Furthermore, four themes were found to be related to an interaction between illness and sickness, namely 'the social dimension of the illness experience', 'the effects of societal conflicts related to the COVID-19 pandemic on the illness experience', 'uncertainty about employment and reintegration abilities', and 'taking steps to bridge the gap between illness and sickness'. These are themes with varying active mechanisms on either side of the illness-sickness interaction. The social dimension of the illness experience was predominantly based on a personally perceived discrepancy in opinion about the illness experience between the participant and their social environment, leading to loneliness or a decrease in their social networks. Furthermore, some participants mentioned how they experienced difficulties reintegrating, and that there were differences in expectations between the employer and the participant regarding reintegration, which caused feelings of regret and anxiety about their employment. Some participants mentioned that societal conflicts and polarization about the COVID-19 pandemic and its measures had impacted their illness experience negatively. A few participants mentioned how they aspired to create awareness about the illness experience to educate people about their experiences and to 'bridge the gap' between sickness and illness.

Lastly, there are two themes related to the interaction between all three concepts of the triad, namely 'perceived justification of the illness experience' and 'issues regarding governmental health-related policy-making and legislation'. These themes are characterized by both the disease and the sickness perception of Post COVID to be lacking in agreement with the illness experience, where the participant feels urged to justify their illness towards others or where they feel that their illness is not given enough attention by society, the healthcare world, or by the government. The interplay between all three components of the triad becomes apparent here where the (lack of) disease knowledge about Post COVID, including its hard to establish physical detectability and its often outwardly invisible symptoms, may result in the participant's perceived invisibility about their condition by medical, legislative or governmental structures, but may also evoke the urge to justify their illness experience to persons who do not understand them. Participants then mentioned how they wished their condition and their illness experience would be met with more understanding, attention, and consideration from the outside world. These findings provide a deeper perspective into the way governmental policy-making, and the behaviour of medical professionals and society at large towards Post COVID patients, may have a substantial negative impact on their quality of life.

The results on the interaction between illness and disease can be further interpreted by the concept of recovery as described by Friedman (2021). According to Friedman, recovery is most often associated with the biomedical, disease-focused perspective; namely, the reduction of the symptoms and the return to the 'former self' before the infection. For example, Post COVID patients might be considered 'cured' from COVID-19 from the biomedical perspective, due to the absence of the SARS-CoV-2-virus in their body, but not cured from the individual illness point of view (i.e. not 'healed') where the patient still experiences prolonged symptoms. Furthermore, as aforementioned, recovery from Post COVID is also an unknown and undeveloped concept due to the lack of medical evidence and detectability of Post COVID and the absence of clinical treatment for it. An individual who suffers from Post COVID symptoms might have a desire to return to the former self, namely to be 'healed', but the undeveloped disease component (i.e. lack of biomedical information and treatment) related to Post COVID inhibits this process. This is reflected in the narratives, namely in issues regarding the lack of treatment for Post COVID and disagreements between the illness experience and healthcare professionals. The concept of wanting to be 'healed' may be especially strong in individuals who are in denial of their illness experience, as they have a great desire to return to their former life and capabilities while simultaneously denying their current illness situation. One participant specified that she partakes in scientific research and looks up various information about Post COVID development, indicating a wish to be healed but also to be cured from a biomedical perspective, by contributing to the development of the disease status for Post COVID.

Furthermore, experiences related to the interaction between the illness experience and sickness perception were often a result from the lack of understanding about the Post COVID illness experience, especially in cases when the illness symptoms were not outwardly visible to others. Ballering et al. (2021) explain that the absence of outwardly visible symptoms in people affected by Post COVID facilitates stigmatisation. For some participants, this expressed itself in the perceived urge to justify their illness experiences to others. Furthermore, as aforementioned by Biordi (2006), stigma from outsiders toward the illness sufferer may lead to the experience of social isolation, which expressed itself in the participants as feelings of loneliness and a decrease in their social networks. Participants also mentioned that Post COVID and its illness symptoms had interfered with their employment, which corresponds with the currently known statistics that one in eight persons from the working population in the Netherlands, who are suffering from Post COVID, are officially declared unfit for work (Pruis & Olde Hanhof, 2022; Sivan, Parkin, Makover & Greenwood, 2021). They also mentioned that they suffered from unsuccessful reintegration attempts, leading to the unwanted cessation of their occupation and application for financial benefits. This also provides a perspective for the need for extension of the Gatekeeper Act (Ministerie van Sociale Zaken en Werkgelegenheid, n.d.) due to the fact that many Post COVID sufferers, besides persons suffering from other long-lasting and functionally impairing chronic diseases, are unable to adequately reintegrate within the rules of this law. A few participants mentioned ways in which they wanted to bridge the gap between the illness experience and the sickness perception of society, indicating the aim for ‘rehabilitation’ on the sickness component (Friedman, 2021). According to Friedman, rehabilitation is subject to social views, and it is formed through social institutions and healthcare policymakers. A lack of empathy and the imposition of stigma by society onto the sufferer of an illness might impair the rehabilitation process – for example, when persons feel the urge to justify themselves or feel that their condition is not given sufficient attention. Ways in which participants expressed their attempts at the creation of rehabilitation were by means of connecting with fellow sufferers or to share their story with society, aiming to inspire them or to create awareness for Post COVID

It was noticed that a few participants were activist about their illness experience. This can be considered a result of the perceived discrepancy between certain triad components and making efforts in reducing this discrepancy with the interests of the illness experience in mind. For example, by actively looking for information about Post COVID on the Internet (related to disease), or by connecting with fellow sufferers (related to sickness), sometimes via digital mediums. From this point of view, it has been a fortunate convenience that we currently live a fast-paced information era where technological advancements and the widespread availability of Internet has made it easier than before to communicate with each other and to be able to use it as a means to search information. This corresponds with the sentiment of Callard & Perego (2021) that Post COVID is one of the first chronic illnesses to have been made visible by its sufferers, and that their stories were used to guide the development of treatment, especially due to its novelty and the urgent need to learn in practice from each other. However, the fast-paced digital environment may also work to the disadvantage of persons suffering from Post COVID due to the fact that misinformation may spread rapidly through social media platforms, eliciting scepticism and conspiracy theories about COVID-19 and, therefore, the existence of Post COVID (Gemenis, 2021). In turn, this sensationalism is one of the issues described in some of the narratives that interfered with the sufferers' quality of life. The use of digital mediums could elicit a conflict between the need for connection and information-seeking about Post COVID while simultaneously putting themselves in a position to become confronted with false media, sensationalism, or conspiracy theorists.

Overall, the illness narratives and Letters from the Future written by the participants, including the varieties in time of mentioned issues related to the triad, can be understood as being a certain snapshot in the time and space of human experience. According to Frank (1998), the content of narratives may evolve over time, and various themes may vary in its dominance at different moments over time. In this study, it might be possible that the written narratives represent various stages into the illness trajectory. For example, some participants mentioned that they contracted COVID-19 during the first wave of the pandemic (i.e. spring of 2020, meaning that these persons suffer from prolonged symptoms for over two years), whereas other participants have experienced a shorter illness period due to later illness onset. the extent of the total timeframe of the illness trajectory may lead to an increased exposure with issues related to illness, sickness and disease, and that this in turn may increase the tension between the personal illness experience and societal and/or biomedical perspectives. This might have an influence on the importance or relevance of the issues and their current needs or wishes for change in the context of time. It could be argued that there are two ‘time-horizons’ that interfere here, namely the collective time-horizon of the pandemic and the developments on biomedical and societal level, and the personal time-horizon of the duration of the illness and how this relates to one’s life history.

4.2 Strengths, limitations, and recommendations for future research

The current research provides a personal view into the illness experience of Post COVID and gives insights into various (inter)personal, societal, biomedical, and legislative conflicts they have endured during the first two years of a novel and contemporary human health condition. By researching the narratives by means of thematic analysis, the current study aimed to explore the narratives in a flexible manner that was able to analyze a complex phenomenon in light of existing sociological literature – namely the perceived position of Post COVID in the disease, illness, and sickness triad as described by Hofmann (2017) – into comprehensible themes that are based on authentic personal experiences. The results may deepen the understanding of the Post COVID experience while also shedding light on the multifaceted complexity of human health, especially with regard to the currently still puzzling biomedical nature of Post COVID.

A limitation of the current research concerns the research sample. The sample of participants used for the current research consisted of only Dutch-speaking individuals. The analysis of narratives from a single cultural context may limit the scope of the current research due to the following reasons. Firstly, according to Groce & Zola (1993), cultures may differ in their beliefs, perception and treatment of chronic illnesses, which could also include Post COVID. As culture is an interpersonal, societal dimension, this implies that there may be culturally imposed differences in the sickness perception of Post COVID and, therefore, differences in the individual illness experiences of its sufferers. Furthermore, the content and construction of illness narratives themselves is heavily influenced by differences in cultural narratives and the social construction of the illness as well, meaning that the inclusion or exclusion of certain information in the content of the illness narrative itself may vary across cultures (Garro, 1994; Kleinman, 1988; Robinson, 1990). Culturally shared understandings about specific illness conditions might differ, which could influence what topics about illness are culturally repressed or deemed ‘taboo’, influencing the content of the illness narrative. This means that the results of the current research might not be particularly insightful to cultures or socio-economic structures that are fundamentally different from the Dutch context. Therefore, intercultural differences in the perception of Post COVID and its placement on the disease-illness-sickness triad would be an interesting topic for future research.

Moreover, the current research was not based on the original, Dutch-written narrative texts. Instead, to be able to correspond with the language of the current research, the narratives were translated into English, on which the analysis was further drawn from. According to Neubert & Shreve (1992), the potential for loss of meaning due to translation is immense, as the content of a text may be embedded in a complex linguistic, textual, and cultural context, making the process of translation a difficult attempt at transferring the genuine meaning in the most reliable way. Thus, the translation of the narratives from Dutch to English may have interfered with the original message or meaning of the narratives due to a possible language barrier, leading certain words or phrases to be ‘lost in translation’ or misinterpreted by the researcher.

Lastly, other limitations concern the following topics. Firstly, the majority of the current sample of participants were middle-aged persons aged 40 to 70, with only a few persons in the age range 25 to 40. This age distribution fits within the incidence of Post COVID, as middle-aged persons are more susceptible to prolonged symptoms after a COVID-19 infection (Sugiyama et al., 2020). Furthermore, the sample of participants utilised for the current research consisted of a large majority of women (86.1%) compared to men (13.9%), therefore, the results of the current research might be largely biased towards the female perspective. Future research could focus on various age groups and could investigate whether there is a ‘generation gap’, namely a difference in values and attitudes between one generation and another, especially as perceptions regarding health and illness may greatly vary between age groups (Walsh, 2011). This may provide insights into generational differences on the illness, sickness, and disease perceptions and experiences of Post COVID and generational differences in the desire for a shift on this triad. On a similar note, there might be differences between men and women regarding their illness experiences and its interaction with sickness and disease. According to Vlassoff (2007), differences in gender play a large role in various determinants and consequences of poor health, including chronic illnesses, especially related to social, economic, and physical aspects of health. For example, chronic illnesses seem to have a more inwardly stigmatizing impact in men as opposed to women (Charmaz, 1995), and women seem to be more marginalized by society due to health problems as opposed to men (Vlassoff, 2007). Investigation into gender differences may provide insights into differences in the illness experience as well as how their illness experience is treated or influenced by external factors related to sickness and disease.

Another interesting topic for future research might be to investigate why certain participants were more activist about decreasing the perceived discrepancy between various triad components regarding their Post COVID experience than other participants. Overall, mentions of activism of activist behaviour among the narratives were scarce, namely only a few of the 36 participants. As the illness experience is a subjective, personal perspective, this experience might vary between persons suffering from the same condition. Thus, various illness experiences might elicit different affects, thoughts, and conceptions about their own suffering, their opinions about the sickness and disease status of their condition, and thus influence their perceived need for change. According to Redd (2003) a person's need for empowerment and dissatisfaction with (conditions of) life can be perceived as psychological attributes and predispositions of activist behaviour. It could be hypothesized that the participants partaking in activism are more predisposed to these psychological attributes and therefore might be quicker to take a more activist stance with regard to their illness experience. However, this did not become evident by means of the current research.

5. Conclusion

This current study provides a valuable contribution to the fields of social science, health care practice and policy-making that are concerned with the illness experience of Post COVID sufferers. The use of a narrative method, by means of illness narratives and the Letters from the Future of Post COVID patients, helps to deepen the understanding of the illness experience and to gain insights into the various themes of Post COVID based on conflicts between concepts of the disease-illness-sickness triad. Results of the current study shows that the illness experiences of Post COVID sufferers can be placed on various positions on the triad disease, illness and sickness, with each interaction highlighting certain personal, societal, or healthcare related issues that Post COVID sufferers are concerned with. For example, the absence of treatment, denial of the illness experience, the occurrence of loneliness, issues with employment and reintegration attempts, and an overall dismay with the way in which the COVID-19 pandemic and Post COVID sufferers have been disregarded or mistreated by various layers of society, such as in healthcare, legislative or policy makers, and society at large. These themes seem to be primarily caused by the novelty and unfamiliarity of Post COVID as a human health condition on biomedical and societal structures, including its (perceived lack of) developments (e.g. of medical, economic, legislative or societal resources), having a negative effect on the personal Post COVID illness experience.

The insights into these experiences provides awareness about the Post COVID illness experience to governmental policymakers, healthcare practices, and public opinion in the way that collaborative interests for policymaking and illness treatment are considered, and the personal illness experiences of Post COVID sufferers are given attention. Moreover, the current research also highlights some ways in which Post COVID patients desire to alleviate their individual suffering and to create awareness for their illness.

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Appendices

Appendix A: 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 ervaringsverhalenwillen 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://utwentebs.eu.qualtrics.com/jfe/form/SV_eE6AAihR3CwUAIu

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,

Lisanne Joling, Luca Schlieper, Marco Richter, Katharina Walzik en Denise Fingal, master-studenten psychologie.

Appendix B: Information letter

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 pauzes 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://utwentebs.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 C: 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 D: Writing a story about the illness experience

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

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

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

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

Appendix E: Letters from the Future method

Brief over uw gewenste toekomst.

Stel u voor dat u in een **tijdmachine** stapt en reist naar een door u **gewenste toekomst**. U kunt uit de tijdmachine stappen op één moment in de toekomst of op meerdere momenten.

Gebruik uw **verbeeldingskracht**: bedenk dat het gaat om iets wat nog niet gebeurd is en dat het een kans is om te verzinnen wat er zou kunnen gaan gebeuren: stel u voor dat u de toekomst kunt ontwerpen!

Probeer met **zo veel mogelijk details** uw brief te schrijven, bijvoorbeeld over wat u belangrijk vindt op verschillende levensgebieden zoals wonen, werk, sociale relaties, of uw karakter of zelfbeeld.

Schrijf wat er spontaan in u opkomt over de gewenste toekomst, probeer niet te veel na te denken. We zijn geïnteresseerd in uw eigen, persoonlijke ervaring.

U sluit de brief af met een **boodschap vanuit de toekomst** aan uzelf of aan anderen in de huidige tijd.

U heeft nu een globaal idee van de opdracht om een brief vanuit de toekomst te schrijven.

Hierna volgen stapsgewijs enkele vragen die u helpen om straks de brief te schrijven. Voel u vrij om vanuit deze suggesties de brief op uw eigen wijze te schrijven.

Het schrijven van een brief vanuit de toekomst duurt ongeveer **15 minuten** (sommige mensen hebben meer tijd nodig en anderen minder). Neem alle tijd die u nodig heeft voor het schrijven van een brief van **minimaal 1/2 A4**.

Prompts:

(1) **Wanneer** speelt uw gewenste toekomst zich af? Hoe ver in de tijd reist u in de toekomst? Het tijdstip in de gewenste toekomst bepaalt u zelf. Dit kan 1 uur, dag, een week, of jaren later zijn. Misschien ziet u uzelf op een bepaalde leeftijd? Of in een bepaalde levensfase? Of waaraan merkt u dat uw gewenste toekomst zich op dat moment in de toekomst afspeelt?

(2) **Waar** bent u in de gewenste toekomst? Beschrijf hieronder bijvoorbeeld de **omgeving** of de **plek van uw dromen**, met zoveel mogelijk details die voor u belangrijk zijn. Of wat ziet of hoort u? Wat ruikt u? Of hoe voelt de toekomstige omgeving?

(3) Speelt de chronische aandoening een rol in uw leven in de gewenste toekomst? Op welke manier wel of niet? En welke rol? Op welke levensgebieden?

(4) **Aan wie schrijft u de brief?**
Bedenk aan wie u de brief wil schrijven: aan uw huidige ik of aan iemand anders (bijvoorbeeld uw kind of kleinkind, leeftijdgenoten, of de volgende generatie, etc.). En hoe spreekt u deze persoon aan? (lieve, beste, geachte, etc.).

U kunt nu de brief gaan schrijven. Het gaat dus om uw gewenste toekomst.

Stel u een gewenst toekomstig leven voor, waarin (met of ondanks uw chronische aandoening) een wens, verandering of droom is uitgekomen. Misschien heeft u iets bereikt wat u graag wilde. Of u leidt het leven zoals u dat wilt leven. Of u heeft een bepaald probleem opgelost. Of u heeft een goede manier gevonden om hiermee om te gaan.

Vertel uw verhaal over een concrete dag, of een specifiek moment, of een concrete gebeurtenis. Geef bijvoorbeeld details over **wie, wat, waar, of hoe** de gewenste toekomst eruit ziet of over **hoe u zich daarbij voelt**. Vertel bijvoorbeeld hoe u daar gekomen bent, of wat u heeft gedaan om dit te bereiken, of wat u achteraf het meest heeft geholpen, of hoe u op het leven van nu terugkijkt.

Met welke **bedoeling** schrijft u aan de ontvanger van deze brief? Of welke **boodschap** heeft u voor deze persoon?