Illness stories of hospitalised COVID-19 patients: a complex story of chaos, restitution and quest

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Abstract

Objective: This study aimed to explore the lived experiences of former hospitalised COVID-19 patients and how they narrate the experiences of their hospitalisation and post-hospitalisation (recovery) period, six and twelve months after hospital dismission. By attaining a better understanding of these experiences, future healthcare services that treat COVID-19 patients may be improved. **Method:** The sample (N=143) was extracted from the patient population of three Dutch hospitals. As part of a larger cohort study, two open-ended questions were added to inquire about patients' experiences. For the narrative analysis, Arthur Frank's story typologies (chaos, restitution and quest) were used to construct a coding scheme containing substory types (e.g. chaos hospitalisation, restitution achieved, quest gratitude). **Results:** The hospitalisation and recovery experiences of former COVID-19 patients contain all three of Frank's story types. The chaos (47%) and restitution story (47%) types are dominant, accounting for 94% of the identified codes. Chaos was more prevalent among the hospitalisation stories and restitution more among the recovery stories. The quest story type occurred in 6% of the data. The substory types of chaos and restitution seem related to events and experiences during the illness trajectory of COVID-19. Alternatively, the quest subtypes appear as a reflection of the illness experience as a whole. **Conclusion:** This study suggests that COVID-19 narratives of hospitalised patients are typically hybrids of the restitution and chaos story type, and this pattern is consistent in narratives related to the hospitalisation and recovery phase. The quest story is much less prevalent. The unique aspects found among the COVID experiences can serve as guidelines for healthcare workers tending to this group of patients. Our current healthcare can be improved and supplemented by applying autobiographical interventions as well as providing aftercare by bringing people together to share and *listen*.

Keywords: COVID-19, illness, hospitalisation, recovery, narrative analysis, Arthur Frank

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Introduction

The novel Coronavirus Disease 2019 (COVID-19, henceforth referred to as COVID) is an acute respiratory disease that affected almost the entire world. The severity of the disease can range enormously between individuals and the virus has the potential to cause a grim illness trajectory with varying sequelae in the short and long term. So far, extensive research has focused on the physical symptoms of the disease. However, the personal experience of the individual affected has gained far less attention. Uncovering these experiences improves our understanding of how they make sense of their illness. Ultimately, this can be used to improve healthcare services to better attend to their needs. To gain a better understanding, a structural narrative analysis will be conducted which focuses mainly on the structural characteristics of a narrative. For this, Arthur Frank's illness typologies will be used as a framework to carry out the analysis. This study will focus on the lived experiences of former hospitalised COVID patients and how they narrate the experience of their hospitalisation and post-hospitalisation period.

The COVID-19 pandemic

Originating in late 2019, COVID expanded into a pandemic at the onset of 2020. The virus is accountable for over 767 million infections and over 6.9 million deaths worldwide, of which 8.6 million COVID cases and 23.000 deaths in the Netherlands as of June 2023 (Dong, Du & Gardner, 2020). On the 5th of May 2023, the WHO declared that COVID was not an international concern of public health anymore (WHO, 2023). As the virus is contagious and transmissible through humid particles in the air, infected people need to isolate themselves or be isolated to prevent further contamination. The general guidelines regarding a COVID infection advise people with mild symptoms to stay home until the symptoms disappear. The virus causes a range of somatic symptoms which, for most people, are similar to the symptoms of the flu; fever, coughing, sore throat and tiredness. For a smaller proportion of infected cases, the symptoms manifest into respiratory problems, which deem hospitalised care necessary. The estimated hospitalisation rate of people infected with COVID ranges from 5% (Wiersinga et al., 2020) to 14% (Wölfel et al., 2020) in the earliest phase of the pandemic. More recent figures show a clear decline in hospitalisation rates, dropping well below 1% (Office for National Statistics, 2023).

The physical impact of COVID is evident, and mounting research shows that COVID is also associated with high rates of psychiatric symptoms. Several meta-analyses show pooled prevalence rates of symptoms of depression, anxiety and insomnia to occur among approximately 40% of COVID survivors, including hospitalised and non-hospitalised individuals (Deng et al., 2021; Liu et al., 2021; Vanderlind et al., 2020). For the group of ICU patients, associations with neurological symptoms such as brain diseases, confusion, loss of smell or taste, and headache among others were encountered (Helms et al., 2020; Mao et al., 2020). The previous studies portray the prevalence of a wide array of symptoms. The subjective experiences of former COVID patients remain undiscovered within these papers.

Researching lived experiences of former COVID-19 patients

The aforementioned studies show clearly that people who have endured COVID suffer from more than only bodily complaints and symptoms. Qualitative research methods can look for deeper insights into a person’s experience. Zhang and colleagues (2022) conducted a meta-synthesis of 23 qualitative studies researching the psychological experiences of COVID patients in retrospect or at the time of their illness. The samples consist of non-hospitalised as well as hospitalised people admitted to a COVID ward or the ICU, or a combination of these groups. The included studies have been conducted among several Western countries and across the Asian and African continents. Five main themes were distilled: the complex psychological course of COVID-19 patients, the impact of the disease on the body, the expectation of support and guidance from multiple sources, coping strategies and post-traumatic growth. The majority of themes describe experiences of unpleasant physical and subsequent psychological and social effects. To a lesser extent, positive experiences related to post-traumatic growth came to the fore. This meta-synthesis shows that the themes which occur in the experiences of people enduring COVID are diverse. These themes provide a content-focused insight into experiencing illness due to COVID, although it explains little about the way people make sense of their illness experience.

Introducing narrative research on illness

Researching the lived experiences of people can be done through phenomenological studies, yet also through narrative research. Despite the different terminology, both research designs show large similarities as they study lived experiences and analyse qualitative data. Narrative analysis is distinct as it focuses not only on the content (*what* is being said) but also on the structure of a narrative (*how* a story is told).

This current study aims to uncover what experiences were elicited due to COVID. Within the broader scope of narrative research, the focus on illness experiences forms a distinct section. A personal story about one's illness is known as an illness narrative, wherein an illness and its effect on the patient's life are told as an autobiographical or biographical account (Le, Miller, & McMullin, 2017). Serious illness, whether chronic or temporary, often emits a disruption in “one’s biography and sense of identity” (Baena, 2021, p. 4). Narratives may aid a person in making sense of an illness or disability, developing meaning about this experience and adjusting their sense of identity. (Bury 2001; Hydén 1997; Smith and Sparkes 2008a, 18–19, as cited in Pohjola, 2020, p. 127). Illness narratives function not only as a way of making sense of illness but also of survival and resilience (Adams, 2015; Baena, 2021). Moreover, the illness narrative also functions as a way to challenge the (bio)medical model which is predominant in Western societies. Hawkings (as cited in Baena, 2021) states that the medical model propagates a strong biophysical focus in understanding illness; however, it overlooks the experiential aspect. The narration of subjective illness experience portrays the messy and often harsh reality of living with illness. In short, illness narratives function as a way of making sense of illness and, in turn, developing meaning about this experience and adjusting their sense of identity.

Narrative literature on COVID-19 experiences

Narrative research has yet been scarcely applied to COVID patients. Two studies by the same authors applied a narrative analysis to the stories of a single sample of people experiencing persistent symptoms after a COVID infection (so-called *long covid*). In their first study (Ladds et al., 2020), they took on a content-focused approach to uncover what was talked about in their stories. Five themes were uncovered: illness experience, accessing care, relationships with clinicians, emotional touch points in encounters with health services and, lastly, ideas for improving services. They conclude that people suffering from long COVID experience the disease and its sequelae as a confusing illness. According to them, this fits the portrayal of the ‘chaos narrative’ as coined by Arthur Frank, in which “an illness experience is uncertain, confusing and with no clear direction or purpose” (Ladds et al., 2020, p. 9).

In a second study, Rushforth and colleagues (2021) conducted a structural analysis by looking at the how, why and to whom their respondents narrate their experiences. They created an analytical framework around core narrative themes based on several different theoretical concepts (e.g., chronology, metaphor, characterisation, suspense and imagination). The narratives are generally characterised by experiencing symptoms of an unpredictable nature, a disrupted chronology, experiencing ambiguity in the healthcare system and the absence of clinicians to witness their stories. The latter often led to a struggle with a fragmented inner monologue before finding a receptive audience among online communities.

These [long covid] communities have also managed to prompt research into undertaking peer-reviewed research to substantiate long covid as an acknowledged phenomenon. The previous studies give insight into the experiences of people suffering from persistent sequelae after COVID infection. The experiences of being hospitalised due to COVID, however, remain uncovered through the lens of structural analysis.

Arthur Frank’s research on illness narratives

A frequently used framework to conduct structural (illness) narrative research is that of Arthur Frank’s (1998) story typologies. Frank’s three typologies constitute different narrative structures which form a means to understand the crossing of culture, meaning and experience. These three story types are restitution, chaos and quest. Frank initially developed these story types in the context of serious, although potentially curable, illness. Since then, his theory has been adopted and expanded, applying to terminal as well as unknown illnesses. Thomas-Maclean (2004) mentions that stories constantly unfold thus, all three story types might be found in the illness narrative, alternatively and repeatedly.

Frank distinguishes three story types: restitution, chaos and quest. The restitution story type is the most frequently displayed type, according to Frank (as cited in Whitehead, 2006). Restitution is the tale of “getting sick, suffering, being treated, and through treatment being restored to health” (Frank, 1998). At first glance, restitution seems to reflect the natural desire of the ill individual to recover. Frank claims, however, that the ill individual’s voice is shadowed by the biomedical perspective dominant in Western societies. In this lies an implicit expectation that for every illness, there is a treatment which, in turn, imposes the expectation that the sufferer will recover. This society-wide focus on restitution poses the risk that other aspects of illness experience and its possible lasting effects are overseen. The latter might apply to people suffering from continuous health complaints after the acute illness phase from COVID, regarding hospitalised as well as non-hospitalised people.

The chaos narrative can be described as ‘illness at its deepest’; disability and pain are there to stay, and physicians have no clue what is wrong or are unable to treat it successfully. The chaos narrative is most recognizable in the listener's response; “when the listener feels sucked into a whirlpool” and subsequently emits resistance or even rejection by the person listening (Frank, 1998, p. 202). According to Frank (as cited in Pohjola, 2020, p. 128), “the chaos narrative can be told only when the person has gained reflective distance to the actual chaos”. Concerning the structural aspects of this narrative, Frank even speaks of an anti-narrative as it lacks a clear sequence, uses incomplete sentences, and events are often enumerated by ‘and then’ constructions. The person portrays themselves as passive and almost literally subject to the events within the story. This type might fit the illness trajectory well for people suffering from severe COVID symptoms and sequelae as the treatment options are scarce which adheres to the feeling of being subjected to the illness.

The quest narrative implicates a quest as finding something to be learned from illness. In other words, quest forms a way of reflecting on the illness experience. The quest story type does not imply that illness is accepted or welcomed by the ill person. However, people do often mention being grateful for how it changed them and their lives. In other words, quest stories focus on what can still be reclaimed from life, potentially leading to new insights or qualities in themself. As for any illness, having suffered from COVID might also spark new insights or instigate the revising of certain life areas for certain people. However, this has yet to be explored through scientific research.

Studies using Frank’s story types

Several studies used Frank's story types as a method to analyse narrative structures, although they focused on a variety of diseases other than COVID (Pohjola, 2020; Spillmann et al., 2017; Thomas-MacLean, 2004; Whitehead, 2006). One overarching finding is that in all studies, all three story types have been encountered. Looking more closely, however, differences in narrative structures are evident which relate to the concerning illness and its discourse. Three of the aforementioned studies on the experience of physical disability (Pohjola, 2020), undiagnosed diseases (Spillmann et al., 2017) and chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME) (Whitehead, 2006) can be clustered as chronic conditions with no available treatment. One study on the experiences of breast cancer (Thomas-MacLean, 2004) stands separately as this is a treatable and therefore potentially temporary illness, nevertheless, with often permanent physical effects.

Among the cluster of chronic conditions, the chaos narrative is dominant. A striking result regarding the sequence can be seen, as people initially present a restitution narrative as they expect that health will be restored in time. This is followed by a chaos narrative once reality presents itself that a clear diagnosis or treatment cannot be provided (Spillmann et al., 2017; Whitehead, 2006). Quest only appears in a few cases as most people remain in a chaos narrative. In Pohjola’s (2020) analysis of the stories of three women with physical disabilities, all narratives appear to be chaos alternated by glimpses of restitution or quest. One striking finding is that the chaos narrative persists even though these stories were written retrospectively one or even two decades after injury. Thomas-MacLean (2004) found that a coherent story often lacks among women who suffered from breast cancer due to a greatly varying discourse of treatment and subsequent long-term effects. A seemingly interesting finding was the misfit of restitution in describing their experience. For this, Thomas-MacLean proposes *reconstruction* as an alternative structure, which is defined by the impossibility of restitution and only managing to achieve a semblance of their prior state.

Different diseases show different narrative structures and these differences seem to trace back to nature and subsequent course of the concerning illness. The chronic conditions, for example, without a clear diagnosis and/or treatment are reflected predominantly through the chaos narrative as people endure a great deal of uncertainty and suspected hopelessness. Aside from the overall finding that all story types were encountered across each appointed study, variance regarding the sequence of story types is another characteristic. The latter proves that ultimately every experience is unique which accounts for fluctuating and varying narrative structures.

Current study

Based on the previous literature research, it is expected that all story types within the illness narratives will be encountered, although in varying degrees. Thus far, the restitution and chaos story types have been the most frequently occurring types within illness narrative research. The symptomatology of CF/ME shows the most resemblance to COVID regarding energetic deficiency (Whitehead, 2006). Spillmann and colleague's (2017) study on people with undiagnosed diseases also shows similarities with COVID regarding limited treatment options as the exact cause of certain symptoms remains unclear. Following the findings of these two studies, it is expected that the chaos story type will be most dominant among the illness narratives. Hospitalised people presumably suffer more from prolonged complaints and subsequently encounter an ineffective treatment or the lack of an effective treatment. With regards to the occurrence of story types at different points in time, a likely outcome might be that the frequency of chaos narratives decreases over time. Thomas-Maclean's (2004) proposition of *reconstruction* rather than restitution to describe the recovery process of breast cancer survivors might also fit the experience of a portion of COVID patients. In this study, it might describe the eventual futile attempt for restitution once a person concludes that attaining their prior state of health is impossible.

An interesting finding in Pohjola’s (2020) study, however, was that chaos narratives still appeared even two decades after a traumatic injury. This seems to suggest that temporal distance to an event or experience does not imply a psychological or emotional distance paired with that certain experience. In line with this finding, it is expected that the chaos narrative will remain prevalent over time. A narrative study carried out by Rushforth and colleagues (2021) on a group suffering from long COVID might show a resemblance with the post-hospitalisation experiences of hospitalised COVID patients. The resemblance might be found in the portrayal of unpredictable symptoms and a disrupted chronology among the narratives, which characterise signs of a chaos narrative. Thus, it might be expected that chaos will appear significantly as well, although not dominantly, in the recovery stories.

By looking at how people narrate their experience we aim to uncover how hospitalised patients make sense of their hospital experience, period of recovery and with that their illness experience as a whole. Specifically, this study will focus on the question: How do COVID-19 patients narrate their experiences during and after hospitalisation? To research these stories, Frank’s story typology will be applied to analyse the structure of these COVID narratives. The goal is to search for patterns of sensemaking, having in mind that each experience is personal and therefore unique and is affected by cultural standards. To this date, this study is the first to research the experiences of specifically hospitalised COVID patients through a structural narrative lens. Through attaining a better understanding of these experiences, future healthcare services may be improved among multiple disciplines (i.e. nurses, doctors, physiotherapists) who treat COVID patients. This might not apply strictly to the treatment of COVID patients, but to other illnesses similar to COVID as well.

Method

Background and procedure

This research was part of a longitudinal, prospective cohort study *Long term impact of COVID-19 hospitalisation on patient reported outcomes* carried out by the MST (Medisch Spectrum Twente) hospital in Enschede in collaboration with the ZGT (Ziekenhuisgroep Twente) in Hengelo and Almelo and the University of Twente. Aside from a prospective study, a retrospective dossier study has been conducted to look at the impact of pre-existent risk factors including present comorbidities, alcohol consumption and tobacco use, length and weight, and numerous sociodemographic data. Their research goal was to investigate whether there is a long-term impact on the general health of former hospitalised COVID patients through quantitative research.

After the outbreak in the Netherlands, the MST set up a COVID-19 patient cohort. All patients in this database were sent a letter containing information about the study and an invitation to participate. After signing the informed consent, participants were sent a digital form containing all questionnaires to their self-administered e-mail address. Participants were also able to receive the form on paper if requested so. For this study, two open-ended questions (see Appendix A) were added to the test battery. The answers to these questions formed the qualitative data on which this study is based. Furthermore, the test battery consisted of a handful of quantitative questionnaires (see Measures) for the aforementioned study. The data collection took place from September 2021 until December 2021 targeting former patients at six and twelve months after hospital discharge. This study comprises an exploratory narrative research design looking into the lived experiences of this target group. The response to either of the two questions forms the unit of analysis.

Participants

After the data collection phase, the initial sample for this study consisted of a total of 154 respondents. The inclusion criteria for this study consisted of a positive COVID test as the reason for hospital administration, sufficiency in the Dutch language and a signed informed consent. To keep the recruitment process simplified, the minimum participation age was eighteen years due to parental consent. Participants were excluded if non-sensical or non-substantive answers to one or both open-ended narrative questions were given. In other words, a valid response to both questions was needed for inclusion. Eventually, four responses contained an answer as 'no' or 'none', three respondents stated they had already told their story (presumably to another researcher) or reported they felt too tired to write down their experience and one person responded with an 'x'. One other participant referred only to an online blog without providing any substantive answer and was therefore excluded. Lastly, one of the respondents was a pregnant young woman who was hospitalised due to her pregnancy and during this period contracted a COVID infection subsequently ending up in a COVID ward. She was excluded as the initial reason for her hospital admission was not COVID related. Those who had missing demographic information such as age and gender have been included nonetheless as this would not affect the validity of this research. The final sample consisted of the complete answers to the narrative questions from 143 participants of which 78 were from the six months and 65 were from the twelve months follow-up.

Both subgroups show similar sociodemographic values concerning gender distribution and average age. The six-month follow-up group (n=78) consists of 40 (51.3%) male, 28 (35.9%) female participants and 10 (12.8%) missing variables with a mean age of 61.8 years (SD=8.9). The twelve-month group (n=65) consists of 40 (61.5%) male, 21 (32.3%) female participants and 4 (6.2%) missing variables with a mean age of 62.4 years (SD=10.3).

Measures

After inclusion, all participants in this study received the test battery in context of the overarching study. This form contained the Short Form Health Survey (SF-36), EuroQol 5D (EQ-5D), Short Fatigue Questionnaire (SFQ), Modified Medical Research Council Dyspnea Scale (mMRC) and one non-validated question regarding sleep. For one subgroup an additional questionnaire about their positive well-being (*Mijn Positieve Gezondheid*) was added and another subgroup received the PTSS Checklist for the DSM-5 (PCL-5).

Specifically for this study, two open-ended questions were added to the test battery at six and twelve months after hospital dismissal to collect the stories from the participants. In constructing these questions, the aim was to set up as few questions as efficiently possible to minimise the risk of respondent fatigue while, simultaneously, maximising the potential for relevant data. In constructing narrative questions, Riessman (2008, p. 26) states that it is preferable to formulate questions that “open up topics, and allow respondents to answer questions in ways they find meaningful”. Following these guidelines, the questions ask the respondent to tell their story about a certain period in time. Additionally, the questions contain a notion to tell their story as elaborately as they want to. This gives the respondent the freedom to share their experiences at any length they see fit.

Data processing and analysis

The data analysis consisted of a structural narrative analysis using Arthur Frank’s story typologies (1998). The goal of this research is to investigate how people make sense of their illness experience, therefore narrative analysis is the most suitable. This form of analysis focuses on how a story is organised, subsequently illustrating how certain elements are used to make sense of an experience (Torbenfeldt Bengtsson & Andersen, 2020, p. 272).

Once a participant filled in a response the input was converted to an xls file which the data administrator distributed to the researcher. The data was provided in two different files; one file containing the data of the measuring point at six months and the other at twelve months after hospitalisation. After this step, the data was pre-processed by arranging all responses with the relevant demographic data in a separate Excel working document. The categorization of the two groups, as well as the responses on the two items, were maintained in this working document to check for patterns in later analysis. In analysis, the response to the first item is referred to as the *hospital story* and the response to the second item as the *recovery story*. To analyse the experiences of the respondents during and around the time of illness the story types by Arthur Frank formed the basis for the narrative analysis. Data processing and analysis consisted of five steps: (1) familiarisation with the data set; (2) labelling fragments which represent Frank's story types; (3) developing an initial coding scheme based on the previous labels; (4) refining the coding scheme; (5) analysing the codes.

After familiarization, the stories were read line by line to determine to what extent Frank's story types occurred among the stories. Relevant fragments were labelled concurrent with one or more story types. A fragment could comprise multiple sentences or a few words (e.g. as part of a sentence). These labels formed the foundation for producing the coding scheme. The goal of the coding scheme was to identify in detail how the story types occurred in the stories. In other words, the codes formed 'substory types' within each of the three main story types. During this process, overlap between the restitution and chaos story was most often encountered. For example, a recovery process which is entailed with setbacks might show signs of chaos, however, might ultimately be a restitution story based on the overall structure of the narrative. To ensure that codes were mutually exclusive, fragments were read repeatedly and where relevant new elements were identified in the narrative so that they could be connected more precisely to different story types. After producing an initial coding scheme, the scheme was iteratively refined. Lastly, the final coding scheme was applied to the selected dataset. A frequency table was produced to project the occurrence of the story types among the data. Subsequently, the codes were qualitatively elaborated to portray in detail how the story types were narrated in the respondent's experiences. The data was processed and analysed in its original language. The quotations used in the results section were translated from Dutch to English.

Results

This next chapter is constructed into two subchapters. The first concerns a brief overview and analysis of the quantitative occurrence of the story types and constructed subtypes across the data. The second constitutes the qualitative description of the results. Each substory type is accompanied by quotations[1] to provide examples which portray the characteristics of each main story type.

Frequency of Frank's story types

The analysis of former patients' stories about hospitalisation and their recovery shows the occurrence of all of Frank's three story types: restitution, chaos and quest story type. Within these story types, several variations have been found that provide a more nuanced insight into what living with COVID means. These variations can be seen in *Table 1* (p.21) in which the main story types have been labelled through codes (henceforth called *substory types* or *subtypes*). In total, ten subtypes were identified among all story types together. The chaos story type accounts for 47.2% (306) of the quotations, the restitution story type for 47.2% (306) and the quest story type for 5.6% (36) of all quotations. One striking remark to be made

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[1] The quotations used in this chapter have individually been translated from Dutch to English. Each original quotation can be found in Appendix B and can be traced by page number and the corresponding participant number, indicated with P00, behind each quote.

is that the restitution and chaos story types are the most frequently appearing story types across all stories, together accounting for 94% of the coded quotations. The chaos narrative is more apparent in the hospitalisation stories, whereas the restitution narrative occurs more frequently in the recovery stories. This pattern is observed across both cohorts. The quest narrative, however, appears more often (absolute, although not statistically) in the hospitalisation stories among the twelve-month cohort in comparison to the six-month cohort.

Qualitative Description of Illness Story Types and Substory Types

Chaos

Chaos might be most easily recognized as a “whirlpool”, as described by Frank (1998, p. 202), and moreover as an assembly of misery, disappointments and setbacks. As long as the chaos story is being told a person usually does not mention any sign or expectation of change in circumstances. The period in which a person becomes ill usually marks the start of a chaos narrative. Not merely does a chaos narrative appear in the case of a person’s declining health, it might also appear later in their illness trajectory, during the period of recovery. For example, if rehabilitation fails to progress or if there are setbacks, a person might describe a chaos narrative. In other words, the different types found within the chaos stories clearly show the temporal occurrence of chaos throughout the participant's responses about their experience before, during and after hospitalisation.

Table 1

Frequency of the occurrence of each story type and substory type

Story type	Substory type	6-month follow-up			12-month follow-up			Total
		Hospital story	Recovery story		Hospital story	Recovery story		
Chaos	*Chaos Pre-hospitalisation*	35 (52.2%)	1 (1.5%)		30 (44.8%)	1 (1.5%)		*67*
	Chaos Hospitalisation	61 (50.8%)	2 (1.7%)		55 (45.8%)	2 (1.7%)		*120*
	Chaos ICU	9 (69.2%)	-		4 (30.8%)	-		*13*
	Chaos Recovery	10 (9.4%)	50 (47.2%)		6 (5.7%)	40 (37.7%)		*106*
	Total Chaos	*115*	*53*	***168***	*95*	*43*	***138***	***306***
Restitution	*Restitution Hospital*	54 (57.4%)	3 (3.2%)		34 (36.2%)	3 (3.2%)		*94*
	Restitution in Process	10 (6.3%)	76 (47.5%)		12 (7.5%)	62 (38.7%)		*160*
	Restitution Achieved	3 (5.7%)	20 (38.5%)		5 (9.6%)	24 (46.2%)		*52*
	Total Restitution	*67*	*99*	***166***	*51*	*89*	***140***	***306***
Quest	*Quest Acceptance/ Coping*	-	6 (33.3%)		2 (11.1%)	10 (55.6%)		*18*
	Quest Gratitude	2 (14.3%)	4 (28.6%)		5 (35.7%)	3 (21.4%)		*14*
	Quest Life priorities	-	2 (50%)		1 (25%)	1 (25%)		*4*
	Total Quest	*2*	*12*	***14***	*8*	*14*	***22***	***36***
Total Hospital story		*184*			*154*			*338*
Total Recovery story		*164*			*146*			*310*
Total per research group		*348*			*299*			*648*

Chaos pre-hospitalisation

The form of chaos in this subtype appears in the period before hospitalisation. It has its onset once a person notices bodily symptoms or when symptoms start to intensify and form a noticeable burden. A key characteristic of this subtype is the change in a person’s illness trajectory which goes in descent. In the narratives this is expressed through the experience from feeling healthy or mildly ill to feeling significantly afflicted by COVID symptoms: “After a positive test I initially continued work (at home), but eventually became increasingly ill (fatigued, loss of weight, oxygen shortage).” (P01, Male, 59 years old). The previous example shows a common structure of chaos before hospital admission. At first, a person notices minor complaints as initial COVID symptoms resemble those of the flu or a cold. This is followed by the process leading up to hospital admission, which shows some variation between participants. For some, the decision for hospitalisation was made, seemingly, swiftly. For others, hospitalisation is preceded by consultation or treatment by applying antibiotics of a general practitioner (GP). The next example contains all the previously mentioned fragments.

> Sunday 21st of March positive for covid. Monday 22nd of March in the course of the day I got complaints such as fever and lethargy. Complaints continued the whole week. Felt like a heavy flu. Lots of coughing, fever and quick out of breath. Sunday 28th of March contacted the general practice centre and they advised me to come over. Once arrived did some tests and I was admitted that day. (P02, Male, 57 years old)

The way chaos presents itself within this subtype is notably implicit. It is presented in a seemingly rational and descriptive way, unlike how Frank describes chaos as being experienced as a “whirlpool”. Generally, the stories concern the process of becoming ill, subsequently focusing on bodily symptoms. Explicit information about, for example, the emotional response and experience to the initial phase of illness is lacking. Chaos is implied due to the sequence of events: (A) feeling healthy/mildly ill – (B) feeling (increasingly) ill – (C) the decision to seek medical attention. Following this sequence it is evident that restitution does not suite itself as a fitting narrative. The lack of information about any emotional response gives a strong impression that the hospital admission and hospitalisation itself are experienced as precarious and frightful. The moment of hospitalisation is where this subtype concludes, although not the chaos narrative per se.

A striking feature of this chaos subtype is that people seem to provide more information than is asked of them. As the first item states the question to describe the respondent's experience during hospitalisation, the pre-hospitalisation chaos type is characterized for some people by a plot that starts before the actual moment of hospital admission. The choice to start narrating their experience at this point in time underscores the importance of this preliminary phase relative to the illness experience as a whole.

Chaos hospitalisation

This subtype encompasses chaos during the period of hospitalisation, consisting of the moment of hospital admission and the period of hospitalisation itself. A person's state of health generally forms the thread throughout their story about hospital admission. This might not be surprising as the main goal of hospitalisation is to control and improve a patient's physical health. The chaos subtype ends when a person's health is stable enough to the point that hospital admission is no longer necessary.

> My hospitalisation doesn't bring back pleasant memories, was picked up 2 x by the ambulance, and the days in the hospital were very tough and anxious, became increasingly short of breath and ill, was very afraid that I wouldn't make it, and had to move around with a walker in my room because of these circumstances […] can still

> remember being scanned twice and with lots of oxygen and medication they tried to help me back on my feet again. (P03, Male, 60 years old)

This participant reflects on his hospital admission by noting that it brings up unpleasant memories as he experienced his time as “difficult and fearful”. He continues to explain that during his hospital stay, he became increasingly ill and short of breath which led to the fear of “not going to make it”. These thought processes make the chaos very clear. This person has not only lost his trust in being able to recover but also bears the thought of losing his life due to his poor health. Also, when mentioning his received treatment he says “with lots of oxygen and medication they tried to help me back on my feet again”. The word “tried” sticks out in this part. It implies an attempt to treat him, however, an expectation concerning the outcome of the treatment is left out. This open ending gives the impression that the participant is unsure of what is coming next and what will happen to him, thus continuing a ‘down-spiral’ direction within the narrative. Another structural characteristic fitting the chaos narrative is the ‘and then’ construction. Through the use of multiple comma’s the participant strings together several events into one sentence.

> Shouldn’t think back about it and others shouldn’t ask me questions about the how and what during the hospital admission. Makes me emotional if people remind me of that or ask me questions concerning how and what. Moreover…. in hindsight the admission etc passed by in a flash for me. Rather don’t want to be reminded of it, have been through more already like hospitalisation with severe pneumonia and hospitalisation for cerebral infarction. During that last one I can only remember that after about 3 hours I saw “the light” again. (P04, Male, 70 years old)

In the previous example, chaos is mainly presented by a negative association with the participant’s hospital admission. Without giving details he states that “he should not think about nor should anyone ask him” about the period of hospitalisation. Also, no concrete emotional response is stated rather than “becoming emotional” if anyone reminds him or asks him questions. Further on in the fragment, he recalls prior hospital admissions which have been burdensome experiences for him.

Chaos Hospitalisation - ICU

Among the Chaos Hospitalisation subtype, there is a portion of people whose stories address their experience in the ICU. As this is often encapsulated in the previously described chaos hospitalisation subtype story, it does not constitute another subtype but rather a sub-sub-type. With regards to the content and structure, it is deemed significantly distinctive to address this separately. The core aspect of this chaos type revolves around having no or fragmented memory due to the coma in the ICU. Generally, two different structures appear. The first is the mere notion of having no recollection during their ICU stay: “I was kept asleep for 9 days and didn’t consciously experience any of it” (P05, Male, 45 years old). Alternatively, the respondent tells what they can recall during their ICU stay.

> I remember being brought into the Emergency Department on Monday evening around 6.30 pm that pulmonary radiographs and a CT scan were made and I was told that I also had 2 pulmonary embolisms. Then I was transferred to a room in the ICU from that moment on I lost a lot. Sometimes when I woke up I thought I was in a theatre with the bed. On the 2nd of March I said goodbye to my wife in person and said goodbye to my children via skype and from my bed went over my last wishes and the funeral arrangements with my eldest daughter this was an intense and emotional moment. Then I was made ready to be put to sleep and whether I would wake up again??...no one knew but I was so ill that I did not realise this at all. Thursday afternoon, 4th of March, I awoke from the coma again. (P06, Male, 54 years old)

The previous example portrays a chaos story in which a participant recalls his experience up to the moment he was transferred to the ICU. His story contains emotionally loaded experiences, based on the described events and the respondent's reflection. However, the structure of this story appears structured and subsequently easy to follow for the reader. It has a chronological sequence, even including dates and timestamps, and the sentences are generally properly formulated. One fragment proves an exception regarding structure, following the moment after which he said his goodbyes to his family: "Then I was made ready to be put to sleep and whether I would wake up again??...no one knew but I was so ill that I did not realise this at all." It shows a vulnerable insight at a crucial and fearful moment; being put to sleep without the reassurance of waking up again. Striking is the use of interpunction in this fragment, placing a string of question marks and full stops to connect a question and contiguously its answer. It seems to implicate emphasis. The double question marks may underline the emotional load of a confronting question. The subsequent full stops symbolize silence as if he is waiting for an answer. In summary, the use of interpunction exposes the emotional load lying underneath what is written.

Chaos recovery

This subtype of chaos appears in the period after hospitalisation. Importantly, the post-hospitalisation period often spans a longer period of time compared to that of the (pre-) hospitalisation period. Hospital admission might span from a few days to a couple of weeks, whereas the post-hospitalisation period might take months to sometimes over a year. In general, two temporal distinctions can be found in the stories. One that appears in the period shortly after hospital discharge and the other which appears later on in the recovery process. These two periods entail some substantive and structural differences. Besides these differences, the underlying message remains equal for each fragment; a sense of hopelessness about future recovery.

As stated before, two temporal differences can be found within this subtype. The earlier form regards the impact of experienced serious illness on the life of the respondent and the confrontation when this is compared to their pre-illness state of health. Structurally, these fragments are most distinguishable by the use of past tense. A second characteristic is the brief and rapid enumeration of remaining symptoms and subsequent complaints. The following fragment shows a fitting example: “Big disappointment. Extremely tired, coughing a lot, Could endure only few stimuli, could sleep all day. Difficulty with concentration memory and very easily irritated as a result.” (P07, Male, 56 years old). This fragment shows the first few sentences of the recovery story. The essence of this person’s experience seems to be concisely captured in the first sentence. The notion of disappointment hints at an unfulfilled expectation and the enumeration of complaints seems to reveal what this expectation might concern. Brief sentences or sentences with long enumerations encapsulate the chaos fittingly.

The second form presents itself at a later moment in the recovery process. The main difference is the shift in written tense, which changes from past to present tense. This transition into the present tense implies the shift to the present time. For some respondents, recovery is still ongoing after six or twelve months. With regards to the content, these fragments might seem similar to the previously discussed. Respondents note varying experienced complaints; physical, cognitive or emotional. A crucial difference, however, is the fact that these complaints are present such a long time after the initial illness. The chaos emits itself in the fact that a person’s recovery stagnates, shows disappointing progression, or that they experience setbacks.

> We are 4 months on. I can't handle any real hustle yet. Stamina is not there yet and don't feel like doing anything. Am not fit. Hard to explain but somehow the energy is not there. (P08, Female, 51 years old)

The fragment starts, perhaps unsurprisingly, by prominently mentioning how much time has passed after hospital discharge. It sets the tone for the reader as it emphasizes the following. The use of ‘yet’ throughout the fragment encases a sense of disappointment relating to the previously mentioned four months that have passed. Followingly, using short sentences complaints and limitations are enumerated. This string of experienced limitations seems cut off in the following sentence: “Am not fit”. It reads as if there is even more to name, instead, she chooses to stop here and summarize the previous with ‘not being fit’. The last sentence shows an interesting statement which underscores the previous observation with the words “hard to explain”. This might imply that it is not so much a choice to stop elaborating, instead, it rests on the (in)ability to give words to what is exactly experienced. The latter fits Frank’s mention of one of the chaos’ characteristics, namely that “chaos cannot in its purest form be *told*” (Frank, 1998, p. 202).

Restitution

The restitution story type comprises the process of reclaiming one’s former state of health and is often portrayed as feeling “just like before [illness]”, following Frank’s definition (Frank, 1998). Restitution is considered a process which generally starts once a person describes a directional change in their story. This change often relates to a person’s physical state of health in which references are made to the alleviation of physical symptoms, thus an ascent in the illness trajectory. The different substory types refer to different temporal occurrences in the restitution process. For each substory type, content- and structural characteristics will be illustrated through relevant quotations.

Restitution hospital

This substory type was encountered mainly in the hospital stories. It encompasses a form of restitution during hospitalisation which represents an ascending turning point in the participant's illness trajectory. The form in which this subtype appears in the stories differs. A few events which are frequently mentioned, in sequence or independently, are the following: (A) receiving treatment, (B) feeling better (C) being dismissed/returning home. The following fragment shows a sequence of all events: "With medication (antibiotics and blood thinners) (A) it went better every day (B). On Thursday I was allowed to go home again. (C)" (P09, Male, 67 years old). Events B and C seem to be most frequently occurring in the stories. Event B consists of the notion of an improvement of 'feeling better' or 'having recovered'. Striking is the often brief and general character of this type of account, as seen in the next example: "Fortunately it started improving fairly quick for me and after a few days I was allowed to the ward again." (P10, Female, 59 years old). Respondents do not specify what entails this improvement, although, in the context of treatment it is assumed that it concerns a physical recovery. Some respondents mention a medical marker which is used to monitor the patient's health, namely the oxygen saturation level in their blood: "After medication and oxygen it started to improve again in the course of Tuesday the 30th of March. Saturation was around 94-95." (P11, Male, 57 years old). These are fitting examples of Frank's theory that the restitution story type often shadows the voice of the healthcare professional. Consecutively, event C mentions the hospital dismission. This is often accompanied by stating the number of days they spent hospitalised or on what day of the week they were dismissed. In some cases, a fragment contains only this piece of information.

Restitution in process

The person is going through the process of recovering and through their story it is evident that recovery is still ongoing. They notice that they have not yet fully regained their former state of health. An essential component within this subtype is the mention, implicitly or explicitly, that a person hopes or expects that their health will further improve. A reflection and subsequent expectation about the further recovery process might be provided.

> After a few weeks a very slow progress. Am still tired quickly and heavy-headed. Can complete an hour of training at the physio with oxygen. And going to work three days each week for two hours a day. I can’t manage more yet hope to slowly improve this. (P12, Male, 60 years old)

The process of rehabilitating is evident in this example. This participant evaluates his progression in the first few weeks as very slow and also notes some persisting complaints “still feeling tired and short of breath quickly”. Despite the slow recovery process, he also writes about his desire to extend his achievements so far. This explicit notion of expressing hope and a desire to work on rehabilitating further is key for this subtype.

In some cases, a person does not show any form of reflection nor a clear expectation about the course of their recovery. They do, however, mention an ongoing treatment with a healthcare provider: “In order to rehabilitate as fast as possible, I went to a physiotherapist and referred to a respiratory therapist.” (P13, Female, 50 years old). Although an explicit reflection is missing in these instances, they are considered as restitution in process nevertheless. It is assumed that people who seek professional help also intend and hope to improve to the extent that they have recovered their former state of health.

Restitution achieved

The person has gone through a recovery process, either individually or with the assistance of one or more healthcare providers (e.g. a physical therapist). The key aspect of this substory type is that the person mentions, implicitly or explicitly, that they feel as they did before illness. This comprises the literal meaning of restitution as well as its desired outcome. The following quotations show examples in which achieved restitution is explicitly mentioned: “I live my life as before.” (P14, Female, 47 years old) and “After about a week or 6 I was fully my old self again.” (P15, Male, 67 years old). Phrases along the lines of “living life like before” and “feeling like my [old] self again” might be the most concrete fragments to portray achieved restitution. Interestingly, these two phrases seem to imply the same outcome although inherently refer to different aspects. One states *living* life as before, whereas the other refers to how a person *feels*. These two aspects may overlap but can be experienced and subsequently measured differently. ‘Living life’ seems to refer to being able to participate in the same activities (e.g. hobbies, sports, work) as a person did before illness: “Currently I am back to doing almost everything I did before COVID-19.” (P16, Age and gender unknown). ‘Feeling like their [old] self’ is assumed to refer to a bodily sense of self. This may be because the person is disrupted by an illness which emits primarily physical symptoms. Now that these physical complaints have faded away, a person experiences their body and, with that, themselves as before illness: “After a few months, I no longer felt any restrictions.” (P17, Male, 70 years old).

Furthermore, another aspect appeared within the fragments of this subtype. Namely, Frank’s (1998) notion that in essence, a restitution story shadows the voice of the concerning clinician involved in the treatment: “At check-up visit to pulmonologist (incl lung x-ray) declared fit again in early July.” (P18, Male, 55 years old). In this example, the clinician’s voice is vivid and clearly related to restitution. The striking difference is the person's agency; the clinician determines and declares (in)complete recovery whereas the patient is passive and subjective. This proves that for some, recovery seems to be a more subjective concept; based on an own observation or feeling. For others, recovery depends on the clinician's verdict who can measure and assess to determine whether a person has (fully) recovered or not.

Quest

The quest story type is significantly the least frequent appearing type within the data. As Frank states a quest story type is told when "the teller claims new qualities of self and believes illness has been responsible for these changes" (Frank, 1998, p. 203). Essential to the quest narrative is that changes are notably meaningful or positive in one way or another. Frank (1998) also underscores that the quest story should not be seen as a triumph over chaos, as chaos is still acknowledged as something that was and also can be again. Adjacently, a quest story can hold a certain ambiguity; having gained something valuable although not without suffering. Within this study, Frank's definition of the quest story type forms the guiding principle. The quest stories found within the data encompass a few nuanced forms which entail the development of new insights or finding ways to accept life after illness. This might be coping with a deteriorated state of health, rearranging priorities in life or experiencing gratefulness for life. The process leading up to these different quest stories might be identical, however. It is rather the way quest takes form for a person which makes the difference for each subtype.

Quest acceptance/coping

This form of quest displays people who have found ways to live with their altered state of health. Initially, people mention a shift in their health due to the illness. This shift might be indicated by mentioning a general or more specific change in their health. Ultimately, this is followed by the notion that a person is capable to accept this new situation or that they have found a way to handle it. How a person manages to accept or cope is often not specified, rather mentioned in a general sense: “living life more calmly” (P19, Male, 74 years old). Others speak more elaborately on how they cope with health changes:

> I have had to learn to accept and take more time for a lot of things and some activities just aren’t possible anymore such as maintenance work on the house (painting), also that my brain can stutter suddenly (not knowing expressions, names e.g.). […] I live with more moments of rest and if I really can’t manage then I cancel all my plans for the week. (P20, Male, 74 years old)

The previous example shows both aspects of accepting and coping fittingly. The first sentence includes the aspect of acceptance literally, containing the phrase “to learn to accept” followed by activities which are not possible anymore or demand more time. In other words, acceptance concerns coming to terms with life in which a person is not able to do things or function as before. The aspect of coping is portrayed throughout the entire passage and encompasses ways of taking action (taking moments of rest) to, or not to do certain things (e.g. maintenance work) or tackle things differently (taking more time). Whereas accepting seems to be a passive and emotional process, coping appears to entail an active and often more behavioural approach. Despite these distinct definitions of acceptance and coping, the example above also proves that both aspects overlap. One might say that coping does not go without acceptance and, vice versa, being able to accept change implies psychological coping.

Quest gratitude

Within this subtype of quest, people may express gratitude for life, their recovered health or a specific aspect of their lives. Their gratitude is outlined against their poor state of health during the period of illness: “After a few months I didn’t feel any limitations anymore.

Am happy and grateful for that, every day still.” (P21, Male, 70 years old). Participants may use comparisons to the situations of others (e.g. a family member, friend or reported cases in the news) who lost their lives due to COVID:

> I do want to mention that my brother-in-law was next to my room with the same symptoms, but he did not make it despite 8 weeks in ICU, this does leave a deep impact, and tells me I was very lucky. (P22, Male, 60 years old).

This example portrays the ambiguity within the quest narrative clearly; gaining something valuable and suffering go hand in hand. In this case, the suffering encompasses his confrontation with death. Another layer to this is in reflecting on the events, which taught him he was lucky. This seems to imply a question along the lines of “how or why did I survive and my relative did not?”. This question seems inexplicable to him and for that, it must have been ‘luck’; a matter of chance. This latter part illustrates the value of having experienced serious illness, which relates to the ambiguity of the quest narrative. Had it not been for the tragic event of losing a relative, this participant might not have gained such gratitude for his life.

Quest life (priorities)

This subtype contains a sparse occurrence of four cases among the data, although it encompasses a significantly distinct form of the quest narrative. Through experiencing serious illness, a person mentions that their view on life has changed and what has become (more) important for them: “I’ve come to face life very differently. Together with my wife who spent 2 weeks in the ICU, we went in a completely different direction. We enjoy life much more now.” (P23, Age and gender unknown). The essence of this subtype is encapsulated in the notion of ‘facing life differently’ and ‘going in a different direction’. These two notions portray two slightly different forms which can occur within this subtype. One is attaining a different attitude towards life and the other comprises taking action to focus on what has become more important in one’s life. These two forms might appear together or separately. In this fragment, it remains unclear as to what entails the change in attitude or ‘going in a different direction [in life]’. Despite its vagueness, it does become apparent that these changes account for a valuable outcome: enjoying life more than before illness. The aspect of the generality of what and how a certain change entails is common among most fragments. The fact that these quest stories are characterized by generality might relate to what Frank (1998) writes about the quest narrative as something that is resisted by the other as “they [the listeners] resist the quest narrative because they still need to believe in a restitution that the teller has had to work to give up […]” (Frank, 1998, p. 205). In other words, a person might sense that their quest story is not fully welcomed and as a result keeps their quest experience vague and general.

The following fragment proves an exception and reveals more explicitly what has changed due to experiencing illness: “After Covid, I started thinking and arranging differently for my family so that they are left well financially after my death. Try to exercise as much as possible and spend time with family and friends.” (P24, Male, 47 years old). For this respondent, the quest has led to action-oriented and concrete intentions in their life. Interestingly, a minor distinction can be observed in the expressed intentions. It appears that the quest might not only affect their life in the short-term, as seen in the latter part of the fragment: ‘spending more time on self-care and with loved ones’. For some, the illness experience also impels actions regarding the future: ‘making arrangements regarding inheritance for family’.

Frank describes that the quest narrative entails acquiring new insights due to experiencing serious illness. Such insights are often not expressed explicitly, however, might still be distilled from the stories. With regards to the latter example, the intention to exercise more might relate to the insight that good health has a preventive function in relation to (future) illness. As for the arrangements for inheritance and spending more time with loved ones, it seems to relate to the realization of life as finite thus spending time more consciously.

Discussion

The goal of this study is to explore how Arthur Frank's story types appear in the narratives of COVID patients during and after hospitalisation. Analysis shows that the experiences of recovery and hospitalisation of the former COVID patients contain all three of Frank's story types: chaos, restitution, and quest. The COVID stories do not seem to be dominated by one specific story type, however, both restitution and chaos are dominant among the data, accounting for 94.4% of the codes combined. The quest story type occurred in 5.6% of the codes. A large variation in both the content and structure of the narratives led to the identification of ten substory types. The diversity within the stories is seen across both patient cohorts and is related to both the hospitalisation and the recovery phase.

Chaos

Chaos appears throughout the whole illness course of COVID. In total three subtypes were identified: chaos pre-hospitalisation, chaos hospitalisation, and chaos recovery. Additionally, a type within the hospitalisation subtype was identified: chaos ICU. These different categories stipulate the temporal occurrence of the chaos story type. The central feature of the chaos pre-hospitalisation subtype involves a transformation from a state of good health or mild illness to a state of deep illness. Concurrently, it shows that people choose to start their story at a point in time to ensure that it is told in its entirety. Asking about the pre-illness period seems evenly important than the illness and post-illness phases. Within the chaos hospitalisation subtype, a person's state of health generally forms the thread throughout their story about hospital admission. Structural characteristics match those of the chaos story type as described by Frank (1998) well; long sentences with an enumeration of events and in general expressing emotional states of fear. Contrary to the explicit mentioning of negative emotions, a lack of emotional expressiveness was also encountered. For some people, narrating the (past) experiences of negative emotions might be portrayed by a reluctance to write about them. For others, it could be that they have difficulty expressing these emotions through writing. A type of chaos identified within the hospitalisation subtype, chaos ICU, revolves around having no or fragmented memory due to the coma in the ICU. Disorientation and fear dictate the content and structure of these story fragments and make the chaos evident. The last subtype, chaos recovery, entails the experience of persisting complaints after acute illness and in essence carries a sense of hopelessness about the future (recovery).

These chaos subtypes show some distinct characteristics in comparison to prior literature. Firstly, describing the onset of symptoms before deep illness is marked as restitution by Spillmann and colleagues (2017) and Whitehead (2006) contrary to this study. In this study, respondents leave out an expectation to quickly recover which is interpreted as characteristic of the chaos story. Additionally, participants tend to quickly continue to the part where deep illness initiates. This might relate to the relatively rapid illness progression of COVID, however, reflects the importance of the shift to deep illness for the patients as well. Furthermore, in other studies, the diagnosis seems to play an important role in the illness process which often emits a restitution story. This is less prominent within the COVID narratives as they already suspect a COVID diagnosis or because their need for medical attention is dire. The chaos ICU subtype appears to be unique due to the experience of the induced coma and its effect on their memory of hospital admission. Suffering from a fragmented memory might impair the ability to make sense of an experience which may form a risk for a person to get stuck in chaos. Chaos recovery seems to fit experiences described by patients of CFS/ME and undiagnosed diseases (Spillmann et al., 2017; Whitehead, 2006). They also encounter precarious and uncertain treatment options with varying results.

Rushforth and colleagues (2021) reported a disrupted chronology and the portrayal of unpredictable symptoms in the narratives of people suffering from long COVID. These characteristics show a slight resemblance with the chaos recovery subtype. Participants in this study do not speak of their persisting symptoms as unpredictable per se, rather mentioning that the symptoms are experienced as tenacious which, for some, is unpleasantly unexpected.

Restitution

The restitution story type was identified in the form of three different subtypes: restitution hospitalisation, restitution in process, and restitution achieved. Restitution was most frequently encountered in the recovery stories. The first subtype, restitution in process, concerns a story in which recovery is ongoing. A vital aspect is a hope or expectation that one's health will improve (further) along the process of recovery. The subtype restitution hospitalisation represents a positive turning point in the participant's illness trajectory. These fragments are generally brief and revolve around noticing an improvement in their health. The last subtype of restitution is perhaps the most vivid as someone describes, implicitly or explicitly, that they feel as they did before illness. An overarching characteristic is the frequent audibility of a healthcare professional through the voice of the narrator which reflects one of Frank's (1998) notions of the restitution story type as speaking from the perspective of medical authority.

Restitution narratives among other illness narrative studies show similar characteristics: the expectation that health will be restored, seeking and undergoing treatment(s), and receiving a diagnosis (Spillmann et al., 2017; Whitehead, 2006). The aforementioned reflects the restitution in process and restitution hospitalisation fittingly. The restitution achieved subtype shows the most resemblance with Thomas-MacLean's study (2004) on women with breast cancer. Thomas-Maclean does, however, state that restitution does not cover illness experiences fittingly. A few differences might be accountable for this. Firstly, cancer in general entails the possibility of recurrence. Secondly, the way breast cancer affects the patient’s body (i.e. breast amputation) is more visible and immutable. The recurrence of COVID is plausible, although hardly expressed as a reason for concern. Regarding damage due to illness, former COVID patients experience a more indirect effect through persisting complaints (e.g. reduced stamina). These effects can restore, whereas breast amputation is more definite. Possibly due to these differences, COVID patients seem more able to achieve or expect to achieve restitution.

Quest

Among the identified quest stories, three substory types were accumulated: quest acceptance/coping, quest gratitude, and quest life (priorities). The acceptance/coping subtype portrays ways, passively or actively, of dealing with a different life due to illness sequelae. The essence of the quest gratitude subtype is the appreciation for life, (recovered) health, or other facets of life. The third subtype, quest life (priorities) concerns adopting a different attitude or (re)arranging life to focus on what has become more important in life.

The quest gratitude subtype appeared to be unique to this study’s sample. An explanation for this distinct occurrence might relate to the relatively high age of this study’s sample. This is under the assumption that illness is generally less disruptive to the life of an older person in comparison to that of a younger person. A study from Peterson, Park and Seligman (2007) on the relation of character strengths and recovery [from illness] shows that strengths such as bravery, kindness and humour lessen the impact on life satisfaction. This poses another theory about which people are prone to express gratitude. The other two quest subtypes showed a resemblance with the findings of Whitehead (2006). The acceptance/coping subtype is reflected in altering perspectives on life (recognizing limitations and making time and space for themselves) and changing pre-illness patterns (gaining new insights and making changes in their life). With regards to the life (priorities) subtype, the clearest parallel to be drawn with Whitehead's study is the mentioning of altering perspectives on life. The essence is similar; reflecting on life after illness and making choices to focus on different things than before (e.g. health, happiness, making time for oneself or with others). Despite the different illness courses of CFS and COVID, some experiences post-deep illness seem alike. Ultimately by presenting these quest stories, both groups accept their altered life, or at least that restitution is unfeasible.

Strengths and limitations

This study has several strengths. Firstly, the sample size of this study (N=143) is quite large for a qualitative study. Generalizing any findings is not within the scope of this study. A large sample does, however, provide a broader portrayal of experiences which ultimately strengthens the quality of this research. Secondly, the composition of the sample consisted of a fairly even distribution regarding gender which is favourable. This is important to gain an equal representation of both men and women. A third strength is that this study is the first of its kind to focus on a Dutch sample of former COVID patients. This adds to a better understanding of potential culturally unique illness experiences. Former research has either focused on a different illness type (e.g. long COVID) or applied solely thematic narrative analysis. Fourthly, including the period after hospitalisation in the questionnaire is considered a strength as well. It acknowledges that illness goes beyond the acute illness phase and that, in this case, illness extends to the period after hospitalisation. The data collection method used in this study poses a final strength. By allowing participants to narrate their experiences through writing, the respondent is minimally affected by external influences contrary to data collection through interviewing. Additionally, Pohjola (2020, p. 136) states that “writing may offer an opportunity to produce chaos narratives, perhaps more than mere interviewing”. Being able to face chaos might contribute to making sense of their experiences, subsequently helping them to transition to another story type.

A few limitations within this study should also be underlined. Firstly, the open-ended questions included in this study were part of a much larger battery of questionnaires. All in all, the time and subsequent cognitive strain it demands from respondents might cause the earlier mentioned respondent fatigue. For a group of people already frequently affected by fatigue and cognitive problems, questionnaires may be more burdensome. Ultimately, this negatively affects their ability to translate their illness experiences into a story (Rosenthal & Rosnow, 1991). As mentioned before the applied data collection method poses its strengths, however, some limitations as well. Collecting narratives through a questionnaire, contrary to an interview, inhibits the opportunity to ask follow-up questions (Patten, 2016). This might lead to unclear fragments which affect the ability to comprehend the essence of a person's story. Another limitation is that it favours people who are more able to express themselves through writing. Those who struggle to express themselves through writing might feel inclined to share even less (Hyman & Sierra, 2016). Another notable observation concerns the length of answers which vary considerably. This shows the duplex character of open-ended data collection methods. On one hand, respondents are offered a lot of freedom to write what they want how they want. On the other hand, it makes it more difficult to compare and analyse the data (Taherdoost, 2016). Very short responses may lack detail or context, whereas very lengthy responses may contain irrelevant information. In the future, this could be prevented by providing guidelines on response length, while keeping the questions open-ended and neutral to minimize the risk of influencing people's answers.

Recommendations

Regarding the recommendations, I would like to propose a couple of implications for practice and some subsequent recommendations for future research. Looking at the high frequency of chaos stories in this study, the beneficial effect of autobiographical writing seems apparent. This is also supported by Pohjola's (2020) findings. Based on the findings in this current study, we can conclude that narrating illness experiences in written form might have a therapeutic effect, as it aids patients to make sense of and process potentially impactful experiences. The first implication is to implement an intervention in hospitals which provides patients with the means to write down their illness experiences. It may help a person shift more readily out of chaos and into a restitution or quest story. This approach is low-cost and easy to implement, requiring little time from the healthcare worker.

Another notable, although common, finding was the low occurrence of quest stories in this study. As the quest narrative constitutes the acquirement of insights, it requires a conscious reflection on past illness experiences and one's current situation. It seems plausible that for some people, it takes a longer time (more than a year) of processing and reflecting to reach certain insights. To accommodate patients after hospitalisation as well, aftercare might be provided in the form of a support group which offers a place to reflect on and share their story, as well as having a listening audience. Another alternative might be to assign social workers. For example, patients are offered (bi)annual meetings with their assigned social worker to discuss their life since or with illness. Following Peterson, Park and Seligman's (2007) study on character traits and recovery from illness, it would be interesting to look into the conditions and patient characteristics necessary for developing quest narratives. In turn, this can be used to help people transition to a quest narrative.

As mentioned before, the narratives in this study are partially retrospective and partially real-time. For some, illness is still ongoing and with that, their illness narratives have not finished yet. Whilst the narrative is still in progress, their illness experience might change in time. Therefore, it might be valuable to conduct a longitudinal follow-up study. The goal would be to revisit the portion of respondents who ended their narratives in chaos to see how their story has developed over time (e.g. five years later).

Conclusion

This study's main contribution lies in providing a first insight into the illness experiences of former COVID-19 patients. All three of Frank's story types appeared in the illness narratives of former COVID patients. Chaos and restitution comprised the vast majority of encountered story types. The quest type was least frequently observed, yet, showed quite some variety relative to its scarce occurrence. Overall, the narration of illness experiences is diverse both in structure and content which resulted in the identification of ten substory types. In this study, substory types of chaos and restitution related to the illness course of COVID. The quest subtypes showed nuanced forms of how respondents reflected on their illness experience and were able to move past illness. In this study, a few characteristics were analysed that seem specifically associated with the COVID narratives. Firstly, the chaos pre-hospitalisation subtype portrayed a unique form. Respondents chose the starting point of their story at the onset of symptoms before hospitalisation, which deviated from the initial question they received. Telling their story as a whole seems important and thus meaningful to them. Moreover, describing the onset of symptoms appeared as chaos in this study in contrast to other studies which assigned the restitution story to this fragment. Secondly, the experience of ICU admission and its effect on the narrative construction was distinctive as well. This portion of COVID patients portrays a chaos story affected by a fragmented memory of their hospitalisation. The ability to make sense of a fragmented experience is doubtful. Ultimately, this poses a potential risk in the long term if an individual is stuck in a story dominated by chaos. Lastly, the subtype, quest gratitude, appeared as a unique form. The latter seems related to personality traits which explain the limited occurrence of this subtype and the quest narrative as a whole. Similarities between the experiences of COVID patients and those of patients with other illnesses can be traced back to overlapping features in the way the illness initiates and progresses. The unique aspects found among the COVID experiences can serve as guidelines for healthcare workers tending to this group of patients. Our current healthcare can be improved and supplemented by applying autobiographical interventions as well as providing aftercare by bringing people together to share and *listen*.

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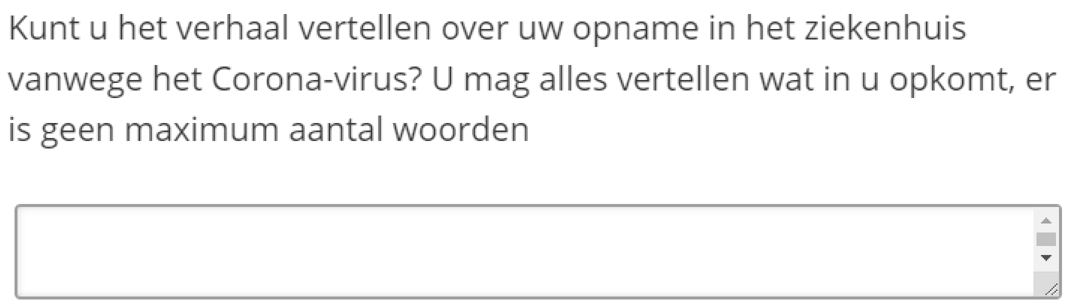
Appendices

Appendix A Open-ended questions



Kunt u het verhaal vertellen over uw opname in het ziekenhuis vanwege het Corona-virus? U mag alles vertellen wat in u opkomt, er is geen maximum aantal woorden

Kunt u het verhaal vertellen over hoe uw leven na uw opname is verlopen? U mag alles vertellen wat in u opkomt, er is geen maximum aantal woorden

Appendix B Overview quotations: original and translation

Quotation number	**Page number**	**Translated quote (English)**	**Original quote (Dutch)**	**Participant information**
		Chaos		
P01	21	After a positive test I initially continued work (at home), but eventually became increasingly ill (fatigued, loss of weight, oxygen shortage).	Na een positieve test heb ik aanvankelijk (thuis) doorgewerkt, maar werd uiteindelijk steeds zieker (vermoeidheid, gewichtsafname, zuurstof tekort).	P3, Male, 59 years old
P02	21	Sunday 21st of March positive for covid. Monday 22nd of March in the course of the day I got complaints such as fever and lethargy. Complaints continued the whole week. Felt like a heavy flu. Lots of coughing, fever and quick out of breath. Sunday 28th of March contacted the general practice centre and they advised me to come over. Once arrived did some tests and I was admitted that day.	Zondag 21 maart positief op corona. Maandag 22 maart in de loop van de dag kreeg ik klachten zoals koorts en lusteloosheid. Klachten hielden de hele week aan. Voelde als zware griep. Veel hoesten, koorts en snel buiten adem. Zondag 28 maart contact opgenomen met de huisartsenpost en zij adviseerden om langs te komen. Daar aangekomen enkele testen gedaan en ik werd die dag opgenomen.	P40, Male, 57 years old
P03	22	My hospitalisation doesn’t bring back pleasant memories, was picked up 2 x by the	Mijn ziekenhuis opname roept geen leuke herinneringen op, ben 2 x gehaald door de	P4, Male, 60 years old

		ambulance, and the days in the hospital were very tough and anxious, became increasingly short of breath and ill, was very afraid that I wouldn’t make it, and had to move around with a walker in my room because of these circumstances […] can still remember being scanned twice and with lots of oxygen and medication they tried to help me back on my feet again.	ambulance, en de dagen in het ziekenhuis waren erg zwaar en angstig, werd steeds benauwder en zieker, was erg bang dat ik het niet zou halen, en moest door deze omstandigheden mij met een rollator op mijn kamer verplaatsen […] kan me nog herinneren dat er 2x een scan is gemaakt en met veel zuurstof en medicatie probeerde men mij weer op de been te helpen.	
P04	23	Shouldn’t think back about it and others shouldn’t ask me questions about the how and what during the hospital admission. Makes me emotional if people remind me of that or ask me questions concerning how and what. Moreover…. in hindsight the admission etc passed by in a flash for me. Rather don’t want to be reminded of it, have been through	Moet er niet aan terugdenken en men moet ook geen vragen stellen over het hoe en wat tijdens de opname. Wordt emotioneel als men mij daarmee herinnerd of wel er vragen over stelt betreffende hoe en wat. Overigens…. de opname etc is voor mij achteraf als een flits voorbij gegaan. Liefst niet meer aan herinnerd worden, heb al meer meegemaakt	P93, Male, 70 years old

		more already like hospitalisation with severe pneumonia and hospitalisation for cerebral infarction. During that last one I can only remember that after about 3 hours I saw “the light” again.	zoals opname met ernstige longontsteking en opname herseninfarct. Van die laatste kan ik me alleen herinneren dat ik na ongeveer 3 uur “ het licht” weer zag	
P05	24	I was kept asleep for 9 days and didn’t consciously experience any of it	ik ben 9 dagen in slaap gehouden en heb daar niks van meegekregen.	P110, Male, 45 years old
P06	24	I remember being brought into the Emergency Department on Monday evening around 6.30 pm that pulmonary radiographs and a CT scan were made and I was told that I also had 2 pulmonary embolisms. Then I was transferred to a room in the ICU from that moment on I lost a lot. Sometimes when I woke up I thought I was in a theatre with the bed. On the 2nd of March I said goodbye to my wife in person and said goodbye to my children via skype	Ik weet nog dat ik maandagavond tegen 18.30 uur ben binnengebracht op Spoed Eisende Hulp dat er longfoto's en een CT scan zijn gemaakt en ik te horen kreeg dat ik ook 2 longembolien had gehad. Daarna ben ik naar een kamer gebracht op de IC vanaf dat moment ben ik veel kwijt. Soms als ik wakker werd dacht ik dat ik in een theater met het bed stond. 2 maart heb ik persoonlijk afscheid genomen van mijn vrouw en via skype afscheid	P35, Male, 54 years old

		and from my bed went over my last wishes and the funeral arrangements with my eldest daughter this was an intense and emotional moment. Then I was made ready to be put to sleep and whether I would wake up again??...no one knew but I was so ill that I did not realise this at all. Thursday afternoon, 4th of March, I awoke from the coma again.	genomen van mijn kinderen en vanaf het bed mijn laatste wensen en uitvaart doorgenomen met mijn oudste dochter dit was een heftig en emotioneel moment. Daarna werd ik klaar gemaakt om in slaap te worden gebracht en of ik weer wakker zou worden???...niemand die het wist maar ik was zo ziek dat ik dit helemaal niet goed besefte. Donderdagmiddag 4 maart ben ik weer ontwaakt uit coma.	
P07	26	Big disappointment. Extremely tired, coughing a lot, Could endure only few stimuli, could sleep all day. Difficulty with concentration memory and very easily irritated as a result.	Dikke tegenvaller. Extreem moe, veel hoesten, Kon weinig prikkels hebben, kon de hele dag slapen. Moeite met concentratie geheugen en heel snel geïrriteerd daardoor.	P28, Male, 56 years old
P08	27	We are 4 months on. I can't handle any real hustle yet. Stamina is not there yet and don't feel like doing anything. Am not fit. Hard to explain	We zijn 4 maanden verder. Ik kan nog geen echte drukte aan. Conditie is er nog niet weer en heb nergens zin aan . Ben niet fit.	P68, Female, 51 years old

		but somehow the energy is not there.	Moeilijk uit te leggen maar de energie is er op de een of ander manier niet.	
		Restitution		
P09	28	With medication (antibiotics and blood thinners) it went better every day. On Thursday I was allowed to go home again.	Met medicatie (antibiotica en bloedverdunners) ging het elke dag beter. Op donderdag mocht ik weer naar huis.	P47, Male, 67 years old
P10	28	Fortunately it started improving fairly quick for me and after a few days I was allowed into the ward again.	Gelukkig ging het vrij snel de goede kant weer op met mij en mocht ik na een aantal dagen alweer naar de afdeling.	P59, Female, 59 years old
P11	28	After medication and oxygen it started to improve again in the course of Tuesday the 30th of March. Saturation was around 94-95.	Na medicatie en zuurstof ging het in de loop van dinsdag 30 maart weer beter. Saturatie was rond de 94-95.	P40, Male, 57 years old
P12	29	After a few weeks a very slow progress. Am still tired quickly and heavy-headed. Can complete an hour of training at the physio with oxygen. And going to work three days each week for two hours a day. I can’t manage more yet hope to slowly improve this.	Na enkele weken heel langzaam vooruitgang. Ben nog steeds snel moe en lusteloos. Kan nu bij fisio met zuurstof gebruik weer een uur training vol maken. En ga drie dagen in de week voor twee uurtjes per dag naar werk. Verder kom ik nog niet hoop dit	P48, Male, 60 years old

			langzaam te kunnen uit bouwen.	
P13	29	In order to rehabilitate as fast as possible, I went to a physiotherapist and referred to a respiratory therapist.	Om zo snel mogelijk te revalideren, ben ik naar de fysiotherapeut gegaan en doorverwezen naar de ademhalingstherapeut.	P75, Female, 50 years old
P14	30	I live my life as before.	Ik leef mijn leven als voorheen.	P14, Female, 47 years old
P15	30	After about a week or 6 I was fully my old self again.	Na een week of 6 was ik weer volledig de oude.	P99, Male, 67 years old
P16	30	Currently I am back to doing almost everything I did before COVID-19.	Momenteel doe ik weer nagenoeg alles wat ik voor COVID-19 ook deed.	P80, Age and gender unknown
P17	30	After a few months, I no longer felt any restrictions.	Na een paar maanden voelde ik geen beperkingen meer.	P96, Male, 70 years old
P18	30	At check-up visit to pulmonologist (incl lung x-ray) declared fit again in early July.	Bij controlebezoek aan longarts (incl longfoto) begin juli weer fit verklaard.	P45, Male, 55 years old
		Quest		
P19	32	living life more calmly	Rustiger leven […]	P33, Male, 74 years old
P20	32	I have had to learn to accept and take more time for a lot of things and some activities just aren’t possible anymore such as maintenance	Ik heb moeten leren accepteren om over veel dingen veel langer te doen en sommige zaken gaan gewoon niet meer zoals grote klussen aan	P116, Male, 74 years old

		work on the house (painting), also that my brain can stutter suddenly (not knowing expressions, names e.g.). […] I live with more moments of rest and if I really can't manage then I cancel all my plans for the week.	huis doen (schilderen), ook dat mijn brein zomaar kan haperen (uitdrukkingen, namen e.d. niet meer weten). […] Ik leef meer met rustmomenten en als het echt even niet gaat dan zeg ik alles af voor een week	
P21	33	After a few months I didn't feel any limitations anymore. Am happy and grateful for that, every day still	Na een paar maanden voelde ik geen beperkingen meer. Ben daar nog elke dag blij en dankbaar om.	P96, Male, 70 years old
P22	33	I do want to mention that my brother-in-law was next to my room with the same symptoms, but he did not make it despite 8 weeks in ICU, this does leave a deep impact, and tells me I was very lucky.	wel wil ik nog even kwijt dat mijn zwager naast mijn kamer lag met dezelfde klachten, maar die heeft ondanks 8 weken ic het niet gehaald, dit laat wel een diepe impact achter, en zegt mij dat ik veel geluk heb gehad.	P4, Male, 60 years old
P23	33-34	I've come to face life very differently. Together with my wife who spent 2 weeks in the ICU, we went in a completely different direction. We enjoy life much more now.	Ik ben heel anders in het leven gaan staan. Samen met mijn vrouw die 2 weken op de ic heeft gelegen zijn we een hele anders kant op gegaan. We genieten nu veel meer van het leven.	P23, Age and gender unknown

P24	35	After Covid, I started thinking and arranging differently for my family so that they are left well financially after my death. Try to exercise as much as possible and spend time with family and friends	Na Covid ben ik anders gaan denken en regelen voor mijn gezin zodat ze na mijn dood goed financieel achter blijven. Probeer zoveel mogelijk te sporten en tijd door te brengen met famile en vrienden.	P27, Male, 47 years old