



Agency constructions in chronic illness narratives

– a discourse analysis

Master Thesis Positive Clinical Psychology and Technology

by

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Abstract

Living with a chronic illness has the potential to greatly influence an individual's life and is frequently connected to physical barriers and limitations in many areas of an individual's life. The loss of agency is a frequently experienced phenomenon by individuals with chronic illnesses. Agency, in the quantitative tradition, can be described as the ability to act. However, in discursive psychology as part of the qualitative tradition, agency is defined in terms of positioning oneself as an active and responsible agent in the own life. While previous research has investigated the agency of individuals with chronic illnesses, more insight is needed not only into what chronically ill individuals experience but also into how they express it in language. By taking a discursive approach toward agency, this research aims to gain insight into how individuals with chronic illnesses construct discursive agency positions as they narrate their experiences. For this, the 10DT Model (Toivonen et al., 2019a) is used which defines ten different discursive positions of nonagency and agency, of which the agentic side is explored, defined, and refined in this thesis. Based on 4 open question interviews conducted online and in person with German chronically ill individuals, diagnosed with Multiple Sclerosis, Crion, and Endometriosis, the different agency positions constructed in their life stories were identified and described. A total of 8 out of the 10 discursive agency tools in the 10DT Model occurred in the interviews, both reporting and reflective tools. The two most displayed discursive agency tools were *Modifying Action* (AT6) and *Cognizance* (AT7). Meanwhile, the discursive agency tools *Reflected Function* (AT8) and *Perspectival Positioning of Others* (AT10) were not displayed in the interviews. Further, participants expressed the different discursive agency positions in very similar ways, despite being diagnosed with different chronic illnesses. However, differences were found concerning the frequency of the display of different discursive agency tools between participants. This study makes an important contribution to chronic illness research by demonstrating that individuals with a chronic illness construct many different agency positions in their life stories. Additionally, the agency side of the 10DT Model was further explored and refined. These findings can be especially important for health care practitioners and other professionals working with chronically ill individuals, to also carefully listen to the agency constructions to then reinforce their sense of agency.

Keywords: Chronic illness, agency, discursive research, narratives

1. Introduction

“I would say never give up. Never give up and just do what you feel like doing. So don't let it get you down. And when people say ‘but you don't look chronically ill’, people don't know what you're like on the inside. You might look great on the outside, but nobody knows what you're like on the inside.

And I also think people should talk more about this topic. Definitely.”

- Helen (participant)

In 2019, the World Health Organization estimated approximately 70% of all deaths worldwide are accounted for by chronic illness (World Health Organization [WHO], 2019). Moreover, in 2022 the German Foundation for Health Knowledge found that 40% of the German population have one or more chronic illnesses. Further, 30% of the German population are living with a chronic illness for 20 years or longer (Stiftung Gesundheitswissen, 2022). According to the Center for Disease Control, a chronic illness is a condition that endures longer than one year and can cause both the requirement for long-lasting medical attention and the limitation of activities (Center for Disease Control and Prevention, 2021). Frequently, chronic illness comes with a great range of difficulties for the individual, such as pain, changes in lifestyle, and the inability to fulfill certain social and developmental roles, and often requires great adjustments in daily life (Hwu, 1995). Moreover, individuals living with a chronic illness often experience difficulties with or loss of personal agency, that is, their sense of self and control over their body (Tang, & Anderson, 1999). For individuals with chronic illnesses, losing their agency is often experienced as losing the ability to action in some areas of their individual lives, which can be especially difficult (Kupferberg & Green, 2005).

As the loss of agency is a frequently experienced phenomenon by chronically ill individuals, more attention to this topic is needed on how this is shown in daily life such as in language. Because of this, the current study focuses on how individuals with chronic illnesses construct their agency in language and narratives. Taking a discursive analytical approach, interviews are conducted and analyzed by the 10 Discursive Tools Model (Toivonen et al., 2019a) to examine which discursive positions individuals with chronic illnesses construct concerning their agency.

Living with a chronic illness often shows to be a great disruption and a major turning point in an individual's life and causes a necessity to adapt as the illness-related challenges never completely

vanish (Bury, 1982; Royer, 1998; Tang & Anderson, 1999). Chronic illness frequently goes beyond the physical aspect of a disease but also affects various other parts of an individual's life such as feelings, thoughts, beliefs, and assumptions about the world, family life and loss of roles, emotional life, and every day (Bury, 1982; Prefontaine & Rochette, 2013; Williams et al., 2019). Therefore, individuals with chronic illnesses are often required to develop new definitions of their self and their life and re-evaluate priorities and search for new meanings in life (Tang & Anderson, 1999).

Furthermore, the course of a chronic illness is often shaped by relative unpredictability and uncertainty causing difficult circumstances for the individual (Bury, 1982; Royer, 1998). In their own life stories, individuals with chronic illnesses frequently mention the physical limitations and lifestyle-related consequences their condition brings (Lee & Poole, 2005). Besides the physical difficulties of living with a chronic illness, individuals also describe communication difficulties in their social environment, such as avoidance of talking about their illness, lack of understanding of their condition or making assumptions about their condition (Lee & Poole, 2005). Further, individuals with a chronic illness frequently experience a loss of their agency which can be especially difficult (Kupferberg & Green, 2005; Tang & Anderson, 1999).

In the quantitative tradition, agency is viewed as the capacity to control resources and the ability to act, therefore, the capacity for effective action, and is a psychological quality that can be measured (Sercombe & Donnelly, 2013; Sewell Jr, 1992). The qualitative tradition, however, mostly analyzes how the concept of agency is constructed in language and stories and how individuals make sense of their agency. Individuals are thought to construct agency in terms of expressing one's own will and acting independently according to it without the necessity of the help of others (Jolanki, 2009). Further, individuals display a full sense of choice, being able to initiate change on their own, and feeling confident in control over situations when they express agency in their life stories (Adler, 2012).

Previous research has focused on the agency in chronic illness narratives in the hospital setting. In the study of Tang and Anderson (1999), stories of individuals with chronic illnesses constructed the loss of agency in terms of their illness management, having difficulties understanding their illness and the treatment, or lacking the resources to facilitate effective illness treatment. Moreover, agency in

individuals with chronic illnesses was lost through ineffective communication in the hospital setting. In the study of Koch et al. (2004), individuals with chronic illnesses described their agency to involve being able to self-manage their illness and life and being able to add input into the doctor-patient relationship.

However, the basis of this research lies in the discursive analytical approach of the qualitative tradition towards agency. Discourse analysis is a broad methodological approach based on theoretical and metatheoretical assumptions that views discourse in language as a medium for constructing human action and through which versions of the world are constructed and produced for sense-making (Potter, 2003; Potter, 2012). Further, discourse analysis views the individual to construct psychological worlds, actions, social life, or histories through their accounts and descriptions, using language, grammatical structures, words, and categories (Potter, 2012; Potter & Edwards, 2001). Instead of language being viewed as an abstract system of words and terms, discourse analysis views talk and texts as part of social practices and addresses the active use of language (Potter, 2003). Studying discourse becomes especially interesting as it is a tool for studying the mind, social processes, and events as they are in real life in human affairs and social interactions (Potter, 2003).

When looking from a social constructionist and discursive perspective, agency construction in language and stories is defined as positioning oneself as an active and responsible agent in the own life and adopting a reflective observant stand, evaluating the past events from the present moment (Seilonen & Wahlström, 2016). Therefore, in alignment with the qualitative tradition and the discursive psychological perspective, in the present research agency refers to displaying a variety of discursive constructions of being-ableness in language, that is, constructing positions for oneself where one is able, aware, or willing (to do something) (Toivonen, 2019; Toivonen et al., 2019a).

Nevertheless, there is no research that takes a discursive analytical approach toward agency in individuals with chronic illnesses. While the traditional work in psychology usually focuses on the factors-and-outcome logic and poses questions such as “What is the influence of X on Y?”, discourse analysis rather emphasizes action and construction in talk and aims to answer questions such as “What is an X? How is X done?”. Taking a discursive approach can be especially useful as it gives insight and highlights the close inferential relationship between versions of “reality” and “the mind”, which

people construct both in their talk (Wiggins & Potter, 2008). Further, the discursive analytical approach does not take a psychologizing perspective toward what a person is or does. Instead, it studies one of the most intimate, omnipresent, complex, and interesting issues about human life, that is, talk and speech (Potter, 2003). Therefore, applying a discursive analytical approach can give insight beyond the objective content level of the phenomenon in narratives and rather consider the role of the phenomenon in terms of the individual's descriptions, categories, and orientations (Potter, 2003). Hence, taking a discursive analytical approach toward studying agency in individuals with chronic illnesses can reveal how they construct agency in relation to their illness experience.

For taking a discursive analytical approach and analyzing discursive agency positions, the 10 Discursive Tools (10DT) Model is used. In the original study, the 10DT Model was created based on nine first psychotherapy sessions and shows how psychotherapy clients ascribed agency or nonagency to themselves through constructing different discursive positions in language. The 10DT Model provides 10 different discursive positions, so-called "tools", identifying and defining two dimensions of discursive positions of nonagency and agency constructed in language, see Table 1 (Toivonen et al., 2019a). When speaking of tools, the 10DT Model refers to a metaphor that emphasizes that taking a nonagentic or agentic position can also be viewed as a discursive act. Further, the ten discursive tools are grouped into non-reflective and reflective discursive positions, meaning that the individual either displays a non-reflective or reflective standpoint towards their description of themselves as the actor (Toivonen et al., 2019a).

Table 1

Summary of the Discursive Tools of Nonagency of the 10DT Model

Nonagency Tool (NAT)	Short Definition
Non-reflective tools	
1. Dismissing (<i>Accepting</i>)	The issue is unrelated to oneself, any meaningful personal relationship with a supposed problem is denied or mitigated.
2. Others as actor (<i>Free to act</i>)	Some phenomenon/event is functioning as the actor, the client's position is either not verbalized or is that of a victim, object, or stooge.

3. Exteriorization (<i>Interiorization</i>)	Experiences exist as their own entities and are not one's own creation.
4. Not initiating action (<i>Initiating action</i>)	Not being able to initiate action.
5. Not stopping or curbing action (<i>Stopping or curbing action</i>)	Not being able to stop what one is doing
6. Not modifying action (<i>Modifying action</i>)	Not being able to make constructive choices.
Reflective tools	
7. Noncognizance (<i>Cognizance</i>)	Not understanding, knowing, noticing, etc. something about one's experiences.
8. Reflected dysfunction (<i>Reflected Function</i>)	Having chosen a way of acting that can no longer be sustained.
9. Discontinuance (<i>Continuance</i>)	The current actions/experiences are not meaningfully related to the past/future.
10. Presumptive positioning of others (<i>Perspectival positioning of others</i>)	Not taking into account other persons' perspective and being unable to coordinate meanings in a situation.

Note. The tools in the brackets are the corresponding agency tools of the 10DT Model.

Moreover, the 10DT Model was applied in another study to the client's initial problem formulations in psychotherapy to investigate how clients construct nonagentic positions at the beginning of psychotherapy. The clients' problem formulations were classified into 10 formulation categories in which the first eight tools of the 10DT Model were found in the problem accounts. Further, all clients used more than one tool in their formulation (Toivonen et al., 2020). Additionally, in a further study, the 10DT Model was used to study discursive discordances in the first psychotherapy session in which there was a misalignment between the client and therapist in terms of how they discursively ascribed agency to the client. Four types of discordances were found in two different dimensions, namely agency ascriptions and reflectivity ascriptions (Toivonen et al., 2019b).

However, the 10DT Model has only been applied to individuals with psychological complaints and in a psychotherapy setting. Because of this, it would be interesting to investigate the construction of agency and, thus, apply the 10DT Model to other groups of individuals who may struggle with agency, such as individuals with chronic illnesses. Further, the original study mainly focused on the

nonagentic positions of the model and the nonagency constructions of the clients. Clearly, putting a focus on agency in studying chronic illness narratives is essential. For individuals with chronic illnesses, agency has been found to enable individuals to productively cope with their illness (Hay, 2010). Hence, this study aims at exploring the agentic side of the 10DT Model.

Overall, there exists no research taking a discursive analytical approach towards agency in the narratives of individuals with chronic illnesses and examining what discursive positions they display. For this reason, the current study investigates the different kinds of discursive agency positions individuals with chronic illnesses construct in their language. This is done by conducting semi-structured interviews with open questions and analyzing the chronic illness stories based on the 10DT Model. Therefore, this study aims to answer the following research question:

“How do individuals with chronic illnesses construct their agency when narrating about chronic illness?”

2. Method

Design and Procedure

The current study was part of a larger study called “How people with chronic health conditions story their past and future lives” and aimed at collecting additional data in the form of interviews with individuals with a chronic illness. The larger study was approved by the Ethics Committee of the University of Twente (ethical approval number 211138). The current study included a quantitative online survey about demographic information and a semi-structured interview conducted in person or online. For recruitment, an invitation flyer was distributed to German patient organizations via email which included a link to an online survey about demographic data. Through the survey tool Qualtrics, I collected general demographic data (e.g. age, gender) and information about the participants’ chronic illness (e.g. type of diagnosis, having received support in form of coaching, counseling, or psychotherapy). Next, in the online survey, I asked the participants about their willingness to participate in the interview study and being contacted for this purpose. If consent was given, I contacted the participants for an interview appointment and sent them an information sheet including the background and content of the study, eligibility criteria, benefits, and burdens of participation, confidentiality, and information on the research team.

I conducted interviews either in person or via video conference online. The interviews served as a means to examine the discursive constructions of agency in the narratives of individuals with chronic illnesses. Two of the interviews were conducted online via videoconference and were recorded over the platform Microsoft Teams. Moreover, two of the interviews were conducted in person and were audio recorded. The data was collected in German, as it is the participants' native language, and it was unclear which proficiency level of English the participants have. Further, research found that individuals who are more advanced in a language (such as native speakers) elaborate more on answers to questions and have the ability to construct and sustain narratives in comparison to intermediate speakers (He & Young, 1998). Hence, the interviews were conducted in German. The data collection period took place in May 2022.

At the interview appointment, I asked the participants to read the information letter about the study and fill out the consent form and give active consent to take part in the study (Appendix A). If the participants understood the information and gave their consent, the interview started, and I gave the participants a short introduction about the procedure and structure of the interview. Following, I provided the participants with several open questions and asked them to talk about their experiences and perspectives of living with a chronic illness (Appendix B). The completion of the interview took the participants approximately 60 minutes. At the end of the interview, I thanked the participants for their openness and willingness to participate. In case the participants wanted further information about the study, they could either ask after the interview or could contact me via email. If participants wished to withdraw from the interview, they could do so at any given time without providing a reason. Participants did not receive any form of incentives for taking part in the interview. The anonymous interview transcripts and study results are saved for 10 years in a secure data-saving place of the University of Twente.

Participants

The inclusion criteria were that participants perceived themselves as living with a chronic illness were able to speak German and had the sufficient energy and cognitive skills to conduct a one-hour long interview and reflect upon their experiences living with a chronic illness. Participants needed to be at least 18 years old. An overview of the participants and the demographical information can be seen in

Table 2. In total, there were four participants (N=4), of which three were women and one was a man with an age ranging between 28 and 55 years. Two of the participants were diagnosed with Multiple Sclerosis, which is a chronic illness affecting the central nervous system, causing inflammation and destroying nerve cells which alters electrical messages in the brain (John Hopkins Medicine, n.d.-b). Further, one participant was diagnosed with Crion, which can be identified by chronic relapsing inflammation of the optic neuropathy (Lee et al., 2018). Lastly, one participant was diagnosed with Endometriosis, which is a gynecological chronic illness in which the tissue that looks and acts like endometrial tissue inside the uterus grows outside the uterus and often causes severe pain (John Hopkins Medicine, n.d.-a). All of the participants were German. Three of the participants had received support in form of coaching, counseling, or psychotherapy, one of the participants had received none of those.

Table 2

Overview of participants and demographical information

Name	Gender	Age	Type of Chronic Illness?	Received talk therapy?
“Hannah”	Female	55	CRION	Yes
“James”	Male	31	Multiple Sclerosis	Yes
“Maria”	Female	28	Multiple Sclerosis	Yes
“Helen”	Female	40	Endometriosis	No

Materials

The purpose of using an interview as a data collection method is to allow the participants to tell their own experiences and to invite rich data for the use of a detailed discursive analysis of their discursive positions of agency. Conducting interviews as a data collection method is an efficient means of evoking “talk on the topic”. Further, open-ended interviews can give room to sharing experiences about topics from the past, present, and future perspectives and often yield longer, more detailed, and more accurate responses in comparison to those containing closed questions (Nikander, 2012; Oxburgh et al., 2010). Participants are given the opportunity to talk about their experiences from their own personal perspectives and have room to express their own opinions and feelings while the

interviewer is able to control the shared information through reactions and questions (Nikander, 2012). Interview data can especially be useful for discourse analysis due to its fine-grained detail in which individuals make sense of themselves and build versions of themselves and the world (Nikander, 2012). Because of this, interviews were used as a data collection method and followed an open-question interview protocol (Appendix B).

An open question can be defined as a question that is framed in such a way that the interviewee is not restricted in their answer (Oxburgh et al., 2010). Based on this guiding principle the open-question interview protocol was created. Firstly, the open questions asked aimed at inviting the participant to freely talk about their experiences with living with a chronic illness, such as “Can you tell me about your story how it is living with a chronic illness?”, “Can you tell me about difficult experiences you have had living with a chronic illness?” and “Can you tell me about positive experiences you have had living with a chronic illness?”. Further, more specific open questions yielding toward the researched topic were asked, such as “Can you tell me about experiences in which your life as living with a chronic illness has impacted your agency?”. Lastly, the two open questions “Is there anything else you would like to share in relation to living with a chronic illness?” and “If you could give yourself a piece of advice at the beginning of your illness, what would you say?” invited the participants to share anything else that was mentioned and to give a concluding statement towards their experiences.

If needed, follow-up questions were used to help specify the interviewee’s responses in cases where only little was narrated. Follow-up questions, such as “What part of the experience made it a negative experience?” or “What part of this experience was especially imprinting?” aimed at helping the participant by initiating further elaboration on their experience.

Data Analysis

Following the data collection phase, the interview recordings were transcribed with the program Happy Scribe. After the transcription of the program was completed, I proofread the transcripts while listening to the interview recording to check the correctness of the transcript. Further, the transcripts were cleaned in terms of filler words and word repetitions (such as “uh” or “I...I...I...I understood”) to increase comprehensiveness.

As a basis for the analysis of the interviews, the 10 Discursive Tools Model (10DT) developed by Toivonen et al. (2019a, 2019b, 2020) was used to identify the participants' discursive agentic positioning. The 10DT Model aims at showing how nonagency (and agency) is discursively constructed in interaction and how nonagentic and agentic discursive positions are constructed in language. However, the existing research on the 10DT Model is focused on the nonagentic discursive positions while this thesis focuses on agency. Therefore, as a part of this thesis, I aimed to define and elaborate on the agency side of the model. For defining the agency tools, the existing definition of each nonagency tool of the 10DT Model was examined and based on the nonagency positions I formulated the conceptual opposites. After formulating and defining the agency tools, consensus meetings were held with the author of the 10DT Model where the definitions of the agency positions were revised. Additionally, to increase the trustworthiness of the definitions, consensus meetings with another master's student and a Ph.D. student, who are also currently working with the 10DT Model, was held where the definitions of the agentic positions were discussed.

For analyzing the data, first, the interview transcripts were roughly scanned for displays of discursive agency positions. A discursive agency position refers to the ascription of agency and can be identified by the individual displaying a position of being-able in language and showing oneself in a responsible and active stance towards actions and situations (Toivonen, 2019; Wahlström, 2016). All interview transcript excerpts (paragraphs) which included such a discursive agency position were extracted and then used for further analysis. I performed the qualitative discursive analysis using the comment function in Microsoft Word as a tool for organizing the use of the different discursive positions of agency. Following, I read the extracted interview transcripts excerpts and scanned for the display of each defined discursive agency tool of the 10DT Model where the individuals constructed agentic positions. Therefore, similar to a coding process, passages where participants constructed one of the defined discursive agency positions were then marked and matched to the corresponding discursive agency tool of the 10DT Model. As an example, the passage "And if it doesn't work, it doesn't work. Then it's okay." was marked as the discursive agency tool *Accepting* (AT1) is constructed. Lastly, the identified interview transcript passages which included a discursive agency tool of the 10DT Model were then translated into English. For this, the online translator machine

DeepL was used for the translation from German to English. Additionally, any inconsistencies in translation were corrected by the researcher, who is fluent in both German and English.

3. Results

An overview of the definitions and distribution of discursive agency positions based on the 10DT Model is presented in Table 3. The abbreviation AT refers to *agency tool*. The main findings show that *Modifying Action* (AT6) and *Cognizance* (AT7) were the mostly displayed agentic discursive tools while *Reflected Function* (AT8) and *Perspectival Positioning of Others* (AT10) were not constructed in the data at all. Both non-reflective positions (AT1-AT6) and reflective positions (AT7 – AT10) were displayed in the interviews. The participants' names in the data extracts are pseudonyms.

Table 3

Summary of Discursive Positions of Agency based on the 10DT Model

Agency Tools	Short definition – The tool displays agency as...	Frequency
Non-reflective positions		
AT1 - Accepting	The issue being related to oneself, being alright with the problem existing	3
AT2 - Free to Act	Nothing is hindering from action, there is no obstacle that is keeping from action	7
AT3 - Interiorization	Accepting that the circumstances are related to who they are and their life, placing the psychological experience inside their mental realm and as part of them	1
AT4 - Initiating Action	Able to initiate action, able to do something	5
AT5 - Stopping or Curbing Action	Able to stop something one does not want to do or experience	1
AT6 - Modifying Action	Able to make constructive choices, being flexible in choice	9
Reflective positions		

AT7 - Cognizance	Understanding, perceiving, knowing, noticing what one is feeling, looking at one's experience from a reflective position	9
AT8 - Reflected Function	Having chosen a way of acting that can be sustained, noticing that there is a good way of dealing with difficulties	0
AT9 - Continuance	Constructing a coherent timeline where the past, present, and/or the future are connected	3
AT10 - Perspectival Positioning of Others	Understanding that the perspective of others is not transparent and can be different than expected, taking this unknowingness into account	0

Accepting (AT1)

With this tool, the participants constructed a position where they displayed themselves as being personally related to an issue. *Accepting* was displayed when the individual acknowledges the issue and can accept the existence of a problem. The connection between the individual and the problematic issue is clearly stated and expressed. This agentic position was constructed three times in the data.

In the following extract, "James" talks about living with a chronic illness and the difficulties he encounters in daily life.

"Of course, I am limited and that will probably never be as good as it used to be." (James)

While James acknowledges his limitations caused by the chronic illness, he also takes an accepting position towards it. First, by starting the sentence with "of course" he acknowledges the self-evident nature of the existence of his chronic illness and the limitations it brings. He points out, that his condition "probably will never be as good as it used to be". By using the word "never" he acknowledges the unchangeable nature of his situation while at the same time by using the word "probably" he leaves room for possible improvements in the future concerning his condition. Further, by speaking of this limitation in the first person he displays his limitations as being part of him instead of the chronic illness being something external that is limiting him. And like this takes an accepting position towards his illness experience.

The following extract is from the end of "Helen's" interview, in which she gives advice on how other individuals with chronic illnesses should deal with the difficulties chronic illness brings

based on her own experiences. Helen is speaking about the days when she experiences a lot of symptoms of her chronic illness and how she deals with these situations when she is unable to do something because of her chronic illness.

“And if it doesn't work, it doesn't work. Then it's okay.” (Helen)

While giving advice to other individuals with chronic illnesses, she displays herself as accepting of such situations. First, by saying “And if it doesn't work” she presents a situation in which she is unable to do something. This display constructs a position in which she considers that such situations can arise, which shows her acknowledgment and acceptance of her condition. Furthermore, her expression can be read as a display of acceptance by saying “Then it's okay”. Here, she constructs an accepting position when the situation presented by her, being unable to do something, arises. Helen constructed this position in the interview twice, both times in relation to displaying acceptance toward her limitations.

Free to Act (AT2)

This agentic position was constructed when individuals expressed that they are not an object in their life but positioned themselves as an agent who is able to act. *Free to Act* was displayed in language as nothing hindering the individual and no obstacle keeping the individual from action. This agentic position was constructed in the data seven times.

In the following extract, “Hannah” was asked what an ideal day looks like for her when she is experiencing only little complaints and limitations caused by her chronic illness. She describes what things she enjoys doing when she is experiencing fewer or no symptoms from her chronic illness.

“...and just go about your day doing whatever you feel like doing at that time.” (Hannah)

Here responding to the directly asked follow-up question in the interview, Hannah is presenting a scenario based on her own experiences in which she is experiencing low symptoms and does what she likes to do. She constructs a position in which nothing is hindering her from doing what she likes to do when it comes to her ability to act. She constructs an agentic position by highlighting having a large scope of action and freedom in her choice of action, hence, not being an object but the subject in her

life story who is free to act. By using the word “whatever” she emphasizes the variety of actions she can do with not being hindered by her chronic illness in her choice.

Below, James is speaking about his life circumstances in daily life and how he manages to live with a chronic illness that limits him sometimes.

I do not need help in the household and also no physical care. (James)

Here, James mentions that he does not require specific aid when it comes to him living at home. He is constructing an agentic position by speaking of himself in the first person and taking an active position in explaining what he does not need any help with. While he is not explicitly verbalizing where his scope of action lies, the tool *Free to Act* is a very basic and low form of displaying agency and is constructed when there is no obstacle that is keeping the individual from action as is the case in this example. Here, James presents having help in the household as a real potential scenario and just the absence of having help in the household allows him to construct this agentic position.

Interiorization (AT3)

Interiorization as an agentic position is constructed in language when the individual discursively displays that they accept that the circumstances are related to who they are and their life and that they place the psychological experience inside of them and as part of them, as an external object. This agentic position was constructed in the interviews once.

This extract was at the end of Helen’s interview where she was given room to share something that was not covered by the previous questions. Helen shares about the pitfall and difficulty of having a chronic illness that is not directly visible on the outside and how she thinks this should be handled. She directs her response toward other individuals who do not have a chronic illness.

“And when people say ‘but you don’t look chronically ill’, people don’t know what you’re like on the inside. You might look great on the outside, but nobody knows what you’re like on the inside.” (Helen)

Here, Helen speaks about the misconception of how people do not always see that an individual is chronically ill on the outside but that nobody can see how the inner experience of the individual is. Helen distinguishes between the outward appearance and the inner experience of living with a chronic

illness. By saying “And when people say ‘but you don’t look chronically ill’, people don’t know what you’re like on the inside” she places the illness experience inside of her and as part of her psychological experience. Like this, she displays the tool *Interiorization* by connecting the chronic illness to her as a person and inside her psychological realm.

Initiating Action (AT4)

This agentic position was constructed by individuals when they displayed themselves as able to initiate a desired action and/or displayed themselves as able to carry it out. This position was constructed in the data five times.

In the following extract, Hannah speaks about the time when she received the diagnosis of her chronic illness and how she reacted to it.

And then there was this fighting spirit, you'll manage, you'll walk down these stairs again someday. (Hannah)

Hannah makes use of inner dialogue to motivate herself to carry out her desired action, such as walking down the stairs again after receiving her diagnosis. Further, she describes her attitude as a “fighting spirit”, constructing a position in which there is a great ambition to carry out the desired action. By speaking in the future tense, she expresses a certainty that she will initiate her action choice, here, walking down the stairs again.

Below, James is talking about how he manages his household while living with a chronic illness.

And every now and then I even go shopping. By bike to the supermarket near here. (James)

Here, James is showing a simple display of initiating a desired action, here, going shopping. By saying “every now and then” and “I even”, he constructs a position in which he emphasizes that initiating this type of action is one that he can manage but it is nothing he takes for granted. Further, he stresses his constructed position by elaborating on how he carries out the desired action, which in this case is driving by bike.

Stopping or Curbing Action (AT5)

This agentic position was constructed by the participants when they displayed themselves as being able to stop doing something they do not want to do or experience or stop something from happening that they do not want to happen. This agentic position was constructed in the data one time.

In the following extract, Hannah is talking about the situation where she wanted to get back into work after receiving her diagnosis. She was not able to return to her normal job due to restrictions caused by her chronic illness and was offered a different job by the institution for disabled people. This was very dissatisfying for her because she did not want to work in that field but in her old job. Below, she describes her reaction toward that job offer.

I have rejected that so far because I said no. (Hannah)

Hannah displays herself as being unhappy with the current work situation and rejecting the turn it has taken. Therefore, she claims an agentic position by verbalizing what she does not want to happen, in this case not wanting to have that job and rejecting the job offer. Further, by saying “I said no” she refers to the actual situation in which she decided to not take the job. Here, she displays herself as someone who is setting boundaries for the things she wants and does not want.

Modifying Action (AT6)

Modifying Action was constructed in language when the individual displayed themselves as able to make constructive choices, having a variety of choices available, displaying themselves as being able to fulfill them, and/or being flexible in choice. This agentic position was constructed in the data nine times.

In the following short example, Helen is talking about how she deals with situations in which she notices that her chronic illness is restricting her and making her unable to take a certain actions.

Then you do something else. So that's how I do it. (Helen)

Helen displays that when she encounters a situation in which she is unable to take a certain action she can easily modify her behavior. She suggests that when one encounters a situation where difficulties arise “then you do something else”. By using the passive form of “you”, this expression can be understood as her not necessarily applying this statement only to herself but also making it a general

piece of advice towards other people. Based on this change of behavior when she is unable to take a certain action, she constructs a position in which she is flexible in choice and can deal with a situation in which she has to change her decision or behavior. Further, she constructs an agentic position by saying “that’s how I do it” and emphasizes her ability to modify her action.

Below, Hannah is talking about situations in which she struggles with the physical symptoms caused by her chronic illness

And of course, sometimes you're also stuck, everything hurts again and so on, but I then try to motivate myself with sport, for example. (Hannah)

First, Hannah constructs nonagentic positions. The expression “sometimes you’re also stuck” can be categorized as a construction of the nonagentic tool 4 (*Not Initiating Action*) and the expression “everything hurts again” can be understood as a construction of the nonagentic tool 2 (*Other as Actor*). However, after she constructed a nonagentic position, *Modifying Action* appears in an expression where she displays being able to change her situation. The expression “but then I try to motivate myself with sport” can be understood as a display of trying to motivate herself to change the course of action. However, the sport itself is not necessarily only an optional other course of action but also serves as a motivating function for her act despite having symptoms caused by the chronic illness. Moreover, by adding “for example” she verbalizes that there are also other options for her, despite sport, in which she can modify her behavior to change a situation to her satisfaction.

Cognizance (AT7)

This agentic position can be identified by the individual constructing being able to understand, perceive, know, and notice what they are feeling and/or have a sense of their experience and actions. *Cognizance* occurs in expressions where the individual looks at their experience in a reflective manner, often using personal pronouns and first-person verb forms such as “I understand”, “I perceive”, “I know”, etc. This agentic position was constructed in the data nine times.

Below, “Maria” is answering the question “What positive experiences have you had in relation to your chronic illness?”. In the following, she is explaining that through living with a chronic illness she learned to appreciate good moments more as she has also been through hardships.

“And somehow I have the feeling that I appreciate it a bit more when I experience beautiful moments. Yes, and even when I experience something negative, I say, OK, this sucks. But I also know that I’ll get better again someday.” (Maria)

Here, Maria is talking about the change of her perception and thoughts through living with a chronic illness. She verbalizes her reflective standpoint towards her experience with personal pronouns and first-person verbs such as “I have the feeling”, “I appreciate”, and “I experience”. She displays herself being able to take different perspectives towards her experience of living with a chronic illness, such as appreciating beautiful moments more. Further, by saying “I also know that I’ll get better again someday” she takes a reflective and understanding position by verbalizing that in difficult situations she is able to have a positive perspective toward the future even in difficult times.

In the next extract, Helen is talking about her experiences when meeting other individuals who suffer from the same chronic illness.

So I feel relieved when I meet people with such a disease, with the same suffering. I feel relieved. It's always such a relief. (Helen)

Helen is constructing a position of understanding towards her emotions and experiences with living with a chronic illness. The repetition of “I feel relieved” emphasizes the strength of the emotions she is feeling and recognizing. While Helen’s reflection toward her experience cannot directly be seen and is somewhat hidden, it must be said that this can be accounted for and explained through the German language. While the 10DT Model suggests, that in the tool *Cognizance* reflection towards the experiences is displayed through cognitive talk, in this data reflection towards an experience is displayed through feeling talk. In German, it is a common way of expressing the own feelings and reflecting on a situation by saying “*I have the feeling that...*” (“*Ich habe das Gefühl, dass...*”). Therefore, while in English “I feel relieved” would just be categorized as verbalizing and noticing their own feelings, the same expression in German is seen as a linguistic means of expressing feelings and reflecting on them and the experience. Having this in mind, the expression “I feel relieved when I meet people with such a disease” can be understood as a display of noticing the feeling of relief and at

the same time understanding and reflecting that the experience of meeting other people with the same disease causes a relieving feeling.

Reflected Function (AT8)

Reflected Function can be understood as a discursive position in which an individual presents themselves as able to face and deal with difficult situations and notice that the chosen way of acting can be sustained and is functional. This agentic position was not constructed in the interviews.

Continuance (AT9)

This agentic position was constructed when individuals displayed themselves as looking at their life in terms of historical continuity and constructed a coherent timeline where the past, present, and/or the future are connected. This agentic position was constructed in the data three times.

In the following extract, Maria is replying to the question “What positive experiences have you had in relation to chronic illness?”. Below, she is talking about a pleasant situation where she won a cycling race despite being chronically ill.

For example, last year or the year before I won a cycling race, road cycling. And that was also a moment for me where I thought, hah, I can still do this. (Maria)

Here, *Continuance* applies to Maria’s example as she is connecting the past, this experience, and the present in terms of a coherent timeline. With the background of being chronically ill, she connects the past with the present by continuing her life story as someone who can win cycling races. While in the first part she speaks of the experience of the cycling race in the past, she emphasizes the impact of this experience on her present way of thinking in the second part of the extract. She constructs an agentic position of being ableness that she is still able to do such things despite being chronically ill.

In the extract below, Hannah is speaking of how being chronically ill has changed her mindset and perspective towards her life. She is explaining that she learned to enjoy the positive moments more because her physical condition can easily change in the future due to the chronic illness.

And that's why I enjoy it, because of course I also have in the back of my mind 'who knows how I'll be next year'. (Hannah)

While Hannah is displaying some uncertainty toward the future, she explains her behavior in the present because of things that might take place in the future, hence, connecting the present and the future. By saying “who knows how I’ll be next year” she constructs a position in which she considers that the future might be different from how her life is now due to her chronic illness. Because of this, she decides to adapt her behavior in the present and tries to enjoy every moment. Therefore, *Continuance* applies to Hannah’s example as she creates a sense of historical coherence, not in a causal way but by explaining her behavior in the present based on the unknown future.

Perspectival positioning (AT10)

This agentic position is constructed when individuals display themselves as not knowing the perspective of other individuals. They consider that they can only make hypotheses about the other person’s mind but acknowledge that it is not something transparent or known. This agentic position was not constructed in the interviews.

Between-interview analysis

The most constructed agency position, *Modifying Action* (AT6) denotes a position where individuals display themselves as being able to make constructive choices and being flexible in choice. Compared to other tools, the occurrence of this tool is quite high. *Modifying Action* occurred when participants verbalized difficulties they encountered while living with a chronic illness and that they were able to find an alternative way of action. The construction of this position gave the impression that the participants viewed themselves as being able to influence their life despite facing difficulties.

The second most used tool, *Cognizance* (AT7), displayed agency as understanding, perceiving, knowing, noticing what the individual is feeling and looking at their experience from a reflective position. Participants constructed this position mostly when they were engaging in feeling talk as a means of taking an understanding and noticing position towards their feelings, and experiences. While the construction of this position seldomly included cognitive talk as a way of taking cognizance of their feelings and experiences it rather included feeling talk as making sense of their emotions and the experience. Further, every participant displayed this tool at least once in their interview considering that the participants had gained different levels of talk therapy for introspection and reflection in the past. One participant is still currently receiving talk therapy in form of counseling,

coaching, or psychotherapy, two participants have only received talk therapy over a short period of time in the past, while one participant has not received this form of talk therapy at all. However, the interviews give the impression that all participants constructed an understanding and noticing position towards their feelings and experiences in the interviews in similar ways.

When looking at the interviews, commonalities and differences can be found between the participants and the display of discursive agency positions. An interesting finding is that the participants expressed the different agentic positions in a very similar way, despite having different chronic illnesses limiting them in different areas of their life. For instance, *Accepting* (AT1) occurred when the participants constructed agency as showing the acceptance of their limitations and their life situation caused by the chronic illness. Moreover, *Initiating Action* (AT4) occurred when the participants constructed agency as being able to start a desired action, such as walking down the stairs or going shopping, despite being chronically ill. Further, *Cognizance* (AT7) occurred when participants constructed agency by positioning themselves as noticing that they appreciate the good things in life more as they have lived through hardships due to their chronic illness.

Furthermore, differences concerning the display of the frequency and type of displayed tools in the interviews can be found. In the interview with Hannah, the most discursive agency positions were displayed. While the interviews with James, Maria, and Helen displayed 7-8 discursive agency positions in each interview, in the interview of Hannah 18 agency constructions were displayed. Further, the interviews with Hannah and Helen included more displays of non-reflective tools than reflective tools. In Hannah's interview, 15 out of 18 agency positions were displays of non-reflective tools. In the interview with Helen, 6 out of the 8 agency positions were displays of non-reflective tools. In comparison, the interviews of James and Maria showed equally as many displays of non-reflective and reflective tools. Furthermore, of one of the most displayed tools, *Modifying Action*, 7 out of the 9 displays could be found in Hannah's interview while in the other participants' interviews the tool was only displayed once or not at all. Likewise, *Initiating Action* (AT4), was displayed 5 times across all interviews of which 4 displays were in Hannah's interview while the other participants only displayed it once (James) or not at all (Maria and Helen).

4. Discussion

The aim of this study was to answer the research question “How do individuals with chronic illnesses construct their agency when narrating about chronic illness?”. With the 10DT Model, agentic positions were identified, that is, the model allowed to pinpoint positions constructed by the participants, where they displayed themselves as able, active, or willing concerning their circumstances, life, history, experiences, or feelings, by using the agency tools of on the 10DT Model. Overall, eight out of the ten agency tools occurred in the data. The 10DT Model is organized into non-reflective and reflective tools, which can be distinguished in taking a reporting position or a reflective position, which both occurred in the data. Two participants in the large part of their interviews displayed non-reflective discursive positions while the other two participants displayed an equal amount of non-reflective and reflective discursive positions in their interviews. Nevertheless, all participants displayed the different discursive positions similarly whilst having different backgrounds and different chronic illnesses. Among all the displayed discursive agentic positions, *Modifying Action* (AT6) and *Cognizance* (AT7) were the most displayed tools in the interviews.

General Discussion

One finding in the interviews was, that the tool *Modifying Action* (AT6) was one of the most displayed tools in the data in which the participants displayed themselves to finding alternative ways of action while living with a chronic illness. In most cases, individuals who are chronically ill frequently encounter physical barriers and other difficulties in daily life (Lindsay et al., 2011). This being the case, a high occurrence of this tool is an especially interesting and important finding as like this the participants create a narrative in which they position themselves as agentic despite being chronically ill. When looking at previous research, this finding can be distinguished from past results. In the original study of Toivonen et al. (2019a) participants mainly displayed the tool *Not Modifying Action* (NAT6) where the participant displayed a position in which they were not able to change the course of actions instead of displaying the agency side of the model. Therefore, this result is especially significant as while previous research has found opposite findings, it is evident that individuals with limitations, such as individuals with chronic illnesses, also display themselves as able to change the course of their actions.

Moreover, the tool *Cognizance* (AT7) also was one of the most displayed tools in the interviews in which the participants construct an understanding, perceiving, knowing, and noticing position towards their feelings and experiences. Previous research on the 10DT Model is able to support and also contrast this finding. In the original study of Toivonen et al. (2019a), clients of psychotherapy mostly constructed the corresponding non-agency tool of the model, *Noncognizance* (NAT7), where individuals displayed a not understanding, perceiving, and noticing position towards their feelings and experiences. However, in some instances, the clients also displayed the agency tool of the model (Toivonen et al., 2020; Toivonen et al., 2019a). In a follow-up study by Toivonen et al. (2020), they describe a situation in which a client discursively displays the tool *Cognizance* (AT7) when reflecting on what led her to break up with her partner. As can be seen, in different instances studies were able to show that both agency and nonagency positions of this tool were constructed. Establishing an understanding and noticing perspective toward the own feelings and experiences can be an important aspect in dealing and coping with a chronic illness. Karnilowicz (2011) reported that psychological ownership of one's own emotions and meaning can be viewed as a form of reflection of the relationship between the individual and their chronic illness. Further, taking psychological ownership serves as a means of expressing the own self-identity. Therefore, one could hypothesize that understanding, noticing, and reflecting upon the own feelings and experiences could be viewed as a form of sense-making in individuals with a chronic illness. In that light, the importance of the finding that both individuals with psychological struggles in previous studies and also individuals with physical difficulties in the current thesis construct the agency position *Cognizance* (AT7) needs to be recognized.

On the contrary, there were also agency tools that were not displayed in the interviews at all, one of them being *Reflected Function* (AT8). It is assumed, that this tool includes an individual displaying themselves as able to face and deal with difficult situations and notice that the chosen a way of acting that can be sustained and is functional. In the previous research of Toivonen et al. (2019b), the display of reflective tools was present, however, only in the corresponding nonagency positions. Participants of the study gave problem formulations at the beginning of therapy in which they were able to take an observing position in relation to their difficulties and, therefore, noticed

dysfunctional ways of acting. Hence, they displayed the corresponding nonagency tool *Reflected Dysfunction* (NAT8). However, the study does not report on the display of the agency tool, *Reflected Function* (AT8). One possible explanation for the absence of this level and type of reflective position may be due to the setting of the interview. In the original study, the findings were based on the transcripts of the first sessions of psychotherapy (Toivonen et al., 2019a). Psychotherapy can be seen as an environment in which reflection is emphasized and encouraged (Leonhardt et al., 2016). Therefore, possibly this type of reflective nonagency position was displayed in the study of Toivonen et al. (2019b) as the data was collected in a therapy setting. Meanwhile, the data of the current thesis was collected in an open-question interview where questions were asked about the general experiences of the participants in relation to living with their chronic illness. Hence, one could argue that this interview environment was not encouraging reflection enough to foster the display of the reflective agency tool *Reflected Function* (AT8).

Furthermore, the tool *Perspectival Positioning of Others* (AT10) also did not occur in the interviews. This tool includes displays of understanding that the perspective of others is not transparent and can be different than expected. Further, individuals take this unknowingness into account. However, perhaps the absence of displays of this tool can be accounted for by the study setup itself. The interview and the questions which were asked focused on the participants themselves and their experiences with living with a chronic illness. Therefore, the center of the interviews was on the individuals themselves and not on the people surrounding them. As the way of questioning was not directed towards how other people in the participant's life perceive or deal with their chronic illness, it possibly was not particularly mentioned. Adding questions about the perspective of others into the interview scheme could perhaps give room for such displays.

Further, besides the display of agency positions, the use of reflective tools specifically is noteworthy. In addition to displaying nonreflective agency tools in the participant's life stories in which they report their experiences, participants also displayed reflective agency tools in which they reflect upon their experiences. As an example, the reflective tool *Cognizance* (AT7) shows how individuals with chronic illnesses express their own feelings, engage in feeling talk, and take an understanding and noticing perspective as a means of sense-making. It is important to understand not

only what chronically ill individuals experience and feel but also how they express their feelings and experiences and in doing so take a reflective standpoint. This is a useful insight for health care professionals to adjust and improve their communication with chronically ill individuals. For this, one can take the concept of *discursive discordance* into account. A discursive discordance takes place when for instance the health care professional's positioning of the chronically ill individual differs in terms of the discursive agency construction from how the individual self-positions him- or herself. Like this, self-ascriptions by the individual are missed and not properly responded to (Toivonen et al., 2019b). Therefore, establishing a sensitivity towards the individual's speech and paying close attention to what the individual is saying and how agency construction is taking place is essential to enabling successful communication.

Strengths and Limitations

This thesis can provide some noteworthy strengths. First and foremost, this thesis was able to extend the application context of the 10DT Model. In the original study of Toivonen et al. (2019a), the model was developed based on psychotherapy transcripts whereas in this thesis the model was applied to transcripts of interviews with chronically ill individuals. Additionally, the original study focuses on the nonagency side of the model while this thesis had its focus on the agency side of the model. Despite the differences in the application context of the 10DT Model, this thesis was able to show that the 10DT Model can be applied to different groups, such as individuals with chronic illnesses. Even further, the model was also proven to be successful in the application of analyzing discursive agency positions in narratives.

Moreover, the qualitative approach in this thesis can be seen as a strength. The qualitative data gathered through interviews is able to provide more detailed and rich information and focuses on explaining complex issues (Queirós et al., 2017). Through this analytical approach, one is able to uncover the meanings, motives, beliefs, aspirations, values, and attitudes of the individual which in this thesis were then used to analyze the agency construction of the participants (Queirós et al., 2017). Therefore, when examining language, the use of interviews can enable an individualistic way of investigating what kind of discourses about illness and agency are displayed in the narratives of individuals with chronic illnesses.

Furthermore, on the other hand, the participant sample can also be seen as a strength. The participants were of different ages, included both males and females, were living with different chronic illnesses, and had either received guidance in form of counseling, coaching, or psychotherapy or not. Therefore, due to the heterogeneity of the participants, the sample is able to represent a broad range of different individuals with different backgrounds.

However, for the interpretation of the results of this study following limitations need to be considered. The participant sample of this study can also be seen as a limitation. On the one hand, all four participants had a Western cultural background and were from Germany. Therefore, it is uncertain whether individuals from different cultural backgrounds would display the agency tools and construct agency positions in the same way. As an example, in collectivistic cultures in which communality is valued individuals might feel more accepted, recognized, and supported and, therefore, deal differently with illness experiences (Goodwin & Hernandez Plaza, 2000). Hence, one should be cautious to apply the results of this study to chronically ill individuals from different cultural backgrounds.

Moreover, the use of the 10DT Model in different languages, as was the case in this thesis, can be seen as a challenge. In the original study, Finnish psychotherapy transcripts were used which served as the basis for developing the 10DT Model which was then conceptualized in English (Toivonen et al., 2019a). This thesis then used the English 10DT Model and applied it to German interview transcripts. According to linguistic theories such as the Sapir-Whorf hypothesis, the language we use is connected to culture and affects the way we think and perceive. This can become problematic when translating from one language and cultural and traditional area to another (Evans, 2004). Frequently, translators are only concerned with finding a way how the desired meaning can be expressed but do not take into account the cultural norms of the languages which can cause censorship through translation (Janfaza et al., 2012). One demonstration of this barrier can be found in displays of the tool *Cognizance* (AT7) in this thesis. While the 10DT Model views *Cognizance* (AT7) to display a reflective position towards the experiences through cognitive talk, in German reflection towards an experience is frequently displayed through feeling talk, by saying “I have the feeling that...”. Therefore, one could argue that, quite literally, some meanings could “get lost in translation” as the

way of expressing and the cultural norms differs from language to language (Janfaza et al., 2012).

Hence, this limitation in the use of the 10DT Model in different languages needs to be considered to effectively apply the model for trustworthy results.

Contribution to research and future recommendations

This study is able to contribute in a small, yet valuable way to the field of studying chronic illness. It provides important and useful insights into how individuals with chronic illnesses display and construct agency in their life stories. That is, the participants constructed many agency positions defined in the 10DT Model in their life stories which gives the impression that they have a sense of having an influence on their life and reflecting on their experiences. These insights can be especially useful for health care practitioners and other professionals working with chronically ill individuals. For instance, professionals should not only pay attention to the nonagency and predicaments that are displayed in the language and life stories of individuals with chronic illnesses but also carefully listen to the agency constructions. By putting a greater awareness and focus on the agency constructions, this sense of agency can be reinforced and strengthened by professionals.

Moreover, this research was able to demonstrate that individuals with a chronic illness construct many different agency positions in their life stories. Unlike the oftentimes held assumption, that the life of chronically ill individuals is determined by their limitations, the results of this study show that individuals should not be viewed merely as nonagentic or as “victims” of their condition or be treated in conversation as such. Taking this into account can contribute to a more healthy and sensible perspective towards individuals with chronic illnesses in society and also in research.

Further, while in previous research the focus in the 10DT Model was on the nonagency side of the model, this study developed, refined, and applied the agency side of the 10DT Model. Hence, the 10DT Model is an effective tool to discursively look at agency. Moreover, the 10DT Model was developed based on psychotherapy transcripts of psychotherapy clients. This study used interviews with chronically ill individuals, that is, focusing on individuals with physical complaints rather than psychological ones. Consequently, the 10DT Model was further refined by using new and different data which was not used when the model was created. This demonstrates that the model is applicable to such data as well and that it makes sense to look at the agency positions in other groups. In addition

to this, to date, the 10DT Model has been used in a psychological and chronic illness context. Besides that, it would be interesting to investigate the nonagency and agency constructions and apply the model to the general population, in specific, individuals who do not suffer from psychological or physical complaints.

Additionally, this thesis was able to contribute to the growing body of discursive research, specifically applying the discursive approach to the life stories of individuals with chronic illnesses and, therefore, serve as an inspiration for future discursive studies focusing on chronic illness. While the experiences of chronically ill individuals have been studied in previous research, this study was able to provide insight into not only what experiences chronically ill individuals narrate but more importantly how they narrate their experiences and position themselves in relation to their agency.

Overall, future research should continue to investigate the life stories of individuals with chronic illnesses to allow an establishment of a greater and deeper understanding of their experiences, especially not only focusing on the predicaments chronic illness brings but also focusing on the resources and abilities of chronically ill individuals. In this sense, I would like to conclude with the words of the participant Helen, who at the end of her interview emphasized the importance of spreading awareness about living with a chronic illness:

“And I think more research should be done on it as well. [...] I think we should talk more about this topic in the future. Also in medicine and in research.” (Helen)

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Appendices

Appendix A: Information Letter and Informed Consent

Informationsschreiben für Teilnehmer*innen an der Studie „Wie erzählen Menschen mit chronischen Krankheiten von ihren Erfahrungen und Perspektiven?“

Willkommen!

Willkommen zu unserer Studie über Ihre Erfahrungen und Perspektiven! Diese Studie richtet sich an Erwachsene mit einer chronischen Erkrankung, d. h. einer Erkrankung, die länger als ein Jahr andauert und medizinische Hilfe erfordert oder das tägliche Leben einschränkt. Wenn Sie sich in dieser Gruppe wiedererkennen, laden wir Sie ein, an dieser Studie teilzunehmen.

Was ist das Ziel der Studie?

Wir interessieren uns dafür, wie Menschen über ihre Erfahrungen und Perspektiven mit einer chronischen Krankheit berichten. Wir sind auch neugierig, wie Ihre Erfahrungen auch Ihre Lebensweise beeinflussen. Dieses Wissen kann uns helfen, mehr Einblick in die Erfahrungen von Menschen mit chronischen Erkrankungen zu gewinnen. Indem wir ihre Eindrücke und Perspektive kennenlernen, hoffen wir, Menschen mit einer chronischen Erkrankung eine Stimme zu geben.

Was erwarten wir von den Teilnehmer*innen?

Wir erwarten von Ihnen als Teilnehmer*in:

1. dass Sie Ihre Erfahrungen und Perspektiven in einem Interview teilen
2. dass Sie einige Fragen über sich, Ihre Geschichte und Ihre chronische Erkrankung beantworten.

Und außerdem: dass Sie die Teilnahme an dem Interview jederzeit ohne Angabe von Gründen abbrechen können. Sie entscheiden, wie viel Zeit Sie dafür benötigen. Wir gehen davon aus, dass ein Interview etwa 1-2 Stunden dauern wird. Aber Sie können sich so viel Zeit und so viele Pausen nehmen, wie Sie wollen.

Welche Vorteile und Nachteile hat die Teilnahme an dem Interview?

Vorteile:

- Manche Menschen teilen ihre Geschichte gerne mit anderen. Es gefällt ihnen, dass ihre Geschichte gehört wird.
- Sie können Menschen mit chronischen Krankheiten eine Stimme geben und auf Ihre Perspektive aufmerksam machen.
- Diese Studie wurde von dem Ethikkomitee des Fachbereichs Geistes- und Sozialwissenschaften der Fakultät für Verhaltens-, Management- und Sozialwissenschaften der Universität Twente geprüft und genehmigt.

Nachteile:

- Es kostet Zeit und Mühe, an einem Interview teilzunehmen und Ihre Erfahrungen zu teilen und Fragen zu beantworten.

Was machen wir mit Ihren Antworten?

Wir, das Forschungsteam, bearbeiten die Antworten anonym, also ohne Ihren Namen oder andere persönliche Informationen zu verwenden. Denn Ihre Privatsphäre und Ihre Anonymität ist uns sehr wichtig. Wir werden die anonymen Informationen für einen Artikel in einer wissenschaftlichen Zeitschrift oder für eine Präsentation auf einer Konferenz verwenden.

Wie bewahren wir Ihre persönlichen Daten auf?

Wir bewahren Ihre persönlichen Daten an einem sicheren Ort auf, getrennt von den Daten der Studie. Nur das Forschungsteam hat Zugang zu den Forschungsdaten und Ihren persönlichen Informationen. Wir müssen die anonymen Forschungsdaten (anonyme Transkripte der Audioaufnahmen) 10 Jahre lang aufbewahren. Falls erforderlich, sollten andere Forscher die anonymen Ergebnisse der Studie überprüfen können.

Wenn Sie Fragen haben, senden Sie bitte eine Email an Luca Marie Schlieper:
l.m.schlieper@student.utwente.nl

Ich danke Ihnen im Voraus im Namen des Forschungsteams der Universität Twente (Enschede, Niederlande).

- Dr. Anneke Sools, Hauptforscherin, Assistenzdozentin an der Fakultät für Psychologie, Fachbereich Gesundheit und Technologie der Universität Twente
- Dr. Heidi Toivonen, Assistenzdozentin an der Fakultät für Psychologie, Fachbereich Gesundheit und Technologie der Universität Twente
- Jacqueline Coppers, Forschungsassistentin der Universität Twente und Ergotherapeutin
- Luca Marie Schlieper, Masterstudentin in Psychologie an der Universität Twente

Einverständniserklärung zur Teilnahme an der Studie „Wie erzählen Menschen mit chronischen Krankheiten von ihren Erfahrungen und Perspektiven?“

Sie erhalten eine Kopie von dieser Einverständniserklärung

	J	Nein
Bitte kreuzen Sie die zutreffenden Boxen an	a	
Teilnahme an der Studie		
Ich habe die Studieninformationen vom 14.04.2022 gelesen und verstanden, oder sie wurden mir vorgelesen. Ich hatte die Möglichkeit, Fragen zur Studie zu stellen, und meine Fragen wurden zu meiner Zufriedenheit beantwortet.	<input type="checkbox"/>	<input type="checkbox"/>
Ich erkläre mich freiwillig bereit, an dieser Studie teilzunehmen, und verstehe, dass ich die Beantwortung von Fragen verweigern und die Studie jederzeit ohne Angabe von Gründen abbrechen kann.	<input type="checkbox"/>	<input type="checkbox"/>
Ich verstehe, dass die Teilnahme an dieser Studie das Teilen meiner persönlichen Erfahrungen und Perspektiven in Form eines Interviews beinhaltet, welches als Audiodatei aufgenommen wird. Diese Audiodatei wird für die Datenanalyse transkribiert und anonymisiert.	<input type="checkbox"/>	<input type="checkbox"/>
Risiken verbunden mit der Teilnahme an der Studie		
Ich verstehe, dass die Teilnahme an dieser Studie folgende Risiken beinhalten kann: Beim Erzählen von schwierigen/negativen Erfahrungen besteht die Möglichkeit, mentales Unwohlsein zu empfinden.	<input type="checkbox"/>	<input type="checkbox"/>
Nutzung der Daten dieser Studie		
Ich verstehe, dass die Informationen, die ich im Rahmen dieser Studie zur Verfügung stelle, anonymisiert werden und diese anonymen Informationen für einen Artikel in einer wissenschaftlichen Zeitschrift oder für eine Präsentation auf einer Konferenz verwendet werden.	<input type="checkbox"/>	<input type="checkbox"/>
Ich verstehe, dass alle Forschungsdaten und persönlichen Informationen an einem sicheren Ort aufbewahrt werden und nur von dem Forschungsteam eingesehen werden können.	<input type="checkbox"/>	<input type="checkbox"/>
Zustimmung für die Audioaufnahme des Interviews		
Ich stimme zu in Form von Audio aufgenommen zu werden.	<input type="checkbox"/>	<input type="checkbox"/>
Zukünftige Nutzung der Daten von Anderen		
Ich stimme zu, dass die anonymen Forschungsdaten (anonyme Transkripte der Audioaufnahmen) 10 Jahre lang aufbewahrt werden und, wenn erforderlich, andere Forscher	<input type="checkbox"/>	<input type="checkbox"/>

die anonymen Ergebnisse dieser Studie verwenden dürfen für zukünftige Forschungen und Einsichten.

Unterschriften

Name des/der Teilnehmers*in	Unterschrift	Datum

Ich habe dem/der potenziellen Teilnehmer*in das Informationsblatt genau vorgelesen und mich nach bestem Wissen und Gewissen vergewissert, dass der/die Teilnehmer*in versteht, wozu er freiwillig seine Zustimmung gibt.

Name der Forscherin	Unterschrift	Datum

Studienkontaktdetails für weitere Fragen:

Luca Marie Schlieper, l.m.schlieper@student.utwente.nl

Kontaktinformationen für Fragen zu Ihren Rechten als Forschungsteilnehmer

Wenn Sie Fragen zu Ihren Rechten als Studienteilnehmer haben oder Informationen einholen, Fragen stellen oder Bedenken zu dieser Studie mit einer anderen Person als dem Forscher besprechen möchten, wenden Sie sich bitte an das Sekretariat der Ethikkommission/des Fachbereichs Geistes- und Sozialwissenschaften der Fakultät für Verhaltens-, Management- und Sozialwissenschaften der Universität Twente unter ethicscommittee-hss@utwente.nl

Appendix B: Interview Scheme

Interview Scheme

Herzlich Willkommen bei der Interview Studie über die Erfahrungen und Perspektiven von Menschen mit Chronischen Erkrankungen im Rahmen meiner Psychologie Master Thesis. Dieses Interview ist semi-strukturiert mit offenen Fragen und hat keine klassische Frage und Antwort Struktur. Das heißt, dass ich dir offene Fragen stelle, bei denen du einfach deine Erfahrungen ganz frei teilen können und gerne viel erzählen dürfen. Dementsprechend gibt es kein richtig oder falsch. Gegebenenfalls werde ich hier oder da eine Folgefrage stellen. Wenn es eine Frage gibt, die du nicht beantworten willst, musst du das nicht. Wenn das im Laufe des Interviews der Fall sein sollte, lass es mich einfach wissen.

Ansonsten darfst du alles erzählen, was dir in Bezug auf dieses Thema auf dem Herzen liegt und du teilen möchtest.

- Hast du noch Fragen, bevor wir beginnen?

Fragen:

- Kannst du mir deine Geschichte erzählen, wie es ist, mit einer chronischen Erkrankung zu leben?
- Kannst du mir von schwierigen Erfahrungen erzählen, die du im Leben mit einer chronischen Erkrankung gemacht hast?
 - Was an der Situation/Erfahrung hat es zu einer negativen Erfahrung gemacht?
 - Was hast du gefühlt, also du diese negative Erfahrung gemacht hast?
- Kannst du mir von positiven Erfahrungen erzählen, die du im Leben mit einer chronischen Erkrankung gemacht hast?
 - Was an der Situation/Erfahrung hat es zu einer positiven/negativen Erfahrung gemacht?
 - Was hast du gefühlt, also du diese positive Erfahrung gemacht hast?
- Was bedeutet Wohlbefinden für dich? Wie definierst du dein persönliches Wohlbefinden?
- Kannst du mir von Ihren Erfahrungen erzählen, in denen im Leben mit einer chronischen Erkrankung deine Handlungsfähigkeit dein Wohlbefinden beeinflusst hat?
 - Vielleicht kannst Du mir von einer Situation erzählen die besonders prägend in dieser Hinsicht für dich war?
- Gibt es noch etwas, das du über dein Leben mit einer chronischen Erkrankung erzählen möchtest?
- Wenn du dir selber einen Rat geben könntest am Anfang deiner Erkrankung, was würdest du sagen?