I do what I can do, and things are going well:
A Discursive Analytical Study on Agency in Chronic Illness Narratives

Marco Richter

1st Supervisor: Dr. Heidi Toivonen

2nd Supervisor: Dr. Kevin Pijpers

30.10.2022

University of Twente

Positive and Clinical Psychology and Technology

Faculty of Behavioral, Management, and Social Sciences

Abstract

The following Master's Thesis aims to examine the ways in which persons with a chronic illness discursively construct their own agency within written narratives. This study was conducted in order to contribute to qualitative research on chronic illness narratives.

This study's sample consisted of 22 Dutch adults. This Thesis is part of the project 'How people with chronic health conditions story their past and future lives'. After employing a purposive sampling method, participants were then asked to produce short written narratives (about one A4 page) about their experiences with being chronically ill. The narratives were then analyzed with a Discourse Analytical approach using the 10DT Model of (Non)Agency (Toivonen, Wahlström, & Kurri, 2019). In this Thesis, agency was conceptualized as a relational and discursive phenomenon.

The results show that all but one of the 10 discursive tools of the model occur within the chronic illness narratives. Moreover, all but three of the analyzed narratives contained constructions of agency. Although being chronically ill brings with it drastic limitations in one's life, participants position themselves as, among others, being able to accept that they are ill, engage in and adjust valued activities, and reflect on their experience.

Since this is the first time the 10DT Model is employed to examine agency in chronic illness narratives there is no directly comparable previous research. However, it appears that the 10DT Model, although developed in the context of psychotherapy, also translates over to the use on chronic illness narratives.

Introduction

The present Thesis aims to examine how agency is discursively constructed by persons with a chronic illness by analyzing written narratives provided by them. According to the World Health Organization 41 million people die annually due to chronic illnesses (also termed noncommunicable diseases), making up 71 % of all global deaths (WHO, 2021).

The common occurrence and far-reaching consequences of having a chronic illness are at the basis of why it is important to research agency in the narratives that ill persons create. Formerly easy activities like work and hobbies become difficult. Chronic illness has been termed a breakdown in life (Synnes et al., 2020), a biographical disruption (Bury, 1982) and a source of loss and crisis (Frank, 1997). Since narratives are assumed to permeate much of human experience, it stands to reason that experiencing a major life event such as being diagnosed with a chronic illness also influences the narratives that people create of their lives. Because the body is the means through which humans relate to their surroundings, Williams (1984) contends "that chronic illness is a rupture in our relationship with that world" (p. 23). Illness, leading to vulnerability, limits the way that a person can be in the world (Carel, 2009).

A defining factor for this rupture is the sudden need for effort regarding formerly mundane activities. This includes contact with other people, the healthcare system, and managing the illness itself (Synnes et al., 2020). Moreover, Frank (1997), among others, pointed toward a tendency within the medical world to mainly see the person with an illness as passive and reduce them to the role of patient. However, he contends that being chronically ill also calls upon the ill person to 'rise to the occasion' and be 'successfully ill'. This view proposes a focus on a person's agency even within a context in which it is easy to lose sight of it. Although a chronic illness limits one's abilities to engage with the world, a person might still present themselves as agentic in their discourse.

According to Dowrick et al. (2005) having to alter one's behavior, deal with social and emotional consequences, and cooperate with medical staff are examples of experiences that everyone with a chronic illness must confront. Having interacted with the illness itself as well as with the changes that it brings to one's life, a person might tell the story via a narrative. Hurwitz (2000) calls narratives "the most

compelling form by which we recount our reality, understand events, and through which we make sense of our experiences and ourselves" (p. 3). He then goes further and terms stories the "vernacular of illness" (p. 3).

Agency has been examined with various definitions, in different fields, and with diverse methodological approaches. Quantitative and qualitative approaches to research form the most salient perspectives on agency. The main difference between the two hinges on their notion of agency. Within quantitative research, agency is seen as an intrapsychological phenomenon, an inner experience that a person might have more or less of and that can be described with a number on a scale (e.g. Alkire, 2005). On the other hand, the qualitative approach views agency as something that is constructed situationally and within the interactions between persons (e.g. Wahlström & Seilonen, 2016). Here, the important tool with which one constructs agency is their language. By choosing to speak one way or another way a person positions him-/herself as agentic or nonagentic and thus brings the concept into being.

The present Thesis takes the qualitative and with it a constructionist approach towards agency. Constructionism puts central emphasis on language. Here, language is thought of as constructed (assembled out of linguistic parts) in interactions and constructive (manifesting phenomena) (Potter & Hepburn, 2008). Wahlström (2021) describes this perspective as examining "the means of language through which social realities are collaboratively fabricated (p. 79)." More specifically, this Thesis employs a discourse analytical perspective on agency meaning analysis adheres strictly to the language level of the narratives and does not aim to make claims on any intrapsychological phenomena. This approach keeps the analysis close to the data and focuses on how agency discursively manifests.

In order to contribute to an understanding of chronic illness narratives the focus of the present Thesis is to examine the ways in which chronically ill persons construct their own agency in written narratives. To analyze these discursive constructions of agency, this Thesis utilizes the 10DT Model of (Non)agency (Toivonen, Wahlström, & Kurri, 2019). The contribution that this study aims for is to better understand the ways agency is manifested in their language. This might be helpful especially in therapeutic conversations with chronic illness patients. A keen eye for agentic constructions that even the

ill person might not be aware they are employing could be helpful in breaking up the strong focus on inability that most chronic illness narratives contain.

The research question is as follows: How do chronically ill people discursively construct their own agency in written form? In the following section, both the method of data collection and analysis are described in more detail.

Methods

In the present Thesis I utilize the data set of a project called 'How people with chronic health conditions story their past and future lives' (original Dutch title: 'Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst'). The project used a qualitative approach to data collection by having participants produce short narratives relating to their chronic illness. Moreover, participants provided information on their age, sex, nationality, and diagnosis.

A purposive sampling was employed that distributed the study within the researchers professional and personal environment via social media platforms and Dutch patient- and healthcare organizations. Ethical approval has been granted under the request number 211138 by the Ethics Committee of the Faculty of Behavioral Sciences at the University of Twente.

Inclusion criteria for participants were the following: (1) perceiving yourself to live with a chronic illness, (2) ability to comprehend and write in Dutch language, (3) adequate digital skills to be able to participate in an online survey, (4) cognitive skills to reflect on the past and imagine the future, (5) being at least 18 years old, and (6) no acquired brain injury as reason for chronic illness.

Prospective participants were given an information letter to read beforehand that gave details on the purpose of the study, eligibility criteria, the survey itself, benefits and burdens that come with participation, confidentiality, and information about the research team. They were then asked to sign an active consent if they wanted to participate.

During the survey, participants were asked to produce a short narrative about their experience so far regarding life with a chronic illness. It took approximately 45 minutes to complete the whole survey.

Researchers were available via telephone and email in case a participant had questions concerning the study. Withdrawal from participation without having to give a reason was possible at any point of the study. No reimbursements or incentives for participation were offered.

With the present study I focus on the narratives regarding participants' life with chronic illness so far. The number of analyzed narratives is 22 (half a page to 1.5 pages long). Of those participants 16 (72.7 %) were female and 6 (27.3 %) male. The average age was 52 years (SD = 14), with the oldest participant being 70 and the youngest being 25. One of the participants did not provide her age, so she was excluded in this calculation. All were of Dutch nationality. A list of diagnoses that were provided by the participants can be seen in Appendix A.

For the search for constructions of agency in participants' narratives I was guided by the framework of the 10 Discursive Tools of (Non)agency, also termed the 10DT Model, laid out by Toivonen, Wahlström, and Kurri (2019a, 2019b, 2020). It presents ten discursive tools with which participants construct agency or nonagency in their narratives. In this context, a single tool is conceptualized as a collection of different kinds of ways to construct a certain discursive position. The following is an example of a tool I found in the analyzed narratives but did not include in the results section: "I can fully participate in sports such as mountain biking, surfing and hiking." This would be an example of a construction made with tool 4, initiating action. The participant lists several activities that they can still engage in despite their chronic illness.

Every tool is dichotomous with each one being used for either constructing agency or nonagency. The ten tools and a short summary of their focus can be seen in Table 1. For this study, I focus on constructions of agency rather than nonagency. This means I look for instances of each tool that position the author of the narrative as being agentic.

The discursive tools grow in reflectivity with increasing numbers. Hence, tools 1 - 6 are termed non-reflective and 7 - 10 are termed reflective tools. In this context, reflectivity points towards the ability of the narrative's author to take a meta-position towards themselves and their environment. For example, in describing one's past and present behavior as functional (tool 8) a participant takes a reflective position

in their discourse. The focus of this model lies in analysis of narrators' discursive positioning. Discursive positioning regards the ways in which people put themselves in relation to their situation and experience within the context of interactions. This process of positioning is dynamic and changes along the course of an interaction as participants exchange their respective contributions. Moreover, positioning is situated, meaning that it is viewed in the context of for example, an interaction's environment, its participants, and what has been said before. In line with the overarching perspective of constructionism, discursive positions are seen as construct*ed* with language and construct*ive* of social reality (Winslade, 2005). In a sense, speech is conceptualized as talking concepts "into being" (Toivonen, 2019, p. 66).

To shortly summarize and distinguish, the tool is the linguistic means that is employed within the written narratives (words, phrases, sentences, idioms, etc.) and the position is what is thereby discursively created; presenting (and thus manifesting) myself in a certain relationship with my environment and experiences, in this case being an agentic actor. Harré (as cited by Wahlström & Seilonen, 2016, p. 2.) describes it in this way: "being an agent and displaying oneself as an agent is one and the same".

I should note, however, that the 10DT Model of (Non)agency is based on conversations in the context of psychotherapy. This Thesis is one of the first to apply the framework to different narratives written by persons with a chronic illness.

Table 1

Short Summary of The 10DT Model of (Non)agency (Toivonen, Kurri, & Wahlström, 2019a, 2019b, 2020)

	Agency	Nonagency	Speaker's position answers question of…
1.	Accepting	Dismissing	Does the problem exist or is it related to me?
2.	Free to act	Other as actor	Is it me who acts freely or am I controlled by circumstances and/or other people?
3.	Interioration	Exterioration	Are thoughts, feelings, and experiences created by me or are they outside entities which I merely possess?
4.	Initiating action	Not initiating action	Do I have problems starting a desired action?
5.	Stopping or curbing action	Not stopping or curbing action	Can I stop an undesired action?
6.	Modifying action	Not modifying action	Am I able to change a course of action in a desired way?
7.	Cognizance	Noncognizance	Do I know and understand my own experiences and actions and their causes?
8.	Reflected Function	Reflected Dysfunction	Do I see past experiences, problems, and actions as functional or dysfunctional?
9.	Continuance	Discontinuance	Can I create a coherent life story to understand/bring order to my present situation?
10.	Perspectival positioning of others	Presumptive positioning of others	Do I assume to know for certain the perspective of other actors?

I downloaded the participants' narratives and diagnoses from Qualtrics, the survey tool used in this project, and put each into a text file. The data was stored in an anonymized format with only an ID to name the cases. Possibly identifying details, like names of places, were omitted when presenting constructions in the results section. After that I and other students with similar studies for their Theses translated them from Dutch to English. Then I read the narratives with a focus on finding passages that

utilize one of the tools from the 10DT model to position the authors as agentic. This could manifest in the form of a single word, part of a sentence, or a whole sentence. If I found a potential use of a tool, I marked it to possibly be included in the results section to serve as an example of the tool. Since there are only a few examples of agentic constructions, taken from the original study by Toivonen, Wahlström, and Kurri (2019a), the analysis was rather exploratory and it was not clear what form they might take within chronic illness narratives. For the first readings, I tried to approach the narratives as open-minded and unbiased as possible, so I marked whatever stood out to me in looking like a position of agency. In general, constructions of agency stand out in the analyzed narratives since the context of chronic illness puts a strong focus on its limitations and incomprehensibility rather than on possibility and clarity. If a participant, then, writes about activities that they are able to do and situations they are able to make sense of, the construction becomes notable. The difficulty lay less in finding the constructions than in correctly assigning them to one of the ten tools. Additionally, I paid attention to the possibility that there might be discursive positions which are not included in this original model.

The analytical process was iterative. This means I read the narratives several times throughout the analysis and made changes to my notations according to my changing understanding of the tools and the positions created with them. This was supported by frequent consensus meetings with my supervisor, one other Master student and one PhD student in order to ensure the validity of the results so far. During the analysis phase I went back and forth between the data, analysis, and meetings, continuously adjusting my notes within the narratives and the phrasing of the results section. Meetings were used to discuss and agree on the relevance of possible agency constructions, which tool they might belong to, and clarify the understanding of how each tool is conceptualized. The unit of analysis in this study is the discursive positions produced by the participants. In the results section I present the different discursive positions of agency found regarding living with a chronic illness.

Since this is a qualitative study, assessing reliability and validity is less straightforward than with quantitative research. Building on the work of Guba (1981), Shenton (2004) explicates four areas of consideration to ensure the trustworthiness of a qualitative study: (1) credibility (congruence of

description with reality), (2) transferability (generalizability of results), (3) dependability (repeatability of results), and (4) confirmability (address researcher bias).

Results

In the following section, discursive positions that were found during the analysis are presented. They are ordered by the discursive tool from the 10DT Model that they correspond with. For each tool, examples are shown that illustrate its use to discursively construct positions of agency within the chronic illness narratives. Citations taken from the narratives are shown within quotation marks and the specific parts of the sentences that indicate the use of a certain tool are underlined.

1. Accepting

This tool of constructing a position of agency is present when the narrative's author discursively constructs a position where they state that their chronic illness exists and has an influence on their lives. In the analyzed narratives they are quite common.

Using the tool of acceptance appears to be straightforward. One participant simply wrote that she accepted her illness: "I have a chronic illness" This formulation puts the author in a relation of ownership with their illness. A chronic illness is something that one 'has'.

Other constructions might go further and point towards acceptance of not just the illness but also the worsening experience that comes with it: "[...] I can accept and experience when things are not going well, there have to be those days too."

Moreover, there are constructions that focus on the maintenance of *Acceptance*: "I've been able to accept that I have pppd[1], but sometimes there are still difficult days when I wish I didn't have it." Here, *Acceptance* is implied not to be something that one obtains and then has forever. Even after an initial *Acceptance* of a chronic illness there might be times during which it wavers.

---

[1] Persistent Postural Perceptual Dizziness, a constant dizziness while standing upright

The focus on time regarding *Acceptance* is also shown in other constructions: "<u>It is and will never be</u> a flat sea in my head and body. <u>It is never quiet again</u>." The author describes *Acceptance* of the fact that things have not only been different in the past and are still in the present, but also that they will be different for all of the foreseeable future. The metaphor of the sea in his head and body serve to communicate how the constant shaking feels to him. Just like the shaking on a boat, it is inescapable. All one can do is accept and live with it.

The participants constructed positions with *Acceptance* in relation to different events and experiences. Some are straightforward statements that one is ill, others focus on accepting that certain activities are out of reach now, and others again emphasize the procedural nature and role of time in coming to accept a now changed life.

2. Free to Act

The tool to position oneself as *Free to Act* is present when an author establishes that there are no other people or circumstances that limit or control the author's actions. Examples of these limiting or controlling factors in the context of this study are the chronic illness itself, the ill person's family, or doctors and other medical personnel.

One instance of the use of the tool is the following: "My asthma <u>does not feel like an obstacle</u>." The reference to the lack of a hindrance in the participant's life is what makes this an example of a free to act construction. Another author concludes their narrative with the following construction: "Many things require attention, <u>to prevent us from being lived by my condition</u>." The verb 'to live' is most often only encountered in its active form. This rare passive use of the verb is interesting because it puts the author's illness as an outside entity that would take control and 'live' her life instead of herself. However, the author constructs agency here by stating that such a situation can be avoided by paying attention to the illness.

The next construction is notable for the role an outside factor takes in it: "Precisely <u>because my healthcare professionals were able to see me</u>, the person instead of the patient or the condition, they were

also able to <u>give me the tools to shape my new life</u>." Healthcare professionals are described differently here than is often the case. Instead of positioning them as a limiting and controlling force, they are described as making the process of acting freely possible in the first place. Compared with other constructions, whereby circumstances and doctors' advice are often put as adversarial to one's own ability to choose, here they are characterized as something helpful and freeing.

Summarizing, this tool is characterized by references to hindrances and controlling factors. Passive verb constructions and reference to outside forces can be an indication for this tool. Agentic uses of this tool reject the existence of obstructions, describe a struggle against being controlled, or even refer to other actors as helpful.

3. Interioration

This tool regards a person with a chronic illness positioning their thoughts, feelings, and experiences within themselves rather than as an outside entity which they possess. Constructions of agency with this tool are rare in the analyzed narratives.

Interestingly, the only two notable instances of agentic constructions with this tool differ from how they are conceptualized in the 10DT Model. Both position the narrators as agentic, but do so with constructions that normally indicate *Exterioration.* The first example of this is the following:

> <u>I have</u> a chronic illness. <u>It is not me</u>. I just give all the discomfort the time it demands. That's all. I write, draw and read a lot, I have a social network and sometimes I am a babysitter and language volunteer. Often I saw people who had made being ill their identity.

What makes this noteworthy is the construction of *Exterioration*. Within the 10DT Model this tool is normally considered to be used for constructions of nonagency by considering experiences as outside entities. However, this author employs it here in a way to reject limitations and tell that she is not

defined by her chronic illness. She uses this tool conversely to how it is described in the 10DT Model by constructing internalizing as a sign of nonagency (being ill as an identity) and externalizing as a sign of agency (keeping the illness at a distance).

Another similar case is the following: "It's <u>my life</u>, full of pain, <u>but still mine</u>." The sentiment of this exclamation at the very end of a narrative is clearly one of agency by claiming ownership of every experience, positive or negative. However, the twofold use of possessive pronouns puts it in the realm of *Exterioration* by putting the narrator in a position of ownership with respect to their life situation.

With these two contrary examples, the tool of *Interioration* somewhat stands out from every other tool discussed here. It begs the question whether it is plausible, although rare, for the other tools to also be used conversely to their conceptualization in the 10DT Model, meaning tools of non-agency to construct positions of agency and vice versa.

4. Initiating Action

This tool was recognized when the author constructed a position of being able to start an action that he/she desires. In the narratives such constructions are relatively common.

At times, such actions are about diminishing the symptoms that a chronic illness brings with it: "I remember well that I would sometimes <u>go for hours into the polder</u> to muffle the stimuli, even when it was raining." This example is focused on an activity that is done frequently to manage an illness . Others regard restarting those actions that were possible previously but have been lost during the course of the illness: "I slowly <u>started working again</u>."

Moreover, these constructions can also be extended to point toward a steady increase in agency as to what the author of the narrative is able to do now compared to before becoming ill:

> I <u>could run, cycle, climb stairs</u> etc. again. After that I could <u>go back to work</u>, which I
> continued to do until I retired [...]. Six months after the rehabilitation, I <u>ran my first 7-hill</u>

<u>run</u> of 15 km. Symbol of my resurrection. After that <u>I kept on doing it</u>, <u>I have now done this run more than 25 times</u> in a reasonable time.

The description of this process as a 'resurrection' by this participant is interesting. The metaphor here is, that she was dead before and through starting to act again she came back to life, in a sense equating agency with life and nonagency with death.

This tool also encompasses one of the idioms used by three of the participants. An example is the following: "I come from [place] myself, so I have the mentality of '<u>no talking, just doing</u>'." In Dutch the phrase is "niet lullen, maar poetsen". This figure of speech points directly at appreciating the worth of acting as opposed to allegedly inferior speech.

By its nature, this tool relies heavily on the use of verbs to construct positions of agency. Among others, participants simply state what they have been doing, describe the process of restarting an activity, or use lists to specify what they are able to do. In these expressions, the authors become positioned as either again or still able to engage in valued action. It is notable here that constructions about initiating action often refer to the workplace. A major share of the participants mention in some way coming back to work at one point and appreciating it. Another large topic is that of recreational activities.

5. Stopping or Curbing Action

A construction of this tool is present when a participant describes not engaging anymore (or at least less) in an activity that is undesired. Three instances of it have been identified. The first construction is the following: "So I have a normal daily rhythm, take good care of myself, dress nicely and try to hang 'garlands' every day[2]. And <u>don't think too much about the problems of the future</u>, because I won't change anything about that as long as there is no treatment." Here, the participant constructs thinking about the future as something undesirable in her situation. The construction could be read as referring back to the

---

[2] borrowed from a Dutch idiom, "Het leven is een feest, maar je moet zelf de slingers ophangen". The original sentence from the narrative reads: "Dus heb ik een normaal dagritme, verzorg mijzelf goed, kleed me mooi aan en probeer elke dag "slingers" op te hangen."

verb 'try' in the previous sentence, which would give a reading of the author attempting to stop worrying. Otherwise, the phrase could also be read as an appeal to herself not to think as much about the future.

The next construction regards the fact that some chronic illnesses are visible from the outside while others are not; a topic that was often found within the analyzed narratives: "The invisibility makes you feel you have to justify and defend yourself automatically. I have learned not to do that and to be clearer." Phrasing it as something that the author has learned is a good example of the increasing reflectivity of the tools, although *Stopping or Curbing Action* is still counted as nonreflective. Instead of simply stating that she has stopped to do a certain action, the author points toward an accompanying change within her mind.

The last construction is noteworthy because it differs from every example found so far: "I was terribly fed up with being tied to a drug from then on and was not always faithful to it until the doctor told me that an asthma attack is worse than inhaling medication for a year." The important point this example shows is that the 10DT Model stays neutral regarding the question of whether something is beneficial or harmful for the narrator. The 10DT Model does not equate agency with positivity and non-agency with negativity. Agency in the context of chronic illness has often been approached as people who successfully cope with their condition and act in their own best interest (e.g. Frank, 1997). However, here the author constructs his agency by going against his doctor's advice, which might ultimately be detrimental to his health.

6. Modifying Action

This tool is about changing a course of action in a desired way. In the context of chronic illness this might mean avoiding certain stimuli or adjusting a valued free time activity. Examples of the use of this tool are numerous within the analyzed narratives.

Constructions can refer to the general need to change without pointing to any specific activity: "Because the disease is progressive, it means that I have to change and adjust more and more things in my

life."; "My life has to progress in a different way."; and "How has my life been since I was diagnosed with endometriosis? Heavy, many adjustments, a time of mourning, but also loving myself again."

However, other constructions are more specific and point towards certain actions that are done differently now, often less intensely: "Despite the asthma, sport and recreation have never been a problem. Long walks in the mountains; sometimes with a little more rest."; "Looking for a different saddle, because I want to keep cycling."

At other points, constructions can become quite long and go into detail on how an author of a narrative restructured their life:

> For 1.5 years I have been working on repacking my life according to an extremely strict protocol (invented myself). I am only allowed to eat specific foods at specific times and need 40 minutes of total rest every 5 to 6 hours to allow the pills to dissolve properly in my stomach. If I move too much, eat something else, or in the two hours before taking it, there is no effect and I can't do much but lie down and wait for another round.

For constructions of this tool the choice of certain verbs pertaining to change can be indicators. Participants speak, for example, of 'changing', 'adjusting', and 'doing differently'. Moreover, dosages, specificity, and timing of activities are constructed as important when dealing with a chronic illness. This is noticeable from the use of phrases that put things in relation to an ideal that can either be adhered to or deviated from. Examples of this are 'more', 'less', 'too much', 'else', 'before', and 'after'.

7. Cognizance

This is the first tool of those considered reflective. That means that this and every following tool are characterized by taking a meta-position towards one's thoughts, feelings, experiences, or actions in the narratives. This first reflective tool is found when an author constructs a position of knowledge or understanding about one or more of these areas.

The first example of such a construction is the following: "In my adult life, I've had to <u>develop a language and feeling</u> for being sick. Taking myself seriously, but also <u>learning to nuance</u> what and with whom to share." The noteworthy element here is the focus on the procedural nature of *Cognizance*. It is something to be 'developed' and 'learned'. Moreover, language is specifically referred to as necessary to understand one's own illness and be able to communicate about it.

The next construction points towards the pondering of the chronic illness and its management: "In the meantime, <u>I have made clear considerations</u> about what works for me and my body." Knowledge about the illness and one's own body is constructed to follow from active thinking engagement rather than merely being a byproduct of living with it.

The last instance of a position of *Cognizance* that was identified points towards both the need to think and the process of learning: "It took some time, but I got that time. I also needed that to experience the limitations myself and <u>to learn to rethink</u> and accept." In the context of chronic illnesses, the wording of '*re*-thinking' is interesting. Since one shared element of all chronic illnesses is a change in one's lifestyle, the construction emphasizes having to think and learn again even about those parts of life that were formerly thought to be known and understood.

As would be expected by a reflective tool to construct positions of *Cognizance*, it utilizes verbs pointing toward thinking. They can be summarized as 'knowing' and 'getting to know'. In the analyzed narratives these were always phrased as lying in the past and often continuing into the present, using tenses of simple past and present perfect.

8. Reflected Function

This is the second reflective tool. It is characterized by assuming an evaluative position towards one's own past and current actions, experiences, and feelings. A position of *Reflected Function* is found when the author states or implies that he/she considers their actions to have been functional in the context of their illness. In the analyzed narratives, constructions of this kind are relatively uncommon compared to previous ones.

The following example illustrates how a participant constructs a position of *Reflected Function*: "Despite my frequent illnesses, I kept up well at primary school." Apart from the direct statement that the author sees his past performance in school as functional, it is noteworthy that he explicitly puts it into the context of his illness. It is not just that what he did worked, but that it did so even though he was limited in his capabilities.

Another participant constructed her position of *Reflected Function* by describing herself: "Fortunately, I was a creative and imaginative child, not a sporty and energetic one." Here, instead of describing what went well or against what kind of resistance, she points towards why she thinks her management of the illness was successful. By starting with the word 'fortunately', the participant adds the reflective and evaluative element to the construction. Rather than merely stating a fact about herself, she puts being creative and imaginative as a stroke of luck that enabled her to better handle her illness. It is notable that the participant explicitly compares herself to 'sporty' and 'energetic children'. The implied dividing line here is between persons with either a thinking or bodily nature, with the latter presented as being at a disadvantage when being chronically ill.

The participants constructed agency with *Reflected function* in relation to not only physical acts, but also to a change in one's way of thinking. Having an epiphany, can also be subsumed under this umbrella if it is constructed as functional afterwards: "Work turned out to be a big part of myself. Later I experienced that I am much more than my job, and that I can also be happy without a career." There are two instances of reflection here. For one, the reflection the author engaged in back when she struggled with the loss of her employment, and secondly the one during the writing of this narrative. The latter describes the author's past thought process as having been functional for enabling her to be happy again. In a sense, it is reflection about reflection. Summarizing, the found examples of *Reflected Function* are characterized by either directly stating (e.g. 'I think') or at least implying that the author has reflected on the matter and concluded a positive outcome.

9. Continuance

This reflective tool is found when an author constructs a position in which his/her past, present, and/or future seem to be connected. The following are examples of constructions that were found.

One construction that was found several times was that of being happy upon learning that the past and present symptoms have a name and what that means for the future: "<u>After three years of research</u> and several differential diagnoses, it was also a <u>relief to know what I had</u> and what the <u>future prospects</u> were like." This construction combines all three time periods together. Past symptoms become a diagnosis and then lead to future outlooks.

In the next construction, a participant writes from his present perspective about hypothetically being diagnosed earlier in his life and what difference that would have made: "<u>Looking back, I come to the conclusion</u> that <u>long before 2015, I had complaints in the direction of CIAP</u>, but that Dutch doctors never look further! Of course <u>nothing would have changed</u>, but knowing is important to be able to estimate what you can and cannot do." Here, symptoms and diagnosis in the past are connected to a point of introspection in the present. The element creating coherence in the narrative is the author's sense of their symptoms. They reach from the past into the present where the author is able to reflect on alternative outcomes.

Finally, one participant used a construction that connects the past directly to the future in a seemingly all-encompassing expression: "[...] on the other hand, every event with <u>a decision in the past is a glimpse into the future</u>." This both positions the author himself as living within a continuing story, but also serves as a neat summary for the concept of *Continuance*. The implication here is that each action of a person is necessarily connected through time with its consequences in the future.

10. Perspectival Positioning of others

This tool is the most reflective of all. It is present when an author refers to the viewpoint of another person as something unknown to him/her instead of assuming to know their thoughts and opinions. In the analyzed narratives such a construction was not found. The topic of other people's

viewpoints does come up in the narratives, but always in an assumptive manner that claims to know their thoughts, e.g. expecting judgement because one's illness is invisible.

Discussion

The present study aimed to examine and carve out the ways in which persons with a chronic illness discursively construct positions of agency for themselves. For this purpose, a discourse analytical approach, using the 10DT Model of (Non)agency (Toivonen et al., 2019), was employed. 22 written narratives of living with a chronic illness produced by participants were analyzed. The narratives were searched for constructions of agency using the framework of the 10DT Model. Of the 10 possible tools, 9 were found in the narratives. Only the 10th and most reflective tool (Perspective Positioning of Others) was not identified in any of the narratives.

In general, it is noteworthy that not only are there examples of all but one of the tools in the analyzed narratives, but also that there are constructions of agency in almost every narrative. Of the analyzed 22 narratives, three did not contain any constructions of agency. However, in the remaining 19 narratives, even in those that heavily focus on the inability and limitations of a chronic illness, there were sections in which participants positioned themselves as agentic. They accepted that they were ill, focused on their behavior, and reflected on past experiences.

This study contributes to the qualitative research on those chronic illness narratives. In the existing literature on chronic illness experience the topic of agency is integral. However, research on how people actually express their agency in language is limited. A large share of the discourse analytical research on agency constructions focuses on interactions in the context of psychotherapy (e.g. Avdi, Lerou, Seikkula (2015); Bury, 2001; Coleman, & Neimeyer, 2015; Wahlström & Seilonen, 2016) but it also includes research on, for example, counseling after drunk driving (Seilonen, & Wahlström, 2016) and narratives about old age (Jolanki, 2009). Indeed, the framework of the 10DT Model of (Non)agency (Toivonen et al., 2019) employed in this study was created by analyzing conversations between clients and therapists and is now for the first time being applied to a different sample of participants. Hence,

there are no similar studies to directly compare the present results to. However, even with this novel approach the results can still be put into the wider context of chronic illness literature.

First of all, one salient difference between the present study and those targeting psychotherapy is that participants have no incentive to present themselves in a certain way. Toivonen et al. (2019) emphasized that persons in the early stages of psychotherapy have a certain motivation to present themselves as being non agentic in order to attain therapeutic aid. That is not the case for this study, for which participants were to provide narratives about their chronic illness, but without the prospect of any such gains. Neither presentation as particularly agentic or nonagentic carried any consequences. Another difference is the data being written narratives instead of transcribed conversations, as is common in discourse analysis of agency.

The results of this study reflect the wider literature on chronic illness narratives. Participants write of their lives as either having changed at some point or having always been different from other people. Constructions of agency in their narratives show the participants' struggle with the limitations of an illness as well as their environment.

One aspect that the literature on chronic illness narratives points toward is a common element of "striving towards normality" (Synnes et al., 2020, p. 2). Although seldom directly addressed, this drive toward leading a 'normal' life pervades many of the participants' constructions. Especially salient for those are constructions of tool 4, 5, and 6, initiating, stopping, and modifying action. The participants write of (re)starting activities that represent normality such as work or hobbies, stopping those that show abnormality like worrying or justifying yourself in front of others, and changing in order to deviate as little as possible.

Another noteworthy finding of this study is that tools can be used in a way that deviates from the 10DT Model. In this study, a reversion of a tool was found. In such a case the participant employs a construction that normally would be considered a non-agentic one, *Exterioration*, but uses it in a way that constructs a position of agency for herself. The important point in that construction is that of identification with being ill. The author positions herself as being agentic only while keeping her illness at a distance

and actively preventing identification with it. In the 22 analyzed narratives, this was the only instance of reversion of a tool. By reversion I mean the use of a discursive tool to construct a position of the opposite side of the agency/non-agency dichotomy (using a non-agency tool in positioning yourself as agentic and vice versa). Other such reversed constructions also seem plausible for other tools, but appear to be rare, at least within chronic illness narratives.

Lastly, it is remarkable that tool 10, *Perspectival Positioning of Others*, was not found once throughout all analyzed narratives. This is interesting because the topic of what other people think of the authors does come up often in their narratives and seems to be important. It spans all persons that the chronically ill person comes in contact with, their partners, family and friends, doctors, as well as strangers and society as a whole. However, none of the participants ever constructed a position for themselves of not knowing what the other person thinks. Instead, there always seemed to be an assumed knowledge about other peoples' minds. Negative evaluation or misunderstanding of oneself is often taken as a matter of course (If my illness is invisible, how could other people ever understand what it is like?). Many authors wrote of a feeling that they have of judgement, lack of understanding and disappointment towards them for being ill. Moreover they treated this feeling as a true reflection of other people's opinions instead of their own impression. Actual instances of other people expressing negative judgement about one's illness are never provided in the narratives. Reaching this highest level of reflection, to treat other peoples' thoughts as unknown, seems to be difficult for many authors who instead treat effective communication with others as impossible from the outset.

In summary, the 10DT Model of (Non)agency fits well to identify constructions of agency within chronic illness narratives. It can be used to achieve a better understanding of how a person with a chronic illness talks about what it means to be ill and how they position themselves as agentic between their own experience, their symptoms and their surroundings.

The strengths of the present study are its application of the 10DT Model of (non)Agency to a novel sample group (persons with a chronic illness) and form of data collection (written narratives). Moreover, there were frequent meetings between the researcher and supervisors as well as peers, adding

to the results credibility and confirmability as described by Shenton (2004). Another strength is the negative case analysis in including those constructions of agency that deviate from the 10DT Model.

Limitations of the study are: (1) The original narratives were written in Dutch and thus needed to be translated into English in order to be workable. Especially when working with a language focused approach as discourse analysis, certain nuances of a language might be lost during translation. To ameliorate this, I worked with another student who is a Dutch native speaker to proofread translations and clarify unknown phrases. (2) The sample of narratives is heavily skewed towards women with a chronic illness (72 % of analyzed narratives). Thus, it is not altogether clear if the analyzed narratives show a particularly female perspective on being ill. (3) Not all suggestions made by Shenton (2004) to ensure trustworthiness could be complied with such as checking back with participants and providing reflective commentary on the course of the analysis.

Future research might expand usage of the 10DT Model of (Non)agency to areas other than chronic illness or use different data such as transcribed interviews. Moreover, it might be fruitful to examine the difference between men and women in narrating their illness. Also, since this study employed a solely Dutch sample, future research could profit from analyzing narratives from other countries, especially non-western ones, to uncover cross-cultural differences in talking about what it means to be chronically ill.

References

Ahearn, L. M. (1999). Agency. *Journal of Linguistic Anthropology*, *9*(1/2), 12-15.

Alkire, S. (2005). Subjective quantitative studies of human agency. *Social indicators research*, *74*(1), 217-260.

Avdi, E., Lerou, V., & Seikkula, J. (2015). Dialogical features, therapist responsiveness, and agency in a therapy for psychosis. *Journal of constructivist Psychology*, *28*(4), 329-341.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, *4*(2), 167-182.

Bury, M. (2001). Illness narratives: fact or fiction?. *Sociology of health & illness*, *23*(3), 263-285.

Carel, H. (2009). A reply to 'Towards an understanding of nursing as a response to human vulnerability' by Derek Sellman: vulnerability and illness. *Nursing Philosophy*, *10*(3), 214-219.

Coleman, R. A., & Neimeyer, R. A. (2015). Assessment of subjective client agency in psychotherapy: A review. *Journal of constructivist psychology*, *28*(1), 1-23.

Dowrick, C., Dixon-Woods, M., Holman, H., & Weinman, J. (2005). What is chronic illness?. *Chronic Illness*, *1*(1), 1-6.

Frank, A. W. (1997). Illness as moral occasion: Restoring agency to ill people. *Health:*, *1*(2), 131-148.

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Ectj*, *29*(2), 75-91.

Harré, R. (1995). Agentive discourse. *Discursive psychology in practice*, 120-136.

Hurwitz, B. (2000). Narrative and the practice of medicine. *The Lancet*, *356*(9247), 2086-2089.

Jolanki, O. H. (2009). Agency in talk about old age and health. *Journal of aging studies*, *23*(4), 215-226.

Potter, J., & Hepburn, A. (2008). Discursive constructionism. *Handbook of constructionist research*, 275-293.

Seilonen, M. L., & Wahlström, J. (2016). Constructions of agency in accounts of drunk driving at the outset of semi-mandatory counseling. *Journal of Constructivist Psychology*, *29*(3), 248-268.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, *22*(2), 63-75.

Synnes, O., Orøy, A. J., Råheim, M., Bachmann, L., Ekra, E. M. R., Gjengedal, E., ... & Lykkeslet, E.

(2020). Finding ways to carry on: stories of vulnerability in chronic illness. *International Journal of Qualitative Studies on Health and Well-being*, *15*(1), 1819635.

Toivonen, H. (2019). *Constructions of Agency and Nonagency in Psychotherapy: The 10 Discursive Tools Model* (Doctoral dissertation). Received from author.

Toivonen, H., Wahlström, J., & Kurri, K. (2019). Constructing nonagency at the beginning of psychotherapy: the 10DT model. *Journal of Constructivist Psychology*, *32*(2), 160-180.

Toivonen, H., Wahlström, J., & Kurri, K. (2019). Discordances in Ascriptions of Agency and Reflectivity in the First Psychotherapy Session. *Journal of Constructivist Psychology*, *32*(4), 424-443.

Toivonen, H., Wahlström, J., & Kurri, K. (2020). Constructions of Nonagency in the clients' initial problem formulations at the outset of psychotherapy. *Journal of Contemporary Psychotherapy*, *50*(1), 77-86.

WHO. (2021). Noncommunicable Diseases. Retrieved from https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases

Wahlström, J. (2021). The narrative metaphor and the quest for integration in psychotherapy. In *New approaches to integration in psychotherapy* (pp. 38-49). Routledge.

Wahlström, J., & Seilonen, M. L. (2016). Displaying agency problems at the outset of psychotherapy. *European Journal of Psychotherapy & Counselling*, *18*(4), 333-348.

Williams, G. (1984). The genesis of chronic illness: narrative re‑construction. *Sociology of health & illness*, *6*(2), 175-200.

Appendix A: List of Participants' Diagnoses

- Allergies
- Asthma
- Bronchitis
- Immune Deficiency
- Chronic Obstructive Pulmonary Disease (COPD)
- Fibromyalgia
- Myalgic Encephalomyelitis (chronic fatigue syndrome)
- Endometriosis
- Selective Antibody Deficiency With Normal Immunoglobulins (SADNI)
- Migraine
- Food Intolerances
- Axial Spondyloarthritis
- Mal de Debarquement
- Tinnitus, Hyperacusis, and Misophonia
- Sinusitis
- Bowel Inflammation
- Mood Disorder Bipolar I
- Persistent Postural Perceptual Dizziness (PPPD)
- Lichen Sclerosus
- Rheumatoid Arthritis
- Polyneuropathy (CIAP)
- Small Fiber Sensory Neuropathy (SFSN)
- Progressive Muscle Disease
- Guillain-Barré Syndrome
- Apnoea
- Thrombosis
- Arrhythmia