

The bumpy road of recovery

A study about the burden of recovery that patients who suffer from recurrent psychoses experience, what role a diagnosis plays in this and how support can decrease this burden.

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Preface

It's a wrap! For the past 7 months I have been working on this research with a lot of passion and enthusiasm. It was not always easy in these crazy Covid-19 times. When I started my bachelor's degree in health sciences, I would have never believed it if someone had said to me that I would write my master's thesis during a pandemic. But, it turns out I did! And with success, if you ask me. Although I missed the cafes in Rotterdam and the personal contact with students, I managed to succeed, thanks to the great guidance of Hester and the alternative online contact with students.

I am grateful to be able to contribute to the knowledge regarding the recovery process of patients who suffer from recurrent psychoses. A good friend of mine has experienced a psychosis a view years ago and I remember very well what impact this had on him and his environment. It made a strong impression on me too. Fortunately for him, it was a one-time psychosis. But knowing what kind of impact this already had, I got even more interested about the consequences for people who suffer from recurring psychoses. Especially, with regard to the recovery process and what that entails for them. Luckily, I got the chance to research this during this study.

Through this way, I want to thank the patients who dared to share their stories in the selected books, for their courage, openness and vulnerability. I highly respect all of you. I hope that I have also been able to raise a little bit awareness about the importance of providing sufficient and appropriate support to people who suffer from recurrent psychoses. And who knows how I might be able to add value on this topic in my future career...

Once again, I would like to thank my supervisor Hester van de Bovenkamp very much. Thanks to you, I have experienced this thesis period as very pleasant. Your enlightening, clear feedback and motivating words have absolutely contributed to this. You gave me confidence and motivation throughout the thesis period, for which I am very grateful!

In addition, I would like to thank my second reader, Rik Wehrens, in advance. I hope you will read my thesis with great interest and look forward to your response! Last but not least, I would like to thank my thesis peers, friends, roomies and family for the endless support. Much appreciated! I become a bit emotional with the thought of my student life coming to an end. However, I am also looking forward to the future and all the wonderful new challenges that will undoubtedly come my way!

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Abstract

Recovery amongst patients who suffer from recurrent psychoses, is a long-term multi-faceted and complex process, which can cause a burden of recovery on patients. Therefore it is important to provide sufficient support during the recovery process. Especially since current studies have shown that adequate recovery support reduces the chances of a getting another psychosis, less (inpatient) care is needed and the quality of life can be increased.

However, little qualitative research has been done, that considers the combination of the disorder experience, burden of recovery and the role of diagnosis in this. Therefore, this study examines what burdens of recovery are experienced among patients that suffer from recurrent psychosis, what role a diagnosis plays in this and how support can decrease this burden.

Within this qualitative study, a thematic analysis has been conducted on patient experience stories from books. Patient stories contributed to a better understanding of the personal experiences and provided insights in how patients' perspectives towards the disorder and recovery process changed over time. In total 94 patient stories were analysed, from three books of different authors.

The analysis shows that receiving a diagnosis plays multiple roles in the experienced burdens during the recovery process. In the beginning of the diagnostic process, it causes relief among patients, because it explains experienced symptoms. Then, the patient needs to process and accept its disorder identity. Consequently, this is where patients also experience the negative effects, such as (self-)stigma and the burden of (non-) transparency. In the end, receiving a diagnosis is necessary in order to start the recovery process.

During the recovery process, the following burdens of recovery are experienced: the burden of diagnosis, the burden of transparency, the burden of stigma and the burden of participating in society and social integration. These burdens can be decreased by participating in peer groups, where patients learn how to accept the disorder and develop a positive mindset. However, a reorganization of the mental health services and recovery support is also necessary. One that is more in line with the shifted definition of recovery and that offers a more holistic perspective on care and recovery.

For follow-up research, it is recommended to conduct additional interviews, that also include other perspectives, such as family and friends. It is also recommended to further investigate what the reorganization of support and care should exactly entail and whether this is possible.

Key concepts: Burden of recovery, chronic psychosis, patient stories, role of diagnosis, (self-)stigma, peer groups, positive mindset, acceptance, recovery support

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1. Introduction

1.1 Problem analysis

"I want to get back to work, I want to get back to a normal, stable life. And looking after my own well-being in the best way I can manage it" (Dilks, Tasker & Wren, 2010, p. 9).

This quote from a patient during a therapy session, gives a description of the desire that people who suffer from recurrent psychosis have to recover. However, it is not very common to be cured from this disorder. For this reason, the definition of recovery changed over time from a medical definition that focuses on returning to a state without any signs of illness, to returning to a state with relatively good health outcomes. The definition has moved further away from the medical perspective and is now more seen as an active, ongoing personal process in which people try to give their lives meaning and direction again (Boevink & Dröes, 2005; Sayce & Perkins, 2000).

However, recovery is a long-term, multi-faceted and complex process, which can cause a burden on patients. This so-called burden of recovery can be caused by certain aspects, such as feeling overwhelmed by the responsibilities and tasks that come along within the recovery process (Nordfonn, Morken, Bru & Husebø, 2019). Furthermore, a large amount of stigma has to be faced, which also leads to a feeling of recovery burden (Salzmann-Erikson, 2013). Some patients argue that this is also influenced by the role of diagnosis, as this classifies people into certain categories and consequently influences their identity (Dehue & Jonge, 2008). This subsequently increases stigma. On the other hand, there is also a patient group that does value the role of diagnosis, since it can medically explain their experienced symptoms and demonstrates that their symptoms were real. This is experienced as a relief (Brody & Waters, 1980). Hence, the diagnosis is perceived differently among patients. Some experience it as standing in their way to recovery, while others are being helped by it.

Even though the impact of a diagnosis can be perceived differently among patients, it is either way of importance to find out what burden of recovery is experienced among patients that suffer from recurrent psychosis. Then, it can be examined what support is needed to deal with this burden and how this can improve the recovery process. Furthermore, it is interesting to take the role of diagnosis into account in this, in order to find out how this affects the burden of recovery. Therefore, this study will research what the burden of recovery entails for patients who suffer from recurrent psychoses and how the role of diagnosis affects this. By gaining more insight within this topic, improved recovery support that fits the patient's needs can be developed.

1.2 Societal and scientific relevance

This research has a substantial societal relevance. In 4 out of 5 patients, a psychosis recurs more often (GGZ standaarden, 2020). This has a significant negative impact on the experienced quality of life and limits patients from actively participating in society. Also, a lot of (inpatient) care is needed. While current research shows that with the right recovery support, this does not need to be the case (Castelein et al., 2021). Therefore, research on what this recovery support should entail is necessary.

Furthermore, there is a high degree of scientific relevance present, because a considerable amount of quantitative literature can be found about the impact of a psychotic disorder on a person's quality of life. However, little qualitative research has been conducted that considers the combination of the disorder experience, burden of recovery and the role of diagnosis in this. While this can particularly provide very interesting insights in their mutual relations and changes over time.

1.3 Objective and research question

This study aims to investigate what burden of recovery patients with recurrent psychoses currently experience and what role medical diagnosis plays in this, in order to improve recovery support and consequently decrease experienced burdens. The research question within this thesis research therefore is the following:

“What burden of recovery do patients that suffer from recurrent psychoses experience, what role does medical diagnosis play in this and how can support decrease these burdens?”

This will be examined on behalf of the following sub-questions:

1. What burdens of recovery are experienced among patients who suffer from recurrent psychoses?
2. What does the role of diagnosis mean in (the burden of) recovery?
3. How can the recovery support of patients who suffer from recurrent psychoses be improved?

Written patient stories will be analysed on themes that are relevant to the recovery process. By gaining knowledge regarding this subject, therapy and support can be improved and the patient's quality of life can be enhanced.

1.4 Reading guide

This study is structured as follows. The next chapter will provide a theoretical framework regarding the burden of recovery and the role of diagnosis. Furthermore, experienced stigma and the burden of (expectations from) society will be discussed. Chapter 3 describes the method of the study, including how data was collected, the way this was analysed, how reliability and validity were

ensured and how ethical aspects were handled. Chapter 4 describes the results of the analysis of the selected patient stories. Based on these results, conclusions will be drawn. These can be found in chapter 5, where the results will also be compared with the findings from the theoretical framework. Then, based on the previously formulated sub-questions, the research question will be answered. Lastly, recommendations for follow-up research and implications for practise will be given in chapter 5.

2. Theoretical Framework

2.1 The changing concept of recovery

In the field of schizophrenia recovery used to be defined as returning to a premorbid state without any signs of the illness (Færden, Nesvåg & Marder, 2008). However, a cure for this disorder was rare, which led to the understanding that this was not an appropriate definition. A more common prognosis was a mild amelioration after an initial psychosis. Therefore, the definition changed to being in a state with relatively good outcomes (Harding et al., 1987). Meanwhile, fulfilling a role in society and living well with the illness despite the experience of chronic symptoms, has been incorporated in the definition as well (Jacobson & Greenley, 2001).

Furthermore, a number of common elements within the recovery process can be found: renewing hope and commitment, redefining oneself, accepting the disorder, overcome stigma, having control over life, empowerment, taking citizenship, dealing with symptoms and feel supported by others (Frese & Davis, 1997). As Davidson et al. (2005) adequately describes, it becomes an attitude to life, a vision and an experience, instead of a return to a healthy state.

The concept of recovery got increasingly used in diverse contexts, with various purposes and most importantly with different meanings. It is striking, that the definition moves further and further away from the medical perspective. Unlike in clinical practice, it does not refer to the elimination of symptoms and returning to the old state anymore. It moves towards a unique, personal process in which people try to give their lives meaning and direction again (Boevink & Dröes, 2005).

The dissociation of the medical perspective can be seen as a response against the medicalization of society, where amongst others patients feel that all negative feelings and behaviours are being classified as a medical problem. Where a person once could just have an off-day, nowadays a psychiatric patient is quickly labelled as depressed and before he notices it, receives the label depression. This is also noticeable among therapists. Whereas in the past, therapists had the task of interpreting the deeper causes of depressed feelings, nowadays it is noticed that psychiatrists mainly focus on how to make it stop as soon as possible. Which reinforces medicalization and classification (Dehue & Jonge, 2008).

This classification movement, changes people. People can start behaving according to their diagnosis. But people can also change classifications, by giving them a new meaning. They try to see themselves not as ill and weak, but try to turn their "abnormality" into a strength. The feelings and behaviours that were classified as a medical problem by therapists, can also be very useful and do not directly need to be seen as a medical problem according to patients (Dehue & Jonge, 2008). Van

Os (2014) therefore states, that the real diagnostic process should not be about looking for the best fitting label, but about what support is needed for the experienced symptoms. And while doing so, the context of someone's story should be taken into consideration. This also requires a change in the type of care that has to be provided. One that is more in line with the shifted definition of recovery and that offers a more holistic perspective on care and recovery.

2.2 The role of diagnosis

In the 19th century, the American Psychiatric Association (APA) developed a classification system for mental disorders, called the Diagnostic and Statistical Manual of Mental Disorders (DSM). This was necessary, because there was confusion among scientists and psychiatrists regarding terms in the literature about psychiatric disorders. Therefore, the main purpose of the DSM was to standardize the language used in psychiatry by formulating clear criteria for the use of disorders (Clegg, 2012). However, in practice it turns out to be predominately used to search for the best fitting label (Dehue & Jonge, 2008; Os, 2014). Experiences in practice show, that sometimes patients receive four or five different diagnoses during their career in the psychiatric care, even though their core symptoms have hardly changed. They see their own "label" evolve, just because the way their symptoms are characterized by psychiatrists have evolved (Francis, 2020). A development that does not fit the ongoing movement of opposition of classification and dissociation of the medical perspective, as mentioned earlier.

The way patients view the role of a diagnosis in recovery differs. One group seems to dissociate from the medical perspective, especially when it is noticed that the diagnosis turns out to be by no means a key to improvement (Van Os, 2014). However, there is also a group that does value the role of a diagnosis. In their view, it is seen as an explanation of the experienced symptoms and confirms that a medically underlying reason is present. This does not only pave the way for obtaining treatment, but also functions as a type of treatment itself. It can be seen as some sort of therapeutic tool, where both behavioural and physical symptoms can be remedied (Brody & Waters, 1980). They feel helped by getting a label and make the classification part of their identity, self-image and their existence.

It should be noticed that by doing so, they make the DSM labels, whose utilization is questionable, into incontrovertible facts. The aim of the DSM was merely to standardize the language of psychiatry, by formulating clear criteria for the use of disorder names. However, it now appears that the labels almost automatically acquire the status of causal entities for their use. This in turn, has consequences for the treatment and perception of the patient (Dehue & Jonge, 2008).

There is also a patient group that opposes the classification system. According to this group, the role of a diagnosis does not only regulate the work of professionals, but also influences the identity of the people it classifies in a negative way (Dehue & Jonge, 2008). The diagnosis of a psychotic disorder is so strongly labelled as a dreadful progressive debilitating syndrome (with very low recovery chances), that someone who is functioning well, can still be dismissed because of the stereotype that is made of the disorder. Even though scientific research shows that the prognoses of psychotic disorders are extremely variable and that different forms of recovery are common (Os, 2014). For this reason, these patients experience that their diagnosis stands in the way of recovery.

2.3 Burden of recovery

Being diagnosed with a disorder that involves experiencing recurrent psychoses, entails many consequences for a person. Literature often speaks of the burden of care, which refers to the burden a chronic condition has on the functioning and well-being in a patient's life. This can contain physical, financial, practical and emotional aspects (Sav et al., 2013). People that suffer from a psychotic disorder, face significant challenges in their everyday life, such as managing symptoms and performing basic tasks, which are made more difficult amongst others by their problems with social interaction (Yanos & Moos, 2007). In order to cope with the burden of care that patients that suffer from recurrent psychoses experience, adequate support in the recovery process is crucial.

However, this recovery process can also cause a burden on the patient, since this can be a long-term, individual and multi-faceted process. Within this thesis research, this is called the burden of recovery. This is an all-encompassing concept, which refers to all burdens a patient has to face during the recovery process. Since recovery for patients who suffer from recurrent psychoses, is a complex process that is influenced by multiple factors.

When it comes to being diagnosed, it is difficult to say what role diagnosis has on the burden of recovery. As mentioned earlier, the way patients view the role of diagnosis differs. Some patients received the diagnosis with feelings of relief and gratitude, while others abhor the label as stigmatizing. However, two aspects that can affect the recovery process, are the meaning a physician assigns to the disease plays a role. And secondly, the ability to master and control the diagnosis plays a crucial role. Feeling able to do this, promotes recovery (Kessler, 1977).

According to Mancini, Hardiman and Lawson (2005), barriers that are experienced during recovery, include paternalistic treatment systems, indifferent professionals and accompanying challenges as a result of the symptoms of the disorder. Patients can also experience a burden of recovery from the responsibilities and tasks that come along within the recovery process. The patient may feel overwhelmed by the lifestyle changes and self-management tasks that are encouraged to

be performed (Nordfonn, Morken, Bru & Husebø, 2019). Furthermore, the patient needs to process and accept its disorder identity. This can be done by putting effort in positive self-reflection, asking feedback from others and relabelling of being different from society (Demain et al., 2015). According to Pettie & Triolo (1999) this includes that the patient shifts his mindset from 'why me' to 'what now'. By creating a new and accepted believe about oneself, a basis for self-direction and meaning in life can be formed (Demain et al., 2015; Pettie & Triolo, 1999).

The recovery process can be improved when the patient surrounds himself with supportive relationships, engages in activities that give meaning to life and receives effective treatments (Mancini, Hardiman & Lawson, 2005). Another crucial element in the recovery process is community integration in an environment that is most meaningful to the patient. The environment plays an important role in the experienced burden of recovery of a patient. The experienced burden can be decreased when the environment provides access to community resources and allows for social interaction (Merryman & Riegel, 2007). However, this is often not the case for patients who suffer from recurrent psychoses.

2.4 Burden of stigma and (the expectations of) society

Patients who suffer from recurrent psychoses, often do not get fair access to community resources and experience difficulties with social interaction. They have to face a large amount of stigma from society. Studies have shown that many Western European nations have stigmatizing attitudes about mental illnesses (Corrigan & Watson, 2002). This prevents people that suffer from a mental illness to get equal opportunities such as good jobs, safe housing and connections with society. These constraints can also be called the burden of stigma, which in turn contributes to the burden of recovery.

The burden of stigma can be strengthened by the role of diagnosis, since stereotyping based on a DSM-label occurs. For example, poor prognosis is institutionalized in the DSM, when being diagnosed with a disorder like schizophrenia. As a consequence, people diagnosed with schizophrenia are seen as unpredictable, dangerous and being capable of relatively little. The media also plays a role in this, by sketching a skewed picture of reality. Situations of violence are being exaggerated, resulting in an increase of misconceptions and stigmatization (Angermeyer, Beck & Matschinger, 2003). When a patient does function well and does not belong to the part that has a poor prognosis, the patient can still be seen that way, because of the stereotype that is created around the disorder. Once classified in a certain group, a person cannot get rid of the stigmatizing thoughts that are associated with it (Os, 2014). As a consequence of these stigmatizing judgements,

self-stigma arises and the self-esteem and confidence of a psychiatric patient reduces (Corrigan & Watson, 2002).

Another aspect that adds to the burden of recovery, is the expectation of patients to participate in society. The Netherlands has a participation society, where individualization and responsibility are key concepts. Patients are therefore expected to actively participate in society, make a contribution and create a social network. However, this contradicts the before mentioned burden of stigma that patients have to face. This means that on the one hand it is important that patients participate in the society, while on the other hand they have to deal with stigmatizing thoughts and therefore often have to deal with social exclusion. Research shows that both labelling, the negative prognosis and the stigmatizing judgements lead to society's desire for this social distance (Angermeyer, Beck & Matschinger, 2003). Therefore, creating and maintaining a social network and participating in society is hard for people diagnosed with a psychotic disorder.

The stereotypes and stigmatizing thoughts on people who are diagnosed with a psychiatric disorder creates a burden and hampers their recovery process. By not being able to meet society's expectation of quick recovery, this burden only gets worse. When all burdens accumulate, patients are more likely to experience recurring psychoses and an increasing demand for healthcare services and their associated healthcare costs will occur (May, Montori & Mair, 2009). In order to cope with the burden of recovery that patients that suffer from recurrent psychoses experience, adequate support in the recovery process is crucial. It is therefore important to discover what this support should entail.

3. Strategy

This chapter will discuss the strategy used for this thesis research. Within this section, the study design, data collection, data-analysis, reliability and validity and ethical aspects will be addressed.

3.1 Study design

To formulate an answer to the research question, a qualitative study is performed. Qualitative research serves as the ideal method for this objective, since it allows a researcher to investigate a phenomenon within a specific context (Erlandson et al., 1993). Since this study seeks to uncover and describe what type of burden of recovery patients suffering from recurrent psychosis experience and what role medical diagnosis plays in this, it also fits the interpretive and descriptive character of qualitative research. In addition, according to Mortelmans (2013), experience-oriented research questions are very suitable for a qualitative research design.

Within this qualitative study, a thematic analysis has been conducted. This method is used, because it aims to reflect the main elements of respondents' stories. In addition, the method is a useful approach for answering questions about salient issues, such as what burdens are experienced during the road to recovery for patients that suffer from recurrent psychosis (Green & Thorogood, 2009). It enables to explore the experiences of individuals and gives an in-depth insight into the to be investigated phenomenon (Cresswell, 2013).

The thematic analysis is applied to patient experience stories from books. This method of using patient stories, is increasingly recognized as an important aspect to improve quality of care (Cordon, 2019). As they provide insight in how a disorder and its associated consequences are experienced, in a way that is neglected in medical research (Frank, 2013). They contribute to a better understanding of the personal experiences of people with chronic psychosis, regarding the burden of recovery and the role diagnosis plays in this, without being structured by a researcher. In addition, the written patient stories provide insights in how patients' perspectives towards the disorder and recovery process change over time. Moreover, similarities and differences between different patient stories can be found (van de Bovenkamp, Bal & Platenkamp, 2019). The sometimes deeply moving and personal stories, are written to show peers that they are not alone and to help them. Furthermore, the aim is to show shortcomings in the provided care and support, in order to make professionals learn from this (Boevink & Plooy, 2006; Ter Kulve, 2008; Romme, 2012).

3.2 Data collection

The data for this study, consisted as mentioned earlier, of patient experience stories from books. In order to select these stories, the website patientervaringsverhalen.nl was used. This website contains

many experience stories in the form of books, blogs, documentaries and (short) ego documents, which can be filtered by disorder/condition, themes and authors. By filtering on the disorder psychosis, 146 results of sources that contain patient stories about having a psychosis were obtained. Subsequently, these results had to be screened on a number of inclusion criteria. These consisted of the following criteria: the patient story had to be written by the patient himself, the patient had to suffer from recurrent psychoses, the stories had to concern the disorder and recovery process and the stories had to have been published in the last 20 years.

Eventually, three patient story collection books met all inclusion criteria. The first book "Van uitsluiting naar aansluiting" (Kulve, 2008) had a focus on patient experience stories and their social position and contained 15 different patient stories. The book "Leven met stemmen" (Romme, 2012) contained 50 experience stories of patients who experienced the symptom of hearing voices in addition to experiencing psychosis and provided a focus on the recovery process. Lastly, the book "Herstel, empowerment en ervaringsdeskundigheid" (Boevink & Plooy, 2006) included 29 experience stories from patients suffering from psychosis and focused on recovery, empowerment and being a peer counselor. The books were borrowed at the Erasmus university library. In total 94 patient stories were analysed, which resulted in a reached saturation (Green & Thorogood, 2009).

3.3 Data analysis

Before collecting data, some sensitizing concepts were already elaborated. These concepts were the definition of recovery, burden of care, stigma and the role of diagnosis. These sensitizing concepts made the qualitative researcher aware of certain important concepts that may have played a role in answering the research question (Mortelmans, 2013). When all data had been collected and selected, an analysis was performed using an inductive approach.

First, the data had been thoroughly reviewed, with the sensitizing concepts in mind. Codes were assigned to paragraphs or specific sections of text where concepts evolved, which is also called open coding. Then, axial coding was performed. Patterns between the assigned codes were explored, in order to identify themes. Finally, selective coding took place, where the key concepts and themes were identified. These are essential, because they are related to most other codes and explain most of what is going on (Green & Thorogood, 2009). Some examples of the main codes that were identified, are burden from environment, burden of (self-)stigma, self-help workgroup and so on. During the coding process, quotes that belonged to certain codes, were collected in an overview in the programme Microsoft Word. Therefore, during the analysis, statements could easily be traced back to the exact passage of a book.

Since the patients stories were almost all structured chronically, the results chapter is also organized in a similar way. It is divided into the three phases “experiencing symptoms”, “being diagnosed” and “complexity of recovery”. Subsequently, the corresponding burdens and coping strategies are discussed. The results of the analysis are presented in these chapters. For the quotes that are being used, abbreviations have been made for the authors of the quotes, of which an overview can be found in the annex.

3.4 Reliability and validity

The reliability of this research is ensured by the following. Prior to the study, the approach, structure, target population and selection of patient stories were described (Mortelmans, 2013). This preconceived research design was also critically reviewed with peers, who did research in a similar topic. Furthermore, the selected patient stories originated from three different books. This enhances reliability, because the patient stories are framed from different perspectives in the selected books (Green & Thorogood, 2009). Moreover, an audit trail has been maintained with an accurate description of how the process was conducted. Important decisions, problems and changes were accurately documented in a logbook. This increases both reliability and validity (Mortelmans, 2013). Also, quotes from selected patient stories are used within the results chapter, in order to highlight certain themes. These quotes show how the researcher interpreted the data. This transparency contributes to the reliability of the research and bias is avoided as much as possible (Green & Thorogood, 2009).

The validity of this research is ensured because the researcher has conducted self-reflection within the audit trail. This was done by creating clarity about the researcher’s own position within the study. Prior to conducting the research, the researcher discussed with peers and the thesis supervisor what her own ideas were regarding the thesis topic. In this way, the researcher became more aware of her own prejudices and to what extent these views could play a role in the data collection and analysis. By creating awareness regarding this, the validity of the study increases (Mortelmans, 2013). Furthermore, peer debriefing was done. A psychology student and a health sciences student were asked to provide critical feedback on the research report. In this way the thesis research was reviewed from different angles and any notable aspects of the research were noted in advance. Moreover, external validity was promoted through thick description. The data were described in detail and attempted to be placed in a broader context (Mortelmans, 2013).

However, it is important to note that there are still methodological shortcomings within qualitative research and the study of narratives. It is important to note that the reliability of the results, depends on the ability and effort of the researcher (Golafshani, 2003). Furthermore, a

limitation in using existing sources, like books, is the possibility of a selective survival bias. Which means that the stories used in books, may not necessarily be a representative of the wider population (Green & Thorogood, 2009). In this case, not all patients who suffer from recurrent psychoses are able to write down their story or perhaps have not been given the opportunity. Reflecting on the limitations of the study and being aware of them, improves the reliability of the study as well (Mortelmans, 2013).

3.5 Ethical considerations

Besides the validity and reliability of the research, ethical considerations should also be incorporated. This includes asking consent from respondents to interview and/or observe them and ensure their privacy (Green & Thorogood, 2009). However, since this research makes use of patient stories that are published, this has already been done and therefore has been taken into account.

4. Results

In this chapter, the results of the thematic analysis of the selected patient stories will be shown. For the description of the results, a chronological structure is partly used, so the shifts that occur within the disorder process can be represented well. Subsequently, the burdens experienced during this process will be discussed and strategies that can reduce these burdens will be identified. Some striking patient stories will be described in more detail, to get a more comprehensive understanding of the observed patterns.

4.1 Experiencing symptoms

Many psychotic disorder stories inevitably begin with psychological suffering. This psychological suffering can manifest itself in different ways and ends in all selected patient stories with the experience of (recurrent) psychosis. In the case of Martijn Kole (W5), it all started with a feeling of fear, which was caused by a deep-seated trauma. He experienced fear of failure, of being alone, being weak and of the unknown. Eventually, his greatest fear became truth, which was the fear of collapsing. He became depressed, psychotic, could no longer study and had to be admitted to a psychiatric ward.

Bart (W4) experienced a short psychosis at the age of 20. There was not a specific trigger for this, since he had not experienced any serious traumas and had a pleasant childhood. This shows that the appearance of a psychosis can vary between individuals. In some cases it is the result of a long process or a deep-seated trauma, while in others it can arise suddenly. In the case of Bart, three more short psychotic episodes followed within 10 years, for which he had to be admitted to a psychiatric ward as well.

“During my psychosis I lost grip of reality. I experienced delusions: delusions of grandeur. I thought I was in contact with the pope, the cardinal and Nelson Mandela. Furthermore, I experienced conspiracy delusions. An admission was needed.” (W4)

Because of this lost grip of reality that many patients within the stories indicate to experience during a psychosis, an admission to a psychiatric ward occurs often. Sometimes this was done by means of compulsory admission with custody, in order to protect the patient and its environment.

4.2 Being diagnosed

When being admitted to a psychiatric ward, the medical and diagnostic process begins. Almost all patient stories discuss the impact of getting a diagnosis, directly or indirectly. An indication that this is an important theme in the life of a patient with recurrent psychoses. When a patient receives his

diagnosis, a combination of sadness, but also relief often prevails. Jose van Beuzekom describes this as follows:

“To my great sadness, yet relief, I was diagnosed. At first it felt like a relief, because it gave a medical confirmation of everything that was not right about me. However, the diagnosis also had less pleasant consequences for me, such as the sobering message that I would have to deal with psychological vulnerabilities for the rest of my life.” (W6)

This feeling of relief was indicated among more patients, since the diagnosis confirmed that the experienced symptoms were real and they did not exaggerate. However, the prospect of having to deal with psychological vulnerabilities for the rest of their life, was especially a prognosis that many patients in the patient stories recognized. They were often told to never be able to live a normal life again and that there was a high probability of being dependent on mental health care and support for the rest of their lives. With this discouraging message, expectations were also set. Patients felt that they were seen by caregivers as incapable of taking care of themselves, unable to make right decisions and considered to need mental health professionals to guide them through life.

“I was being observed and treated as a walking diagnosis that required a particular therapy or treatment.” (W8)

Many patients experienced, such as described above, that everything they did, said or thought was subsumed by mental healthcare professionals under symptoms of the diagnosis and reduced for the sake of diagnostic research. Personal meaning got exchanged for medical meaning and the most important role became that of being a patient. For instance, Martijn, who as mentioned earlier had to be admitted because of his anxieties, reported that after a year of living in a psychiatric institution, he had traded his identity as a young person with dreams and ambitions, for that of a long-term care patient (W5).

This trade of identity is mentioned often within the patient stories. According to some patients, this is because a psychiatric disorder is often intertwined with who you are as a person and its manifestations can dominate the entire personality. Wilma describes this as follows:

“The longer you are a psychiatric patient, the more likely you are to forget about the laws and rules of ordinary life. You forget that normal life is not always wonderful and that you were a person with good and bad sides.”(W1)

Living in the environment of a psychiatric ward and being surrounded by caregivers who look at you in a certain way, eventually makes patients look at themselves in the same way. Furthermore, as Wilma describes, it makes them forget about the reality of normal life. The environment’s main

priority has become to make the psychotic symptoms disappear and therefore patients tend to experience that this becomes their main priority as well. They often still feel confused and insecure about their psychosis and therefore put all their trust in the hands of the caregivers. For this reason, patients indicated that it was hard to maintain their own self-esteem, wisdom and judgement, since the caregivers always acted like they knew what was best for them. While afterwards, many reflect that it would have been better to take matters into their own hands and not let everything be decided by others.

Despite the criticism many patients have about being pushed into the dependent patient role, they do indicate the importance of receiving a diagnosis. It gives them a sense of validation for the experienced symptoms and makes them feel like they are not alone. Furthermore, it gives the opportunity to take part into a supportive community with people who have similar experiences. And by receiving the diagnosis, educational support is also offered. Which puts patients at ease. Also, almost all patients indicate that getting a diagnosis is necessary to start the recovery process.

4.3 The bumpy road of recovery

After receiving a diagnosis and a possible admission to a psychiatric ward, a long and complex process of recovery follows.

“Recovery is not a success story. It is important to realize this: recovery processes do not follow an upward trend. There are many lines and their only similarity is that none of them runs smooth and straight upward” (W1)

This quote describes well how most patients view the process of recovery and that it does not come without challenges. As mentioned in the theoretical framework, the concept of recovery for people who are suffering from recurrent psychosis, has changed over time. It is no longer primarily about the absence of illness, but more about being able to give meaning to life again. This is also commonly reflected in the patient stories.

“In my opinion, recovery is about looking beyond the diagnosis, look at things that really matter in life and finding ways to do that.” (W3)

Patients that suffer from recurrent psychoses cannot ‘heal’ or ‘cure’ from their disorder or psychological vulnerabilities. According to the patient stories, the challenge is to learn how to deal with the disorder. Especially moving on with life after recently experiencing a psychosis, is indicated as a challenging phase among patients. The environment is and remains concerned, while the patient wants to live life again and have fun like before the psychosis. By doing so, they regularly run into choices or differences of opinion.

A frequently mentioned step in the recovery process, is the transition from being a dependent psychiatric patient to a strong client. According to the patient stories, a patient is dependent and takes little initiative. A client, on the other hand, has a more critical attitude towards the condition of the disorder and is less dependent. It is experienced that by remaining in the dependent patient role, the recovery process is hindered. Patients dissociate from their diagnosis identity and therefore do not see themselves as “psychiatric disorders with care needs” anymore, but as people with a whole life to live, with sometimes the need for professional care or services. They take control of their own lives and feel useful instead of useless. Suzanne (W10) describes her transition from patient to client as follows:

“I have learned in recent years how to use mental health support in the right way. My caregiver no longer determines what I need, but I decide for myself what I need and what it should look like. This was a long process and did not happen overnight, but I feel so much better now.” (W10)

As the quote shows, it involves the patient deciding for his self which mental care support he needs and how they want it to look like, instead of listening to a caregiver that determines what the patient needs. According to the patient stories, common aspects that were indicated as what the patient needs were looking for possibilities instead of limitations, having control over your own life and learn how to become an expert in managing the disorder by yourself. All under the condition that happiness is the starting point.

4.4 Experienced burdens:

The long and complex process of recovery as just described, involves various burdens. These are the burden of diagnosis, the burden of transparency, the burden of stigma and the burden of participating in society and social integration. All these burdens together constitute the burden of recovery. This burden of recovery illustrates the substantial burden that a patient with chronic psychosis must bear during the road to recovery. The different burdens, except for the burden of diagnosis (since this has already been elaborated on), will now be explained in more detail.

4.4.1 The burden of (non-)transparency

When patients get diagnosed with the disorder chronically psychotic, they are faced with the choice whether or not to share the diagnosis with their environment. After all, the people around the patient will also have to get used to the fact that he has a psychiatric condition, just like the patient itself needs to get used to the disorder. If a patient does open up about his diagnosis, this often happens in familiar circles, such as family or close friends. How the environment subsequently responds to this, differs. One patient reported that her family looked at her in the same way as her caregivers, as a psychiatric patient instead of a human being:

“It is as if the whole world has put on a pair of glasses that prevents them from seeing you as a human being and therefore they only see you as a disease. If you do not smile, it is concerning and if you smile too much, it is concerning too. Almost everything you do is understood in the light of your illness.” (W2)

This quote shows that the environment can cause an extra burden on the patient, instead of providing support. However, it is also common that the environment of the patient does not know about the existence of the diagnosis. This, on the other hand, is also experienced as a burden by the patient, since he has to hide his diagnosis and lie about it. Leendert describes this as follows:

“You basically live with a lie. And that is not what a relaxed life looks like, because you're always afraid that people will find it out, with all its problematic consequences.” (W9)

In addition, patients indicate that they experience feelings of loneliness. They have to deal with the disorder by themselves, while support from the environment is actually desirable. By hiding the diagnosis, patients also notice that they automatically become more distant from their surroundings. This is not beneficial to the relationship with their environment and then also contributes to the perceived burden.

There are a few exceptions in the patient stories read for this study, where people do share a positive experience about being transparent regarding the diagnosis towards their environment.

“At field hockey and golf, they were curious what was going on with me. On September the 27th I gave a presentation to them about my disorder. That was very enlightening. I also got a lot of positive responses.” (W4)

The person from this quote had a positive experience with sharing his diagnosis and did not receive any negative responses. In another patient story, a patient describes how important her family and close friends were in the recovery process and that she could not have done it without them. In these cases, being transparent about the diagnosis gives a feeling of relief. Furthermore, it can contribute to the patient's recovery and can reduce the experienced burden :

“In the beginning, my friends and family also had to get used to the fact that I was diagnosed with a psychotic disorder. Just like I had to learn how to cope with it, they did too. But over the years, they have got to know me so well, that they know what I need when I am not doing so well. That support helps enormously.” (W8)

However, some patient stories show the downside it can have. In many stories, patients share that when they opened up about their disorder, they had to face a large amount of stigma.

4.4.2 The burden of (self-)stigma

A reason that is commonly mentioned in the patient stories for not being transparent about the diagnosis towards the environment and regardless from that, is experienced as a burden during recovery, is stigma. Patients indicate that the generally existing image of patients who suffer from recurrent psychoses is often an underestimated, but serious problem for them. Where the patient in most cases already has a hard enough time with the consequences of the disorder itself, he also has to fight the prejudices that exist in his environment about the disorder. The daily life of a patient who suffers from recurrent psychoses with all his normal activities, dreams and fears does not fit into the image that society gives them. The disorder may be incurable and the tension of a possible relapse is always present, but when a patient is not psychotic, a reasonably "normal" life can be lived, according to the patients. Leendert (W9) shows that this does not correspond with the prejudices he has to face:

"I think that every patients who suffers from recurrent psychoses has had the experience of fighting against the prejudices that we are all dangerous, violent and scary. Besides the fact that this is frustrating, it is also a dangerous misconception, that in many cases pushes the psychotic patient into deeper isolation." (W9).

As Leendert describes, these stigmatizing thoughts can push patients into deeper isolation. Furthermore they experience feelings of shame and feel judged. This is demonstrated in a the story of a patient who was occasionally allowed to visit her parents during psychiatric hospitalization on weekend leave, only to spend the two days inside, because she had been the subject of the village gossip and was too ashamed to participate in community life. It was an obstacle for her to make social contact, especially in a place where she knew a lot of people. An example of how stigma stands in the way of the recovery process. These stigmatizing thoughts are not only experienced from the community, but also from friends and family. Judi describes:

"In particular after receiving my diagnosis, I noticed to my surprise that many of my friends, who had known me for years, became afraid of me overnight. While, I as far as I know, had not given them any reason to. The image of the unpredictable and therefore dangerous and crazy person, which apparently is deeply rooted in our society, has cost me some very precious friendships at the time." (W7)

Other examples of perceived stigma that were mentioned within the patient stories, are people avoiding the patient, not being taken seriously and some even got fired from work without a legitimate reason. This also shows the dilemma regarding the choice whether or not to be

transparent about the diagnosis, and what the associated consequences of this might entail for the patient.

In addition to the stigmatizing thoughts that have to be faced from the environment, patients also suffer from so called self-stigma. Through their long career as a psychiatric patient and many confrontations with stigma (both from the environment and from mental health services), they indicate to have developed a negative self-image with low self-esteem, little confidence and a lot of insecurities.

“The impression remains, that your life is over as soon as you become a patients who suffers from recurrent psychoses. And if others think that, you naturally start to believe it yourself as well, with the coherent consequence that it becomes a self-fulfilling prophecy.” (W7)

This self-fulfilling prophecy makes patients see their disorder as a weakness and find their selves worthless. This burden of self-stigma, is partly why patients find it difficult to share their diagnosis with others. Which can result in a small group knowing about the diagnosis, or sometimes no one at all. Sometimes it even leads to patients suppressing their disorder:

“It [experiencing a psychosis for the first time] felt like mental aberration, which could not have a place in the rest of my life. I tried to repress it. In fact, I stigmatized myself.” (W9)

Patients indicate that it is important to notice that they do not only need to recover from the psychotic disorder, but also from the effects of (self-)stigma. As well as from the associated effects of discrimination, poverty and second-class citizenship.

4.4.3 The burden of (not) participating in society and social integration

Patients are often confronted with the standards of society. According to them, it already is difficult to meet these standards without a psychotic disorder, let alone with one. Wilma describes:

“A psychosis can be drastic and overwhelming. It is accompanied by a severe deregulation of meanings, which can make the world look no longer recognizable and therefore turn into a great threat. It can make you suffer in life and makes nothing for granted anymore.” (W1)

This quote shows how complicated it can be to participate in society, when suffering from recurrent psychosis. Patients have to face the reality of people from their environment achieving goals that they might never be able to accomplish. This is experienced as confronting and hard, especially because it is common for patients who suffer from recurrent psychoses, to end up on sick leave. This can create a feeling of uselessness towards their selves and towards society.

"I ended up on sick leave. That was the first time I really felt "ill", marginalized and not useful for society." (W8)

Sometimes patients try to hide their disorder and try to live a 'healthy' life like everyone else in society, just to fit in. Besides, this gives them more chances in their return to society, since patients noticed that it is not beneficial to share their psychiatric background. Several patients indicated that they no longer share anything about their psychiatric background, because it prevents them from getting a job. However, hiding their disorder is exhausting and not maintainable and the risk of a relapse is always present.

In addition, there is a lot of social incompetence experienced in society, which complicates social integration. This is demonstrated by the following patient story:

"The place [the local bakery] was pleasantly crowded with chatter and so on. Until the door opened and two new customers came in. I recognized the wheelie bag immediately. The conversation hushed and people separated a bit. Everyone looked at them and glimpses were exchanged. I could tell by the nervous behavior of the two psychiatric clients that they felt it. Just as I did at the time." (W1)

The patient who reported this story, recognized the two psychiatric patients from her own previous assisted living period. At that time the 'nice weather talk' was also never intended for her. This social discomfort, which sometimes can be caused by a small unintentional comment, can make social integration more difficult. Let alone how stigmatizing thoughts and statements can complicate this, such as the mentioned experiences of being yelled at in the street, or having garbage or dog poop dumped on the doorstep of a house. The patient stories show, that having a patient label makes it difficult to participate in society and socially integrate. Patricia describes this as follows:

"Receiving the label psychotic patient, means receiving a total package that includes poverty, trauma, dehumanization, devaluation, limited freedom and unemployment." (W2)

4.5 Strategies to cope with experienced burdens:

In addition to the experienced burdens, many patient stories have also shared strategies to reduce these burdens. An often mentioned strategy to reduce the experienced burdens is to participate in so-called peer groups/self-help workgroups. Within these self-help workgroups, a number of core elements can be identified. These will now be outlined in more detail.

4.5.1 Peer groups

Many patients reported participating in self-help workgroups as helpful, in order to cope with experienced burdens and improve their recovery process. Within this workgroup, peers help each other by exchanging experiences, ideas and advices. They share challenges, like for example how to

overcome stigma and encourage each other to make the best out of life. The working groups help patients by looking at themselves as more than just psychiatric patients. Furthermore, by helping others, they give meaning to their own life as well. Which in turn contributes to their recovery process and that of their equals. Stan describes his experience with the self-help workgroup as follows:

“The exchange of experiences gives hope and strength and teaches to value yourself again and to rejoin society. By doing so, everyone can find a recovery path that suits them.” (W11)

According to the patient stories, the self-help workgroups and client initiatives are a response to the fact that the individuality, experiences and knowledge of patients are not sufficiently reflected in mainstream mental health care. The emphasis is therefore on one’s own strengths, instead of hearing discouraging messages and thinking in terms of limitations. According to a recovered patient, this was exactly what she would have needed in the times she found out about her disorder:

“ It would have helped me so much if someone had told me about surviving a psychiatric disorder, about the possibility of recovery and about building a new life for myself. If I would have had these examples back then [people with a job, relationships and a home for themselves] I definitely would have been better off.” (W2)

4.5.2 The importance of a positive mindset

One of the core elements that patients identify as often discussed within a self-help workgroup, is the importance of creating a positive mindset. Many patients indicate that by developing a positive mindset, the recovery process improves. This is accomplished by looking at things in a different way and use happiness as an indicator. For example, instead of focusing on the shortcomings, they rather think about what can still be done or how something can be done in other ways. Crucial in this, is to indicate what support someone needs in order to achieve this. Even though asking for help is often experienced as difficult. Joining a self-help workgroup with equals, who might be further along in the mindset and recovery process, is experienced to be helpful with this.

4.5.3 Acceptance of the disorder

The acceptance of the disorder is indicated as an important element for the recovery process. By learning to deal with what cannot be cured, the acceptance process can begin. It is about accepting the disorder to be part of the identity. The following quote expresses this process well.

“I have been angry and sad about it [the disorder]. But now I know it belongs to me. It has become a piece of myself and I have found resignation in that. By this I mean something else than patiently

undergoing my illness. It means that the limitations I have, no longer stand in the way of my possibilities.” (W2)

As the quote describes, the complex process of recovery includes that what has happened to a person, and made someone a psychiatric patient, is given a meaningful and accepted place in life, in order to move on from there. Patients indicate that by doing this, possibilities can be discovered and used and the psychiatric disorder becomes part of the identity, instead of becoming the whole identity. Furthermore, by accepting the disorder, realistic and achievable goals can be set. The following quote shows how a patient succeeded in this:

“Having a job used to be important for me, prior to my psychosis. Similarly, marriage and family were something to be taken for granted. Now I think having a good balance in my activities is important.” (W11)

The self-help groups continue to develop through the accumulation of knowledge gained through experience and can be useful for various target groups:

“We pass on our knowledge from experience. To fellow clients who come after us, so that they can derive hope from us. To social workers, so that they can hear our voice. And to people outside of psychiatry, so that they can see our human face.” (W1)

5. Discussion & Conclusion

This chapter discusses how the results found, relate to the reviewed literature. Based on this, the formulated sub-questions and subsequently, the main question will be answered. The limitations of this study will also be discussed. Finally, recommendations for possible follow-up research and practice will be given.

5.1 Comparisons with the literature

5.1.1 Being diagnosed

A similarity that can be seen between literature and the analysis, is that patients feel that all negative feelings are being classified as a medical problem (Dehue & Jonge, 2008). This corresponds to patients in this study who indicate that caregivers exchange personal meaning for medical meaning as soon as a patient receives a diagnosis. Patients experienced that everything they did was subsumed under symptoms of the diagnosis and reduced for the sake of diagnostic research. That not everything should directly need to be seen as a medical problem (Dehue & Jonge, 2008), is acknowledged by patients in the results. The only priority has become to make the psychotic symptoms disappear, which made the patients feel like “walking diagnoses”, instead of human beings.

According to the literature of Brody & Waters (1980), receiving a diagnosis can be seen as an explanation of the experienced symptoms for patients and confirms that a medically underlying reason is present. This corresponds to the results found in this research, where patients have indicated to experience feelings of relief after receiving the diagnosis. Furthermore, literature shows that patients feel helped by getting a label and making this part of the identity (Brody & Waters, 1980). The results however, show that this is more complicated. In the beginning of the diagnostic process, making the disorder part of the identity is indeed seen as beneficial, because as mentioned earlier, it explains experienced symptoms and patients feel relieved. However, the identification with the disorder quickly causes negative consequences. Patients face stigma and project the stigmatizing thoughts that others have of them, onto themselves. Which is not beneficial for the recovery process. However, in the long run it does help again to make the illness part of the identity. Because, it helps to accept the disorder and focus on strengths instead of limitations. Furthermore, goals that were set in life can be changed to new achievable ones. All this can only be done, when the new identity is embraced.

According to Pettie & Triolo (1999), embracing the new identity includes that the patient shifts his mindset from 'why me' to 'what now'. This corresponds with the results, where it is indicated that self-help groups pay attention to developing a positive mindset. Many patients state, that by developing a positive mindset, the recovery process improves. This is consistent with the literature.

The dissociation of the medical perspective, that is mentioned in the literature, is also observed in the results. According to the literature, patients find that there must be a stronger focus on what the patient can independently do to give its' life a favourable turn. According to them, this must be done by accepting the limitations and make a progressive transformation from patient identity to citizenship (Boevink & Dröes, 2005). This point is also often indicated in the analysis of this study. According to the patients, an important step in the recovery process is the transition from being a dependent patient to a strong and more independent client. Patients dissociate from their diagnosis identity and become people with a whole life to live, with sometimes the need for professional care or services. Literature and the results from the analysis correspond very well on this topic.

5.1.2 Complexity of recovery

According to the literature the recovery process can amongst others feel like a burden, because patients might feel overwhelmed by the lifestyle changes and self-management tasks they have to do (Nordfonn, Morken, Bru & Husebø, 2019). The results state as well that it is a challenge how to deal with the disorder. Especially just after experiencing a psychosis.

Furthermore, literature shows that the meaning a physician assigns to the disease can affect the recovery process of a patient (Kessler, 1977). The results show several examples of this. Patients were told to never be able to live a normal life again and that there was a high probability of being dependent on mental health care and support for the rest of their lives. Patients valued the opinion of professional practitioners highly, while afterwards many reflect that it would have been better to take matters into their own hands and not let everything be decided by others. A vision that fits in with the previously mentioned transition from patient to client.

5.1.3 Experienced burdens

Within the literature, several burdens are addressed. One of these burdens is the burden of disease, which refers to the impact of the disorder on the patient. The patient needs to process and accept its disorder identity, which can be experienced as an intense process, that might increase the sense of burden (Demain et al., 2015). However, little attention is paid to this type of burden in the results. The impact of the diagnosis on the patient and the burden associated with it, is discussed more in the analysis.

Furthermore, the literature addresses the burden of stigma. According to Corrigan & Watson (2002) studies have shown that stigmatizing attitudes about mental illness prevents patients from getting equal opportunities such as good jobs, safe housing and connections with society. Housing is not discussed in the results, but the experienced difficulties of finding a job and connecting with society are. Several patients indicated that they no longer share anything about their psychiatric background, because it prevents them from getting a job. The same applies for transparency towards the environment. Many patients hide their disorder to their environment, because they are afraid to lose or already have lost many friends and colleagues by being open about the disorder.

According to the literature the burden of stigma is strengthened by the role of diagnosis, since stereotyping based on a DSM-label occurs. This corresponds with the patient stories, where a patient tells how he constantly has to fight against the prejudices that all patients that suffer from recurrent psychosis are dangerous, violent and scary. According to the literature the media plays a big role in this as well. The results mainly focus on the role that society has in this and do not focus so much on the media.

One of the consequences of the stigmatizing judgements, is that self-stigma arises and the self-esteem and confidence of a psychiatric patient reduces, according to Corrigan & Watson (2002). The patient stories also address the presence of self-stigma. According to the patient stories, it becomes a self-fulfilling prophecy, that is caused by society as well as caregivers. However, literature only mentions society and the media as a cause.

An important contradiction that the literature addresses, is that patients who suffer from recurrent psychoses are stigmatised on the one hand, while at the same time they are expected to actively participate in society. This contradiction is not mentioned literally in the patient stories, but can be deduced from what is said. The patient stories show, that having a patient label makes it difficult to participate in society and socially integrate and that when they for example end up on sick leave, feel not useful for society.

What is not mentioned in the literature, but has been highlighted in the results is the burden of (non-)transparency. The patient stories have indicated that the consideration and subsequent consequences of being transparent or not about the disorder, entails a certain burden. While the literature only discusses the stigmatizing consequences of being transparent about the diagnosis.

What is also absent within the literature, are the strategies in order to cope with the burdens. According to the patient stories, these consist of participating in peer groups, the importance of a positive mindset and the acceptance of the disorder. The importance of accepting the disorder is discussed within the literature, however it is not explained how to do so. Furthermore

it is striking, that both literature and the analysis, only mention coping strategies that concern adaptations for the person itself. Strategies that discuss how others could change are not mentioned, while society, for example, also plays an important role in embracing patients with chronic psychoses.

5.2 Conclusion

In this chapter, this main question will be answered based on the formulated sub-questions.

5.2.1 Different types of experienced burdens

The first sub-question concerns what burdens of recovery are experienced among patients who suffer from recurrent psychoses. The long and complex process of recovery, involves various burdens. These are the burden of diagnosis, the burden of transparency, the burden of stigma and the burden of participating in society and social integration. All these burdens together constitute the burden of recovery.

The burden of diagnosis is about the consequence that when a patient receives a diagnosis, everything is seen as an explanation of the experienced symptoms for patients and confirms that a medically underlying reason is present. Everything a patient does, says or is subsumed by mental healthcare professionals under symptoms of the diagnosis and reduced for the sake of diagnostic research. Personal meaning gets exchanged for medical meaning and everything else does not matter anymore. Furthermore, the patient needs to process and accept its disorder identity. They have to make the diagnosis part of their identity, self-image and their existence.

After receiving the diagnosis, the consideration and subsequent consequences of being transparent or not about the disorder towards the environment, entails a certain burden as well. This is called the burden of (non-) transparency. A trade-off has to be made, which may lead to different consequences. When a patient has shared the diagnosis with the environment, there can be a response in a way that is perceived as a burden, rather than as support. While if the diagnosis is not shared, the patient experiences a burden from hiding the disorder and from the lack of support. It is however, important to note that not every patient experiences this burden, since in some cases the environment responds very supportively and patients gain a lot of support from that.

The third experienced burden, that all patients with recurrent psychoses face is the burden of (self-)stigma. Patients have to deal with many prejudices from society, such as being dangerous, crazy and unpredictable. As a consequence of the stigmatizing judgements, self-stigma arises and the self-esteem and confidence of a psychiatric patient reduces. This burden of self-stigma, is partly why patients find it difficult to share their diagnosis with others. Which can result in a small group knowing about the diagnosis. Which in turn leads to a lack of support and the possibility of further isolation.

The last burden is the burden of (not) participating in society and social integration. Patients are often confronted with the standards of society, that are hard to meet when suffering from recurrent psychosis. Not only because their disorder stands in the way of this, but also because they do not always get equal opportunities due to stigma. In addition, there is a lot of social incompetence present in society, which complicates social integration.

All these burdens together constitute the burden of recovery. This burden of recovery illustrates the substantial burden that a patient who suffers from recurrent psychoses, must bear during the recovery process.

5.2.2 The role of diagnosis in recovery

The second sub-question is about what role diagnosis plays in (the burden of) recovery. Receiving a diagnosis plays multiple roles in the recovery process. In the beginning of the diagnostic process, it has a positive impact on patients, because it explains experienced symptoms. This gives patients a certain feeling of relieve. Furthermore, it is seen as an important step in order to start the acceptance of the disorder.

However, it also has some negative consequences. Receiving the diagnosis of being chronically psychotic, goes along with the assumption that a patient will never be able to live a normal life again and that there is a high probability of being dependent on mental health care and support for the rest of their lives. It makes caregivers look at the patient in a certain way and pushes patients in a dependent patient role.

Also, a diagnosis causes the previously explained burden of (non-) transparency and it correlates with the burden of (self-)stigma. Being labelled as a patients who suffers from recurrent psychoses, exposes the patient to a lot of stigmatizing thoughts and reduces his or her chances of participating in society and integrating socially. Diagnosis therefore also plays a role in the burden of (not) participating in society and social integration.

However, the diagnosis also plays an important role in the start of the recovery process and with the right support, a patient can recover from the disorder.

5.2.3 What recovery support is needed

The final sub-question is about how recovery support of patients that suffer from recurrent psychosis can be improved. According to this research, participating in peer groups has a positive influence on recovery. Within this self-help workgroup, peers help each other by exchanging experiences, ideas and advices. By helping others, they give meaning to their own life as well. Important elements that

are discussed during the peer groups are acceptance of the disorder and the development of a positive mindset.

Furthermore, it has been noted that the concept of recovery has changed over time. It is not about the elimination of symptoms and returning to the old state anymore. It is about looking beyond the diagnosis and finding ways to look at things that really matter in life. This also requires a change in the type of care that has to be provided. A reorganization of the mental health services and recovery support is therefore needed. One that is more in line with the shifted definition of recovery and that offers a more holistic perspective on care and recovery. This involves the patient deciding for his self which mental care support he needs and how he wants it to look like, instead of listening to a caregiver that determines what the patient needs. Common aspects that are indicated as what the patient needs are: looking for possibilities instead of limitations, having control over your own life and learn how to become an expert in managing the disorder by yourself. All under the condition that happiness is the starting point.

5.2.4 Answering the main question

The main question within this study was:

“What burden of recovery do patients that suffer from recurrent psychoses experience, what role does medical diagnosis play in this and how can support decrease these burdens?”.

In conclusion, this can be answered as follows. The different type of burdens that patients that suffer from recurrent psychoses experience are the burden of diagnosis, the burden of (non-)transparency, the burden of (self-)stigma and the burden of (not) participating in society and social integration. The role of diagnosis plays a substantial role in this, which has already been elaborated on by means of the second sub-question. Lastly, appropriate support can reduce the experienced burdens in different ways. Moreover, a reorganization of the mental health services and recovery support is desired, as described in the last sub-question.

5.3 Limitations

Within this study, there are a number of limitations. These will now be discussed, in order to enhance the quality of the research.

Within this research, patient stories have been analysed. It should be noted that all these stories are written from a patient perspective. This can give a biased view, because other perspectives are not taken into account. Other perspectives, from instance from a friends and family perspective, might have given a different view on certain topics. For example, in a selected patient story, a patient mentioned that a number of friends had left him, without him giving any reason for

that. In such a case, it would have been valuable to be able to speak to the patient's family and friends and ask whether the patient had indeed given no reason for this. Or that the patient may not have consciously experienced this himself.

Furthermore, the data for this study consists of books that contain patient stories. Two things should therefore be noticed. First, the patient stories may not fully represent the patient population that suffers from recurrent psychosis, because there may have been made a selection of stories that were most suitable for the book. Furthermore, there is a possibility that a certain group of patients is not adequately represented, because patients who are not doing so well or who might be in a psychosis, will be less capable of and/or willing to write a story. These patients are not represented in the books and can therefore give a biased image.

The patient books that have been selected for this study, all have a certain theme. One book is focused on recovery, empowerment and peer support. The second book is focused on the social position of people who have experienced recurrent psychosis and the third book is specifically focused on recovery. Therefore, some patient stories may not have been chosen for the books, because they did not fit in the theme of the book. Although it beneficial for the research, that the books used do not have the same themes. It is still important to note that some patient stories may not be chosen because it did not match with the theme.

Because a narrative analysis of patient stories was used, there was no possibility for further questioning. Sometimes, clarification of a particular story would have been desirable, but because of the chosen research method, this was not possible.

5.4 Recommendations for follow-up research

Within this study, interesting findings have emerged. Some findings have raised questions for further research. These will now be discussed.

Firstly, it would be interesting for follow-up research, to include stories from a different perspective, such as caregivers and the environment of the patient, like friends and family, in order to take into account how they view the researched topics and look for similarities and differences. This would contribute to the quality and reliability of the study.

One of the conclusions of this study, is that a reorganisation of the mental health services and support is considered to be necessary. It would be interesting, if not necessary, to further investigate what this reorganisation should exactly entail. Again, based on different perspectives.

Lastly, it is recommended to conduct this research with additional interviews. So that there is an opportunity to ask additional and in-depth questions and ask clarification if needed. This would be a useful addition for the completeness of the study.

5.5 Recommendations for practise

Lastly, a number of recommendations for use in practice will be made.

Many patients have indicated that they want to be treated as human beings instead of “disorders”. Therefore the advice for caregivers and mental health professionals is, to take a better look at the personal needs of patients, instead of only looking at guidelines on how a certain disorder should be treated. Furthermore, whenever this is possible, it is advised to make choices together with the patient instead of for the patient. This gives the patient the feeling of having some control over his own life.

Furthermore, policy makers in mental health institutions and hospitals are advised to look critically at their recovery support. Do patients get all the tools they need to become an expert in managing their condition? Or is there still room for improvement here? In case there is still room for improvement, it is advised to talk to patients who are admitted, but also with patients who are discharged. From the patient stories, it appears that they often have many ideas about how things can be improved.

Finally, it would be useful to pay more attention within society to the consequences of existing stigmatizing thoughts and actions. After all, it is also important that a patient returns to a pleasant and supportive environment, in which he gets equal opportunities and the possibility to recover optimally.

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Appendix A

Overview of analysed stories

Book	Writer of story	Abbreviation reference	Diagnosis
Herstel, empowerment en ervaringsdeskundigheid	Wilma Boevink	W1	Chronically psychotic
Herstel, empowerment en ervaringsdeskundigheid	Patricia Deegan	W2	Schizophrenia
Van uitsluiting naar aansluiting	Jeanny	W3	Chronically psychotic
Van uitsluiting naar aansluiting	Bart	W4	Schizophrenia
Leven met stemmen	Martijn Kole	W5	Chronically psychotic
Herstel, empowerment en ervaringsdeskundigheid	José van Beuzekom	W6	Schizophrenia
Herstel, empowerment en ervaringsdeskundigheid	Judi Chamberlin	W7	Chronically psychotic
Herstel, empowerment en ervaringsdeskundigheid	Ellen Dekker	W8	Chronically psychotic
Leven met stemmen	Leendert Hartog	W9	Chronically psychotic
Herstel, empowerment en ervaringsdeskundigheid	Suzanne Angels	W10	Schizophrenia
Herstel, empowerment en ervaringsdeskundigheid	Wouter van Doorn	W11	Chronically psychotic
Leven met stemmen	Stan de Laat	W12	Chronically psychotic