

***A narrative analysis of the experiences of people diagnosed  
with a psychotic disorder with regard to social integration in  
terms of social support***

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# Preface

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You are now looking at the final result of my master's thesis. Although it has cost me a lot of investment in time, I have worked on my master's thesis with interest and enthusiasm over the past seven months. I have always been interested in the world of experience of people suffering from mental illness. Therefore, when choosing a thesis topic, my eye immediately fell on the thesis group "Stories on social integration of people diagnosed with psychotic disorders". I was very happy when I heard that I was invited to write my thesis on this topic. I enjoyed reading the experience stories in books and blogs. The stories of experience have created an admiration in me for how people diagnosed with a psychotic disorder cope with their clinical picture, and how they cope with the challenges that come with it, such as the rejections they experience due to the prejudices that prevail in society about their clinical picture. Reading the stories of experience has made me realize that the prejudices that prevail in society need to be corrected. I hope that by writing this master's thesis I have been able to contribute to this, and that in the future the prejudices will disappear and people diagnosed with a psychotic disorder will be better integrated into society.

I would like to thank my study supervisor Hester van Bovenkamp for critically reviewing my work over and over again. I have always found the feedback and meetings to be very valuable and motivating. I would also like to thank the people whose books and blogs I have analyzed. Despite the prejudices in society, I admire that they have had the courage to write openly about their experiences with their clinical picture. Without this courageous contribution, I would never have been able to conduct this research. Finally, I would like to thank all the other people around me who have supported me in this process. With this thesis, I conclude my study period. Although it was not always easy, I look back on this learning period with great pleasure and satisfaction. It is now time for the next step!

Enjoy reading!

Yarah Foree

Amsterdam, 14 June 2021

# Summary

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Social integration and the receipt of social support contribute positively to the quality of life of people diagnosed with a psychotic disorder. With the emergence of the participation society, being socially integrated and receiving social support from the social network has become even more important for these people. However, having a social network that provides social support is not a given for them due to challenges they face in their process of social integration. To address this, it is important to gain a better understanding of the experiences that people diagnosed with a psychotic disorder have with regard to their social integration and receiving social support. Therefore, the aim of this study is to gain insight into the preferences and challenges that people diagnosed with a psychotic disorder experience with regard to social (re)integration in terms of social support, and how they cope with these challenges. The research question is therefore as follows:

*What are the challenges and preferences concerning social (re)integration in terms of social support of people diagnosed with psychotic disorders and how do they cope with these challenges?*

To answer the research question, written patient stories in books and blogs of people diagnosed with a psychotic disorder are analyzed. The analysis shows that the social integration of people diagnosed with a psychotic disorder is hindered by challenges they experience. These challenges are caused by prejudice prevailing in society, a sensitivity they experience to social stimuli, and by a person's perception during a psychotic episode. To increase their opportunities of social integration and receiving social support, they deal with these challenges by tactically keeping their social network small and by choosing to only be open and honest about their diagnosis to a selective group of people. In this way they also try to manage their chance of receiving effective social support. Their needs in terms of receiving effective social support appears to be related to three main aspects, namely the type of social support received, the amount of social support received, and from whom the social support is received. Managing to receive effective social support, that meets their specific needs in these three main aspects, contributes positively to their quality of life and social integration, by providing them with the necessary tools to maintain themselves in society. However, there is still room for improvement in the provision of effective social support, which could be achieved through the development of appropriate policies and interventions.

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# 1. Introduction

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It is well known that social integration has a positive influence on human health (Cohen & Syme, 1985; Kahn, Hessling & Russell, 2003; Wallston, Alagna, DeVellis & DeVellis, 1983). Social integration reduces mortality risk and improves mental health (Seeman, 1996). It is defined as the degree to which a person participates in social relationships (Holt-Lunstad & Uchino, 2015). Therefore, social relationships can be seen as the basis for social integration. Social relationships provide social support that helps people to cope with social stressors, which in turn has a positive impact on a person's quality of life (Sias & Bartoo, 2007).

All of someone's social relationships together, is defined as someone's social network (Umberson & Karas, 2010). A person's social network is embedded in a wider context, in which a broad range of factors can influence the structure of someone's social network (Berkman, Glass, Brissette & Seeman, 2000). In the Netherlands, with the emergence of the participation society, a political and social change is underway. In the speech from the throne in 2013, the king introduced the participation society by stating that, where possible, everyone should take responsibility for their own life and for the lives of people in their environment (*Troonrede 2013*, 2014). With the emergence of the participation society, the social integration of citizens is considered more important and higher demands are made on the social network of those in need of care. Therefore, having a social network that provides social support becomes even more important for people in need of care with the emergence of the participation society (Witteveen, Post & Visser-Meily, 2014).

However, having a social network that provides social support is not a given for everyone. Creating and maintaining a social network appears to be especially a problem for people diagnosed with a psychotic disorder. They commonly have a smaller social network compared to the general population and to patients with other mental disorders (Macdonald, Hayes & Baglioni, 2000; Giacco, McCabe, Kallert, Hansson, Fiorillo & Priebe, 2012). In addition to the finding that people diagnosed with a psychotic disorder have difficulty creating and maintaining a social network, this phenomenon can also be explained by the reality that citizens commonly avoid social relationships with people diagnosed with a psychotic disorder because of the perception that they are unpredictable and dangerous (Angermeyer, Beck & Matschinger, 2003). As a result, they often experience social isolation and a lack of social

support, which has a negative impact on their quality of life (Davidson & Stayner, 1997; Eack, Newhill, Anderson & Rotondj, 2007).

Thus, in addition to the fact that receiving social support is important because it contributes positively to the quality of life of people diagnosed with a psychotic disorder, receiving social support has become even more important for this group of people with the emergence of the participation society (Witteveen, Post & Visser-Meily, 2014). It is therefore all the more important that the social support, which people diagnosed with a psychotic disorder receive from their social network, is considered to be of greater value (Davidson & Stayner, 1997). In order to achieve this, it is of value to investigate what preferences and challenges people diagnosed with a psychotic disorder experience with regard to social integration in terms of social support, and how they cope with these challenges. This research aims to identify these issues by conducting a narrative analysis that focuses on analyzing written patient stories. This form of data is considered as a promising and rich source of information with regard to examining patient experiences (Van Bovenkamp, Platenkamp & Bal, 2020).

## 1.1 Scientific and societal relevance

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This research is scientifically relevant in two ways. First, this research focuses on analyzing written patient stories. Written patient stories are an increasingly valued form of data for research, providing the opportunity to gain insight into interrelated facets of life with a disorder (Van Bovenkamp, Platenkamp & Bal, 2020). Despite the growth in interest, analysis of this form of data is still little used in the literature. This overlooked form of data, therefore, offers the possibility of gaining new insights into the relatively still unstudied experiences of people diagnosed with a psychotic disorder with regard to their preferences and challenges towards social integration in terms of social support. In addition, there has not been any research done on how people diagnosed with a psychotic disorder cope with the challenges they face towards social integration in terms of social support.

Research on the social integration of people diagnosed with psychotic disorders in terms of social support is socially relevant, because of the emergence of a participation society, the need for these people to rely more on social support, and therefore the need for them to become more socially integrated into society, is nowadays considered to be even more important (Witteveen et al., 2014; Delsen, 2016). By focusing on patients' experiences,

through the analysis of written patient stories, the results of this study can provide insights that contribute to a better understanding of the experiences related to the social integration in terms of social support of people diagnosed with a psychotic disorder. By providing information from the patient's perspective, this study can contribute to the development of policies and interventions that better meet the needs of these people. Developing policies and interventions that improve the social integration and social support received by people diagnosed with a psychotic disorder is also important for the individual, as it provides positive health benefits (Seeman, 1996; Cohen & Syme, 1985; Kahn et al., 2003; Wallston et al., 1983; Eack, Newhill, Anderson & Rotondj, 2007). Therefore, because of its focus on improving the social integration in terms of social support of people diagnosed with a psychotic disorder, this research can be of great importance both for the individual and for the society as a whole. (Killaspy, White, Lalvani, Berg, Thachil, Kallumpuram & Mezey, 2014).

## 1.2 Research questions and objective

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The aim of this study is to gain insight into the preferences and challenges that people diagnosed with a psychotic disorder experience with regard to social (re)integration in terms of social support, and how they cope with these challenges. With the emergence of the participation society, the social integration and social support received by people diagnosed with a psychotic disorder, is considered all the more important (Davidson & Stayner, 1997). The results of this study, obtained by conducting a narrative analysis, are therefore intended to contribute to an improved social integration in terms of social support of people diagnosed with a psychotic disorder, by providing information that can contribute to a better understanding of the experiences they have, with regard to social integration and social support, which can be used to develop policies and interventions that respond better to their needs. The research question is therefore as follows:

*What are the challenges and preferences concerning social (re)integration in terms of social support of people diagnosed with psychotic disorders and how do they cope with these challenges?*

The main question is divided into the following sub questions:

1. *What are the preferences concerning social (re)integration in terms of social support of people diagnosed with psychotic disorders?*
2. *What are the challenges concerning social (re)integration in terms of social support of people diagnosed with psychotic disorders?*
3. *How do people diagnosed with psychotic disorders cope with these challenges?*

### 1.3 Reading guide

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This paper is structured in the following way. Chapter two begins by laying out the theoretical dimensions of this research and looks at social integration as a feature of the participation society. It also addresses what social support means, and what social support makes effective according to the relational theory. The third chapter is concerned with the methodology used for this study. The fourth chapter presents the findings of the research, focusing on the three main aspects to be important when receiving social support. Chapter five compares the results obtained with the literature, after which the research question is answered, and finally limitations of this study and recommendations for follow-up research and practice are given.

## 2. Theoretical framework

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This chapter elaborates on the concepts mentioned in the introduction. First, social integration as a feature of the participation society is discussed, followed by the prevailing criticism of the feasibility of the participation society. Subsequently, the role of the social network in providing social support is elaborated, using the relational regulation theory to explain how received social support can make a positive contribution to a person's life. After this, the implications of the relational regulation theory on people diagnosed with a psychotic disorder are discussed.

### 2.1 Participation society

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In the speech from the throne of 17 September 2013, it was stated that the classic welfare state is slowly but surely changing into a participation society (*Troonrede 2013, 2014*). The principle behind a welfare state is that people's social rights are guaranteed by the state when they need them, such as in health care, education, employment and social security (Kersbergen & Vis, 2016). In this way, in a welfare state, the government is considered responsible for the care of citizens from birth to death (Arts, Entzinger & Boos, 2004).

Gradually, however, doubts are expressed as to whether a welfare state is the best for its citizens (Ballin, 2013). It is assumed that the welfare state has taken away a large part of the responsibility from the citizen, so that the citizen's own responsibility has disappeared into the background. As a result, in recent years the policy philosophy has changed from a welfare state to a participation society in which the responsibility of citizens is seen as increasingly important (Houwelingen, Boele & Dekker, 2014). The principle of the participation society is based on the assumption that today's citizens are increasingly well educated and capable of taking responsibility for their own lives. The idea behind the emergence of a participation society would mean that people become less dependent on government support by becoming more self-reliant while also relying more on family and community solidarity. In other words, a participation society underlines that people should take responsibility for their own future and create their own social and financial safety nets (Delsen, 2016).

However, it can be questioned whether citizens are willing and capable to take responsibility for their own lives and those of their loved ones. Research by Van den Broek, Dyskstra & Van der Veen (2015) shows that at the beginning of the 21st century there has in

fact been a shift among Dutch citizens towards an ideal of care in which great value is placed on the provision of care by the state, and minimal care responsibility by loved ones. This shift from the ideal of citizens goes against the policy development towards a participation society. It can be concluded that the results of this study indicate a gap between the ideals of citizens and the stated policy in the Netherlands.

In line with the previous, Bredewold, Duyvendak, Kampen, Tonkens & Verplanke (2018) state in their book that in practice it is difficult to involve the social network in the support or assistance of someone in need of care. They argue that this problem is caused by both the person in need of care and the social network of a care seeker. The person in need of care does not always want to ask for help from their social relations. One of the reasons for this is that they want to protect their relationships with people from their social network because they are afraid that dependency will negatively affect their relationships with a chance of disrupting the balance in the relationship. Also, they are not used to sharing their problems with members of their social network, because of feelings of guilt and shame. Another reason why people in need of care may not want to rely on their social network is because of a loss of trust in informal care resulting from previous bad experiences, such as abuse or not feeling understood by an informal caregiver. Moreover, the possibilities of social relations to provide care to their loved ones are often limited. The social network of people in need of care appears to be already burdened, has problems of their own or can even be non-existent.

These perceived challenges with regard to involving the social network in the provision of support have led to the fact that, in practice, the formulated policy of the participation society is generally not adhered to (Bredewold et al, 2018). Consequently, the social support received from the social network of people in need of care appears to be limited. However, receiving social support is considered important as it has a positive influence on the quality of life of people in need of care (Sias & Bartoo, 2007). In addition, with the emergence of the participation society, the role of the social network in providing social support is nowadays considered to be increasingly important (Witteveen et al., 2014; Delsen, 2016). Therefore, it is important to look more closely to the role of the social network in providing social support for people in need of care. The theoretical insights regarding the role of the social network in providing social support will be further explained in the next section.

## 2.2 The role of the social network in providing social support

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After evaluating the political movement towards a participation society in the Netherlands, it has become clear, that the policy expectation is, that citizens should first call on their own social network if they need care, before they call on professional care (Schoenmakers & Suanet, 2018). Therefore, the emergence of the participation society has made the role of the social network in providing social support increasingly important for people who are in need of care. However, it is not yet clear exactly what the role of the social network in providing social support means. This is why, for the scope of this study, it is important to go deeper into what social support is and how the social network can make a positive contribution by providing social support to people diagnosed with a psychotic disorder.

Social support is provided by supportive relationships from the social network, which are seen as essential in helping a person get through life crises (Caplan, 1974). Psychosis can be seen as such a life crisis. Social support has been defined in different ways in the literature. Lin, Simeone, Ensel & Kuo (1979, p. 109) define social support as “support accessible to an individual through societal ties to other individuals, groups and the larger community”. Social support is a multidimensional concept, which can be received in different forms. In general, social support is distinguished into the following types: emotional, instrumental and informative (Östberg & Lennartsson, 2007). Emotional support refers to the availability of appreciation, trust, concern, and a listening ear. Instrumental support refers to support obtained through tangible assistance and services, such as goods, money, or labor. Informational support is support obtained from receiving advice or information.

The positive effect of social support for someone appears to depend differently on the sources of support obtained. Findings highlight that receiving a variety of social support sources is related to positive health outcomes (Östberg & Lennartsson, 2007). This indicates that receiving more diverse resources from different types of social support could be beneficial for the individual, when facing stressors or problem. However, it appears to be difficult to predict the relative importance of different types of support sources, in a specific population, such as people diagnosed with a psychotic disorder. Receiving different types of social support can be important for a particular person at different times or for different reasons (Beels, 1981). Nevertheless, it has been shown that in people diagnosed with a psychotic disorder, the more social support received, the better, is not the case. Patients report that they can be overwhelmed, rather than supported, by the support they receive from their

social relationships (Beels, 1981; Wing, 1978). They can become overwhelmed because they are sensitive to social stimulation, which comes with receiving social support. In this way too much social stimulation can cause them to relapse into a psychotic episode. The receipt of social support must therefore be carefully managed.

In order to be able to manage social support, it is important to understand what makes received social support actually effective. The relational regulation theory developed by Lakey & Orehek (2011) is useful for further insight into this. The relational regulation theory explains the main effects between social support and mental health. As this theory focuses on the relationship between social support and mental health, it is relevant to this study because people diagnosed with a psychotic disorder struggle with mental health problems, which in turn affect other aspects of their lives such as social aspects.

The relational regulation theory exists of a few key principles. In the field of psychology, it is argued that people need personal relationships to maintain their emotional well-being (Bowlby, 1969; Baumeister & Leary, 1995). This is why, according to the relational regulation theory, the link between social support and mental health can be primarily explained by social interaction (Lakey & Orehek, 2011). Social interaction, that is, exchange between people, arises from social integration. Whether social interaction actually leads to social support depends on the personal taste of the recipient. Relational regulation, which is the desired effect of social interaction with others, is experienced more effectively when reciprocal elaboration occurs. Reciprocal elaboration occurs when, during a social interaction, new information from one of the participants is in line with the thoughts of the other participant. In this way, not all forms of social support received actually contribute to better mental health for someone. According to the relational regulation theory, received social support only leads to better mental health "in conversations that provide a social context for lingering with and elaborating on representations of relationships and quasi relationships." (Lakey & Orehek, 2011, p.488). People have the desire to optimize their relational regulation, and thereby their social integration. They try to increase their affect by continuously changing interaction partners, activities, or conversations where necessary. Freedom in a society that promotes social integration, while offering a wide range of options to choose with whom citizens want to build a relationship, increases the effectiveness of relational regulation.

However, experiencing this freedom of choice, does not come as standard to everyone. People diagnosed with a psychotic disorder do not seem to experience the freedom to integrate socially, making it difficult for them to optimize their relational regulation (Beels,

1979). This freedom is limited for them by the prejudices involved in being diagnosed with a psychotic disorder (Perry & Pescosolido, 2012). Due to these prejudices, people who have experienced acute psychosis no longer experience freedom to build their social network on their own initiative. After an acute psychosis, people often feel forced into a new social network, with the structure and ideology of this social network being largely determined by a new label (Beels, 1979). As a result, the diagnosis of a psychotic disorder commonly leads to a decline in the size of the social network, as members of the social network tend to reject a person after the diagnosis has been made. This decline can be explained by the loss of status associated with the label of a psychotic disorder. In particular, social contacts with relatively weak social ties tend to leave the social network after the diagnosis (Perry, 2011). In addition, this diminishing effect of social contacts is likely to be reinforced by the person diagnosed with a psychotic disorder themselves. They tend to isolate themselves from weak social relationships to avoid stigmatization (Link, Yang, Phelan & Collins, 2004). However, strong relationship ties of close friends and family seem to be less sensitive to this stigmatizing effect (Perry, 2011). As a result, despite the reality that the social network commonly decreases in size after the diagnosis is made, the core of their social network remains relatively intact. It has been found that those people who remain in social networks for an extended period of time are usually those who fulfil a wide range of support needs (Perry & Pescosolido, 2012). However, the shrinking of the social network can have adverse effects on individuals' sense of power and independence. In addition, a smaller social network can also make it more difficult to access new resources and information, which can be of use in the process of social integration (Perry & Pescosolido, 2012).

In short, the relational regulation theory provides insights into what makes received social support effective for someone, and that people have a need to increase their opportunities for receiving effective social support throughout their lives. However, people diagnosed with a psychotic disorder do not experience the freedom in society to optimize their opportunities to receive effective social support due to stigmatization, which usually goes hand in hand with a decrease in the size of the social network. However, it is not yet clear, how this change and challenges with regard to social integration are experienced and how these challenges are coped with. These experiences of people diagnosed with a psychotic disorder will become clear from the analysis of written patient stories.

## 3. Strategy

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This chapter explains the methodology used for this study.

### 3.1 The study design

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A qualitative research design was chosen to answer the research question of this thesis. Qualitative research is useful in exploring the meaning of social processes, social relationships, feelings, attitudes and experiences of people (Plochg, Juttmann, Klazinga & Mackenbach, 2006). Furthermore, qualitative research helps to obtain information from people from their own perspective (Fossey, Harvey, McDermott & Davidson, 2002). These characteristics of qualitative research are valuable for this study, in order to investigate what people diagnosed with a psychotic disorder experience, with regard to social integration in terms of social support.

To be more precise, the research question is answered by analyzing experience stories of people diagnosed with a psychotic disorder, both in books and in blogs. The choice of conducting a narrative analysis is made because analyzing stories provides the opportunity to develop an understanding, from the perspective of someone diagnosed with a psychotic disorder, of what it is like to live with a psychotic disorder to a very detailed level (Greenhalgh & Hurwitz, 1999).

First, stories of experience written in books were analyzed. In increasing numbers, patients write books about their experiences with regard to their diseases. Analyzing these stories in books is valuable because the stories contain a rich source of patients' attitudes and assumptions about all aspects of their illnesses (Hawkins, 1999). Another valuable medium for collecting patient stories is social media. More and more people use social media on a daily basis, which has ensured that social media has been integrated into the daily management of illness (Johnson, 2014). In doing so, the rise of social media created new possibilities for expressions and interactions for patients, for example through the use of blogs (Isika, Mendoza & Bosua, 2016). Therefore, in addition to analyzing books, the choice was made to analyze blogs as well. Blogs in this way complement the information obtained from books by providing actual information about coping with a psychotic disorder from a person's perspective.

A blog is a website on which messages are posted in reverse chronological (Hookway, 2008). This study focuses in particular on illness blogs. An illness blog is a blog that expresses a narrative of illness. Analyzing the information provided in illness blogs is valuable in identifying the experiences and needs of people diagnosed with a psychotic disorder (Heilfeirty, 2009). A blogger can post posts anonymously. This anonymity allows bloggers to write more honestly and candidly about their lives than they might do during face to face contact (Hookway, 2008). Therefore, the use of blogs in qualitative research is a useful technique for examining everyday life from the perspective of someone diagnosed with a psychotic disorder.

### 3.2 Target group

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Psychotic disorders are mental disorders characterized by fundamental disturbances in thinking, perception and emotions, which are linked to symptoms such as hallucinations, delusions and disorganized speech (Lieberman, 2018). The psychotic disorders in the DSM-5 are distinguished, by the duration of symptoms, the profile of symptoms, the cause of the symptoms, and by the relationship between psychotic symptoms and episodes of mood disorder (American Psychiatric Association, 2013). However, the current classification of psychotic disorders is criticized. Among the psychotic disorders, for example, the diagnosis of schizophrenia is criticized as being a collection of diverse psychotic syndromes with a highly varied course and prognosis (Havenaar, 2005). From this critique it is argued that the classification of psychotic disorders should be fundamentally revised. This study therefore concentrates on the course of the symptoms rather than on a specific psychotic disorder. The inclusion criteria, among others, therefore state that a writer or blogger must have experienced more than one psychotic episode, i.e., there must be a recurrent pattern of psychotic episodes. The additional inclusion criteria are listed in Appendix 1.

### 3.3 Data collection

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This thesis is part of an NWO research project focusing on the societal integration of people diagnosed with a disorder in the psychotic spectrum. The research group related to this project has made a pre-selection with relevant books on stories of experience that relate to the

research group's overarching topic. To compile this list of relevant books, the research group used the collection of stories of experience of the CCC Foundation (CCC Foundation, n.d.). This predefined list of books is used to select the most relevant books in line with the main question of this thesis. The selection was made by first reading the summaries of the books on the list. For each book, the themes related to social integration and social support such as friendship, family relationships, loneliness, problems with social integration, etc. were written down. In this way, an overview of themes related to the research question was created of all the books from the pre-defined list. This list has subsequently been used to select the most relevant books with regard to the research question. One by one, relevant books were chosen from the list, in order to ensure that the most varied source of information possible could be selected. Variation was considered important on two counts. When selecting a book, the thematic list drawn up beforehand was used to check whether the book was likely to provide new insights. In parallel, a selection of books was sought that was as varied as possible in relation to the author's characteristics. This process of selecting books continued until saturation was reached after reading six books (Fusch & Ness, 2015).

After saturation was reached in collecting information from books, relevant blogs were collected. For finding relevant blogs, the search function on Google was used. In the online search function of Google, search terms have been entered that fit the inclusion criteria of this study (see Appendix 2). For this study, only blogs that have a blog page with several blog posts were included. This was considered important because by analyzing multiple blog posts from the same blogger, a more detailed impression of a blogger's experiences could be formed, than when only one blog post from a blogger was analyzed. A selection of relevant blogs was made by first scanning the blog pages that emerged from the search function, checking whether the bloggers' background information matched the inclusion criteria, and whether blogs were posted that matched the research question. In the final selection of the relevant blogs, as with the selection of the books, variation on the two previously mentioned points was sought as well. Despite the fact that it soon became clear that blogs written by people diagnosed with a psychotic disorder are limited, relevant blog pages were still identified and selected, after which saturation was reached after analyzing three blog pages (Fusch & Ness, 2015).

### 3.4 Data analysis

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The characteristics of the analyzed books and blogs are shown in Appendix 4. The selected books and blogs were analyzed using a thematic analysis. Through thematic analysis, patterns from the stories of experience are identified, explored and documented. The aim of a thematic analysis is to minimally describe data according to themes in a detailed way (Andrew, 2019). In doing the analysis, the phases of a thematic analysis according to the article by Braun & Clarke (2006) were followed.

First, the books and blogs were read through to get an overview of the data. Then the books and blogs were converted to a file, so that they could be imported into ATLAS.ti (ATLAS.ti 9.0.7. Mac). ATLAS.ti is a qualitative research tool that is useful for coding and analyzing data. After importing the data into ATLAS.ti, the books and blogs were re-read, and interesting passages, based on the theoretical framework, were coded into the tool. Recurring potential themes were identified and documented in the tool on the basis of these coded codes. After repeating these steps for each book and blog, the potential themes were compared and, where possible, merged, resulting in the final identification of the most important main themes (see Appendix 3). The results section is drawn up on the basis of these main themes.

### 3.5 Reliability and validity

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During the research process, the following points were considered in order to achieve the highest reliability possible for this research. First, the research strategy was established through critical discussions with members of the research group, whereby the research strategy was designed and stated prior to data collection (Brink, 1993). Subsequently, during the analysis of the data, the researcher was aware of the importance of taking an objective position with regard to the data collected in order to ensure the reliability of the study. Objectivity was achieved by critically evaluating the researcher's (pre)judgements on this subject prior to the research. On the basis of this evaluation the underlying subjectivity of the researcher was taken into account when analyzing the data (van Zwiete & Willems, 2004). The objectivity of the research was also increased by methodically processing the data using the software programme Atlas.ti (van Zwiete & Willems, 2004). In addition, transparency was given on the selection and analysis of the data, and the coding done in Atlas.ti was saved and

stored. Subsequently, by citing quotes obtained from the empirical analysis, transparency was also given regarding the interpretation of the analyzed data (Green & Thorogood, 2004).

In order to increase the validity of this study, data triangulation was used in collecting the data, with various books as well as blogs being analyzed to create a more comprehensive and detailed overview of the studied topic. In addition, when selecting books and blogs, an active search has been conducted for books and blogs with deviating experiences (van Zwiete & Willems, 2004). Subsequently, the selected stories of experience were analyzed from different perspectives, on the basis of a theoretical framework established in advance. By defining the most important concepts, obtained from the literature, in advance, it was ensured that the right issues were being investigated (Mortelmans, 2013).

### 3.6 Ethical consideration

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The analyzed books and blogs used in this research were publicly accessible. Since they were publicly available, the IRB guidelines justify using this type of data for research (United States National Commission for the Protection of Human Subjects of Biomedical & Behavioral Research, 1978). Informed consent for the analysis of this data is therefore not considered necessary. Despite the fact that the information obtained is public and informed consent is not necessary, it should not be forgotten that personal data are processed, which still makes it important to consider the ethical aspects of this research.

According to the literature, for ethical reasons, it is considered important that the analyzed data is irreducible to the analyzed persons at all times (Pagoto & Nebeker, 2019). This has been achieved in this study by anonymizing the books and blogs. In addition, when sharing data in the future, solely for research purposes, it will be ensured that the recipient will also treat the ethical and privacy issues of the analyzed persons with respect (Pagoto & Nebeker, 2019).

## 4. Results

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The results section is structured as follows. First, the characteristics of the authors of the books and blogs are described, which serves as background information for the description of the individuals who were analyzed. Second, it is described why receiving social support is effective for people diagnosed with a psychotic disorder. Third, the types of social support received and what people diagnosed with a psychotic disorder consider to be effective social support are outlined. Fourth, the challenges experienced in receiving an appropriate amount of social support are described. Fifthly, the challenges experienced in creating a social network are described. Finally, the influence of these experienced challenges on the social integration of someone diagnosed with a psychotic disorder is described.

### 4.1 Characteristics of the books and blogs

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The books and blogs analyzed for this study are all about experience stories of people who are diagnosed with a psychotic disorder and have experienced multiple psychotic episodes. A total of six books and three blogs written by three men and four women have been analyzed for this study. Both one book and one blog have been analyzed from the same man and the same woman. The writers and bloggers are all of Dutch descent and have a varying age between 28 and 60 years old. The majority of the writers and bloggers analyzed, consider themselves unsuitable to work on a permanent basis due to their vulnerability to psychotic episodes but do engage in volunteer work. The books were published between 2011 and 2015, and the blog posts were published between 2014 and 2020.

Despite the fact that the writers and bloggers in this study have all dealt with multiple psychotic episodes, there are differences between the diagnoses they have been labeled with: among the writers, four writers have been diagnosed with schizophrenia and two writers have been diagnosed with schizoaffective disorder; among the bloggers, two bloggers have been diagnosed with schizophrenia and one blogger has been diagnosed with schizoaffective disorder. The difference between these two diagnoses is that people diagnosed with schizoaffective disorder, also suffer from symptoms of mood disorder, besides the symptoms of schizophrenia (American Psychiatric Association, 2013).

*“I have a 'schizo-affective disorder', as stated in the DSM-IV. That means I have a sensitivity to psychotic episodes and mood swings.” (B1)*

Despite the difference in diagnoses between the writers and bloggers, no notable differences are noted between these two diagnoses regarding the results obtained in this study. Therefore, no further distinctions are made in the result section between these two diagnoses.

Almost all writers and bloggers indicate that they want to share their story and experiences through a book or blog to help people who are dealing with psychotic episodes themselves or in their social network, to break the taboo around psychotic disorders and to correct misconceptions. In this way, the writers and bloggers want to offer informative support to people who are dealing with psychotic episodes in some way.

*“This book has been written by an expert by experience, and because of everything he has done and experienced, he wants to “share it”, in order to present today's clients in a much better light than is currently the case.” (W5)*

## 4.2 Function of social support

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The analyzed writers and bloggers indicate that social support is offered to them by people in their social network. The members of their social network varies from family members, friends, partner, fellow patients, colleagues and/or neighbors. Because of their vulnerability, the analyzed individuals indicate that they have difficulty in being self-reliant. However, they state that members of their social network can increase their self-reliance by providing social support. To illustrate, one of the writers states that there is a call from the government for more self-reliance on the part of citizens, but that clients in psychiatry cannot achieve this because of their vulnerabilities. He indicates that this group of people need support from others in order to create self-reliance for them.

*“The civil servants, policy staff and counter staff plead for more self-reliance, but clients in psychiatry cannot realize this and need someone to create this self-reliance for them. What is considered normal for normal people (what is normal?) is for clients in psychiatry a very big mountain, which they cannot climb alone!” (W5)*

Partly by increasing their self-reliance, the experience stories show that receiving social support promotes social integration in such a way that people diagnosed with a psychotic disorder are better able to hold their own in society. For example, it can give them just the needed support to be able to live on their own or to volunteer. However, social support can be provided by different people in a variety of ways, and not every form of social support received, is experienced as effective. The stories reveal that people diagnosed with a psychotic disorder consider three main aspects to be important when receiving social support, namely the type of social support received, the amount of social support received and who the social support provides. The results are explained in more detail in the following sections based on these three main aspects.

### 4.3 The types of social support received

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As mentioned before, social support can be divided into three different types, namely: emotional, instrumental, and informative support. All three types of social support emerged in the experience stories. However, not all the writers and bloggers analyzed receive the same degree of social support. It depends on their social network and the closeness of the relationships in their social network what type and to what extent they receive social support. The support received will be discussed in the following section according to the three types. For each type, the aspects that are important for the effectiveness of the social support received will be indicated.

#### 4.3.1 Instrumental support

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Instrumental support is mainly provided to the writers and bloggers analyzed by family and neighbors, where the family takes on more of the demanding tasks compared to neighbors. Instrumental support is often described as practical help in the stories of experience. The practical help for someone diagnosed with a psychotic disorder is characterized in practice by helping with household tasks, assistance in moving or providing shelter when living on their own is no longer possible. In addition, where necessary, financial support is provided by the social network or social contacts provide products such as clothing and food.

*"On Saturdays the neighbour would give me a sausage roll or an ounce of sliced cheese. My sister would bring me jeans that had become too small for my brother-in-law." (B3)*

With instrumental support, it is noticeable that often small gestures are highly appreciated by the individuals analyzed. The small gestures they receive from people in their social network give them the feeling that they are not alone and that they are allowed "to be there" despite their vulnerability. These are the little things they say they need to boost their self-esteem.

*"I was very happy that my family had cleaned up my mess at home, because I couldn't have done it myself at that time." (W2)*

#### 4.3.2 Informative support

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Informative support is provided to the analyzed writers and bloggers by all types of members from the social network. They consider receiving informative support to be especially effective, when informative support relates to their disease process. Their social network appears to be important in recognizing a psychotic episode. It is usually the case that someone going through a psychotic episode experiences their thoughts as truth, particularly during their first psychotic episode. Therefore, the analyzed individuals report that their social network has often played an important role in recognizing the first symptoms of their psychotic episode.

*"If you have never been psychotic, you have no reason to doubt your own observations. Therefore people who go into a psychotic episode for the first time will usually be told by those around them that there is something 'wrong'." (B2)*

People diagnosed with a psychotic disorder remain vulnerable to psychotic episodes throughout their lives. This is why the writers and bloggers analyzed indicate that throughout their lives the social network continues to play an important role for them in recognizing a relapse to a psychotic episode. To be precise, they even use their social network to recognize possible recurring psychoses at an early stage by checking their feelings and experiences with members of their social network.

*"I check my experiences and emotions with my parents or other people who know me well. This is how I stay on the right track and avoid slipping back into a psychotic episode."*  
(B2)

In addition, the social network of the writers and bloggers analyzed often plays an advisory role in making decisions about actions to be taken. Whereas people from the social network who have no experience of psychotic episodes themselves tend to give advice on general subjects, fellow patients in particular offer valuable support on how best to deal with a vulnerability to psychotic episodes. As an example, one of the writers states that conversations with fellow patients leads to positive solutions for coping with a psychotic vulnerability.

*"Being open to the other person's story and sharing similarities lead to finding positive solutions for living with a mental vulnerability."* (W1)

In addition to receiving informative support regarding the disease process, the stories of experience show that fellow patients also offer each other practical informative support when someone is new to a clinic. For example, one of the writers indicated that Harry, a fellow resident, showed her around the neighborhood. This helped her to feel more at ease in her new home.

*"Harry, a fellow resident, showed me around the neighborhood. He showed me where the supermarket was and where the doctor and the pharmacy were and so on. In this way, I also got to know the neighborhood a little."* (W3)

#### 4.3.3 Emotional support

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The writers and bloggers analyzed mainly receive emotional support from friends, partners or fellow patients. Receiving emotional support occurs in the stories of experience mainly when someone offers a listening ear or receives a compliment. One of the writers stated that he gets the positivity out of life from compliments he receives from others.

*"The positivity of life comes from the compliments you get from others!"* (W5)

Being offered a listening ear in itself is often not immediately considered valuable by the analyzed individuals. An important component in this is that they must also feel understood in order to actually feel supported. When they feel understood, they experience reciprocal elaboration, in which the information they provide is on the same line as the recipient's thoughts, giving them a positive feeling. As an example, one writer indicates that because she was understood by her friend, she felt supported, which made her feel comfortable and safe.

*“Because I was listened to and understood, I felt supported. This made me feel that I was not alone. I found that a nice and safe feeling.” (W2)*

In this way, the positive effect of emotional support thus appears to occur when a person receives social support from someone with whom they feel aligned. Subsequently, when the analyzed individuals do not feel aligned with their social contacts they indicate that they do not receive effective emotional support, which results in a feeling of loneliness. As an example, one of the bloggers explains that despite having people around her, she still had a lonely childhood because she felt different from everyone else around her. Very occasionally, however, she ran into someone with whom she was on the same page, but she had difficulty in getting these people to commit to her. As the following quote shows, in addition to finding like-minded people, the difficulty of maintaining friendships also appears to be a recurring problem among the writers and bloggers analyzed.

*“I have always felt different from everyone else around me. I had a lonely childhood because of this. Very occasionally, just for a moment, I would meet someone who was on the same wavelength as me.” (B1)*

If the analyzed individuals receive emotional support from people with whom they do not feel aligned, this can lead to even worse negative consequences than when they do not receive any emotional support at all. One of the writers gave an example of this when he received cards from his family while he was admitted to a clinic. The cards he received from his family were from their vacation destination. This caused that even though the cards were meant to be sweet from his family, it generated negative feelings. The cards from the vacation paradise confronted him with the fact that they could do things, such as go on vacation, which he could not do since he was admitted to a clinic.

*“Sometimes I would receive cards from relatives, with greetings from some holiday paradise. Instead of liking the mail, it irritated me. They were free, I was trapped here in an asylum. ” (W1)*

During an admission, the received emotional support appears to be a bit different. Besides receiving emotional support through conversations and compliments during visits of social contacts, social support obtained from fellow patients plays a significant role as well. Fellow patients seek each other out in a clinic, after which they exchange feelings and thoughts. Due to the reality that they often have similar experiences and thoughts, they feel that they are on the same page with each other, which causes reciprocal elaboration. Despite their difficult period in the clinic, this gives them the positive feeling that they are not alone in this. As an example, one of the writers states that in the clinic where she stayed, everyone helped each other and was there for each other. Receiving this kind of emotional support from fellow patients generated a pleasant and safe feeling for her.

*“The great thing about it is that even though everyone is not feeling 100%, everyone still helps each other and is there for each other. There was a lot of respect for each other and I find that admirable. That was a super nice and secure feeling” (W2)*

#### 4.4 The amount of social support received

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As described in the previous section the writers and bloggers analyzed receive a diverse range of emotional, instrumental, and informative support from people in their social network. The stories reveal that it depends on the moment what type of social support someone diagnosed with a psychotic disorder needs, and that this varies over time. One writer, for example, emphasizes that she appreciated getting some practical instrumental support from those around her just after she had been hospitalized and, in parallel, she also appreciated emotional support at that time, namely having a listening ear.

*“It takes a lot of energy, willpower, discipline and perseverance to resume everything at home and not to slip away. In the beginning, it is also very nice to get some practical*

*support from those around you and it is nice to have a listening ear, to have someone to go to with your feelings and to get a little support in the right direction.” (W2)*

As also stated in the quotation above. Receiving a combination of different types of support is considered most valuable. However, for the individuals analyzed, it does not seem to be the case that the more social support they received, the better. They indicate that they are constantly searching for a balance in receiving an appropriate amount of social support that match their needs, in order to keep their mental health as optimal as possible. In the search for this balance, they face an internal challenge. The following section explains what this internal challenge entails and how people diagnosed with a psychotic disorder cope with this challenge.

#### 4.4.1 Challenge 1: Social integration without becoming over-stimulated

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As noted above, the writers and bloggers analyzed indicate that it is not the case for them that the more social support they receive, the better. This is due to that receiving social support involves social interaction, which is accompanied by social stimuli. People diagnosed with a psychotic disorder report difficulty in processing these social stimuli. If they receive too many stimuli, they indicate that there is a greater chance of relapsing into a psychotic episode. It therefore takes a lot of energy for them to maintain control over their vulnerability to psychotic episodes during social activities. This is why it is important for them to balance their social interaction. As a result, people diagnosed with a psychotic disorder report that they experience a constant dilemma with regard to finding a balance between on the one hand the need for social interaction in order to feel mentally happy and on the other hand ensuring that they do not become over-stimulated by engaging in social interaction. In the quote below, one of the bloggers explains this ongoing struggle.

*“It is actually very simple. In order to prevent my brain from going out of control, it is best to minimize the amount of stimuli I receive. Social contacts are stimuli (and often very complicated ones as well) and I have to stay away from them. But not too much, because just like everyone else, I need company to avoid falling into a depression. So it's a search for balance and the right contacts.” (B2)*

People diagnosed with a psychotic disorder thus indicate that they experience a constant dilemma as to whether or not to participate in social interaction. This perceived dilemma has a direct effect on receiving social support, since social support cannot be obtained without social interaction. This is therefore experienced as a very difficult dilemma by them to deal with.

#### 4.4.1.1 Coping

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The writers and bloggers analyzed appear to respond differently to this challenge. The fear of becoming over-stimulated and relapsing into a psychotic episode can take over, causing them to reject social support that is offered. As an example, one of the bloggers indicates that she will only accept social support if the received support ensures that she can live even more independently in the future. Her psychosis sensitivity, and fear of relapse has led her to prefer not to integrate socially. She sees being lonely as the only way to deal with her psychotic disorder.

*“Many people want to help me and I turn almost everyone away. Many people want to visit me, but my front door remains hermetically sealed. I only accept help if it makes me more independent. I don't think it's a choice to be lonely. I think it's the only way I can manage my illness.” (B2)*

However, rejecting social support, and thereby choosing not to integrate socially into society, can cause negative effects on the mental health of someone diagnosed with a psychotic disorder. This is why, despite the fear of a relapse into a psychotic episode due to over-stimulation of social interaction, the majority of the bloggers and writers indicate a need for social interaction occasionally. As an example, one blogger indicates that it is a never-ending dilemma for her to stay alone and not get over-stimulated, or to go out for socializing and then feel confused and sick for days. She indicates that she usually chooses to stay alone but sometimes she seeks out the sociability because people in her social network are so fun and sweet that she then takes the consequences of being together for granted.

*"It is an eternal dilemma. Stay alone and enjoy the peace and the fact that my brain doesn't boil over? Or seek out the company, have fun with others and catch up on things, with the result that I am confused and sick for days afterwards? I usually choose to stay on my own, but sometimes I accept the challenge. I have enough people around me who are so nice and cozy, that I take the consequences of being together for granted. But I always have to make a trade-off" (B2)*

Although most writers and bloggers choose for social interaction from time to time despite their fear of overstimulation, this dilemma makes social integration and receiving social support enormously difficult for them. It is therefore of great importance for them to be surrounded by the right people to receive effective social support.

#### 4.5 The provider of social support

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The writers and bloggers analyzed indicate that not it is not the case that every person is suitable for providing every type of social support. The positive impact of receiving a certain type of support depends on the relationship. For example, one of the writers emphasizes that, while she could receive instrumental support from her parents, she could not receive emotional support from them as their relationship was not built on sharing feelings.

*"I could never go to my parents. I never found the support I needed there. If I needed help with the household or if something had to be arranged, they were there for me, but they have difficulty with emotions." (W2)*

It is therefore important to them that their social network is constructed in such a way, that it consists of different people who are altogether suitable for providing all three types of social support. In order to get the most out of their social network and to increase the likelihood of the positive effects obtained from social interaction, named relational regulation, the stories of experience show that people diagnosed with a psychotic disorder feel the need to adapt their social network to their current needs. To illustrate, one of the bloggers emphasizes that people are embedded in a group of people, with one person who is more advanced in a particular area helping another. In this way, they are constantly looking for who can provide them with effective social support that matches their needs at that particular moment.

*”Every human being is surrounded by other people, and I think that is how life should be, that you are 'embedded' in a group, a kind of clan, of people. That makes you strong. With one person you are completely in line, another is more advanced in a certain area (of life) and helps you and yet another can lean on you. However, this also changes in the course of time.” (B1)*

In order to optimize their relational regulation, people diagnosed with a psychotic disorder thus indicate that they have the desire to adapt their social network in such a way that it meets their needs at that moment. However, they experience a number of challenges in doing so.

#### 4.5.1 Challenge 2.1: Difficulty with social integration due to prejudice

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The individuals analyzed experience unpleasant prejudice in society about their clinical picture. One of the writers indicate that people think that people diagnosed with a psychotic disorder have multiple personalities and that they are dangerous.

*”Many people think that 'schizophrenia' or 'schizo' means that someone has multiple personalities. People also think that someone with schizophrenia is dangerous, as in the film 'psycho' for example. None of this is true. The image of 'danger' is horribly distorted by the media.” (W6)*

Because of these prejudices, the analyzed individuals experience that people in their social network may react fearfully to them after their diagnosis and distance themselves from them as a result. Therefore they often face rejection, which leads to a decrease in their social network, with fewer opportunities to optimize their relational regulation. In addition, their deviant behavior during a psychotic episode also plays a role as a reason for people from the social network to turn their backs on them. They do not understand why someone is suddenly behaving this way and do not want to deal with someone who, in their eyes, is acting crazy. One of the writers says that while he was going through a difficult period and suffered from psychotic thoughts, he looked for love, understanding, affection, and some food and drink by visiting his friends. Increasingly, however, they kept the door closed because they thought he was crazy.

*“I walked from address to address, for food, drink or just a bit of warmth. With my soul under my arm, I looked for love, understanding and affection. More and more often, the door remained closed. I was crazy, others thought.” (W1)*

These prejudiced reactions from the social network, which can come about in response to a diagnosis of a psychotic disorder, are at odds with the social support that someone diagnosed with a psychotic episode says they need. As an example, one of the writers indicates that his social network did the exact opposite of what he needed at the time he was diagnosed with a psychotic disorder; they distanced themselves from him due to the prejudice and fear that accompanied the diagnosis, instead of giving him support during this difficult time. Therefore, he indicates through his experiences, that an environment that is understanding and supportive with people diagnosed with a psychotic disorder, is more healing and helpful than an environment that is fearful, prejudiced, and closes off from the person.

*“An environment that is understanding and supportive is a more helping and healing environment than one that is fearful, prejudiced and closes in on the person.” (W6)*

#### 4.5.1.1 Coping

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The analyzed persons indicate that they generally do not experience their environment as understanding and supportive. When they are open and honest about their psychotic disorder, they often experience rejection.

*“I feel best when I can be open and honest, so I would prefer to just tell people that I have schizophrenia. But that doesn't always go down well. There are people who don't want to know anything about it, probably find it scary and therefore tactically (or a little less tactically) ignore me.” (B2)*

To avoid this rejection they admit that they often lie about, or conceal, their clinical picture to other people. It is notable that although the writers and bloggers write openly about their experiences with the aim of breaking the taboo around psychotic disorders and correcting misconceptions, in their daily lives, they choose not to be completely open and honest about their clinical picture in order to avoid rejection. One of the writers even indicates that his fear

of rejection by people in his social network caused him to lead a double life for many years. He kept his sadness and problems to himself for years, so that even friends and family did not know about his condition.

*"When I look back on my life, I realize all too well that I led a double life. For years, I kept my sadness and my problems to myself. With success. By lying and cheating, I came a long way, even good friends and my family knew nothing of my problems for years." (W6)*

However, on the other side people diagnosed with a psychotic disorder indicate that they need social support, especially in relation to their vulnerability to psychosis. As a result, they state that they find it helpful if they can be open and honest about their vulnerability to psychotic episodes to people in their social network. Therefore, the stories of experience reveal that they commonly choose to be open and honest about their diagnosis to a selective group, from their social network, and more often lie about their diagnosis, or conceal, it from people further away from them. In this way, one of the authors indicates that by being open and honest with a few important people, the chance of receiving social support when necessary will be increased. She also indicates that people not have to be ashamed of having a psychotic episode. It is precisely by being open that one can discuss with others how they can help to make a relapse as pleasant as possible.

*"By being open and honest with a few important people, they can be there for you when you need them. It is not a problem to be in a mood like that. You are who you are. There is nothing to be ashamed of. By being open, you can discuss with others how to find a solution that is as pleasant as possible for you." (W2)*

As a result, the stories of experience reveal a contradiction: in order to increase their chances of social integration, people diagnosed with psychotic disorders may choose to lie about their vulnerability to psychosis, but in order to receive effective social support they need to be open and honest about their diagnosis. To deal with this contradiction, they make a compromise between the two experiences and selectively choose to, inform a few people in their social network about their diagnosis, while not informing the larger group with whom they come into contact. In this way there appears to be a difference in coping with regard to increasing their chance of social integration and increasing their chance of receiving effective social support.

## 4.5.2 Challenge 2.2: Difficulty with social integration due to delusions

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The stories of experience show that people who have been diagnosed with a psychotic disorder can also hinder their social integration themselves during a psychotic episode. They indicate that during a psychotic episode they usually experience their thoughts as truth. This makes it difficult for them to accept that they are experiencing a psychotic episode, and thus their thoughts differ from reality and those of others. They state that this phenomenon can cause them to adopt a defensive attitude towards the outside world. As an example, one of the writers indicates that in the first years of having schizophrenia, she had no idea what was happening to her. She became angry at anyone who pointed out her voices. She hated the world because she didn't understand why what she saw and heard was wrong. She wanted to be alone, so that she did not have to think about what is true and what is not.

*"For about the first six years that I had schizophrenia, I had no idea what was happening to me. I became angry with anyone who told me about my voices. I hated my parents for confronting me with my delusions. I actually hated the whole world, because why was what I saw and heard wrong? And what they saw and heard right? That's not fair! I wanted to run away, I wanted to be alone. I wanted to be left alone and not have to think about what is or isn't true." (B2)*

### 4.5.2.1 Coping

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The bloggers and writers analyzed indicate that they begin to cope with this challenge as soon as they receive help from other people and begin to realize that they are dealing with a psychotic episode. They indicate that receiving informative and emotional support from the social network can play an important role in this, through the timely detection of a psychotic episode and subsequently helping someone suffering from a psychotic episode, by talking to them in an understanding and supporting way.

## 4.6 The impact of the challenges faced on the social integration

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The stories of experience show that because of the experienced challenges, it is not straightforward for the writers and bloggers analyzed to be socially integrated. They indicate that the challenges they face started as soon as they were diagnosed with a psychotic disorder,

which changed their social network from that moment on. They state that the challenges caused, by both the social network and by themselves, generally lead to a decrease in the size of their social network. In general, the weaker ties in the social network disappear, while the stronger ties remain intact. Since the stronger ties remain intact, their social network is commonly characterized by intimate relations with the few members of their social network. They indicate that they receive social support from these social contacts where necessary. Due to the small size of the social network, social support is often received from mainly the same social contacts in their social network. However, a small social network is not considered a negative thing by them. The stories revealed that quality is considered more important than quantity, with regards to the social network of someone diagnosed with a psychotic disorder. This is how the analyzed individuals cope with the challenges that comes with their psychotic vulnerability. By interacting with a small group of people they try to receive social support without becoming over-stimulated by too much social interaction.

*"My friends can be counted on two hands. That's okay; they are real friends. Friends who supported me and did not run away when the party was over and I was confronted with my illness." (W6)*

This quote is an example of one of the authors analyzed who, along with others, indicates that their social network changed as soon as they experienced a psychotic episode. In particular, the social network of the analyzed individuals changed most drastically when someone was admitted to a psychiatric clinic. This is due to the ongoing attempt of the analyzed persons to optimize their relational regulation. When hospitalized, they are suddenly placed in a new environment, which forces them to draw their social needs from a different environment than when they lived at home. This causes them to make contact with other people who are also admitted, which changes their composition of the social network over the duration of their admission. People from their former social network become a bit more in the background while they make more contact with people from their clinic, where social support is exchanged. In particular, they state that fellow patients provide effective informative support, regarding living with vulnerability to psychotic episodes, which people in the social network without experience in this area cannot offer them.

*"I learned to communicate what I was feeling or thinking. The contact with fellow patients was enlightening and supportive. I had a good time." (W1)*

It can be concluded that the writers and bloggers analyzed, despite the challenges they face, constantly search throughout their lives for a balance in terms of receiving effective social support that matches their needs, while at the same time being dependent on people who wants to offer social support to them. As a result, their social network changes with the life events they experience. Their needs relate to finding a balance in the amount of social support received, the types of social support received and the provider(s) of the social support. Successfully forming a social network, which provides social support that meets their needs in these three aspects, contributes positively to their social integration. Having a well balanced social network, and thereby receiving effective social support, enables them to be more self-reliant, to maintain themselves despite their vulnerability and to become part of society. To illustrate this process, one of the bloggers states that the combination of having fellow patients and "normal" people in her social network helps her to achieve her needs. The fellow patients in her social network provide the needed emotional and informative support. In addition, she has also managed to have "normal" people in her social network by explaining her clinical picture and therefore managed to overcome the challenge of a few people's prejudices. These "normal" people in her social network make her feel connected to the outside world. They support her in feeling socially integrated, which she considers to be a pleasant feeling.

*“I do feel a lot less lonely than when I was young. If only because we know a lot of fellow patients. People who, like us, have experienced one or more psychotic episodes, with whom we can share such things. But we don't only have contact with fellow patients. We also interact with so-called 'normal' people. I think because we can explain things well, so that people (start to) understand and can sympathize with our situation. This allows us to literally have contact with the outside world. And that's nice.” (B1)*

## 5. Discussion & Conclusion

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This chapter is structured in the following way. First, the interpretation of the results in the context of the literature will be discussed, after which, the conclusion of the analyzed data will be given, followed by limitations of this research and recommendations for follow-up research and practice.

### 5.1 Reflection of the results in the context of the literature

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The results of this study show that people diagnosed with a psychotic disorder have the need to be part of society. However, because of their clinical picture, they indicate that striving for full participation, such as in areas of work, is usually not feasible for them. Their need with regard to social integration is therefore limited to their capabilities. They indicate that receiving social support can, however, extend their capabilities. The results of this research therefore show that receiving effective social support from the social network can contribute positively to their possibilities for social integration by making them more self-reliant, and partly as a result of this, they can commonly maintain themselves in society. However, not every form of social support received is actually experienced as effective. This study identified three main aspects that are considered important by people diagnosed with a psychotic disorder when receiving social support, namely what kind of social support is received, how much social support is received and who provides the social support. In line with the relational regulation theory, they feel the need to optimize the social support received throughout their lives according to their needs related to these three main aspects (Lahey and Orehek, 2011). However, this process is made more difficult for them by several challenges.

The first challenge that emerged in this study concerns finding a balance in receiving the right amount of social support. It is not the case for people diagnosed with a psychotic disorder that the more social support they receive, the better. As confirmed in research by Beels (1981) and Wing (1978), they state that receiving too much social support can be overwhelming for them and can lead to a relapse into a psychotic episode. Based on their sensitivity to social stimuli, the results of this study provide new insights into the reality that people diagnosed with a psychotic disorder constantly experience a challenge in finding a balance in receiving the right amount of effective social support while not becoming over-

stimulated by it. In finding this balance they must constantly weigh up whether the benefits of receiving that particular type of social support outweigh the disadvantages.

The results of this study indicate that the composition of the network, and thus who provides social support, is considered important in maintaining this balance. The effectiveness of social support appears to depend on the relationship with the provider. This makes it important for them to have people in their social network who are likely to provide effective social support. As an example, the results of this study show that emotional support is only perceived as effective when the recipient feels understood by the provider. This finding is consistent with the relational regulation theory; as the recipient feels understood, reciprocal elaboration occurs, which in turn causes relational regulation, proving that the social support received has turned out to be effective (Lakey and Orehek, 2011). In order to receive the most effective social support possible, people diagnosed with a psychotic disorder experience the need to adjust their social network throughout their life. A person's need to adjust their social network in order to optimize their relational regulation is also consistent with the relational regulation theory (Lakey and Orehek, 2011). However, similar to previous research by Perry & Pescosolido (2012), the findings of this study suggest that people diagnosed with a psychotic disorder experience challenges in optimizing their relational regulation. They do not experience the freedom to look for suitable people to include in their social network in order to optimize their relational regulation. The findings of this study confirm that this challenge arises from society's prejudices about psychotic disorders (Perry & Pescosolido, 2012). In addition, the results of this study provide new insight into how social integration is also impeded by someone who is experiencing a psychotic episode themselves. Because a person during a psychotic episode often considers their delusions to be true, this can cause them to turn away from everything and everyone in the outside world as soon as they are confronted with the reality that what they are experiencing is not the truth. This in turn creates challenges for those around people diagnosed with a psychotic disorder; it seems that they also need to find a balance in how best to deal with someone experiencing a psychotic episode, in whether or not to offer social support at a particular time.

The findings of this study also show that the challenges that people diagnosed with a psychotic disorder face, towards social integration, cause the social network to adapt. In general, fellow patients enter a person's social network as soon as they experience psychotic episodes, since they can provide a form of social support, namely informative support related to how best to live with a vulnerability to psychotic episodes, that people in their social network without experience in that area cannot offer them. This finding is consistent with the

relational regulation theory, in a way that a person suffering from a psychotic episode adapts his social network, according to his needs to increase his chances of receiving the most effective support at that time (Lakey and Orehek, 2011). Apart from the addition of fellow patients, the results of this study show that the size of the social network generally decreases once a person has been diagnosed with a psychotic disorder. The weaker connections in the social network disappear, while the core of the social network remains mostly intact. This finding is in line with the findings of research by Perry (2011) and Perry & Pescosolido (2012). The literature, however, indicates that the causes of the challenges experienced are mainly those of society, whereas the results of this study show that people diagnosed with a psychotic disorder play a major role in this themselves and consciously choose to have a small social network in order to control their vulnerability to psychotic episodes, and in this way are able to maintain themselves in society (Perry, 2011; Beels, 1981; Perry & Pescosolido, 2012). It can be said that this way of dealing with their vulnerability, with the aim of being able to maintain themselves in society, corresponds to the rationale behind the participation society. Research by Link, Yang, Phelan & Collins (2004) suggests that this change, in which the size of the social network decreases, is associated with negative consequences for the individual's sense of power and independence. In contrast, the results of this study show that this literature is presented too negatively in the case of people diagnosed with a psychotic disorder. Due to their vulnerability to social stimuli, they indicate that they prefer quality over quantity when it comes to constructing their social network. They indicate that they feel positive about receiving social support from a small group of people because it enables them to maintain a balance with regard to receiving social support without becoming over-stimulated, which makes them more able to maintain themselves in society. Remaining the balance, therefore, outweighs the benefits of having a large social network for people diagnosed with a psychotic disorder.

Thus, despite the perceived challenges of social integration, the writers and bloggers, analyzed in this study, commonly manage to receive social support from a small but strong social network. However, it may be the case that these individuals analyzed, who write openly about their experiences in relation to their psychotic disorder, are further along in their development of living with a vulnerability to psychotic episodes than the average person diagnosed with a psychotic disorder. Looking at the results of this study it can be concluded that the findings are not entirely in line with the book of by Bredewold et al. (2018) in which the feasibility of the policy expectations of the participation society are criticized with arguments that people would not want to call on their social network when they need care, or

that the social network would not have the capacity to provide social support. In contrast, the results of this study show that people from the small social network of those analyzed are indeed willing to provide social support and in fact support them in maintaining themselves in society. However, despite the fact that they do receive social support and which does contribute to their ability to maintain themselves in society, the social support they currently receive cannot, on its own, enable them to actually participate in society, such as in the area of work.

However, the results of this study show that there is still room for improvement with regard to the effectiveness of the social support provided, as the results of this study showed that not every form of social support received proved to be effective. Increasing the effectiveness of the social support provided by the social network could improve the quality of life of people diagnosed with a psychotic disorder and at the same time give them more opportunities to participate in society, which would be conducive to the policy expectations of the participatory society. A promising way of achieving this would be to support people in the social network of someone diagnosed with a psychotic disorder in how best to provide effective social support. In this way, the small social network of someone diagnosed with a psychotic disorder can be optimally utilized in the provision of social support.

## 5.1 Conclusion

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The conclusion of this research is given by first answering the sub-questions, followed by the main question.

1. *What are the preferences concerning social (re)integration in terms of social support of people diagnosed with psychotic disorders?*

Being socially integrated is not straightforward for people diagnosed with a psychotic disorder because of the challenges they experience in this process. The nature of these challenges will be discussed in the conclusion of the second sub-question. Their need with regard to social integration is therefore restricted to their capabilities. Social support can provide them with the necessary tools to maintain themselves in society, which forms the basis for further integration into society. However, not every form of social support received is considered effective. They consider three main aspects to be important when receiving

social support, namely, the type of social support received, the amount of social support received and from whom the social support is received. To increase their chances of relational regulation, and thus their chances of receiving effective social support, they have the desire to match their needs on the basis of these three main aspects.

*2. What are the challenges concerning social (re)integration in terms of social support of people diagnosed with psychotic disorders?*

For people diagnosed with a psychotic disorder, it is not the case that the more social support they received, the better. They experience an internal challenge, as they can become over-stimulated by social stimuli, that comes with receiving social support. They must therefore constantly weigh up whether the benefits, that come with receiving social support, are worth the drawbacks. In making this choice, it is important for them to only interact with the right people, in order to increase their chances of receiving effective social support while not being over-stimulated by a large number of social stimuli. However, they experience challenges in forming their social network. These challenges are caused both by people in the social network and by someone diagnosed with a psychotic disorder themselves. The prejudices that exist in society and the perceptions that someone experiences during a psychotic episode together limit their opportunities for social integration. Being socially integrated and creating a social network that provides effective social support is therefore not necessarily straightforward for someone diagnosed with a psychotic disorder.

*3. How do people diagnosed with psychotic disorders cope with these challenges?*

Despite the risk of becoming over-stimulated during social interaction, the majority still choose to engage in occasional social interaction. However, this choice is only made if this social interaction is expected to be accompanied by the receipt of effective social support and therefore the benefits outweigh the disadvantages. In order to increase this likelihood, they have the need to adapt their social network to their needs. As a result, the social network is usually kept small with strong social ties to decrease the risk of over-stimulation. Only these strong social ties in the social network are usually informed about their diagnosis of psychotic disorder. This is done tactically, as a prerequisite for receiving effective social support is that they can be open and honest about their diagnosis. By not disclosing their diagnosis to the rest of society, they increase their chances of social integration by avoiding the risk of rejection

based on prejudice. In this way they manage their chances of both social integration and of receiving effective social support.

#### Main question

*What are the challenges and preferences concerning social (re)integration in terms of social support of people diagnosed with psychotic disorders and how do they cope with these challenges?*

People diagnosed with a psychotic disorder face challenges in their process towards social integration, with sensitivity to social stimuli, prevailing prejudices in society and the perception of someone during a psychotic episode hindering their possibilities of social integration. Due to these perceived challenges, their need to be socially integrated is restricted to their capabilities. In order to increase their possibilities for social integration, they deal with the experienced challenges by tactically keeping their social network small, consisting mainly of strong social ties, which are told openly and honestly about their diagnosis. In this way they also manage their chance of receiving effective social support, which depends on three main aspects, namely, the type of social support received, the amount of social support received and from whom the social support is received. In order to increase their chances of receiving effective social support, they have the desire to match their needs, and therefore the composition of their social network, on the basis of these three main aspects. Receiving effective social support in turn also increases their possibilities for social integration, as it provides them with the necessary tools to maintain themselves in society. To increase their possibilities for social integration in another way, they conceal their diagnosis from the rest of society. By dealing with the challenges in this way, people diagnosed with a psychotic disorder try to increase their possibilities for social integration and receiving effective social support.

## 5.2 Limitations of this research

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A weakness of this research is that the diversity of the writers and bloggers analyzed is limited. The analyzed individuals are all of Dutch origin and between 28 and 60 years old. The relatively small range in age, and no difference in ethnicity, limits the generalizability of the results of this study. However, in the search for relevant books and blogs, no younger and

older people were encountered, or people from other ethnic backgrounds. Research by Klarenbeek (2017) shows that the average age at which a writer publishes a book in the Netherlands is 50.7 years. This may explain why no younger or older writers were encountered. However, when researching blogs, it was expected that a younger population of bloggers would be encountered, as research shows that most bloggers are predominantly under 30 years of age (Schler, Koppel, Argamon & Pennebaker, 2006). The stigma that prevails in society towards psychotic disorders, however, may explain why people start blogging at an older age about their experiences of living with a psychotic disorder.

The individuals analyzed were either diagnosed with schizophrenia or schizoaffective disorder, which may have caused underlying differences in the results. However, these differences did not feature prominently in the stories of experience, which is why it was decided not to distinguish between them in this study. The lack of unequivocal differences between the diagnostic groups corresponds to the criticism that prevails in the literature concerning the current classification of psychotic disorders (Havenaar, 2005).

The choice of the analysis of books and blogs may have meant that these analyzed persons, who are able to write openly about their experiences in relation to their psychotic disorder, are further along in their development of living with a vulnerability to psychotic episodes than the average person diagnosed with a psychotic disorder. The results obtained with regard to social integration in terms of social support from the group of persons analyzed may therefore be more favorable than for the average person diagnosed with a psychotic disorder, which would create problems for the generalizability of the results of this study.

Another disadvantage of analyzing books and blogs is that there was no opportunity to ask questions about the data collected. Therefore, ambiguities or interpretations could not be checked with those being analyzed, as is the case with interviews, for example.

An advantage of analyzing blogs, however, would be that the comments under a blog post could serve as an additional source of information, allowing for the analysis of different people's experiences in relation to a discussed topic. However, external reactions to the analyzed blogs were rare or non-existent, which is why it was decided not to examine these reactions separately in this study. The reason for not responding to the analyzed blog posts is unknown, however, this could have been a rich source of information and an interesting additional point of researching blogs alongside books.

### 5.3 Recommendations for follow-up research

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Three recommendations are made for follow-up research.

First, analyzing blogs and books is a useful and relatively accessible source of information if you want to investigate patient perspectives. However, the diversity of bloggers and writers does not appear to be very varied, with people of Dutch descent aged between 28 and 60 mainly writing about their experiences with a psychotic disorder. For follow-up research it would be valuable to analyze other ethnicities and the experiences of younger and older people as well. Since analyzing blogs and books about these groups of people does not appear to provide adequate information, it may be of value to use another source of information, such as conducting interviews as well. Analyzing different ethnic groups is especially valuable on this topic since research suggests that that behaviors toward seeking social support differ across cultures (Taylor, Sherman, Kim, Jarcho, Takagi & Dunagan, 2004).

Second, this research did not take into account the time perspective when the analyzed stories of experience took place. However, it may be interesting for follow-up research to investigate whether the experienced needs and challenges of people diagnosed with a psychotic disorder regarding their social integration in terms of social support have changed over time. It might be interesting in this regard to examine whether political movements, such as the introduction of the participation society, have influenced the receipt of social support and the social integration of people diagnosed with a psychotic disorder.

Third, because this study focused on the experiences of people diagnosed with a psychotic disorder, no information was collected on the experiences of the social network. However, the results of this study suggest that the behavior of people diagnosed with a psychotic disorder can in turn cause challenges for people in the social network, in terms of whether or not they should offer social support at a particular moment and in what way. In addition, no information was collected on how burdening the provision of social support is for the social network. Investigating the burden on the social network is especially important in the case of people diagnosed with a psychotic disorder since the results of this study show that they receive social support from a small group of people. The consequence of having a small social network may be that the burden of care increases for the members of the social network. Excessive burdening of people from the social network could, in the long run, cause serious negative consequences for these people (Flyckt, Löthman, Jörgensen, Rylander & Koernig, 2013). Since providing and receiving social support are inter-related, it will give a complete

picture if the experiences of people from the social network of people diagnosed with a psychotic disorder are also analyzed.

#### 5.4 Recommendations for practice

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The results of this study show that it is especially important for people diagnosed with a psychotic disorder to receive effective social support, because of their clinical picture and the challenges they experience. However, not all the social support received turns out to be effective, which means there is still room for improvement in this respect. The results of this study provide initial indications of what makes received social support actually effective for this group people. These findings can serve as a basis for developing policies and interventions, with the aim of making the social support provided more effective. Success in ensuring that the social support provided is actually considered effective by people diagnosed with a psychotic disorder has promising consequences for their quality of life and their opportunities for social integration.

## 6. References

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- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed). Arlington, VA: American Psychiatric Association
- Andrews, S. (2019). Thematic and narrative analysis in the context of courtroom examinations with alleged victims of child abuse. In *SAGE Research Methods Datasets Part 2*. SAGE Publications, Ltd.  
<https://www.doi.org/10.4135/9781526498878>
- Angermeyer, M. C., Beck, M., & Matschinger, H. (2003). Determinants of the public's preference for social distance from people with schizophrenia. *The Canadian Journal of Psychiatry, 48*(10), 663-668.
- Arts, W. A., Entzinger, H. B., & Boos, K. (2004). *Verzorgingsstaat vaar wel*. Uitgeverij Van Gorcum.
- Beels, C. C. (1979). Social networks and schizophrenia. *Psychiatric Quarterly, 51*(3), 209-215.
- Beels, C. C. (1981). Social support and schizophrenia. *Schizophrenia Bulletin, 7*(1), 58-72.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
- Bredewold, F. H., Duyvendak, J. W., Kampen, T., Tonkens, E., & Verplanke, L. (2018). *De verhuizing van de verzorgingsstaat : hoe de overheid nabij komt* (Ser. Tijdschrift voor sociale vraagstukken. jaarboek). Van Genneep.
- Ballin, E. H. (2013). Participatiesamenleving en overheidsbeleid.  
Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social science & medicine, 51*(6), 843-857.
- Brink, H. I. (1993). Validity and reliability in qualitative research. *Curationis, 16*(2), 35-38.
- Cechnicki, A., Wojciechowska, A., & Valdez, M. (2007). Social network and quality of life of people suffering from schizophrenia in seven years from first hospitalization. *Psychiatria polska, 41*(4), 527-537.
- Caplan, G. (1974). *Support systems and community mental health: Lectures on concept development*. behavioral publications.
- Cohen, S. E., & Syme, S. L. (1985). *Social support and health*. Academic Press.

- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis *Psychological bulletin*, 98(2), 310.
- Davidson, L., & Stayner, D. (1997). Loss, loneliness, and the desire for love: Perspectives on the social lives of people with schizophrenia. *Psychiatric Rehabilitation Journal*, 20(3), 3.
- Delsen, L. W. M. (2016). Realisatie van de participatiesamenleving. Hervorming van de verzorgingsstaat in Nederland: 2010-2015.
- Eack, S. M., Newhill, C. E., Anderson, C. M., & Rotondi, A. J. (2007). Quality of life for persons living with schizophrenia: more than just symptoms. *Psychiatric rehabilitation journal*, 30(3), 219.
- Flyckt, L., Löthman, A., Jörgensen, L., Rylander, A., & Koernig, T. (2013). Burden of informal care giving to patients with psychoses: a descriptive and methodological study. *International Journal of Social Psychiatry*, 59(2), 137-146
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian & New Zealand Journal of Psychiatry*, 36(6), 717-732.
- Foundation CCC.(n.d.). *Patientervaringsverhalen* [Dataset].<https://patientervaringsverhalen.nl>
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The qualitative report*, 20(9), 1408.
- Giacco, D., McCabe, R., Kallert, T., Hansson, L., Fiorillo, A., & Priebe, S. (2012). Friends and symptom dimensions in patients with psychosis: a pooled analysis. *PLoS One*, 7(11), e50119.
- Green, J., & Thorogood, N. (2004). *Qualitative Methodes for Health Research*. Londen: SAGE Publications Ltd.
- Greenhalgh, T., & Hurwitz, B. (1999). Why study narrative?. *Bmj*, 318(7175), 48-50.
- Hawkins, A. H. (1999). Pathography: patient narratives of illness. *Western Journal of Medicine*, 171(2), 127.
- Heilferty, C. M. (2009). Toward a theory of online communication in illness: concept analysis of illness blogs. *Journal of Advanced Nursing*, 65(7), 1539-1547.
- Holt-Lunstad, J., & Uchino, B. N. (2015). Social support and health. *Health behavior: Theory, research and practice*, 183-204.

- Holt-Lunstad, J., & Smith, T. B. (2012). Social relationships and mortality. *Social and Personality Psychology Compass*, 6(1), 41-53.
- Hookway, N. (2008). Entering the blogosphere': some strategies for using blogs in social research. *Qualitative research*, 8(1), 91-113.
- House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science*, 241(4865), 540-545.
- Isika, N., Mendoza, A., & Bosua, R. (2016). The use of social media by adults with chronic illness: analysing the support mechanisms of four social media platforms.
- Johnson, S. A. (2014). "Maternal devices", social media and the self-management of pregnancy, mothering and child health. *Societies*, 4(2), 330-350.
- Kahn, J. H., Hessling, R. M., & Russell, D. W. (2003). Social support, health, and well-being among the elderly: what is the role of negative affectivity?. *Personality and Individual Differences*, 35(1), 5-17.
- Killaspy, H., White, S., Lalvani, N., Berg, R., Thachil, A., Kallumpuram, S., ... & Mezey, G. (2014). The impact of psychosis on social inclusion and associated factors. *International Journal of Social Psychiatry*, 60(2), 148-154.
- Klarenbeek, G. D. (2017). De rol van sekse en leeftijd in de Nederlandse literaire productie en receptie. Een kwantitatief en kwalitatief onderzoek naar de verhoudingen tussen mannen, vrouwen en debutanten binnen de Nederlandse literaire productie en receptie uit 2015.
- Lakey, B., & Orehek, E. (2011). Relational regulation theory: a new approach to explain the link between perceived social support and mental health. *Psychological review*, 118(3), 482.
- Lieberman, J. A., & First, M. B. (2018). Psychotic disorders. *New England Journal of Medicine*, 379(3), 270-280.
- Lin, N., Ensel, W. M., Simeone, R. S., & Kuo, W. (1979). Social support, stressful life events, and illness: A model and an empirical test. *Journal of health and Social Behavior*, 20(2), 108-119.
- Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia bulletin*, 30(3), 511-541.
- Moreno-Küstner, B., Martin, C., & Pastor, L. (2018). Prevalence of psychotic disorders and its association with methodological issues. A systematic review and meta-analyses. *PloS one*, 13(4), e0195687.

- Mortelmans, D. (2013). *Handboek kwalitatieve onderzoeksmethoden*. Den Haag: Acco Nederland.
- Norman, R. M., Malla, A. K., Manchanda, R., Harricharan, R., Takhar, J., & Northcott, S. (2005). Social support and three-year symptom and admission outcomes for first episode psychosis. *Schizophrenia research*, 80(2-3), 227-234.
- op Havenaar, C. (2005). Waarom geen diagnose schizofrenie (sec). *tijdschrift voor psychiatrie*, 47(3), 157.
- Östberg, V., & Lennartsson, C. (2007). Getting by with a little help: The importance of various types of social support for health problems. *Scandinavian journal of public health*, 35(2), 197-204.
- Pagoto, S., & Nebeker, C. (2019). How scientists can take the lead in establishing ethical practices for social media research. *Journal of the American medical informatics association*, 26(4), 311-313.
- Palumbo, C., Volpe, U., Matanov, A., Priebe, S., & Giacco, D. (2015). Social networks of patients with psychosis: a systematic review. *BMC research notes*, 8(1), 1-12.
- Patton, M. Q. (2005). Qualitative research. *Encyclopedia of statistics in behavioral science*.
- Perry, B. L. (2011). The labeling paradox: Stigma, the sick role, and social networks in mental illness. *Journal of health and social behavior*, 52(4), 460-477.
- Perry, B. L., & Pescosolido, B. A. (2012). Social network dynamics and biographical disruption: The case of “first-timers” with mental illness. *American Journal of Sociology*, 118(1), 134-175.
- Pinto, R. M. (2006). Using social network interventions to improve mentally ill clients’ well-being. *Clinical social work journal*, 34(1), 83-100.
- Plochg, T., Juttman, R. E., Klazinga, N. S., & Mackenbach, J. P. (2006). *Handboek gezondheidszorgonderzoek*. Bohn Stafleu van Loghum.
- Schoenmakers, E., & Suanet, B. (2018). Sociale netwerken van ouderen krimpen niet, maar veranderen wel. *Geron*, 20(3), 6-9.
- Seeman, T. E. (1996). Social ties and health: The benefits of social integration. *Annals of epidemiology*, 6(5), 442-451
- Schler, J., Koppel, M., Argamon, S., & Pennebaker, J. W. (2006, March). Effects of age and gender on blogging. In *AAAI spring symposium: Computational approaches to analyzing weblogs* (Vol. 6, pp. 199-205).

- Schwarzer, R., Knoll, N., & Rieckmann, N. (2004). Social support. *Health psychology, 158*, 181.
- Sias, P. M., & Bartoo, H. (2007). Friendship, social support, and health. In *Low-cost approaches to promote physical and mental health* (pp. 455-472). Springer, New York, NY.
- Taylor, S. E., Sherman, D. K., Kim, H. S., Jarcho, J., Takagi, K., & Dunagan, M. S. (2004). Culture and social support: Who seeks it and why?. *Journal of personality and social psychology, 87*(3), 354.
- Tempier, R., Balbuena, L., Lepnurm, M., & Craig, T. K. (2013). Perceived emotional support in remission: results from an 18-month follow-up of patients with early episode psychosis. *Social psychiatry and psychiatric epidemiology, 48*(12), 1897-1904.
- Tonkens, E. (2014). Herover de participatiesamenleving. *Socialisme & Democratie, 71*(1), 85-94.
- Troonrede 2013. (2014, September 16). Toespraak | Rijksoverheid.nl  
<https://www.rijksoverheid.nl/documenten/toespraken/2013/09/17/troonrede-2013>
- Umberson, D., & Karas Montez, J. (2010). Social relationships and health: A flashpoint for health policy. *Journal of health and social behavior, 51*(1\_suppl), S54-S66.
- United States. National Commission for the Protection of Human Subjects of Biomedical, & Behavioral Research. (1978). *The Belmont report: ethical principles and guidelines for the protection of human subjects of research* (Vol. 2). The Commission.
- van de Bovenkamp, H. M., Platenkamp, C., & Bal, R. (2020). Understanding patient experiences: The powerful source of written patient stories. *Health Expectations: an international journal of public participation in health care and health policy, 23*(3), 717.
- van den Broek, T., Dykstra, P. A., & van der Veen, R. J. (2015). Zorgidealen in Nederland: verschuivingen tussen 2002 en 2011. *Mens en maatschappij, 90*(1), 25-52.
- van Houwelingen, P., Boele, A., & Dekker, P. (2014). *Burgermacht op eigen kracht?: Een brede verkenning van ontwikkelingen in burgerparticipatie* (Vol. 2014). Sociaal en Cultureel Planbureau.
- van Kersbergen, K., & Vis, B. (2016). *De verzorgingsstaat*. Amsterdam University Press.
- van Staa, A., & Evers, J. (2010). 'Thick analysis': strategie om de kwaliteit van kwalitatieve data-analyse te verhogen. *KWALON. Tijdschrift voor Kwalitatief Onderzoek in Nederland, 43*(1), 5-12.

- van Zwieten, M., & Willems, D. (2004). Waardering van kwalitatief onderzoek. *Huisarts en wetenschap*, 47(13), 38-43.
- Wallston, B. S., Alagna, S. W., DeVellis, B. M., & DeVellis, R. F. (1983). Social support and physical health. *Health psychology*, 2(4), 367.
- Wing, J. K. (1978). The social context of schizophrenia. *American Journal of Psychiatry*, 135(11), 1333-1339.
- Witteveen, E., Post, M., & Visser-Meily, A. (2014). Participatiesamenleving: naasten direct betrekken bij de revalidatie. *Nederlands Tijdschrift voor Revalidatiegeneeskunde*, 2014(1), 42-43.

## Appendix 1 Inclusion criteria books and blogs

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### *Books*

- Autobiography
- Written by someone diagnosed with a psychotic disorder who has had more than one psychotic episode
- Written about themes concerning social integration and social support
- Written in Dutch

### *Blogs*

- A blog page that contains several blog posts by the same person
- Written by someone diagnosed with a psychotic disorder who has had more than one psychotic episode
- Written about themes concerning social integration and social support
- Written in Dutch

## Appendix 2 Search terms

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Search terms for finding blogs via Google:

- blog

OR

- blog page

OR

- blogger

AND

psychotic disorder OR schizophrenia OR schizoaffective OR disorder OR schizophrenic OR psychosis OR psychotic episode OR schizophreniform disorder OR delusional disorder

## Appendix 3 Main themes identified in the analysis

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- Social network function
- Difficulties of social integration
- Coping with social integration difficulties
- Social integration/network
- Preferences social integration

## Appendix 4 Characteristics of the writers and bloggers analyzed

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### Characteristics of the writers

<b>Writer</b>	<b>Gender</b>	<b>Age</b>	<b>Diagnosis</b>	<b>Year of publication</b>
1	Male	58	schizophrenia	2015
2	Female	34	schizophrenia	2015
3	Female	41	schizoaffective	2014
4	Female	40	schizoaffective	2012
5	Male	60	schizophrenia	2011
6	Male	28	schizoaffective	2013

### Characteristics of the bloggers

<b>Blogger</b>	<b>Gender</b>	<b>Age</b>	<b>Diagnosis</b>	<b>Year(s) of publication</b>
1	Female	40	schizoaffective	2014-2020
2	Female	56	schizophrenia	-
3	Male	58	schizophrenia	2018-2020