

**Echoes of the Mind: Understanding Schizophrenia through Personal Perspectives, a
Mixed Method Biographical Study**

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Abstract

Background: Schizophrenia is frequently labelled as highly heterogenic both in its aetiology and its demands from treatment and care professionals. Qualitative research studies on schizophrenia's origins concentrating on the three factors (psychological, sociocultural and biological) and treatment perspectives have been valuable in providing comprehensive individual accounts. However, a qualitative analysis of the three common aetiology factors and extensive research on personal perspectives on received treatments are still lacking.

Aim: This study aims to investigate the role of the three factors for schizophrenia aetiology and explores alignment or differences to a qualitative sample. Additionally, personal perspectives on treatment strategies and care types are examined and connected to the current level of symptoms.

Methodology: Eight participants ($N_{Female} = 4$, $N_{Male} = 4$, $M_{age} = 53.12$) with a diagnosis of schizophrenia or schizoaffective disorder were recruited from the Alexianer hospital in Münster. Semi-structured interviews were conducted employing the Brief Psychotic Rating Scale. Thematic analysis was applied to identify overarching themes and patterns in the interview data.

Results: The symptoms of schizophrenia in seven out of eight participants could be fully or partially explained by the three factors. Participants' views on the effectiveness of different care types and treatment strategies could be categorised into four different groups: pharmacological treatment, nonpharmacological treatment, stationary care, and personal narratives and perceptions. Notably, conversations with psychologists, individual freedom and distraction techniques were mentioned to be the most helpful for coping with schizophrenia symptoms.

Conclusion: This study highlights schizophrenia to be highly heterogenic. Biological, psychological and sociocultural factors largely explain the disorder's aetiology. However, it is recommended to extend the current factors and incorporate techniques such as neuroimaging and machine learning. Non-pharmacological treatments are perceived as helpful but used inconsistently. Persistent severe symptoms require a higher frequency of psychological interventions and education for hospital staff about them.

Keywords: Schizophrenia aetiology, Narrative research, Precision medicine, Positive psychology

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Without the help of the aforementioned people, this Bachelor's thesis would not have been possible.

*Don't let us forget that the causes of human actions are usually
immeasurably more complex and varied than our subsequent explanations
of them.*

Fjodor Dostoevsky, *The Idiot* (1869/1996)

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Echoes of the Mind: Understanding Schizophrenia through Personal Perspectives, a Mixed Method Biographical Study

The elusive and destructive nature of schizophrenia embodies a unique role in psychopathology. It is the cause of severe individual suffering, confusion, the loss of an individual's personality and identity, and the pure inability to take part in their community. With around 24 million people affected worldwide (World Health Organization: WHO, 2022), the disorder has a tremendous impact, and its societal burden has constantly been increasing over the last decades (He et al., 2020). Still, the aetiology of schizophrenia remains subject of heavy debate, without extensive understanding of its origin. Moreover, effective care systems are still not clearly established, as they are primary based on the biomedical model of schizophrenia, but partially leave out psychological and sociocultural factors. This thesis aims to focus on schizophrenia's aetiology and roots, especially by considering individual factors that play a role in the development, and effective care. Finally, this bachelor's thesis has the objective of proposing recommendations for future strategies of care for individuals diagnosed with schizophrenia.

Prevalence, Symptoms, and Treatment Approaches

Schizophrenia affects 0.32% of people worldwide, and it is often diagnosed between later adolescence and the mid-twenties, although females experience symptoms a few years later in life (World Health Organization: WHO, 2022; Abel et al., 2010). Additionally, the life expectancy is lower than that of the general population, leading those diagnosed with schizophrenia spectrum disorders to die approximately 15-20 years earlier (Peritogiannis et al., 2022), and up to 10% end their life by committing suicide (Davis et al., 2021). Schizophrenia is seen as a multifaceted disorder. It causes disturbances in thought, language, sensory perception, emotion regulation and behaviour (American Psychiatric Association, 2022). The disorder mainly manifests itself through positive and negative symptoms. Positive symptoms mainly manifest themselves through delusions (i.e. fixed beliefs which remain despite overwhelming counterevidence). Delusions are the most common symptom in acute and active stages of schizophrenia (Baker et al., 2019). Additionally, positive symptoms of schizophrenia include hallucinations (perceptions without external stimuli), disorganized thinking and speech, and abnormal motor behaviour. These symptoms are termed positive because they represent an

addition to the individual's typical experience. Negative symptoms are characterized by slowing and depressing behaviours, those include alogia, autism, ambivalence, and affect blunting (Arantes-Gonçalves et al., 2018). Overall, the symptom range of schizophrenia is broad, unique and mostly results in significant environmental ramifications for those impacted.

Schizophrenia typically progresses through three stages. Symptoms emerge during the prodromal phase, characterized by a gradual decline from typical functioning to the onset of delusional thoughts. This takes place over a period from approximately 6 months and can take up to 5 years. Symptoms begin with a withdrawal from normal life, during which the individual often experiences inappropriate emotions (for example confusion, lack of pleasure and blunting) and problems at work (George et al., 2018). Then, vigorous psychotic symptoms appear in the active stage; this is mostly considered as the first psychotic episode, also named psychosis (Lally et al., 2017). The term psychosis is defined by a collective of symptoms, during which the individual experiences several disturbing and distressing symptoms, including e.g. extreme hallucinations or delusions (Gäebel & Zielasek, 2015). Lally et al. (2017) estimates that almost half of the individuals improve after a first psychotic episode, meaning that they do not experience further psychotic episodes and only mild or no positive and negative symptoms. The other half is entering the third stage which is termed the residual (or chronic) stage. It is defined by cognitive impairment, several negative symptoms (like depression or lack of motivation), social deficits, and a remaining possibility of relapse into an active stage (Lieberman et al., 2001). In general, the illness progression of schizophrenic clients after the first active stage is highly unique.

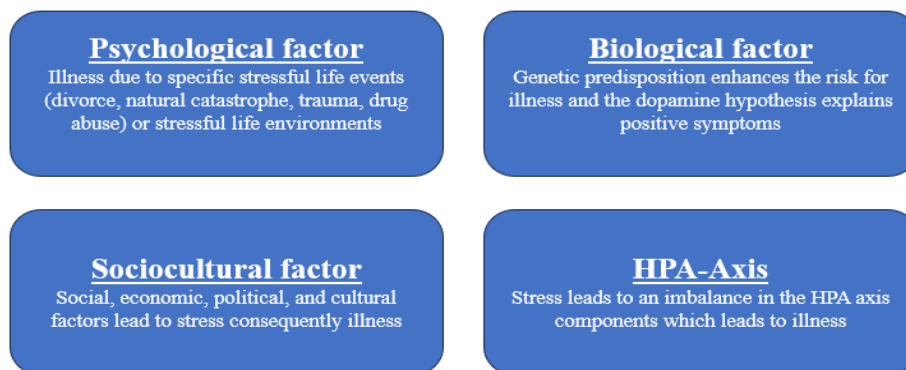
Schizophrenia symptoms mainly seem to appear through neurological processes. Biomedical models showed connections between the dopamine system and the positive symptoms of schizophrenia (Yang and Tsai 2017), however, the dopamine theory showed insufficient to explain the disorder entirely, as negative symptoms could not be explained (Kanahara et al., 2021). A psychological model like the diathesis stress model uses a more comprehensive approach, stating that psychotic symptoms may arise from an inherent biological vulnerability that is triggered by psychological stressful life events (like divorce, natural catastrophe, trauma, drug abuse) and daily stressful patterns (Jones & Fernyhough, 2007; Myin-Germeys & Van Os, 2007). The emergence of psychotic symptoms is commonly attributed to the confluence of a preexisting genetic predisposition alongside specific psychological stressors (Pruessner et al., 2017). Furthermore, the hypothalamic–pituitary–adrenal axis (HPA axis) is frequently used to explain the interplay of psychological stressors

and the human hormonal system. Pruessner et al. (2017) suggest that HPA axis imbalance, particularly marked by amygdala hyperactivity, can trigger severe psychopathological symptoms, such as psychosis. Moreover, Jones and Fernyhough (2007) propose that constant stress leads to increased cortisol production in the HPA axis, thereby triggering schizophrenic symptoms in people who have a pre-existing genetic vulnerability, which according to Hilker et al. (2018) the majority (80%) of schizophrenia cases possess. Consequently, the HPA axis is related to the diathesis stress model, wherein an imbalance in the HPA axis caused by psychological stressors can trigger a biological vulnerability for psychotic symptoms. Croft et al. (2019) supports this dynamic by illustrating that experiencing stressful trauma before reaching the age of 17 raises the likelihood of encountering psychotic experiences by the time one reaches the age of 18. These findings indicate the essentiality of grasping how environmental factors contribute to an individual's stress experience when exploring the aetiology of schizophrenia. Environmental influences are integral to the framework of broader sociocultural theories.

Several sociocultural theories suggest that social, economic, political, and cultural factors can lead to increased levels of stress that consequently trigger the genetic predisposition causing schizophrenia symptoms. Such risk factors could be belonging to an ethnic minority or having a family history of migration (King et al., 2005), child sexual abuse (McGrath et al., 2017), or lower social and economic class (Mallett et al., 2002). Furthermore, Goldberg and Morrison (1963) proposed the drift hypothesis which states that individuals with schizophrenia experience a social downward drift to a lower social class because of early symptoms. As this leads to a more stressful environment, it can worsen the progression of schizophrenia or increase the chance of the onset of the disorder. Sociocultural theories support the HPA theory and the diathesis stress model and show how important research on individual biographies is, to find more information on schizophrenias aetiology. Biographical studies focus on personal perspectives and investigate the influence of factors (such as stress) which work as a control variable for schizophrenia and can prevent or promote the appearance of symptoms.

Figure 1

Three factors that aim to explain schizophrenias aetiology and the HPA-Axis.



Previous biographical research in schizophrenia showed that reduced social stigmata and precision medicine led to improvements in schizophrenia illness progression (Kosorok & Laber, 2019). Furthermore, Georgaca and Zissi (2019) mentioned seminal clues about the positive effects of community mental health services, interpersonal relationships and social networks on psychotic individuals, using biographical interviews. Additionally, narrative research of Steinert et al. (2007) investigated the aetiology of schizophrenia by providing evidence for the appearance of stressful life events, prior to psychotic symptoms. Overall, these studies show that biographical research provides more flexibility and adaptability to explore unexpected themes and emphasises empowerment for individuals with schizophrenia by giving them a voice and platform to share their experiences and insights. Moreover, this kind of research offers insightful leads for elucidating the aetiology of schizophrenia by concentrating on in-depth approaches that captures the uniqueness of the cases. Additionally, revealing which aetiology factors explain the aetiology also provides clues concerning the form of therapy that may be the most suitable (Evers et al., 2014). Given the highly individual and unique nature of this disorder, an investigation of personal biographical narratives becomes necessary. However, a detailed and comprehensive biographical analysis on how individual perspectives align with or differ from the three common aetiology factors is still missing. To the researchers knowledge, there is no biographical analysis which focuses on sociocultural, biological and psychological factors. Therefore, the first research question is proposed:

“How do biological, psychological and sociocultural schizophrenia spectrum disorder aetiology theories and factors align with or differ from personal biographical perspectives, especially looking at risk factors prior and during the onset of symptoms?”

Additionally, this research aims to investigate the types of care and treatment individuals received during and after the onset of the disorder, as interventions and the type of care may influence the severity of the individual’s illness progression. To date, there are several

antipsychotic drugs available with strong side effects, and although most antipsychotic drugs do significantly improve most positive symptoms, negative symptoms are difficult to target through this type of medication (Haddad & Correll, 2018). Therefore, clients need to undergo different interventions like social care, psychoeducational and other psychological therapies to improve their experienced symptoms (Xia et al., 2011). Biographical studies were performed on individuals' opinions and thoughts about these diverse types of care (Looi et al., 2022). Yet, there is still a gap in biographical research examining individual differences and alignments concerning the comprehensive integration of diverse care interventions, particularly focusing on how these interventions impact both psychotic symptoms. Furthermore, there is limited understanding of how patients perceive the effectiveness of these combined treatments and their influence on long-term illness progression and quality of life. Here, an investigation is needed, which focuses on individual perspectives on care and treatment to explore the multifaceted demands of their care. Furthermore, to elaborate whether care provision is tailored to the specific needs of individuals, considering their unique social context and cultural perspectives. This can be done by a comparison of the care and treatment individuals received, the current psychological symptoms they experience and the individual suggestions and recommendations they give. Therefore, the following second research question is proposed:

“How do schizophrenic individuals reflect on the care strategies they received during and after their diagnosis of schizophrenia, and how does this treatment relate to their current level of schizophrenia symptoms?”

Methods

The present research employed a mixed methods design, incorporating a qualitative approach through biographical interviews with individuals diagnosed with schizophrenia to investigate the aetiology and narratives towards care strategies. Additionally, a quantitative assessment of psychotic symptoms was conducted using the Brief Psychiatric Rating Scale (BPRS) to evaluate current symptomatology. This methodological approach was selected to integrate and compare individual perspectives.

The research was approved by the Ethics Committee of Behavioural, Management & Social Sciences at the University of Twente on the 7th of February 2024 with the request number 240095.

Setting

The research was conducted on the main campus of the Alexianer hospital in Münster, Germany. The hospital accommodates a diverse array of individuals with schizophrenia with different severity, duration, and complexity of symptoms. The residential facilities within the Alexianer Hospital are specifically designed to accommodate both chronic and acute psychotic clients. These facilities include a psychiatric acute care clinic as well as shared living communities located on the campus. The clients residing in these facilities are mostly chronic cases of schizophrenia and other mental disorders, supported by a multidisciplinary team of medical practitioners, social workers, psychiatric nurses and pedagogues.

Participants

In total, eight participants were recruited through contacting the nursing and medical professionals of the facility. The sample size was selected in accordance with the recommendations of Pietkiewicz and Smith (2014), who suggest a smaller sample size in qualitative research, arguing that the focus on a smaller number of participants allows for a more in-depth and comprehensive understanding of the data, as opposed to a broader but more superficial analysis that might result from a larger sample.

The researcher was in direct contact with the hospital professionals to assess which clients showed interest in taking part in the research. The inclusion criteria were: Being diagnosed with schizophrenia or schizoaffective disorder, being between 18 and 75 years old, being able to communicate clearly, showing interest to talk about their biography in the past, possessing the cognitive abilities to understand the procedure of the interview and not having experienced traumatic situations recently. People who did not meet these criteria were excluded by the researcher in accordance with the nursing and medical professionals. Notably, the majority of residents residing in the facilities exhibit various levels of comorbidity. Clients with comorbidity were included, because it is common for schizophrenic individuals to have additional diagnoses (Jeste et al., 1996). Including these cases is essential for comprehending the complexities of their individual situations.

Qualitative and Quantitative Measures

Qualitative Measures

Semi-structured interviews were conducted as qualitative measures. This type of interview style was chosen, since it provides both standardisation of questions and the

possibility for the researcher to address significant statements the interviewee provides directly (Adeoye-Olatunde & Olenik, 2021). The biographical interview consisted of 37 questions and 17 prompts. The complete interview scheme can be found in appendix A and the themes are provided in Table 1.

Table 1

Interview categories and main themes.

| Category | Main themes of questions | Number of questions (prompts) |
|--|---|--------------------------------------|
| General information | Gender, birthplace, birthday, marriage status, siblings, education, work experience, time living in hospital setting | 8 (5) |
| Childhood and adolescence | General living environment, relationship with and between family, childhood friendships, financial situation, home as a stressful environment, negative and stressful memories, child neglect | 13 (7) |
| General schizophrenia factors | Relatives with psychological problems, grew up in city or countryside, normal child development, drug consumption, parental drug abuse and birth complications | 6 (4) |
| First signs of disorder | First appearance of symptoms, life changes because of the disorder, social reactions to symptoms | 3 (0) |
| Disorder onset and social reactions | Age of disorder onset, first care and treatment received, feelings during that time, reflection on that time | 4 (3) |
| Care and treatment outcome | What kind of treatment and care afterwards, outcome of strategies, recommendations for future care | 4 (1) |
| Relapse | Additional psychotic episodes | 1 (1) |

Notes: The first column of table 1 consists of the seven categories used to structure the interview. The second column shows the main themes of the 37 questions asked. The third column gives the total number of questions and prompts in brackets.

The questions were created by the researcher and were based on previous research. The 13 questions on upbringing and adolescence were primarily taken from the Life Events Checklist for DSM-5 (LEC-5) (Weathers et al., 2013), but solely the questions focusing on childhood were included, as they targeted stressful events and environments during childhood. Additionally, the factors of genetics (question 1-2), living environment (question 3), cognitive development (question 4), drug influence (question 5), and complications during birth (question 6) were informed by Janoutová et al. (2016) analysis of schizophrenia risk factors and predictors. Moreover, the participants were asked three questions about the first appearance of the disorder, in order to investigate their first experiences and additionally social stigmata. This was done following the research of Hoftman (2016), who noted that stigmata can lead to a worsened illness progression in schizophrenia.

In addition to the interview, the client files from the hospital database were analysed and information about current medication and diagnosis was obtained. Furthermore, past biographical data written by the hospital professionals was employed to explore additional information about the illness onset, symptoms during that time and further substantial biographical details such as education, upbringing and family structure. This compensates for missing data the participants did not memorise and to verify certain information given by them. All participants showed different symptoms of delusions, hallucinations and disorganized thinking patterns. Therefore, this additional data collection was necessary since the potential risk was present that biographical information from the interviews could be a result of delusional thoughts and memories of the participants.

Quantitative Measures

The Brief Psychiatric Rating Scale (BPRS) is both an individual self-report and an observation tool, which evaluates psychotic symptoms. The rating scale assesses 18 categories of psychotic symptoms, of which nine categories are self-reported and nine are observed by the interviewer (Hahlweg et al., 1995). The questions are solely focusing on the participants experience over the last two weeks. Each self-report category comprises 1-5 items, with guidelines established for interviewers to determine the optimal number of items required per category to comprehensively assess the participant's situation (Ventura et al., 1993). For example, if the participant states that they experience no feelings of sadness, the depression category is not investigated further. The observation categories are scored by the interviewer after the interview. Each category has a seven-point Likert scale ranging from 1 (non-existent)

to 7 (extreme severe) for each of the 18 categories. The total score was calculated by adding up the scores of the 18 categories. The BPRS ranges in total scores from 18 to 126, whereas higher scores indicate stronger psychotic symptoms. Following the research of Leucht et al. (2005) a total score of 31 is considered mildly ill, a total score ranging from 32 to 41 is considered moderately ill and a total score ranging from 42 to a score of 53 indicates a markedly ill client.

This quantitative measure was chosen in agreement with the medical professionals, as it can be performed in a short amount of time, but still has a good validity and reliability (Hofmann et al., 2022). This was important to not overwhelm the participants after an extensive biographical interview. The BPRS is one of the most frequently used rating scales for assessing psychotic symptoms and can be administered in only a few minutes (Maust et al., 2012).

Procedure and Data Collection

Data collection occurred between March 25 and April 17, 2024. Interviews were conducted in a private 20 square meter room on the Alexianer hospital campus, which was only equipped with a table and three chairs. The researcher, the participant and the individual appointed caregiver, who is responsible for the wellbeing of the participant were present at all times. The caregiver was part of the interview to ensure a trustful and secure environment for the participant but was not allowed to ask any questions or interact in the interview situation, to make sure that the interview structure was followed. The researcher was equipped with a laptop containing the interview questions, the data protection declaration for the participant and a microphone to record the interview. The participants were fully informed about the aims and goals of the research.

The participants were informed about the interview structure, and the instructions were given to respond as detailed as the participants desired. Participants were informed that they had the possibility to withdraw from the interview at their discretion. Participants were assured of confidentiality, and informed consent was obtained before the interviews. The data protection declaration (see appendix B) was provided and filled out by the participant. It entailed that the researcher is allowed to record the interviews audio, to cite them anonymously, to obtain additional information from the hospital database and to use this data anonymously for the research. The participants were informed about potential risks, specifically that they could be remembered of past traumatic events. The data protection declaration was signed both by the participant and the researcher. Next, the interview took place and lasted between 14 and 49

minutes ($M_{time} = 31$ minutes, $SD = 5$ minutes). The individual interviews and the BPRS took place in one session, multiple sessions were not required.

After the interview, additional data of the participants was obtained from the hospital computers with support of the hospital staff. The interview and BPRS audio data was transcribed with the help of the Amberscript software. The transcripts and audio files were stored in a secure Microsoft Team's environment for which only the researcher and the first supervisor of this thesis had access to.

Data Analysis

Quantitative Data Analysis

The quantitative dataset was based solely on scores derived from the Brief Psychiatric Rating Scale (BPRS). Individual total scores for each participant were calculated.

Qualitative Data Analysis

The analysis of the qualitative data entailed multiple stages. After the data was transcribed, it was analysed using the software, Atlas.ti 24. This software offers the ability to analyse data using a specific analysis named applied thematic analysis. Guest et al. (2012) characterized this qualitative data analysis as involving continual reinterpretation of data using codes, which subsequently emerge as overarching themes through iterative comparison. In order to apply this method, the data must be read multiple times, and every aspect of the research question needs to be labelled with a specific code. This process leads to the creation of a coding scheme, which is evaluated constantly by screening the data multiple times and looking for patterns. The coding scheme was developed post hoc to mitigate the potential for various biases, such as confirmation bias, wherein researchers may primarily seek patterns in alignment with their predetermined expectations. The coding scheme was developed solely by the researcher.

Once the data was coded completely, the exploration for overarching themes began. For the first research question, investigating the aetiology of schizophrenia, the three overarching factors for schizophrenia aetiology (psychological, sociocultural and biological) were used as overarching themes as all aetiology codes showed consistent levels of overlap with them and the research question entailed a comparison of these factors with the interview data. Regarding the second research question, investigating personal perspectives on treatment and care, themes and patterns were investigated that concerned helpful and non-helpful factors experienced during care and treatment.

Results

Sample Characteristics

In total, eight individuals were recruited, all of whom are currently residing in the Alexianer hospital in Münster. The sample consisted of four males and four females that are aged between 29 and 69 years ($M_{age} = 53.12$ years, $SD = 12.56$). The participants age during illness onset ranged between 20 and 28 years of age ($M_{time} = 23$ years, $SD = 2.24$). Furthermore, all the participants participated in the German school system of which three visited the Hauptschule, three the Realschule, two completed the German Abitur, and two completed an apprenticeship. Notably, two of the participants did not agree for the interview audio to be recorded. Therefore, these interviews only exist in the form of a memory protocol written by the interviewer during and after the interview. Additionally, participant three provided incorrect information about his highest education. This was corrected when visiting the hospital data. Nonetheless, the participant was included in the study, because the rest of the demographical data showed no additional false information when being compared to the hospital data.

Table 2

General information for the participants who took part in the research.

| Partici- pant | Gender | Age | Age of Illness Onset | Diagnoses (ICD-10) | Highest Education | Migration History |
|--------------------------|---------------|------------|-------------------------------------|-------------------------------|------------------------------|------------------------------|
| P1 | Male | 29 | 23 | F20.0, F10.1, F12.2, F19.2 | Realschule | None |
| P2 | Male | 65 | 24 | F20.0, F17.1 | Abitur | None |
| P3 | Male | 53 | 20 | F20.0, F25.0, F15.1, F17.1 | Realschule | None |
| P4 | Male | 69 | 21 | F20.0, R63.0 | Apprenticeship | Polish |
| P5 | Female | 59 | 22 | F25.0, F06, F17.1, F51.2 | Hauptschule | None |
| P6 | Female | 46 | 23 | F20.1, F17.1, F11.2 | Realschule | None |
| P7 | Female | 62 | 28 | F20.0 | Abitur | None |
| P8 | Female | 42 | 23 | F20.0, K50.1 | Apprenticeship | Turkish |

Research Question 1: Differences and Overlaps of Schizophrenia Aetiology Theories and Personal Biographical Perspectives

The thematic analysis of the eight interviews led to several different codes, which are described in **Table 3**.

Table 3

Overall codes for all participants

| Aetiology Model | Code (Number of appearance) | Code description |
|------------------------|---------------------------------------|--|
| Psychological | Childhood stress (20) | Stressful events or patterns |
| | Childhood loneliness (6) | patterns or instances indicating a propensity for solitary behaviours or social withdrawal |
| | Domestic violence (1) | Experiencing violence at home |
| Sociocultural | Inner City (4) | Living in a densely populated urban area |
| | Financial problems (2) | Experiencing financial problems at home |
| | School problems (2) | Experiencing problems during education |
| | Migration (2) | Indicating a history of migrating in the individuals family |
| Biological | Taking drugs before illness onset (6) | Individuals engaged in substance use prior to the onset of symptoms |
| | Drugs during pregnancy (1) | Indication of drug use of the individual's mother during pregnancy |
| | Biological relative (5) | Being genetically related to individuals with schizophrenia |
| | Organic cause (1) | Indicating an organic cause for psychological problems |

Overall, 27 codes were found which support the psychological factor. 10 codes promoted the sociocultural factor, and 13 codes supported the biological factor. There were no

aetiology codes identified that were completely independent of the three factors. All showed at least some overlap with sociocultural, psychological or biological factors. Moreover, five participants demonstrated a clear pathway regarding the origin of their schizophrenia symptoms. These participants provided a combination of codes belonging to all three overarching themes. Especially, biological codes in combination with at least one psychological or sociocultural code were conclusive indicators of a distinct schizophrenia aetiology. Three additional participants did not show codes for a completely distinct history of origin.

Table 4

Individual Codes for the different participants

| Aetiology Model | Code (Number of appearance) | Code example |
|------------------------|---------------------------------------|---|
| Participant 1 | | |
| Psychological | Childhood stress (7) | “That’s why there was a lot of arguing in my parents’ marriage. At some point, my mum could not even stand it and looked for someone else and then moved out.” |
| Sociocultural | Inner City (1) | “I grew up here in the city” |
| | School problems (2) | “I tried to do my A-levels, but I had problems with marijuana and so I didn’t study, I just went out with friends, [...] I dropped out after year 11” |
| Biological | Taking drugs before illness onset (4) | “I started using marijuana when I was 16, around the time I finished secondary school. [...] I actually smoked weed almost every day from the age of 16 until I collapsed. [...] From the age of 24, [...] I also regularly took amphetamines.” |
| | Drugs during pregnancy (1) | “She smoked a lot [...] until she noticed that she is pregnant [...] which she noticed quite late [...] even then she did not fully stop to smoke.” |
| Participant 2 | | |

| | | |
|----------------------|--------------------------|--|
| Psychological | Childhood stress (3) | “I was always stressed and had few social contacts” |
| | Childhood loneliness (3) | “I only played alone, was bullied a lot and my brother never helped me” |
| | Domestic violence (1) | “He was in the war himself, on the Eastern Front, and he beat us children a lot. Most of the time my brother messed up badly and [my father] beat me for it, even if it was not my fault, it was very unfair.” |
| Sociocultural | Financial problems (1) | “We had little money overall, that was actually always a problem” |
| Biological | Biological relative (2) | “But she was severely mentally ill [Schizophrenic] and was not good at bringing up children” |
| Participant 3 | | |
| Psychological | Childhood loneliness (1) | “No, [I did not have a lot of friends], they all bullied me” |
| Participant 4 | | |
| Psychological | Childhood stress (3) | “They drove my brother to death with a care [when I was a child]” |
| Sociocultural | Migration (1) | “[We migrated from] Upper Silesia” |
| Participant 5 | | |
| Biological | Organic (1) | “Yes, that is where I had the encephalitis. [Then the symptoms started].” |
| Participant 6 | | |
| Psychological | Childhood stress (5) | “My father was always drunk.” “My mother was taken away by the East German authorities.” |
| | Childhood loneliness (1) | “I was always bullied at school. The other kids were cruel to me.” |

| | | |
|----------------------|---------------------------------------|--|
| Sociocultural | Financial problems (1) | “We had little money overall, that was actually always a problem” |
| | Inner city (1) | “I grew up in the city centre of [...]” |
| Participant 7 | | |
| Psychological | School problems (1) | “I passed my A-levels. But only barely” |
| Sociocultural | Inner city (1) | “I grew up near the city centre.” |
| Biological | Taking drugs before illness onset (2) | “I started smoking cigarettes with 15 years [...] I smoked approximately 1 ½ packs per day.” |
| | Biological relative (1) | “My cousin [...] also gets antipsychotics and antidepressants.” |
| Participant 8 | | |
| Psychological | Childhood stress (2) | “I wasn't treated well at home, which is why I later left and went into a home” |
| | Childhood loneliness (1) | “I did not have many friends. Mostly I was alone.” |
| Sociocultural | Inner city (1) | “I am from the central part of the city.” |
| | Migration (1) | “Both my parents are from Turkey.” |
| Biological | Biological relative (2) | “My cousin [...] also takes antipsychotics and antidepressants.” |

The thematic analysis demonstrated a clear interplay between biological, sociocultural and psychological factors for five different participants. For participant two, seven and eight the origin of schizophrenia symptoms appears to be connected to biological factors and their interplay with patterns or instances of stress in their life, specifically during childhood and adolescence (see Table 4). P2 summarised the negative consequences his mother’s psychotic episode had on his mental wellbeing in the following manner:

I first lived with my mum, but she was seriously mentally ill and was not good at bringing up children. After that, I went to live with my father. My parents separated early on when I was still very young. My mum was in a lot of clinics back then, she had psychoses like me and therefore could not raise us.

Additionally, P8 stressed how the schizophrenia symptoms of both her parents impacted her life:

My parents were both mentally ill [...]. [As a child] I wasn't treated well at home, which is why I later left and went to a children's home.

The onset of schizophrenia symptoms in P1 appears to be associated with persistent substance abuse, specifically marijuana and amphetamines, during adolescence. This is further intensified by a history of dysfunctional family dynamics (see Table 4).

I started using marijuana when I was 16, around the time I finished secondary school. [...]. I had a psychological addiction to it because I just could not really relax. [...] From the age of 24, [...] I also regularly took amphetamines. I had very little, even small, self-esteem, and this stuff triggers a lot of happiness hormones here, [...] Um, and then I became addicted very quickly and took it regularly until my breakdown, even beyond that.

There was a lot of arguing in my parents' marriage. At some point, my mum couldn't even stand it and looked for someone else and then moved out.

P5's history of schizophrenia symptoms starts with the occurrence of encephalitis which can be referred to as a distinct aetiology factor.

Yes, that is when I had the encephalitis. [Then the symptoms started].

However, three participants showed no distinct explanation for their schizophrenia symptoms. More precisely, participants three, four and six exhibited no codes for the biological model in their interviews, although participants four and six did show sociocultural and psychological codes with regard to various reoccurring patterns and instances of stress during their childhood and adolescence. P4, especially, remembers two distinct stressful life events during childhood late adolescence:

My brother was killed in a car accident when I was a child. I was only a child and it made me very sad.

My symptoms started when I was at the military for one year. Because I was afraid of the explosions and the shooting. Then I started hearing voices that I should kill people.

P6 mentioned dysfunctional family experiences during her childhood:

[As a child living at my father's] everything was dirty. And when I wanted something sweet, there was nothing. I ate sugar. Or I would get up at night to have a drink. There was only beer in the house. Or I only came to my father because he told on my mother to the Stasi. That was in the DDR. It is really absurd that the child does not come to his mum.

Moreover, P3 showed only one aetiology code, namely experiencing loneliness during childhood, but otherwise mentioned having a happy childhood with lots of friends and a stable family structure which shows no signs of genetic predisposition:

Interviewer: Do you have any relatives with a history of psychological problems?

Interviewee: No, they are all healthy, my siblings, my family, they are all healthy.

Interviewer: Did you take any drugs before you first experienced symptoms?

Interviewee: No, only after when I was older, I took drugs, but not before my first symptoms. My first drugs were my medication.

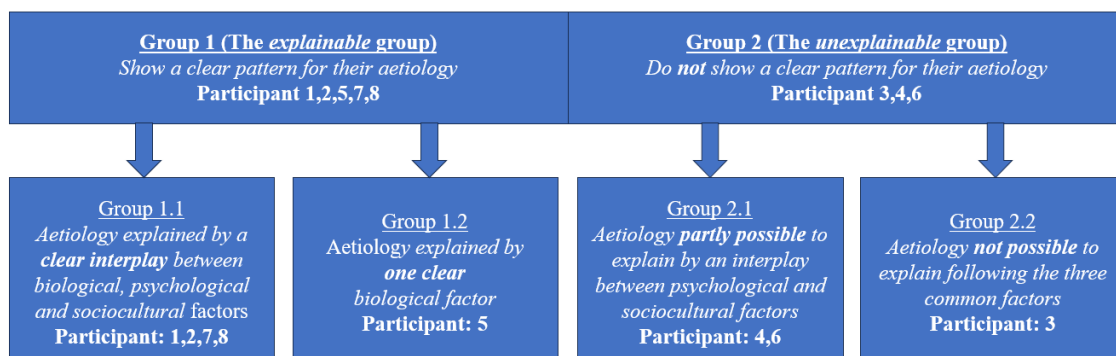
P3 mentioned a story that might be perceived as unconventional, describing his onset of symptoms in connection with a conversation with a Buddhist monk. The following is taken from a biographical quote found in the participant's hospital data:

When I was at the upper secondary school, I felt an emptiness in my head and started engaging in Zen Buddhism. That is when it started. That thoughts are placed in my head, and I was able to control others.

Interpretation of the Results RQ1

Figure 2

Identified groups and subgroups following the results section.



Two distinct groups emerge out of the qualitative sample. The first group's aetiology can be identified from the interplay of biological, psychological and sociocultural factors, or solely from one biological factor (see participant five's encephalitis). However, there is a second group (participant three, four, and six) that does not show a clear origin story in accordance with the common aetiology factors. This group can be split into two subgroups. The first one consists of participants four and six, who show a stable history of highly stressful psychological and sociocultural patterns and instances during childhood and adolescence. Despite that, participant three independently forms a second subgroup that does not show relevant codes of any of the three aetiology factors. In this case, while common factors are considered, they do not fully explain the entire aetiology of the disorder. Importantly, the understanding relies exclusively on participants' self-reported information and hospital data.

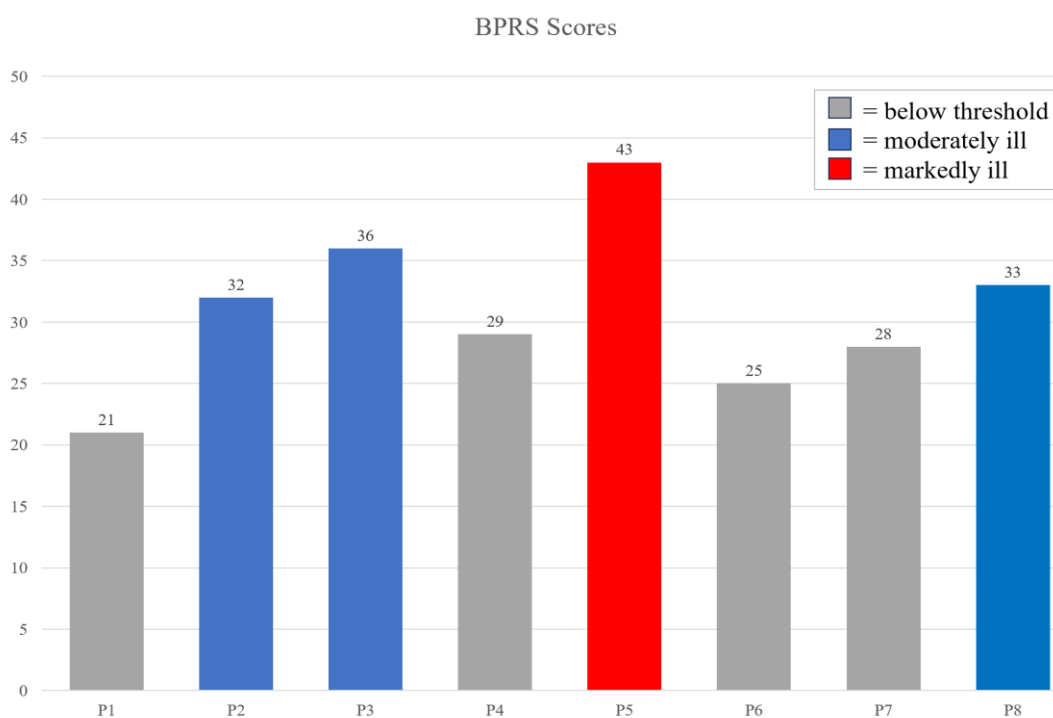
Research Question 2: Reflection of Received Treatment and Connections to Current Levels of Symptoms

Quantitative Results RQ2

The quantitative outcomes encompass the results derived from the Brief Psychiatric Rating Scale (BPRS).

Figure 3

Outcomes of the BPRS for each participant



Overall, four participants scored below the cut of score of 31 and therefore show no significant signs of schizophrenia symptoms following the recommendations of Leucht et al. (2005), although it is worth noticing that nearly all participants experienced some levels of delusions, hallucinations and negative symptoms. Furthermore, three participants scored above the cut-off score of 31 and below the score 41 and are therefore categorised moderately ill. Additionally, one participant scored above 42 and is therefore considered markedly ill.

Qualitative Results RQ2

Table 5

Showing the qualitative results including the overarching themes, codes and if they were perceived helpful or not

| Overarching themes | Total codes (Helpful) | Specific Codes | Participants who showed these codes | Helpful | Not helpful |
|--|------------------------------|--|--|----------------|--------------------|
| Non-pharmacological interventions | 22 (17) | Occupational Therapy | P1, P5, P6, P7, P8 | 4 | 1 |
| | | Exercise therapy | P1, P5, P6, P7 | 5 | 2 |
| | | Psychoeducation | P1, P5, P6 | 3 | 1 |
| | | Talks with psychologists | P1, P3, P6, P8 | 4 | 0 |
| | | Group therapy | P1, P7 | 1 | 1 |
| Pharmacological interventions | 21 (7) | Ignoring Comorbidity | P1, P2, P8 | 0 | 3 |
| | | Medication effects and side effects | P1, P2, P3, P4, P5, P6, P7, P8 | 7 | 4 |
| | | Sole focus on positive symptoms | P1, P8 | 0 | 3 |
| | | Medication connected to schizophrenic symptoms | P3, P5 | 0 | 4 |

| | | | | | |
|--|---------|------------------------------|------------------------|---|---|
| Stationary care | 7 (5) | Including family in care | P1, P3 | 2 | 0 |
| | | Other gender as care person | P7 | 1 | 0 |
| | | Establishing a daily routine | P1, P7 | 2 | 0 |
| | | Restricted personal freedom | P3, P7 | 0 | 2 |
| Personal narratives and perceptions | 18 (12) | Distraction from symptoms | P1, P4, P5, P6, P7, P8 | 6 | 0 |
| | | Spirituality | P2, P4 | 2 | 0 |
| | | Stigmata | P1, P2, P5, P7, P8 | 0 | 5 |
| | | Taking illegal drugs | P1, P3, P4, P5, P6 | 4 | 1 |

The thematic analysis for the second research question identified four main themes, encapsulating the 16 unique codes, which collectively showed 68 occurrences. These four main themes are: *non-pharmacological interventions*, *pharmacological interventions*, *stationary care*, and *personal narratives and perceptions*. All specific codes corresponding to the four distinct themes were categorized as either *helpful* or *non-helpful*. It was common for many specific codes to be perceived as helpful by one participant and not helpful by another.

Theme 1: Non-Pharmacological Intervention

This overarching theme consists of all types of interventions that are non-pharmacological and therefore concentrate on psychological and sociocultural factors. The interventions the participants received in their history of care were: occupational therapy, exercise therapy, group therapy, psychotherapy, and specifically psychoeducation. In total, 22 codes were found. The interventions were perceived as helpful by 77.27% of the participants, whereas talks with a psychologist and psychoeducation were perceived as the most helpful (8 codes and 87.5% perceived as helpful). This was, for example, mentioned by P6:

Yes, talking to the psychologist helped a lot, [...]. I have always been able to talk to her about all sorts of things. No one has ever done that with me.

Theme 2: Pharmacological Interventions

Pharmacological interventions include all kinds of interventions that involved prescribed drugs and medication with the aim to improve the symptoms of schizophrenia. Overall, 21 codes were found in this theme. Most of the participants solely focused on the side effects and negative experiences of the medication, often not acknowledging the benefits they may receive. In total, only 33.33 % of the codes found the pharmacological interventions to be helpful, whereas four codes showed personal narratives of participants that connect certain medication to enhanced symptoms of suffering. For example, P7 talked about her experience:

[At the illness onset] I was pumped full of medication [...]. So I was really afraid that I was going to die, and at the beginning it was a very high dose for years, so it was very difficult for me, and then came a phase where it was reduced[...] the experience of the last 20 years with the low dose was just that I was much more resilient and that I can manage with little, so the dose, that's not a must, but that was also a valuable experience, that I'm stable with little.

P1 talked about an often-named side effect:

As a result [of the medication], I put on a terrible amount of weight, which led to a suppressed sense of self-worth when I got too fat. I am still struggling with that today.

Theme 3: Stationary Care

This theme contains all codes (*seven in total, 71,43% perceived as positive*) regarding the stationary care institutions the individuals live in. The five codes that were perceived as helpful contained: having a different gender than the care person of someone; involving the individual's family in care strategies; and establishing a daily routine. For example, P7 mentioned that it was important for her that someone of a different gender became her caretaker:

It was also difficult at the beginning that a man was responsible for me. [...] there are simply topics that are not suitable for a man.

The only code marked unhelpful was for a restriction of personal freedom. All of these codes show that the participants profit from a care system that listens to their preferences and personal perspectives.

Theme 4: Personal Narratives and Perspectives

The fourth overarching theme consisted of several individual narratives, strategies, and perspectives that the participants engaged in during their time of care. In total, 18 codes were found, of which 66,67% were perceived as helpful. Here, especially distracting oneself from the symptoms was coded (six times), whereas the codes for spirituality and taking illegal drugs fall in the same category. For example, as mentioned by P7:

Yes, yes, I just start to brood, and then it's better to distract myself, and I'm always so worried about everything, and then: Oh, then it's much better to do something else.

However, perceiving stigmata from the outside world in reaction to their symptoms was perceived entirely negative by several participants. For example, by P5:

I only came home a quarter of a year later. And my relatives. They tortured me... They tortured me. [...] Yes, they treated me like a brain amputee.

Discussion

The primary objective of this study was to investigate the personal perspectives of individuals with schizophrenia regarding the alignment with or divergence from established psychological, sociocultural, and biological factors. Furthermore, the study intended to explore their preferences towards various treatment and care strategies. The findings indicate that each participant presents a unique psychopathological history, with the three common factors accounting for seven out of eight participants. Additionally, the participants demonstrated distinct preferences for care and treatment strategies, alongside varying levels of psychotic symptoms.

Findings and Discussion: First Research Question

The findings of the first research question indicate a high variety in the causes of schizophrenia spectrum disorders. Every individual narrative provides a unique array of factors influencing the onset of the disorder. Numerous narratives mentioned high levels of everyday stress preceding the onset of symptoms, supporting a connection between highly stressful life events, daily patterns of high stress levels and the emergence of schizophrenia symptoms, as indicated by previous literature (Jones & Fernyhough, 2007; Myin-Germeys & Van Os, 2007). Additionally, several participants showed genetic factors, specifically having relatives with

schizophrenia, underscoring the highly heritable nature of the disorder, which is estimated to account for 80% of its aetiology (Hilker et al., 2018). Furthermore, various social and cultural factors were mentioned. Although histories of migration and ethnic minority status were less common than suggested in the literature (King et al., 2005), lower socioeconomic status was frequently noted by the participants (Mallett et al., 2002).

Overall, all participants exhibited at least one of the three common aetiology factors for schizophrenia. This finding suggests that these factors are generally adequate in explaining the aetiology of schizophrenia and should be applied in future research investigating its origins. However, some participants showed a more distinct interplay with these factors, while others showed less alignment. Consequently, it is plausible that while the three factors account for a substantial portion of the origins of schizophrenia, additional factors may be required to fully explain the remainder. This assumption is affirmed by ongoing academic debates. Furthermore, Howes and Murray (2014) propose an alternative approach to understanding schizophrenia by investigating neural network factors (neurodevelopmental and neurodegenerative), and cognitive factors. This perspective highlights the dynamic interactions within neural networks and cognitive processes that may contribute to the disorder's development. These factors partially overlap with the traditional biological, psychological, and sociocultural factors but focus on the internal and external influences on the brain that could lead to schizophrenia symptoms. This includes the role of dysfunctional thinking patterns and brain abnormalities. This raises the question of whether existing factors are incomplete in investigating the aetiology of schizophrenia and need refinement by incorporating additional components. Future research should consider clients of schizophrenia that remain unexplained by current factors and explore alternative aetiological factors. For example, cognitive and neural network factors, immune and inflammatory mechanisms and genetic components (Howes & Murray, 2014; Rees et al., 2015; Watkins & Andrews, 2016;). Moreover, combining advanced neuroimaging techniques with artificial intelligence and machine learning has shown promising opportunities in schizophrenia research. This approach has revealed new patterns of brain connectivity and abnormalities, enhancing the possibility to predict symptom progression and treatment responses in schizophrenia. (Baribeau & Anagnostou, 2013; Jimenez-Mesa et al., 2024).

A concentrated effort to identify patterns in cases not fully explained by biological, psychological, or sociocultural factors could explore discussions in other psychopathological research regarding the variability of symptoms across different disorders. For instance, Cusack et al. (2024) found that the overlap of anxiety and eating disorders with depression predicted

symptom heterogeneity, highlighting the heterogeneity, comorbidity, and variability in depression. Investigating these patterns in schizophrenia could provide valuable insights on the variety and overlap of symptoms and disorders.

Findings and Discussion: Second Research Question

The second research question identified four unique themes with nonpharmacological interventions being perceived as the most helpful and a critic of pharmacological interventions being present. Although, four clear patterns emerge, the individual preferences regarding care and treatment of schizophrenia are highly individual. Whereas some individuals identified specific therapy forms, such as occupational therapy and group sessions as particularly helpful, others did not find them effective. The variability in treatment effectiveness may be attributed to differences in the participants' symptom profiles, personal experiences, and unique psychosocial contexts. Additionally, factors such as the stage of illness, individual coping mechanisms, and the quality of the therapeutic relationship could significantly influence treatment outcomes. Overall, these findings are aligning with current academic discussions on precision medicine, which aims to include differences of individuals genetics, social environments and preferences in care (Kosorok & Laber, 2019). This research underscores the necessity of personalized treatment plans in schizophrenia care, highlighting that a one-size-fits-all approach may not be effective. Future research should further explore these individual differences to develop more tailored and effective interventions. One might argue that every individual requires a unique set of treatment and care strategies to improve. Non-pharmacological treatment strategies were generally perceived as most helpful. However, only P1 had access to all such treatments, including psychotherapy, exercise therapy, occupational therapy, and group sessions. Additionally, all participants were critical of the medication they received. This suggests a connection between high psychotic symptoms and being critical towards medication and aligns with previous research by Janssen et al. (2006) who mentioned that high psychotic symptoms frequently lead to less compliance with the prescribed medication. However, the results of this research need to be interpreted with caution due to small sample size that made statistical testing unfeasible.

Overall, participants expressed a preference for greater empowerment, independence, and increased access to non-pharmacological interventions. The predominant narrative was that, following years of insufficient symptom management through pharmacological means, participants desired alternative approaches such as psychotherapy, occupational therapy, and

group sessions. According to Fifer et al. (2022), there is a growing demand among individuals with schizophrenia to be involved in treatment discussions and engage in shared decision-making. This study's findings substantiate this trend. Participants appeared to lack future perspectives, particularly concerning improvements in well-being. This is highlighted by quantitative data indicating that, despite prolonged treatment and diligent care, half of the participants continued to exhibit significant schizophrenia symptoms that were not effectively moderated by previous therapeutic interventions. This result, combined with the personal perspectives of the participants suggest three main actions for schizophrenia treatment and care: First, maximize the availability of current non-pharmacological interventions and educate the clients about these and about pharmacological interventions. Second, educate hospital professionals (nurses, social workers, pedagogies) about current nonpharmacological interventions for clients with chronic schizophrenia. Primarily, because the participants mentioned that they helped the most and are not available for everyone. Third, include clinical psychologists in the hospital setting and treatment system. Clinical psychologists have the potential to work on individual empowerment and provide future perspectives for the participants.

Additionally, future research should offer recommendations for incorporating additional objectives into the treatment framework for schizophrenia, as not all participants were satisfied with the current interventions. For instance, a comprehensive narrative synthesis by Leamy et al. (2011) identified five key categories frequently mentioned in studies examining narrative perspectives on recovery processes in mental disorders. These categories are connectedness (to others), hope and optimism about the future, identity, meaning in life, and empowerment. The current hospital environment does not fully meet the needs in all five of these categories. For instance, psychological interventions such as psychotherapy and psychoeducation are infrequently implemented, and the current treatment system lacks clear elements that provide individuals with meaning in life, optimism about the future, and empowerment. Seminal research by Rector and Beck (2012) has shown that various psychological interventions and therapies focusing on these attributes can significantly enhance the well-being and personal recovery of clients with chronic schizophrenia. Kraiss et al. (2023) further investigated this effect, finding that a compassion-focused positive psychology intervention for people with bipolar disorders effectively improved mental well-being and personal recovery. The participants in this research could likely benefit from similar psychological interventions and psychoeducation at Alexianer Hospital.

However, including well-educated clinical psychologists in the treatment system is costly and finding suitable professionals is challenging. Therefore, a first step should be to educate current hospital professionals (social workers, nurses, pedagogues) in psychological interventions like positive psychology and cognitive behavioural therapy (Rector & Beck, 2012), focusing on the five elements identified by Leamy et al. (2011). Such interventions can be Strengths-Based Therapy (Jones-Smith, 2013), Hope Therapy (Cheavens & Whitted, 2023) and Narrative Therapy (Fernandez et al., 2023). Thus, applying education about these particular psychological interventions can be a first step at significantly improving the life of clients with chronic schizophrenia and provides the hospital professionals with more tools to support them.

Limitations

Despite the meaningful insights, three limitations of the study must be acknowledged. First, most participants exhibited psychotic symptoms, which may have influenced their interview responses. Second, participants' answers could have been affected by factors such as social desirability bias, recall bias, or cognitive distortions. Although biographical statements were compared to hospital data, some participant-provided information may have been influenced by these factors. Consequently, the accuracy and reliability of some self-reported data may be compromised, potentially impacting the study's findings and interpretations. Third, the sample size was limited by time and recruiting possibilities. A larger sample could have revealed more profound insights into the nature of schizophrenia aetiology and treatment preferences.

Future research should address these limitations by including participants living outside clinical facilities, who may exhibit fewer psychotic symptoms and a more advanced recovery. Additionally, future research should include participants that received more different psychological interventions to show more diverse personal narratives on these treatment techniques.

Implications

Revisiting the first research question shows that future research on schizophrenias aetiology should focus on individuals showing clear, only partly or no clear patterns following the three common aetiology factors (biological, psychological, sociocultural). It is recommended to extend the investigation by using advanced neuroimaging techniques combined with artificial intelligence and machine learning. In detail that means to conduct

longitudinal studies that combine narrative analysis and advanced neuroimaging. Furthermore, to ensure diverse sample populations that consist of individuals with schizophrenia that are accountable and unaccountable by one or more of the three common factors. Here, personalized approaches need to be developed to investigate overarching patterns in aetiology.

The results of the second research question suggest that maximizing the availability of current non-pharmacological interventions and educating both clients and hospital professionals about these options is essential. Additionally, integrating clinical psychologists into hospital settings could enhance individual empowerment and provide future perspectives for participants. It is recommended to integrate one or more of the following interventions: Strengths-Based Therapy (Jones-Smith, 2013), Hope Therapy (Cheavens & Whitted, 2023), and Narrative Therapy (Fernandez et al., 2023). Educating practitioners about these interventions and implementing them will help align treatment with the preferences of clients with schizophrenia.

References

- Abel, K. M., Drake, R., & Goldstein, J. M. (2010). Sex Differences in Schizophrenia. *International Review of Psychiatry*, 22(5), 417–428. <https://doi.org/10.3109/09540261.2010.515205>
- Adeoye-Olatunde, O. A., & Olenik, N. L. (2021). Research and Scholarly Methods: Semi-structured Interviews. *JACCP: Journal of the American College of Clinical Pharmacy*, 4(10), 1358–1367. <https://doi.org/10.1002/jac5.1441>
- American Psychiatric Association. (2022). *Diagnostic and Statistical Manual of Mental Disorders*. (5th ed.). <https://doi.org/10.1176/appi.books.9780890425787>
- Arantes-Gonçalves, F., Marques, J. G., & Telles-Correia, D. (2018). Bleuler's Psychopathological Perspective on Schizophrenia Delusions: Towards New Tools in Psychotherapy Treatment. *Frontiers in Psychiatry*, 9. <https://doi.org/10.3389/fpsy.2018.00306>
- Baker, S. C., Konova, A. B., Daw, N. D., & Horga, G. (2019). A Distinct Inferential Mechanism for Delusions in Schizophrenia. *Brain*, 142(6), 1797–1812. <https://doi.org/10.1093/brain/awz051>
- Baribeau, D. A., & Anagnostou, E. (2013). A Comparison of Neuroimaging Findings in Childhood Onset Schizophrenia and Autism Spectrum Disorder: A Review of the Literature. *Frontiers in Psychiatry*, 4. <https://doi.org/10.3389/fpsy.2013.00175>
- Cheavens, J. S., & Whitted, W. M. (2023). Hope Therapy. *Current Opinion in Psychology*, 49, 101509. <https://doi.org/10.1016/j.copsyc.2022.101509>
- Croft, J., Heron, J., Teufel, C., Cannon, M., Wolke, D., Thompson, A., Houtepen, L. C., & Zammit, S. (2019). Association of Trauma Type, Age of Exposure, and Frequency in Childhood and Adolescence with Psychotic Experiences in Early Adulthood. *JAMA Psychiatry*, 76(1), 79-86. <https://doi.org/10.1001/jamapsychiatry.2018.3155>

- Cusack, C. E., Ralph-Nearman, C., Christian, C., Fisher, A. J., & Levinson, C. A. (2024). Understanding Heterogeneity, Comorbidity, and Variability in Depression: Idiographic Models and Depression Outcomes. *Journal of Affective Disorders*, 356, 248–256. <https://doi.org/10.1016/j.jad.2024.04.034>
- Davis, S., Patil, J., Aziz, S., Chaudhury, S., & Saldanha, D. (2021). Suicidal Behavior in Schizophrenia: A Case Series. *Industrial Psychiatry Journal*, 30(3), 230-234. <https://doi.org/10.4103/0972-6748.328868>
- Dostoyevsky, F. (1996). *The Idiot*. Wordsworth Editions. (Original work published 1869)
- Evers, A. W., Gieler, U., Hasenbring, M. I., & Van Middendorp, H. (2014). Incorporating Biopsychosocial Characteristics into Personalized Healthcare: A Clinical Approach. *Psychotherapy and Psychosomatics*, 83(3), 148–157. <https://doi.org/10.1159/000358309>
- Fernandez, K. T. G., Martin, A. T. M. B., & Ledesma, D. a. S. (2023). The Use of Narrative Therapy on Paranoid Schizophrenia. *Psychological Studies/Psychological Studies*, 68(3), 273–280. <https://doi.org/10.1007/s12646-022-00709-z>
- Fifer, S., Keen, B., Newton, R., Puig, A., & McGeachie, M. (2022). Understanding the Treatment Preferences of People Living with Schizophrenia in Australia; A Patient Value Mapping Study. *Patient Preference and Adherence, Volume 16*, 1687–1701. <https://doi.org/10.2147/ppa.s366522>
- Gäebel, W., & Zielasek, J. (2015). Focus on Psychosis. *Dialogues in Clinical Neuroscience*, 17(1), 9–18. <https://doi.org/10.31887/dcns.2015.17.1/wgaebel>
- Georgaca, E., & Zissi, A. (2019). Socially Differentiated Life Trajectories of Individuals with Experience of Psychosis: A Biographical Study. *Mental Health & Prevention*, 14, Article 100153. <https://doi.org/10.1016/j.mhp.2019.02.001>

- George, M., Maheshwari, S., Chandran, S., Manohar, J. S., & Rao, T. S. (2018). Understanding the Schizophrenia Prodrome. *PubMed*, 59(4), 505–509. https://doi.org/10.4103/psychiatry.indianjpsychiatry_464_17
- Goldberg, E. M., & Morrison, S. L. (1963). Schizophrenia and Social Class. *The British Journal of Psychiatry*, 109(463), 785–802. <https://doi.org/10.1192/bjp.109.463.785>
- Guest, G., MacQueen, K., & Namey, E. (2012). *Applied Thematic Analysis*. <https://doi.org/10.4135/9781483384436>
- Haddad, P. M., & Correll, C. U. (2018). The Acute Efficacy of Antipsychotics in Schizophrenia: A Review of Recent Meta-Analyses. *Therapeutic Advances in Psychopharmacology*, 8(11), 303–318. <https://doi.org/10.1177/2045125318781475>
- Hahlweg, K., Dürr, H., & Müller, U. (1995). *Familienbetreuung schizophrener Patienten: Ein verhaltenstherapeutischer Ansatz zur Rückfallprophylaxe* (1st ed.). Weinheim: Beltz.
- He, H., Liu, Q., Li, N., Guo, L., Gao, F., Bai, L., Gao, F., & Lyu, J. (2020). Trends in the Incidence and DALYs of Schizophrenia at the Global, Regional and National Levels: Results from the Global Burden of Disease Study 2017. *Epidemiology and Psychiatric Sciences*, 29. <https://doi.org/10.1017/s2045796019000891>
- Hilker, R., Helenius, D., Fagerlund, B., Skytthe, A., Christensen, K., Werge, T., Nordentoft, M., & Glenthøj, B. (2018). Heritability of Schizophrenia and Schizophrenia Spectrum based on the Nationwide Danish Twin Register. *Biological Psychiatry*, 83(6), 492–498. <https://doi.org/10.1016/j.biopsych.2017.08.017>
- Hofmann, A. B., Schmid, H., Jabat, M., Brackmann, N., Noboa, V., Bobes, J., García-Portilla, M. P., Seifritz, E., Vetter, S., & Egger, S. (2022). Utility and Validity of the Brief Psychiatric Rating Scale (BPRS) as a Transdiagnostic Scale. *Psychiatry Research*, 314, Article 114659. <https://doi.org/10.1016/j.psychres.2022.114659>

- Hoftman, G. D. (2016). The Burden of Mental Illness Beyond Clinical Symptoms: Impact of Stigma on the Onset and Course of Schizophrenia Spectrum Disorders. *The American Journal of Psychiatry Residents' Journal*, 11(4), 5–7. <https://doi.org/10.1176/appi.ajp-rj.2016.110404>
- Howes, O. D., & Murray, R. M. (2014). Schizophrenia: An Integrated Sociodevelopmental-cognitive Model. *Lancet*, 383(9929), 1677–1687. [https://doi.org/10.1016/s0140-6736\(13\)62036-x](https://doi.org/10.1016/s0140-6736(13)62036-x)
- Janoutová, J., Janácková, P., Serý, O., Zeman, T., Ambroz, P., Kovalová, M., Varechová, K., Hosák, L., Jirík, V., & Janout, V. (2016). Epidemiology and Risk Factors of Schizophrenia. *Neuro Endocrinol Lett.*, 37(1), PMID: 26994378.
- Janssen, B., Gaebel, W., Haerter, M., Komaharadi, F., Lindel, B., & Weinmann, S. (2006). Evaluation of Factors Influencing Medication Compliance in Inpatient Treatment of Psychotic Disorders. *Psychopharmacology*, 187(2), 229–236. <https://doi.org/10.1007/s00213-006-0413-4>
- Jeste, D. V., Gladsjo, J. A., Lindamer, L. A., & Lacro, J. P. (1996). Medical Comorbidity in Schizophrenia. *Schizophrenia Bulletin*, 22(3), 413–430. <https://doi.org/10.1093/schbul/22.3.413>
- Jimenez-Mesa, C., Ramirez, J., Yi, Z., Yan, C., Chan, R., Murray, G. K., Gorriz, J. M., & Suckling, J. (2024). Machine Learning in Small Sample Neuroimaging Studies: Novel Measures for Schizophrenia Analysis. *Human Brain Mapping*, 45(5). <https://doi.org/10.1002/hbm.26555>
- Jones, S. T., & Fernyhough, C. (2007). A new Look at the Neural Diathesis Stress Model of Schizophrenia: the Primacy of Social-Evaluative and Uncontrollable Situations. *Schizophrenia Bulletin*, 33(5), 1171–1177. <https://doi.org/10.1093/schbul/sbl058>

- Jones-Smith, E. (2013). *Strengths-Based therapy: Connecting Theory, Practice and Skills*. SAGE Publications, Incorporated.
- Kanahara, N., Kimura, H., Oda, Y., Ito, F., & Iyo, M. (2021). Recent Discussions on Dopamine Supersensitivity Psychosis: Eight Points to Consider when Diagnosing Treatment-Resistant Schizophrenia. *Current Neuropharmacology*, *19*(12), 2214–2226. <https://doi.org/10.2174/1570159x19666210125152815>
- King, M., Nazroo, J., Weich, S., McKenzie, K., Bhui, K., Karlson, S., Stansfeld, S., Tyrer, P., Blanchard, M., Lloyd, K. E., McManus, S., Sproston, K., & Erens, B. (2005). Psychotic Symptoms in the General Population of England. *Social Psychiatry and Psychiatric Epidemiology*, *40*(5), 375–381. <https://doi.org/10.1007/s00127-005-0900-7>
- Kosorok, M. R., & Laber, E. B. (2019). Precision Medicine. *Annual Review of Statistics and Its Application*, *6*(1), 263–286. <https://doi.org/10.1146/annurev-statistics-030718-105251>
- Kraiss, J. T., Klooster, P. M. T., Chrispijn, M., Stevens, A., Doornbos, B., Kupka, R. W., & Bohlmeijer, E. T. (2023). A Multicomponent Positive Psychology Intervention for Euthymic Patients with Bipolar Disorder to Improve Mental Well-Being and Personal Recovery: A Pragmatic Randomized Controlled Trial. *Bipolar Disorders*, *25*(8), 683–695. <https://doi.org/10.1111/bdi.13313>
- Lally, J., Ajnakina, O., Stubbs, B., Cullinane, M. P., Murphy, K. C., Gaughran, F., & Murray, R. M. (2017). Remission and Recovery from First-Episode Psychosis in Adults: Systematic Review and Meta-Analysis of Long-Term Outcome Studies. *The British Journal of Psychiatry*, *211*(6), 350–358. <https://doi.org/10.1192/bjp.bp.117.201475>

- Leamy, M., Bird, V., Boutillier, C. L., Williams, J., & Slade, M. (2011). Conceptual Framework for Personal Recovery in Mental Health: Systematic Review and Narrative Synthesis. *British Journal of Psychiatry*, *199*(6), 445–452. <https://doi.org/10.1192/bjp.bp.110.083733>
- Leucht, S., Kane, J. M., Kissling, W., Hamann, J., Etschel, E., & Engel, R. R. (2005). Clinical implications of Brief Psychiatric Rating Scale scores. *British Journal of Psychiatry*, *187*(4), 366–371. <https://doi.org/10.1192/bjp.187.4.366>
- Lieberman, J. A., Perkins, D. O., Belger, A., Chakos, M., Jarskog, F., Boteva, K., & Gilmore, J. H. (2001). The Early Stages of Schizophrenia: Speculations on Pathogenesis, Pathophysiology, and Therapeutic Approaches. *Biological Psychiatry*, *50*(11), 884–897. [https://doi.org/10.1016/s0006-3223\(01\)01303-8](https://doi.org/10.1016/s0006-3223(01)01303-8)
- Looi, J. C., Bastiampillai, T., Allison, S., & Maguire, P. A. (2022). Considering Patient Narrative-Based and Medico-Scientific Epistemologies in Framing Psychiatric Care. *Australasian Psychiatry*, *31*(1), 58–60. <https://doi.org/10.1177/10398562221126427>
- Mallett, R., Leff, J., Bhugra, D., Pang, D., & Zhao, J. (2002). Social Environment, Ethnicity and Schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, *37*(7), 329–335. <https://doi.org/10.1007/s00127-002-0557-4>
- Maust, D. T., Cristancho, M. A., Gray, L. B., Rushing, S. E., Tjoa, C., & Thase, M. E. (2012). Chapter 13 - Psychiatric Rating Scales. In *Handbook of Clinical Neurology* (Vol. 106, pp. 227–237). <https://doi.org/10.1016/b978-0-444-52002-9.00013-9>
- McGrath, J. J., Saha, S., Lim, C. C. W., Aguilar-Gaxiola, S., Alonso, J., Andrade, L. H., Bromet, E. J., Bruffærts, R., Caldas-De-Almeida, J. M., Cardoso, G., De Girolamo, G., Fayyad, J., Florescu, S., Gureje, O., Haro, J. M., Kawakami, N., Koenen, K. C.,

- Kovess-Masfety, V., Lee, P., . . . Kessler, R. C. (2017). Trauma and Psychotic Experiences: Transnational Data from the World Mental Health Survey. *The British Journal of Psychiatry*, *211*(6), 373–380. <https://doi.org/10.1192/bjp.bp.117.205955>
- Myin-Germeys, I., & Van Os, J. (2007). Stress-Reactivity in Psychosis: Evidence for an Affective Pathway to Psychosis. *Clinical Psychology Review*, *27*(4), 409–424. <https://doi.org/10.1016/j.cpr.2006.09.005>
- Peritogiannis, V., Ninou, A., & Samakouri, M. (2022). Mortality in Schizophrenia-Spectrum Disorders: Recent Advances in Understanding and Management. *Healthcare*, *10*(12), 2366. <https://doi.org/10.3390/healthcare10122366>
- Pietkiewicz, I., & Smith, J. (2014). A Practical Guide to Using Interpretative Phenomenological Analysis in Qualitative Research Psychology. *CPPJ*, *20*(1). <https://doi.org/10.14691/cppj.20.1.7>
- Pruessner, M., Cullen, A. E., Aas, M., & Walker, E. F. (2017). The Neural Diathesis-Stress Model of Schizophrenia Revisited: An Update on Recent Findings Considering Illness Stage and Neurobiological and Methodological Complexities. *Neuroscience & Biobehavioral Reviews*, *73*, 191–218. <https://doi.org/10.1016/j.neubiorev.2016.12.013>
- Rector, N. A., & Beck, A. T. (2012). Cognitive Behavioral Therapy for Schizophrenia. *The Journal of Nervous and Mental Disease*, *200*(10), 832–839. <https://doi.org/10.1097/nmd.0b013e31826dd9af>
- Rees, E., O'Donovan, M. C., & Owen, M. J. (2015). Genetics of Schizophrenia. *Current Opinion in Behavioral Sciences*, *2*, 8–14. <https://doi.org/10.1016/j.cobeha.2014.07.001>
- Steinert, T., Bergbauer, G., Schmid, P., & Gebhardt, R. P. (2007). Seclusion and Restraint in Patients with Schizophrenia. *The Journal of Nervous and Mental Disease*, *195*(6), 492–496. <https://doi.org/10.1097/nmd.0b013e3180302af6>

- Ventura, J., Lukoff, D., Nuechterlein, K., Liberman, R. P., Green, M., & Shaner, A. (1993). Brief Psychiatric Rating Scale (BPRS) Expanded Version 4.0: Scales, Anchor Points and Administration Manual. *International Journal of Methods in Psychiatric Research*, *13*, 227–243.
- Watkins, C. C., & Andrews, S. R. (2016). Clinical Studies of Neuroinflammatory Mechanisms in Schizophrenia. *Schizophrenia Research*, *176*(1), 14–22.
<https://doi.org/10.1016/j.schres.2015.07.018>
- Weathers, F. W., Blake, D. D., Schurr, P. P., Kaloupek, D. G., Marx, B. P., & Keane, T. M. (2013). *The Life events Checklist for DSM-5 (LEC-5)*. Retrieved March 6, 2024, from https://www.ptsd.va.gov/professional/assessment/temasures/life_events_checklist.asp
- World Health Organization: WHO. (2022, January 10). *Schizophrenia*. Retrieved June 14, 2024, from <https://www.who.int/news-room/fact-sheets/detail/schizophrenia>
- Xia, J., Merinder, L., & Belgamwar, M. R. (2011). Psychoeducation for Schizophrenia. *The Cochrane Library*. <https://doi.org/10.1002/14651858.cd002831.pub2>
- Yang, A. C., & Tsai, S. (2017). New Targets for Schizophrenia Treatment beyond the Dopamine Hypothesis. *International Journal of Molecular Sciences*, *18*(8), 1689.
<https://doi.org/10.3390/ijms18081689>

Appendices

Appendix A: Interview schema

Growing up (Childhood/Adolescence):

With whom did you live as a child

With parents, grandparents, or something else?

Does anything in particular stand out about your childhood?

What was the relationship like with your

Father, mother, sibling(s), others?

How did your parents (or adults in your environment)

understood each other?

Were there arguments?

Problems?

Did you have good friends as a child and teenager?

How were things financially at home?

Did you have financial problems, or was money not a problem?

Was your home a stressful environment as a child and teenager?

stressful environment?

Were you supported by your parents and family when you were stressed as a child?

supported when you were stressed?

Were you ever treated particularly coldly or without compassion at home?

treated?

Were you ever neglected or left to your own devices (e.g. left alone

left alone, left without food, kept away from the house)?

Have you ever been unfairly criticised or told that you are not good enough?

not good enough

(By whom? How was it? How old were you? How often?)

Was there a particularly bad event in your childhood or youth that

event that really affected you?

Were there any particularly stressful events in your life before or

during the onset of your illness?

Illness factors

Do you have any ancestors or relatives with mental health problems?

o Do they live in an institution?

o Schizophrenia, autism or bipolar disorder (formerly called manic-depressive)?

Did you grow up in the city or in the country?

Would you say that as a child you went through the same development as other children your age?

Have you ever used drugs?

o Only tobacco?

o Alcohol, cannabis, heroin, methamphetamine etc.

Did your parents use drugs during pregnancy?

Do you remember any difficulties or problems during your birth?

First signs of the illness

When did you first realise that something had changed as a result of your illness?

How has it changed your life?

How did the people around you react to you and your condition?

Onset of the disease and reactions of the environment (factors)

When and how did the illness really break out in you?

o What symptoms, behaviours occurred?

o Was it slow or very strong at one moment?

How did your environment react?

o Stigma, medical/psychological interventions, hospitalisation?

How did you feel during this time?

How do you look back on that time today?

Treatment and results of treatment later in the course of the disease

To what extent were you treated as a result?

Psychoeducation, medication, inpatient?

Did the treatment lead to an improvement?

What would you improve or do differently in treatment today?

Relapse

Were there several such phases that you experienced?

When and how many?

Now: Performing of the Brief Psychiatric Rating Scale (BPRS) Test

Appendix B: Data protection agreement (in german)

Heute werden wir ein Interview haben, in dem es um die Lebensgeschichte und persönliche Erfahrung mit der Erkrankung Schizophrenie geht. Es wird ungefähr 30-45 Minuten dauern und die interviewte Person kann das Interview jederzeit verlassen. Die Fragen werden sich um das Leben des Interviewten drehen.

Das Forschungsprojekt wurde von der BMS-Ethikkommission geprüft und genehmigt.

Bei weiteren Fragen können Sie sich an den durchführenden Studenten wenden.

Justus Theiling: j.l.theiling@student.utwente.nl

Einverständniserklärung für des Interviews für die Bachelorarbeit „Schizophrenie durch persönliche perspektiven verstehen“

SIE WERDEN EINE KOPIE DIESER INFORMIERTEN EINWILLIGUNGSFORMULAR ERHALTEN

| <i>Bitte kreuzen Sie die entsprechenden Kästchen an</i> | Ja | Nein |
|---|--------------------------|--------------------------|
| Teilnahme an der Studie | | |
| Ich habe die Studieninformation vom [/ /] gelesen und verstanden bzw. sie wurde mir vorgelesen. Ich konnte Fragen zur Studie stellen und meine Fragen wurden zu meiner Zufriedenheit beantwortet. | <input type="checkbox"/> | <input type="checkbox"/> |
| Ich stimme freiwillig zu, an dieser Studie teilzunehmen und verstehe, dass ich die Beantwortung von Fragen verweigern und jederzeit ohne Angabe von Gründen von der Studie zurücktreten kann. | <input type="checkbox"/> | <input type="checkbox"/> |
| Risiken im Zusammenhang mit der Teilnahme an der Studie | | |
| Mir ist bekannt, dass die Teilnahme an der Studie folgende Risiken birgt: Erinnerung an ein möglicherweise traumatisches Erlebnis und Befragung zu solchen Ereignissen. | <input type="checkbox"/> | <input type="checkbox"/> |
| Verwendung der Informationen in der Studie | | |
| Ich verstehe, dass die von mir bereitgestellten Informationen für das Projekt des aktuellen Moduls für eine der Projektgruppen an der Universität Twente verwendet werden. | <input type="checkbox"/> | <input type="checkbox"/> |
| Ich stimme zu, dass meine Aussagen in Forschungsergebnissen zitiert werden dürfen. | <input type="checkbox"/> | <input type="checkbox"/> |
| Ich stimme zu, dass der Test Audio aufgezeichnet und transkribiert wird. | <input type="checkbox"/> | <input type="checkbox"/> |
| Ich stimme zu, dass Informationen aus der Datenbank der Alexianer gesichtet werden dürfen und in die Forschung eingebunden werden können. | <input type="checkbox"/> | <input type="checkbox"/> |

Unterschriften

Name des Teilnehmenden

Unterschrift

Datum

Ich habe dem potenziellen Teilnehmer das Informationsblatt genau vorgelesen und nach bestem Wissen und Gewissen sichergestellt, dass der Teilnehmer versteht, worauf er freiwillig einwilligt.

Name des Forschenden

Unterschrift

Datum**Kontaktinformationen für Fragen zu Ihren Rechten als Forschungsteilnehmer**

Wenn Sie Fragen zu Ihren Rechten als Forschungsteilnehmer haben oder Informationen erhalten, Fragen stellen oder Bedenken zu dieser Studie mit jemand anderem als dem/den Forscher(n) besprechen möchten, wenden Sie sich bitte an das Sekretariat der Ethikkommission/Bereich Geisteswissenschaften und Sozialwissenschaften der Fakultät für Verhaltens-, Management- und Sozialwissenschaften der Universität Twente von ethicscommittee-hss@utwente.nl