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‘Gypsum on water. That schizophrenia.’ schizophrenia – a meeting of stories: a qualitative study

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ABSTRACT
The purpose of the study was to enrich our understanding of how personal and master narratives ‘met’ in stories of individuals who experienced schizophrenia. Qualitative, in-depth and semi-structured interviews conducted in Poland with people diagnosed with paranoid schizophrenia were processed using the thematic analysis method. Interview analysis yielded three ways in which the master and the personal narratives of schizophrenia met: reception of master narrative content, its negotiation within personal narratives, and application, i.e. using phrases from the master narrative to fill in or supplement descriptions of own experience. We emphasize the importance of self-awareness in using master narrative in encounters with individuals diagnosed with mental illness and its associated consequences. We point out the need to support the construction of personal narratives and, as postulated by phenomenological psychiatry, we stress the need to recognize subjective stories of the experience of schizophrenia as a special mode of human existence.

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Schizophrenia; personal and master narrative; qualitative paradigm; phenomenological approach

Points of Interest

- This article looks in detail into stories created by people with a diagnosis of schizophrenia about their experiences and into the way they construct their narratives.
- Participants of this study recall in their stories statements of medical specialists and people from social environment talking about schizophrenia.
- Terms and phrases about schizophrenia cause versatile reactions among people with this diagnosis. Sometimes participants accept them, often they disagree with them, other times, however, they ascribe new meanings to them.

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- It is important to be attentive in our use of language when speaking about schizophrenia and when talking to people with this diagnosis.
- The accounts of the participants in our study are another voice in the debate on the idea of abandoning the label of 'schizophrenia'.

Introduction

The article aims to present 'the meeting' of master and personal narratives in the accounts of the experience of schizophrenia. The phenomenon of schizophrenia is invariably the subject of researchers' interest, with a plethora of publications providing a broad perspective on its contemporary understanding. Based on a review of literature on the subject, studies can be categorised into several distinct areas. The authors describe diagnostic tools (e.g. Mosiołek et al. 2018; Phang et al. 2020; Pickard 2015; Pîrlog et al. 2018; Silić, Ostojić, and Karlović 2020), causes and symptoms of schizophrenia (Balzan et al. 2014; Carr et al. 2004; Tandon, Nasrallah, and Keshavan 2009), pharmacotherapy in schizophrenia (Chan et al. 2021; Garnock-Jones 2017; Tandon, Nasrallah, and Keshavan 2009), factors influencing the recovery of patients with schizophrenia (De Jong et al. 2020; Degmeþiü 2018; Health Quality Ontario 2018; Ho, Dahle, and Noordsy 2018; Rosca et al. 2018; Sathyanarayanan, Vengadavaradan, and Bharadwaj 2019; Schweitzer, Greben, and Bargenquast 2017), their use of psychoactive substances (Lum et al. 2018; Simonienko et al. 2018), the situation of families of people with schizophrenia (Chrząstowski 2004; Lloyd et al. 2017) and the impact of the condition on the patients' lives (Chudzicka-Czupała and Biernat 2018). Most research is conducted in the quantitative paradigm, but there is also a growing number of qualitative studies (Faulkner and Bee 2017; Health Quality Ontario 2018; Knight, Wykes, and Hayward 2003; Lloyd et al. 2017; Lysaker et al. 2002; Mak, Loke, and Chiang 2019; Nieto-Rucian and Furness 2019; Pańczak and Pietkiewicz 2016; Wagstaff et al. 2018) analysing the narratives of people diagnosed with schizophrenia, exploring the meanings given to the phenomena in their world. There are also multiple autobiographical accounts describing personal experiences of schizophrenia (Lauveng 2019; Saks 2007). The focus is also on what has been termed (Dimaggio and Semerari 2004; Hermans 2003; Lysaker and Lysaker 2006) 'irregularities' in these narratives: storyline inconsistencies, loosely defined main characters and disturbances within internal dialogues. This term exposes the fact that many aspects of narratives are regulated by social norms and conventions and captures which factors determine whether a given narrative content or form is 'appropriate' or 'successful' (Ewick and Silbey 1995).

Attention is also drawn to the master narratives about mental illness (Adame and Knudson 2007; Baldwin 2005; Roberts 2000). These are culturally shared stories that create frameworks within which individuals can locate themselves and recount their experiences (Bamberg 2016; Bamberg and Andrews 2004; McLean et al. 2018). These stories are not only an amalgam of socially shared understandings; we also use them to make sense of our experience and justify our actions (Nelson and Lindemann 2001). In master narratives about mental disease, the reductionist discourse of the medical model of mental illness tends to be the dominant one. This has far-reaching implications, since people construct personal narratives about their experiences using already existing language and pre-existing master narratives (Bamberg 2016; Bruner 1991). Personal narratives are a source of knowledge about the personality of an individual in the subjective dimension: their way of naming and interpreting events and how personal understanding of the world is expressed in the actual life-story of that person (Bruner 2004; Gadamer 1998; Gergen 1994; Ricoeur 1989). Master narratives, on the other hand, do not represent each individual's life experience; there are alternative accounts of mental health and healing that challenge traditional understandings of norm and psychopathology. People may reproduce dominant master narratives, but they can also look for their own stories and create counter narratives that undermine the existing order. Thus, personal narratives may draw on a variety of alternative or counter narratives to make sense of and give voice to personal experience. An important example of a counter narrative is the one that expressed the protest of the psychiatric survivor movement against the medical descriptive model. Later, the movement went beyond counter narrative to formulate its own alternative narrative, one that is not defined by its opposition to the master narrative but instead participates in a wholly separate discourse (Adame and Knudson 2007).

The master narrative of schizophrenia in the Western culture is rife with ambiguities and competing concepts. Many concerns are expressed about the direction of modern psychiatry's development. Authors of articles published in 'Lancet Psychiatry' (Stephan et al. 2016a, 2016b) point out problems with classification and diagnosis, as well as pathogenesis and aetiology, linking them to the lack of comprehensive, consistent, and detailed systematic explanations that plagues psychiatry. A dimensional approach is proposed, which does not apply rigid diagnostic categories but assumes that certain symptoms occur on a continuum. It is also postulated to reject the construct of 'schizophrenia'. In view of the fact that traditional subtypes of schizophrenia have proved to be of little clinical or research utility, Tandon, Nasrallah, and Keshavan (2009) suggest to completely abandon the construct.

As noted by Foucault (1998), scientific discourse has established norms and precisely delineated the extent of what is considered normal and abnormal, inextricably linking power with knowledge. The latter provides, on the one hand, an objective and unquestionable (because scientific) rationale for existing social norms. On the other, it implements, through the process of socialisation, the concepts of health and social order that become the foundation of individual identity. This way non-normative behaviour, instead of constituting mere disobedience, becomes labelled as disease or at least a disorder. The pre-emptive quality of this power-knowledge apparatus consists in weaponizing knowledge as part of individual identity that determines the way individuals perceive themselves and the world. Narratives may thus contribute to hegemony, acting as a control measure which constantly reminds subjects what is expected and warns them about consequences of dissent (Ewick and Silbey 1995).

Another approach gaining in popularity, alongside reductionist biological psychiatry, is the one proposed by philosophers of psychiatry hailing from the phenomenological school (Andreasen 2007; Conneely et al. 2021; Lorem and Hem 2012). Phenomenological psychiatry, in contrast to its reductionist counterpart, sees schizophrenia as a special kind of human experience and existence: it admits the possibility of treating the patient as a whole person and creating an area of agreement not with the norm, but with alterity. In this approach, psychiatric diagnosis is a social construct. What we consider an illness, a condition that we begin to recognize as an illness, or what we cease to recognize as an illness, at some point, may be subject to social contract (Szaulińska and Szafrański 2015). In the present research, we are guided by the assumptions of the phenomenological approach and we recognize that the understanding of illness and the associated phenomena varies depending on the context and is reflected both in the narrative of a given society and in the narrative of an individual.

The dialogue of communities providing assistance is a specific dialogue of master discourses in which people with schizophrenia are immersed. We too understand this tension as a space for creative development and finding useful ways of coping with the illness. An important step supporting this process is, in our opinion, listening to the voice of people experiencing schizophrenia, who live at the intersection of the master narrative, be it medical or social, and the personal one. The universal value of the personal construction of meanings prompted us to explore this issue. As part of our research, we identify with a group of people who are often unheard of and deprived of useful forms of support. We listen to their personal narratives with the hope of discovering new perspectives where the phenomenon of schizophrenia is expressed with all the relativity and diversity of its experience.

Objective of the study

Most research on the experience of schizophrenia focuses on exploring the main themes in personal narratives. In order to capture how people diagnosed with schizophrenia, immersed in the master medical and environmental narrative about mental illness, create their own personal stories, we focus on showing how the master and personal narratives co-exist, how they intertwine.

We are giving voice to people diagnosed with schizophrenia in order to hear them construct their narratives. We want to explore how the master and personal narratives meet – which concepts are compiled in either? We raise these questions being aware that the content of narratives may be important for the daily functioning of people diagnosed with schizophrenia.

Methodology

Epistemology

The material collected in the study was analysed using the thematic analysis (TA) method proposed by Braun and Clarke (2006), both in the deductive and inductive approach. TA is used in research involving interpretative analysis to demonstrate the complexity, depth, and nuance of a person's individual perspective (Boyatzis 1998) and to search for repeating patterns both in people's lived experience and in the context to which they refer (Chambers et al. 2020; Willig 1999). The interpretivist paradigm (Creswell 2014; Hammersley 2013; Pham 2018) emphasises the importance of contextual analysis (Botham and Nicholson 2014): data is interpreted and patterns identified by drawing from a broader discourse (Gephart 1999). The analysis was conducted in two stages: deductive and inductive. The first was intended to identify and mark the contents of narratives about schizophrenia corresponding to the adopted definitions of master and personal narratives derived from literature (Adame 2006; Adame and Knudson 2007; Bamberg 2016; Bamberg and Andrews 2004; Bruner 1991). Under inductive analysis within the TA method, the extracted data was processed until final results: content was 'derived' from the material and organised into themes. The constructivist approach was also adopted: we proceeded from the assumption that the contents of the collected material revealed the way in which individuals constructed personal meanings by drawing from various discourses and their interactions (Braun and Clarke 2006; Ewick and Silbey 1995; McDowell 2021; O'Byrne and Muldoon 2019).

Sampling

In the study, we re-analysed the existing raw material of five in-depth interviews originally collected as part of the research project titled: 'How people diagnosed with schizophrenia experience the disease: content analysis' (unpublished: Walicka and Cierpka 2017). The authors recognised the need and opportunity to conduct a more indepth analysis of the material, this time focused on the specifics of narrative construction.

We used purposive sampling specifying three selection criteria of study participants: 1/formal requirement: attending the Support Centre (a facility that provides daily support in illness, care and help in developing various skills); 2/minimum illness duration: 15 years; 3/current health condition: illness in remission. These criteria helped achieve homogeneity of the sample: participants were unemployed and attended the Support Centre. In addition, the long duration of the disease meant that their experience available for analysis was rich. The manager of the Support Centre provided assistance in selecting candidates. The interviews were conducted by a volunteer at the Centre who regularly took part in daily activities and workshops and therefore was known to the respondents. Her influence on the study and collected content was – as acknowledged by other authors – unquestionable and should be examined (Willig 2008). The sense of security and trust towards a familiar interviewer may have contributed to openness and ease of participants in constructing rich, personal narratives. On the other hand, the language of the questions asked in the interviews was also an important determinant of the narratives' tone and content, and the responses may have constituted attempts to satisfy the anticipated expectations of the interviewer.

The candidates gave their consent for participation after having its purpose and procedures explained, including the need to record the interview. The interviews were conducted according to a previously prepared plan in a quiet, separate room of the Support Centre. They lasted from 20 to 60 min. Next, recordings were transcribed, preserving original statements of the respondents and additionally labelled with accompanying moods.

The interview design included questions about the 3 main areas of interest:

- How do people diagnosed with schizophrenia experience their illness?
- How do they experience the symptoms of the illness?
- What are their goals, dreams, and values?

Additional questions were prepared for each of the main questions to further probe a given topic. They were only used if not answered spontaneously in the respondent's original statement.

Participants

The material collected in the interviews was obtained from three women (age: 36, 46, 55) and two men (age: 38, 58) diagnosed with paranoid schizophrenia. All participants attended the Support Centre for people with mental disorders. All respondents had been ill for at least 15 years (range 17 to 43 years) and were hospitalised at least three times (range 3 to >50 times) in a psychiatric ward. They were people with vocational (1) and secondary (4) education, currently unemployed, on disability allowance, making the group highly homogeneous in terms of daily functioning. However, a variety of their subjective experiences, defined in the medical narrative as symptoms of schizophrenia, were noted. Three people reported positive symptoms: delusions (thought broadcasting), visual and auditory hallucinations (commenting, accusing, laughing voices). Two participants experienced impaired cognition: deficit of attention (concentration), reasoning, working memory and orientation. All reported negative symptoms of the illness: diminished emotional expression (blunted affect), avolition (abulia), asociality (extreme social withdrawal), inappropriate affect (depressive mood), anhedonia.

Data analysis

Data analysis was conducted by two of the authors (AW, JS-K) and followed the six phases of thematic analysis described by Braun and Clarke (Braun and Clarke 2006, 2013; Frith and Gleeson 2004; Frydecka et al. 2018; Nowell et al. 2017). The six phases of the analysis covered: (1) *familiarising with the data* by reading and re-reading the data and noting down initial ideas, (2) *generating initial codes* across the entire data set in systematic fashion, (3) *searching for themes* by collating codes into broad thematic groups, (4) *reviewing themes* by checking the relation to the coded extracts and the entire data set, (5) *defining and naming* main *themes* to refine specifics of each theme and generate a thematic 'map' of the analysis, (6) *producing the report* by final analysis of selected extracts and relating back of the analysis to the research question and literature (Braun and Clarke 2006).

The analysis was conducted independently for stages (1) and (2), and partially for stage (3). From stage (4) onwards, the authors conducted the analysis together. In the first stage (1), the authors read the transcripts of the interviews repeatedly and thoroughly in order to take notes. Then (2) in the whole raw material both researchers identified and marked statements matching definitions of personal and master narratives based on literature on the subject.

The parts for which no agreement was reached were negotiated with another independent researcher until coherence and saturation of the common meaning of the data extract was achieved. The aim of this procedure was to focus on the analysis of material relating solely to the subject of the study.

Following the Braun and Clarke (2006) approach, the content of respondents' statements was organised into first-order codes that were strongly related to the data corpus and – from this stage on – analysed inductively. In the third phase (3), first-order codes were independently organised into meaningful broad thematic groups corresponding to the areas in which personal and master narratives met. Then, researchers jointly marked and categorised corresponding source material into several thematic groups. By reviewing and interpreting their contents, subthemes were formulated one by one (4). Next (5), they were redefined in order to capture their specificity and the story told 'through' them. At this point, subthemes were combined into meaningful clusters that allowed for the development of the main themes; they were given labels and descriptions. In the last phase (6), expressive data extracts were selected. The final part of TA was to relate our conclusions to research aims and literature.

Final interpretations and wording were specified jointly in order to ensure internal consistency and avoid duplication. The individually conducted analyses were, in the opinion of all authors of this paper, convergent in terms of meanings and interpretations and synonymous in terms of labels and descriptions. Finally, 3 main themes and 7 subthemes were formulated and illustrated with quotations to demonstrate the reliability of the analysis.

The six phases of the analysis included the transition from identification and description of data relating to the definition of personal and master narratives (deductive approach) to an interpretative description of the main themes – areas where personal and master narratives meet (inductive approach). Afterwards, they were discussed in the context of their broader implications corresponding to the objectives of the study.

In the course of the analysis, both authors reflected on their own potential influence or personal positionality, which might have shaped the manner and direction of their interpretations. The academic and professional environments where the two authors gained knowledge and experience of working with people diagnosed with schizophrenia are dominated by scientific, psychological, and medical language. As such, while analysing the interviews, the authors were aware of their immersion in the master narratives. However, they have also attended psychotherapy schools that emphasise how the language we use shapes our reality. This experience helped them pay closer attention to the linguistic aspects of the analysed material and be attentive of their own manner of describing the results and conclusions from the study. The two authors supported each other in reflecting on their influence on the process.

The immersion in the master narrative described above also affected the interviewer and the participants themselves. On a daily basis they interact with specialists who use the language of medical description and, in the context of the interview, they answered questions formulated in the language of the master narrative. Aware of these limitations, the authors realise the possibility of collecting material with different content if the context of the study was altered, from the enrollment process to drawing conclusions. Thus the specifics of this study and the small number of participants mean that, as is typical for research of this kind, caution should be exercised when generalising and interpreting our findings.

Findings

The primary aim of the research was to show how the meeting of master and personal narratives is revealed through the story of the experience of schizophrenia, what the nature of this phenomenon is and what its characteristic features are. It has been observed that this meeting takes place in three areas: *reception, negotiation,* and *application* (main themes*)*. Moreover, within each of the three main themes, dominant subthemes that reoccur in the stories told by multiple respondents can be identified. Our findings are summarised in Table 1 below:

Table 1. Main themes and subthemes in explored narratives.

	MASTER NARRATIVE meets PERSONAL NARRATIVE		
MAIN THEMES	Reception	Negotiation	Application
SUBTHEMES	1. Medical terminology 2. Describing schizophrenia mechanisms	1. Medical terminology 2. Describing schizophrenia mechanisms 3. Specialists' recommendations and opinions 4. Social discourse on schizophrenia	1. Naming 2. Explaining the mechanisms of schizophrenia 3. Developing coping strategies

Reception

The first of the main themes – *reception*, includes responses that suggest acceptance of master narrative statements. This means that the respondents have previously encountered someone else's statement about schizophrenia and drew on it in their narratives, without changing or questioning its meaning. They accept the meaning assigned by the original sender without attempting to create their own interpretation or responding to the content of the master narrative.

Included in this type of response was the participants' repetition of other people's statements without adding their own comments, as well as quoting what someone else said and continuing the topic using that person's language. Two subthemes present in the narratives of all participants were identified within the main theme: *medical terminology* and *describing schizophrenia mechanisms.*

Medical terminology

Our analysis showed that participants were sometimes receptive to the master narrative, mentioning overheard statements containing medical terminology, e.g. terms typical of psychiatry (names of symptoms such as hallucinations, pseudo-hallucinations, thought broadcasting) and of medicine in general (health-illness, terms describing the course of illness and relating to treatment, e.g. relapses, pharmacotherapy, remission). Interestingly, while this was the case with the names of symptoms and their definitions found in psychiatry and other medical descriptions, the same was not true of diagnostic labels: these were not accepted by the respondents. The following excerpt is a good illustration of reception:

> Researcher: If you could describe these visual [hallucinations] again because they are quite rare.
>
> Participant: Well, as the doctor told me, they are pseudo-hallucinations or psychotic hallucinations that I see as images superimposed on actual images.
>
> R: Mhm, and how do you see them?
>
> P: More or less like I've just said, as images superimposed on actual images.

We note here that the respondent repeats heard phrases and treats them as commonly used, easily understood by the interlocutor and exhausting the subject matter. The participant likely considers them as adequately and sufficiently reflecting his or her experience.

Describing schizophrenia mechanisms

The second subtheme covers medical topics reported and accepted by the respondents. These are phrases and terms describing the mechanisms related to schizophrenia, such as the causes of 'falling ill', the disease process, and treatment.

> Well, as experts say, it is a certain biological and genetic predisposition. As well as certain predispositions and environmental factors. I've even read that identical twins were studied, like in the USA, and one was sick, the other was not, and they were brought up in completely different families. And that one was sick, and the other had a different upbringing and even could be a valuable person, develop somehow.

Participants choose those statements that offer explanations of causal relationships present in schizophrenia, as well as the favourable and adaptive attributions of the underlying causes of falling ill or the course of illness. This is a way to view the problem as a result of external factors and not the respondents' fault, with consequences that are limited rather than defining their entire human identity. Acceptance of such ideas may be significant in the process of respondents' recuperation.

In summary, the interviews included portions suggesting that participants internalised some content from the master narrative without developing it or commenting upon it based on their personal understanding. This usually takes the form of repeating encountered statements and thus accepting them. Those statements appear to be embraced indiscriminately. Importantly, language from the master narrative usually appeared when participants discussed theoretical issues related to health rather than their own experience, memories, self-descriptors or other more personal content. Responses of this type reveal little about individual opinions; at best they may serve as clues that suggest what a given person thinks. On the one hand, we can interpret this as approval for the statements and an attempt to adapt to a given narrative form proposed by the interlocutor. On the other, it is possible that those less personal accounts reflect the participants' cautiousness and serve a protective function.

Negotiation

The second main theme highlighted in the process of analysis was labelled *negotiation*. It covers a broad spectrum of participants' responses in which they engage in a discussion and express their attitudes towards the contents of the master narrative. Negotiation is expressed with numerous examples by all respondents, therefore four subthemes have been distinguished: *medical terminology*, *describing schizophrenia mechanisms, specialists' recommendations and opinions*, and *social discourse on schizophrenia*.

Medical terminology

This subtheme includes statements in which participants engage in a dialogue with their assigned diagnoses and with other defining terms, such as 'mentally ill'. In this context, participants often take the opportunity to recall the diagnostic process that led to them being labelled as having schizophrenia. They are fairly direct in expressing their disagreement and discontent. They object both to the diagnosis itself and the process of being diagnosed, perceived as unwanted or dishonest. The way participants grapple with such memories is well illustrated below:

> I wasn't hearing any voices before. There were also those doctors who said I was healthy, but when push came to shove, the discharge papers said paranoid schizophrenia. I do not appreciate being treated this way, all this meddling. […] I don't like when someone pulls my leg, so to say, and tells me I'm healthy and then there's a note that it's paranoid schizophrenia. Or the paranoid syndrome. That there is something, that something is wrong after all. It's like, why give me that hope in the first place?

Noteworthy the subtheme of *medical terminology* appears under *reception* as well as *negotiation*. However, while the respondents are more willing to accept the terms of symptoms in schizophrenia and more reluctant to agree with the diagnosis of the illness, in the *negotiation* dimension the proportions are reversed: the respondents negotiate the terms relating to diagnosis more often than to the symptoms. These results are therefore complementary and they suggest that accepting a diagnosis of schizophrenia is truly challenging.

Describing schizophrenia mechanisms

Noticeable in the participants' responses is their tendency to comment on the portions of the master narrative that describe the mechanisms of schizophrenia, i.e. aetiology, process, treatment. Usually, as was the case in the *medical terminology* subtheme, participants disagree with the content of the master narrative. This is especially apparent with respect to narratives about the treatment:

> Supposedly there is this progress in drug therapy and it's supposed to be so uplifting, and yet these drugs do not work for me … They tried in those hospitals, a lot of these new-generation drugs on me, but they did not work. I also once suspected that it was from these drugs of this new generation that I had these cenesthetic

> hallucinations. Now I am saying the reality is rather that it is just a reaction to medication change, that can happen to me. Although now, come to think of it, it is also … well, to change drugs, well … from these … I'm not, I'm not too keen on these new-generation drugs, yeah. Although doctors say that they are so good and so on, that they help people, that they do not have so many side effects, but, well, they have not worked for me so far. Not been effective. For the symptoms of the illness.

Pharmacotherapy is often the physicians' treatment of choice in the management of patients diagnosed with schizophrenia. It is therefore no surprise that the participants often cited specialists' opinions encouraging them to take medications: they must have heard them numerous times. However, their comments convey doubt, apprehension and disappointment with drug therapy, as well as a lack of confidence in their physicians. Notably, the expressions used by the participants suggest that they feel like objects of pharmacotherapy rather than individuals choosing that particular treatment.

The responses differ when participants engage in a discussion with the content of the master narrative about the genesis of schizophrenia. In such cases they often conduct a dialogue supplementing it with their experiences, illustrating them with personal examples. Then instead of challenging the content of the master narrative, they try to relate it to their own experience.

> In a way they made it sound like that influence, you know, that parents can try to raise, raise the child well. I was always well-fed and I have been sick since I was a child, hormonally from the age of five, so I also went to these hospitals, and maybe it was because of these hormones, the hormone imbalance. I even had one psychiatrist tell me I got ill that way.

We can speculate that the master narrative in this case is a source of information bringing relief from feeling responsible for the illness. The usefulness of master narrative to participants is demonstrated by their willingness to incorporate it in a narrative about personal experience, making the story consistent and coherent.

Specialists' recommendations and opinions

Participants respond variously to recommendations and opinions of specialists formulated in the language of the master narrative. Again, many opinions regarding pharmacological treatment are challenged, e.g.:

> Psychiatrists say these drugs are good, but you know, even sugar is bad for you, not in… No, no, it is bad for your health, I'd say, let alone a psychotropic drug that makes your muscles feel stressed. And I just feel it with some physical effort that these muscles are blocked by these drugs. And these drugs put such a burden on a person that, I don't know, you could just die sooner of another disease, well, you somehow just die sooner. These drugs are terribly toxic.

The participants repeatedly cite and disagree with the opinions of specialists which contain assurances that drugs are highly effective and that side effects are rare. Moreover, the respondents are disappointed with low efficacy and with the discomfort associated with treatment. It is therefore rather difficult to find common ground between participants and healthcare professionals.

Recommendations offered in the process of therapy and other support meetings are more favourably commented on. Participants seem to appreciate specialists' willingness to help, see positive results of recommendations and use them as a point of reference for their own thoughts.

> Yes, there are also such thoughts. But you have to wait them out and I was, I was given advice by the previous priest, therapist, and psychologist, at the same time to, firstly – occupy myself with something else, while these thoughts occur, secondly – they will pass. Just like that. They will pass, so you have to wait. […] thoughts that come with anxiety, only it is so changeable, because it can be corrected by talking, for the time that passes, when time goes by and you do something for health all the time, it will be such that you will feel better. For example, if I am trying to heal, and there are some anxiety thoughts, how I work all the time and strive for health, despite the fact that it is, I am working on it and it decreases. As I know from my example, it has decreased.

Social discourse on schizophrenia

The last subtheme, which involves the participants' negotiations with the language expressed in the master narrative, is the *social discourse on schizophrenia*. In contrast to the three subthemes discussed above, this content does not originate from specialists in the medical or scientific community, but members of the society in which the participants live on a daily basis. The overall tone of this discourse is perceived by the participants as offensive and carrying negative connotations.

> Some people have this narrow understanding – crazy lady or something … […] I know that, for example, some people may say one thing to my face, and something else behind my back, that I am crazy, or a lunatic, or some idiot. They call me many different names.

Importantly, we found no passages in the analysed corpus in which the respondents would recall the society's opinions about schizophrenia with positive or at least neutral implications. It appears that the consequence of falling ill and receiving a diagnosis of mental illness is the sense that society sees the affected individual only in demeaning terms. Considering how widespread this phenomenon is, its negative impact on perceived social support, self-image, and other factors of key importance for the individual's well-being is difficult to overstate.

To sum up the main theme *negotiation*, while engaging in a discussion with the content of the master narrative, participants typically respond with rejection, disagreement, doubt, and references to their own experience. The only exceptions are reactions to the statements of specialists from outside the medical world – psychologists, therapists, or people working at aid centres. Participants were more likely to agree with their interpretations of the phenomena related to schizophrenia (however, this is not automatic acceptance, as it was described previously for the main theme *reception*). Perhaps this is because during a conversation with a therapist or psychologist, there is room to work out a common system of meanings: a person diagnosed with schizophrenia can present their own understanding of their experience and confront it during an exchange with the interlocutor.

Application

Although in the description of the two previous main themes (*reception* and *negotiation*), reactions of disagreement to the master narrative dominate over acceptance and confirmation, it would be wrong to conclude that the master narrative is of little use for the participants. We identified multiple instances where participants rely on the master narrative to complete or supplement the description of their experiences with schizophrenia. These situations are categorised under the main theme called *application*, covering those statements in which participants' use of the master narrative does not appear directly in relation to a question or someone else's statement of a master narrative nature. Instead, it appears spontaneously and is woven into the description of individuals' personal history. We distinguished three subthemes within this main theme: *naming, explaining the mechanisms of schizophrenia,* and *describing coping strategies*.

Naming

In the spontaneous statements of the respondents, as in the previously mentioned statements of specialists, we find diagnostic labels, names of symptoms, and other terms typical for the medical community. Participants use them for various purposes, for example to emphasise the importance of the described experience or to summarise (name) it:

> Sometimes you are barely alive, sad, depressed, but people think you are happy-go-lucky. It was like that in my case. […] it was like this concealed depression.

They also use them as a kind of criteria for assessing their condition or comparing themselves to other people:

> Yes, I can see that somehow I am different among these people, I feel like I'm inferior. Because in my opinion, others behave better and have some more cognitive abilities, for example during classes and they can do more than me, intellectually, I mean.

Although participants usually use the same phrases from the master narrative about schizophrenia (e.g. relapse, auditory hallucinations, voices, visual hallucinations), we found that sometimes when they use them spontaneously in their own narratives, they give them completely different meanings. They try to construct their own system of meanings based on the vocabulary borrowed from the master narrative.

> I hear voices, auditory hallucinations. I would say that perhaps your senses are heightened and that is why you feel these things… and they have not invented anything from the point of view that, for example, something is wrong with hearing and that is why you have these auditory hallucinations, or there is something wrong with your eyesight.

> Because auditory hallucinations can also be explained as some, I don't know… sensitivity to the surroundings, or something like that, that you hear whistling, a dog barking, and you immediately imagine something and think it is addressed to you. Like, maybe the brain somehow misinterprets sounds.

> I hear voices when it's like you, for example, had everything happen to you, everyone failed you, so it is as if you are up against a wall. You are alive, but life is practically over. And then these voices come that replace your friends, husband, children, everything.

Thus, on the one hand participants use terms derived from the master narrative in accordance with their accepted meanings to organise (summarise, categorise, compare) their experience. On the other hand, they sometimes try to explain their experience by using those same master narrative terms but with their own meanings assigned to them. By doing that, they reveal parts of their personal systems of meanings and supplement their personal story.

Explaining the mechanisms of schizophrenia

Participants willingly use phrases from the master narrative to explain the genesis and course of schizophrenia in their own way, creating unique explanations, specific only for a given person. When it comes to explaining the causes of schizophrenia, the respondents often emphasise the importance of environmental factors (mainly family) for the occurrence of the illness, while diminishing the importance of biological factors, e.g.:

> The family situation definitely has a huge impact… on psychology, general psychological well-being. It is the family situation that has a significant impact here because it is known that when things go wrong in the family, you have a low sense of value compared to those around you, you think you won't be able to cope, that some things in life will overwhelm you, you won't be able to handle them, won't be able to manage, so I believe that the basic important issue in mental health is family situation […] I think that the external factors influencing the illness can have even more serious consequences than even the biological ones.

It is apparent that medical knowledge helps respondents organise their experience of the course of schizophrenia:

> This might be a side effect of drugs, but it can also be a positive symptom, and especially since, for example, when I had my antidepressant changed, when I have my dose increased, there is a greater probability that of having hallucinations, right, these positive symptoms. And I am sensitive to that.

As we can see, some of the knowledge contained in the master narrative is useful to participants, to the point that they incorporate it in their own understanding of the mechanisms operating in schizophrenia. In their attempts to explain various phenomena, respondents tended to choose messages that reinforced the view that the occurrence and progress of their illness is caused by external factors beyond their control.

Developing a coping strategy

Respondents find the language of the master narrative useful to describe various strategies for coping with difficulties related to schizophrenia. In this case, they seem to speak a language more typical of psychology than of medicine. We can assume that this is the language they encounter during therapeutic or support meetings. Sometimes the way participants say these statements suggests that they are convinced of their accuracy, e.g.:

> Psychological diagnostics enrich human consciousness. If you work on the subconscious, it helps you survive. To bring out the link that connects you with the environment.

Other times, they describe them more as a goal, a task to be completed:

> You have to be a little bit critical about these voices because they too, I think, they benefit from it.

These observations prompted us to conclude that the participants internalised some of the specialists' recommendations. Sometimes it may be practical advice regarding daily functioning, at other times they refer to internal processes: thoughts and emotions. In either case their purpose is to maintain well-being and be better equipped to cope with everyday challenges.

To sum up the description of the three main themes (*reception*, *negotiation*, and *application*) and the subthemes distinguished within each of them, it should be emphasised that in all interviews one can find content that can be classified into each theme. It seems likely that, depending on the context, participants find various ways of responding to the master narrative useful. Reception usually occurs with respect to general medical categories and reveals the least about participants' personal attitudes towards the content of the master narrative. Negotiation is a way of commenting on encountered statements and revealing one's critical attitude towards them. It is typically used with regard to personal experiences, such as the process of receiving diagnosis or treatment. Finally, application means that phrases from the master narrative are incorporated into one's own language and used as one understands them. We can therefore notice a certain gradation of ways in which participants integrate the contents of the master narrative. Sometimes they are able to hear it and repeat uncritically (*reception*), while at other times they reflect and comment upon it (*negotiation*) or they borrow phrases from the master narrative and use them as they see fit (*application*).

A meeting of master and personal narratives during the interview

A thorough analysis of the interviews allowed the researchers to note that the interviews themselves were another occasion for the meeting of the master and the personal narratives. The interviewer, using phrases typical for the medical community, creates an additional opportunity to observe in real time the responses of participants as they encounter the master narrative. At the same time, the authors are aware that the choice of words and phrases made by the interviewer might have had an influence on participants' answers. Reflections on this and other limitations of the study are described in more detail in *Data analysis*.

While categorising the interviewer's statements that featured phrases from the master narrative, we found they were all medical terms related to schizophrenia. Due to this homogeneity the focus was not on specifying themes, but on the precise analysis of the respondents' reactions to these statements. As in the case of recalling past encounters with the master narrative, in an ongoing interview, the respondents either accepted or negotiated the proposed meanings. The ability to observe responses as they occurred in a conversation enabled us to uncover a wider spectrum of cognitive, behavioural and emotional responses.

Accepting the meaning described in the language of the master narrative was identified in situations where a fragment of the researcher's statement was repeated:

> R: So due to your poorer cognitive functioning do you feel worse, depressed?
>
> P: Yes, depressed and worse to others.

Participants also matched the language of their answer to the master narrative present in the question, e.g.:

> R: What is your attitude towards your symptoms?
>
> P: Well, when I have relapses, I may be less discerning. It happens that I don't know what is real and what is a hallucination or reality.

Matching the language creates a platform for a concise and quite precise exchange of information. This presents the participant as the one who meets the researcher's anticipated expectations and constructs a narrative using only the terms recognized in the medical community. At the same time, it is apparent that participants reveal only general labels, instead of insightful, well-constructed personal examples of their rich experience.

We also observe a variety of reactions in the negotiation of meanings. Sometimes participants comment on the terms they hear, supplementing them with their opinions and memories. They accept the narrative they hear as capable of describing their own experience.

> R: How do you see your illness?
>
> P: I mean, it seems to me that mental illness is not so obvious that the way you sometimes perceive it. so. you might think … that it is not so obvious. That other people, even healthy people, can have similar experiences. And you feel sorry for yourself, that you cannot cope properly and that others are coping, I would say something like that … How I perceive the illness…

Participants express their disagreement with the overheard content in various ways. Reactions may take the form of explicit aversion to the proposed subject, e.g.:

> R: I am writing a paper about mental illness – about schizophrenia […].
>
> P: I have to say in advance that I don't feel mentally ill. I don't feel like I have schizophrenia. […] Schizophremia… It's a mystery. It's just something that is fine as long as you don't talk about it. Because when you start talking about it, there are complications.

rejecting the meaning commonly assigned to terms and using terms in a different context or changing their understanding to a personal one, e.g.:

> R: And what do you think about recovery from schizophrenia? Is it possible?
>
> P: About recovery? It is possible because I can have a healthy spirit. Say that I am healthy.

or more subtle expressions of disagreement through mispronouncing terms ('schizophremia' instead of 'schizophrenia'), avoiding responses and changing the subject.

In participants' negotiations with the master narrative, they demonstrate numerous responses: from supplementing it with their personal narratives, through altering the commonly accepted meanings, to more or less openly expressed opposition to the contents of the master narrative. In our opinion this illustrates a kind of struggle with the labels assigned to respondents by healthcare professionals. These categorisations are sometimes perceived as extraneous, unfamiliar, and incompatible with what participants believe about themselves, perhaps even threatening their identity. This is why they feel compelled to respond to medical jargon used by the experimenter by constructing their own resistant narrative. The process of expressing resistance to the master narrative observed here supplements existing literature that describes strategies of using narrative resistance (e.g. Hochman and Spector-Mersel 2020).

It is worth emphasising that reception occurs more often as an immediate response to researcher's statements during the interview than a reaction related to encounters of the master narrative from the past. This seems understandable: the time that passes since the contact with the master narrative may help to process its contents emotionally and intellectually, what enables the individual to respond with a personal, critical commentary. Otherwise, pressure to respond to the master narrative immediately after hearing it from the interviewer may limit participant's time for reflection, resulting more likely in indiscriminate response. The phenomenon may be amplified due to inequality of the two interlocutors' positions. A conversation with the centre's staff member may facilitate adaptation to his anticipated expectations.

Consistently with previous findings, during the interview the predominance of statements discussing the master narrative content rather than their uncritical acceptance can be observed. Moreover, reception occurs mainly at the beginning of the interview, later giving way to negotiation. We assume that rapport built during the interview invites more relaxed, personal, often critical opinions about the contents of the master narrative.

Another important observation is that participants differ in the proportion of exhibited reception and negotiation of statements from the master narrative. Therefore we suspect that certain individual differences may be important for preferred responses to the master narrative. However, it was not possible to draw specific conclusion in that regard from our study.

Discussion

The aim of the analysis was to find out how master and personal narratives met in the story of schizophrenia in people with this diagnosis. Our focus was on showing how these narratives intertwined and how their contents were compiled. Three areas of the meeting of personal and master narratives in the stories of research participants were distinguished. They are described by the main themes: *reception*, *negotiation*, and *application*.

First of all, the participants accept the content of the master narrative and recreate it in their own story, drawing primarily on medical terminology and professional descriptions of the mechanisms of schizophrenia. Therefore, they adopt the description contained in the common understanding of the distinction between mental health and illness, they accept the medical terms of reductionist psychiatry, and through them they understand themselves and their behaviour. Interestingly, such statements were the least frequent compared to the other two ways of organising content. The interpretive frame of the story about oneself, although it contains fixed points, is nevertheless subject to discussion.

Its first form is negotiating meanings. Participants repeatedly challenge and express their attitudes towards the content of the master narrative that they encounter. They dispute their diagnosis, express disbelief and disagree with the label they were given. They refuse to be contained within the description they are presented with – a medical formula, an interpretation of themselves. Therefore, respondents are more likely to accept medical terms describing symptoms of schizophrenia, while objecting to diagnosis-related terms. Similarly, they dispute the content of the master narrative concerning the genesis of schizophrenia, its progress, and the treatment process. They also protest against the content of the *social discourse on schizophrenia*, which is perceived as negative, difficult, and devaluing.

The voice of the participants in our study is part of the increasingly common debate in literature about the idea of discarding the name 'schizophrenia' (Gaebel and Kerst 2019; Lasalvia et al. 2015; Tandon, Nasrallah, and Keshavan 2009). The term is frequently questioned by researchers, clinicians, patients, and their families. Many specialists view it as stigmatising and harmful. According to a review of literature (Lasalvia et al. 2015), advantages of renaming 'schizophrenia' far outweigh potential costs. The benefits in communication between doctors, patients, and families are emphasised, as well as the reduction of the stigma associated with this label. So far, however, the scientific community in the West has not yet come to an agreement on an alternative. Meeting the appropriate criteria for a new name, finding agreement among all groups involved, and replacing the set term is seen as a complicated process (Gaebel and Kerst 2019). The change will also not be useful if it is not accompanied by parallel changes in legislation, services, and education of professionals and society.

As mentioned, approval for the master narrative is at best marginal. It is mainly contested and the meanings related to the diagnosis and the treatment process are subject to negotiation. It turns out, however, that the master narrative is also used as a reference point – participants of the study fill or supplement the description of their experiences of schizophrenia with the master narrative (the main theme *application*).

Narrators use diagnostic labels, names of symptoms, and other terms specific to the medical community to describe their perception of illness mechanisms and symptoms, assess their condition, compare themselves to others – to understand their experience of mental illness. The use of the medical narrative is also a strategy to obtain relief with its explanations of the genesis of schizophrenia, the origin of symptoms, and the aetiology of the mental state. The master medical narrative also seems to be useful as a common ground – with a doctor, medical staff, and paradoxically also with a researcher – in a dialogue about the experience of the disease. Additionally, the language of the master narrative turns out to be useful in describing various strategies for dealing with difficulties in experiencing schizophrenia – in these cases it is the language of psychology rather than the language of medicine. This is the second component of the master narrative – the environmental narrative. It originates mainly from people at the day-care centre, the closest social environment for the participants of the study. Supportive environmental narrative offers explanations and provides assistance by suggesting coping strategies.

Regardless of the source of the master narrative, analysis of the material shows that it is through its lens that people perceive themselves and their experience. Therefore it seems that the master narrative can be a useful framework for building a personal narrative. Following the point of view of medical professionals, narratives of people suffering from schizophrenia may indicate numerous problems in creating self-narratives – developing the main character, maintaining the coherence and polyphony of the narrative. According to researchers, self-narratives of people diagnosed with schizophrenia are often poor, constructed as a monologue with one dominant voice or as a cacophony of voices creating diverse but incoherent content (Lysaker et al. 2002; Lysaker and Lysaker 2006). Poor self-narrative coherence may be indicative of problems with the sense of self-continuity, difficulties in finding a meta-perspective from which to interpret one's own life (Holm, Thomsen, and Bliksted 2016). Building on the foundation of a master narrative may in some way help people diagnosed with schizophrenia construct their own stories and it may even help them find a meta-perspective for understanding their own experience.

On the other hand, it is worth considering the lens of definitions-attributes through which people diagnosed with schizophrenia perceive themselves. What meanings they find about schizophrenia in the structure of sense, a socially constructed semantic reality? According to this study, it is mainly the content of the narrative of reductionist psychiatry about the genesis, course, prognosis, and treatment of schizophrenia. These are negatively marked terms in the *social discourse on schizophrenia*. It is a stigma, a harmful label, and a limiting story of dysfunction. What comes to the fore is the hegemonic effect of master narrative content regulated by socially accepted conventions. Taking into account that the life of an individual, especially in its sense-creating aspect, develops under the influence of various discourses (van Dijk and Kintch 1978), the situation of people diagnosed with schizophrenia is nothing short of tragic. Participants in our study used the master narrative (automatically hegemonic) to formulate a counter narrative of protest in opposition to the medical model's description and treatment of psychopathology (Adame and Knudson 2007; Bamberg and Andrews 2004). Counter narratives are created by individuals looking to find their own voice in some relation to master narratives. This is a positional category, in tension with the dominant narratives (Bamberg and Andrews 2004). Counter narratives are in strong opposition to the master narrative:

> I don't really trust doctors. I do not believe that they are all-knowing and will diagnose a man well. On the contrary, I believe that they can even harm a sick person by diagnosing incorrectly [schizophrenia]. That's how I think that I don't trust these doctors, they can be wrong too, and they have the right to be. Anyway, to define someone in terms of health is a difficult thing. Also, I do not believe that they would be wise enough to be able to define a person well. Because for this you also need intuition, a certain sense, intuition, and not just knowledge. Some empathy is also needed, a sense of this type of subtlety. And not just relying on knowledge alone.

Using the framework of the master narrative as foundation helps people diagnosed with schizophrenia construct their own stories. The alternative narrative is not defined in opposition to the master narrative but instead participates in an entirely different discourse – it is another critical construct raised on the framework of the master narrative (Adame and Knudson 2007; McLean et al. 2018):

> I'm glad to have been able to pull through this mess. To regain my sense of self. To feel like myself. Needed, normal, well-behaved. Warm, caring. I will not let myself be overrun by that schizophrenia, it is what it is and I believe you can learn to live with it and not have your life derailed by it. And life is based on perfections. You learn, you work on yourself, I am not putting on airs, I am normal, calm, I like many things, sometimes I find everything interesting, I feel like reading, watching TV, run errands, have dinner, bathe, wash clothes. I am glad, because I went through… my mom died, I survived, and I'm doing more or less fine.

The analysis of the narrative also shows that no discourse, no dialogue is free from the negative framing. The meeting of the master and the personal narratives also takes place during the interview – the interlocutors exchange concepts, which in this case belong to medical terms and expressions related to schizophrenia. The researcher – unintentionally – also draws on master narratives, introducing specific meanings into the dialogue. As proposed by Gajda and Opoczyńska-Morasiewicz (2014), it is worth considering the consequences of this and asking after Laing (1999, p. 28): 'how to express the humanity and the actual meaning of the patient's condition by means of words that were created precisely in order to isolate them and reduce the importance of their existence to the role of a specific clinical case?' Thus, psychiatric terminology further distances the 'patient' determined by the social contract from the 'specialist', 'reifies the human being' and, as a consequence, provides 'false knowledge' about him (Laing 1995, p. 27). It is a reductionist and inadequate jargon that labels patients using 'a vocabulary of slander and insults' (Laing 1999, p. 21). This means reducing a human being to a mere collection of symptoms and mechanisms, someone who can be explained but cannot (or even should not) be understood.

What can we offer instead? Perhaps following the path of the Japanese authors (Maruta and Matsumoto 2019; Sato 2006; Takahashi et al. 2009; Umehara et al. 2011) we could suggest the transition from 'schizophrenia' to 'disturbance of the integrity of the self'? The term 'schizophrenia' is still a focus of conflict and dispute in the West, which seems unable to find a coherent solution to this issue. Perhaps, in the footsteps of Erich Fromm (2010), we should try to answer the question: what mental health really is? Perhaps it is something that only a handful of people actually achieve? Another promising solution would be to follow phenomenological psychiatry and see the human being in his or her experience of schizophrenia, that exceptional way of being human (Frankl 1975), with the unique, personal configuration of experienced symptoms. In recent years, phenomenological psychiatry has advanced the self-disorder model of schizophrenia, referred to in literature as 'ipseity disturbance' (Pérez-Álvarez et al. 2011; Sass 1992; Sass and Parnas 2003, 2007). Ipseity disturbance involves two complementary processes: it affects the basic sense of self as subject of experience (diminished sense of Self) and comprises intensified self-awareness of aspects of implicit, pre-reflective Self (hyper-reflexivity). Researchers have suggested that these dispositions make at least some individuals diagnosed with schizophrenia natural phenomenologists (Sass 2001). This is particularly relevant in the context of promoting psychotherapy models that draw on the phenomenological approach and support self-integration in people diagnosed with schizophrenia (Pérez-Álvarez et al. 2011).

It seems that helping people diagnosed with schizophrenia construct their personal narratives could be beneficial. In this context, we need to consider what determines the content of personal narratives and how we could reinforce the narratives of individuals experiencing schizophrenia. Literature mentions four possible ways by maintaining narrative continuity, maintaining narrative agency, countering master narratives and by paying attention to little (personal) stories (Baldwin 2005).

Another developing trend of therapy for people with a diagnosis of schizophrenia are dialogical methods. The Open Dialogue approach is one of them (Seikkula et al. 2006; Seikkula 2011; Trojańska 2018). It is based on inviting a person with a mental crisis experience and their relatives to create conversatory community of unique voices and mobilise their natural resources of coping. 'The healing element of any practice is simply to be heard, to have response, and that when the response is given and received, our therapeutic work is fulfilled' (Seikkula 2011, p. 185). Exceptional in its simplicity, this approach is proved to be effective and highly assessed by participants.

Finally, we give the voice to people diagnosed with schizophrenia:

> P: So I don't like talking about schizophrenia, because it's like gypsum on water. Gypsum on water. That schizophrenia.
>
> R: What does 'gypsum on water' mean?
>
> P: It's something people have no use for.

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