ResearchOnline@JCU



This file is part of the following work:

Murray, Malcolm D. (2023) Understanding how adults with lived experience of Schizophrenia interpret recovery processes: a qualitative study with thematic synthesis. Masters (Research) Thesis, James Cook University.

Access to this file is available from: https://doi.org/10.25903/xhrd%2Dfg93

Copyright © 2023 Malcolm D. Murray

The author has certified to JCU that they have made a reasonable effort to gain permission and acknowledge the owners of any third party copyright material included in this document. If you believe that this is not the case, please email researchonline@jcu.edu.au

Understanding How Adults with Lived Experience of Schizophrenia Interpret Recovery Processes: A Qualitative Study with Thematic Synthesis.

Malcolm D. Murray BSocSc, GradCertSocSc. GradCertResMeth, GradDipSocSc

> Submission for the degree of Master of Philosophy



College of Arts, Society and Education (CASE) James Cook University Nguma-bada Campus Cairns "Human existence is a mystery, and the authentic person is one who reflects on that mystery and yet lives in the real world, making the most of their possibilities" (Butler-Bowden, 2015, p.126).

Acknowledgments

I acknowledge the Aboriginal and Torres Strait Islander peoples as the first inhabitants of the nation and acknowledge traditional owners of this land where I learn. I express my sincere gratitude to my supervision team Professor Tsey, Dr Menadue and Dr Roberts, without whom I would not have been able to complete this research, and without whom I would not have made it through my master's degree. They displayed the patience of a nation when giving me thoughtful comments and recommendations on this dissertation. So too Damian Palmer, Professor Alan Clough and Associate Professor Hillary Whitehouse, for their insightful suggestions and ideas at numerous stages of the research journey. I am also thankful to the James Cook University Nguma-Badu Campus library staff for all their considerate help.

Collaborative contributions: The literature review in Chapter 2 is currently under review for publication (Murray & Menadue, 2022)

Abstract

This study examines how adults with schizophrenia experience recovery. YouTube video logs (Vlogs) created by adults who identify as having schizophrenia in recovery, are employed as primary sources (PS). This is a qualitative study employing thematic analysis. The methodology is social constructivist (interpretative) with the discussion leaning towards an interpretation of philosophy. The research goal was to analyse and understand the interpretations, meanings and experiences recorded by chosen PSs about how they understood their experiences of recovery. A critical finding is the importance of "connection" with the self, meaning, suffering, medication and stigma. Connecting with these are interpreted as steps in the recovery process. This study supports the growing field of recovery literature. It will aid professionals to support recovery and respect and understand that recovery is a unique and individual experience rather than a process that can be readily achieved by medical and health service interventions alone.

Keywords: Philosophy, connection, schizophrenia, recovery process, qualitative.

Table of Contents

Acknowledgmentsii
Abstractiii
Table of Contentsiv
List of Tablesvi
List of Figuresvi
1.0 Introduction
1.1 Research Question
1.2 Aim
1.3 Objectives
1.4 Epistemological Position 4
1.5 Ontological Position
1.5.1 Rationale
1.5.2 Methodology
1.6 Thesis Structure
1.7 Main findings
1.8 Personal Reflection and Reflexivity7
2.0 Systematic Literature Review
2.1 Search Methods
2.1.1 Review Aim
2.1.2 Review Research Question
2.1.3 Study Eligibility
2.1.4 Exclusion Criteria
2.1.5 Search Criteria and Procedures14
2.1.6 Data Management and Screening
2.1.7 Data Extraction and nalysis
2.1.8 Quality Appraisal17
2.2 Search Results
2.3 Characteristics of Lived Experience of Recovery Studies
2.3.1 Study characteristics
2.3.2 Thematic Classification

2.5 Discussion	
2.6 Limitations	
2.7 Conclusion	
3. 0 Methodology, Methods and Research Rigour	
3.1 Introduction	
3.2 Research Design	
3.3 Key Epistemological Positions	
3.4 Qualitative Study	33
3.4.1 Realism and Relativism	
3.4.2 Phenomenological Method	
3.4.3 Phenomenological Strands of Inquiry	
3.4.4 Hermeneutic/Interpretative Phenomenology	
3.4.5 Ethics approval	
3.4.6 Sample	39
3.4.7 Research Rigour	
3.4.8 Transferability	
3.4.9 Credibility	
3.4.10 Dependability	
3.4.11 Confirmability	
3.4.12 Personal Reflection and Reflexivity	44
3.5 Analysis	
3.5.1 Step 1: Become Familiar with the Data	46
3.5.2 Step 2: Generate Initial Codes	
3.5.3 Step 3: Search for Themes	
3.5.4 Step 4: Review Themes	49
3.5.5 Step 5: Define Themes	50
3.5.6 Personal Reflection and Reflexivity	52
4.0 Results	55
4.1 Concepts of Recovery	56
4.1.1 Theme 1 Medication	61
4.1.2 Theme 2 Suffering	63
4.1.3 Theme 3 Stigma	66
4.1.4 Theme 4 Self	67

4.1.5 Theme 5 Meaning	. 71
4.2 Personal Reflection and Reflexivity	. 72
5.0 Discussion	. 74
5.1 Connection & Medication	. 76
5.2 Connection & Suffering	. 78
5.3 Connection & Stigma	. 79
5.4 Connection & Self	. 80
5.5 Connection & Meaning	. 82
5.6 Thoughts on Heidegger and Connection	. 83
5.7 Limitations	. 84
References	. 87

List of Tables

Table 1. Study characteristics	20
Table 2. Thematic classification of publications, number in category	22
Table 3. CASP TOOL	28

List of Figures

Figure 1. PRISMA diagram of the screening and filtering process	19
Figure 2. Example of coding of transcribed vlogs	.47
Figure 3. Codes form emerging themes	.49
Figure 4. The emerging theme of 'medication.'	50
Figure 5. Mind map of the themes and meta-theme of 'connection.'	51
Figure 6. Themes	55
Figure 7. Meta-theme of Connection	74

1.0 Introduction

Underpinning this study is my belief that schizophrenia is a human condition and is a debilitating illness of the self that is best understood as a social phenomenon. A disturbance of the basic sense of self may underlie difficulties present in schizophrenia where due to this, the disorder itself could be of the person, and not just of the brain (Sass & Parnas, 2003). Psychiatric practices have been criticised as being governed by the medical model, which is depicted as having a narrow focus on disease, treatment and biological reductionism underwritten by evidence-based medicine (Perez-Alvarez, et al., 2016). Most psychiatric clinicians ascribe to this model of mental illness. What they are in fact ascribing to is an early 1900s view of schizophrenia being a degenerative disease where the sufferer has no hope of recovery. This is the foundation on which the modern neurobiological model of schizophrenia is based. This medical model of schizophrenia and the more palatable values and their development approach to schizophrenia where recovery in schizophrenia is possible, can, but do not have to, be mutually exclusive.

This study combines them with a third dimension, that being the experience of schizophrenia in the recovery process with interpretations by myself and the primary sources of the study. According to Aho (2019), living with schizophrenia can be living in a changed experiential reality, which has significant impact for a person's understanding of him/herself and his/her world. So it is that Aho argues our existence brings itself into being by constantly interpreting itself anew considering past and future possibilities along with the possibility of a process of interpretation, depending on understanding one's existence and furthering it by reinterpretation (Aho, 2019). Consequently, we exist, in this world of recovery for example, caring for this world in particular ways by simple virtue of being a practical person with experience. For the sake of interpretation, this experience I have of being a person with

schizophrenia is of self-interpretation where my illness can be either a disturbance or malfunction of my practical realisation of life being my own, and not someone else's manifesting as a disturbance of my existentiality, and not due to a chemical imbalance in the brain. Human experience is not found inside the brain, but rather bound up in worldly existence. The meaning of experience can be grasped only by attending to existential situations such as knowing who you are. Clinical accounts of the symptomology, family history and age of onset, and genetics of schizophrenia classify schizophrenia as a medical condition, but the explanation is scientific while interpretation/understanding is philosophically existential, present in a different dimension. My interpretation of the Heideggerian notion of Dasein is that it is not to be regarded as a living organism or biochemical substance but as a situated, self-interpreting way of being. It is driven by the notion of the mind; the mental is put back into mental health of schizophrenia in recovery. Aho (2019) articulates Dasein's existence as being constituted not by "what it is" but by "how it is" (p.51). This means how it understands and interprets itself not only within but against a context of shared meanings. Therefore, ways of making sense and understanding people, things and surroundings are what constitute our ability to be, as well as to be in recovery.

What is needed for recovery is individual self and social connection. As part of this process, the person with schizophrenia needs to be treated with medications by the medical profession to enhance individual self-connections (gain insight) which implies the outcomes focus of recovery. The process perspective then allows insight to be elaborated further where the individual makes social connections with other people and the world. Importantly both perspectives are required for recovery.

The aim of this study is to understand how adults with schizophrenia experience recovery, with the expectation that this will be of value to people with an interest in mental

health. I have a personal interest in this study as I have been clinically diagnosed with schizophrenia and have been in recovery for many years. A major issue of recovery is how it is defined. Recovery can be outcomes focused (symptom remission) or process oriented (personally defined vision).

This chapter contextualises the study, reports the aim, research question and objectives, along with the terms of the topic. Then I consider the importance of the study, epistemological and ontological positions, answering the overarching question, the rationale, important concepts, methodology and main findings. Lastly, I outline the thesis structure. The contextualisation of this study is borne out by a chapter of a stand-alone systematic review of the literature relating directly to adults with schizophrenia in recovery, which is included in more detail below.

The concept of mental health recovery has been a topic of discussion for decades (Jacob, et al., 2015). One of the major areas of discussion has been how mental health recovery has been defined. Service providers prefer recovery to be outcomes focused. Consumers prefer recovery to be process oriented. This study views recovery as a multidimensional process with recovery not defined in rigid terms. In this study recovery for the PSs was personal, not clinical. The former emerged from people with lived experience of mental illness while the later emerged from the expertise of psychiatrists and other service providers (Slade, 2009).

1.1 Research Question

How do a certain group with schizophrenia experience recovery as documented in vlogs?

1.2 Aim

To understand how adults with schizophrenia experience recovery.

1.3 Objectives

- conduct a systematic literature review of how adults with schizophrenia experience recovery
- conduct a thematic analysis of publicly available video logs (Vlogs) created by adults with schizophrenia
- discuss the results of the thematic analysis in the context of the existing recovery literature.

1.4 Epistemological Position

A qualitative research approach was taken for the study. The philosophical standpoint is interpretivist. There were many truths identified and interpreted in the study that can be attributed to the lived experience of the PSs in their individual contexts.

1.5 Ontological Position

My relationship with the reality of this study revolved around my interpretations of the PSs' interpretations of their experiences and meanings regarding being in the process of recovery. This double hermeneutic helped construct the importance of what it is like for the PSs to not only live with schizophrenia but be in recovery. From an ontological point of view, recovery is in the mind of the PSs but is brought into being in the day-to-day activities in and through the world of recovery. The meta-theme of connection driven by moods is important in not only how the PSs understand how to be a human being, but also how important is connection with themselves, others and the environment in deciding the experience of recovery.

1.5.1 Rationale

This research study does not eliminate a gap in the literature relating to recovery and schizophrenia. What it does is offer a fresh perspective relating to methodology and method

of research in mental health and illness. The communication medium YouTube was used to gather primary source (PS) understandings about experiences of schizophrenia in the recovery process. Further, the hermeneutic process was used to give depth and further nuance to the PS understanding and experience of schizophrenia in recovery. Recovery is not something that the mental health system did to those with schizophrenia. Rather, it is a vision that is made up of attitudes, values, beliefs, and desires of those with personal experience of schizophrenia who through the lens of philosophy show that recovery is about the importance of who they are and not how sane or normal they are.

1.5.2 Methodology

Methodology encapsulates both the overall framework and research strategy within which the different specific methods were used along with their theoretical underpinnings. For example, the study was qualitative in terms of research method, and thematic regarding analysis, with interpretative philosophical beliefs aiming to improve our understanding of lived experience of recovery. This aided in the determination of how the PSs' moods helped form connections with and relate to other individuals, themselves and the world.

1.6 Thesis Structure

Chapter 1. Introduction

This covers the complete outline of the thesis: the research question, aim, objectives, design of the study, method, rationale, and main findings.

Chapter 2. Systematic Literature Review

The systematic literature review includes qualitative literature that related to people with schizophrenia in the recovery process.

Chapter 3. Methodology, Methods and Rigour

This chapter explores the constructionist/interpretative approach to design. As well, it explores the methods needed to explain how the sample was chosen along with ethics approval and analysis. The rigour of the study was explained to enhance trustworthiness.

Chapter 4. Results

This chapter highlights the recovery processes those with schizophrenia saw as important.

Chapter 5. Discussion and Conclusion

A philosophical approach to the discussion of the themes and the meta-theme of connection has been viewed through the lens of Heidegger. It concludes that those with schizophrenia need something to do, somewhere to go, and someone to talk to when transforming the self from being in remission (outcomes focused recovery) to being in recovery (process of existing) where what was important was knowing who they are and not how sane or normal they could be.

1.7 Main findings

The main findings of the research are that moods linger from PS to PS and recovery is a process with "connection" a major driver of that process. What is found in the study about how the PSs understand recovery is that without medication recovery does not seem possible. Therefore, the outcomes approach to recovery complements the process focus. An understanding is made by the PSs that schizophrenia is real, and both the ingestion of antipsychotic medication and personal mood allow the gaining of insight where connection with self, others, activities and the world become clear.

The PSs in this study appear to recover with little professional help. This is a significant observation because it supports what William Anthony (1993) proposed nearly 30 years ago: that professionals do not hold the key to recovery. This study contributes to the

notion that recovery is a vision. It is not something to be done to people. The study supports the findings of the systematic review and other literature that has recovery as an ongoing process of developing new meaning and purpose in life and not as an outcome due to professional help alone (Perez-Alvarez, et al., 2016; Jacob, et al., 2015; Leamy, et al., 2011; Davidson, 2020).

In this study, when I refer to "mood" it is analogous to Heidegger's *Befindlichkeit* – which does not mean mood but rather "how one finds oneself"; the way in which one is found by oneself in a specific situation at a certain moment. The usual German word for "mood" is *Stimmung* – which means "attunement", or a way of being in the world that is in tune with the world or out of tune with the world, and that this feeling of "attunement" is a vital part of how humans feel connected both to their internal and external realities. In this regard, mood is a refinement of connection – being "in tune" or "out of tune" or "how one finds oneself" at any time or in any specific situation has a significant impact on the quality and feasibility of connection.

1.8 Personal Reflection and Reflexivity

(Ideas for this extract come from Haynes, K. (2012); Finlay, L. (2008).

The reason I use reflective and reflexive practice is that they have aided how I have planned the thesis, how I monitor it, and how I evaluate not only my own practical experiences of research but the way my supervisory team has gone about helping me learn. What I engaged in during the thesis was both reflective and reflexive practice. These were manifest by way of being cited in the thesis as "My Extracts". My process of continuous learning was reflective because I thought about what I was doing, and reflected on it, sometimes negatively but positively at other times. For example, I was critical of myself when discussing the intricacies of my ethics journey. Then again, I was positive when talking about reading Heidegger's

texts. In fact, I was learning from experience as I will not make mistakes in the future like the one I made about relying on legalities instead of consent guidelines. Everyone of course thinks about what has happened, as it is part of being human. However, the difference between causal thinking and reflective practice is that the latter needs a conscious effort to think about events and develop insights into them. Reflective practice for me is a process where I stop and think about my process of doing things, try to analyse what I am thinking, and how I came to have these thoughts, and hopefully draw on an idea to relate it to what I am doing (Heidegger) or not doing (ethics) in practice.

Reflexivity, on the other hand, was more engaging for me because I needed to question myself. In my mind, selves are my attitudes and ideas. How did I come to have ideas about the study's design and method and the method for the study, for example? Being reflexive made me active in helping to shape the way the thesis evolved. For example, the process of moving from the purposive sample to the use, or disuse of the reductive aspect of interpretation that saw me connect with the PSs using the double hermeneutic and the hermeneutic circle to aid in the critical reading of the transcripts where the parts made up the whole of the thesis itself and back to parts in the results, only to have these contextualise into the discussion again. I was active in shaping the thesis as I took the preceding ideas, their circumstances and the relationship I developed with the thesis into consideration, describing the PS's interpretations as I was aware of reacting to them. Hopefully, I have attuned myself towards revising my ethical ways and my being and relating to the world of Heidegger's hermeneutic circle and hermeneutic phenomenology and schizophrenia in the recovery process.

The challenge for me lies in the fact that I learn despite kicking and screaming! Thinking about what, when, and how of the Master of Philosophy (Research) was difficult for me even at the individual level. Trying to accept the objective view to not only schizophrenia but my

ADULTS WITH LIVED EXPERIENCE OF SCHIZOPHRENIA INTERPRET RECOVERY PROCESSES

thesis in general had to be done even though it is qualitative, part phenomenological, part thematic and part philosophy. It was difficult for me to sustain the reflection/reflexive mind. Doing it and heading towards accomplishment has been fraught with many mooded interpretations of struggle. My beliefs and habits were upset but I am resilient, tenacious, and optimistic towards everything with my world of schizophrenia in recovery, and change can be a good thing. Bob Dylan once sang: "I am gonna change my way of thinking, give myself a different set of rules" and so too me. I came to university to open my mind and brain to the complexity of life and its practicalities and what I have learned in a huge way is how reflective and reflexive practices complement the social sciences. I am not just helping myself but also the furthering of knowledge that views the social sciences as complementing the bio-science approach to mental health and illness.

2.0 Systematic Literature Review

The individuals most likely to receive help from this review would be those with schizophrenia in the recovery process. Psychiatrists, general practitioners (GP) who refer those in the recovery process that are voluntary to the system, and psychiatric clinicians, would benefit as well. A GP being aware of how important the self is to schizophrenia and not just as a chemical imbalance, would be more inclined to suggest the need for psychotherapy to both the psychiatrist and the individual in personal recovery, as self is central to this type of therapy. Both the medication and philosophical therapy should be provided together as they complement each other (Galletly, et al., 2016). It was reported in the Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the management of schizophrenia and related disorders (Galletly, et al., 2016) that there is growing evidence to support the use of philosophically focused psychotherapy for schizophrenia. This form of therapy transforms self. This leads to the gaining of insight about who is the person with schizophrenia in the recovery process. Knowing who you are is important for recovery. This review contextualises the study towards the view that the self is in recovery.

Recovery as a lived experience in schizophrenia is an idiosyncratic and debated process that appears from the perspectives of people who experience schizophrenia. Recovery literature is gained from qualitative accounts and synthesising these accounts supplies an overview of the evidence base for recovery. Systematic reviews of qualitative literature are increasingly important to contribute to the growing number of qualitative accounts describing recovery from schizophrenia from a lived experience perspective. The aim of this study was to conduct a review of literature which explores lived experiences of the manifestation, appearance of meaning and interpretation of the recovery process in schizophrenia. A search

of Medline, Emcare, Cinahl and Scopus databases discovered 11 studies published between 2016-2020 that met the scope of the review. Studies were included if they used qualitative methodology to explore how individuals with schizophrenia experience the process of recovery. Studies were subjected to quality assessment using the Critical Appraisal Skills Program (CASP) Qualitative Research Checklist. Several themes were identified during the qualitative analysis. On reflection it became evident that these themes were linked by a common thread. This "meta-theme" is "connection": Connection with individual sense of self and connecting with the social world. Connecting with self enhances the capacity of those with schizophrenia to be able to connect interpersonally and intersubjectively with the social world, which is seen to lead to recovery.

Protocol, Prospero registration number: CRD42020214483.

The World Health Organisation (WHO) describes schizophrenia as a serious mental disorder which affects around 26 million people worldwide (2008). It can be persistent as well as recurrent (Ko, et al., 2013). The characteristics of this illness are disturbances of perception, thought, emotion and behaviour (Ko, et al., 2013). Mental health providers are increasingly tasked with providing recovery-oriented treatment (Lee, et al., 2020). Historically, education and training of mental health providers has tended to focus more on schizophrenia being a neurobiological, permanent condition where the person with this disability has little hope of returning to full functioning (Feiner & Frese, 2009). Mental health recovery has become popular, especially focused on the process of recovery, as an alternative to historic medication-centred approaches to treating schizophrenia.

This review complements existing knowledge by reviewing approaches that indicate recovery is a holistic lived experience that cannot be meaningfully achieved by taking antipsychotic medication alone. Medication is an important contribution towards the enhancement of recovery and is one of many factors that contribute to the lived experience of

a person in recovery. Patricia Deegan, a researcher with lived experience of schizophrenia, argues that recovery depends on the person with schizophrenia being able to reclaim and recover a sense of self (Deegan, 1988). Deegan suggests the subjective aspects of schizophrenia are paramount to recovery. This can be about becoming who you are rather than trying to evaluate how sane or how normal you can be (Deegan, et al., 2008). Recovery is now understood to be both a possibility and the goal of mental health treatment (Anthony, 1993). Recovery is a dynamic evolving and unique process within the life of each person faced with schizophrenia's challenges. It is not an end point or achievement but a way of living and a constant choice that a person in pursuit of recovery makes (de Wet, et al., 2015). Being a choice highlights the entitlement of the basic human right of all individuals with or without a mental illness. The person with schizophrenia can choose to be in recovery and not remission. They are entitled to receive adequate care and the right to make individual choices. By recovering the sense of self, the person with schizophrenia can become stronger, confident, and powerful as an autonomous and self-determining human being better able to make such choices (Bejerholm & Roe, 2018).

Autonomy and self-determination enable the person with schizophrenia to take control of their life and claim the right to become who they are. This contrasts with traditional models that apply subject-independent criteria to determine whether an individual is normal or sane and for which the individual perspective is out of the scope of the model – disqualified in the case of schizophrenia by diagnostic definitions of unreliability due to psychosis. The qualitative, subjective, lived experience of recovery for people with schizophrenia highlights how disenfranchisement and disconnection, caused by being externally assessed and evaluated, compartmentalised and judged, diminish the potential for meaningful recovery. This is because it distances them from the essential human need for

connection and socially meaningful interaction that is required to be able to identify as a healthy, functioning human being.

Recovery is oriented towards the process of developing new meaning and purpose in life. The evaluation of this is troublesome if it is solely focused on external evaluations of productivity and conformity to externally defined standards created by people who do not have the experience of schizophrenia. This does not have to be employment, it can be education and/or physical activity that adds value to the unique experience of the person with schizophrenia (Anthony, 1993). As recovery is a unique and subjective process it can also be exciting because the processes are self-defined and ultimately challenge assumptions about normality (Bejerholm & Roe, 2018). This may be especially significant for those with a serious mental illness, who are not accustomed to self-identifying as "normal". The process of interacting socially for those with this illness to form, maintain or even cease relationships can help develop new meaning and purpose as the person with schizophrenia grows over and beyond the catastrophic effects of their illness. As William Anthony points out, recovery processes involve a change of attitude, values, feelings, goals, skills and/or roles (1993). This can be attitude towards the diagnosis of schizophrenia, or revaluing of the self, feeling empowered, having future goals, understanding that recovery is possible, and honing skills for sustaining internal/social connectedness and exploring/managing new-found roles and identity.

2.1 Search Methods

A review protocol exists and can be accessed from Prospero. No. CRD42020214483

2.1.1 Review Aim

The aim was to review literature where the researcher explores the manifestation and appearance of meaning and interpretation of the recovery process in schizophrenia.

2.1.2 Review Research Question

How do those individuals with schizophrenia experience the process of recovery?

2.1.3 Study Eligibility

The review considered studies that conformed to the following criteria:

a) Focused on qualitative data;

b) The primary aim was exploring recovery from the lived-experience

perspective, in other words, examining respondent subjective interpretations about recovery;

c) The respondents were diagnosed with schizophrenia;

d) Respondents were adults;

e) Studies were in the English language; and

f) Studies contained primary source information from research respondents who were making sense of their experiences in the recovery process of schizophrenia.

2.1.4 Exclusion Criteria

Studies were excluded if they were examining recovery in those with organic psychosis, postpartum psychosis or substance misuse disorders as these have different characteristics to schizophrenia. Purely quantitative studies were also excluded.

2.1.5 Search Criteria and Procedures

The search was conducted on the 28th of August 2020 by the Primary Investigator (PI) and a research librarian from James Cook University, Nguma-bada, Australia. Medline, Emcare, Cinahl and Scopus databases were used to search for studies published between 2016-2020. These search engines were chosen to ensure extraction across both medical and psychological journals. Search modes were Boolean/Phrase. Combinations of the following key words were used in the search:

Medline

"exp schizophrenia spectrum and other psychotic disorders"/ or psychotic disorders.mp., 2) (interview* or experience* or qualitative).mp.,3) recovery.mp.,
 1 and 2 and 3, 5) limit 4 to year = "2016-2020", 6) exp Communications Media/, 7) 5 and 6.

Emcare

exp schizophrenia spectrum disorder/, 2) exp social media/, 3) recovery.mp, 4)
 *personal experience/, 5)1 AND 2 AND 3 AND 4, 6) 1 AND 3 AND 4, 7) limit 6
 to year = "2016-2020".

Cinahl

1) (MH "Psychotic Disorders+"), 2) (MH "Recovery"), 3) (MH "Interviews") OR experience*/ OR qualitative, 4) (MH "Interviews) OR experience*/ OR qualitative) AND (S1 AND S2 AND S3), 5) (MH "Interviews") OR experience*/ OR qualitative) AND (S1 AND S2 AND S3) with date limit to year = "2016-2020", 6) (MH "Blogs") AND recovery AND mental

Scopus

1) (interview*) OR (experience*) OR (qualitative), 2) (interview* OR experience* OR qualitative) AND (recover*), 3) (interview* OR experience* OR qualitative*) AND (recover*) AND (schizophren* OR psycho*), 4) (interview* OR experience* OR qualitative) AND (recover*) AND (schizophren* OR psycho*) AND (social AND media), 5) (interview* OR experience* OR qualitative) AND (recover*) AND (schizophren* OR experience* OR qualitative) AND (recover*) AND (schizophren* OR psycho*) AND (social AND media), 5) (interview* OR psycho*) AND (social AND media) AND date limit to year = "2016-2020"

Literature identified in the search was extracted and reference lists were explored. There were 25 searches carried out in total across the four databases.

2.1.6 Data Management and Screening

A PRISMA process (Liberati, et al., 2009) was followed for the management of the screening and filtering of the findings of the searches. All results from the database searches were entered into the referencing management software program Endnote, which was used to group results by database source and to identify and remove duplicates. The initial screening to determine relevance was made by comparing the titles and abstract content to the inclusion /exclusion criteria.

2.1.7 Data Extraction and Analysis

The primary author extracted the data on study characteristics. This was crosschecked by the secondary author for consistency and conformity with the research aims and criteria. The study characteristics are described and presented in Table 1. Analysis was guided by the thematic synthesis of the qualitative research approach. This type of synthesis focuses on the synthesis of qualitative studies using themes (Wood & Alsawy, 2018). The findings of this review were coded and explored for analytical themes and concepts. It was necessary to make decisions regarding the use of thematic synthesis in a reliable and valid manner. The critical realist perspective of Braun and Clarke (2006) was employed for this purpose. Coding was done manually and occurred at a semantic level. This was because the data presented within individual studies was already subject to diverse methods of qualitative analysis. Exploring each study became an iterative process that called upon the reflection of the researcher to make connections between and within studies. This entailed utilising the essences of the quotes from the lived experience of the respondents with schizophrenia riding recovery processes. It was the patterns, resemblances and regularities from respondent experiences in the studies, that were chosen for analysis to reach the conclusions of the experiences given to the process of recovery in schizophrenia. Braun and Clarke (2006) suggest that researchers could use the following five steps for analysis: 1) familiarisation with

the review studies; 2) generation of initial codes; 3) searching for themes; 4) review themes; and 5) defining and naming of themes.

Braun and Clarke's (2006) suggested steps were not followed sequentially. It became apparent that the data was directing the primary investigator rather than a predefined theoretical model in this instance, and that this was a suitable modification of the method, based on an inductive approach to analysis. Such bottom-up thinking is central to qualitative research where subjectivity and meaning are a characteristic of inductive reasoning according to Seale (2012) and Creswell (2013).

2.1.8 Quality Appraisal

As the review was qualitative by nature each included study was subjected to the Critical Appraisal Skills Programme (2019) (CASP). The CASP is a tool for assessing the applicability, reliability and validity of published qualitative research according to 10 criteria: 1) aim of research; 2) methodology; 3) design; 4) recruitment; 5) data collection; 6) relationship between researcher and respondents; 7) ethics; 8) data analysis; 9) findings; and10) value of research.

The CASP tool assists in the gaining of insights along with understandings that can extend or enhance the effectiveness of results and/or point to future effectiveness studies. It can be used to complement the Effective Public Health Practice Project (2015) (Evans, et. al) Quality Assessment Tool for Quantitative Studies where studies use mixed methods. There were mixed-method studies in the current review, but this tool was not used in conjunction with the CASP as quantitative mixed-method aspects of included papers were outside scope. The CASP was used for the qualitative aspects of the included studies. Qualitative studies were the focus of the review. The CASP tool enhanced trustworthiness. This was employed alongside the general exclusion criteria incorporated in the review used by the PI. The CASP

was employed to verify the credibility and dependability of the included papers. This was cross-checked by the secondary author of the review and an additional independent academic.

2.2 Search Results

The search identified 478 results within the date limit of 2016-2020 and five from other sources for a total of 483 articles (Figure 1). After the removal of 100 duplicates, 383 studies remained. Assessment of study titles led to 291 being excluded. The abstracts of the remaining 92 studies were then screened by the candidate and 74 further studies were excluded on this basis. Of the remaining 18 studies, seven studies were excluded after reading the article content in full so that 11 studies remained to be included in the final analysis. The reasons were varied for the removal of the seven studies and the 365 irrelevant items from the search return of 383. Qualitative studies can be viewed as being jealously guarded in terms of their trustworthiness (Creswell, 2013). The screening process is important. Many studies were excluded due to being quantitative in focus rather than qualitative. Studies were also excluded due to being originally published before 2016. The other exclusion factors were by age group (inclusion of non-adults), substance-induced psychosis, diagnosed across the full schizophrenia spectrum and not specifically diagnosed with schizophrenia alone, and no Discussion of recovery processes. There were also studies that referred to the structure of hallucination and delusion from a theoretical perspective.



Figure 1. PRISMA Diagram of the screening and filtering process

2.3 Characteristics of Lived Experience of Recovery Studies

2.3.1 Study characteristics

The Study Characteristics Table (Table 1) shows studies completed in England (4), Australia (3), Germany (1), Scandinavia (1), the United States of America (1) and Poland (1). The publication date range was 2016-2020: two in 2020 (Lee, et al.; Tuffour,) along with three in 2019 (Nxumalo Ngubane, et al.; Peter & Jungbauer; Sangeorzan, et al.) one study in 2018 (Williams, et al.), two studies in 2017 (Hargreaves, et al., Sumskis, et al.) and three studies from 2016 (de Jagger, et al.; Gray & Deane; Nowak, et al.).

Table 1.	Characteristics	of publications	used in the review.

Publication	Aim	Country	Study Characteristics	Method of Analysis	Themes
Nowak, et al. (2016).	Explore definitions of recovery by those with lived experience of schizophrenia.	Poland	Twenty-eight respondents. Aged 18 years and above diagnosed with schizophrenia.	Thematic analysis	 Psychological dimension of recovery Relationship with others Wellness strategies Clinical understanding of recovery support systems
Sangeorzan, et al. (2019).	Investigate experiences of people self- identified with schizophrenia who video log (vlog) about their illness on YouTube.	England	Thirty respondents. Nine respondents self-identified as having schizophrenia. Ages not stated.	Interpretative Phenomenological Analysis (IPA)	 Minimising isolation Vlogging as therapy Fighting stigma
Tuffour, et al. (2020).	To explore how religion influences recovery from mental illness.	England	Twelve respondents aged 19-57 years. Semi-structured interviews. Eleven respondents with schizophrenia. Lived experience.	(IPA)	 Pentecostalism African healing systems
Hargreaves, et al. (2017).	To explore the meaning of individual experiences of physical activity (PA) in people with schizophrenia in recovery.	England	Eight respondents. Aged 18-65. Lived experience of schizophrenia.	Hermeneutic phenomenology	 Not ready to engage Initial steps to engaging in PA Becoming more active Doing PA
Nxumalo Ngubane, et al. (2019).	Aim was to explore the experiences and meanings of recovery for women living with schizophrenia.	England	Fifteen respondents. Lived experience of schizophrenia.	(IPA)	 Emotionality Pain She is mad ignore her, Being better.
Gray & Deane (2016).	To highlight how internal struggles are complicated for people with first episode psychosis regarding medications.	England	Twenty respondents. Aged to 35 years with schizophrenia. Lived experience.	Thematic analysis	 The drugs do work The drugs don't work Side effects Indirect effects of medication Rage against the machine Not trivial issues about medication.

Williams, et al. (2018).	Explore how service users experienced viewing lived experience videos as well as its influence on recovery.	Australia	Thirty-six service users with experience of website use. Lived experience of schizophrenia.	Grounded theory	 Being inspired, Knowing not alone, Believing recovery is possible.
Sumskis, et al. (2017).	Understand meaning of resilience as described by people with schizophrenia.	Australia	Fourteen respondents with schizophrenia. Lived experience.	Psych phenomenological method	1) Dynamic of support and challenge experiences of schizophrenia
De Jager, et al. (2016).	The importance of services to be sensitive to the differing styles of a person's recovery and their readiness for change.	Australia	Eleven respondents. Semi-structured interviews. Lived experience.	Narrative inquiry	1) Despair/ exhaustion
Lee, et al.:(2020).	Point out the importance of self-efficacy, emotion management and social giving in recovery process without medication.	United States of America	Nineteen respondents. In-depth interviews. Lived experience.	Grounded theory	 Hope, lived experience recovery via multiple pathways holistic approach social, family and community support strengths (Themes that relate to internal and external processes in recovery).
Peter & Jungbauer (2019).	Investigate how those with mental illness experience psychiatric label.	Germany	Sixteen adult respondents. Five with schizophrenia. Lived experience.	Grounded Theory	1) Diagnosis: concealing or revealing

The review identified a total of 11 qualitative studies with 209 respondents. Of these 209 individuals 86 were specifically diagnosed with schizophrenia alone from eight studies (Hargreaves et al., 2017 (4); Lee, et al., 2019 (6); Nxumalo Ngubane, et al., 2019 (15); Nowak, et al., 2017 (28); Peter & Jungbauer, 2019 (5); Sangeorzan, et al., 2019 (8); Sumskis, et al., 2017 (14); Tuffour, 2013) (6)). The 123 respondents that remained were not specifically labelled as schizophrenic. Gray and Deane (2016) reject the diagnosis of schizophrenia by referring to psychosis for their sample of 20 respondents. Williams, et al. (2018) also preferred to use psychosis to identify their 36 study respondents. The remaining

67 were specified as respondents having a serious mental illness (SMI). The ages of respondents ranged from 18 years (Nowak, et al., 2016) to 65 years (Hargreaves, et al., 2017). To ensure the quality of the research, the characteristics of the included papers were crosschecked by the secondary author of the review. No anomalies were found.

2.3.2 Thematic Classification

The Thematic Classification of Publications Table 2. shows four themes generated from a possible 35.

Eight of the 11 included studies found medication to be important in the recovery process. Five studies saw relationship with self and the social world as being important. Six studies saw the transformation of identity to be relevant in the process of recovery. Personal meaning of recovery was viewed as essential for understanding the recovery process.

Table 2. Thematic Classification of Publications, Number in Category.

Theme	Number of studies in each category
Personal meaning of recovery	10
Medication: importance of in recovery	8
Identity transformation	6
Relationship with self and social world	5

Medication

There were eight studies that reported on differing aspects of medication. According to de Jager, et al. (2016) the role of medication in the recovery process was seen as an important contributor to recovery. Medication facilitated recovery processes such as participation in the labour market. Gray and Deane (2016) found their respondents talking about the positive role for medication as it reduced psychotic symptoms, which reduced distress. Hargreave et al. (2017) saw some individuals report that medication coupled with

physical activity acted as a coping mechanism towards the bad chemicals they believed medication released into their body. Lee, et al. (2020) found their respondents in the process of recovery without ongoing medication use. Nxumalo Ngubane, et al. (2019) identified that medication was beneficial in the process of recovery but only if other supports were also available.

In the Nowak, et al. (2017) study, participants believed that medication had to be carefully managed to be of benefit. Appropriate medication was generally considered to be important for recovery. It was also reported that medication for schizophrenia does not prevent relapse. Sumskis, et al. (2017) suggested that medication is the cornerstone of treatment for schizophrenia. They also proposed that side effects are the major challenge for those with schizophrenia. Efficacy of different medication has been found to be similar but individual responses to medication may vary. It was reported that many in their study refused to take medication due to side effects. Lastly, Tuffour (2020) suggested that the role of religion was more important than medication for some of their respondents in the process of recovery.

Relationship with Self and the Social World.

Some of the respondents in the de Jager, et al. (2016) study described how, when the symptoms of schizophrenia were most severe, the needs of the body were neglected, which made it impossible to participate in physical activity. For them it was as if the mind, self and body were seen as separate entities, where the body did not feel as though it belonged to them, and they were completely absorbed in their mental processes. Others reported that their auditory hallucinations became an integral part of themselves. A positive sense of self was critical for recovery according to de Jager, et al. (2016). According to Lee, Eads, Yates, and Liu (2020) other internal recovery processes included changes in how respondents viewed themselves as integrated with their mental health concerns. For example, some respondents

recovered their self and perceived themselves to be a whole person, not a diagnosis. Caring for self was important for the respondents in the work of Lee, et al. (2020), and exercise was seen as being extremely helpful. A sense of estrangement from the self was common for most respondents in their study. Nxumalo Ngubane, McAndrew and Collier (2019) found that some of their respondents discussed how schizophrenia brought about changes to self. These included uncontrollable, dehumanising and/or risky behaviour. As reported in this study, a motivating factor in the recovery process for these participants was to regain a sense of self which helped them to go beyond the limitations of schizophrenia to become the best they could for self and significant others. These others were also important for the subjects of the Nxumalo Ngubane, et al. (2019) study as families and significant others played an important role by providing emotional and financial support. A positive effect on self was experienced when some respondents were accepted socially and able to contribute to their family and community. Giving back was viewed as important in the recovery process.

Leading on from the recommendations of the respondents in their study Nowak, et al. (2017) emphasise that recovery goes beyond the reduction of symptoms. They argue that it is of equal importance that the process of recovery be about finding meaning and purpose in life, along with respondent self-management, physical and mental health. These considerations can foster the development of relationships with others. Relationships with others create a sense of belonging according to Sangeorzan, Andriopoulou and Livanou (2019), where this was evident in their study of respondents creating and publicly sharing mental health videos (vlogging) about the lived experience of schizophrenia. This study provided the first empirical evidence that engaging in the act of vlogging about mental illness can benefit and encourage recovery in people with serious mental illness (Sangeorzan, et al., 2019). Importantly, vlogging is more common an experience for individuals without a mental illness (Sangeorzan, et, 2019). This being the case the impact of YouTube on the serious

mental illness (SMI) population is perhaps a breakthrough. It was found that vlogging facilitated an environment where those with schizophrenia uploading videos about their condition connected with viewers with similar illnesses and this validated the experience of mental illness, reducing feelings of loneliness, and reinforced a sense of normalcy (Sangeorzan, et al., 2019).

Identity Transformation

The de Jager, et al. (2016) study found their respondents were moving beyond developing a positive sense of self to describe an essential transformation in identity because of becoming unwell and experiencing auditory hallucinations. This "illness identity" was seen as a positive for some respondents. In the Hargreaves, Lucock and Rodriguez (2017) study some participants reported that exercise training in a gymnasium enhanced recovery by rebuilding identity. The transformation was from one of being ill to one that saw participants identify as a sportsperson. Other participants in their study displayed substantial behaviour change, reverting to the types of training/physical activity respondents did before they endured schizophrenia (Hargreaves, et al., 2017). Respondents in the Lee, Eads, Yates, and Liu (2020) research discussed the importance of finding social roles as a facilitating factor in their recovery process. The transformation was experienced in shifting from being seen as a patient with schizophrenia to identifying as a recovered person. It was reported by one participant for example that the role they moved towards was that of an active citizen, as someone who is contributing/participating in the social world. Nowak, et al. (2017) discovered that their respondents referred to identity transformation as a number of processes: personal growth; developing a positive self-identity; acceptance of their schizophrenia; developing self-esteem and self-empowerment; and stigma-management. Again, the transformation is one of the individual's identities being formed through drawing on their personal resources. Identity was transformed from being ill to identifying as being recovered.

Peter and Jungbauer (2019) found that notions surrounding identity and loss of identity were very present. Re-authoring/transforming identity was important for their respondents. The diagnosis of schizophrenia was seen to lead respondents to redefine their selves by creating new perspectives. The illness was viewed as a mere part of the self, not the centre of self. This was seen as a pivotal task for those in the study who were diagnosed with schizophrenia (Peter & Jungbauer, 2019).

Personal Meaning of Recovery

There were differing connotations regarding what recovery means for those individuals with schizophrenia. For respondents in the de Jager, et al. (2016) study, being bold about what they had achieved through the process of recovery was significant – this included "being strong" and rejecting stigma. In the Hargeaves, Lucock and Rodriguez (2017) research it was shown that controlling symptoms of schizophrenia through physical activity was very meaningful for the respondents. Lee, Eads, Yates, and Liu (2020) found that for some in their study recovery did not mean the absence of symptoms but instead a different relationship with their symptoms. Some experienced their auditory hallucinations as being meaningful or interpretable. While others in the Nxumalo Ngubane, McAndrew and Collier (2019) research defined the meaning of recovery as "feeling better". Nowak, et al. (2017) found in common with de Jager, et al. (2016) that respondents not stigmatising themselves, not being identified as their illness, and viewing themselves as people with worth because they had survived schizophrenia was extremely meaningful. In addition, like many respondents in the preceding studies the meaning of recovery for those in the Peter and Jungbauer (2019) study was how to be able to cope with stigma; specifically, how to cope with labels. Sangeorzan, et al. (2019) indicated in their study that giving people control of the understanding of what their recovery process meant to them was a fundamental requirement for recovery. This was in the context of video logging about their experience of

schizophrenia. Respondents found meaning in their recovery was aligned with what they could do for others undergoing the same lived experience. Meaningful recovery was characterised by having resilience, the attitude of striving to overcome the severe adversity caused by schizophrenia, for the respondents in the Sumskis, Moxham and Caputi (2017) study. For those in the Tuffour (2020) research, recovery gained meaningfulness from being close to God. Being without God meant no recovery at all for the subjects of the study. Williams, et al. (2018) discussed with participants what recovery was and what it meant. This included the concepts of "getting back to normal", "being positive" and "having good thoughts".

2.4 Assessment of Methodological Quality

All studies were assessed against the CASP tool (Table 2) against criteria aimed at evaluating the quality and reliability of the research. The assessment of the 11 qualitative research studies indicated consistently high quality. The "strong" results were achieved by having a score of between eight and 10 "yes" scores respectively. All 11 studies were strong across all criteria of the CASP tool. Ten of the included studies scored 10 (de Jager, et al., 2016; Gray & Deane, 2016; Hargreaves, et al., 2017; Lee, et al., 2020; Nxumalo Ngubane, et al., 2019; Nowak, et al., 2017; Peter & Jungbauer, 2018; Sunskis, et al., 2017; Tuffour, 2020; Williams et al., 2018), with one scoring nine (Sangeorzan, et al., 2019). There was one study that did not meet the criteria – "relationships between researcher and respondents" – but this was expected as the data collected by Sangeorzan, et al. (2019) was limited in depth of content by the inability to ask to follow-up questions. The study aimed to investigate the experiences of respondents with self-identified SMIs who video log about their SMI on YouTube. CASP analysis indicates the studies included for the purpose of review provide a high standard of qualitative information regarding how those with schizophrenia experience

Publication	Clear statement of aims?	Qualitative methodology appropriate?	Research design appropriate for aims?	Recruitment strategy appropriate for aims	Data collection addresses research issue?	Relationship between researcher and respondents considered?	Ethical consideratio ns accounted for?	Rigorous data analysis?	Clear statement of findings?	Research is valid?	Rating
De Jager, et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Gray & Deane (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Hargreaves, et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Lee, et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Nxumalo Ngubane, et al. (2019)	Yes	Yes	Yes	yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Nowak, et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Peter & Jungbauer, 2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Sangeorzan, et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Sumskis, et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Tuffour (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Williams, et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
the process of recovery, making their findings meaningful in this context and purposeful as reliable and well-formulated sources for analysis.

2.5 Discussion

When considering the themes that emerged from the analysis of the studies under review in the context of individual studies and the stories and experiences of participants reported in the studies, it became apparent that there is an overarching, or meta-theme that is identified with recovery by the 86 respondents diagnosed with schizophrenia. After reduction from 35 initial themes, four descriptive themes were identified that were expressed from a remarkably consistent perspective. This was expressed by respondents describing meaningful recovery in terms of connections made of several types between study subjects, other people - including personal and professional contacts, societal structures and institutions and the manifestations of their own internal processes, physical and mental experiences. The interpretative construct "connection" is identified as this meta-theme. In essence, what recovery meant for those with schizophrenia was that success or failure depended on the type and quality of connections they were able to make. The core of lived experience for those with schizophrenia in the recovery process was that connection gave meaning to the recovery process. By way of interpretation, medication allowed the person to connect with themself (de Jager, et al., 2016; Gray & Deane, 2016; Hargreaves, et al., 2017; Lee, et al., 2020). This enabled the person to connect with others more successfully and participate/connect in the social world (de Jager, et al., 2016; Nxumalo Ngubane, et al., 2019; Nowak, et al., 2017). This, in turn, leads to a shift in identity from being ill and isolated to and transformation of identity into active citizens (Hargreaves, et al., 2017; Lee, et al., 2020; Peter & Jungbauer, 2019). This enabled the person with schizophrenia to give meaning to their recovery process. Respondents were in recovery and not in remission (Nowak, et al., 2017; Sangeorzan, et al., 2019). Connection functioned as the mediator between the medical approach and lived

experience models of recovery. They are not presented as challenges to each other but as complementary. The self of the person with schizophrenia is shown to be of equal importance to their use of medication in the recovery process (Deegan, 1988). Recovery is identified by the respondents as being about who they are and not about how sane or how normal they could be. Respondents find meaning and purpose in life is enabled by connection. Connection aids the recovery process and gives value to the uniqueness of those with schizophrenia (Anthony, 1993). The strength of the findings was apparent as current approaches are supported by the results of the reviewed literature. The answer to the research question (how those with schizophrenia experience the process of recovery) is discovered by the respondents of the reviewed literature as a varied, complex and uniquely subjective experience.

2.6 Limitations

A limitation of the review was that during the screening process additional human resources were lacking due to Covid-19. However, the risk of the review, being seen as selection bias and excluding any relevant studies, was reduced due to strong inclusion/exclusion criteria as well as secondary cross-checking during data extraction and analysis. Further, included studies were subjected to the CASP tool for assessing applicability, reliability and validity and cross-checked by both the secondary author and an independent academic reviewer. As a review focused by necessity on qualitative studies, it should be noted that there is no statistical analysis of quantitative findings to support the conclusions reached, and this should be considered as there may be potential for future work to focus on quantitative assessment of the reported experiences of individuals identifying as having schizophrenia in recovery.

2.7 Conclusion

One of the most important findings in the current literature is that the recovery process is uniquely subjective. This was mirrored by the respondents in the reviewed literature. The current state of the reviewed literature is extremely supportive of the lived experience of the recovery processes for those with schizophrenia. Recovery is a process that is exciting and ultimately challenges assumptions about normality (Bejerholm & Roe, 2018). Connecting with self and the social world means those with schizophrenia understand that recovery is possible (Anthony, 1993) and their new-found identity is not one of being in remission but of being in recovery. One future area for study in the light of this concept is that of schizophrenia being a disorder of the self. The reviewed literature supported the theoretical approach that the person with schizophrenia needed to regain their lost self before taking further steps in the recovery process. Future research of schizophrenia as a selfdisorder being phenomenologically designed would further highlight the necessity of this for the recovery process. This would link to existing knowledge in two areas: recovery as lived experience and symptomatic recovery. Recovery is not viewed as an end. It is not an achievement. Rather, as de Wet, Swartz and Chiliza (2015) argue, it was a way of living and a constant choice that those with schizophrenia must make in pursuit of a healthy, meaningful, and above all "connected" existence.

3. 0 Methodology, Methods and Research Rigour

3.1 Introduction

This section describes the methodological processes that underpin this thesis. This includes an overview of the epistemological and philosophical beliefs that will aid PS meanings and experiences given regarding the recovery process, and the steps taken to gather the PS narratives and the analysis. The research design was constructivist/interpretative with a realist assumption bounded by the lived experience of the PSs who are being, becoming and moving through the world in intersubjective relationships with others, and other things such as their schizophrenia. Phenomenological inquiry was used, and bracketing is explored. Then the method of research with ethics, sampling and the trustworthiness of the study is explained. Analysis saw the use of thematic analysis to interpret the patterns, codes and overall themes. Both forms of hermeneutic were used such as the circle and the interpretative theory of Martin Heidegger.

3.2 Research Design

When applied to dissertation research, methodology encapsulates both the overall framework and research strategy within which different specific methods are to be used, and the theoretical underpinnings (Punch, 2016). Exploring the philosophical framework that underpins the research is a way of clarifying the research aim, design and analytical methods. There is an abundance of research methodologies that can be adopted by investigators that arise from different paradigms (Punch, 2016). The reason for these differences is that there are conflicting philosophical beliefs relating to the nature of knowledge (epistemology) that influence conceptions of the way in which phenomena can be explored or understood (Joseph, et al., 2009).

3.3 Key Epistemological Positions

Creswell (2013) argues there are two key epistemological positions that can be employed to consider the relative philosophical stances of different research approaches. These are positivist epistemology and interpretative epistemology. Advocates of the former believe there are clear predictable relations between the world and how it can be experienced, being independent of individual perceptions. What exists according to a positivist researcher is a set of universal laws, which govern reality and research can be better understood in the context of these laws. The interpretivist researcher on the other hand, would view the search for a unitary definitive truth as futile (Creswell, 2013). Importantly for this study there are many truths in the world that vary due to lived experience of individuals and their contexts (Tuffour, 2017). Hence, interpretivism underpins this work. Quantitative research methodologies are often better aligned with positivist epistemology.

3.4 Qualitative Study

Qualitative studies usually employ interpretative philosophical approaches with the aim to improve our understanding of lived experience by exploring how individuals form associations with themselves, or relate to other individuals or things in the world around them (Creswell, 2013). Qualitative research explores and understands the meanings individuals give to their experiences. To inquire qualitatively the researcher can shed light on meanings that are less perceptible. It is the complexities of the social world that are important (Tuffour, 2017). As this type of research is inductive it therefore shares similarities in examining "what" and "how" questions as opposed to "how much" and "how many" preferred by quantitative studies (Tuffour, 2017, p. 1). As there are different strands of qualitative research, it is important to distinguish between them by considering another epistemological divide.

3.4.1 Realism and Relativism

These concepts are significant to the study because they can influence the way in which data are collected and analysed and the diagnosis of schizophrenia itself. For example, the realist researcher argues that the world around him/her is made up of phenomena that can be identified, described, and categorised (Creswell, 2013). This differs from that of the relativists as they believe that while some phenomena can be real, individual perceptions and experiences of these phenomena can vary considerably. The idea behind relativism is that all people have unique lived experiences. This type of experience is the knowledge and understanding a person can get when they have lived or are living through something (Vagle, 2014), an example being schizophrenia in recovery. From this point of view, research explores and describes the experiences, but the descriptions are also subject to interpretation by others. Consequently, both the lived experiences of the research participants and other interpretations of those experiences are inherently unique (Vagle, 2014). As this study is qualitative, and phenomenological, lived experience is the experiences and choices that the person with schizophrenia makes and the knowledge gained from these experiences and choices (Vagle, 2014).

As for the diagnosis of schizophrenia, by adopting a realist epistemology psychiatry makes two critical errors in defining mental illness. It assumes that knowledge that is in the mind along with its mental functions is reducible to the chemical or electrical operations of the organic brain (McLaren, 2010). Such a reductionist model of the mind is an essential aspect of biological thought. The biological model reduces the operations of complex wholes to the properties of their individual parts of neurons, ganglia and chemicals. The logic of this realist model reduces mental illness to disordered molecular or cellular structures in the brain. According to the realist model, the primary causes of mental diseases are genetic and biochemical factors (McLaren, 2010). By locating the pathological qualities of psychological

conditions in the material properties of brains, the symbolic systems of propositional content that constitute the mind are seen as unimportant for diagnosis (McLaren, 2010). This is the second mistake that biological psychiatry makes. McLaren (2010) argues that a category mistake is committed by reifying mental illness by defining symptoms-based diagnoses as quasi-disease entities. A symptom of mental illness, or even a cluster of symptoms, is not an objective natural entity.

My interpretation of McLaren's argument is that "*if it was not a category mistake*" it would be like saying that a belief that I could recover from schizophrenia arises from the organic disease of values, desires, doubts and assumptions because these would have to be some sort of biological substances. McLaren (2010) correctly argues that realist assumptions are valid in relation to the physical brain but not when it comes to propositional content as it is these that constitute the complex and dynamic subject matter of the mind. Epistemic content of the mind is not physical material like the brain and diagnosis of mental illness is not identical to an organic disease (McLaren, 2010).

3.4.2 Phenomenological Method

The objective of this study is to understand the meanings and experiences of those with schizophrenia in recovery. The focus on understanding based on analysis of data collected from personal experiences is phenomenological in nature. According to Moran and Mooney (2002), the study of phenomena is to be understood as "manifesting and appearing" (p.5). Here, this is applied to the process in recovery of those with schizophrenia. By studying this process phenomenologically, there will be no attempt to get into the minds of the PSs. Rather, what is contemplated and explored will be the ways it can be envisaged that the PSs experience the giving of meaning to how they are in recovery from schizophrenia. The reason for this is that the recovery process manifests and appears in and through the PS being in the world (Vagle, 2014). The phenomenon of the study is schizophrenia in the process of

recovery. The assumption is that the PSs with lived experience of schizophrenia are being, becoming and moving through the world in intersubjective relationships with others, and importantly with other things such as schizophrenia, making them, ideally, authentic subjects capable of best describing the phenomena of their lived experience in this context.

3.4.3 Phenomenological Strands of Inquiry

There are two main strands of phenomenological inquiry. Both are founded on different philosophical assumptions. The first of these is descriptive phenomenology which is based on realist epistemological beliefs (Giorgi, et al., 2017). Descriptive phenomenology stems from the works of Edmund Husserl that began in 1900 with the publication of Logical Investigations (Giorgi, et al., 2017). The key to descriptive phenomenology is the process known as bracketing (also known as reduction or "epoch") (Moran & Mooney, 2002). Husserl proposed, according to Giorgi, Giorgi, and Morley (2017), that it is possible to identify key elements of lived experience common to groups of individuals who have experienced similar life events. However, the researcher must shed all her/his belief or existing knowledge (bracketing) to develop an unbiased view of elements common to the phenomena being studied (Moran & Mooney, 2002). This form of phenomenology aims to objectify the nature of lived experiences independently of social context and in doing so it is centred on unearthing universal truths about the nature of reality. The result is that descriptive phenomenological research values the achievement of scientific rigour that is often associated with positivist methods of enquiry (Zahavi, 2019). In this study it is important to recognise that the objective is not to find a single set of beliefs about experiences of the recovery process in schizophrenia that would be representative of the views of all those in the recovery process. The aim of the research is to explore the meanings and experiences of those with schizophrenia in the recovery process in the context of their own lived experiences within the world. This approach is not compatible with descriptive phenomenology. The second strand

of phenomenology, the alternative to descriptive phenomenology, is a theoretical framework known as interpretative (or hermeneutic) phenomenology. This has been used in this study to guide the approach to data collection and analysis.

3.4.4 Hermeneutic/Interpretative Phenomenology

The German philosopher Martin Heidegger developed interpretative phenomenology, which is closely aligned with a relativist philosophical belief (Tuffour, 2017). Heidegger's view of reality, according to Spiegelberg (1982), places greater emphasis upon the social and environmental contexts. These shape the meanings and experiences that individuals place upon the world around them. Therefore, interpretivist phenomenology is more aligned with relativist philosophical beliefs than with the realist perspective (Moran & Mooney, 2002). This sharp departure from descriptive phenomenology to Heidegger's interpretative phenomenology is based on the principles that reduction is impossible and rejects the idea of suspending personal perspectives in favour of interpretation of experience (Tuffour, 2017). The researcher takes an active and embedded role in the research process. It is argued that greater insights are gained by this approach into the PSs' unique views, opinions, feelings, and beliefs within the context of their own natural setting (Smith, et al., 2014). Within interpretative phenomenology, the researcher's beliefs are taken as being a necessary factor in guiding the investigative process. The experiences and meanings held by both the researcher and the PSs are entangled. This lived-experience approach incorporates concrete narrative descriptions of the experiences with theoretical discussion thus driving forwards personal reflection to a deep and/or nuanced analysis that embellishes experiences (Creswell, 2013). As a person experiencing the lived experience of schizophrenia in recovery, I believe that this helps me to make a significant contribution to the strength of analysis and interpretation in this study, as it is grounded in interpretative phenomena.

3.4.5 Ethics approval

The study was approved by James Cook University Human Research Ethics Committee (H8585). The process involved when gaining approval was laborious and emotional for me. An earlier minor thesis I completed as a precursor to this study was an analysis of recovery using blogs written by people with schizophrenia retrieved from the internet. I did not need to apply for ethics approval for this because it was for internal use within the university system. I did not ask any questions about this and made a mistake to think the present study would be the same, due to the data of both studies coming from social media. I treated the data generated by the PSs like any other article retrieved from the web. The reason for this was due to me relying on the Creative Commons licence and the fair dealing doctrine, both legal approaches that relate to the use of copyright material. I discovered that you can have research that can be legal, but it does not necessarily mean it is ethical. What I needed to do early in the study was engage with the PSs and seek consent. The legalities, argue Sangeorzan, Andriopoulou, and Livanou (2019), do not require consent seeking from the PSs. It is evident, however, that social media retrieved data in research can raise several ethical challenges with regards to privacy, consent and confidentiality. These challenges were overcome, and ethical approval granted including seeking consent but on condition that data from the vlogs will not be published. The rationale is to protect the anonymity of the PSs.

3.4.6 Sample

The purpose of the present study was to understand how people with schizophrenia recover. The sample was taken via YouTube video logs (vlogs) where people with schizophrenia uploaded their stories of recovery. Officially launched in 2005 and bought by Google a year later (Schuman, et al., 2019), YouTube is a free online digital technology streaming platform allowing registered amateur videographers to upload short videos that are taken with a mobile phone or camera for unregistered users to view them. Although YouTube is not the only video-sharing platform, it is the largest, reaching close to one-third of internet users (Schuman, et al., 2019). Primary sources (PS) in the study were recruited purposively. This type of sampling involves selection of PSs to maximise the richness and depth of data relevant to the aim of the research (Seale, 2012). Historically, purposive sampling has been viewed as being methodologically inferior because the extent to which they are representative of the population being studied cannot be statistically appraised (O'Leary, 2004). Consequently, this view of scientific rigour is reflective of positivist epistemological assumptions that (as mentioned previously) have not been used to guide the research project. Within research paradigms underpinned by relativist epistemologies such as the social constructivism used in this study, it is not considered possible, or necessary, for PS samples to be wholly representative of a broader population (Smith, et al., 2012). Rather than striving to produce generalisable findings, according to Smith, Flowers, and Larkin (2012) the aim of interpretative research is to present an interpretation of the experiences and meanings of the PSs, upon which others can in turn draw their own interpretations and learning. Therefore, purposive sampling was a legitimate approach to selecting PSs for study. Moreover, purposive sampling increases the likelihood that potential research PSs have specific knowledge and experience relevant to the proposed research question.

The interactive aspect of the Web 2.0 platform was used. The world of the vloggers to be approached as PSs was entered by way of an informal consent process where potential sources were asked whether they had schizophrenia and were at least 18 years of age. To achieve this, my supervisors and I set up an informal consent process that consisted of the following:

"Hi, is it OK to include your vlog [... name of vlog ...] in my study? I am an adult and have schizophrenia too. I have been in recovery for many years and am interested in how we recover. The study would be of benefit because we can learn not only more about ourselves but connect with others too. There is great depth in personal stories with rich expression."

Responses were received from six of 12 vloggers. These were positive and varied from being excited to be involved, to accepting absolutely without question. Given this, this six led me to believe that it was reasonable to believe that there could have been personal issues involved for the other half of the sample and that was why they did not respond to the request for consent. Also, there was, however, the problem of the subscriptions of the channels being dated somewhat and this was why they may not have responded. Allowing for this, the 12 original vloggers' transcriptions were analysed. However, before this I followed with another message to vloggers who responded to the first approach and asked for their age. Again, the six vloggers responded by telling me they were adults above 18 years of age. After four weeks another message was sent to the six vloggers who did not respond asking again if they would like to be involved in the study. There were no more replies. Even though six vloggers replied and six did not I still used the 12 transcriptions for analysis as it was reasonable to think that if the circumstances were more suitable for the six who did not respond then they too would have given consent. The scope of the proposed study is 12 adult PSs over 18 years of age diagnosed with schizophrenia where six of the 12 consented to be in

the study and six did not respond to contact. Vlog selection was limited to a total joint viewing length of approximately 3.5 hours to ensure the scope of the study was achievable. Vlogs are online video diaries. Vlog transcriptions are used in the study as the source data from the PSs.

A benefit of using video logs as a data source is that as well as transcribed speech it is possible to find how PS information and experience of recovery is explored by the PSs unhindered by the pressure of professional face-to-face interviewing and questionnaires. As Hookway (2008) argues, "one of the key advantages of diary research" as he calls it, is that "it can aid in the avoidance of any problems associated when collecting sensitive information using traditional survey or interview methods" (p. 95). Again, another area of importance of using video logs (diaries) for PSs is that they are not "contaminated" by the interests of the researcher (Hookway, 2008, p.96). The PSs are more inclined to tell how schizophrenia evolves and the important points to be considered in recovery.

A YouTube title search of online video logs (Vlogs) and text in the English language was undertaken by the Principal Investigator (PI). These vlogs are works that have been uploaded by people independently of the research project and were not asked for but selected by the PI as primary sources based on their clear relevance to the research question. The vlogs were created by adults with schizophrenia in recovery. The vlogs are original thinking and experiences. Vlogs were not filtered by location, or gender of the author, but selected only on the basis that the author supplies information about the experience of recovery. They were filtered by age and having schizophrenia. As well, the filtering aspect of YouTube was used. For example, after I signed into YouTube, I filtered the upcoming searches by: 1) any date; 2) time duration of vlog; 3) only video; 4) relevance; 5) and the Creative Commons licence. Search terms used were "schizophrenia"; "schizophrenia and recovery"; "adults with schizophrenia in recovery"; "recovery from schizophrenia"; "recovery in schizophrenia".

Then I viewed the first 20 of each page and excluded vlogs that were affiliated with government or non-government organisations that aided those with mental illness. After this, channels were sought from a brief view of the video logs' content ranging in times from 20-30 seconds. This was continued until sufficient appropriate source material had been identified to fulfil the relevance criteria.

3.4.7 Research Rigour

Brigitte Cypress argues in "Rigour or reliability and validity in qualitative research" that rigour of a naturalistic inquiry such as the qualitative nature of the present study can be operationalised using the criteria of transferability, credibility, dependability, and confirmability (Cypress, 2017. p.257). This, along with the direction from my supervisory team about rigour when constructing the systematic literature review, made me think about my audience for my thesis from an early stage. I carried in my mind through the results process how I was going to persuade the readers of the results that the meaning units generated by the PS and approached hermeneutically by myself were not only worth paying attention to but also worth considering by others.

3.4.8 Transferability

Transferability was enhanced using purposive sampling (Cypress, 2017). I used this type of sampling to generate dense description and robust data. Special attention was given to the collection, identification and analysis of all data that was pertinent to the study. Immersing myself into the phenomenon (PSs with lived experience of schizophrenia in the recovery process) so I could know, describe, interpret and understand it fully thoroughly and comprehensively is an activity that is central for sustaining rigour. The very idea of qualitative research for me is exciting because it can be very messy (Creswell, 2013), but the eventual results are worth the effort. In essence the iterative nature of this type of research

can cause such messiness but then in the process the deductive aspect of the study manifests in the categorisation and ordering of the meaning units to make sense of the results by way of themes appearing that are valid and enable sense to appear from the apparently incoherent mass of original data.

3.4.9 Credibility

To achieve accurate and truthful depictions of the lived experience of the PSs schizophrenias in recovery, I read and reread the dataset many times and repeatedly viewed the vlogs. This allowed me to constantly check the PSs' interpretations, which enhanced credibility. So too did the reading of the dataset by my secondary supervisor along with the readings of the meaning units in the results section. These were then discussed at supervisory meetings.

3.4.10 Dependability

Closely corresponding to the notion of reliability in quantitative research is the use of dependability in qualitative research (Cypress, 2017). This is achieved by having two expert researchers (my supervisors) review the transcriptions to confirm the themes and descriptors. Any new themes and descriptors highlighted by my colleagues were acknowledged and considered. The notion of recovery as a theme is an example of this. I compared their analysis with my own and synthesised the results.

3.4.11 Confirmability

I achieved confirmability by my reflexive journal during the research process. As well as the preceding paragraphs relating directly to rigour in qualitative research, the following are some of the entries in my reflexive journal.

3.4.12 Personal Reflection and Reflexivity

(Ideas for this extract come from Horwitz, A. (2002).

There are two ways of reasoning about schizophrenia, and they derive ultimately from the mind-brain split; they are understanding and explanation. These two perspectives are important for enhancing the links between methodology and method and analysis. To understand or make sense of the experiences or behaviours of the PSs in this study the PSs are understood as subjects. This meant I approached the PSs from the inside. The subjectivity of the interpretations of recovery by the PSs in the study was to be highlighted. What the study is about is seeking meaning/interpretations based on meaningful connections between experiences and events. The study dealt with data that was intangible such as contents of the mental, or phenomenal world of those with schizophrenia in recovery. This world was interpreted by me as the PSs being experiencing selves. This was important for design such as constructivism /interpretivism. In addition, it made the links obvious, compelling and satisfying.

Consequently, viewed through the method of causal explanation, the subjects or PSs, can also be viewed as objects/organisms. The mental phenomena were also considered as forms. It had to be like this though, as those with schizophrenia suffered from hallucinations and delusions and as such were discerned regardless of their content. Even though, it is hard for me to see how a neural activity, even one as detailed as the dopamine hypothesis, enables me to understand not only why the PSs want to recover but how it is experienced. However, viewed as a causal explanation, schizophrenia is a disease. In this instance data are seen as tangible and the realm is of matter rather than meaning. This is a powerful perspective as it is the reason that most individuals believe there is no recovering from schizophrenia, only remission. The gulf between understanding and causal explanation derives from the gap between mind and brain, between mental and physical events. While it is possible to correlate

some mental with neural events, the way in which the latter are transformed into the former remains a mystery.

3.5 Analysis

When approaching the analysis of narrative discourses such as the YouTube vlogs, the belief that these individuals derive unique meanings from the world in which they exist is social constructivist or interpretivist (Daher, et al., 2017). Based on this, the aim of the analytical processes is to deconstruct these meanings so they can be better understood. To capture experience and meaning the approach proposed by Heidegger is based on interpretation processes (Smith, et al., 2012). Thematic analysis is the process of identifying patterns or themes within qualitative data. Braun and Clarke (2006) suggest that it is the first qualitative method that should be learned as "... it provides core skills that will be useful for conducting many other kinds of analysis" (p. 78). An interesting advantage particularly from the perspective of recovery is that it is a generic method (Braun & Clarke, 2006). This means that unlike many qualitative methodologies, it is not tied to a particular epistemological or theoretical perspective. For me this allows it to be a flexible method which offers considerable advantages when exploring the diversity of the subjective nature of recovery.

By using thematic analysis in the analysis of data my understandings of the meanings with that data evolved through a process described by Daher, et al. (2017) as the "hermeneutic circle" (n.p). This circle complements the analytical standpoint. The aim of hermeneutics is to understand how we understand (Daher, et al., 2017). The circle is a dynamic cycle where I repeatedly reviewed and reflected upon dialogue from the PSs while at the same time considering how my own values, experiences and background contributed to the construction of understanding (Smith, et al., 2012) regarding mood and connection. I as an insider having been diagnosed with schizophrenia contributed to the interpretations in a caring manner while being able to be as objective as possible within the rules of thematic

analysis. It is the dynamism of interpretation that mirrors the qualitative nature of the proposed research. By using thematic analysis, I engaged in a "double hermeneutic". This is where I make sense of the PSs' sense making (Smith, et al., 2012, p.36). There is a dynamism between the hermeneutic circle and the double hermeneutic due to the interpretation and reflection of the circle that deals with the relationship between the part and the whole. The part relating to the encounter I have with the vlog PSs and the whole, the drawing of knowledge and experience I have regarding recovery (Smith, et al., 2012, pp. 34-38). Having developed my own factors around being in recovery, I am positioned as understanding just how dynamic the hermeneutic circle and the double hermeneutic make the interpretative process. In this sense the relationship between myself and the PSs' interpretation of recovery that the PSs have found was exciting, as intersubjectivity is a factor I have tried to craft in my own recovery process. Intersubjectivity means something is shared between two minds. It is the relationship between me and the latent moods of the PSs, such that this relationship highlights the firsthand experiences of recovery by emphasising the inherently social aspects of the PSs and myself as recovering humans.

The following five steps in data analysis were adopted from Virginia Braun and Victoria Clarke (2006, pp. 87-93).

3.5.1 Step 1: Become Familiar with the Data

To familiarise myself with the dataset the first step was to view and listen to the vlogs. This was where I was alerted to the nuances of the PSs in relation to mood, but I did not want to code this as latent at the time because this could have meant that I would have to resort to content analysis of the actual videos themselves. As such, this could have shifted the emphasis of analysis of the transcripts from being reported as diary research to a whole new analytic approach to the study. There could have been design confusion. I did not do the transcribing but when completed I spent more time familiarising myself with the data and

checked the transcripts with the original vlogs for accuracy. The original links for the vlogs were sent to the secondary supervisor to aid with inter-rater coding of the hard copy transcripts to enhance trustworthiness of the study. During this time, I marked ideas for coding into my code book as well as on to the transcriptions themselves. These were also sent to the secondary supervisor. Braun and Clarke (2006) argue that "... as there is no one way to conduct thematic analysis, there is no one set of guidelines to follow when producing a transcript" (p.88). The important thing was that the transcripts had the information that was needed. (Figure 2).

01 mer of a PI we No P2 doubt 500 Marken Mark 11 12 P4 11 confidence where I was they p ut it. daulst le online, it kinda PS w?". If they ha all m did you get the results y and when I lay it out th igs I say È 26 27 28 29 30 31 P6 but a fair few pe they ple can read thei not give insta D7 31 32 32 they are p Recovery process 33 34 35 36 37 35 36 37 P8 39 40 41 42 43 40 41 42 of me l is it just a case of not be pq ork right no ust so muc - of proce P10 46 mertatizaba int and sud in that sp cific po tattara

Figure 2 Example of coding of transcribed vlogs (Note. Figure 2 demonstrates the approach

to coding the transcribed dataset).

Coding is identified by colour highlighting, identifying both semantic and latent forms of coding. Transcriptions are numbered by line and paragraph for ease of referencing when constructing themes. Preliminary themes are noted in red with latent codes in black, while green highlights a meaning unit.

3.5.2 Step 2: Generate Initial Codes

The second step generates more codes from the data. This is done at both the semantic and latent level, which is proper because the analysis went beyond the semantic coding to an exploration of the underlying ideas, assumptions and conceptualisations that acted to shape and inform the semantic content of the data (Braun & Clarke, 2006) (Figure 2). Latent thematic analysis was not only a link with the constructionist design but also involved interpretative work, for example being involved with the recovery of self and discovering how the PSs are understanding recovery. By utilising latent coding, the data is reviewed with a specific question in mind, which is "how do adults with schizophrenia experience recovery?" All coding was done manually. Notes and words were written on the transcripts to identify segments of the data and different coloured markers to indicate the patterns across the dataset.

3.5.3 Step 3: Search for Themes

The third step began when all the data had been coded and collated (Figure 3) This step involves analysis of the codes to consider how these codes can be classified into themes. The first theme identified was medication (Figure 4). This will be used as an example regarding how the remaining themes were classified.

ADULTS WITH LIVED EXPERIENCE OF SCHIZOPHRENIA INTERPRET RECOVERY PROCESSES



us g

Figure 3. Codes form emerging themes.

3.5.4 Step 4: Review Themes

Figure 4 shows the re-focusing of the analysis that involved collating all the relevant coded data extracts within the theme "medication" for example. In step four of Braun and Clarke's (2006) thematic method, the themes are reviewed. As a way of checking to see whether the themes were coherent and distinct from each other I asked myself two questions: Do the themes make sense? Does the data support the themes?



Figure 4. The emerging theme of "medication."

3.5.5 Step 5: Define Themes

The preliminary theme of recovery was not a theme at all. This was picked up during the inter-rater process. It was an overarching concept. Due to this it did not hold and was combined with the other existing themes that appeared and as a concept aided in the deduction process that saw the emergence of mood and connection. Note, the map shows recovery as being a theme. The coded extracts were merged with existing themes after this map was constructed.

A mind map of the themes (Figure 5) shows the significance of the individual themes. As was mentioned earlier, thematic analysis according to Braun and Clarke (2006) can be flexible and, when doing research, steps 5 and 6 of their method can be used in a non-linear fashion. The themes were defined and written-up during the search for themes at different stages of the analysis. At this stage most themes were formed and stable, however, what I tried to do was identify the essence of each theme. I concluded that connection was the metatheme that encapsulated the emergent themes. Then mood was construed as being a mind-set that cannot be learned. Figure 5 is a mind map of the themes and the meta-theme connection in pencil with a question mark, as this was when it became clear.



Figure 5. Mind map of the themes and meta-theme of "connection."

Morse and Richards (2002) argue that the seeking of themes can begin at the beginning of a study. Consequently, I began analysing the data concurrently as soon as it was made. I already had a strong idea of how I was going to analyse it because I had determined early in the study that I was going to use interpretative phenomenological analysis to analyse the data. Applying this method, abstracting (looking for themes) can occur during the first stages of data gathering as earlier ideas and knowledge are not bracketed. Thematic analysis offers an analytical approach to rapidly developing an overall overview of qualitative research topics. Given this, I already had derived themes from the data and was to some extent informed by an earlier minor thesis on the topic of schizophrenia. Therefore, the scope and content of each theme was merged into steps 3 and 4 and the flexible nature of thematic analysis accommodated this. Applying inductive reasoning aided the development of empirical generalisations and helped find relationships between codes across the dataset.

This experience of generating meanings from the dataset helped me understand the processes of research that will help me in my future undertaking of doctoral research. For example, I will be able to interpret the experiences and meanings of the PSs about the process involved with schizophrenia in recovery through reviewing the dataset, looking for any regularities and drawing general ideas about the meanings and nuances from them. Such bottom-up thinking was central for the study as subjectivity and meaning are a characteristic of inductive reasoning (Creswell, 2013). It was the patterns, resemblances and regularities in the PSs' experiences that were observed to reach the conclusions of the meanings given to recovery. Deductive thinking was also employed, as shown in all the analytic figures, when the themes were being developed and constantly checked against the data. (Creswell, 2013).

3.5.6 Personal Reflection and Reflexivity

(Ideas for this extract come from Braun, V. & Clarke, V. (2006)).

My thoughts on the analysis are that the process presented me with some challenges that I think would be apparent not only for the inexperienced researcher like myself but also for the initiated. However, it was a good decision to use the "how" of analysis of Braun and Clarke's (2006) thematic framework as it helped me illustrate the work involved in getting from transcripts to themes. During the lead-up to the analysis of the dataset, I found collecting the data straightforward as I was aware that immersing myself in the field happens in several ways. I realise now though how fortunate I was to be able to view the vlogs while reading the transcripts. I was able to use multiple senses in viewing, listening, and reading, in particular, the results chapter. What might have enhanced this even further was if I had transcribed the dataset myself. This would have familiarised me even more with the PSs' experiences and meanings of schizophrenia in the recovery process.

My Extract (Ideas for this extract come from Roberts, B. (2007).

I have had to learn not to neglect my experiences of the research process. For me, the experience is an adventure. It is what Roberts (2007) argues is a "voluntary departure from the mundane world" (p. 5). A world that at times can be a lonely experience outside the academic department. It can be a monkish experience (Roberts, 2007). The adventure is what creates the excitement of social investigation and a sense of discovery. Such discovery is not only "out there" but within me. For example, many times I asked myself "whose side am I on" as a researcher? The social structure or am I pathologising situations with my research? The research has been distressing and emotionally isolating at times where I am in two minds. One, is the research about me or two, the connection with the PSs? Research to me is more than just graduating with a Master of Philosophy (I have a few academic qualifications and have never been to a graduation ceremony). Rather, research to me is about helping the existence of being-in recovery for those who are not fortunate enough to be in my position. That is, knowing that I am acquiring knowledge through the required training for research in a Higher Degree Research area at university with professional and expert guidance coupled with my own lived experience of being in the recovery process of schizophrenia. It is a big responsibility knowing that the credibility of my qualitative research study depends on my ability and effort. Researcher bias can be real, but I truly listen, read and take on board the PSs' stories, experiences, and meanings and therefore it is extremely important not to neglect my experiences of the research process as these PSs not only depend on themselves but those who are academically privileged to be reliable in giving their voices. The key strategy that I use to ward off neglect is being reflexive. I am learning that through reflexivity I have become more self-aware and check and control biases by reverting to my personal recovery but not to the extent that all those in recovery are like me. Rather, I think they are not like me because not everyone has my disposition. So therefore, those differences are seen by me as exciting personal resources emanating from the PSs that are certainly worthy of further

attention by mental health professionals and non-professional people with schizophrenia in the recovery process.

4.0 Results

The purpose of this chapter is to present the key findings and describe them within an analytical framework. The "existential structure of being" (Frenchette, et al., 2020, p.1) is found in the themes of 1) Medication, 2) Suffering, 3) Stigma, 4) Meaning, and 5) Self. These themes are not implied to be sequential. The reason for this is because the nature of schizophrenia in the recovery process is ultimately non-linear. The themes described in the results section are the elements that go towards making the whole through synthesisation with the phenomena experienced in recovery. Synthesisation of the themes as parts and then into the whole is described in the discussion chapter. After extensive analysis, an explanatory framework appeared to describe the results (Figure 6). These results suggest that moods of the PSs were necessary for connection to matter to them as they became attuned to recovery.



Figure 6. Themes that go towards the structure of being for recovery.

A total of 12 adults with schizophrenia in recovery uploaded their experiences onto YouTube. Only six responded to a request for consent to use their vlogs in the study. However, the uniform enthusiasm of the six who responded indicated that for the remaining six there should be a high likelihood of them responding if they were in receipt of the request and physically able to respond. Some were uncontactable through their channels perhaps due to the vulnerability of side effects of medications for schizophrenia. Others had channels that were quite old. Therefore, because the likelihood a positive attitude seemed high, all 12 vlogs were transcribed and used in the study. They were purposively sampled. To answer the research question themes were derived from the PSs' experiences within the recovery process. The analytic process was done manually. After "fracturing the data" (Morse & Richards, 2002, p. 115) they were then categorised into themes. Across all themes moods manifested in different ways. This is a holistic process expressed as taking the whole apart only to use the individual extracts at this point to make up the whole again later in the discussion chapter. In introducing each theme, a concise summary of what was found will be described.

4.1 Concepts of Recovery

An important consideration when interpreting the phenomenological experiences of individuals in recovery is to determine the meaning they assign to recovery itself. Moods are detrimental to such experiences. As the concept of recovery varied between the PSs, it seems helpful to illustrate how the PSs view recovery in their own terms before proceeding to extract the themes that arise from their descriptions of their own experiences.

PS/2 argues that recovery requires:

"Numerous vitamins and minerals first of all" (L, 18-36) "... then a ketogenic diet ... would be worth it if that leads to a recovery from schizophrenia" (L, 69-70). Then he/she recommends "... you initiate an exercise routine ... [as this] ... boosts your cognitive ability ... in schizophrenia. It gets rid of a lot of the cobwebs in your brain" (L, 76-8). "Mostly aerobic exercise and weight training three times a week for 20-60 minutes each session" (L, 81-3). The next step, 3, is a lifestyle intervention. One needs to stay "highly occupied as your mental health is a lot better" (L, 97-102). Being occupied means "having a robust routine, being socially engaged, having meaningful things that you do during the day, reflecting well

on your day, having variations in your environment such as going to a store or going to school or going to a workplace" (L, 104-7).

PS/3 describes the elements in the recovery process:

"... include minimum medication, useful occupation, supportive friends and family, rest and relaxation and talking therapies. I like to think of it as trying to create a place for you in the universe" (L, 29-33).

PS/5 argues that:

"... everybody has to have discipline not to allow the agitation that initially comes, not to buy into it and let it take its own course because it doesn't go in the right place, it doesn't end up in a good place, so we must practice discipline, not to buy into negativity and just burden it. I mean, do it, deal with it. Be brave. Have integrity. Be noble (L, 88-93) ... your recovery will be much quicker ... [if you do] ... [.]" (L,105).

PS/5 believes the best process in recovery is to:

"... tell the voices you love them ... you support them. Tell them, we, I or we, support you. I believe in you" (L, 34-6). "If you try to talk to yourself, I know the voices will intrude upon the mind to the point where one is actually convinced that they can hear your thoughts and it's hard to have just a thought on your own without their interference, but you need to work through that. You know if I'm hearing something as I'm walking down the street, just ignore it. Just mind your own thoughts ..." (L,45-5). So, PS /5 suggests that recovery is "... not about what happens to us so much, it's how we deal with it. It's how we think about it" (L, 70-2).

PS/5: This PS had not the usual ideas of being in the process of recovery. Rather he psychologically consoled his voices. For example, he said:

"... you have to make sure that you do not, do not feed the beast. So, if the voices are antagonising you with negativity, calling you names, accusations, you do not want to engage

with the voices. You know, in your mind I mean, right. You are not talking it; you are thinking it. You don't want to engage with the voices in a negative fashion (L, 16-21). Obviously if we are hearing positive messages, words and message, words and phrases it can be inspirational, it can motivate us. However, ... the tragedy is, most of the time at least, for the first 10 years or so ... [of schizophrenia] ... the voices are hostile. They say different things that are derogatory, judgements, accusations, and such" (L, 10-2). Then again exercise was important in the process of recovery argued PS/6 as it "... keeps you motivated through the recovery ... like I personally used to run 10 minutes a day and just running 10 minutes a day would clear my mind and it would bring down the symptoms up to a large extent" (L, 57-8). In addition, he/she like most of the PSs in the project took "medication regularly" (L, 63).

Medication was the first step in the recovery process for PS/7 "I had nothing to lose so I stayed on medication" ... [and] ... "since the medication was working well, I made a plan for the rest of my life and I started studying substance abuse counselling" (Ls, 20; 33-4) He/she kept taking medication and:

"... got involved with NAMI, the National Alliance for Mental Illness by joining a support group where I learned more about my illness ..." she/he said (L, 24-5). Step 2 in my recovery process, PS/7 said, was that "... I made a plan for the rest of my life, and I started studying substance abuse counselling" (L, 33-4). I began "... volunteering at a non-profit that provided substance abuse education courses". Thirdly saw PS/7 join a "clubhouse" situated in his/her local mental health centre (L, 44-8). The next step "... in my recovery was establishing a social network. Schizophrenia made me isolated. I didn't see anybody. I didn't have any friends or anything while I was undiagnosed" (L, 50-1). Now he/she was constantly "working on my career, ...and I have a job in the hotel industry and I'm just starting to look at jobs beyond my experience and more towards jobs based on my volunteer work and education" (L, 55-7).

Also, another factor reported by PS /8 that aids in the process of recovery is finding meaning such as:

"... connecting with goals and activities ... [that can make] ... life worth living" (L, 112-13) as well as "connecting with their aliveness" (L, 121). The extracts from the uncited papers she references also argue that people with schizophrenia find it important to connect with themselves, particularly "... their feelings, needs and sense of self" (L, 123-5). Moreover, PS/8 referred to several articles he/she claimed to have been authored by reputable researchers in the area of the social sciences. For example, it was said that one of the main things that aid those with schizophrenia in the recovery process is:

"... the belief that recovery is actually possible" (L, 88).

PS/9: Saw talking therapies as beneficial for recovery. Therapies such as cognitive behavioural therapy (CBT) and psychotherapy along with a ketogenic diet were put forth as being beneficial in the process of recovery. Not that this PS had used any of these, but she was eager to suggest that:

"... people were able to recover from schizophrenia fully, without medication" (L, 4-5). She does say that "... it's a scary disease ... so it is hard to realise that it may be possible that people can live without medications with schizophrenia because people are scared. They are scared that that is possible because what if something goes wrong, you know?" (L, 46-9).

PS/10: The recovery process for this PS was finding a purpose in life. This was firstly done by connecting socially, contributing. PS/11 said:

"... I think it's really good to get out there and be part of something and then from that really try and, what helped me was really trying to give myself a purpose like somehow feel like I am contributing to something" (L, 52-4).

To get the life you want to live, to get back to who you want to be (L, 98-100). PS/10: "Saw sleep, sleep and more sleep as the key to recovery". He said:

"I have discovered sleep is extremely important" (L, 133). He goes on to say "... I mean, I was sleeping one or two hours a night if I was lucky for months and months and months and obviously this escalates your symptoms" (L, 140-1). A lot of people "get quite a few hours' sleep but don't really sleep deep and so it doesn't really register because it's all cellular rejuvenation and cellular growth and your mind needs that respite every evening. Every night. Shut down. If that's not happening that is one thing that can really affect your mental health and your path to recovery" (L, 160-3). PS/12: This PS had a particular mindset that enhanced the recovery process: Being in recovery "... it's a fight, you know. It's a struggle. It's something you have to wake up every day with a mindset and be determined to do ... and it's something we have to actively do and who would not want to fight for their existence?" (L, 64-5; 71-2)

PS/12 views recovery as a psychological destination: He notes, "... we shouldn't think that there is just one way to get to the destination, through meds or sometimes people say that you can eat certain foods or drink a certain amount of water" (L, 178-81). He goes on to say that "... the route I took never gave me results overnight, it wasn't just over a year, it was consistency and determination and over a few years I got better and better until one day I was walking, and I realised everything stopped. Nothing." In addition, "... I was so used to being abused and tormented that I went looking for the voices. I didn't know how to exist without them. It was pathetic. Then sure enough they came back, and they beat me down and I regretted ... looking for them so when that happened, I remembered how they came back and I just kept walking and I just kept being grateful you know, and that's really how it is" (L, 187-200). PS/12: Argues that keeping occupied is the key to the recovery process: He says "... if you're just sitting there waiting for the cure, well there is something you can do in the meantime because life still goes on and unless you start doing something this illness is going to be chipping away at you" (L, 204-7). The thing PS/12 says to do is "... embrace

today and start taking back yourself today. You might as well get ready to fight. It's for your life" (L, 213-1).

4.1.1 Theme 1 Medication

The important thing found in theme I was that the PSs talked openly and positively about taking medication and how well it worked. PS/6 implies that the only way to achieve self-determination and autonomy is to adhere to the medication regime. For example, PS/6 argues: "I have had two relapses in the past" (L,3) "Now I am on medications and have been for the last five years" (L,4). Before this "when the onset of the illness started, so for the first three years I denied taking any medication. I just thought it was in my head and just in my thoughts. So, I tried to control everything, but I was deteriorating in my work life, in my social life and my studies were getting very poor so everything was degrading, and I was totally coming to the road" (L,4-7). Medications are essential for the PSs in the recovery process. The process of taking medication can be subjective. To begin with, a low dose with gradual titration up to an effective level is generally recommended, but some psychiatrists do this, and some do not (McLaren, 2010). There are those that prefer to begin with a large dose and work back. PS/3 sees part of the strategy for recovery as: "Minimum medication … and finding the right medication … for recovery".

There are high levels of non-adherence to medication among people with schizophrenia (Galletly et al., 2016) but this was not prevalent among the PSs in the study. The PSs spoke of medication as being extremely beneficial in the recovery process. For PS/7, like most of the PSs, the medication allows them to connect with self and gain insight to their illness. For example, given that PS/7 "needed more psychoeducation than a two-paragraph printout" it becomes evident from the extract that for PS/7 cognition is clearer when taking medication. He/she said: "… I was given a two-paragraph printout from a website telling me what schizophrenia was … I remember thinking what are hallucinations? and I had extremely

poor insight, which is typical of most people with schizophrenia" (L, 16-8). Then after taking medication PS/7 thought "my mum can't see my thoughts, that's impossible" (L, 22). Overall, the PSs interpretations of medication supported the de Jager, et al. (2016) study, in that medication contributed to recovery by enabling those with schizophrenia to function better, communicate with others, engage in activities, and think more clearly. PS/7 is clear in the expectation that the medication enhances the ability to think. This PS also reports that the medication works well.

Moreover, for PS/7 medication is described as the first step in the recovery process: "I had nothing to lose so I stayed on medication ... [and] ... since the medication was working well, I made a plan for the rest of my life and I started studying substance abuse counselling" (Ls, 20; 33-4).

Ultimately, according to Theme 1, this is what helps several of the PSs to make sense of their experiences in recovery However, PS/1 expresses mixed emotions about the ability of the medication to work. PS/1 says: "I don't have the ability to go to the psychiatrist to get medication that works" (L, 65). PS/3 considers the question of which type to take. According to PS/4, the medication did not work at times, and at others PS/4 was grateful the medication was taken. This appears to support Gray and Deanes' (2016) study that found medications were often considered both good and bad at the same time. Further, there is no miracle cure when the medication was taken, according to PS/4.

PS/4 supplies an example of meds not working for the person at times but still being eventually grateful they were taken: "Some people could be led on to believe that the second you receive medication you are instantly better. No, not at all". (L, 262-3). PS/4 goes on to say later, "Thank fuck I didn't stop taking the medication" (L, 274) and proposes that "the problem with taking medication in schizophrenia is that there is no miracle cure in the sense

that there is not one specific brand they give you and suddenly everything is fine and dandy" (L,278-9).

PS/7 suggests that when talking about recovery and medication there is a rule of thirds that needs to be discussed: "... one-third of people who recover from schizophrenia are med compliant, respond well to medication, have few symptoms and can work and maybe have a family. The next third "... are also med compliant, still have symptoms and require some hospitalisation but are usually able to work and maybe have a family. Then there is the "...one-third of people with schizophrenia who do poorly, don't respond well to medication or usually don't even take medications". This PS "... was lucky enough to be med compliant and I have my side effects, but medication works well for me" (L, 4-14).

For PS/12 the ability to express oneself relies on taking medications. The only way to express him/herself is to take medication, but it challenges him/her at the same time it supports him/her, and this is a struggle for him/her. He/she reports: "... if I want to express myself, how can I do that without a fight? Or medication? Well, the medication gives you, the medication comes in, it doesn't take away the illness, it suppresses it. It's kinda like, when I think about it now, it's kinda like those Aspirins or whatever, those pills, that they say when you take it doesn't take away the headache, but it kinda just numbs it. Something like that right? It just kinda suppresses it. It's still there but it just suppresses it." (L, 104-110).

PS/9 identifies not taking medication as the key to recovery. For example, "... people were able to recover from schizophrenia fully, without medication" (L, 4-5). He/she says "... it's a scary disease ...so it is hard to realise that it may be possible that people can live without medications with schizophrenia because people are scared. They are scared that that is possible because what if something goes wrong, you know ..." (L, 46-9).

4.1.2 Theme 2 Suffering

ADULTS WITH LIVED EXPERIENCE OF SCHIZOPHRENIA INTERPRET RECOVERY PROCESSES

PS/1 has trouble getting to the psychiatrist due to being miserable. Suffering from frustration, PS/1 remarks: "I will just lay it out there thick. So, things that frustrate me about schizophrenia, yes, I see shit. Do I like it? No. No, I don't. Yes, I hear stuff. Do I like it? No. Do they say terrible things? Yes. Very terrible things. Things I would never repeat to another human being because it is the worst things I have ever heard in my life" (Ls, 17-20).

In addition, PS/1 is affected by the effects of schizophrenia. He suffers from frustration due to not being understood by others, so he opts to self-isolate and says: "... I lock myself in the bedroom for a week at a time, you know, that's just part of what it is for me, you know, that's just kinda how it has worked for me unfortunately" (L, 39-41). PS/1 (L, 67-9) has trouble getting to the psychiatrist due to being miserable: "... I just give up on going to the psychiatrist's office. You know, is that bad? Yeah, probably. Do I have miserable moments? Yeah, almost every day I wake up pretty miserable and I hate to say that but it's pretty miserable." PS/1 also adds: "OK it sucks, I'm miserable, I hate everyone. Not really though, it just seems like it because I'm never around anybody. But hey, that's just because I can't be around people too much. I'm too paranoid. I have things going on in my head to where I can't feel comfortable being around other people. You know, is that person talking about me? Is this person talking about me? I don't know. Who knows? We'll see." (Ls, 83-87).

Another form of suffering used frequently to describe schizophrenia is the existence of positive symptoms. PS/1 puts forth the experience of suffering what at times can be said and written but is generally taken for granted that in recovery it is not uncommon to be suffering positive symptoms. For example, PS/1 believes he/she has "cockroaches" on his/her hands (L,48). He/she thinks "do I? No. Do I? My wife/husband says no, so no, but every time I look down that's all I see. It sucks. Does it? Yeah, it really does. It's terrible but you know, it is what it is" (Ls, 49-50). For PS/4 stress and aggression are prevalent. PS/4 argues that
stress is a good example of suffering. He reports that he: "still has thoughts of, well, destroying stuff but I know why it happens. It happens because I get stressed and that's a common thing I guess because every single person in this world at one point in their life imagines murdering someone they truly hate" (L,112-16). On the other hand, PS/5 is philosophical about suffering and offers hope for the future: "... the people that suffer the most will have the most to offer in their future. That's how it is going to be, and it always has been that way" (L,70-1). PS/6 recognises the philosophical side of suffering when he/she remarks that: "Life is a suffering, but you know you have to decide how you want to suffer" (L, 67-8).

PS/10 sees hobbies as a wonderful way to distract from inner pain. PS/10 contends that occupying him/herself can be an aspect of recovery but also a painful one: "hobbies are an effective way to distract from worrying thoughts ... [and he/she] ... used to do a lot of artworks. Work with clay and stuff and I know for some people their artwork is a great form of release from all this kind of manic energy. All this suffering and inner pain" (L, 121-4). In the Hargreaves, et al. (2017) study, a hobby and any form of meaningful activity was found to provide many benefits towards distracting from pain and suffering associated with schizophrenia. The same PS argues that those who are suffering are driving change in the mental health system: "I think it's really good now that people in the mental health system are really starting to be recognised more and people outside the mental health system as well but people who have suffered are really standing up ... for who they are and what they have gone through and helping the public understand" (L, 12-5).

PS/12 also sees keeping occupied as the key to recovery processes. He/she says: "... if you're just sitting there waiting for the cure, well there is something you can do in the meantime because life still goes on and unless you start doing something this illness is going to be chipping away at you" (L, 204-7). The thing PS/12 says to do is "... embrace today and

start taking back yourself today. You might as well get ready to fight. It's for your life" (L, 213-17).

4.1.3 Theme 3 Stigma

For PS/4, the public desire for movies to supply insanity, drama and action is the reason that movies never really get anything right about schizophrenia.

PS/11 appears to think similarly, and comments about schizophrenia not being as bad as everyone thinks. PS/4 asks: "Have you ever stopped to wonder why media never really gets anything right? You know, professions and life, mental illness, whatever" (L, 7-9). Then he asks what the last movies were like you viewed that featured someone with schizophrenia. He says "... I can tell you one thing, the last movie I saw with someone was a flick with schizophrenia. They had two things in common which the media loves to regurgitate every single fucking time. They have murderous tendencies is the first thing they like to portray them as, and they hear voices" (L, 11-7). Why the media has portrayed schizophrenia so incorrectly is "... because nobody likes the story where people are just being normal, and things are working out. They want drama, action, the insanity" (L, 101-3).

For PS/10 such stigma is what drove them to upload their comments about stigma on YouTube, "because I mean the media more or less every day or you know within some newspaper or something, might have something negative to say about mental health patients and I think it's up to us, the people who are well enough to speak out on behalf of everyone because it's not on, really" (L, 15-8). The importance of this behaviour by the PSs cannot be overstated. Most forms of stigma in the wider literature focus on either self-stigma or public stigma. For example, public stigma can be the reaction that the general population has towards the PSs with schizophrenia. Self-stigma is the shame that those with schizophrenia internalise due to the public attitudes towards them that are usually negative and over time the person with schizophrenia may come to believe that there is a truth to such public

attitudes. As Sangeorzan, et al. (2019) note in the literature review, fighting stigma was paramount for the respondents in their study.

PS/11 states [there is] "... such a stigma around what schizophrenia is. Like people automatically assume that schizophrenia is a multiple personality disorder, when that is the opposite of what we are ... Then there is also the idea that we are dangerous and violent ... people really do believe that that is true. That is not true at all. We are not dangerous. We are not violent. Yes, like any human being in the world with any type of whatever, there is a possibility that someone will be dangerous and violent. That is a possibility with anyone who doesn't have a mental disorder. Yes, there is a possibility out there. That does not mean that all as a group, as a whole schizophrenia is dangerous or violent. It's not true" (L, 10-22).

4.1.4 Theme 4 Self

Schizophrenia can have a catastrophic effect on the affected person (McCann, 2016). Apart from the actual symptoms of schizophrenia that can interfere with the individual's ability to think and cope, which on its own can cause suffering, schizophrenia can also influence the person's relationships with others and themselves (Schon, Topor & Denhov, 2009; Borg & Kristiansen, 2004; Rosenberg, 1984). The illness challenges the individual's understanding of who they are, and this affects the very epicentre of their sense of self. There is a wide literature that has suggested that schizophrenia involves alterations in selfexperience and in how the afflicted person experiences themselves as well as during their interactions with others and their world (Perona-Gecas, 1982; Estroff, 1989; Sass & Parnas, 2003; Lysaker & Lysaker, 2005a; Lysaker & Lysaker, 2010 b; Perez-Alvarez, Garcia-Montes, Vallina-Fernandez & Perona-Garcelan, 2016; Fernández & Bliss, 2016).

For PS/4 loss of the self equals loss of the mind, and he/she is reminded of it when connecting socially. He/she said: "OK, so, I am just going to get down to the nitty gritty of it all, you know. Like, I know everybody is like 'where did he go', you know, 'he was making

so many jokes', he 'was so funny'. Well, I'll tell you where I went. I have been here the whole time; I've just been losing my mind. Just a little crazy" (L, 18-22). PS/5 reports that responding to the hallucinations negatively leads to negativity from the voices and responding positively saves a lot of time and energy and makes recovery easier. For example, "... if the voices are antagonising you with negativity, calling you names, accusations, you do not want to engage with the voices. You know in your mind I mean, right. You're not talking it you're thinking it. You don't want to engage with the voices in a negative fashion (L,13-5). Then PS/5 says "... no one likes to be picked on, no one likes to be abused, and it really is abuse but if you can avoid responding negatively you will save yourself a lot of time and energy and you will make your recovery that much easier to get forthwith. So, practice that. You hear negativity, respond positively" (L, 40-2).

PS/10 also believes that connecting with self is an important process in recovery. For this PS, personal dignity is a significant factor: "Dignity is really important ... especially when I got ill, I didn't clean myself for months and months and months. I wore the same clothes. Wasn't looking for my hygiene. My teeth. Everything you know, I lost a lot of dignity in myself because of that and because of what I went through, and you know going to psychiatric hospital and being in there for months and months, it's not very good for your sense of self dignity and self-confidence at times" (L,93-7). Like PS/12 he also argues that "... it's not going to happen overnight. If you want to get better and you feel like recovery is the right thing for you, working on your self-confidence and doing things step by step by step to improve your confidence is important." Talking therapies are seen as beneficial for recovery by PS/9, who mentions cognitive behavioural therapy (CBT) and psychotherapy along with a ketogenic diet as being beneficial in the process of recovery and recovery of the self. PS/12, however, views recovery as a psychological destination: "... we shouldn't think that there is just one way to get to the destination, through meds or sometimes people say that

you can eat certain foods or drink a certain amount of water" (L, 178-81). He adds that "... the route I took never gave me results overnight, it wasn't just over a year, it was consistency and determination and over a few years I got better and better until one day I was walking, and I realised everything stopped. Nothing ... I was so used to being abused and tormented that I went looking for the voices. I didn't know how to exist without them. It was pathetic. Then sure enough they came back, and they beat me down and I regretted ... looking for them so when that happened, I remembered how they came back and I just kept walking and I just kept being grateful you know, and that's how it is" (L, 187-200).

To get the life you want to live, to get back to who you want to be (L, 98-100), PS/10 sees sleep, sleep and more sleep as the key to recovery. He/she says: "I have discovered sleep is extremely important" (L, 133). He adds "... I mean, I was sleeping one or two hours a night if I was lucky for months and months and months and obviously this escalates your symptoms" (L, 140-1). A lot of people "get quite a few hours' sleep but don't really sleep deep and so it doesn't really register because it's all cellular rejuvenation and cellular growth and your mind needs that respite every evening. Every night. Shut down. If that's not happening that is one thing that can really affect your mental health and your path to recovery" (L, 160-3).

PS/12 has a particular mindset that he/she sees as enhancing the recovery process: Being in recovery "... it's a fight, you know. It's a struggle. It's something you have to wake up every day with a mindset and be determined to do ... and it's something we have to actively do and who would not want to fight for their existence" (L, 64-5; 71-2).

For PS/3 the elements in the recovery process: "... include minimum medication, useful occupation, supportive friends and family, rest and relaxation and talking therapies. I like to think of it as trying to create a place for you in the universe" (L, 29-33).

PS/5 argues that: "... everybody has to have discipline not to allow the agitation that initially comes, not to buy into it and let it take its own course because it doesn't go in the right place, it doesn't end up in a good place, so we have to practice discipline, not to buy into negativity and just burden it. I mean, do it, deal with it. Be brave. Have integrity. Be noble ..." (L, 88-93) "... your recovery will be much quicker ... [if you do] ..." (L,105). As a mode of temporality PS/5 believes the best process in recovery is to: "... tell the voices you love them ... you support them. Tell them, we, I or we, support you. I believe in you" (L, 34-6). "If you try to talk to yourself, I know the voices will intrude upon the mind to the point where one is actually convinced that they can hear your thoughts and it's hard to have just a thought on your own without their interference, but you need to work through that. You know if I'm hearing something as I'm walking down the street, just ignore it. Just mind your own thoughts ..." (L,45-5). PS /5 suggests that recovery is "... not about what happens to us so much, it's how we deal with it. It's how we think about it" (L, 70-2).

PS/5 does not seem to express traditional ideas of being in the process of recovery by rejecting symptoms and manifestations. Rather he psychologically consoles his voices. For example, he says: "...you have to make sure that you do not, do not feed the beast. So, if the voices are antagonising you with negativity, calling you names, accusations, you do not want to engage with the voices. You know, in your mind I mean, right. You are not talking it; you are thinking it. You don't want to engage with the voices in a negative fashion" (L, 16-21). If we are hearing positive messages, words and messages, words and phrases it can be inspirational; it can motivate us. However, he adds: "... the tragedy is, most of the time at least, for the first 10 years or so ... [of schizophrenia] ... the voices are hostile. They say different things that are derogatory, judgements, accusations, and such" (L, 10-2).

PS/6 states exercise aids the process of recovery, as it "... keeps you motivated through the recovery ... like I personally used to run 10 minutes a day and just running 10

minutes a day would clear my mind and it would bring down the symptoms up to a large extent" (L,57-8). In addition, he/she like most of the PSs in the project took "medication regularly".

4.1.5 Theme 5 Meaning

For PS/1, having schizophrenia seemed at first to have little meaning, but he/she adds that it did mean a lack of hygiene. For PS/12 it means a struggle, fight and a particular mindset needed for existence. PS/1 states: "I am a schizophrenic. So, what does that mean? It doesn't mean a lot really." (L, 1-2). He/she adds, however,: "I don't even want to take a shower most days which is part of the illness unfortunately." (L, 15-6). PS/12 expresses a mindset that enhances the recovery process. Being in recovery means "... it's a fight, you know. It's a struggle. It's something you have to wake up every day with a mindset and be determined to do ... and it's something we have to actively do and who would not want to fight for their existence" (L, 64-5; 71-2).

For PS/8 finding meaning aids in the process of recovery: "... connecting with goals and activities ... [that can make] ... life worth living" (L, 112-13) as well as "connecting with their aliveness" (L, 121).

The extracts from the uncited papers PS/8 references also argue that people with schizophrenia find it important to connect with themselves, particularly "... their feelings, needs and sense of self" (L, 123-5). Moreover, PS/8 refers to several articles claimed to have been authored by reputable researchers in the area of the social sciences. PS/8 states that among the main things that aid those with schizophrenia in the recovery process, a fundamental concept is: "... the belief that recovery is actually possible" (L, 88). Williams, et al. (2018) in the literature review (Chapter 2) found not only being inspired: their respondents also reported that knowing that recovery is a possibility helps in the recovery process.

Therefore, to be in recovery meant that there must be a particular mindset, a belief built into the setting of goals and becoming active, that life must be worth living.

4.2 Personal Reflection and Reflexivity

(Ideas for this extract come from Heidegger, M. (1993)).

When I was describing the recovery concepts experienced by the PSs what was clear in my mind was the moods that are apparent. At first, I thought about such moods as being psychological but after many reads of parts of Martin Heidegger's text Being and Time (1993) my mind shifted to the practicalities of the affective nature of schizophrenia. Moods do not have to be anything other than an attunement with the world. I say this because I still have moods though. So, if I still have moods, it only seems reasonable that the latent aspect of the experiences of recovery processes the PSs report in the results must be seen as a mist of moods that lingers from PS to PS. Unlike a mood, an emotion can be the result of an external stimulus. The key difference that I can gather is that moods can last for a longer period, unlike emotions that can last only for a brief period. This was an exciting finding as reading Being and Time had a distinct sense that I was in fact understanding only a small percentage of it. Without exception that text was the most challenging at times Ununderstandable text, I have ever read. The main challenge was the unfamiliar words. This was such an uneducated experience I thought at first because I was expected by my supervisory team to understand. Clarity was expected as being the hallmark of proficient writing and because I kept thinking I cannot read this because I do not know what the words Heidegger uses mean. This put me in a mood of hopelessness until I just kept reading and kept thinking it is only one word here and there so even not having a clue what it meant I just kept reading and by the end of some sections of chapters, even stuck on some paragraphs for quite a while here and there I sort of became attuned to the gist of it. I did not read the text from cover to cover. What I did was select through the contents list and the index and read a companion

text of Being and Time by William Large (2008) and then I let go of the pre-understandings I had regarding understanding and trusted that a knowing would come. In other words, even though my study was qualitative my mind still found my brain anxious for logical reasoning, but Heidegger's text uses familiar words differently. In doing so my mood changed to one of a learning. That is, I have learned through Being and Time to be opened to not-yet-found possibilities. Be patient, everything is not scientifically bound by reason. "Voila" I thought, because this was when I had the understanding that mood was the foundation for connection. Reading with a sense of not understanding turned out to be a new insight beyond conscious engagement. I had become interpretative because Heidegger allowed me to look for what lies behind things. It is as though I received a gift from the struggle of reading Heidegger!!! It is philosophers that open the positiveness of possibility as a way for mood and connection to deepen understanding of the phenomena, recovery, central to this thesis. In essence, what would be the use of completing a Master of Philosophy without input from, for example, a philosophical thinker such as Heidegger. My interpretation then, of experience, means to learn. No one can teach me how-to-be in the moods I find myself in and this is a reason the lived experience of the PSs in this study are a wealth of information for professional and nonprofessional people around mental health/illness and schizophrenia in recovery.

5.0 Discussion

The aim of this study is to understand how adults with schizophrenia experience recovery. This study adds to the body of literature about recovery. In this section the results are situated in the broader literature. The interpretative design, qualitative approach and the thematic focus to dataset analysis have proved to be a good fit for the study. The reason for this is because the objective was to understand the meaning and experiences of those with schizophrenia in the recovery process. I agree with Spiegelberg (1982) when he argues that Heidegger places greater emphasis upon the social and environmental contexts. These contexts shaped the meanings and experiences that the PSs placed upon the world around them in recovery. The meta-theme becomes clear, and this is connection (Figure 7). The everyday existence of the PSs appeared to be permeated by many affective experiences of themselves, others and the world around them. They seemed to motivate, and I would go so far to say even compel them to pursue connection to recovery with all its fundamentals. It is mood that makes connection possible.



Figure 7. Meta-theme of connection

In the discussion the themes described in the thematic analysis (Figure 2) overlap once a meta-theme of connection is applied, which anchors the individual themes in an overarching interpretation of how the lived experience of recovery is described by the sources.

Interpretation is what synthesises the themes into the meta-theme of connection. Using medication allows individuals to connect with self, where gaining insight allows a connection with others. This results in connecting with activities, and this meta-theme becomes a major characteristic of schizophrenia in the recovery process. Arguably, the individuals being-there, existing, appears to be a connection. In discussing the themes, they are condensed and the meta-theme of connection is revealed. The discussion will be of a generic nature addressing the core of the PSs' moods, thoughts and experiences. This means extracts from the results section will be used sparingly in the discussion. By focusing on the generic after being sure to pitch at the analytic idiographic level in the results section, feels strange as it was important to focus on individual experiences which make up the totality of experiences that constitute the recurrent themes. However, the generic focus illustrates the part-whole relationship of the hermeneutic approach (Smith, Flowers & Larkin, 2012).

There are many, and often differing, examples of what is needed for recovery as experienced within the recovery process: numerous vitamins and minerals and a change in diet, exercise and keeping occupied. Minimum medication along with being occupied, friends, rest, and relaxation and talking therapies are all presented as beneficial for recovery. Practicing discipline, being brave, with integrity and nobility, enhances recovery, and even the best way to experience recovery may be to interact with voices in a positive way by consoling the hallucinatory voices. Exercise is important along with taking medication regularly. Having support both professionally and from family and friends, along with a good medication regime, aids recovery. Recovery is possible and finding meaning through

connecting with self is important in the recovery process. The results showed that talking therapies were viewed as beneficial in the recovery process. So too the benefits of sleep as a key to recovery, while connecting with self where dignity is important. The desire to get the life you want to live and back to who you want to be is what recovery is about, with the process of recovery consisting of finding a purpose in life and connecting socially and contributing. Recovery requires a mindset, a mood that enhances the recovery process, being determined to do something to fight for existence, accepting that recovery is a non-linear process, and it is essential not to just sit there but keep occupied.

Consumer definitions of recovery appear from different historical and experiential contexts. People with schizophrenia have been a marginalised minority, stigmatised both from within and outside the mental health system. Rather than outcomes, William Anthony's (1993) definition of recovery emphasises recovery as a process: personal development and the restoration of meaning and purpose. What is important for those with schizophrenia is that they work on who they are, and the illness does not define them. Being-there in the process of recovery for those who have schizophrenia means they have taken medication and transformed their self where mood has played a role in creating an environment that enables them to connect with other individuals also.

5.1 Connection & Medication

Connection is the key to recovery. By creating possibilities through moods, an understanding can be made by those in recovery where they accept that the illness is real and gaining insight about this comes from taking anti-psychotic medications. In this study professionals did not appear to hold the key to recovery. Rather, those with lived experience did. In the present study phronesis played a central part in the process of recovery. Such practical wisdom saw existence "attuned" to possibilities of connection with their selves primarily (Brencio, 2018). This allows the gaining of insight to their schizophrenia (Sumskis,

et al., 2017) which in turn allows the PSs to have a distinct presence of self when engaging with the world (Escudero, 2014). Medication is essential for reconnecting with the self, and this is needed because schizophrenia can lead to a disconnection of self. Researchers such as Lysaker and Lysaker (2010), and Lysaker and Lysaker (2005) along with Sass and Parnas (2003) argue that schizophrenia causes a form of exaggerated self-consciousness and a diminished sense of existence in the world.

Existence, in Heidegger's Being and Time (1993) is not to be understood through the traditional philosophical distinction between what something is and the fact that something is; rather, through possibility. In other words, human existence does not just exist in the way that a stone, plant or animal exists. It makes its own existence because it is something that matters to it individually. Existence will always be mine/yours, and not merely an indifferent logical statement about all things (Large, 2008). It could also be "an ability to be, as one which is in each case mine, is free either for authenticity or for inauthenticity or for a mood in which neither of these has been differentiated" (Butler-Bowden, 2015, p.126). That mood, for example, I interpret as being-in-the-world and being conscious of schizophrenia in recovery as an embodied, worlded human being (Escudero, 2014). Being then gets you access to existence and allows for the connection with recovery. For those with schizophrenia gaining access to their existence, and ultimately what it means to experience recovery, means this is life. Recovery can be experienced positively because mood and the medication allow insight to be prevalent. Relating to self and what is around them, wondering about it and asking lots of questions can be how their selves are situated regarding how to be. To exist in the process of recovery within the notion of being-in-the-world is viewing life from the inside out. This is where Dasein (the kind of being you are when you are being there) (Large, 2008) becomes relevant, being-there for instance is being in recovery, and tormented due to the loss of self

that is a characteristic of schizophrenia. This is highlighted by many PSs in the study, and an attunement, a mood towards medication allowed a connection.

Dasein's existence can be understood in terms of possibilities and not properties, making every existence singular. Large (2008) argues that it can be perfectly possible that people can face the same possibilities (recovery), given that the same world can be shared, but how each person faces such possibilities and the meaning given to such is always going to be deeply personal. Recovery is highly personal and using the example by Large (2008) this is because Dasein's existence can be understood in terms of possibilities that makes existence singular, individual. As existence is an individual thing explored and interpreted as being individually theirs, such mineness enhances the possibilities towards authenticity. This is where the choice evolves of being who you are, and not being how sane or normal you are. The person with schizophrenia can own their ways of being/existing. Interestingly, Heidegger does not use authentic existence as the template for what it is to be a human being. Rather, he begins with average everyday existence (Large, 2008). To appear to exist authentically recovery is chosen in relation to possibilities. This highlights that existence, or way of being, can be personal for those with schizophrenia in recovery. Importantly recovery can be owned. Those in recovery exist as a who and not as a what. They leave the categorical world of things (remission, schizophrenia) behind and take up the existential being of Dasein; in other words, existing as a who and not as a thing such as a schizophrenic.

5.2 Connection & Suffering

Suffering can certainly be an issue for many with schizophrenia. It can be a frustrating and miserable experience, which can make connecting socially difficult. However, due to practical wisdom, those suffering can be full of hope for the future and very philosophical. Such an intrinsic connection can be a careful attunement towards the disposition of the person with schizophrenia in recovery overall where being miserable –

while making connecting with others challenging – also allowed for the possibility of virtuous existence. It becomes clear that phrenetic behaviour can make those with schizophrenia in recovery attentive not just to what is happening but also to what could happen. In other words, according to Comte-Sponville (2003) this type of prudent behaviour goes far beyond the mere avoidance of unpleasurable experiences. Rather, it assumes courage. Repeatedly, from my own experiences with schizophrenia, I have recognised this. According to Aho (2019) connecting through a sense of being immersed or belonging to the world is constituted due to an attunement to the world by mood, and suffering.

5.3 Connection & Stigma

Stigma creates dangerous moods in all those with schizophrenia, in recovery or not. Not that I personally have been forensically violent towards myself or another, but the affective nature of schizophrenia can be extremely challenging for mood attunement towards the world. YouTube can be an avenue for dissemination of comments about the reason the media loves to regurgitate the dangerous tendencies those with schizophrenia are supposed to have. That being said, many people want movies to be action packed, dramatic or filled with insanity. Such dissemination allows for connection with others and fosters relationships. Sangeorzan, Andriopoulou and Livanou (2019) found that in their study of those vlogging about the lived experience of schizophrenia, creating and publicly sharing mental health vlogs can not only benefit, but encourage recovery in people with serious mental illness such as schizophrenia. The second aspect is that moods can be insightful regarding ways of existing.

Existence must be situated. Moods allow for understanding the concrete situation that individuals find themselves in. Moods point to where they are and what they are doing. In situating a sense of being-there, moods can act as a way of being connected to the specific world of recovery (Sass, 2004). The stigma situates them whether they like it or not and this

is a fundamental part of who they are. Existing is being deeply involved in the situation of schizophrenia in recovery and stigma. Being affected means that lives are organised in certain ways. They are organised around their moods, and these tend to structure the way they think about being-in-the-world (connecting). Existing is interacting with what is possible (Large, 2008) and moods are central for this.

The positions that people take can reveal the way in which they are and where they are. The way a person can exist shows there is a connection to a world that they were always in. At this point I felt as though I was getting somewhere into the mind of Heidegger with the aid of Brencio (2018) and the excellent adumbrate of the pathic dimension of existence, and how relevant this is in schizophrenia and recovery. Brencio (2018) uses Heidegger to argue that moods play a pivotal role in schizophrenia. As an interpretation, I would also add that due to experiencing such, I cannot exist apart from the world. My basic way of being connected to the world comes from my emotional mood-based attunement, not perhaps through reason or intellect. I am aware how this contradicts with the views of many psychiatrists, but I too am existing, actively connecting with the world around me due to moods, and stigma plays a certain role in my understanding of who I am. Stigma helps deepen self-understanding as it reveals how to become free from prejudices/stigma.

5.4 Connection & Self

A disconnection of self is common for those with schizophrenia. Heidegger's text, *Being and Time*, is largely an account of what it means to be a self. Each Dasein is a self. Escudero (2014) argues selves are neither fictions nor are they artificial constructs fabricated by anxious people. Dasein possesses certain possibilities, understandings of the sense of its being, and of being in general that is determined by a strange kind of self-generating temporality. This means that those with schizophrenia can stand outside time and project themselves through the understanding of recovery into the future and into the world through

the past and be able to reconnect with themselves in the present. Viewing temporality and time in this way is existential as opposed to categorical. By going mad, such temporality in this sense can broaden the horizons of those with schizophrenia where experience about recovery, situations of connecting with other people, and eventually with him/herself are apparent. Jesus Escudaro (2014) appropriately points out that for Heidegger, having a self-experience does not mean that the experiential interaction with the world and others is interrupted to strive for a detached and ontological self-contained self. From this view the self is not something that exists independently of, or separate from, the experiential flow. According to Escudaro (2014) the reason for this as explained by Heidegger is that self-reference of a world-immersed self.

Phenomenologically the self is wholly compatible with a strong emphasis on the fundamental being-in-the-world of each self. From this point of view then, even finding themselves disconnected from themselves due to schizophrenia, the PSs are still primarily a worldly situated self already connected to the world of recovery. For Heidegger, the self is not to be interpreted as the large core that gives identity to the experiences of the PSs' lives. If this was the case, it would objectify and de-world the PSs' existence. Dasein is always in the world, the PSs involved in recovery, their experiences being worldly where escape from the world of recovery is impossible. Even with schizophrenia, the PSs' existence is a co-givenness of self and world. What one PS did is connect with his/her existence. Another PS questions, wonders about it and ultimately understands that he/she is in the process of recovery by not wanting to engage negatively with hallucinations. From my own lived experience with schizophrenia, what he/she means is that he/she could hear his/her own thoughts, so rather than talk aloud when trying to converse with hallucinations, he/she thought them and would hear his/her own comments in retaliation to the hallucinations that were calling him/her names. When one is suffering with schizophrenia, one hears what one

thinks and hears what one reads. Such connection occurs with not only existence but with self-aided recovery in schizophrenia. Such articulation requires practice as dealing with itself Dasein is intriguing for the PS, and in so doing, the PS makes recovery easier by responding positively (thinking it, not saying it) when hearing/thinking negatively.

5.5 Connection & Meaning

Heidegger (1993) explains the care framework as "Dasein's primordial totality of Being" (p. 227). Such an existence reveals itself as care. By using a framework of care, "the way for the problematic of fundamental ontology – the question of the meaning of being in general" was prepared by Heidegger (1993, p.227). What the care framework makes clear is of consequence to the individual. Horrigan-Kelly, et al. (2016) suggest that the framework of care exposes what an individual is concerned with or cares about. People with schizophrenia are first and foremost concerned with their existence and recovery. In other words, they all appear to know that they need some general sense of their environment and where they are in it before they can understand recovery. However, this is found to cause anxiety (angst) and suffering in some instances. Further, Horrigan-Kelly, et al. (2016) argue that what the care structure can expose can be the individual's "future directionality or indeed their future aims, goals, desires or ambitions" (p.3). Heidegger distinguishes two kinds of care: care for things (concern) and care for other Daseins (solicitude). According to Heidegger (1993) solicitude is a type of care that reveals certain other beings, not as ready-to-hand or present-to-hand (i.e., like an object) but as there with us in the world. Consequently, there is not only connection with the world per se, but a connection with other PSs for example who have schizophrenia, and people who do not.

The suggestion is that there is both a specificity of focus (those with schizophrenia) and a type of caring that recognises the being-ness of the person with schizophrenia. Such focus and recognition connect those in recovery to the world and such a connection enhances

meaning for the person with schizophrenia in recovery. Care is what is argued by Heidegger (1993) as the source of the will, and my interpretation of this argument is that the will is part of the mind just like mood comes from the mind, and not the brain, and due to this a mood can be a deep connection to a world that is needed for any human activity. As such, a being-in-recovery is who they are. The understanding of what this means is that being in recovery is part of who they are, and the practicality is that they are being-there in the world of recovery. This is the project they are absorbed in where being occupied is essential. For Heidegger being involved is not a mere attitude, it is a way of behaving as involvement in life is practical (Butler-Bowdon, 2015). The interpretation is, connecting by being-in-the-world gives meaning to existence and recovery.

5.6 Thoughts on Heidegger and Connection

What has been presented as discussion is a view of recovery with moods and emotion being completely different from a conventional psychological interpretation. According to Butler-Bowdon (2013), Heidegger views the nature of being for humans as a constant state of varying moods. Feelings and moods are not to be passed over or belittled in relation to our real life or what activities pursued. As appears through the analysis, and especially in this discussion, moods are central to being and connection. All the time for those with schizophrenia in recovery, the experience of moods is understood to be feeling their way towards recovery. Through mood, connections are made with understandings becoming manifest either in a positive or negative way. These moods are enablers of those adults with schizophrenia to respond to the world of recovery. With moods there is no possibility of remaining neutral as they make the individuals in recovery mindful of what it is like to exist with schizophrenia in recovery. Butler-Bowdon (2013) aids the interpretation of meaning by suggesting that understanding of the world does not happen through neutral logical reasoning. Rather it springs from an individual's moods or dispositions. Further, Butler-Bowdon (2013)

uses Heidegger to point out that understandings always have their moods. The connection is the attunement of existence of those in recovery with the world around them. There is no primacy of world or individual: they are interconnected. In the first stages of recovery, individuals can be interpreted as being out of tune with existence/recovery. Then medication places them in tune with themselves, connects them with others, as well as connecting with events such as exercise, education and recovery. It can be the mood however, that allows those with schizophrenia in recovery to gather the understandings to be able to connect with their existence, themselves, others, and to participate in recovery and society by constantly attuning themselves to the understanding that connection is the key to recovery.

5.7 Limitations

The limitation that had the greatest potential impact on the study in general and could have hampered the ability to effectively answer the research question was not having the primary sources respond to any queries they may have had regarding my interpretations of their interpretations of schizophrenia in the recovery process. The potential to impact the findings was real. However, even with such a limitation I can defend the trustworthiness of the study due to the inter-rater coding procedure where part of my supervision team was active.

6 Conclusion

In essence, my interpretation of the interpretations given by the PSs in this study about their understandings of their experiences of being attuned to the process of recovery, revolved around attitudes such as beliefs, values, desires, doubts and assumptions, that constituted the dynamic subject matter of how they understood the experience of schizophrenia in recovery. There was something in the way the PSs found themselves in recovery that exceeded and surpassed rationality. They made recovery possible. How they found themselves revealed recovery, and its world, meant that any disclosing of being passed

ADULTS WITH LIVED EXPERIENCE OF SCHIZOPHRENIA INTERPRET RECOVERY PROCESSES

through not only reason and rationality but also the way in which they found themselves. As an ontological response, these characteristics of the mind make up not only what it meant to be in the process of recovery but also the constitution of this process and what it meant to be who they are. Being mooded beings disclosed a connection to the world of recovery where in this world things to do, places to go, and people to meet mattered to them.

For those suffering schizophrenia, gaining access to their existence, and ultimately what it means to experience recovery in the way that the primary sources (PSs) understood it, meant this is what life is. It is being connected with self and what is around you, wondering about it and asking lots of questions: to explore how to situate oneself or how to *be*. To exist in the process of recovery within the notion of being-in-the-world is viewing life from the inside out. This is where Dasein (the kind of being you are when you are being there) is tormented due to the loss of self that is a characteristic of schizophrenia. This is highlighted by many individuals in the study. Throughout the experience of schizophrenia in recovery, the majority report worldly significance is at times a fragmented congregation of conspicuous, obstinate and most times obtrusive states of affairs. Heidegger highlights that schizophrenia is a disturbance of the PSs' practical involvement in the world. Throughout their recovery the PSs are concerned with the inner-worldly beings they encounter, which they sometimes find it hard to communicate with, but know this was essential for recovery.

The study showed that moods can enhance an understanding of the concrete situation that the primary sources (PSs) found themselves in. It is one thing to describe and analyse connection to oneself, others, activities and things, but another to think of how the connections come about in the first place. Moods of the PSs were interpreted by me as being latent across all themes of the study. It was something I could sense, something I became attuned to which was my being-there where I found myself and the limits of rationality due to being a sufferer of schizophrenia. Existence and recovery must be connected and situated,

ADULTS WITH LIVED EXPERIENCE OF SCHIZOPHRENIA INTERPRET RECOVERY PROCESSES

and moods appeared to point to where the PSs were at, and what they were doing. In situating a sense of being-there, moods acted as the way the PSs connected to the specific world of recovery. Moods cannot be learned, and therefore recovery was self-initiated due to the affective nature of schizophrenia. Being affected meant that all the respondents' lives were organised around their moods which tended to structure the way they became attuned to connecting. This allowed for the subjective nature of recovery along with its visionary approach. So, not just connection plays a pivotal role in recovery, but moods do too.

References

- Aho, K. (2019). Contexts of suffering: A Heideggerian approach to psychotherapy. U.K. Rowman and Littlefield.
- Anthony, W. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11-23.
- Bejerholm, U., & Roe, D. (2018). Personal recovery within positive psychiatry. Nordic Journal of Psychiatry, 72 (6), 420-430.

https://doi.org/10.1080/08039488.2018.1492015

- Borg, M., & Kristiansen, K. (2004). Recovery-oriented professionals: Helping relationships in mental health services. *Journal of Mental Health*, 13(5), 493-505. https://doi.org/1080/09638230400006809
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101 1478088706qp0630a
- Brencio, F. (2015). Heidegger and Binswanger: Just a misunderstanding? *The Humanistic Psychologist, 43*(3), 278-296 <u>https://doi.org/10.1080/08873267.2014.993069</u>
- Brencio, F. (2018). Disposition: The pathic dimension of existence and its relevance in affective disorders and schizophrenia. *Theaumazein, 6,* 138-158. https://thau.v6iO

Butler-Bowdon, T. (2013). 50 philosophy classics. London: Nicholas Brealey.

- Comte-Sponville, A. (2003). A short treatise on the great virtues: The uses of philosophy in everyday life. London: Vintage.
- Cox, G. (2009). How to be an existentialist or how to get real, get a grip and stop making excuses. London: Continuum International Publishing Group.
- Creswell, J. W. (2013). Qualitative inquiry & research design: Choosing among five approaches. (3rd edition.). Los Angeles. Sage.

- Critical Appraisal Skills Programme (2019). CASP Qualitative Checklist. Available at: www.casp-uk.net
- Cypress, B. S. (2017). Rigor or reliability in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing, 36*(4), 253-263 DCC.0000000000025
- Daher, M., Carre, D., Jaramillo, A., Olivares, H., & Tomicic, A. (2017). Experience and meaning in qualitative research: A conceptual review and a methodological device proposal. *Forum: Qualitative Social Research*, 18(3), Art, 9, fgs-18.3.2696
- Davidson, L. (2020). Recovering a sense of self in schizophrenia. *Journal of Personality, 88,* 122-132 <u>https://doi.org/10.1111/jopy.12471</u>
- de Jager, A., Rhodes, P., Beavan, V., Holmes, D., McCabe, K., Thomas, N., McCarthy-Jones, S., Lampshire, D., & Hayward, M. (2016). Investigating the Lived Experience of Recovery in People Who Hear Voices. *Qualitative Health Research*, *26*(10), 1409–1423. <u>https://doi.org/10.1177/1049732315581602</u>
- de Wet, A., Swartz, L., & Chiliza, B. (2015). Hearing their voices: The lived experience of recovery from first-episode psychosis in schizophrenia in South Africa. *International Journal of Social Psychiatry*, 61(1), 27–32. <u>https://doi.org/10.1177/0020764014535753</u>
- Deegan. P.E. (1988). Recovery: The Lived Experience of Rehabilitation. *Psychosocial Rehabilitation Journal*, 11(4), 11–19. <u>https://doi.org/10.1037/h0099565</u>
- Deegan, P.E., Rapp, C., Holter, M., & Riefer, M. (2008). A program to support shared decision making in outpatient psychiatric medication clinic. Psychiatric Services, 59(6), <u>http://ps.psychiatryonline.org</u>
- Evans, N., Lasen, M., & Tsey, K. (2015). A Systematic Review of Rural DevelopmentResearch Characteristics, Design Quality and Engagement with Sustainability,Appendix A. Effective Public Health Practice Project (EPHPP) Quality Assessment

Tool for Quantitative Studies, <u>https://link.springer.com/content/pdf/10.1007/978-3-319-</u> 17284-2.pdf

Escudero, J.A. (2014). Heidegger on selfhood. American International Journal of Contemporary Research, 4(2), 6-17,

http://www.aijcrnet.com/journals/Vol_4_No_2_February_2014/2.pdf

Estroff, S. (1989). Self, identity, and subjective experiences of schizophrenia: In search of the subject. *Schizophrenia Bulletin*, *15*(2), 189-196

Feiner, J., & Frese, F. (2009). Recovery in schizophrenia. In B. Sadock, V. Sadock & P. Ruiz (Eds.), Kaplan & Sadock's comprehensive textbook of psychiatry. (9nth ed., pp.1582-1593). Lippincott Williams & Wilkins.

- Fernández, J., & Bliss, S. (2016). Schizophrenia and the estranged self. *Journal of Evaluation in Clinical Practice*, 22(4), 615–621. <u>https://doi.org/10.1111/jep.12583</u>
- Finlay, L. (2008, January). *Reflecting on reflective practice*. A discussion paper prepared for PBPL CETL, PBPL paper 52, The Open University <u>www.open.ac.uk/pbpl</u>

Frechette, J., Bitzas, V., Aubry, M., Kilpatrick, K., & Lavoie-Tremblay, M. (2020).
Capturing Lived Experience: Methodological Considerations for Interpretive
Phenomenological Inquiry. *International Journal of Qualitative Methods*, 19, 160940692090725–. https://doi.org/10.1177/1609406920907254

Galletly, C., Castle, D., Dark, F., Humberstone, V., Jablensky, A., Killackey, E., Kulkarni, J., McGorry, P., Nielssen, O., & Tran, N. (2016). Royal Australian and New Zealand
College of Psychiatrists clinical practice guidelines for the management of schizophrenia and related disorders. *Australian and New Zealand Journal of Psychiatry*, 50(5), 410–472. <u>https://doi.org/10.1177/0004867416641195</u>

Gecas, V. (1982). The self-concept. *Annual Review of Sociology*, *8*, 1-33. https://www.jstor.org/stable/2945986

- Giorgi, A., Giorgi, B., & Morley, J. (2017). The descriptive phenomenological method, In Willig and Rogers, (eds.), The Sage handbook of qualitative research in psychology, (2nd ed.), pp. 176-192.
- Gray, R., & Deane, K. (2016). What is it like to take antipsychotic medication? A qualitative study of patients with first-episode psychosis. *Journal of Psychiatric and Mental Health Nursing*, 23(2), 108–115. <u>https://doi.org/10.1111/jpm.12288</u>
- Hargreaves, J., Lucock, M., & Rodriguez, A. (2017). From inactivity to becoming physically active: The experiences of behaviour change in people with serious mental illness.Mental Health and Physical Activity, 13, 83-93.

https://doi.org/10.1016/j.mhpa.2017.09.006

- Haynes, K. (2012). Reflexivity in qualitative research. Qualitative organizational research: Core methods and current challenges, 72-89.
- Heidegger, M. (1993). Being and Time. Blackwell.
- Hookway, N. (2008). Entering the blogosphere: some strategies for using blogs in social research. *Qualitative Research: QR*, 8(1), 91–113.

https://doi.org/10.1177/1468794107085298

Horrigan-Kelly, M., Millar, M., & Dowling, M. (2016). Understanding the Key Tenets of Heidegger's Philosophy for Interpretive Phenomenological Research. *International Journal of Qualitative Methods*, *15*(1), 160940691668063–. https://doi.org/10.1177/1609406916680634

Horwitz, A. (2002). Creating mental illness. Chicago. University of Chicago Press

Jacob, S., Munro, I., Taylor, B.J., & Griffiths, D. (2017). Mental health recovery: A review of the peer-reviewed published literature. *Collegian (Royal College of Nursing, Australia)*, 24(1), 53–61. <u>https://doi.org/10.1016/j.colegn.2015.08.001</u>

- Jelscha, S. (2017). Disordered existentiality: Mental illness and Heidegger's philosophy of Dasein. *Phenomenology and the Cognitive Sciences*, 17(3), 485–502. https://doi.org/10.1007/s11097-017-9523-1
- Ko, C., Smith, P., Liao, H., & Chiang, H. (2014). Searching for reintegration: life experiences of people with schizophrenia. *Journal of Clinical Nursing*, 23(3-4), 394–401.
 https://doi.org/10.1111/jocn.12169
- Large, W. (2008). Heidegger's Being and Time. Indiana: Indiana University Press.
- Leamy, L., 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. <u>https://doi.org/10.1192/bjp.bp.110.083733</u>
- Lee, M., Eads, R., Yates, N., & Liu, C. (2020). Lived experiences of a sustained mental health recovery process without ongoing medication use. Community Mental Health Journal, <u>https://doi.org/10.1007/s10597-020-00680-x</u>
- Liberati, A., Altman, D.G., Tetzlaff, J., Mulrow, C., Gøtzsche, P.C., Ioannidis, J.P.A., Clarke, M., Devereaux, P.J., Kleijnen, J., & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *BMJ*, *88*(2009), e1000097–b2700. https://doi.org/10.1136/bmj.b2700
- Lysaker, J., & Lysaker, P. (2005). Being interrupted: The self and schizophrenia. *The Journal* of Speculative Philosophy, New Series, 19(1), 1-21 https://www.jstor.org/stable/25670546
- Lysaker, P.H., & Lysaker, J.T. (2010). Schizophrenia and Alterations in Self-experience: A Comparison of 6 Perspectives. *Schizophrenia Bulletin*, *36*(2), 331–340. <u>https://doi.org/10.1093/schbul/sbn077</u>

- McLaren, N. (2010). *Humanizing Psychiatry: The Bio cognitive Model*. Future Psychiatry Press. USA.
- Moran, M & Mooney, T. (eds.). (2002). The phenomenology reader. Psychology Press.
- Morse, J.M., & Richards, L. (2002). Read me first for a user's guide to qualitative methods. California: Sage.
- Murray, M., & Menadue, C. B. (2022). Exploring lived experience of recovery processes in those with schizophrenia: A systematic review with thematic synthesis of qualitative evidence, *Mind & Society*, (Manuscript under review).
- Nxumalo Ngubane, S., McAndrew, S., & Collier, E. (2019). The experiences and meanings of recovery for Swazi women living with "schizophrenia". *Journal of psychiatric and mental health nursing*, *26*(5-6), 153–162. <u>https://doi.org/10.1111/jpm.12520</u>
- Nowak, I., Waszkiewicz, J., Świtaj, P., Sokół-Szawłowska, M., & Anczewska, M. (2016). A Qualitative Study of the Subjective Appraisal of Recovery Among People with Lived Experience of Schizophrenia in Poland. *Psychiatric Quarterly*, 88(3), 435–446. https://doi.org/10.1007/s11126-016-9459-6
- O'Leary, Z. (2004). The essential guide to doing research. Sage.
- Parnas, J., & Zahavi, D. (2000). The link: philosophy-psychopathology-phenomenology. In. Zahavi, D. Exploring the self: Philosophical and psychopathological perspectives on self-experience, 1-16.

https://ebookcentral.proquest.com/lib/jcu/reader.action?docID=622553&ppg=9

Pérez-álvarez, M., García-Montes, J.M., Vallina-Fernández, O., & Perona-Garcelán, S. (2016). Rethinking schizophrenia in the context of the person and their circumstances: Seven reasons. *Frontiers in Psychology*, *7*, 1650–1650.
<u>https://doi.org/10.3389/fpsyg.2016.01650</u>

Peter, O., & Jungbauer, J. (2019). Diagnosis talk and recovery in people with a mental illness: A qualitative study and perspectives for clinical social work. *Clinical Social Work Journal*, 47, 222-232. <u>https://doi.org/10.1007/s10615-018-0646-9</u>

Punch, K. (2016). Developing effective research proposals, (3rd edn). Sage.

- Ratcliffe, M. (2013). "Why mood matters." In M. Wrathall (ed.), *The Cambridge Companion* to Heidegger's Being and Time (1st Edition). U.K. Cambridge University Press.
- Roberts, B. (2007). Contextualizing personality psychology. *Journal of Personality*, 75(6), 1071-1082. <u>https://doi.org/10.1111/j.1467-6494.2007.00467.x</u>
- Rosenberg, M. (1984). A symbolic interactionist view of psychosis. *Journal of Health and Social Behaviour, 25*(3), 289-302. https://www.jstor.org/stable/2136426
- Sadock, J., Sadock, V.A., & Ruiz, P. (eds). (2009). Kaplan & Sadock's comprehensive textbook of psychiatry, Vol 1. (9th Edition.). Philadelphia: Wolters Kluwer, Lippincott Williams & Wilkins.
- Sangeorzan, I., Andriopoulou, P., & Livanou, M. (2019). Exploring the experiences of people vlogging about severe mental illness on YouTube: An interpretative phenomenological analysis. *Journal of Affective Disorders*, 246, 422–428.

https://doi.org/10.1016/j.jad.2018.12.119

- Sass, L. (2000). Schizophrenia, self-experience, and the so-called "negative symptoms":
 Reflections on hyper reflexivity. In D. Zahavi (Ed.), *Exploring the self: Philosophical and psychopathological perspectives on self-experience* (pp. 149–182). John
 Benjamin's Publishing Company. <u>https://doi.org/10.1075/aicr.23.11sas</u>
- Sass, L., & Parnas, J. (2003). Schizophrenia, Consciousness, and the Self. *Schizophrenia Bulletin*, *29*(3), 427–444. <u>https://doi.org/10.1093/oxfordjournals.schbul.a007017</u>

- Schon, U-K., Denhov, A., & Topor, A. (2009). Social relationships as a decisive factor in recovering from severe mental illness. *International Journal of Social Psychiatry*, 55, 336-347. <u>http://doi.org/10.1177/0020764008093686</u>
- Schuman, D.L., Lawrence, K.A., & Pope, N. (2019). Broadcasting War Trauma: An Exploratory Netnography of Veterans' YouTube Vlogs. *Qualitative Health Research*, 29(3), 357–370. <u>https://doi.org/10.1177/1049732318797623</u>

Seale, C. (Ed.). (2012). Researching society and culture. (3rd Edition.), London: Sage.

- Slade, M. (2009). Personal recovery and mental illness: A guide for mental health professionals. Leiden: Cambridge Uni Press.
- Slade, M., & Longden, E. (2015). Empirical evidence about recovery and mental health. *BMC Psychiatry*, *15*(1), 285–285. <u>https://doi.org/10.1186/s12888-015-0678-4</u>
- Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., Perkins, R., Shepherd, G., Tse, S., & Whitley, R. (2014). Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems. *World Psychiatry*, *13*(1), 12–20. <u>https://doi.org/10.1002/wps.20084</u>
- Smith, J.A., Flowers, P., & Larkin, M. (2012). Interpretative phenomenological analysis: Theory, method and research. Los Angeles: Sage.
- Spiegelberg, H. (1982). *The phenomenological movement: A historical introduction* (3rd ed.). Hague: Martinus Nijhoff. <u>https://doi.org/10.1007/978-94-009-7491-3</u>
- Stephensen, H., & Henrikson, M. (2017). Not Being Oneself: A Critical Perspective on "Inauthenticity" in Schizophrenia. *Journal of Phenomenological Psychology*, 48(1), 63–82. https://doi.org/10.1163/15691624-12341322
- Sumskis, S., Moxham, L., & Caputi, P. (2017). Meaning of resilience as described by people with schizophrenia. *International Journal of Mental Health Nursing*, 26(3), 273–284. <u>https://doi.org/10.1111/inm.12268</u>

- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45–45. <u>https://doi.org/10.1186/1471-2288-8-45</u>
- Tuffour, I. (2020). "There is anointing everywhere": An interpretative phenomenological analysis of the role of religion in the recovery of Black African service users in England. *Journal of Psychiatric and Mental Health Nursing*, 27(4), 352–361. https://doi.org/10.1111/jpm.12589
- Tuffour, I. (2017). A critical overview of interpretative phenomenological analysis: a contemporary qualitative research approach. *Journal of Healthcare Communications*, 2 (4). p. 52. <u>http://repository.uwl.ac.uk/id/eprint/4082</u>
- Vagle, M.D. (2018). Crafting phenomenological research. (2nd Edition.). New York: Routledge.
- Williams, A., Fossey, E., Farhall, J., Foley, F., & Thomas, N. (2018). Recovery after psychosis: Qualitative study of service user experiences of lived experience videos on a recovery-oriented website. *JMIR Mental Health*, 5(2), e37–e37.
 https://doi.org/10.2196/mental.9934
- Wood, L., & Alsawy, S. (2018). Recovery in psychosis from a service user perspective: A systematic review and thematic synthesis of current qualitative evidence. Community mental Health Journal, 54, 793-804. <u>https://doi.org/10.1007/s10597-017-0185-9</u>
- World Health Organisation. (2008). The global burden of disease: 2004 Update. <u>http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/index.ht</u> ml
- Zahavi, D. (2019). Phenomenology: The basics. Routledge.