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WITH

NEW SCHOOL OF PSYCHOTHERAPY AND COUNSELLING

Experiences of mental illness, treatment and recovery in schizophrenia.

An existential-phenomenological exploration.

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Abstract

This study explores in depth the narratives and experience of recovery from a convenience sample of seven participants with a schizophrenia diagnosis, but now remitted (Andreasen *et a*l, 2005). Three lifeworlds (phases) emerged using hermeneutic phenomenology: (A) Losing existential grounding; (B) Being-within-the-system (i.e. hospitalised); and (C) Outside schizophrenia. Outside has a double meaning as it both emerges from the narratives and also is an important base for existential exploration: what else needs to happen except psychiatry?

Each lifeworld had a different meaning and different behaviours connected to it. Two necessary transitions were identified: First, accepting help; and second, an existential construction or re-construction depending on where in your life course you become affected. Psychotherapy was useful, but not necessary for remission and recovery.

Keywords: schizophrenia, recovery, hermeneutic phenomenology, existential exploration, lifeworld, psychotherapy

Statement of authorship

I certify that I, Paul O Olson, am the real and only author of this dissertation and that the research is likewise original: the demographical data are true as are the recorded interviews. Hopefully I have been accurate enough to avoid conflating quotes for my intentions – I have done my very best.

The use of pseudonyms

Participant names in this research are of course not their real names and I have done my best to avoid giving away their identity in any way. Such details are unavoidable to some extent in the recorded interviews, but have been bracketed out and in two cases wholly excluded from the transcripts. Narratives however have materials of a character and content that may well be recognised by one or the other reader, therefore the full transcripts will only be available on a need-to-know basis. The participant's pseudonym will be made available to the participant such as to recognise his or her own contribution.

Experiences of mental illness, treatment and recovery in schizophrenia. An existential-phenomenological exploration.

1 INTRODUCTION

Background

My interest in psychosis did not start until 2002, when I needed extra income and applied for 'milieu therapist' in a university hospital long-term unit. With a fresh master's degree in psychology it was easy to get accepted and it seemed a perfect laboratory for personality psychology, which was one of my interests at the time. Milieu therapy is a humanistic and person-oriented rather than symptoms/medical approach; rather than a standard regime implicit in the notion Treatment As Usual (TAU), we add a daily regime to deal with individual problems, interests and abilities. Its weakness lies mostly in implementation and lack of consistency from too many 'parents', yet it makes a lot of sense to systematically use elements from behaviour therapy, parenting, healthy behaviours and daily structure. It is not just common sense, either, because without good training, respectful listening and a sense of achievement and mastery, the same problems predictably occur as in any family. There is a very fine line between power and therapy, between coercion and participation, in particular in a locked ward.

I have seen life conditions that bring people back sooner rather than later; and vicious circles of non-compliance, chaos, anger and compulsory treatment. It is obvious that psychiatry is not enough to restitute a meaningful life, if there indeed was one before hospitalisation, so I have wanted to know more about those who do not return. I have wanted to learn more about the bridges from hospital to recovery and well-being; in particular how psychologists can make it an easier walk for those affected, for their families and friends – taking in consideration sometimes adverse environments.

A psychologist perspective has been important. Even if schizophrenia is diagnosed via a set of symptoms, mental health and recovery cannot be defined as the absence of those symptoms. I have needed to look at psychiatric systems as such and was surprised to find how very different they are – what it means is that the reader must keep in mind that my research was conducted in Norway and with biological psychiatry as a stronghold.

But importantly, I found that schizophrenia did not become the life sentence that some of the participants were told that it would be. We can afford to become more optimistic. And we should be.

Rationale and purpose

The purpose of my research is to learn as much as possible from research participants about their recovery from schizophrenia from an existential point of view; existential because as a perspective it should capture ontology, intersubjectivity, meaning, well-being and indeed the art of living.

Participants have had a confirmed diagnosis with extended hospitalisation (severity), now well under the threshold symptoms required for diagnosis (remission) with a stable life for many years (recovery).

The research area is both complex and complicated: from a utility point of view (is the diagnosis helpful for psychotherapy and prognosis); from a practice point of view (how can we help this particular person); and from an ethical point of view (respect, freedom, danger, care *et cetera*). While medication is helpful to most you might have to pay with severe side-effects (e.g. Leucht *et al*, 2012). In any case the rationale for psychotherapy must be ethically justifiable, e.g. compliance is not a therapeutic goal, even if paradoxically a necessary outcome.

I have wanted to differentiate between schizophrenia as a diagnosis and psychotic episodes as something else. Sitting bedside and observing psychotic episodes makes you wonder what exactly is it that creates dream-like episodes that are often not even recorded in memory. I asked a patient, who had needed physical restraints, if he remembered peeing on the floor, playing a grand role in a Christmas theatre and singing the same song for hours. It was a total blank. At other times people do remember. Psychotic episodes are phenomenologically different from the habitual state; they are about losing control and not being able to remember things from your life. So I wanted to know how the participants would describe those lived experiences.

While Hornstein (2007) has created a reference list with 33 pages of survivor stories in English only, such stories are generally missing from psychiatric research (Davidson, 2003; Rulf, 2003).

There are several epistemological and technical issues, even historic reasons for their absence in psychiatry, but what if they can actually provide clues to lived experience and meaningful therapy?

Beliefs about yourself, others and the world influence behaviours and have consequences for your relations with other people. Living with schizophrenia can be a Sartrean type of project i.e. finding and living your purpose in life, whereby you can also become totally absorbed in beating schizophrenia or denying it. A therapeutic environment should make it easier to accept that schizophrenia is not created by psychiatry and thus nothing to blame on psychiatrists.

Speculations and theories have resulted in a wide range of care systems with divergent assumptions about causes, prognosis and treatment. As psychologists we are in a unique position to work with the whole human being and provide much needed ‘scaffolding’ – research including mine conclude that recovery is not something you can achieve without help (e.g. Davidson, 2003), which in turn generates a rationale for milieu therapy or social psychiatry as container, daily structure and behavioural change supervised by appropriately trained psychologists.

Last, hospital workers see those in an initial stage and those who return – we ought to understand the nature of schizophrenia better if we study those who do not return.

The research approach

The research recruited seven participants. Although I planned for a purposive selection, I had to choose a convenience sample instead. The university hospital head of research where I work was positive to the research, but they could not help because the project was outside the Norwegian educational system and I would need a supervisor from a Norwegian faculty.

The best alternative was to approach the largest Norwegian independent mental health organisation, Mental Helse (hereafter called Mental Health). They kindly agreed and a letter asking for participants was distributed nationwide. I needed participants who could say something about the experience of schizophrenia, from the vantage point of being psychologically stable and underway with recovery if not recovered. The criteria stipulated that participants should have had a formal diagnosis of schizophrenia with extensive hospitalisation to rule out any lighter cases, but as token of recovery not re-hospitalised for at least six years prior to the interview.

The main framework is van Manen's (1990) version of hermeneutic phenomenology, adding some hermeneutic of suspicion (Ricoeur, 1981) and concepts appropriate for an existential analytic. As predicted generally by van Manen, the dissertation required many rounds of rewriting as I discovered new perspectives and reached new levels of insight. Merleau-Ponty's (1962) primacy of perception and the Sartrean negation (Sartre, 1956) definitely were lightposts, as was the recognition that we may have no choice in the here-and-now other than believe what we perceive (our natural attitude). With psychosis come failures in consciousness and with schizophrenia the world can no longer be fully trusted.

Definitions

The literature research confirms that schizophrenia is complex, conceptually and experientially. As if that was not enough, the same words can mean different things in different paradigms. Assumptions create incompatible theorems. Ricoeur (1981) usefully calls the result *polysemy* – words, in particular metaphors, can be inherently ambiguous and mean different things. Therefore we may nod when we actually should not.

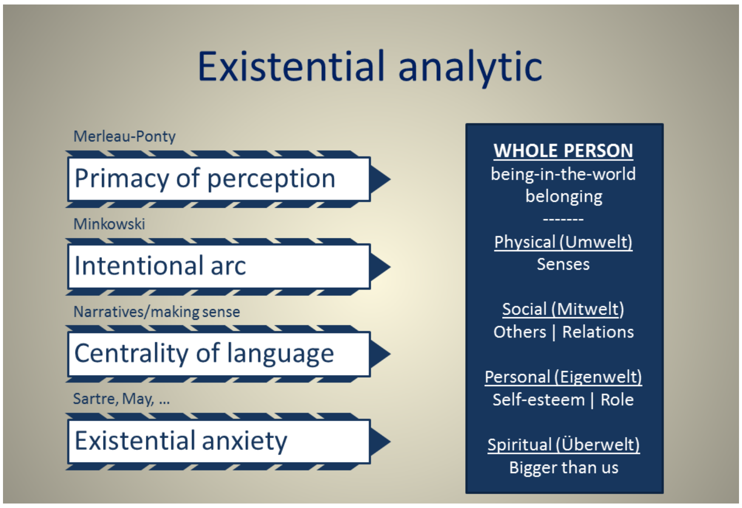
For this research I define:

- *Consciousness* in the sense of consciousness of something, rather than the neural network.
- *Milieu therapy* as an empathic and person-centred approach, in theory informed by psychology, in practice more common sense, but always recognising the whole person (not just symptoms) including complaints, problems in living, individual interests and abilities.
- *Polysemy* as the realisation that the same words, in particular abstract words and metaphors, usually represent different things to different people.
- *Recovery* not as remission of symptoms, but lifeworld re-construction or even construction.
- *Survivor* is generally used in a narrative sense i.e. how the participants see themselves.

Brief overview

The full existential model can be seen in figure 2. The method used to get there is hermeneutic phenomenology as a combination of van Manen (1990) and Ricoeur (1981). Although similar, Ricoeur differentiates between explication (what is in the data i.e. lived experience) and interpretation (what it means for the researcher), thus allows for a clean interpretation/perspective such as narrative analysis or clinical interpretation. The existential analytic/exploration used in stage 2 is depicted in figure 1.

Figure 1 Existential analytic for Ricoeur stage 2 (interpretation)



Existential analytic

Merleau-Ponty

Primacy of perception

Minkowski

Intentional arc

Narratives/making sense

Centrality of language

Sartre, May, ...

Existential anxiety

WHOLE PERSON
being-in-the-world
belonging

Physical (Umwelt)
Senses

Social (Mitwelt)
Others | Relations

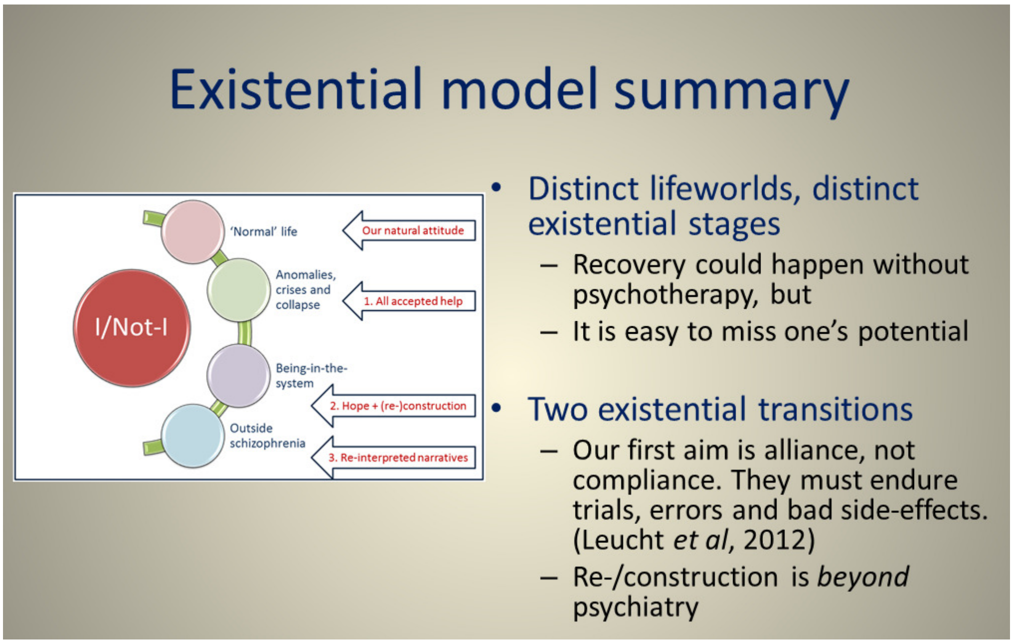
Personal (Eigenwelt)
Self-esteem | Role

Spiritual (Überwelt)
Bigger than us

The right hand side covers the whole person with Deurzen's 'Four worlds' and the addition that I was primarily interested in how the participants are active in their own lives. In psychosis this 'being-in-the-world' (Heidegger) becomes strange and since our world is actually partly a non-shared world, it can even give us a feeling of not 'belonging' (Gadamer). We simply take the world we live in for granted ('our natural attitude'). Minkowski used the term 'intentional arc' for the fact that we expect certain effects from our actions, and in a psychotic episode the intentional arc is disrupted to some degree. Pre-dopamine psychiatry is a relevant source as several authors were interested in existential anxiety.

During the research three lifeworlds and two transitions emerged from the data, from which it has been possible to outline a set of recommendations.

Figure 2 Existential model, the final version



Existential model summary

- Distinct lifeworlds, distinct existential stages
  - – Recovery could happen without psychotherapy, but
  - – It is easy to miss one's potential
- Two existential transitions
  - – Our first aim is alliance, not compliance. They must endure trials, errors and bad side-effects. (Leucht *et al*, 2012)
  - – Re-/construction is *beyond* psychiatry

2 LITERATURE REVIEW

2.1 INTRODUCTION

The literature about schizophrenia is enormous and a hundred years of theories with different *Zeitgeist* and epistemology has resulted in *polysemy* (Ricoeur, 1981) i.e. abstract words mean different things to different people as assumptions are embedded rather than explicit. While I can agree with the symptoms of pneumonia, should I suffer from it, schizophrenia is by definition thwarting my relationship with reality such that I no longer know what is going on. Indeed, as late as Rollo May (1977) a differentiation was still attempted between organic and psychogenic, while today we regard schizophrenia as primarily organic and psychological effects as secondary.

There are several mysteries that made me interested for more than ten years with psychotic in-patients and study to the extent of a doctorate. I asked myself: Must not age sensitivity indicate neurodevelopment? When does schizophrenia become madness? Is the prognosis better if the prior years were apparently normal? Why is it that we in psychotic episodes do things and experience things that we do not otherwise? As an example of *polysemy*, Parnas (2011, 2012) has called for an improved *clinical core Gestalt* because he like many others differentiate between consciousness as a mental act and meaning making and consciousness as a representation of something: *"Consciousness (subjectivity) is at the forefront of today's scientific debate, constituting perhaps its most important challenge. […] Unfortunately, these developments have largely eluded mainstream psychiatry."* (p.67)

One of my main inspirations was Davidson's (2003) *Living Outside Mental Illness* (with a foreword by John Strauss): "*It has been our experience that the area of overlap between these two interests, that is, qualitative psychological research and serious mental illness, is relatively small and only sparsely inhabited by a few rare, but resilient, birds. […] Consider this book a mating call."* (p. 1)

2.2 THE INSIDE OF SCHIZOPHRENIA

2.2.1 Abnormality and diagnosis

Closely related to diagnosis is dysfunction or abnormality, but what is normal in one culture may be ab-normal in another. DSM-IV simply acknowledges that cultural beliefs should be considered. What is bizarre to some is cultural beliefs to others e.g. reincarnation (Hindu), angels (Jews, Christians, Moslems), aliens (Scientology), chakra (taken up by New Age) and the Jinn

(Moslems). Taken literally in today's global society this makes the whole idea of delusions difficult to say the least.

Flanagan & Blashfield (2002) discuss how the concept of schizophrenia reflects folk psychology. Deviations from the norm may not be sufficient for distress and the boundaries for abnormality are subject to social psychological processes. If there is distress for the affected person, the contemporary question is whether it is the organic root cause that schizophrenia presumes.

Schizophrenia is a ‘psychotic disorder’ and all participants in my study have been diagnosed according to ICD-10 (although two cases possibly ICD-9). In ICD-10 (1992): "*Its use [the word psychotic] does not involve assumptions about psychodynamic mechanisms, but simply indicates the presence of hallucinations, delusions, or a limited number of severe abnormalities of behaviour”* (p. 4) While ICD-10 uses one month as sufficient for diagnosis, DSM-IV uses six months, and the DSM-5 (2012) task force disagreed specifically with the one-month criterion.

In DSM-IV (APA, 1994):

> “The narrowest definition of *psychotic* is restricted to delusions or prominent hallucinations, with the hallucinations occurring in the absence of insight into their pathological nature. A slightly less restrictive definition would also include hallucinations that the individual realizes are hallucinatory experiences. Broader still […] positive symptoms.” (DSM-IV, p. 273)

Definitions such as these are important for the discussion of whether recovery is possible at all – a key topic for this research, but for which psychiatry provides few answers and diagnostics provides none.

Hallucinations

Research confirms that psychotic symptoms are more widespread in the general population than believed earlier (Nordentoft *et al*, 2006; van Os *et al*, 2000; Verdoux & van Os, 2002). Merleau-Ponty’s (1962) finds that hallucinations merge with reality such that consciousness does not know what it is doing, but Stanghellini *et al* (2012) found that virtually no studies had addressed the differences between clinical and non-clinical samples. Non-clinical subjects by definition are able to distinguish hallucinations from reality also called pseudo- or para-hallucinations (e.g. Berrios

& Dening, 1996; El-Mallakh & Walker, 2010; Vellante *et al*, 2012; Zwaard & Polak, 2001). We do not yet know if or how these phenomena mark different neural locations.

Romme & Escher (1989) find that hallucinations are quite common and that those with supportive hallucinations (i.e. self-talk) even find them useful. Further back, in 1894 The Society for Psychical Research issued their first *Report of the census on hallucinations.* (Sidgewick, 1894) 8% of men and 12% of women reported at least one vivid hallucination (or pseudo-/para-hallucination), 'the most common being a vision of a living person who was not present at the time, or of a religious theme'. Sleep deprivation is known to cause psychotic episodes for some people, and to cause or accelerate bipolar manic episodes. (Adams & Sutker, 2001) In other words our ability to regulate attention and focus plays a role in non-clinical cases, which in turn is commensurate with the dopamine hypothesis. The Sidgewick census was replicated fifty years later (West, 1948) and Tien (1991) in an epidemiological catchment area study (ECA) estimated 11-13% prevalence in the population. The phenomenon of hallucinations in most cases does not indicate schizophrenia, i.e. the issue is if a hallucination as counted in these surveys was clinical or non-clinical.

Delusions

In DSM-IV a delusion is: *"A false belief based on incorrect inference about external reality and firmly sustained in spite of what almost everyone else believes and in spite of what usually constitutes incontrovertible and obvious proof or evidence to the contrary."* (APA, 1994) The definition does not differentiate between organic (schizophrenia) and psychological origins – it may be an impossible task because in clinical practice we invariably find delusional content as a mixture of secondary effects and personal pre-disposition such as personality and childhood experiences. Maher & Deldin (2001) question if delusions can be known by the diagnostic assumption that they be idiosyncratic and personal, as they often contain commonly shared topics (grandiose, jealous, persecutory, somatic, erotomanic) across different cultures and thus seem part of normal psychology. Gonçales *et al* (2002) suggest:

> "We believe that meaning making is the central aspect of human knowledge and the process of understanding different features of human experience. Moreover, we believe that these meanings express themselves through narrative discourse." (p. 156) "To diagnose is, in this perspective, to examine the patients' narratives ... Thus, clinicians need to develop new instruments to look at the content, process and structure of the narrative matrix, not only as a way of coming to a more naturalistic and ecologically valid

> understanding of the client but also to create conditions for an alternative and more adaptive prognosis." (p. 172)

Here, using the word 'prognosis' would be unwarranted if the authors meant a cure for schizophrenia *qua* organic illness, but the authors are referring to factors such as resilience, insight and coping.

Diagnostically, for many years the bizarre or impossible in Schneider's First Rank Symptoms was alone sufficient as symptom of schizophrenia (in addition of course to its involuntary nature), similar to Jaspers' (1963) concept of 'un-understandable' (the two exchanged ideas). We must as Jaspers and Heidegger did, ask: "Does it make sense?" It is also more plausible to look at delusions as secondary rather than primary symptoms, a view that is supported by clinical experience as well as my participants. In fact Escher *et al* (2002) found that only 9% of the adolescent schizophrenics in their study had developed delusions after three years.

Cognitive processes and differential diagnosis

Longitudinal research seems to verify early signs of deterioration, but as with all other symptoms they are not unique markers. Schizophrenia-like symptoms can result from non-schizophrenia failures in language areas, executive functions, working memory and attention. It is important to note that we clinically are looking for patterns in addition to symptoms.

Requests raised in the DSM-5 process (APA, 2012) demonstrate some contemporary issues:

- splitting flat affect into a) Flat affect/diminished expression and b) Avolition, asociality and anhedonia;
- eliminating subtypes and instead use axis II personality disorders;
- removing the weight of Schneiderian first-rank symptoms as sufficient for diagnosis;
- maintaining the six-months requirements versus one month in ICD-10;
- including mania and depression in all psychotic disorders.

The task group also propose a Clinicians Personality Trait Rating Form: Negative affectivity (experiences negative emotions frequently and intensely); Detachment (withdrawal from other people and from social interactions); Antagonism (engaging in behaviours that put the person at odds with other people); Disinhibition (engaging in behaviours on impulse, without reflecting on potential future consequences); and Psychoticism (unusual and bizarre experiences, the Schneiderian heritage).

The DSM-5 criteria (APA, 2013) (in strong letters) were not radically different:

- **Delusions:** Mistaken but firmly held beliefs that are easy to prove wrong, like thinking you have superpowers, are another famous person, or people are out to get you
- **Hallucinations:** Seeing or hearing things that aren't there
- **Disorganized speech (e.g. frequent derailment or incoherence):** Using words and sentences that don't make sense to others
- **Grossly disorganized or catatonic behaviour:** Strange behaviours such as acting in an odd or repetitive way, like walking in circles or writing all the time, or sitting perfectly still and quiet for hours on end
- **Negative symptoms (i.e. diminished emotional expression or avolition):** Showing no feelings or motivation, or lacking interest in normal daily activities

This shows a clear need for increased collaboration between professions such as neuroscience, phenomenology and neuropsychology.

Table 1 lists some of the scales used for diagnostic and research purposes. Prodromal lists have little prognostic value, but help *post hoc* to verify the deterioration that is usual for schizophrenia.

Table 1 Some typical diagnostic and research scales

Conceptualisation	Categories
Parnas *et al* (2005) EASE: Examination of Anomalous Self-Experience	Cognition and stream of consciousness; Self-awareness and Presence; Bodily Experiences; Demarcation/Transitivism; and Existential Reorientation.
Gross, Huber, Klosterkötter *et al* (1987). BSABS: Bonn Scale for the Assessment of Basic Symptoms (self-perceived)	Dynamic deficiency; Disturbances of thought, perception and motor action; “Coenaesthesia”; Disturbances of the central autonomic nervous system; and Sleep disturbances.
Yung, Yuen, McGorry *et al* (2005). CAARMS: The Comprehensive Assessment of At-Risk Mental States	Used in the Melbourne studies. Disorders of thought content (TC), Perceptual anomalies (PA), conceptual disorganisation (CD), motor disturbances (MD), disorders of emotion and affect (EA), impaired energy (E) and impaired tolerance to normal stress (S).
Häfner, Löffler, Maurer *et al* (2003). IRAOS: Interview for the retrospective assessment of the onset and course of schizophrenia and other psychoses	Used in the ABC Schizophrenia Study. 65 symptoms including social biography and pathways to care later expanded to include mood disorders. A bigger screening instrument (ERIraos) by the same authors includes 110 signs in 12 symptom groups that cover both affective and schizophrenia prodromes.

Schultze-Lutter & Klosterkötter (2004). SPI-A: Schizophrenia Prediction Instrument, Adult version	A development of BSABS. 7 groups: Overstrain, emotional deficits, cognitive impediments, cognitive disturbance, “body perception” disturbances, perception and motor disturbances, and “estrangements”. Has been successfully validated.
Kay, Fiszbein & Opler, 1987). PANSS – Positive and Negative Syndrome Scale.	PANSS is probably the most widely used scale among many in schizophrenia research. Includes three sub-scales covering what is believed to be clinical markers:. 7 positive symptoms: Delusions, Conceptual disorganization, Hallucinations, Hyperactivity, Grandiosity, Suspiciousness or persecution, and Hostility. 7 negative: Blunted affect, Emotional withdrawal, Poor rapport, Passive/apathetic social withdrawal, Difficulty in abstract thinking, Lack of spontaneity and flow of conversation, Stereotyped thinking. 16 items for General pathology: Somatic, concern, Anxiety, Guilt feelings, Tension, Mannerisms and posturing, Depression, Motor retardation, Uncooperativeness, Unusual thought content, Disorientation, Poor attention, Lack of judgment and insight, Disturbance of volition, Poor impulse control, Preoccupation, Active social avoidance. Generally considered valid, but concerns include factors (van der Gaag *et al*, 2006a, 2006n) and calculations (e.g. Obermaier *et al*, 2008).

2.2.2 Diagnostic stability or lack thereof

There are known overlaps between schizophrenia and other psychotic disorders, and between schizophrenia and bipolar disorder, including schizoaffective disorder. Although there are pointers to genetics and neurodevelopment, we do not yet know what exactly causes schizophrenia, whether it can have several causes and whether it covers several different illnesses.

The validity of schizophrenia as a diagnosis is assumed via clinical consensus, a practice that can be defended as a necessary intermediate step for any medical research. Taking Chronic Fatigue Syndrome (CFS) as an example, Scadding (1998) defines: *“A syndrome properly refers to a recognisable pattern of symptoms without causal implication, and chronic fatigue indicates the most prominent and constant symptom”*. (p. 595) He counters one part of critical psychiatry by recognising that in mainstream medicine a syndrome is sufficient for treatment. However a reliable syndrome is not satisfactory until it has been validated by a causal chain, which schizophrenia does not yet have.

Houts (2002) in one of the more useful critiques compares psychiatry’s position with somatic medicine and Scadding’s ladder: from ‘(1) Signs and symptoms or syndromal classification’ the chain goes back to ‘(2) Structural anomalies’, ‘(3) Disorder or function or pathophysiology’, and ‘(4) Aetiology or causal explanation’. For schizophrenia we are still at the lowest step and thus Szasz’ (1991) can only be right that we still are at risk of diagnosing illness where there is none. Following Szasz’ provocation Scadding reflects:

> “I share Szasz’ condemnation of any assumption that patterns of behaviour that deviate from accepted norms must be explained as the effect of disease of the brain. But here I think he is putting up an Aunt Sally; for surely, only a totalitarian using psychiatric diagnoses as a means of political control [obviously referring to the Soviet Union] could be accused of holding this view. The opposing generalisation – that all disorders of behaviour are to be regarded as effects of environmental and social factors – is equally untenable.”
>
> (Scadding, 1991: 689)

Scadding (1991) thus assumes that psychiatry is evidence-based, ref also the World Psychiatry Association's Madrid declaration (see below page 20). Progress would not have been possible, he says, if medicine had not been willing to follow clinical intuition and experiment with treatments. Conceptualising schizophrenia as a syndrome and treating it without knowing its cause is perfectly permissible and ethical as long as the treatment itself is proven to be effective. This is not so different from somatic medicine where doctors must take decisions without asking the patient, but the risk is that diagnosis becomes a power outside of the legal system. As for my own position, I find it of course regrettable that antipsychotic medication is a matter of searching for the right type and quantity, but I fully accept that the reason seems to be metabolism. Provided that it actually helps it is defensible also as a more humane intervention than physical restraints and days in full blown psychosis perhaps without sleep and no 'landing'. I know what I would prefer.

What must remain nonetheless is a worry that validity is an effect of consensus formation after attending the same training. Reading the same books and hearing the same explanations (e.g. Andreasen, 2007; Rulf, 2003) creates inter-rater reliability, but is not evidence of construct validity. For example, one wide-spread clinical consensus proposed for DSM-III was that homosexuality must be a mental illness; another that a wife who doesn't leave a violent husband must be addicted to it i.e. a masochistic personality disorder (Kutchins & Kirk, 1997). Another potential problem is that clinical practice relies on health insurance funding and therefore even minor problems will need a diagnosis (depression is probably over-used).

As alluded to above, training is a significant factor for diagnostic and clinical practice, with UK psychiatrists historically rather more conservative than US colleagues. Copeland *et al* (1971, in Read, 2004) included 134 US and 194 British psychiatrists who were given a description of a patient. Among the US psychiatrists 69% diagnosed schizophrenia but only 2% of the British.

Rosenhan in his famous experiment, *On being sane in insane places* (1973), listed in *Forty Studies That Changed Psychology* (Hock, 1994), posed with seven others as patients for hospitalisation, claiming they had heard a voice saying “empty”, “hollow”, and “thud” sounds. After admission, they behaved in perfectly normal ways, but seven of the eight were diagnosed with schizophrenia. All were medicated and protested, but were made to stay between 7 and 52 days. (Rosenhan, 1973; Rosenhan & Seligman, 1995) The results were contested by Spitzer (1975) and others who said it could not happen in their hospitals, but it did show practices that would inflate statistics. Although one can defend the admissions on grounds that one would not expect malingering, actually diagnosing schizophrenia with no observed symptoms and keeping them there for 52 days is quite another matter.

Slater (2004) wrote *Skinner’s Box*, a prose where she claimed to have replicated Rosenhan’s initial study, without saying that she actually had not. To prove her wrong, Spitzer and colleagues arranged for a counter-experiment (Spitzer *et al*, 2005) and created a vignette based on her book. 74 psychiatrists volunteered. The null hypothesis must have been for the 74 psychiatrist subjects to reject the case, where the correct diagnosis would be malingering. Only 3 psychiatrists suspected this, and an additional 17 refused diagnosis. Of the 74, 11 would have hospitalised her, and 25 indicated that they would have given her an anti-psychotic. In other words, 54 of 74 diagnosed false positives: psychotic depression (4), tentative psychosis not otherwise specified (46), or other diagnoses with the caution to rule out psychotic depression (4). But then again, why would anybody want to fake schizophrenia?

Bromley (2007) reports that 40 random clinicians attending the 2006 APA (American Psychiatric Organisation) annual conference answered that they were confident to diagnose cognitive deficits i.e. negative symptoms, but most could give only labels such as ‘follow-through on the big picture’, ‘attention and concentration deficits’, and ‘emptiness’.

Baca-Garcia *et al* (2007) and Veen *et al* (2004) find that schizophrenia from first hospitalisation is confirmed by re-assessment some years later in between 70% and 90% of the cases, varying with the investigated settings e.g. acute vs. long-term or mixed. But does it mean 10-30% false positives, as many would have it, or 10-30% full recovery such as to question the chronicity/atrophy theorem? Anyway, these are huge issues in interpreting epidemiological research for schizophrenia across countries.

2.3 THERAPEUTIC ENVIRONMENTS

2.3.1 Freedom and the concept of care in Norway

Compulsory treatment is an issue in the treatment of schizophrenia. Statistics show huge differences even within Europe (Salize, Dressing & Peitz, 2002), much of which the WHO studies indicate as systemic or cultural factors (e.g. Sartorius & Jablonsky, 2008). The EUNOMIA project documented this between 12 countries in EU and it will probably result in guidelines (e.g. Fiorillo *et al*, 2011) supported also by the World Psychiatric Association's Madrid Declaration on Ethical Standards for Psychiatric Practice: *"No treatment should be provided against the patient's will, unless withholding treatment would endanger the life of the patient and/or the life of others. Treatment must always be in the best interest of the patient."* Furthermore, *"Research that is not conducted in accordance with the canons of science and that is not scientifically valid is unethical."* (WPA, 2005)

Country and regional differences cannot be attributed to epidemiology so must be caused by systemic, cultural and/or legal factors. A deterioration criterion is used in the Nordic countries and the UK, which should inevitably push the number upwards. Yet this does not seem to explain why Denmark and the UK have lower numbers. In Germany involuntary hospitalisation is decided by a judge, while in Norway any two doctors can decide together. Availability of beds is a contributing factor and in my experience changing patients from involuntary to voluntary hospitalisation is not usual practice because doctors don't want the patients to leave prematurely. Whether this is ethical is another matter.

Anyway, the Norwegian authorities have admitted several system flaws (NOU, 2011) and some are being addressed by early intervention, self-admission to low-threshold beds, scheduled ambulatory care rather than just handing out medication at the patient's doorstep, advance contracts in case of psychotic episodes *et cetera*.

Table 2 Compulsory treatment (Salize, Dressing & Pelz, 2002)

Country	Days detention per 100.000 inhabitants
Norway (2001)	253
Finland (2000) [1]	218
Germany (2000)	175
Sweden (1998)	114
England and Wales (1999)	48
Netherlands (1999)	44
Denmark (2000)	34
France (1999)	11
Portugal (2000)	6

Several shortcomings are acknowledged in the Norwegian Government's report NOU 2011:9 concerning increased rights to self-determination in psychiatric treatments, which documents that there have been virtually no improvements in the use of compulsory care from 2001 to 2009. Importantly they assert:"*Compulsory care is very intrusive and the patients' legal rights are today secured to a very small [sic!] degree, both with regards to the competence of the tribunal and the patients' possibilities to have their arguments heard."* (p.212, my translation[2].) Their solution is to maintain the appeals principle, but doctors may be simply too cautious and/or not sufficiently trained in ethics. The NOU acknowledges the case for alternative institutions such as Soteria, Earth House *et cetera*, and refers to projects in Norway and elsewhere where user control and prior agreements have reduced the use of compulsory care and the persons' total time of hospitalisation (NOU, 2011).

At the time of the NOU report, another public report (Bremnes *et al,* 2008) had already shown that with more liberal funding, the *total* number of acute ward stays doubled and *compulsory* stays increased from 253 to 260 per 100.000 inhabitants. In 2009 the number decreased to slightly below 250, with Finnmark, the most northern part of the country, at 350 days and in the south 180. One explanation was the difficulty to recruit enough personnel and thus patients were ill for

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[1] Although the Finnish numbers are from 2000 and their legislation changed in 2002, the decay principle was maintained and for somebody with a psychotic disorder, dangerousness is still interpreted rather broadly as danger of health and failure to act e.g. take medication. The underlying system has not been changed, but the number may be somewhat reduced due to family and social interventions.. (Putkonen & Völlm, 2007)

[2] NOU 2011: 9 In «Økt selvbestemmelse og rettssikkerhet. Balansegangen mellom selvbestemmelsesrett og omsorgsansvar i psykisk helsevern.» Original text: 'Tvangsbehandling er svært inngripende og pasientenes rettsikkerhet er i dag svært dårlig ivaretatt, både når det gjelder klageinstansens kompetanse og pasientens muligheter for å få gjort sine synspunkter gjeldende.'

a longer time before they were treated and thus needed to stay longer. As for the effect of the decay/deterioration criterion, Bremnes *et al* (2008) find that almost 70% of involuntary hospitalisation were *not* a danger to themselves or others, but were locked in because 'they needed treatment'. Funding is liberally available in Norwegian psychiatry, in particular medication, much more so than in Sweden. This is in contrast to Germany, where involuntary treatment is a legal, not welfare matter, although the thresholds vary between the states.

Based upon the EU project EUNOMIA, Kallert *et al* (2011) discuss: *"On average patients show significant but limited symptom improvements after coerced hospital admission, possibly reflecting the severity of the underlying illnesses. Social factors, but not the psychiatric diagnosis, appear important predictors of outcomes."* (p.1)

2.3.2 Recovery as goal

Early intervention is important, but raises the issue of false diagnosis. Bond (2000) is a great resource for thinking ethically about the issues of coerced treatment, real or felt alike. Medication is a considerable help, but raises the issue of side-effects vs. main effect and whether the same dosage should be maintained throughout. A good alliance with the psychiatrist is invaluable as each case is different.

Farkas *et al* (2005) sum up their findings: *"there are at least four key values that support the recovery process and that appear to be commonly reflected in the consumer and recovery literature. These values are: person orientation, person involvement, self-determination/choice and growth potential".* (p. 144) Person orientation means seeing the whole person, listening and respect rather than superficial; person involvement includes some level of therapeutic contact; self-determination/choice and growth potential means such things as believing that the person can take care of herself and achieve something despite conditions. Such values instigate hope, but are of recent origin. When Strauss & Carpenter (1977) published their part of the International Pilot Study of Schizophrenia, the big surprise was their finding that most persons with schizophrenia improved and many recovered fully. It had taken four years to get it publicized, because reviewers insisted that it could not be true. (Davidson, 2003) Meta-analyses have since concluded with more than 50% chance for at least partial recovery (e.g. Carpenter & Kirkpatrick, 1988; Harding, Zubin & Strauss, 1987). Jablensky & Sartorius (2008) find that the differences portrayed by the WHO studies could plausibly stem mostly from social support and reduced psychological stressors which in turn reduce the need for medication. Of course, the longer, deeper and more isolated your distress, the worse the psychological effects and your possibilities to recover. Even if prodromes are not valid for prognosis, early psychological issues like anxiety and isolation are conceivably less severe in collectivistic countries.

Similar issues of course in the USA. Recovery is a humanistic goal not well served according to Pres. Bush New Freedom Commission on Mental Health (2003): "[the mental health system] is not oriented to the single most important goal of the people it serves – the hope of recovery" (page 3 cited in NASMHPD (2004). Onken *et al* (2002) in *Mental Health Recovery: What Helps and What Hinder* contrast the 'Chronicity Paradigm' with the Emerging Recovery Paradigm and as a guideline defines recovery as:

> Recovery is an ongoing dynamic interactional process that occurs between a person's strengths, vulnerabilities, resources and the environment. It involves *a personal journey of actively self-managing* [my italics] psychiatric disorder while reclaiming, gaining and maintaining a positive sense of self, roles and life beyond the mental health system, in spite of the challenge of psychiatric disability. Recovery involves learning to approach each day's challenges, to overcome disabilities, to live independently and to contribute to society. Recovery is supported by a foundation based on hope, belief, personal power, respect, connections, and self-determination. (p. 2)

This is a definitive rationale for psychotherapy and therapeutic environments on the way to recovery.

2.3.3 Effective, ethical therapies

Therapeutic environments and the connected assumptions vary and make comparisons with such 'treatment as usual' (TAU) difficult to say the least. In addition there are difficulties with several scales, including PANSS (van der Gaag, 2006a/b; Leucht *et al*, 2010; Obermaier et al, 2011). NICE CG82 (NICE, 2012) stresses that care should be person oriented and that good communication is essential, with due consideration of any cultural, disability or language problem. CG82 stresses the need to take users' needs and preferences into account, giving the opportunity to make informed decisions about the possible involvement of families and carers; the use of antipsychotic medication; as well as advance statements about their care and treatment. CBT and family intervention are to be offered routinely, although with the promising results from early intervention, psychotherapies are again becoming secondary to medication. Family interventions are difficult to measure and compare. CBT with group therapy and social support look particularly impressive and support a mixed approach to treatment. (Roder *et al*, 2006).

It can be argued that the recommended therapies are not necessarily better for schizophrenia. Instead they could have the advantage of being easier to put into manuals and measure, have more practitioners or simply more funding available for research.

Quite another way of thinking is demonstrated in Lieberman & Murray (2001) as editors of *Comprehensive Care of Schizophrenia.* They believe that medical science is close to an answer: *"we know what constitutes good care for schizophrenia"* (p. xv). Based on the belief that schizophrenia is a chronic, lifelong illness that must be controlled with medication, they seem to blame community care and psychiatric nursing for deficits in individualised treatment (case management) and lack of compliance. Siegfreid *et al* (2001) are more welcoming to other approaches:

> "Although pharmacologic agents have substantially advanced the treatment of schizophrenia much remains to be done to develop novel and more effective compounds. In addition, although pharmacotherapy provides *the foundation* [my italics] optimal treatment *should* [my italics: i.e. not important, but should] also include appropriate psychosocial therapies." (p. 87)

Clinical staging seems an ethical alternative (Francey *et al*, 2010) supported by several sources. A Cochrane review (Bola *et al*, 2011) says data is too sparse to assess the effects of antipsychotic medication on early episodes (yet I believe this is far too cautious); Marshall & Rathbone (2011) find some but inconclusive evidence in favour of such early intervention for psychosis; McGlashan (2006) reviewed the neurotoxicity hypothesis and could not find good enough evidence to support it; and Leucht *et al* (2012) provide evidence in a meta-analysis of 65 trials that medication is useful. Disadvantages to watch include weight gains, sedation and neurological effects from D2 dopamine receptors, such as sudden death, tardive dyskinesia, late onset Parkinsonism.

NICE CG82 recommends cautious usage of antipsychotics (but not other medication), while CBT and family therapy must be routinely offered.

Eack *et al* (2007) review Gerard Hogarty's contributions to psycho-social treatments: Major role identification (an early version of case management, they argue, although probably closer to interpersonal therapy); Family psycho-education (important to manage expressed emotion and avoid psychotic episodes); Personal therapy aimed at mastering daily life; and Cognitive enhancement therapy, a precursor to cognitive remediation. He was driven by continuous improvements i.e. practice based: *"This evolution of Hogarty's contributions covers a substantial* *proportion of all the evidence-based psychosocial approaches available for persons with schizophrenia."* (p. 1061)

It must be noted that there is little evidence that psychotherapy is enough for schizophrenia, so a good alliance with a psychiatrist is crucial for minimal medication, adjustment and compliance.

Davidson (2003) asserts that recovery is hard work and takes somebody on the outside that believes in you and supports you when the going gets tough. There is good evidence in survivor narratives that user communities such as Soteria (Aderhold *et al*, 2007), Windhorse (Herrick *et al*, 2007; Podvoll, 1990), Parachute (Cullberg *et a*l, 2006; Cullberg, 2006) and halfway houses in general contribute to recovery. One surprising finding is that non-medicated acute phases may pass within ten days and that it is possible to avoid a full blown psychotic episode (Bellion, 2007), however the author does not mention that an un-medicated episode by its very nature is more severe than one that is successfully medicated; and clearly more taxing on everybody involved. Whether it then constitutes ethical treatment depends on prior contract and intermediate clinical judgement.

The process of recovery has been conceptualised by several authors, some of which are summarised in table 3. It was the hope that this research could achieve a similar kind of modelling through a purposive sample of persons who have remitted from schizophrenia and are at least partially recovered. In fact, this has been the case.

Soteria stands for a low-drug milieu-therapeutic approach to acute schizophrenia, using small and calm crisis homes. Similar theories are present in other therapeutic environments, too, even if more common-sense than formal theory. Since 1984 Soteria has been connected with Ciompi's concept of affect-logic and specific milieu requirements (Ciompi & Hoffmann, 2004). Taking into account that such communities probably have medium to low severity the theory is plausible. In fact CBT has also been successful in reducing intensity, frequency, emotions and delusional content. Negative delusions *qua* belief system create expectations i.e. drives vigilance and increases dopamine in the expectation/goal system. Any re-attribution can work for impulse, control and anxiety; as do also behavioural interventions and milieu therapy. Furthermore, they will do so with a more permanent effect than a tranquiliser or antipsychotic; this is not to say that such interventions can replace antipsychotic medication.

Table 3 Three of many conceptualisations of recovery in schizophrenia

Source	Categories
Davidson (2003). Living Outside Mental Illness.	Negative loop: Cognitive intrusions and disruptions. Decline in functioning. Delusions and other idiosyncratic ways of making sense. Diminished sense of agency and increased vulnerability. Increasing withdrawal and isolation. Path out: Belonging and hope (I am somebody!). Successes and pleasures. Enhanced sense of agency and belonging. Active efforts at coping and adaptation along with increased community involvement. Warnings: Experiences of failure, stigma and rejection.
Rulf (2003). Phenomenological contributions on schizophrenia: A critical review and commentary on the literature between 1980-2000	Changed bodily awareness, retreat/isolation, unreality, and fragmentation; hallucinations including embeddedness, natural attitude and changing representations of reality (hallucinations as being-in-the-world); and changing self-awareness such as hyper-reflexivity involving a constant need to think yet inability to understand, as well as disordered thought and formation of beliefs using bizarre but hard-to-break logic
Wilkens (2007). Understanding recovery from psychosis: A growing body of knowledge.	Five clusters: A developmental and self-empowering process over time; Motivation/drives for recovery; Competences/skills for coping with illness, environment and self-care; Social engagement/shifting social status; and Environmental resources.

Alternative environments are clearly under-researched. Calton *et al* (2008) in a systematic review find even for Soteria only 3 controlled trials satisfying both methodology and the Soteria critical elements. Of these the two US cohorts (Bola & Mosher, 2003) are favourable, while the one from Soteria Berne shows no significant difference between Soteria patients and controls. The authors assert that the data is more impressive than it seems, because of positive outcomes for completers in areas beyond remission, such as living alone or with peers, global psychopathology, and number of readmissions. They also conclude that the medication-poor environment has not been harmful and appears to be a service user favourite as compared with medication-based treatment as usual.

Although the role of systems and society has not been included specifically in this review, several trends should be noted. First, the modern view of schizophrenia treatment is no longer limited to psychiatry and medical epistemology. Second, it is encouraging that early intervention seems to work such as to reduce the extent of bad experiences and social problems. However, a number of affected persons either reject treatment or the treatment is not effective, in both cases there is an open path towards illegal drugs as self-medication. Third, for those who have effective medication the need for non-psychiatric services becomes easier to manage. Society does not have to accept that young adults with schizophrenia end up un-employed and alone as a consequence of stigma and lack of opportunity. With appropriate opportunities and effective treatment (medication and psychotherapy) almost all should be fully capable of meaningful relationships and at least part-time employment.

2.4 THE PERSON IN SCHIZOPHRENIA

> I didn't know that you could do that, talk with people who had schizophrenia. I would have thought that either they would be too disorganized to respond to an interview or, if they did respond, then what they would have told you wouldn't have made any sense. But those people didn't have any difficulties making sense. They were even eloquent. (An 'esteemed professor', quoted in Davidson, 2003: 7)

2.4.1 The nature of psychosis

Accounts of hallucinations and psychotic-like episodes can be found throughout human history. Socrates describes such experiences and religious practitioners have successfully experimented with changes in consciousness. In medieval times madness was a parallel world or diabolic influence, a concept that lingers in some countries and religions. Davidson (2003) asserts: *"there is no definitive experience of psychosis per se from which a person might then infer independently "I am suffering from a psychotic disorder""* (p. 133)

The paucity of research into the experience of psychotic episodes is somewhat surprising, considering Hornstein's (2007) 33 pages of English language survivor narratives. Survivors seem to define psychosis as an acute and episodic loss of control or something new, different from their habitual state. This loss of control in psychotic episodes has in my experience often been connected with a loss of memory for what has actually happened, again different from their habitual state. Sass & Parnas (2003) point out that significant cognitive effort is needed to compensate for this blurring of self-presence, which may become a loop of hyper-reflexivity, fear and avoidance that in turn triggers dopamine. Unfortunately, they say, neither psychosis as a failure of self-concept nor consciousness are properly defined in diagnostic manuals and research literature.

During my ten years of observing and talking with probably a hundred patients with different kinds of psychotic episodes, I posit that psychotic episodes should be regarded a distinct phenomenon rather than an ongoing 'mental illness'. Some examples:

Bellion (2007) vividly recounts a medication-free psychotic episode (her decision, unwise or not):

> *Beings without bodies, mere spectres, forced me to drink and then to lie quietly again. They wore the faces of my friends. The perfect disguise! These intruders were planning something evil. Only a sacrifice could appease them. Only my death could save the world from complete destruction. I had to hang myself – immediately. But I was not allowed to budge; they held me down.. […] Much later I discovered that I had spent the whole week in a psychotic state.*" (p.77)
>
> *When a psychosis abates – having experienced it without the damper of neuroleptics – I finally feel my own body.* (p.82)

In a similar fashion Hannah Greenberg (1964), diagnosed with schizophrenia before antipsychotic medication, had long conversations with dramatic storylines including a gallery of creatures using an artificial, secret language. Her story is hardly totally accurate, but eventually the psychotic world yielded and attention shifted such that the real world started to occupy more and more ground and became important, bright and beautiful. It is as if the background, the dorsal stream of objects, had become filled with hallucinatory material at the expense of reality, maybe an overload in the secondary perceptual areas that temporarily blocked the primary areas. Lauveng (2005) gives voice to a different phenomenon:

> *"…the most salient warning sign was that my identity, the safety of 'I', started to fall apart. I became more and more unsure that I really existed, or if I was a person in a book, or something that somebody had just invented. And I was no longer sure who controlled my thoughts or my actions." (p. 19, my transl.)*

Podvoll's (1990) *The Seduction of Madness* resurrect the story of John Perceval (1803-1876), son of a British prime minister and after his psychoses a renown human rights activist and instigator of 'the Percival code'. He was involuntarily hospitalised at nineteen. While it might or might not have been 'true' schizophrenia (perhaps mercury poisoning) he experienced 'a loss of reason' where his mind felt like living a life with the gods: with heavenly places, subjugation, nightmares, consolation, a miracle of being in two places at the same time, spiritual/egocentric ambitions, and arrogance. He explained: *"until then I had in fact maintained a kind of withholding power over* *my thoughts and opinions; now I had none; […] I became one who is awake, but still dreams, present in the world only through the body."* (Perceval, 1961:44 in Podvoll, 1990: 48).

Henri Michaux, a poet and artist who died in 1984, experimented with the hallucinogen mescaline. Podvoll (1990) summarises Michaux's 'the other condition': *"You cannot change direction or keep your attention to a detail. You cannot stop or start; a kind of inert system is gone, you cannot 'manoeuvre' the machinery.'"* (p. 180) Michaux categorised his experiences as involuntary 'micro-operations': repetition, multiplication, acceleration, thought-image association, spatial uncertainty (within/outside), ruminating chains of thoughts, diabolical and pervert impulses, self-distortion, certitude (magical), two places at the same time, reorientation, and increased alertness. A mind running wild…

It would be very useful to investigate psychotic episodes as a separate phenomenon apart from psychotic disorders – we know there are functional, structural and psychological processes going on.

2.4.2 The first episode

Although the psychotic episode that eventually leads to hospitalisation is bizarre and maybe acute, it will often have been preceded by months or years of depressed mood, anxiety, irritability, aggressive behaviour, suicidal ideation and substance use, followed by a shorter period of social withdrawal and deterioration. *A posteriori* the early signs of schizophrenia may be evident, but they are unfortunately very weak predictors as the majority do not deteriorate (Bromet & Naz, 2006; Morrison *et al*; 2007; Pukrop & Klosterkötter, 2010; Schneider & Deldin, 2001; Seidman *et al*. 2006; van Os *et al*, 2009; Yung *et al*, 2007)

In a major systematic review van Os *et al* (2009) argue for a proneness-persistence-impairment pathway, estimating about 8% prevalence for psychotic experiences (interpreted as vulnerability), about 4% for psychotic symptoms including schizotypy, and 3% who develop a psychotic disorder. They cite evidence that schizophrenia is more frequent (incidence rate) with younger age, male sex, single marital status, unemployment and ethnic minority group. Social challenges/issues seem to make for an earlier onset, while the long-term outcome (prevalence) looks like it is inevitable.

Another avenue is to apply psychotherapy on major complaints (e.g. Bentall, 2003) without guessing whether or not it is a precursor to schizophrenia. Distress and suicidal ideation can build quickly and result in loss of job, money, family and friends; and should be treated as such even after diagnosis. This is particularly important after remission, when schizophrenia is no longer the main reason for distress.

The early phase of schizophrenia seems to be connected with increased suffering that can result in suicide and homicide. Pomplili *et al* (2011) reviewed 100 studies and found that most indicated a relatively high risk of suicidal behaviour (plans and attempts) in FEP patients. Although the prevalence of schizophrenia is less than 1%, patients with schizophrenia comprise between 5% and 20% of all homicide offenders across 9 studies: England & Wales, Canada, Germany, USA, New Zealand, Australia, Finland and Israel. Paranoia is of course at increase generally and becomes part of psychosis. Offending and violence including homicide follow country statistics (Large, Smith & Nielssen, 2009; Large & Nielssen, 2011), with a 4 times greater risk before than after first episode. Violence is associated with involuntary treatment, forensic history, hostile affect, mania, illicit substance use, lower levels of education, younger age, male sex and duration of untreated psychosis (DUP). The risk of major self-mutilation was 25 times higher before than after initial treatment (Large & Nielssen, 2011). Offending seems a feature of schizophrenia but not of other mental disorders (Fazeel & Yu, 2011).

Some connections with neurodevelopment are worth mentioning at this point. Studies have shown that monozygotic twins seem to have the same early neurodevelopment leading also to cognitive impairment. In the affected twin the MRI scans show accelerating destruction, while in the other the impairment reverses. CT and sMRI has yielded inconsistent data (Lawrie *et al*, 2008; Pukrop & Klosterkötter, 2010), but scientists hope to find a genetic source, with gene copying, intrauterine environment and obstetric complications all probable factors for neurodevelopment (Sharma & Harvey, 2006). The Dutch Famine Study describes what has been called a natural experiment: *"Using data from national psychiatric registries, rates of schizophrenia were found to be approximately doubled for individuals conceived at the height of the famine, similar to findings on central nervous anomalies. Nutrient deprivation for the mothers of this group fell below 1000 kcal/day during early gestation."* (Susser & Opler, 2006: 9) Note that late gestational exposure did *not* increase the risk. A Chinese study of the 1959-1961 famine (St Clair *et al*, 2005) confirms these findings, both pointing towards a particular critical period for brain development.

As for cognitive development, there is some evidence for early signs, but they are unlikely as markers for any psychiatric purpose. MacCabe (2008) reviews three British birth cohorts, six conscript studies (Sweden, Israel and Finland) and three school performance studies (Finland and Sweden). He concludes: *"Almost all studies have found a generalized deficit affecting most or all domains, with no clear pattern of differential deficits."* (p. 82). The two Finnish school studies had more subtle changes, which the authors think may be a result of more structure and support for children with learning difficulties in Finland. These are correlational studies and the data might not be accurate. However, very recently an Israeli retrospective study found that those with schizophrenia in a Jerusalem cohort had below-average performance in academic activities in 8th grade, and much below in teacher ratings and non-academic activities. For those with affective disorders no such effect was measured. (Ulman *et al*, 2012).

Arguments for early intervention are convincing and seem to lead to higher recovery rates – yet such intervention must consider the risk of increased false positives and side-effects from unnecessary medication. (Bromet & Naz, 2006; Bromet *et al*, 2005; Harrigan *et al*, 2003; Hegelstad *et al*, 2012; McGlashan *et al*, 2012).

2.4.3 Self and subjectivity

Schizophrenia affects, by definition, your relationship with the real world. In addition the epistemological position in psychiatry is that of natural science with no reference to vague psychological concepts however important. The focus shifted away from psychology with the dopamine theory. When Davidson (2004) discusses the Yale Program for Recovery and Community Health, he criticises Jaspers for a hermeneutic of pathology, a criticism that he shares with Rulf (2003) and several others referred to earlier. Instead he and his colleagues want us to regard people with schizophrenia as people who experience the extraordinary and try to cope. Strauss (2011) in an interesting and highly unusual article deepens this view to say that subjective data are neglected and largely excluded from psychiatric theory and research, primarily because of epistemology. He argues that assessment, research and therapy need to be based upon genuine interest:

> *The need to have a sense of self, a sense of security, a sense of understanding reality, and a certain amount of predictability and control in the world have certainly been a major need throughout human history. Sometimes this need seems to lead to the cultural acceptance of rather special beliefs. [...] for instance, that the sun was really Apollo driving a chariot through the skies.* (p.11)

Flanagan, Davidson & Strauss (2010) would like to see the concept of 'self' re-introduced in the next version of the diagnostic manuals. More generally, Golsworthy (2004) in a paper commissioned by the BPS Division of Counselling Psychology discusses this clash of culture between *“a value base grounded in the therapeutic relationship [and] a classification system that largely denies the importance of the client’s world, other than in gathering of pre-specified symptomatic information”* (p.27). Representing the German school Bürgy (2008) agrees: *“The core syndrome of schizophrenia can be described as a disorder of self-consciousness.”* (p.1207) And Andreasen (2007) laments ‘the death of phenomenology in America’ because in her view symptoms and pathology make us less interested in patients’ lives and experiences: they succumb under a diagnostic that explains everything.

Arguing for psychological factors, Strauss (2008) similarly laments*: “One variable strikingly lacking from these more traditional biological and social considerations is the possible role of the individual in affecting the course and outcome of disorder.”* (p. 245). Other authors (e.g. Bentall, 2003, 2009; Parnas, 2012) agree that psychiatric practice should consider the whole person. Davidson (2003) is consistent with Heidegger as he points out that we always do things with an intention even as our senses fail or we are moved by bizarre delusions.

Existentially, our subjective world is both a perceived world (primacy of perception) and an interpreted world as we make sense of it; consciousness of something is not just the perceived something but includes a sense of self, thinking and agency that is definitely not automatic. Phenomenology provides a necessary exploration. The approach was demonstrated in one of the Zollikon seminars: Heidegger discusses a visual hallucination brought to him by Dr F and states emphatically that we should not start with reality and un-reality, but instead look at the patient’s relationship with the world in the here-and-now[3]. (Heidegger, 1987) Auditory hallucinations are not just thoughts mistaken for voices, but may contain a gallery of persecutors with perfect knowledge of your weaknesses, shame, doubt and guilt. There is nowhere to hide and nowhere to rest, and you play exactly the role that you want to avoid.

The importance of relationships (Mitwelt) should not be under-estimated as a main reason for better outcomes in developing than developed countries (Jablensky & Sartorius, 2008). It flies in the face of pharmaceutical predictions but is not at all alien to a psychologist.

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[3] “Beim Verstehen des Halluzinierens darf nicht von der Unterscheidung ‚Wirkliches’ und ‚Unwirkliches’ ausgegangen werden, vielmehr von der Untersuchung des Charakters des Weltverhältnisses, in dem der Patient jeweils gerade steht.“ (Heidegger, 1987: 196)

A Norwegian study (Melle *et al*, 2005) similarly concluded: *"Poor global satisfaction is predicted by being single, abusing drugs, being depressed, having a diagnosis of psychotic affective disorder, having good premorbid adjustment [i.e. falling harder] and a DUP over 10 weeks."* (p. 482) And in what was at the time probably the first meta-analysis Eack & Newhill (2007) included 50 of 502 studies from 1966 to 2005 and conclude: *"An emerging literature of these influences suggests that helping individuals with schizophrenia build broad networks of support and meet their basic needs are promising starting points for treatments targeting quality of life."* (p. 1233)

Law *et al* (2005) in a Hong Kong first-episode study interestingly found that Quality of Life measures did not correlate with negative or positive symptoms, but negatively with depression. They also found that extroversion and agreeableness in the five-factor model of personality (FFM), self-esteem, style of coping and social factors were important positive contributions.

Wilkens (2007) notes that recovery usually starts only after 'several turbulent years'. While this is not necessarily true for everybody, it is not unusual for the onset to be preceded by a period of distress before hospitalisation and then a period of trial, errors and non-compliance. During this time social bonds are often destroyed, even family relations, and expectations for a future can go from hopeful to zero. After loss of control and disintegration comes stabilisation and possibilities to gradually regain personal, interpersonal and community functioning. A recovery process needs 'powerful fuel' in terms of support and motivation, but crucially, small steps and lots of encouragement may be necessary: *"The challenge is to move into roles that are meaningful, productive and valued by the larger society."* (p. 662)

So what if people around you promise nothing and expect nothing except madness and chaos? In the late eighties and early nineties (and still in folk psychology), recovery was regarded an illusion in the Norwegian system:

> It isn't easy to say how long I was ill, because it took several years to slide into the illness, and it took several years to struggle out of it again. I suffered from suicidal thoughts and sensory distortions for many years before anybody knew that I was on my way to becoming schizophrenic. And I had regained much health, safety and insight long before the system believed I would become healthy. (Lauveng, 2005:13 my transl.).

> They said it was a chronic, maybe genetic disorder that I might have to live with or the rest of my life. To buy this 'insight' I would have needed to pay with my hope. I didn't want to then, and I still think that the price is too high." (Lauveng, 2006. 98 my transl.).

Lysaker *et al* (2010) review recovery research more broadly and discuss several conceptualisations. They propose an objective dimension measured by symptom (i.e. Andreasen *et al,* 2005) but propose two subjective dimensions: 'the subjective appraisal of life circumstances' (Umwelt and Mitwelt) and 'the subjective experience of oneself as an individual human being' (Eigenwelt).

Last, the importance of subjective experience in coping with voices has been recognised since the seminal works of Marius Romme and Sandra Escher in the Netherlands. Romme *et al* (2009) tell stories about how the content of voices can be controlled, even if the phenomenon itself cannot; and Romme & Escher (2012) give advice for handling psychosis, not as illness, but as a personal crisis with individual patterns, meanings and therapeutic needs.

2.5 IMPACT OF CHILDHOOD TRAUMA AND ADVERSITY

A clinical-intuitive cause

Since many years clinical intuition has recognised bad childhoods as disproportionately represented on the severe end of psychiatric and personality disorders. If a normal childhood gives you reason to trust other people, then a bad childhood could lead to equally correct beliefs in the opposite: you might have very good reasons not to trust other people. Self-talk (voices) will then reflect your core beliefs about yourself, others and the world. Genes don't invite rape and sexual abuse and therefore genetics cannot explain why so many people with schizophrenia also had a bad childhood – we know that it is a factor for non-psychotic disorders and persons with schizophrenia must be similarly affected over and above their schizophrenia-as-illness diagnosis.

Another diagnosis, dissociative disorders seems from clinical narratives to be more obviously connected with childhood abuse. Whether it is best accounted for as a separate reaction or a dose-response phenomenon is still under investigation – the two could also be linked. (Varese *et al*, 2012).

The dopamine theory continues to be a likely part of psychosis, but does not explain it. The same symptoms can have different causes: when a chain breaks the exact location does not matter for the result.

The traumagenic neurodevelopmental model (Read *et al*, 2001) pointed to obvious flaws in psychiatric practice: Antipsychotic medication is not enough.

Indeed, there is little doubt that an inclusive theory of schizophrenia must account for psychological consequences of an adverse childhood. Traumagenic models seem capable of integrating more aspects than any other theory before it. (Read *et al*, 2014). Whether they will have paradigmatic quality remains to be seen.

Varese et al (2012) have a ground breaking meta-analysis that supports this: *"In conclusion, our review of 41 studies found evidence that childhood adversity is substantially associated with an increased risk for psychosis."* (p.669)

As pointed out earlier (2.2.2) historical data are unreliable because the underlying definitions have been neither stable nor valid. With the dopamine theory psychiatrists have continued to regard schizophrenia as non-psychological, with the consequence that they don't ask and patients don't tell. The ratio of child abuse in the schizophrenia population must have been severely under-estimated. Childhood adversity seems much more widespread than we think.

The support for traumagenic theory is therefore increasing, while genetic theories (now expanded to epigenetic) have little evidence. Larkin & Read (2012) agree: *"Overall, the body of research reviewed [a critical systematic review] indicates a convergence of evidence across multiple studies and while not without limitations, suggests that childhood trauma is a causal factor in psychosis, and for specific experiences considered indicative of psychosis and schizophrenia."* (p.66)

We should add one note regarding psychosis and schizophrenia. Differential diagnostics is quite complex with overlaps in symptoms for psychotic disorders. Even if a trauma sequela is perhaps the main cause for schizophrenia, as pointed out earlier (2.4.3) there are several pathways leading to psychotic episodes and thus the concept of psychosis is far from satisfactory.

Model

Romme (2012) laments that most research has recognised only trauma (PTSD) and not effects of sustained stressful environments. This is a sensible point as we should be interested in the continuum with non-clinical voice hearers – the differences lie in coping and with dopamine regulation many patients will remit. This is an obvious question for recovery research in relation to a tramaugenic theory.

As adverse conditions Romme (2012) considers: sexual abuse, emotional neglect, adolescent problems, high stress, being bullied and physical abuse. Of course, adverse conditions can run in families and therefore seem hereditary!

The weakness of traumagenic theory has been its reliance on clinical/empirical logic and correlational evidence. Bentall et al (2014) discuss the magnitude of correlations and come up with plausible attributions for a) thought disorder, b) auditory-verbal hallucinations and c) paranoid delusions. Additional support for such pathways comes from revisiting the 2007 APMS study (Bentall *et al*, 2012) and the US National Comorbidity Survey (Sitko *et al*, 2014). The latter analyse and discuss the origins and impact of attachment styles in psychopathology. Attachment is no longer a hypothesis for schizophrenia as such, but a factor for personality development and certainly psychological problems.

Dopamine obviously plays a role in the model. Kapur (2003) aptly calls dopamine 'the wind of psychotic fire', demonstrated also by the role of high expressed emotion in psychotic episodes is established (e.g. Adams & Sutker, 2001).

The difference from earlier hypotheses is that dopamine sensitization is more likely an effect of trauma and enduring negative stress than pre-disposition. We know such dysregulation and vulnerability can occur as a consequence of other factors e.g. famine, prenatal developments, peri-natal trauma, and possibly gene copy errors. Dopamine sensitization has been connected to enduring stress also in animal studies. Dopamine has a key role in regulating focus on *both* positive and negative expectations – these effects are well accounted for by psychology.

Specific pathways?

A dynamic model will need to explain dopamine dysregulation/sensitization, neurodevelopment and psychological factors. Pre-dopamine researchers did some work on phenomenology, but it is only recently that we have been able to study the role and impact of dopamine in psychotic episodes irrespective of diagnosis. Although psychiatry acknowledge the role of psychology (as in bio-psycho-social), both schizophrenia and bipolar disorder are primarily attributed to biological dysregulation as the root cause.

The traumagenic pathway cannot be explained as dopamine sensitisation alone, simply because the latter does a poor job to explain the onset. Synaptic pruning (and puberty) does provide an explanation both the timing and severity of the onset – and it is fully compatible with the model. As noted earlier neurodevelopment as such has an element of chance and even monozygotic twins have different development before they are born and during birth; there is sufficient room for individual development and they are not likely to have exactly the same interactions: we must expect the dose-response to be different. A traumagenic theory could be a more likely explanation for the elevated risk of schizophrenia in both MZ twins. It has been noted earlier that most persons with schizophrenia do not have any others in the family with the disorder. Given the extra burden of being a son or daughter in a difficult family, this is another logical explanation for trauma as a more likely cause than genetics.

Romme (2012) sees vulnerability as resulting from the original trauma: duration, severity, protective factors and the degree of disruption to the developmental trajectory. These ideas seem confirmed by Sitko *et al's* (2012) attachment study; as well as a growing body of other research confirming the impact of trauma on the HPA axis and striatum – exactly as expect from D2.

Along these lines, Howes & Murray (2014) present their 'integrated sociodevelopmental-cognitive model', where they combine dopamine theory with neurodevelopment and psychological factors. They locate the most likely source to be pre-synaptic over-supply, again coherent with both a sensitised system and EE producing psychotic episodes. In turn, this fuels the argument that outpatient dosage should be much lower than during a psychotic episode.

In effect, this can only mean that schizophrenia cannot be managed by medication, only facilitated. This is totally coherent with recovery research and 'survivor' narratives.

Psychotherapies

The treatment regime resulting from a traumagenic model is different from the dopamine theory and will need psychologists in a central position. Leucht *et al* (2012) document the utility of antipsychotic medication, yet 22% have little or no effect. Some resort to illegal drugs and claim that this is helpful, perhaps denying problems or blaming psychiatry.

One of the emerging neuro-based therapies is cognitive remediation, a concept already used after brain stroke and traumatic injuries. It is based upon exercises and computer technology to restore functions; but could also be used for behavioural change, desensitization and mindfulness. It could be useful in re-programming striatum and associative processes.

Specific CBT for psychosis has grown since Chadwick, BIrchwood & Trower (1998) – in the foreword Aaron (Tim) Beck applauded them for creating an important shift in thinking: *"…that an hallucination is an activating event and not an 'automatic thought'. This simple step suddenly clarifies the cognitive therapy approach to voices."* (p. x). The 'bad-me' and 'poor-me' belief systems connect to self-talk – a continuous negative stream that you come to expect.

CBT for PTSD is also well established e.g. Mueser *et al* (2008) – the traumagenic model can combine the two in whatever fashion needed for each individual.

Turner *et al* (2014) update this in their meta-analysis by comparing psychological interventions for psychosis: Befriending, CBT, Cognitive remediation, Psychoeducation, Social skills training, and Supportive counselling. We should expect some interventions to work better for a person primed to expect negative things; the findings seem to confirm that specific therapeutic goals are better served by specific interventions. This is clearly opposite to some recent meta-analyses that by averaging everything have found little difference between therapeutic modalities.

Last, van den Berg & van der Gaag (2012) have run an open pilot study as preparation for a larger survey. They argue that when trauma is part of schizophrenia, then EMDR could be a beneficial therapy. They found reductions in auditory verbal hallucinations, delusions, anxiety and depression.

Conclusions

As clinicians we certainly make mental notes about what seems a disproportionate share of bad childhood experiences, but have largely excluded them as a possible cause for schizophrenia. Connecting the dots may now be easier with traumagenic theory. Establishing the connection between childhood trauma/stress and vulnerability for psychosis seems very likely and logical; it promises a major breakthrough and possibly a new paradigm because it replaces several key assumptions with new ones that now include more data. It could become a radical departure from today's medical treatments.

How traumagenic theory will affect interventions, treatment regimens and therapeutic environments is not clear. It could become a paradigmatic shift by explaining diathesisstress/vulnerability as a result of neurodevelopment – the shift would have more impact on the psychiatric system than on psychology, where traumagenic theory seems like illuminating what we already intuit. We should also expect considerable resistance as the validation of the theory will mean an obvious shift from medication to psychotherapy. Modern psychiatrists should have no problems with the theory as such, but their training, legislation, systems funding and resources would also need to change.

Varese *et al* (2012) assert that connecting psychosis and recovery with childhood experiences is directly useful for psychotherapy: *"Our findings suggest that clinicians should routinely inquire about adverse events in childhood in order to develop comprehensive formulations and treatment plans when working with patients with schizophrenia or similar diagnoses."* (p. 669)

As a closing remark none of my participants thought they had trauma in their childhood, but several of them had recollection of enduring distress. I had a clinical vibe that Oscar might have been sexually abused – as he referred to an experience that he hadn't told anybody, not even his psychologist. Ronny had been physically and emotionally bullied by his stepmother; Mary and Oscar experienced neglect and bullying. It would seem like more than a coincidence that only 2 of 7 (Harold and Russell) called their childhood harmonious.

This incongruence between what theoretically could be a contributing factor and their evaluations is certainly interesting. Traumagenic theory does not yet have a threshold analysis, but at least we can posit a negative correlation between severity and recovery. Bad childhoods indeed seem over-represented in the clinic – yet this is not necessarily because their schizophrenia is worse, but because they are not offered psychological treatment commensurate with their history.

A likely hypothesis is that more severe cases are more intrusive as memories. In any case, remitted schizophrenia in this view continues as a psychological or adjustment disorder.

I will consider the implications of traumagenic theory my clinical recommendations.

2.6 TOWARDS EXISTENTIAL EXPLORATION

Literature Review as pre-understanding

How should these different perspectives contribute to my pre-understanding? On the one side we have psychiatry with a clinical interpretation and shorthand, while on the other subjectivity might be called a naïve interpretation. Quite recently the DSM-5 has created problems for the relationship between psychologists and psychiatrists[4] (BPS, 2013) and also with health authorities in several countries, a more severe conflict than what Kutchins & Kirk (1997) document for DSM-III. The debacle is not only about the evidence base for psychiatric diagnoses as such, but also about epistemology and health policies. The mental health system is based on diagnoses and its purpose is to treat illness.

To start with it is natural to trust your senses, rather than doubt and discard what seems real. While senses connect us with ‘reality’, in a secular era we may also return to the more mystical world of former centuries, with new age beliefs definitely neither rational nor credible to most of us. An existential hermeneutic must consider all lived dimensions including religious and cultural beliefs.

Crucially, schizophrenia can only make sense as some kind of development, involving a change from (apparent) function to dysfunction for which we do not know the mechanism. The strength of diagnostics is not its accuracy but the role as clinical shorthand; its weakness is over-simplification. In terms of method we should explore the changes via hermeneutic or descriptive phenomenology to call forward lived experience and accept a subjective narrative as a valid perspective.

Herein lies one of the main difficulties in the literature – psychiatry is not funded to take care of a whole person, only to diagnose and treat objective illnesses. The distress is however of a peculiar kind – often obvious to others and either not recognised or denied by the affected person! Psychiatry’s role in society has from its conception reflected society’s treatment ideas, and has unfortunately resulted in a rather unpleasant history at that.

The research has resulted in splitting the literature in three blocks, each of which a pre-understanding. The first, Inside Schizophrenia, recognises the view that schizophrenia is a mental illness and that it can be researched within an epistemology of psychiatry *qua* medical science. This kind of research relies on clinical heuristics, scanning, serum levels, questionnaires, observations and genetics. The core assumption is that by getting to the root cause of each ‘mental illness’, a cure will be found. Psychologists on the other hand point out that there cannot

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[4] Some authors have called this relationship a *Pax Medica*, agreeing to disagree but continue working together.

be a mental illness that does not have psychological consequences – no mental illness has a clean cause-and-effect path.

The second block, Therapeutic Environments, recognises the view that schizophrenia is a life condition that requires needs-based intervention beyond medication. The role of the psychiatrist is therefore different from that of physicians. Luckily, the psychiatrists I know do consider schizophrenia as more than symptoms, even though they specifically treat symptoms and under-utilise psychological interventions.

The third block, The Person in Schizophrenia, argues that the voice of the affected person is partially and sometimes wholly missing. One reason is that subjective accounts are not taken seriously as research data in natural sciences and Ricoeur (1981) notes that a hermeneutic circle between subjectivity and objectivity is impossible. I would argue that this is an open paradox particularly for schizophrenia research, because by definition it is our natural attitude that fails – we are biologically programmed to rely on our senses. Indeed, the goal of insight demands that we doubt our senses and interpretations. In the worst cases, this can hardly be achieved without considerable dissonance, stress and ultimately survival behaviours (flight, fight, and freeze). In this view paranoia is a functional and healthy response to scaring experiences.

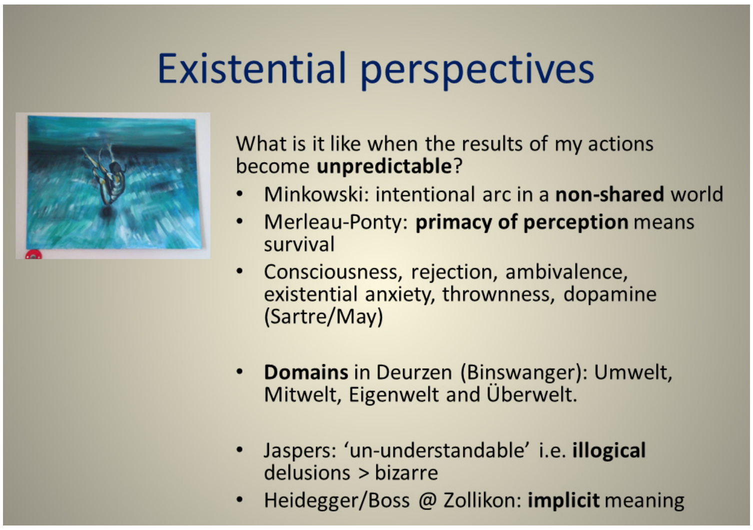
The core issue is that subjectivity, including survivor narratives, is not seen to constitute valid information for psychiatry *qua* natural science. I do not need to weigh one against the other but simply conclude that different perspectives give different information. The three perspectives in the literature review are more or less the pre-understandings of the three defined roles in psychiatry (psychiatrist, carers and patient), and to a large degree epistemologically incompatible.

Exploring schizophrenia as lived experience

Is there then a gap between ‘schizophrenia’ and the ‘psychology of schizophrenia’? This can be answered by opening up relevant perspectives, vantage points and horizons. We must differentiate between psychiatry as system, psychiatrists as practitioners, and psychiatry as research paradigm – the latter creates the basis (and bias) of the former. I take it for granted that the participants have been correctly diagnosed and their stories show severe symptoms – recovery not diagnosis is here the matter.

Lived experiences are streams in time and space simultaneously; anchored in a sense of oneself; and understandable in a wider cognitive activity and sense making. In our daily life this includes our natural attitude to believe that the world is as it comes to us; and that others experience the same physical world. We are also familiar with our uniqueness and subjectivity – so we take it for granted that we are not somebody else, that we have a will of our own that is often different from others', and that there are causes and effects. We understand that 'I' can observe 'me', and even have moments where we realise that 'me' doesn't make sense. Phenomenology will have brain correlates.

Figure 3 Some core existential perpsectives



Existential perspectives

What is it like when the results of my actions become **unpredictable**?

- Minkowski: intentional arc in a **non-shared** world
- Merleau-Ponty: **primacy of perception** means survival
- Consciousness, rejection, ambivalence, existential anxiety, thrownness, dopamine (Sartre/May)

- **Domains** in Deurzen (Binswanger): Umwelt, Mitwelt, Eigenwelt and Überwelt.

- Jaspers: 'un-understandable' i.e. **illogical** delusions > bizarre
- Heidegger/Boss @ Zollikon: **implicit** meaning

The brain is existentially very different from a foot or any other physical organ; it is the key to how we make sense of ourselves. It seems currently impossible to tease functional and dysfunctional processes apart – my own attempts to triangulate via brain correlates and neuropsychology were illuminating and interesting while also clearly premature.

Insight and lifeworld

Can the failure to know that you are ill be used as a marker that you are ill? The clinical meaning of 'insight' cannot be knowledge in the usual sense, but acceptance that you are losing control of reality and need help. Watching yourself from outside is a wider 'insight' as both psychological faculty and meaning. The attempt to place schizophrenia in a pathological hierarchy is clearly incomplete and therefore difficult to sustain. If schizophrenia changes our grounding in the world, it seems to do so without our recognising what is going on, at least not precisely in a perceptual and cognitive sense. Psychiatrists have always varied in taking personal factors into account, from those who argue that schizophrenia may lead to a self-disorder, to those who argue that schizophrenia must be limited to a list of basic symptoms (functional maps rather than symptoms).

Even if you have insight, take medication to avoid psychotic episodes and totally accept that you have schizophrenia, your relation with the world will inevitably have changed. It is common in clinical practice to hear how hallucinations and emotions are accounted for as religion or parapsychology, not mental illness.

It is therefore very useful to introduce the term lifeworld as a metaphor for the subjective totality of a person's experiences: past and present as well as perceptual and cognitive.

I think Merleau-Ponty (1962) is right to call the lived world of humans an ambiguous world. We name and use objects by learning from others and we make sense of the difference between touching and being touched through our role in the act. It is a learnt world over and above a natural world. Our lived world is one of experiences and we become *absorbed* by them (Deurzen-Smith, 1997: 67). Spinelli (1989) similarly calls our world *an interpreted world*.

I would also add that sense-making is enabled and limited by language. Schizophrenia is probably new only by name. Depending on *Zeitgeist* it would have been interpreted as a parallel reality, as evil, and in benign cases as a divine gift. Today those affected and their relatives grapple with psychiatric concepts instead. But we should not be surprised that hallucinations and delusions have contemporary and cultural content – implanted microchips may still be a long way from controlling the brain, but it can be used for tracking your movements and move an artificial limb. History is full of the impossible, so why could not impossible things happen to anybody? From an existential point of view schizophrenia is about making sense rather than understanding a diagnosis - the research has found tht insight requires a shift and not a total acceptance of mental illness. This is more psychological than medical.

Is it a problem of consciousness?

In first-person accounts the word psychosis is not typically used to describe daily living with schizophrenia – but something different from it. My old introduction to psychology (Atkinson *et al*, 1996) includes a chapter on 'Consciousness and its altered states' covering readily accessible phenomena such as sleep and dreams, meditation, hypnosis and drugs: *"To most psychologists, an altered state of consciousness exists whenever there is a change from an ordinary pattern of mental functioning to a state that seems different to the person experiencing the change."* (p. 187)

Should schizophrenia be understood existentially as a special, involuntary type of experience? Will it then make more sense and respond better to what those affected try to tell us about its nature? Kolb & Whislaw (2003) define: *"Consciousness, a property of complex brains, binds diverse aspects of sensory information into a single event that we experience as reality."* (p. 606) And Merleau-Ponty (1962) says: *"If hallucinations are to be possible, it is necessary that consciousness should at some moment, cease to know what it is doing."* (p.401)

At some point in our lived experience those phenomena are no longer just neural representation, but changes to psychological meaning. While it is possible to create definitions that delimit the concept, without brain correlates schizophrenia cannot be verified. Bizarre delusions are probably a marker of a schizophrenic process, but for every such case there seems to be 10 that don't have them. Hallucinations are about the same: in its form as a streaming phenomenon where you participate, it must somehow be outside conscious control i.e. outside attention, awareness and focus. Consider that people talk about voices and hallucinations as embedded in reality. And for negative symptoms the causation and phenomenology are very different.

To explain this as biochemistry has made schizophrenia a weak theory, much as Freud's unconscious that became a black box.

What we need to explore for this thesis is not the symptoms or even phenomenology of schizophrenia, but changes in their lifeworlds. The affected persons start with their natural attitude seemingly intact. Their hermeneutic (naïve) position is based upon how things used to be and their expectations of how the world behaves and their agency in it. Reacting to hallucinations, for example, is incongruent with context and you might only be able to sense that something is wrong without knowing what exactly. Of course, you can learn to recognise psychotic episodes, but initially, thinking that you have an organic failure in the brain is hardly a natural reaction. Davidson (2003) summarises: *"there is no definitive experience of psychosis per se from which a person might then infer independently: 'I am suffering from a psychotic disorder.'"* (p. 133)

The literature research has exposed three fore-structures of interpretation. I do not want to – nor need I – assume priority of one interpretation over the other. For this thesis I am less interested in the psychiatric pre-understanding than in the participant's inner world and her being in the outer world. I borrow from several sources, in particular Heidegger's (1927/1963) being-in-the-world and the later Husserl's life-world. Heidegger reminds us that we are always becoming until we are dead and meaning is until then incomplete. In existential terms we belong in the world, but constitute it as our personal life-world, upon which we as *Being-in-the-world* (German: Dasein, a noun) act deliberately – through our *being-in-the-world* (German: dasein, a verb). It is the latter concept that places schizophrenia in an active relation with the world around us – a confusing subjective and intersubjective phenomenon and not just strange behaviours and thoughts.

Gadamer (1995) states that an experience (das Erlebte) has exactly the property of both the immediate and its lasting result, the change of horizon (Wirkungsgeschichte). Schizophrenia is not just immediate experience, but very much that as a core. When we experience and act in our lives we influence our horizons. Usefully, one of my inspirations, Ricoeur (1981) positions himself closer to Gadamer's (1995) belonging and confirms:

> "Belonging is expressed by Heidegger in the language of being-in-the-world. The two notions are equivalent. The term 'being-in-the-world' expresses better the primacy of care over the gaze, and the horizontal world which *precedes reflection* [my italics]" (p.106).

Importantly, a hermeneutic circle in an existential exploration will then be between the person and the life-world, as well as between whole and parts. Ricoeur (1983) rejects specifically a hermeneutic circle between subject and object as it *"will merely become a vicious circle"* (p.57).

3 METHODOLOGY AND METHODS

> Theory is constructed to make sense of the data collected through observation […] It is generally accepted that sense perception does not provide direct and uncontaminated access to 'the facts'. The more we know about a phenomenon, the more detail we perceive when we observe it. Perception is inevitably selective and people can be trained to observe the same phenomenon in different ways. (Willig, 2001: 3)

3.1 Researching lived experience in schizophrenia

The purpose of my research is to learn as much as possible from research participants about their recovery from schizophrenia from an existential point of view. Participants should therefore have a confirmed diagnosis with extended hospitalisation (severity), but now be well under the threshold symptoms required for diagnosis (remission) with a stable life for many years (recovery).

Psychosis is a rather mysterious phenomenon to most of us. It is difficult enough to explore the lived experience of another person when we share background and history, but by definition schizophrenia includes distortions. Fortunately, with better treatments the *Zeitgeist* has changed:

> Schizophrenia no longer represents a lack of, or an alternative to, reality, but a state in and out of which people can move over time, no longer trapped for the remainder of their lives in their own, separate world. (Davidson, 2003:11)

For an existential-phenomenological exploration I have considered three alternatives: descriptive phenomenology, hermeneutic phenomenology and grounded theory. Via rather broad and open questions in the interviews my interest is to develop an understanding of active coping and recovery for a limited number of participants who have been diagnosed with schizophrenia. I hope to discover activities, meaning-making, narrative adjustments and coping mechanisms that have made their lives liveable. My research is both lived experience and psychological principles; but my lens is the interview as a narrative.

Narratives are not accurate. When Caesar crossed Rubicon it represented challenge, betrayal and foolhardiness; his narrative changed immediately from that of a loyal army officer. While his dreams and aspirations are necessary to understand his actions, his crossing the Rubicon could not lead to a certain future. Motives and reasons are important elements of narratives, but we are clever to weave causation that suits us. Bad things are often blamed on bad luck, while it is tempting to attribute a good life to hard work and cunning decisions. Any text or conversation has a) a purpose and b) is removed from the original context – "dead" says Heidegger. Narratives are connections *from present* to past and any attempt to recall a particular point in time is a combination of interpretation and description to fit the story we want to tell.

Some events are big enough to change a person's life totally and serve as a new existential position or anchor. When your beliefs about yourself, others and the world change, then your behaviours are likely to change too. Rather than describing what schizophrenia was like, I am interested in the participants' adjustments and active coping, in intersubjectivity, belonging and relating (i.e. their being-in-the-world).

I discarded descriptive phenomenology for my purpose. Giorgi (1987, 1997) insists on description and general structures, and Moustakas (1994) is sure: "*Interpretation not only adds nothing to heuristic knowledge but removes the aliveness and vitality from the nature, roots, meanings and essences of experience.*" (p. 19) Dahlberg *et al* (2001) and Davidson (2003) rely on the late Husserl lifeworld conceptualisation mixed with Gadamer (1995) but still seem anchored in descriptive phenomenology.

My choice of hermeneutic phenomenology over grounded theory was more pragmatic and has to do with the scope of research and limitations in the data.

The Grounded Theory alternative

Grounded theory emerges from the data, and there should be no pre-conceived categories. Charmaz (2006) demonstrates an initial process similar to hermeneutic phenomenology with a choice of line-by-line, word-by-word, incident-by-incident and *in vivo* coding followed by focused coding and memo writing. She shares the idea of emergence through writing with van Manen (1990), whereby iterations of memo writing and clustering lead to conceptual categories and finally theory. Glaser is less clear as for him new data seem to mix with extant research, and vice versa ('all is data'). Strauss & Corbin (1998) rely on ordering data into a hierarchy (axial coding) perhaps at the risk of being pre-conceived rather than emerging, and descriptive rather than intepretive of the being-in-the-world of an immediate person-context. They are aware of the weaknesses of hierarchies, but say it was partly necessary to reduce the complexity of grounded theory for learning purposes.

Smith *et al* (2009) suggest that IPA based studies can be used as data for grounded theory. They also say: *"Compared with other strands of grounded theory, the constructionist version [i.e. Charmaz, 2006] appears to offer a greater flexibility of process, and a clearer epistemological position"* (p.202).

Charmaz (2006) differentiates between grounded analysis and grounded theory, as many projects fall short of generating useful theory, and on the basis of only seven participants and a convenience sample I am unfortunately stuck closer to analysis than theory. She is post-modern and social constructionist, her grounded theory is more about critical awareness than deconstruction or critical interpretation. She provides good guidance through coding transcripts, focused notes and eventually theory building.

Hermeneutic phenomenology

Similar to grounded theory, the analysis in hermeneutic phenomenology starts with the question what's going on in the text. References include IPA (Smith *et al*, 2009), van Manen (1990) and Langdridge (2007). I also found it useful to go into depth with Gadamer (1995) and Ricoeur (1981), in particular Ricoeur's advice to separate the inside view (explication) from the outside perspectives (interpretations). In a social constructionist view psychiatric research, recovery research, life narratives and psychology are just frameworks for interpretation. An existential-phenomenological exploration such as this research can therefore take both an inside view (empathy) and a more critical route (suspicion). Langdrige's (2007) Critical Narrative Analysis is another example of the latter and this research has defined a novel existential analytic based upon the uniqueness of schizophrenia as a phenomenon. Because of this uniqueness we cannot rely on our own recollection, recognition, empathy and natural attitude alone; this is the initial stage for van Manen (1990): *"What first of all characterizes phenomenological research is that it always begins in the lifeworld. This is the world of the natural attitude of everyday life which Husserl described as the original, pre-reflective, pre-theoretical attitude."* (p.7)

Ricoeur (1981) provided useful inspiration to fix this issue. Schizophrenia has been researched from several perspectives. Among these, psychiatric research is a branch of medicine and natural science, while other research is more compatible with psychology: psychiatric nursing, pedagogy and recovery research all focus on meaning and coping as opposed to illness and cure. Rulf

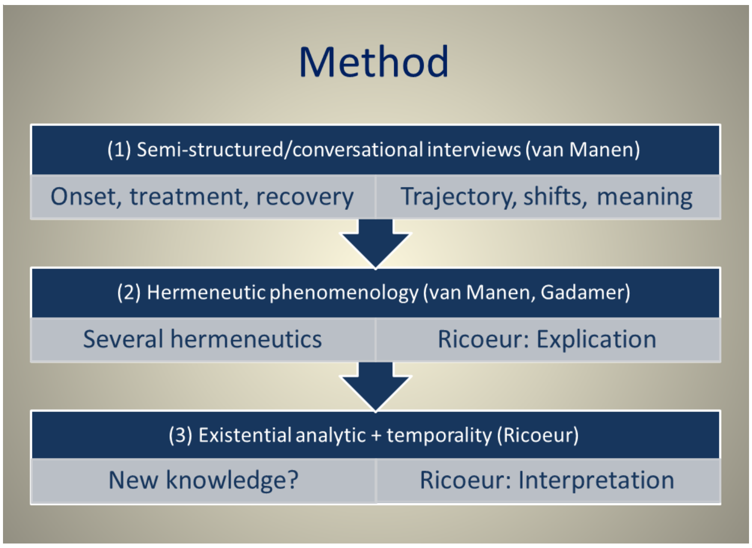
(2003) points out that the word phenomenology in psychiatric research is usually the outsider view rather than an exploration of subjective experience. In contrast, working with narratives is an amalgamation of meaning and subjective experience, from which psychological insight ought to emerge.

The research does not assume that schizophrenia is a mental illness that can be treated by medicine and then life continues; rather it affects your relationships, possibilities, self-image, social functioning, job opportunities, marriage/partnership opportunities, cognitive abilities, somatic health (incl. side-effects) and so on. Schizophrenia is thus not phenomenologically comparable to somatic illness and its manifestation by no means uniform.

These are main reasons for my choice of hermeneutic phenomenology. IPA could have been an alternative, as Smith *et al* (2009) say that it rests upon 1) phenomenology, 2) hermeneutics (the theory of interpretations), and 3) ideography i.e. the particular instead of psychological theory. They recommend reading and re-reading initially, making initial notes before proceeding to develop emergent themes and then look for connections: 'magnets', clustering, parallels or similarity, abstraction, subsumption, polarization, contextualization, numeration, or function. The clusters are then brought forward for comparison and adjustment in the next case.

Grounded theory and hermeneutic phenomenology have stood out as the main alternatives. When my eventual choice became van Manen (1990), one reason was that it seemed less prescriptive than Smith *et al* (2009) and another that it is less restrictive in terms of interpretations. In hindsight this now appears somewhat exaggerated, but admittedly the topic of schizophrenia is very complex both phenomenologically and research wise. Arguably pedagogy, in particular for people with special needs, is epistemologically close enough to the topic at hand. An additional comfort came from knowing that van Manen (1990) had been used for research into schizophrenia and severe mental illness from the perspective of both patients and caretakers (e.g.

Figure 4 The three research phases



Method

(1) Semi-structured/conversational interviews (van Manen)

Onset, treatment, recovery | Trajectory, shifts, meaning

(2) Hermeneutic phenomenology (van Manen, Gadamer)

Several hermeneutics | Ricoeur: Explication

(3) Existential analytic + temporality (Ricoeur)

New knowledge? | Ricoeur: Interpretation

Anderson, 2011; Barnable *et al*, 20016, Koh, 2005; Song, 2011; Wiens & Daniluk, 2009). As further support of my choice, Langdridge (2007) says about van Manen (1990) that *"it represents one of the most complete and popular hermeneutic methods."* (p. 109)

3.2 A critical discussion on phenomenology and reflexivity

The following represent the backbone of phenomenology, as relevant for a discussion of methods and methodology in this research.

Phenomenology: from philosophy to psychology

Phenomenology *qua* philosophy is a shift from objectivity, reductionism and metaphysics to lived experience as consciousness; it also separates analytical and continental philosophy. Continental philosophy of course does not deny that there is a physical world out there.

Husserl (1901) started this interest as a 'meditative' exploration, noting that our *natural attitude* is to believe that it is reality that we are conscious of. Kantian reductionism as well as a mathematical background colour his conceptualisation: crucially, von Uexküll had already noticed how ants must have unique vectors of seeing simply by occupying a unique space. Humans similarly don't see the same object, but a particular angle. Our horizons are therefore personal and not necessarily overlapping: it is a powerful thought. How then can we describe the world? Husserl would resolve this by bracketing, i.e. allowing us to consider the phenomenon proper (noema) in an unbiased and complete way (noesis).

While the mathematical metaphor is tempting, there is obviously more at play: We need our intuition to infer even physical objects, not to mention abstract concepts. I have used the photographs of Holmenkollen, the ski jump in Oslo, as an example of the limits of perception. From right behind it (noema) does not appear to us as a ski jump at all, it is a slim tower and I have to know what it is and verify its position or otherwise I will indeed mistake it for a tower that I have never seen before. If I have never seen a ski jump in my life, my experience even from a 360 degrees flying by won't make much sense. There are necessary presuppositions – my experience is correct, but paradoxically the object of my observations is not valid if I only consider what I see. In other words not even the physical world reveals itself without personal experience.

In another example a hammer is not just a physical object, it associates with purpose (its *raison-d'être* is hammering nails and it is not a screwdriver), the context of where it is used, its relevance in the toolbox and possibilities beyond its primary purpose. Consciousness is more than the object itself, and phenomenology can be interested in both how we make sense of the hammer and the experience of hammering (not the same phenomenon or noema). Our experience of the noema will vary with what we are after (noesis).

So evidently consciousness can 'do' a lot of things disconnected from the world and this problem applies to any description of human beings, events, activities, concepts and metaphors alike – intentionality is not enough, to describe the world we depend upon language constructed to serve this purpose. Or as Merleau-Ponty says in *Phenomenology of Perception* (1962): *"Because we are in the world, we are condemned to meaning [his italics]."* (p. xxii). Our being in the world is neither finite nor complete; it is at any time given and temporal. Interestingly, he also proved formally that the Cartesian split between body-mind (*proprioception*) as object-subject is not perceptually possible. Proprioception can even be lost e.g. in schizophrenia the feeling that I am somebody else or no longer exist.

Sartre's descriptions of emotions and mood are also real enough: 'reality' seen from the gutter it is different from the world seen from a professor's ivory tower. So although impressive for a revolutionary thought, Husserl's early meditations *('zu den Sachen selbst')* now seem naïve and with too much of a Kantian flare; indeed his later lifeworld meditations make more sense for psychology.

Because psychotic experience by definition is both un-real and non-shared, it is obvious from a methodology point of view a layer of interpretation cannot be avoided. Of interest here is Heidegger's Zollikoner Seminare with Medard Boss (Heidegger, 1987), where he questioned the idea of primary delusions. Delusions are usually secondary and circular with hallucinations, which is a foundation in CBT for psychosis. It does not mean that they are not both dysfunctional and destructive.

Phenomenology as method

Phenomenology is for these reasons not a unified methodology, but is mostly seen as a continuum between descriptive and hermeneutic phenomenology (Finlay, ; Langdridge, 2007). If Husserlian descriptive phenomenology attempts to eschew interpretations altogether, this ambition is rejected in hermeneutic phenomenology and replaced by reflexivity.

Psychosis is *inside* consciousness

All phenomenologists study consciousness. The world out there is real enough, but consciousness associates experiences, concepts and ideas that make sense of the physical world. Any attempt to bracket empathy would seem futile and counter-productive for psychology in particular. To understand others we need to add care over gaze (Gadamer, 1995; Heidegger, 1927/1962).

As psychosis by definition is consciousness mistaken for reality (as opposed to fantasy and dreams) this immediately poses a challenge: what is it that we are studying? If we study the lifeworld as it appears for the psychotic person, at least initially we cannot bracket the participants' natural attitude even when she hallucinates. This is because it is exactly the natural attitude that we would want to study. In fact psychiatric manuals miss the core of psychosis, which is its real-ness. Put differently, when talking with a person who has had a psychotic episode it is only by personal experience that I can infer that the other person is psychotic.

Behaviours should be understood as reactions to whatever presents itself as reality, as consciousness – often mysterious to the outside but logical to the person herself. CBT for psychosis (CBTp) is based upon this assertion. Persons with schizophrenia react upon lived experience with a natural attitude and what Heidegger calls their unique 'being-in-the-world'.

This is my Heideggerian interest: their way of living is at any point in time a natural attitude towards the world, others and themselves; it is their being-in-the-world. This way of thinking about phenomenology is absolutely central for my research. By definition psychosis or hallucinations cannot be perceived as such; although we can know them by checking with others or in hindsight through reasoning. As a matter of degree rather than kind, research should study both clinical (real) and non-clinical (pseudo- and quasi-hallucinations). Insofar as behaviours are based upon a non-shared and psychotic world, the world does not behave back as they expect. Delusionary thinking itself is then mostly a normal, not ab-normal consequence.

Descriptive phenomenology

Descriptive phenomenology is based upon the concept of bracketing as discussed earlier, with the goal of revealing the true phenomenon (*'zu den Sachen selbst!'*). Merleau-Ponty (1962) contradicts this formally: *"Because we are in the world, we are condemned to meaning [his italics]"* (p. xxii) We obviously need different types of phenomenology to study different things.

While the natural attitude is simply to recognise and believe things as they appear, the phenomenological attitude encourages doubt. For reasons of replicability descriptive phenomenology uses a sequence of steps e.g. based upon Husserl (1936/1970): 1) the epoché (bracketing) of the natural sciences; 2) the epoché of the natural attitude; 3) the transcendental reduction (standing above life; and 4) the eidetic reduction. Eidetic reduction is a form of imaginative variation. Eidos (εἶδος) is a Greek word meaning "image," "form," or "shape" i.e. what is meant is a reduction to discover the necessary components of a phenomenon (essentials) by removing characteristics and see if the phenomenon changes.

Later in his life Husserl went from lived experience to exploring his concept of lifeworld, albeit his transcendental reduction still meant standing aside, viewing the world with pure, essential consciousness:

> I stand *above* the world, which has now become for me, in a quite peculiar sense, a *phenomenon*. [his italics] (Husserl, 1936/1970, p. 152).

Giorgi (2009) has four methodical stages: a) read for sense of the whole; b) determination of meaning units; c) transformation of participant's natural attitude expressions into expressions sensitive to phenomenology and psychology; and d) through the use of imaginative variation, articulating the essential structure of experience.

Spinelli (1989) has three steps. Step A, the rule of epoché, consists of bracketing biases and assumptions. It presupposes the capacity to focus on the other person and the noema, as a kind of forgetting yourself. Step B, the rule of description, similarly abstains from explanations by realising alternatives. The latter is a particular challenge in interviews, because a conversation invites us to co-create the content while being totally silent may not be helpful, either. Step C, the rule of horizontalization/equalization, says that we should not prematurely start to see connections, categories or hierarchies of data. The key point is patience and reflexivity.

Langdridge (2007) has a slightly different version. After epoché he places phenomenological reduction as three elements: description, horizontalization and verification.

Most phenomenologists would agree that Husserlian reductions are more philosophy than psychology. Finlay (2012) says about Giorgi's four steps: *"Crucially, it is through the use [Giorgi's use] of phenomenological reductions (including Husserl's eidetic reduction using free imaginative variation) that the essences, or structures of meaning, are disclosed."* (p. 185).

It is easy to agree with Dahlberg *et al* (2001) in *Reflective Lifeworld Research*: *"In lifeworld research, analysing data is a process that is directed towards finding meanings"* (p.182). It is however not clear why they seem to propose Gadamerian openness and Giorgi's four steps as equivalent methods.

Hermeneutic phenomenology

Davidson (2003) demonstrates how a lifeworld approach takes more than description to be useful. As alluded to earlier, psychotic experiences appear as real and are phenomenologically inside consciousness. We are embedded and embodied, rather than a subject observing ourselves. This is confirmed by neuroscience: consciousness is a neural representation of the world; at the same time we are also being conscious of our consciousness – which roughly corresponds to intentionality itself. This is exactly what becomes so interesting in this research – psychosis can be at fault on both levels – a chain reaction where we only know psychosis by its end result.

While Heidegger created the existential shift, Gadamer's (1995) formulated an alternative approach (not method) for studying lived experience. His 'history of effect' (*Wirkungsgeschichte*) captures Heidegger's ideas of fore-'s nicely, as does his metaphor of horizons that may or may not be shared. Understanding others is achieved through both empathy and reflection. He does not provide a method as such, but discusses at length the importance and practice of openness as an attitude.

Heidegger uses terms like *Being-in-the-world* (Dasein, the person acting and belonging in the world) and *being-in-the-world* (dasein, the verb denoting agency). Using Heidegger's existential turn, I would formulate the following shift:

> A lifeworld view no longer pre-supposes that lived experience is a phenomenon to be investigated such that it can emerge, but rather that experience itself can be an emerging and complex phenomenon (reacting, belonging, being-in-the-world).

For this research several hermeneutic methods were considered e.g. Dahlberg *et al* (2001); van Manen (1990); Smith *et al* (2009); but also Charmaz' (2006) version of Grounded Theory can be modified for the purpose. So when I place Ricoeur (1981) on top of van Manen (1990) this is because I wanted to split the analysis into two phases. The first phase should be loyal to the transcripts, using a phenomenological attitude and constant comparison (not reductions). The second phase takes a particular perspective, an existential analytic is a theoretical inquiry beyond description and empathy.

The role of empathy in psychological research is obvious, indeed it is part of the understanding that you try to bracket. An explicit yet cautious and reflective *hermeneutic of empathy* is what Gadamer adds to Heidegger.

When Ricoeur intervened in the Gadamer-Foucault debacle his *hermeneutic of suspicion* became a move towards post-modernism and constructionism, an acknowledgement that language is constitutive and associative with multiple meanings (polysemy). Although with a solid first anchor in phenomenology, Ricoeur (1981) creates a new hermeneutic circle to interrogate the text/transcript using theory.

With any lapse of time from experience to narrative, we are likely to fill in the blanks and reconsider 'facts' such that they make sense: it is a major problem for forensic interviews. The longer it takes the more intervening events, meanings and interpretations. Smith *et al* (2009) aptly call this a double hermeneutic; Ricoeur (1981) uses the concept of distanciation (the 'c' alludes to distance rather than distant). A distant experience is still valid as noema, but it cannot be trusted to reflect the original lived experience and therefore *needs* to be doubted. As we know, Schleiermacher and Dilthey devised two alternative positions to analyse this: one is to imagine Caesar's experience when he crossed Rubicon with weapons; the other is hindsight.

We have above discussed three levels: a phenomenal level, an empathic level and a theoretical interrogation. What connects them is the phenomenological attitude.

The phenomenological attitude

It is certainly not the case that any subjective analysis can count as phenomenological: there has to be something defining what is and is not phenomenological research.

The phenomenological attitude involves a stubborn and intense focus, awareness and attention on the 'something' that we want to explore. If helping the participant to bring content forward, we must refrain from influencing, offering interpretations, or co-creating content. Even re-phrasing and summarising might be too much, while it is admissible to repeat what was being said or follow up with open questions and prompts.

Merleau-Ponty (1962) wants us to see behind the natural attitude and into the silence of meaning; van Manen (1990) wants us to immerse and forge a "strong relation" (p.33), a goal that Ricoeur (1981) calls appropriation (which occurs despite distanciation). Seeing with fresh eyes is the core of phenomenology, or as Finlay (2012) says:

> "The immediate challenge for the researcher having this passion or curiosity is to remain open to new understanding – to be open to the phenomenon – in order to go beyond what they already know from experience or through established knowledge. The researcher starts to engage in a phenomenological attitude, which is one of noninterference and wonder." (p.175)

Hence, the phenomenological attitude is all about suspending our natural attitude to discover what then comes to the fore; what emerges as a phenomenon. The problem of language seems generally under-estimated – Ricoeur points to the obvious fact that you cannot describe experience without words; and words are used exactly to construct meaning. Often they are less exact than we think and even have multiple meanings (polysemy). What comes across may not be what we meant to say, and certainly not everything we needed to say.

Generally speaking, a phenomenological attitude means holding ourselves back, focusing intensely on the person or text in front of us, and trying to see what is being communicated in a way that captures both the whole and the parts. It is an attempt to become totally immersed while at the same time holding ourselves back.

Can reflexivity in hermeneutic phenomenology replace the Husserlian systematic steps? Empathy is implicated in both reductions and reflexivity. It is a tool that cannot be bracketed – it would be like putting your hammer away such that you cannot drive the nail.

Finlay (2008) calls for (and demonstrates) a *'dance between reduction and reflexivity'*. Notably, such reduction is not limited to Husserlian or Duquesne concepts as she acknowledges phenomenology as a continuum from descriptive to hermeneutic (Finlay, 2009) even if certainly not a *carte blanche* to mix and match:

> "I have concerns about research which purports to be Husserlian, for example, when there is no evidence of any reductions being attempted. Similarly, researchers who claim to have bracketed and, therefore, transcended their assumptions while using a hermeneutic approach would seem to be both naïve and confused." (p.8)

Finlay (2012) notes four stages following after a) embracing the phenomenological attitude viz. b) entering the lifeworld through descriptions of experiences; c) dwelling with the horizons of implicit meanings; d) explicating the phenomenon holistically; and e) integrating frames of reference.

Reflexivity in this research

Reflexivity is a way of supporting and validating analyses: a necessary companion to subjective data, whether in descriptive or hermeneutic phenomenology. Additionally, for research to be phenomenological Finlay (2009) requires:

> My own position on this question is that phenomenological research is phenomenological when it involves both rich description of the lifeworld or lived experience, and where the researcher has adopted a special, open phenomenological attitude which, at least initially, refrains from importing external frameworks and sets aside judgements about the realness of the phenomenon. (p.8)

A phenomenological attitude must be held throughout: *"The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's fore-meanings."* (Gadamer, 1995: 269).

Empathy is always implicated whenever we are dealing with lived experience, and the further away from the phenomenon the more participants will have inferred meaning already. Perhaps equally under-estimated, we need to be aware of how we influence interviews both in direction and content through our mere presence. For texts our solitude and disconnection from what really happened is another point to be considered. Finlay (2012) outlines the phenomenological process as iterative stages, but in reality it is not neat at all, but rather *'continuous, iterative, layered, and paradoxical'* (p. 179).

Reflexivity can be thought of as a way to focus our empathic openness away from theoretical or experiential inclinations:

> One critical danger of engaging researcher reflexivity is falling prey to navel gazing. The researcher needs to avoid preoccupation with emotions and experience if the research is not to be pulled in unfortunate direction which privilege the researcher over the participant. The focus needs to stay on the research participant and the phenomenon in its appearing. (Finlay, 2009: 13)

Here it is important to note that my analysis has two phases. In the Results I try to close a *hermeneutic of empathy* (Gadamer, ; van Manen, 1990); while in the Discussion I am adding a *hermeneutic of suspicion*. Ricoeur's interpretation takes the form perhaps more of a hermeneutic circle than a sorting, consolidation or filtering mechanism; it is an effort to reflect upon the findings with a particular perspective in mind. Finlay (2009) confirms:

> Ricoeur has made a similar distinction [as Gadamer] between the "hermeneutics of meaning-recollection" which he says, aims for greater understanding of the thing to be analysed in its own terms, where meanings are brought out, and the "hermeneutics of suspicion" which involves deeper interpretations *needed to challenge surface accounts* [my italics]." (p. 11)

During the interviews I have attempted to keep my focus on the participant and avoid following my own train of thoughts. While direct verification, repeating, silence and prompting are non-directive; already re-phrasing, summarising, clues and body language can be directive. Total passivity is however also sure to remove energy – content emerges because there is somebody there – research is intersubjective not a vacuum.

A semi-structured interview is then a sort of dialogue where experiences are teased out, and so also checking your intuition. Some intuitive thoughts will be discarded, some will signal that something is missing, that the story isn't coherent, or pick up on clues that might need elaboration. I was also aware that these are not the same as in therapy e.g. there is more distance and less involvement. Suggestions or challenges are avoided, the implicit power is different, I had no historical knowledge and there was no alliance with a privileged view behind the façade.

Personally, I find that focus and presence are key words for reflexivity. You focus your attention fully on the person in front of you; I allow myself very little time to reflect except for a sense of consistency, coherence and closure.

Working with the transcripts is a different process – the other party is gone and what remains are the words and your memory. Although you can imagine a conversation with the text, it is neither current nor social. This is not necessarily a problem, but something to be reflected upon. I will in hindsight be concerned about the quality of the interview itself: did I stay close enough to the phenomenon? Did I divert, lead; did I lose energy, miss clues *et cetera*?

A second area concerns the participant(s). Were they engaged? If not, why? What would they want to hide, if anything? Did they keep away from certain topics, not following up on clues? Should I have asked, or would it be unethical? Was something missing? Hidden?

The third area would be relational and connected to the two other areas. What did the situation feel like? Was I involved? Engaged? Curious? Bored? Distracted? Respectful? Interested? Did I get carried away? If any of this, how did it influence them and how might this have affected the interview? Does some of this belong in the transcript? In my reflexivity journal? Or perhaps in the write-up if it is important.

This is of course a very incomplete list, but serves to show how I have attempted to implement a phenomenological attitude. To the best of my ability.

Ricoeur's version

The unsurpassable presupposition

In the essay Phenomenology and hermeneutics, Ricoeur (1981) argues that *"phenomenology remains the unsurpassable presupposition of hermeneutics"* (p.101) but at the same time he refuses Husserlian idealism (*'zu den Sachen selbst!'*). Imaginative variation cannot be void of language and hence meaning. It is similarly idealism to reduce a phenomenon with natural attitude, in which we assume that things are as they appear to us i.e. without thinking.

Appropriation is understood as a growing familiarity with the phenomenon, whereby the phenomenon starts a belonging ('primacy of care over gaze') and also stands in contrast to what it is not i.e. dis-appropriation. I need to reflect on intentionality and being-in-the-world. Here idealism becomes even more difficult because the phenomenon comes to involve a 'structure of anticipation': *"explication precedes its object in the mode of the Vor-habe, the Vor-sicht, the Vor-Griff, the Vor-Meinung (SZ, 150; BT 191)"* (p.107)

If Husserlian idealism as a 'pure' phenomenology is not possible, the question is: for which phenomena does this matter? It clearly matters in psychosis – where psychotic content is neither real (by definition) nor shared (because it is not reality). Merleau-Ponty (1962) points out that hallucinations are a failure of consciousness to know what it is doing – ironically psychosis is precisely a natural attitude (*qua* experience and anticipation) that is out of touch with the real world where the natural attitude is thought to be anchored.

His phenomenological attitude

Ricoeur (1981) goes further to distance himself from Husserlian idealism and calls for the phenomenological attitude as 'a choice in favour of meaning':

> It is difficult, admittedly, to formulate this presupposition in a non-idealist language. The break between the phenomenological attitude and the naturalistic attitude – or as we said, the choice in favour of meaning – seems to amount to nothing more than an opting for the consciousness 'in' which meaning occurs. (p.115)

Ideas in particular can have no *a priori* character distinct from their meanings. When imaginative variation cannot lead to essences or *eidos*, Ricoeur's solution leads to a dialectical process of appropriation, dis-appropriation and interrogation. Clearly not an easy process as he wants to enable something beyond empathy and openness; it is certainly not deconstruction and it is not application of theory. Indeed he criticises psychoanalysis for forcing content into a straightjacket.

He is aware of time and space when dealing with 'the theory of a text': distanciation not only means that the author comes between the phenomenon and the researcher, which Smith *et al's* (2009) call a double hermeneutic; but also means that a phenomenon should not be conflated with the psychology or deflection of the author. In my research distanciation is apparent in the narratives and indeed leads to the three lifeworlds.

His *hermeneutic of suspicion* enables my existential analytic, an interpretation before which the explication (Auslegung) must be phenomenological. But it is also a more radical act of interpretation and therefore requires caution because it is partial rather than holistic; an inquiry or interrogation.

3.3 Van Manen and lived experience

Van Manen (1990) positions his methods away from descriptive phenomenology and he is sympathetic to both the later Husserl and Gadamer. He suitably shows allegiance to “continental sources" and a lifeworld perspective: *"What first of all characterizes phenomenological research is that it always begins in the lifeworld. This is the world of the natural attitude of everyday life which Husserl described as the original, pre-reflective, pre-theoretical attitude."* (p. 7)

Hermeneutic phenomenological research is to van Manen always the study of unique persons: lived experiences; reflexivity; and meanings. He builds upon both hermeneutic circles as well as Gadamer's (1995) History of Effect (Wirkungsgeschichte): "*Understanding is, essentially, a historically effected event* [his own italics]." (1995:299). The metaphor of horizons is useful for schizophrenia as it explicitly assumes subjectivity even if we can achieve a fusion of horizons when we come to understand what we investigate: *"The horizon is the range of vision that includes everything that can be seen from a particular vantage point."* (p.301)

His use of the word 'essence' is not a Husserlian principled sense, but simply signifies that which is important and meaningful. He encourages us to study people who interest us, as we will otherwise become bored. In his method a hermeneutic circle is not necessarily between whole and parts, but rather emerging between phenomena and different interpretations. Van Manen admits:

> To do hermeneutic is to attempt to accomplish the impossible: to construct a full interpretive description of some aspects of the lifeworld, yet to remain aware that lived life is always more complex than any explication of meaning can reveal." (1990: 18)

Rather than rules he offers rather broad heuristics and advice, from which I have picked some main points using his own headlines:

Turning to the nature of lived experience (1)

Our own experience is the core of phenomenology described already, but he asserts it is just as problematic to know too little as too much. We need a keen motivation for the subject matter and an interest in the people we study.

Investigating experience as we live it (2)

When the original experience has faded, phenomenological research must aim to re-establish a sense of contact and overcome the created distance in narratives. For van Manen (1990) the hermeneutic interview is likely to have interviewees as participants or collaborators in exploration and we are allowed to follow an intuition that would otherwise be lost. Conversational interviews thus:

> In hermeneutic phenomenological human science the [conversational] interview serves very specific purposes: (1) it may be used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon,, and (2) the interview may be used as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience. (p. 66)

Essential preparation is still needed: *"Sometimes it happens that a researcher is confused about his or her real interest or research question, and then the interview is somehow expected to bring about that clarity. Usually this is idle hope."* (p.66)

Reflecting on essential themes (3)

When meaning units, each a block of text that forms a sensible unit for analysis, have been identified, van Manen (1990) reflects upon them and refines them until themes emerge as structures of lived experience. Compare with Sartre who captures exactly such essential themes, in particular of course the experience of shame. It is almost like we live through the phenomenon. In comparison symptoms and causes are not essential themes of experience. Maybe schizophrenia research should take more interest in survivor narratives, of which there are several thousands.

Van Manen (1990) summarises different aspects:

1. *Theme is the experience of focus, of meaning, of point.*
2. *Theme formulation is at best a simplification..*
3. *Themes are not objects one encounters at certain points or moments in a text.*
4. *Theme is the form of capturing the phenomenon one tries to understand.* (p.87-88)

The art of writing and rewriting (4)

Van Manen sees anecdotes and 'poetizing activity' as writing tools to capture recognition: *"a thematic phrase only serves to point at, to allude to, or to hint at, an aspect of the phenomenon."* (p.92). It is easy to see how this is a parallel to Ricoeur's (1981) symbolic meaning or metaphors.

Van Manen quotes Merleau-Ponty (1973:142): "When I speak I discover what it is that I wished to say" and says himself:

> "The aim of phenomenology is to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a

> reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience." (p.36)

Essence for van Manen is not a reductionist kind of essence, of course. My own experience resonates with this as I discover that what I say makes sense. The expression is that 'it sounds right': "As I speak, I discover what makes sense". Writing similarly fixes thought on paper, or as Sartre said: *"The only point to my life was writing. I would write out what I had been thinking about beforehand, but the essential moment was that of writing itself."* (Sartre, 1977:5 in van Manen, 1990:126).

Maintaining a strong and oriented relation (5)

A phenomenological researcher cannot afford an attitude of detachment or distance, says van Manen. Hermeneutic phenomenological research is difficult and a strong focus on the other person is necessary to prevent speculation. It is easy to lose the grounding in the phenomenon and instead look for confirmation that fits our pre-understanding. Adding Ricoeur (1981) avoids premature speculation as explication is limited to a *hermeneutic of empathy*.

Balancing the research context by considering parts and whole (6)

Van Manen (1990) identifies possible reading approaches: a) holistic; b) selective; and c) detailed. According to van Manen one should try to keep the evolving part-whole relation in mind, like a painter does to prepare the canvas – our main brush and tool is empathy. The meaning becomes meaning as we try to capture it through reading and re-reading e.g. we may conclude *"It is possible to be very satisfied with life despite schizophrenia."* It is here that the quality of the interview shows itself, as a good body in an interview will feel like the interview has achieved its end in producing themes and insights.

Another selective tool is to interrogate the text (read: transcript in this case) for fundamental themes that emerge through the initial reading. Van Manen however emphasizes existential *a priori* themes as helpful: lived space, lived body, lived time and lived human relation. The idea is parallel to that of Ashworth (2003) for descriptive phenomenology. There are several more in existential literature, and you can *"weave one's phenomenological description against the existentials of temporality (lived time), spatiality (lived space), corporeality (lived body), sociality (lived relationship to others)."* (van Manen, 1990: 172).

For an existential approach the concept of four worlds provides another hermeneutic (e.g. Deurzen-Smith, 1997; Deurzen & Arnold-Baker, 2005).

3.4 Additional points

As with many things, some of the findings seem evident in hindsight, but were not evident during the analysis. While it might seem that I jumped to conclusions with the concept of three lifeworlds, the truth is that it emerged gradually from focused memos, reflexvitiy and intermediate themes. The division of the literature review by epistemology – subjective, psychological and medical – came while writing the Discussion.

Ricoeur (1981) has influenced my working with Findings (explication) and Discussion (interpretation) separately, while Bloomberg & Volpe (2008) somewhat belatedly helped me bring everything together into a Conceptual Framework.

Van Manen (1990) says his methods are neither exhaustive nor mutually exclusive. The topic (diagnosis and treatment of schizophrenia) itself contains discursive elements that made Ricoeur's *hermeneutic of suspicion* a useful addition to van Manen. Ricoeur (1981) questions our relationships and connections with the world, and agrees with Gadamer (1995):

> Belonging is expressed by Heidegger in the language of being-in-the-world. The two notions are equivalent. The term 'being-in-the-world' expresses better the primacy of care of the gaze, and the horizontal character of that to which we are bound. It is indeed being-in-the-world which precedes reflection. […] Despite the density of meaning in the expression 'being-in-the-world', I prefer, following Gadamer, to use the notion of belonging, which immediately raises the problem of the subject-object relation and prepares the way for the subsequent introduction of the concept of distanciation. (p.106)

This being-in-the-world is agency laden and includes actions, reactions, meaning and personal theories. A personal theory is a belief system saturated with meaning to be explored: *"by opening up the values of the past only through their differences from those of the present, history opens up the real towards the possible."* (p. 17). In *La fonction herméneutique de la distanciation* Ricoeur (1981) explains this difference as four forms of distance (his *distanciation* is closer to the concept of distance rather than something that is necessarily distant), which need to be handled to recover the meaning of a text (including interview transcripts): (1) the loss of anchor in the present; (2) the loss of the author i.e. self-reference; (3) the loss of reference to the world which it claims as background; and (4) the loss of audience i.e. the interlocutor to whom the text was addressed.

Different assumptions and interpretations are present in everyday life and discourse, and it leads to *polysemy* as multiple *possible* meanings, in particular when we talk about non-physical objects, symbols and metaphors. Different researchers will inevitably produce different themes from the same data because our positions and horizons differ – another way is to say we have different perspectives (noesis) on the phenomenon that we study (noema). Replicability in hermeneutic phenomenology may however have been exaggerated as shown by Madill, Jordan & Shirley (2000) and Braun & Clarke's (2006) exposé of thematic analysis. Themes are likely to pick up the same phenomena and after all we live in the same physical world – one of the exceptions being: the non-shared world in schizophrenia.

3.5Methods

3.5.1 Design and sampling

In the research I wanted to investigate the lived experiences of so-called survivors of schizophrenia. I contacted an organisation for mental health in Norway (Mental Helse) and their Secretary General agreed to invite participants from their membership. Survival was operationalised as a confirmed diagnosis of schizophrenia with a lengthy period of hospitalisation, but no hospitalisation since at least five years. There would be no age restrictions, even though this would make the sample more heterogeneous in terms of psychotherapeutic, pharmaceutical and social treatment.

The interview guide was semi-structured with additional prompts and performed as conversational interviews, and the interviews were then transcribed verbatim. Analysis and writing would follow from van Manen (1990) *Researching Lived Experience* as outlined above.

3.5.2 Participants

The research analyses the experiences of seven participants who were diagnosed with schizophrenia and had been hospitalised for at least one year, but not for at least the last five years. They were recruited via a nationwide user organisation in Norway and their age when interviewed was between 32 and 54 years. Explanations and treatments for schizophrenia have changed over the thirty years since the oldest participant was hospitalised for the first time. All have had long-term hospitalisations of more than one year's duration. Harold is the only who has not been compulsorily detained and has only one hospitalisation in acute psychiatry while the others have from two to five.

Norway is a 'small' country where we must expect that people will have been hospitalised together and therefore might recognise each other. For this reason and more generally to protect the identity of the participants, biographical data are omitted except for the below.

Table 4 Psychiatric history

	Age when interviewed	Age onset	Year of first hospitalisation	Year of last hospitalisation	Compulsory?	Reason given by the participant
Eric	57	25	1979	2004	Yes, twice	Psychosis/confusion
Harold	30	21	2000	2002	No	Confusion
Mary	39	19	1989	2004	Yes, once	Suicidal
Nicole	43	21	1987	1996	Yes, once	Suicidal
Oscar	37	17	1989	2001	Yes, many	Psychotic and paranoid
Ronny	40	28 (23)	1997	2004	Yes, several	Suicidal
Russell	50	24	1983	1999	Yes, several	Psychosis

Table 5 Further information provided by the participants

	Current medication	**Current partner**	**Paid work**	**Children**
Eric	Not available	Yes	No	No
Harold	Olanzapine (Zyprexa)	Yes	Yes	No
Mary	Risperidone (Risperdal)	No	No	Yes
Nicole	Clozapine (Leponex)	No	Yes	No
Oscar	Clozapine (Leponex)	Yes	Yes	No
Ronny	Clozapine (Leponex)	No	No	Yes
Russell	Olanzapine (Zyprexa)	No	Yes	No

3.5.3 Interviews and transcripts

The day before the interview I contacted the participant by telephone to confirm the appointment and get a feeling for his/her readiness and mental state. Before the actual interview I conducted a formal assessment using Brief Psychiatric Rating Scale (BPRS) to rule out active psychosis and potential aggression (table 5). We were interviewing in rooms where we were alone and the interviews lasted between 1 and 1½ hour. Three of the interviews had a minor interruption or break. All interviews felt like we had completed the agenda. On recommendation from a fellow doctorate student, the digital recordings were securely encrypted and stored using TrueCrypt, a

PC program that has been cleared for NSA Top Secret (CNSS, 2003). The signed original consent forms have been scanned and are kept on file.

Table 6 Brief Psychiatric Scale (BPRS) scores (Likert 0-6, 18 questions)

Participant	Score	Highest score
Eric	15	Anxiety (3)
Harold	5	Hallucinatory perceptions (3)
Mary	9	Emotional withdrawal (3)
Nicole	6	Tension (2)
Oscar	5	Anxiety (3)
Ronny	4	Depressive mood (2)
Russell	12	Depressive mood (3)

All values in table 5 are within the remitted scale given by Andreasen *et al* (2005) and using my clinical experience I did not detect any signs of an active psychotic episode in any of the participants.

The interview guide was divided into three periods: a) before the diagnosis; b) during hospitalisation; and c) afterwards. We must acknowledge that they do not usually talk about these experiences and may in fact not have made full sense of their experiences. We should be aware of sedative effects from medication, while cognitive degradation can also be a long-term effect of anti-psychotics. Anyway, I am used to thinking and speaking problems from the clinic so defaulted to my natural conversational style.

This style, conversational interviewing, takes special skills but as a psychotherapist trained in the phenomenological method it was rather natural and does not seem to have impaired the quality of the interviews. The interviews were done in Norwegian only and lasted between 50 minutes and 1 hour 40; they were transcribed by me and as agreed with my supervisor two of them translated into English as research examples/evidence. Even if Norwegian is my mother tongue, I have been using English on an almost daily basis since 1984 and so should be qualified to deal even with the nuances of translating between the two languages.

3.5.4 Emergent themes

In van Manen (1990) any text can be broken down to meaning units that convey a specific thought or an object of thought that can be analysed separately: *"the theme or themes that are embodied and dramatized in the evolving meaning and imagery of work"*. (p.78) There must be a clear link between a theme as "*the experience of focus, of meaning, of point*" (p. 87) and its origin within a meaning unit.

The unit of analysis in this research is meaning units (van Manen, 1990), exemplified in the following table. The marked sentences stand out as quotable, or they contain preliminary ideas similar to *in vivo* coding.

Table 7 Excerpt from Harold's transcript. Meaning units start on new line.

Meaning units	**#**	**Emergent themes**
My teacher, the history teacher, had a pistol from the war that he brought along and wondered if we would like to buy. The next day I brought the 500 kroners to school, I remember wanting to buy it but he hadn't brought it with him.	24	Thoughts of suicide
Yes I collapsed. I smashed everything in the apartment, I smashed three guitars and lamps and furniture and everything. Then I sprayed – that's maybe not so relevant – but I remember spraying fire extinguisher all over the room. And then I called my mother, too, who took me home.		
Then I slept and she explained that he had tidied everything up, and my father was there, too. But by then I had slept for two days and nights, I cannot remember so much, but I was in bed all the time. So – remember actually – that I was awake in between and had something to drink and eat.		Crisis/collapse Called mother first Slept at his mother's place Both mother and father were there
You were around 18?		
Yes. It was kind of, I had a feeling that nobody liked me. I was kind of, no (interrupts) [I got a sense that he had opened up too much, so he rounds it off] Nobody wanted to get to know me so I was very depressed.	25	Importance of being liked Loneliness at school Very depressed

A need for selective reading?

After the initial analysis a complication came up in the meeting with my supervisor in February 2011, as he noticed a degree of fragmentation across the first interview.

Table 8 Illustrations using MS Word to find keywords and quotes

I: Have you been compulsory hospitalised?

49 No, I haven't [been compulsory hospitalised]. I have let them keep on with their thing, don't know quite why.

I was very much opposed to talk with a psychologist, but when I did, it was all right and the real reason for wanting hospitalisation was a lump in my throat, I still have it – it is a kind of, I don't quite know – a piece of cloth that comes and goes and it was very much there at the time. Had just gotten it, started in [omitted]. It was like I wanted to get rid of it then. That's why I agreed. I didn't think anything was wrong with my head, but I thought they could remove the lump in my throat. But they couldn't (said with emphasis).

It was a way, it was at least my own excuse maybe, no I don't know – couldn't simply agree that I was crazy. Thought that the lump at least was something that really hurt. But it didn't disappear. But I did get medication and realised that I needed them to avoid becoming psychotic again.

It is not unnatural as the participants might not be used to talking for an hour or more about these things and they might be hard to formulate when you become self-conscious and the tape is running. However, fragmented or disorganised thought might also be a residual symptom of schizophrenia. The idea arose to find a way to assemble thoughts by selective reading. Given the purpose of the interview we thought that they would be talking about 'things' such as hospital, psychiatrists, family, friends *et cetera*; and that we would find these objects of thinking ('keywords') by using the search function in MS Word (above table).

Independently of this exercise nice quotes or ideas were highlighted (in vivo coding) in yellow e.g. *"couldn't simply agree that I was crazy"*. Table 8 illustrates how not only Harold, but also Oscar was talking about several such topics in the same sentence. Here Oscar talks about his voices as something different from drug induced psychosis.

Table 9 Extract from Oscar's transcript

psychosis hallucinations drugs	It may have been why the psychosis came on, that it started it. But then I did have voices before I started with hashish too.	45
	You mentioned it was self-medication.	
hallucinations	So I was bothered by voices and found things were easier with hashish, but then the side effect was that I became psychotic. So it was a very bad combination. Then the teacher at	46

drugs psychosis	the school didn't dare to keep me up there any longer.	

The idea was to read meaning units selectively, with keywords as tags. These keywords seemed to emerge from the text as narrative topics rather than given *a priori*, an important point for any inductive method. After the analysis the resulting emergent themes would be put back into the original transcript such that keywords would not become higher level themes. The final set of 16 topics and keywords are listed below.

Table 10 Keywords used to search for meaning units

Keyword	Norwegian search	Keyword	Norwegian search
diagnosis	diagnose	drugs	narkotika, rus, hasj, amfetamin
family	familie: mor, mamma, far, pappa, bror, søster	friends	venn, vennine, kamerat, kompis
hallucinations	hallusinasjon, stemme	job	jobb, arbeid, yrke
pills	pille, medisiner, tabletter, injeksjon	psychiatrist	psykiater, doktor, lege
psychologist	psykolog, terapeut	psychosis	psykose, psykotisk
schizophrenia	schizofreni, schizofren	suicidal	suicidal, selvmord
crisis	krise, kollaps	studies	studier, utdanning
therapy	terapi	treatment	behandlinng

In effect, this selective reading contributed little and the eventual analysis has relied on coding every meaning unit separately and ignoring the keywords altogether. When later reading Ricoeur (1981) in depth it occurred to me that the keywords could easily have primed me toward a specific perspective that I did not want, namely a psychiatric interpretation.

The main analysis

The full transcript for the case of Harold can be found as an appendix. The selective keywords were kept to serve as a reminder that the participants had actually used these words and that it was necessary to look for several meanings.

Table 11 Fully annotated excerpt from Harold's transcript

Selective	Meaning units	#	Emergent themes
	.		
Diagnosis Psychosis	Would like to begin before I got the diagnosis. I am not sure when it started, have thought back imagine that I have this, this susceptibility to psychosis, don't know exactly when I was psychotic, but	1	Difficult to know that you're psychotic Susceptibility a credible cause
	Can you remember the first time you heard voices?		
Drugs	Yes, I actually do remember. It was, is in fact rather strange because [it was] a friend of mine, we had been, yes we had thrown a party and then I became very anxious I remember, because we had used a lot of drugs.	2	Drugs caused anxiety
	Can you remember how old you were?		
Hallucinations	Guess I was about (thinking) I was 18-191 think, yes. Then it was my friend, my neighbour at the time, he lived across the street from me. Then I heard a voice that said "Yes, these are high frequency sounds that only you can hear", the voice said. And calmed me down: "don't be afraid" and that kind of things. But this was quite natural, even if sounds that only I could hear and it was the way it was supposed to be. I didn't have much contact with him then, so I didn't try to talk with him about it. (short pause)	3	Ego-syntonic voice taken for his friend

It is interesting to note that the participants have adopted psychiatric words. Although this is natural, there are some differences in usage/definition that would amount to what Ricoeur (1981) calls polysemy. They cause many a discussion … 'psychotic' is one of the words where the psychiatric definition is not the only valid definition.

3.5.5 Harold's intermediate themes

More than one hundred emergent themes in the first transcript were clustered and re-clustered, with an apparent temporal order but not for all initial themes. Temporality is indeed how narratives are usually created so would not necessarily be the most important pattern. Between the below coding and the final version there were 15 additions, 7 deletions and 12 changes of wording.

Even if the natural sequence seemed to be chronological, themes such as family, friends, studies and making sense of it all were more continuous.

Something changed: Different kinds of psychosis? (H 8). Existential loneliness in the military. (H 9). Emotionally instable. (H 9) Never had it better (early). (H 14) Ego-syntonic delusions (H 24). Cognitive problems (H 24). Misreading intentions (H 24). Anxiety already in grammar school. (H 24) Very depressed. (H 25) Suffered a lot (later). (H 28).

Trusting your senses: Nothing wrong. (H 13) Paranoia loop to crisis (H 23) Difficult to know that you're psychotic. (H 39). He didn't feel crazy. (H 49) Every psychosis is different (H 67).

Hallucinations: Difficult to know that you're psychotic (H 1) Ego-syntonic voice taken for friend. (H 3 Voices had identity (H 4) Thought voices would go away. (H 4) 'Mysticism' as possible attribution. (H 5) Hallucinating sounds (early). (H 5) He could control 'the magic'. (H 6) Imagery or hallucination? (H 6) Special gift or sign as cause. (H 7) Many fake illness in military so wasn't believed. (H 12) Next psychologist suspected schizophrenia. (H 14) Hallucinations or spontaneous imagery. (H 14) Didn't talk about it. (H 14) Ears and noses – didn't match. (H 14) Imagery or hallucination? (H 17) Paranoid hallucinations. (H 23) Psychologists can find wrongs with you. (H 49)

Crises and collapse: Thoughts of suicide. (H 24) Crisis/collapse. (H 24) Called mother (attachment?). (H 24) Existentially outside, paranoid. (H 24) Felt dumb compared to others. (H 24) Importance of being liked. (H 25) Loneliness at school. (H 25) Severe depression. (H 91) Planning suicide. (H 91) Would shoot himself at home. (H 92)

Drugs: Drugs caused anxiety. (H 2) Moved and quit hashish. (H 4) Both beginning and quitting drugs can cause psychosis. (H 8) Rejected drugs to avoid psychosis. (H 24) Not self-medication. (H 24)

Being diagnosed: Susceptibility a credible cause. (H 1) Psychiatrist just instructed him to take pills. (H 20) Cautious to diagnose. (H 20) Psychiatrists mean something's wrong. (H 27) Diagnosis as relief (ambivalent). (H 28) Diagnosis concerns treatment (cure?). (H 28) Schizophrenia means crazy. (H 49)

Help: Psychiatrist didn't explain the diagnosis. (H 20) Psychiatrist didn't do psychotherapy. (H 100)

Attributions: Schizophrenia as something that ‘comes’. (H 14) A diagnosis is tiring. (H 88) Got long term psychotherapy. (H 99) No psychotherapy the first 6-9 months. (H 100) Now everybody gets a psychologist. (H 100)

Reactions: Didn’t see the need for a psychologist. (H 10) Others were even worse. (H 39) There were worse psychosis. (H 39) Schizophrenia means crazy. (H 49) Couldn't agree he was crazy (H 49) Parents' divorce, reason for schizophrenia. (H 75) Strange thoughts as symptom. (H 75) No childhood trauma. (H 80) No schizophrenia in the family. (H 82)

Medication trials & errors: No information – no compliance. (H 20) Took pills when he was down. (H 20) Need medication to avoid psychosis. (H 49) Medication – a battle you must lose. (H 93) Wonders if medication is placebo. (H 93) Non-compliance because of side-effects. (H 93) Sedation isn’t cure. (H 93) Psychiatrist relied on medication. (H 100)

Hospital: No trust – no compliance. (H 20) Felt comfortable and liked the ward. (H 28) Good working alliance. (H 28) Good boy, no force. (H 37) Control and possibly insight. (H 39) Afraid to end up with ‘the really crazy ones’. (H 39) Good boy – pays off. (H 42) Psychologists are ok to talk with. (H 49) It’s easy to get ‘loads of theories’. (H 73) Alliance is important he says. (H 93) Couldn’t agree he was crazy. (H 49) Compulsion should be avoided. (H 93) The system too tough (girlfriend). (H 93) Police is a punch in the face. (H 94) Advocates user participation. (H 95) Nice female nurse VIP. (H 100) Expression therapy a waste. (H 101) Psychologists make you feel better. (H 103)

Activities: Isolation as treatment. (H 44) Privileges in isolation. (H 46) Good boy – let them do their things. (H 49) Place for treatment with no treatment (H 50) Not so meaningful days. (H 50) Lifeworld changes (brand new world). (H 51) He stayed in for a very long time. (H 51) Physical activity is meaningful. (H 52) Let out - a brand new world! (H 52) Playing music is meaningful (H 70) Successful treatment. (H 71) Wasted treatment (expression therapy). (H 72) Losing control is bad. (H 94)

Well-being: Very satisfied with outcome. (H 70) No cognitive deficits he says (H 99)

Family: Good relation with sister. (H 5) Good relation with sister. (H 10) Family support and care. (H 10) Mother was there accompanying him. (H 14) Called mother first. (H 24) Both mother and father were there after the collapse. (H 24) Slept at his mother’s place (safe haven?). (H 24) Parents divorced. (H 75) Parents still friends. (H 75) Family has really supported him. (H 86)

Friends: Friends reacted and cared. (H 10) Loyal friends despite strange behaviours. (H 86) New friends with similar background. (H 86) Changing friends is natural as you change yourself. (H 86) Drug friends are not real friends. (H 88) Friends can get tired of you. (H 88)

Work: Milieu worker is meaningful[5]. (H 54) Alternatives that he didn't want (H 56) Milieu worker motivates him. (H 60) Changed from patient to colleague. (H 61) Milieu worker – need to know yourself. (H 64) Feeling respected: knowledge and mastery. (H 67) Can fill his days if he wants to (milieu worker and carpenter). (H 69)

Studies: Completed intro course despite psychosis. (H 26) Two months in chemistry despite. (H 27) Not allowed to study. (H 27) Completed as house builder despite diagnosis. (H 55) Alternatives he didn’t want, disappointed. (H 56) Game programming – feeling behind (H 57) Game programming – too much theory (H 58) Game programming – self-confidence (H 59)

3.5.6 Intermediate themes

All transcripts were analysed in this manner one by one, with comparisons and integration after each case. The below table is an extract at a more advanced stage of analysis when the lifeworld concept seemed to organise and simplify the material from a content point of view.

Intermediate themes are more conceptual and abstract in that they bridge from explication to interpretation (Ricoeur, 1981; van Manen, 1990). The former would generate Findings, while the latter would be more grounded in theory and include a specific existential analytic.

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[5] Milieu worker means a person who unlike a milieu therapist does not have a health qualification, but is working on the floor in a psychiatric ward.

Table 12 Intermediate themes for B3 Reactions to medication (* means a quote)

	Emergent themes	Intermediate themes
Eric	Pills take his energy and finer muscle co-ordination, impact drawing. (E 4)	Side-effects
	Side effects: tremors, salivation, stiffness like you're 80 – still didn't take voices. (E 18*)	Side-effects
	Medication helped against anxiety. (E 18)	Desired main effect
	Wanted him to quit drinking but resisted. (E 19)	Side-effects
	Didn't want to quit drinking and just be ill. (E 27*)	Side-effects
	Pills affects your health negatively. (E 46)	Side-effects
	Many pills feels like chemical lobotomy. (E 51)	Side-effects
	Medication makes me drowsy. (E 52)	Side-effects
Harold	No information – no compliance. (H 20)	Compliance
	Took pills when he was down. (H 20)	Compliance
	Need medication to avoid psychosis. (H 49)	Desired main effect
	Sedation isn't cure. (H 93)	Side-effects
	Medication – a battle you must lose. (H 93)	Compliance
	Wonders if medication is placebo. (H 93)	Compliance
	Non-compliance because of side-effects. (H 93*)	Compliance
	Psychiatrist relied on medication. (H 100)	Compliance
Mary	Feeling fat and blames medicine – doesn't protest (M 40)	Side-effects
Nicole	Trilafon didn't work. (N 53)	Side-effects
	Tried Haldol, Orap, Cisordinol. (N 54)	Side-effects
	Leponex since 96, doesn't eliminate voices but she sleeps well. (N 57, 69*)	Desired main effect
Oscar	Leponex turned things around. (O 17)	Desired main effect
	Not obese. (O 19)	Side-effects
	Blood samples though. (O 20)	Side-effects
	Vival for emergency, but not used. (O 21)	Desired main effect
	Very happy with the medication. (O 22)	Desired main effect
	No side effects except sleeping one hour more. (O 29)	Side-effects
	Didn't quite understand that he needed medication. (O 59)	Compliance
	Couldn't avoid injections, so "cooperated". (O 132)	Compliance
	Extreme side effects from Trilafon. (O 146)	Side-effects
	Akineton to fix side effects. (O 147)	Side-effects
Ronny	Pills suppress voices. (Ro 16)	Desired main effects
	Tried most others before Leponex (acc. to clinical guidelines). (Ro 17)	Side-effects
	Too many neg effects of Zyprexa and Trilafon.	Side-effects
	Leponex was 'the first that really helped', now adding Seroquel. (Ro 20)	Desired main effects
	Take medication or be forced. (Ro 22)	Compliance
	Voices have told him to not take medication. (Ro 23)	Compliance
	Often threats of forced medication. (Ro 26)	Compliance
	He became apathetic from too much medication – had to take it. (Ro 55)	Side-effects
	Doesn't like being a zombie. (Ro 55*)	Side-effects
	Dissatisfied - more time with patients can reduce medication. (Ro 74)	Compliance
	Not much hope for recovery but satisfied with medication. (Ro 107)	Desired main effects
Russell	Most ill, most rejecting of pills and other help (why?). (Ru 33)	Compliance
	On Zyprexa, Rivotril and Norvasc. (Ru 52)	Side-effects
	Cisordinol worked fine but very unpleasant. Haldol terrible. (Ru 53)	Side-effects
	Only Kemadrin took anxiety (a side-effect), but he quit abruptly. 5 days of hell then free. (Ru 54)	Side-effects
	Medication can make masturbation and sexuality difficult. (Ru 88-90)	Side-effects
	Medication (Zyprexa) delays saturation so eats too much and risk for diabetes). (Ru 90-94)	Side-effects
	Doesn't like sedation. (Ru 99*)	Side-effects

3.5.7 Main themes

There are six ways that van Manen (1990) recommends as analytical attitudes or methods, all of them used to a lesser or greater extent. His aim is to find and present in writing convincing and important themes, by which he however does not refer to early Husserlian/descriptive phenomenology definitions of essence or transcendence. Rather with 'essence' he simply means something in the data that is important enough to be focused upon: Writing and re-writing are his key tools to establish solid main themes from emergent/initial themes, similar to grounded theory (Charmaz, 2006). Creativity plays a big role after you have found the emergent themes that properly reflect and index the data (e.g. Braun & Clarke, 2006; Smith *et al*, 2009; van Manen, 1990).

Such analysis must not only lead to natural categories. In my research I asked them about their experiences of psychiatry and should not be surprised to find psychiatric wording. Lifeworld perspectives are of a different kind, as they reflected a change in roles from ‘normal’ to ‘patient’ to ‘survivor’. The survivor role is of course their current narrative role – they were speaking as survivors, not patients. Whether they spoke of themselves earlier as victims or patients is another matter.

Importantly, there is no direct route from emergent themes to main themes (or super-ordinate themes) in any of the methods relevant for my purpose (Braun & Clarke, 2006; Charmaz, 2006; Dahlberg *et al*, 2001; Smith *et al*, 2009; van Manen, 1990). In lifeworld research it is important that the material remains transparent through the layers of coding and I agree with van Manen (1990) that this is a matter of writing and re-writing. My choice of van Manen (1990) proved very appropriate for my purpose.

Because the lifeworld concept became so central from this point on, it would be important to explore the rationale for using it as an organising vehicle.

Simplification. At one level the three lifeworld concept made the themes much easier to understand. Early on Harold obviously had no clue that he was developing a mental illness i.e. he did not know what was going on. Unlike pneumonia or a lost leg that are recognisable objects, his whole understanding of the world and emotional life was changing and finally got out of control. The brain is not just an organ, it is where we make sense and it determines our capacity to deal with the world around us.

This was before I completed the Literature research so still struggled with theory. Like for Harold some seem to live in a different world with no going back after the experience to what used to be. Schizophrenia is therefore different from a chronic somatic condition and I hesitated to use words like psychiatry, psychosis, hallucinations because they have implicit pre-understanding. In contrast a lifeworld concept is a safe existential concept.

Temporality. It became apparent already in the first narrative that Harold would have told a different story of his initial experiences those years ago before or during his first hospitalisation. This temporality appears in *what* they are talking about, but also in *how*, as something that they had been through rather than something that persisted. I became fascinated by how they validated other research, viz. that there is a *sense of being trapped inside schizophrenia* that becomes gradually overtaken by an *existence outside schizophrenia* - a sick identity can be replaced with a survivor identity.

The lived world changed as before hospitalisation there was no attribution to schizophrenia; in the hospital the assumption that it could be schizophrenia shed new light on what they had experienced. Harold talks about his early experiences as something that was very real to him, but no longer is and which he can no longer experience because his knowledge about himself and the world has changed.

Narratives look back from the present (even though also provide motivation and projects for the future). Although not the only possible framework, it was logical that I would discover lifeworlds in my own research directly from the emergent themes (Davidson, 2003; Dahlberg *et al*, 2001; Lysaker *et al*, 2010; Rulf, 2003; and Stanghellini, 2010).

Not knowing. This was important as the first lifeworld exists prior to psychosis or schizophrenia. Even if life becomes increasingly difficult we should not expect that diagnosis of schizophrenia will be met with acceptance, but rejection rather. Madness usually happens to other people, not us, and the word schizophrenia has connotations that are not pleasant to say the least. Several participants didn’t talk about it to anybody.

In the second lifeworld there is not only an explanation (accepted or not), but a physical change of surroundings; they also know that the system can take their little freedom away if they don't 'behave'. They get a formal diagnosis and became by definition mentally ill and so could be treated involuntarily i.e. their protests would feel valid to them but to no avail. In the locked wards where I have worked, patients often compare themselves to prisoners and we can only admit that there are similarities. At the same time we remind them that they can cooperate and thus be in charge of their own relations – but it is not like they are free.

The third lifeworld has a narrative distance – an ‘outside again’ even if different from the before-lifeworld, including possible residuals of the illness. Trying to merge this third lifeworld with the others seems theoretically incorrect or at least uncomfortable.

Psychology of lived experience. The research tries to capture a 'psychology of schizophrenia' while realising that different researchers will inevitably create different although probably similar versions, at least if looking for the same things. There is often a delicate balance between theory and analysis, for instance I changed an initial formulation about ‘attachment theory’ to simply ‘family support’ because ‘attachment’ is theory laden and invokes a pre-understanding and even re-definition. In a different situation I kept hallucinations and sense-making apart for similar theoretical reasons because hallucinations are sensory and embodied, while sense-making is primarily psychological. The importance of keeping them apart was given by statements such as: *“Even if they said I was quite psychotic and confused when I came in”* (Harold: 39) – it was family and friends who reacted to his behaviours and thoughts, while he says he was missing such insight.

In a similar way I singled out ‘suicidal planning’ as an initial main theme, but changed later because phenomenologically it is not the suicidal attempt I am after, but the preceding distress that is as severe as to plan or attempt suicide. I avoided the word ‘chaos’ because there may be an inherent order for the participant, even if the experiences are kept secret and would have sounded surreal and bizarre to the outsider. ‘Crisis’ was also followed by collapse rather than resolution; hence I decided that the main theme was “Crisis and collapse”. It captured an essential theme.

The emerging themes were finally falling into place under suitable intermediate themes, many of them providing main theme definitions. All main themes have been given a first letter for lifeworld and then a number. For example, A3 Crises and Collapse contains intermediate themes such as Losing Control and being Suicidal; B2 Making sense (while in hospital) includes psychiatric myth, hearsay and comparisons with others, and more personal beliefs such as telepathy and being chosen.; while B3 Reactions to medication (previously Medication trial and error) contains three sub-themes: Desired main effect, Side-effects and Compliance. Harold’s case provided intermediate and main themes that were modified by Oscar’s as number two and others' later. By the 6th and 7th participants no additional themes or changes seemed necessary, and some main themes could be combined further in Discussion.

3.6 Ensuring quality through reflexivity

Reflexivity is a quality assurance in quantitative research. The following issues will be discussed in this section: Simplification, Temporality (of narratives), Un-knowing, Psychology of lived experience, and Phenomenological validation. In comparison with a more limited phenomenon, a lifeworld narrative grows and changes over time – it is 'condemned to meaning' (Merleau-Ponty, 1963).

The issues lie perhaps not so much in how the interviewer might mislead interviewees to say something they don't really mean, but we certainly have influence over both the choice of topics and the depth of contents – what is omitted might be just as important as what is said; what lies between the lines and behind statements can be more important than the words; and the unsaid might need to be explored specifically. As a novice I didn't always follow the participant's flow and I didn't always explore where I could; a semi-structured interview is not about free association so the goal is instead the common horizon that is achieved when both interviewer and interviewee are satisfied with their hermeneutic circles. If this is not achieved, then the quest must continue. Then the interviewee feels like the story is both completed and understood; and the interviewer should have achieved harmony between the whole and the parts while also covering the items in the Interview Guide.

In each interview I felt like we had achieved this – and I asked if there was more to add. Of course, this does not mean that they wouldn't remember something more later and I encouraged them to call or write in that case.

While this was a one-shot interview it is clear that re-visits might have been useful. I shall reflect on this later. In Grounded Theory this is part and parcel of the method, while this research is based upon one-shot interviews that are analysed in depth. In the following I shall bracket Ricoeur (1981) and concentrate on van Manen (1990), whose aim to find and present convincing and important themes in writing. Such important themes are not essences or transcendence in the Husserlian sense; they are emergent rather than reductionist. After you have found the emergent themes that properly reflect and index the data (e.g. Braun & Clarke, 2006; Smith *et al*, 2009; van Manen, 1990) creativity plays a big role. To him knowledge is not just conclusions, but must be in a form that can also be taught. Writing and re-writing are his key tools to establish solid main themes from emergent/initial themes, here a similarity with Grounded Theory and focussed notes (Charmaz, 2006).

Such analysis needs to go beyond stereotypes and natural categories. The category in psychiatric research is mental illness and patients – this is what you are looking for and this is what you find. I wanted to consider them as survivors i.e. ex-patients because the only real difference between Harold, you and me in daily life is that he takes Zyprexa every morning. The belief that schizophrenia is chronic and latent maximises the role of medication beyond any rational logic and ignores the person's own influence and resources.

Phenomenological comparisons

Simplification. At one level a three-lifeworld concept made the themes much easier to understand. Schizophrenia is therefore different from a chronic somatic condition and I hesitated to use words like psychiatry, psychosis, hallucinations because they have implicit pre-understanding. The brain is not just an organ; it determines our capacity to deal with the world. Early on it is therefore difficult to know except that something is changing.

This pre-assumption is phenomenological but also psychological. It came before I completed the Literature research while I still struggled with theory: how is schizophrenia from the inside? Being a survivor is a different lifeworld from not having been through schizophrenia – this was obvious in all narratives. Schizophrenia changes your life and there is no going back.

Temporality. There was a striking difference between their stories today and what it must have been like at the time. The whole meaning of their experience has obviously changed several times underway. I'm not sure exactly when and how transition 2 emerged (the hope of recovery and a better future), but it is clearly a huge narrative change. Transition 1, the acceptance of help is similarly a huge narrative change. Both transitions are important markers for psychotherapy.

This temporality therefore appears in *what* they are talking about today, but also in *how*, as something that they had been through rather than something that persisted. I became fascinated by how they validated other research, viz. that there is a *sense of being trapped inside schizophrenia* that becomes gradually overtaken by an *existence outside schizophrenia* - a sick identity could be replaced with a survivor identity. Harold talks about his early experiences as something that was very real to him, but no longer is and which he can no longer experience because his knowledge about himself and the world has changed.

Narratives look back from the present (even though also provide motivation and projects for the future). Although not the only possible framework, it was logical that I would discover lifeworlds in my own research directly from the emergent themes (Davidson, 2003; Dahlberg *et al*, 2001; Lysaker *et al*, 2010; Rulf, 2003; and Stanghellini, 2010).

Un-knowing. I would try to avoid pre-conceptions about what recovery is about and I was fortunate enough to have almost no experience with the recovered population. In an acute clinic most patients are either chronic in the true sense of the world or they have quit medication for whatever reason.

I asked myself what it would be like if I had schizophrenia, what would my reactions have been? Madness usually happens to other people, not us, and the word schizophrenia has connotations that are not pleasant to say the least. Several participants didn’t talk about it to anybody. Perhaps we don't know – or we don't want to know.

I needed to transcend the me-them boundary and simply regard them as ordinary people about whom I didn't know anything. This was actually true as I didn't have access to psychiatric journals or any materials. The interviews are all I know about them.

Here the third lifeworld has an interesting narrative distance – an ‘outside again’ that is full of meanings and interpretations; different from the before-lifeworld but inclusive. Actually, the re-interpretations make their stories re-lived rather than lived experiences. Fascinating indeed!

Psychology of lived experience. The research tries to capture a 'psychology of schizophrenia' through hermeneutic phenomenology, something beyond lived experience itself. I wanted to stay within a phenomenology of empathy when dealing with the transcripts; this I thought would lead to empathic data and emergent categories. Ricoeur (1981) calls this appropriation. A second level analysis would use the categories as a pattern as well as go back to the original data for more – the combination of both steps merges in what Ricoeur calls interpretation.

In the first step I could therefore discard the overwhelming amount of theories and delay them until the Discussion. For instance I changed an initial formulation about *attachment theory* to simply *family support* because the word attachment is heavy with theory and invokes a pre-understanding that limits my choice of alternative meanings.

I split hallucinations in two because hallucinations are sensory and embodied, while sense-making is primarily psychological. The importance of keeping them apart was given by statements such as: *"Even if they said I was quite psychotic and confused when I came in"* (Harold: 39) – it was family and friends who reacted to his behaviours and thoughts, while he says he was missing such insight.

And I first had 'suicidal planning' as an initial main theme, but changed later because phenomenologically the core is not really the suicidal attempt, but the distress that is so severe as to plan or attempt suicide. In the same vein I avoided the word 'chaos' because there may be an inherent order for the participant, even if surreal and bizarre to the outsider. 'Crisis' was better, noting that it was followed by collapse rather than resolution; hence I decided that the main theme was "Crisis and collapse". It captures an essential theme.

The intermediate themes were then sufficiently phenomenological while they later organised into suitable main themes with a first letter for lifeworld and then a number. Importantly, by the 6th and 7th participants no additional themes or changes seemed necessary, and some main themes could be further combined in Discussion.

Phenomenological validation

Finlay's (2012) five principles will be integrated in the below discussion: (1) Entering the lifeworld through description of experiences, (2) Dwelling with horizons of implicit meanings, (3) Embracing the phenomenological attitude, (4) Explicating the phenomenon holistically, and (5) Integrating frames of reference.

First it must be noted that the research is not about lived experience in the form of a separate phenomenon, but in the form of narratives that inevitably mix experiences, attributions and meanings. Referring here to Ricoeur (1981) then item 5 is split between explication as a hermeneutic of empathy; and the interpretive process that culminates with the chapter on Clinical implications.

Hearing the existential requires the phenomenological attitude (Finlay's item 3). The state that I strive for in the interview can be formulated as *"a feeling of total immersion while holding back"*. This state allows my empathy to flow with the interviewee while it resonates with my intuition: *"The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's fore-meanings."* (Gadamer, 1995: 269).

How did I contribute to and impact the interviews?

Researcher bias. The *epoché* of natural sciences was somewhat difficult to bracket because the participants used psychiatric terms. Moreover, diagnoses and syndromes collect similar patterns such that the word schizophrenia becomes a prototype within implicit descriptions and reductions that may or may not fit the participant. I tried to handle this by taking their diagnosis for granted and then concentrate fully on their told experiences.

As discussed earlier the *epoché* of the natural attitude is actually difficult for psychosis, where by definition the un-real is subjective (but non-shared) reality for the participant. I am helped by my attitude in clinical work to initially accept all experiences as reality for the participants. My urge to label something as a delusion is nothing but an interpretation that leads my focus away from the participant.

I had some difficulty to bracket some personal beliefs. Among these is *my belief in recovery as the rule rather than exception* – perhaps this has led to excessive celebration of my findings, while the findings might of course be nothing but a consequence of my selection criteria? I am of course not be surprised to find recovery among the recovered, and given time and resources I would also have been interested to compare with others who have not been successful.

Another is *that psychotherapy is useful*. I remember my surprise that psychotherapy was not a factor for everybody and some relief when Russell called cognitive psychotherapy a turning point; same with Oscar and Harold. I'm not particularly disturbed about this, though, because offering such (voluntary) treatment can only be helpful. However, I had to change my hypothesis to a matter of quality of life rather than necessary for recovery; the prior an obvious corollary of the fact that psychotherapy actually works at least at placebo level.

I know I was hoping for something to confirm my belief *that personal resources can be recovered*. Unfortunately I could not substantiate this for everybody, perhaps because of medication. I was actively looking for signs and had to be careful to not bias my findings; which I caught myself doing about halfway. When I found that Mary had not recovered her personal resources, I needed to revisit my other data for signs of negative symptoms. Both Oscar and Nicole confirmed a decline in cognitive skills.

I sometimes felt *drawn towards asking clinical questions* such as when Oscar said he had trained as a cook, but lost his skills and had to retrain. He found it easy to retrain, but this loss of procedural skills was similar to his complaining that he struggles with the sequence of memories. Except for Harold they all complained about fatigue, probably a consequence of medication. They would have to reduce medication for us to know, which is likely but very much outside my research. I didn't ask clinical questions as they would hardly have led anywhere – I had confidence that the existentially significant would emerge in the interviews.

I also believe *that systematic milieu therapy is very important* – it is widespread in Norway so we had considerable common understanding. Phenomenologically I however concentrated on how their days had been in terms of activities such as to avoid technical terms and frameworks.

My response to style deserves some initial reflection. Ronny's transcript was the first and he was an easy person to interview. I found the interview coherent and interesting; the timeline less of a problem compared with Oscar later. Harold, Ronny and Russell were more conversational than the other four. Ronny was definitely less intense than Nicole, who sometimes felt like dumping her whole story during the short interview. After a short break she started to talk again long before I could turn on the recorder. She provided a considerably more detailed narrative than the others, but the themes indicate that these differences in flow were not so important for theme coverage. When I asked if there was something else they would like to have told me, I think everybody said they felt satisfied and understood.

Interestingly I felt more relaxed and concentrated with Harold and Russell, which may be because they had tidier timelines. The most difficult was Oscar, who was very eager but complained underway that he had problems to remember the sequence of things.

The participants cooperated well. I felt closer to Harold, Russell and Ronny than to the others. For instance I was very impressed with Russell's master degree; and with Harold being able to work more than full-time.

Timeline issues. The need for a timeline came as an additional challenge and one that I didn't foresee. Recovery research depends on chronology; while recall is naturally associative and not always chronological. When probing for the timing of events; I sometimes didn't hear or forgot an important question.

For instance, Ronny responded to my question if disability pension is satisfactory:

> "It is now. I don't think I could have handled – if then a job all to myself. I do work for Mental Helse as a volunteer; ok, it takes up a lot of time. I recognise it in myself; I'm not one who could work from 9 to 4. There's a reason why I have disability. (He sighs)." (Ro, 42)

Here I heard and followed up how Mental Helse was meaningful, but forgot to follow up on why he sighed or what his dream would be. Now my interview with Ronny was my first and he felt understood. I had the same unsolicited feedback from others, which seems to say that I was able to complete a hermeneutic circle and cover the important things – ref. Finlay's (2012) item 4. Being more self-critical, though, I could see sequences in transcripts with too many questions at the same time or probing that turned out to be less helpful than intended. It is hard to say if we then lost information, but in most cases I was able to pick up the missing topic later. In any case, the interviews have been rich enough to work on.

Clinical boundary. There were many examples of implicit meanings hiding something deeper, such as when Oscar said: *"Felt so extremely lonely. People everywhere but I felt an extreme loneliness. Indescribable. Felt totally, totally alone."* (O, 67) In this case I followed up, but in another case it would have been inappropriate and even harmful: *"Because there are things in life that I have never told anybody, that a psychologist may have tried to get me to talk about, but I didn't want to."* (O, 125) Other examples were safer but the emotionality was a yellow sign that exploration might have led into in psychotherapeutic domains: Russell's comment about being afraid of communists and bearded people might have led to revoking paranoia and ideas of an unsafe world; Harold's destruction of his living quarters definitely connected with suicidal contents; Nicole's comment that her childhood was 'dark'; and so on. In other cases there was no such risk, for instance Harold talking about his Buddha experiences.

I may have been too protective, but I sensed the risk of leaving the voluntary interview for an inappropriate clinical role. No matter my qualifications, I would have been outside the contract.

Hearing and exploring the existential. Recovery research seemed to require a special hermeneutic circle. In other words, my stance was about *hearing the existential* and *explore deeper if appropriate*. I will reflect on hermeneutic circle later under 'explicating holistically'.

As discussed above under 'implicit meanings' there were areas that were clearly existential, but where exploration might be inappropriate. It might be surprising that I didn't explore the clinical side, but I wanted to **avoid a clinical interview**.

Oscar's interview was definitely the richest on clinical content. Preceding the first hallucination: *"Every time I had painful thoughts, I started to run. And slept very little."* (O, 2) He later says about his therapy: *"I had a psychologist two hours per week. And what you haven't reached is ok to leave alone."* (O, 25) I certainly heard that this was something important that he wanted to leave alone or was very reluctant to talk about, but also that it was too deep for our interview. Another hint: *"So I don't like to be locked up due to events in my life. When they close me in and lock the door in front of me."* (O, 34)

I would probably have asked a very cautious question at the end of the interview, but later he actually comes forward: *"I was mugged in high school, so even then I started to think about killing myself."* (O, 72) but responds to my question about elementary school: *"No, elementary school was very good."* (O, 73) Then *"…Dad has problems with alcohol, and then it may be that he has the same diagnosis as me."* (O, 90) and later: *"and I was in the tough group where we were to sit down and solve the problems. It didn't work for me. Because I never came that close to my feelings, so I was placed in another group that did more innocent things."* And then he continues: *"Because there are things in life that I have never told anybody."* (O, 125)

This is certainly rich and clinical, yet must not be over-analysed because it is not unique to schizophrenia and not really about recovery. Fortunately, the past does not predict recovery.

In the interview his part-time job as church attendant **sounded like** a relevant existential theme: *"And it is called inclusive working life and I find it very nice. And when I meet people in the train or on the bus I say that I'm a church attendant."* (O, 30)

With Harold we **co-created** a sense of coherence after he had talked about his hospitalisation. We had been talking about how he accepted the care and restrictions in the hospital, so I challenge him: *"So you were always a good boy, then?"* to which he answers: *"Have probably been a good boy, yes."* (H, 37) This was somewhat cautious, but a few moments later I ask him about self-control: *"I have been a good boy, I have, the whole time (sounds almost surprised). I have kind of benefited from it."* (O, 42). And when I ask him about compulsory treatment, he answers: *"No, I haven't. I have let them keep on with their thing, don't know quite why."* (O, 49).

These examples, Oscar and Harold, say a volume about two very different persons and how they have different sets of needs. I am graciously reminded of the good milieu therapy at my ward: you just got to see each individual and treat him or her with respect.

Last, a couple of examples that further illustrate sensibility and good listening. Russell says he reacted to the diagnosis with *'disbelief'* (R, 8) and so a couple of minutes later I could ask: *"So you reacted with disbelief you said. Others around you, how did they react?"* As he had been diagnosed in the early 80ies he directly related to it as shameful. Because mothers were still blamed for causing schizophrenia, one of his reasons to keep the diagnosis a secret was to protect her. The word 'disbelief' thus stood out as existential and **expanded** nicely.

Often existential themes are the result of **condensing** instead of expanding. This was the case with Nicole, where the existential condenses into a spiritual dimension. She refers to a common belief: *"[…] but we have been an artistic family [omitted] – you are more sensitive if you are artistic."* (N, 119) She rejects her diagnosis also because she feels 'intelligent and strong' compared with others (N, 77) and she has obeyed voices only as good friends or Jesus; who would never harm anybody (N, 5; N, 12). She has always known voices as voices and considers it a special skill i.e. it condenses into a religious and/or new age beliefs.

Explicating holistically. This is Finlays's (2012) item 4. Each interview reached a completed hermeneutic circle, the common horizon where both participant and interviewer feel that the interview is complete. The innermost circle is however not the interview, but already the participant's established meanings. This is what we tell ourselves and it is the base for a meaningful narrative for the purpose of a short interview. On top of this, recovery research requires another hermeneutic circle, the comparisons between transcripts.

In hindsight I think it is quite an achievement to bring these three levels together, and it was a good decision to read Ricoeur (1981) thoroughly and then come up with an existential analytic. It was an idea directly connected to his discussion of legal, historic, religious and psychoanalytic hermeneutics.

It is also in hindsight that it is easier to see what I actually did… Each interview should not only be a hermeneutic circle, but I needed to feed the interview by listening for existential content – the ontological above the ontic – the way participants are and were living their lives.

To reflect on commonalities between the transcripts, they are mostly coherent and cover a lot of ground. I seem able to pick up on important points later if not immediately – a good sign that I was motivated and listening well.

The Discussion brought up new questions and it is interesting to see how they could be themes for Grounded Theory. For instance, a highly important question for recovery research and psychotherapy is to establish when/if hallucinations over time will continue to non-clinical pseudo-/quasi-hallucinations. It is a very likely hypothesis but under-researched.

Similarly, with now more solid evidence for traumagenic theory I would have liked to explore their early years for signs and experiences of enduring distress and trauma. It was something that I recognised long when writing the Discussion.

It is not possible to follow all clues and angles in any research project – schizophrenia research seems to be a particularly difficult area.

4 FINDINGS

4.1 FINAL TABLE OF MAIN THEMES

The Findings part is meant to constitute primarily a *hermeneutic of empathy* later to be followed by a more interpretive Discussion drawing upon different perspectives and in particular an existential analytic. As shown by the Literature Review schizophrenia is clearly a manifestation of underlying dysfunction but has many interpretations across research clusters, *Zeitgeist* and epistemologies. It is clearly social constructionist and I have wanted to keep clear of controversy in the Findings by focusing on the participants' own data. My usage of the word 'lifeworld' is similar to that of other researchers (Dahlberg *et al*, 2001; van Manen, 1990) and consistent with Gadamer (1995) and Ricoeur (1981) when they talk about belonging and agency. Generally, from an existential point of view this research is about persons who experience major changes that affect both their position in the world and their relation to it. We are situated in our own lived worlds with perceptions and horizons constrained by it.

The final table across the participants was constructed by continuing to cluster and re-arrange themes.

Table 13 Final count of emergent themes (1)

	Eric	Harold	Mary	Nicole	Oscar	Ronny	Russell	All
A1 Not knowing what was going on Something changed | Trusting your senses | Emotional changes	4	3	20	4	2	6	2	41
A2 Making sense of hallucinations Strangeness | Intrusiveness | Powerful | You don't talk about it	5	13	3	11	3	7	2	44
A3 Crisis and collapse Suicidal | Crisis and losing control	6	5	6	7	4	6	5	39
A4 The mediating role of self-image Positives: trust, resilience, optimism | Negatives: loneliness, trauma, shame	4	8	8	11	9	6	0	46
A5 Effect of drugs Why starting with drugs | Why quitting drugs	3	5	1	1	7	15	2	34

In the discussion A1, A2 and A5 go together under "Consciousness and primacy of perception", while A3 and A4 go together under "Crisis, collapse and self".

It may be useful to compare Smith *et al's* (2009) concept of super-ordinate themes as roughly equivalent to van Manen's (1990) main themes:

> "Phenomenological themes may be understood as the *structures of experience*. So when we analyse a phenomenon, we are trying to determine what the themes are, the experiential structures that make up that experience. It would be simplistic, however, to think of themes as conceptual formulations or categorical statements. After all, it is lived experience that we are attempting to describe, and lived experience cannot be captured in conceptual abstractions." (p.79)

Table 14 Final count of emergent themes (2)

	Eric	Harold	Mary	Nicole	Oscar	Ronny	Russell	All
B1 Accepting the diagnosis Being diagnosed | Accepting or not	5	9	4	3	8	17	2	48
B2 Making sense of 'it' Attributions | Myth and comparisons | Insight?	10	15	3	11	3	3	8	53
B3 Reactions to medication	1	5	0	1	9	4	1	21
B4 Alliances and power balance	1	6	0	2	2	3	3	17
B5 Hospitalisations and treatment	1	2	1	4	5	6	2	21
B6 Meaningful activities	4	3	0	3	1	3	4	18
B7 Some treatments seem wasted	1	4	1	2	2	2	1	13

In the discussion B1 and B2 go under "Accepting help and making sense"; B3 is called "Patience and medication"; B4 and B5 go together as "Hospital treatment and alliances"; while B6 and B7 are discussed as "Daily activities".

Table 15 Final count of emergent themes (3)

	Eric	Harold	Mary	Nicole	Oscar	Ronny	Russell	All
C1 Coping with residuals Contacts with psychiatry | Living with voices | Psychological	5	0	2	3	9	3	12	34
C2 Living with identity issues	1	1	3	0	2	5	2	14
C3 Family support	2	9	2	6	1	6	1	27
C4 Friends, friendships Daycentre friends not friends | Lost friends | Real and new friends	6	15	6	12	11	18	8	76
C5 Job	0	5	0	4	3	2	2	16
C6 Studies	0	4	0	4	1	0	5	14
ALL THEMES:	100	172	88	142	133	176	98	576

In the Discussion C1 goes under "Coping with residuals"; C2 goes under "A reconstructed self | Identity and Eigenwelt"; while C3-C6 form the basis for "Social recovery".

To save space I have in the below used the participants' initials instead of full pseudonyms. Also, when working across transcripts the themes no longer seemed 'initial' and so I have preferred to use the word 'emergent' for the participant themes. Themes in bold are intermediate and part of the main themes.

Lifeworld A – Losing your ground

A1 – Not knowing what was going on.

It is our natural attitude to trust our senses. This theme covers the sense that something is changing, that something is not right, feelings of incongruence and emotional unease.

This is a rather vague category of course, but phenomenologically important. Notably, I felt no need to compare with any list of known prodromes, which would have brought me out of a phenomenological attitude and into symptoms and psychiatric theory. When asked to talk about 'the time before diagnosis' they mentioned these as very early experiences that something was happening to them.

Emergent themes: **Something changed:** Long before voices he felt that things were not quite right. (E 2) Different kinds of psychosis? (H 8) Army psychologist didn't suspect psychosis so didn't ask. (H 14) Ego-syntonic delusions. (H 24) Cognitive problems. (H 24) Misreading intentions. (H 24) Every psychosis is different. (H 67) Learning problems (M 16) Concentration failed in grammar school, dropped out (M 56) Running to escape bad thoughts. (O 71). Feeling lost and alone between systems. (Ro 10) A drug addict trying to kill himself. (Ro 65) Dual diagnosis meant being shuffled around endlessly. (Ro 66) That they didn't treat schizophrenia and drug addiction at the same time. (Ro 66) Withdrawal and strange behaviours appeared in grammar school. (Ru 10) **Trusting your senses:** Paranoid ideas. (E 9) Difficult to separate reality and phantasy (earthball). (E 61) Difficult to know that you're psychotic. (H 1) Don't realise that you're acting strange. (H 1) Voices had identity. (H 4) Nothing wrong. (H 13) Ego-syntonic voice (H 24) Difficult to know that you're psychotic. (H 39) He didn't feel crazy. (H 49) Didn't think she was ill (M 55). **Emotional changes:** Existential loneliness in the military. (H 9) Emotionally instable. (H 9) Anxiety, depression, trying cutting herself (M 13) Never had it better (early). (H 14) Stopped self-harming (M 14) Psychosis is unpleasant. (H 24) Anxiety already in grammar school. (H 24) Very depressed. (H 25) Suffered a lot (later). (H 28) Got psychosis from depression too. (Ro 69) Existential loneliness. (O 79).

Sample quotes:

“But now I have insight. Insight that I am ill and that it is my own fantasy. But sometimes there are borders where I am not sure what is real. I realise that I am not healed yet.” (Ru 21) Here he says succinctly that he was ill but didn’t know it.

“There were voices telling me which house to break into. And you often believe what they say there and then.” (O 39)

“Because I was often walking alone, muttering. I think I muttered a lot and cried a lot, irrational things.” (H 9)

A2 – Making sense of hallucinations

Hallucinations are strange and intrusive (come and go as they wish), powerful in a sensory sense as well as psychologically. Includes reasons why they kept experiences to themselves. There is a clear sense of re-writing in the narratives, i.e. they explain what was in light of what they know now.

Phenomenologically this seemed important as either the emotion or the perception may come first. Early intervention should therefore deal with complaints generally.

It felt like it had been easier for them to reformulate hallucinations as unreal, while emotions *were* real and could not be disputed

Emergent themes: **Strangeness:** Imagery or hallucination? (H 6) The earth ball disappeared into his head, was amazed. (E 7) Difficult to separate reality and phantasy, but could explain even the earthball experience. (E 61) Is God's voice a hallucination? (M 33) Ordinary people and political persons alike send her voices, but she doesn’t talk back. (N 98) Super-imposed on reality. (Ro 13) **Intrusiveness:** First voices at 22-23 when working. (E 4) Onset of voices was sudden at work, behind him. (E 5) Hallucinating sounds (early). (H 5) Different, harassing voices at 21 that she couldn’t control. (N 1) Voices of teachers who laughed and told the children she was no good. (N 2) Commanding her to eat a pear instead of an apple – it confuses her. (N 5) Bad experiences with voices and visuals. (O6)

Managed to ignore the voices. (Ro 23) Known and unknown, threatening, critical (mostly) or positive. (Ru 55-58) Scary voices. (O 63) **Powerful:** Voices changed from supportive to arrogant and exposing – considered suicide. (N 4) Foreseeing a future meeting, but not marriage. (N 6) Disobeyed voices and studied German, failed 'of course' (cognitive impact). (N 8) Hearing that she would never marry, felt terrible. (N 8) Incident with critical voice and her biting a hand. Police. (N 81) Destructive voices. (Ro, 16) You often believe what voices say. (0 39) **You don't talk about it:** Hadn't told about voices before the crisis (E 15) Thought voices would go away. (H 4). 'Mysticism' as possible attribution. (H 5) He could control 'the magic'. (H 6) Special gift or sign as cause. (H 7) Many fake illness in military so wasn't believed. (H 12) Next psychologist suspected schizophrenia. (H 14) Hallucinations or spontaneous imagery. (H 14) Didn't talk about it. (H 14) Ears and noses story – didn't match. (H 14) Imagery or hallucination? (H 17) Psychologists can find wrongs with you. (H 49) Saw no reason to mention voices, people would find her crazy. (N 30-32) Nobody asked about voices. (N 34) Voices started with amphetamine. (Ro, 1) Psychiatry didn't ask about voices, but B did! (Ro, 4) Voices as taboo despite a frequent enough phenomenon. (Ro, 5) At B they asked specifically. (Ro, 5) Seems to have had control? (Ro 13) CBT as a massive turnaround. (Ru 25, 40, 44)

Sample quotes:

"Then I feel, sense that Jesus is present at my side. As a shadow. But some of the things he says are quite wild. […] But I spoke with a Catholic who also hears voices. You cannot know that it is Jesus, he said." (N 98)

"I believe the big turning point was cognitive therapy. That's what I think. I got insight into how ill I was." (Ru 45)

"I started to hear voices when I was about 21 I believe, and was in good shape so I didn't think of it as an illness, because I didn't feel the voices take over and I felt in good shape so just lived with it." (N 1)

"That voices was a natural development somehow. So I didn't think much about it. Thought that such is life. […] But I didn't talk about hearing voices." (H 13-14)

A3 – Crises and collapse

This theme captures how distress was building up from bad to worse and all participants ended up in hospital. With reference to the previous two categories and literature research, these incidents were phenomenologically and existentially a separate category; whether or not it is also called a first psychotic episode there is a loss of control.

I certainly expected a crisis, but was surprised that four of them had actually tried suicide. Indeed, because they were now 'outside schizophrenia' I had probably expected that they would be less severe cases to begin with. Yet this seemed not to be the case. Nicole threw herself in front of a tram; Oscar overdosed; Harold wanted to buy a gun to kill himself; and Ronny tried repeatedly to overdose.

Emergent themes: **Crisis and losing control:** Doesn't think they noticed except maybe more fearful and suspicious (E 10) Decrease in concentration and creativity, lot of pressure (E 11) Depressive, more voices, worse sleeping (E 14) Collapsed in the office (E 14) Told doctor about voices and got hospitalised first time. (E 15) Voices, chaos and anxiety. (E17) Crisis/collapse. (H 24) Severe depression. (H 91) Nothing worked – quit school, no job, bleak prospects (M 1) Incident with critical voice and biting a train attendant. Police. (N 81) Non-compliant after the biting episode. (N 83) Three really bad months in Bergen. (O 12) Most ill in Bergen and was 'expelled' from school. (O 153) Before psychiatry he got pills from his GP that he refused to take. (Ru 3) First psychosis added to the end of a love affair. (Ru 3) Paranoid psychosis (Biafra, Pinochet, Kennedy) which lead to first sectioning. (Ru 3) Knew he needed help, but first time the criteria were not completely fulfilled. (Ru 5) He jumped out of the window and the psychiatrist laughed. (Ru 60) **Suicidal :** Planning suicide (pistol). (H 91) Would shoot himself at home. (H 92) Hospitalised 5 x suicidal, the 2nd led to diagnosed schizophrenia. (M 18) Serious suicide attempt, intox (M 20) She was ”cowardish”, didn't manage to kill herself (M 21) Thoughts of suicide. H 24 Hospitalised with severe depression, changed to schizophrenia (M 32) Sectioned after scolding class and suicidal thoughts. (N 44-47) Railway rails must hurt though. (N 45) An attempt at suicide before a tram – thinks she was strong though. (N 73-74) Sucidal thoughts when she heard she wouldn't get married. (N 115) A genuine suicide attempt. (O 69) Suicide thoughts with 14 already because of mugging. (O 72) Suicidal - not much to live for when you lose both job, home and family.

(Ro 86) 4 x overdosed on medication. (Ro 88) Three days coma. (Ro 90) Normal procedure – locked ward. (Ro 95) Only once after the diagnosis. (Ro 96) Brother and mother saved him by following him up closely. (Ro 91) You don't want people to know that you're suicidal or psychotic. (Ro 142).

Sample quotes:

"No, first the job went away because of amphetamine and then the family. And you know when you lose both job, house, home and family then I didn't have much to live for." (Ro 86)

"Remember when I was 17 I collapsed on the floor, was numb in my whole body and hospitalised first time. [...I had] exercised to an extreme extent, went to school and had many painful thoughts. I started to run. And I slept very little." (O 1-2)

"I was out of work, right, and then I had many voices. And I was angry at a voice that criticised my feelings and my person, when I waited for the train. Then I became so angry that I bit the attendant." (N 81)

A4 – The mediating role of self-image

The category appeared late in the analysis. Self-image seems to play a separate role for the content of hallucinations as well as making sense.

Emergent themes: **Positives: trust, resilience, optimism:** Ego-syntonic voice taken for friend. (H 3) Hopes for the future. (H 19) Called mother (attachment?). (H 24) She has had trusted best friends (why not now?) (M 47) She felt more 'normal' in the foster family (M 47) At 6-7 experienced 'the voice' and a feeling that Jesus advised her. (N 21) At 6-7 then not for a long time, until another 'feeling' as a voice (about nature). (N 19-21) Discovered that she had a future still. (N 46) Knows real from unreal, and right from wrong. (N 50) Suicide attempts demonstrate strength. (N 74) Regards that she knows how people are, that others say so too. (N 77,90) She is too strong or direct so people avoid her. (N 121) Some resilience as 'basically positive' despite bad experiences. (O 65) Said yes to almost everything because he didn't want compulsion. (Ro 28) **Negatives: loneliness, trauma, shame:** Bigger brother defended him against mugging. (E 3) Only locked ward doors felt safe. (E 24) No trauma. (E 28) Feeling of being monitored when it's dark outside. (E 30)

Paranoid hallucinations. (H 23) Existentially outside, paranoid. (H 24)Felt dumb compared to others. (H 24) Importance of being liked. (H 25) Loneliness at school. (H 25) She yielded and her daughter got foster parents. (M 7) Embarrassed of her mother (M 10) An only child (M 11) She didn't know her father and was mugged for it (M 12) Grammar school was hell (M 15) Could only invite her best friend because her mother was 'always' depressed and her stepfather was not kind. (M 47) Didn't mention her voices to anybody. (N 2) A child lost in a lifeworld that she shared with nobody? (N 21) Worries that people might attack or harass her. (N 40) Has not been mugged much. (N 41) He has well guarded secrets. (O 25) Felt totally outside and alone despite people everywhere - existential. (O 67) Existential loneliness. (O 67) Everybody else were nicely matched and he was utterly alone. (O 70) Mugging made him think of suicide. (O 72) Believes bad circumstances made schizophrenia start earlier. (O 75) Well guarded secrets. (O 125) Bad childhood experiences (trauma?). (O 125) Used to being lonely. (N 16) Very socially insecure inside. (N 41) Had kept the voices to himself for several years – a sign of craziness that he denied. (Ro 5) Had learnt from seeing others being forced. (Ro 29) You feel small again. (Ro 52) More disorganised, not aggressive or paranoid so avoided sectioning. (Ro 33) When forced it is natural to become aggressive and want to revenge. (Ro 52)

Sample quotes:

"I was very angry and I was very depressed, I remember, and it was very dark inside me." (N 26)

"Yes, Dad signed a compulsory hospitalisation. That's what he's done for me. (laughs) Dad has problems with alcohol, and then it may be that he has the same diagnosis as me." (O, 90)

A5 Effect of drugs

Ronny seems correct with *dual disorder*; while the others have used drugs but do not seem to have had a dependency problem. Several participants have used illegal drugs but talk about it as having negative effects, to the extent that they have experienced a connection between drugs and psychosis.

Emergent themes: **Why starting:** Hashish calmed him down in the weekend, didn't want uppers like others. (E 5) Hashish better than cocaine and amphetamine. (E 12) Lots of alcohol due to musical band activity. (E 13) Not for self-medication. (H 24) No drug problems (sic). (N 17) Self-medication with hashish. (O 46) First amphetamine a wonderful experience. (Ro 35) Used amphetamine to work. (Ro 35) Alcohol and hashish as self-medication. (Ro 37) Only used it at home. (Ro 38) Self-medication for the problems he had. (Ro 67) Alcohol and hashish made voices disappear. (Ro 68) Fighting depression with hashish. (Ro 69) No self-medication (socialization he says). (Ru 54) **Why quitting:** Drugs caused anxiety. (H 2) Moved and quit hashish. (H 4) Both beginning and quitting drugs can cause psychosis. (H 8) Rejected drugs to avoid psychosis. (H 24)Hashish got him psychotic. (O 10) Voices didn't start with hashish. (O 45) Voices before hashish too. (O 45) Voices preceded hashish. (O 45) Psychosis as side-effect of hashish. (O 46) Hashish messed it all up? (O 46) Tried drugs once, but not more (M 57) Amphetamine caused the first voices (1998). (Ro 1) Psychiatry didn't want anything to do with drug addicts. (Ro 2) Both systems defied responsibility. (Ro 10) Scared so quit amphetamine. (Ro 37) Alcohol and hashish made voices disappeared. (Ro 68) Became very scared so quit amphetamine immediately. (Ro 68) Coped with psychosis by sitting still and hoping it would pass. (Ro 69) First the job because of amphetamine and then the family. (Ro 86)

No good sample quotes.

Lifeworld B – Being-in-the-system

B1 Accepting the diagnosis

This theme is about being diagnoses; about accepting, rejecting or denying the diagnosis; and about accepting help. Two things were against my pre-conceptions and in the interview I either noted it or explored.

First, I was surprised that their reactions to the diagnosis were not stronger as we often hear of diagnosis as traumatic. Second, I was even more surprised when Nicole said she had never accepted the diagnosis, but kept taking antipsychotics because it helped her. And then others confirmed her.

Whether or not they accepted the diagnosis then and/or now – accepting the diagnosis has not been necessary for their treatment and recovery. This rubs the concept of insight that we as mental health workers simply take for granted. Of course it makes perfect sense; you comply because the treatment helps you. In the interviews I did not try to make sense of it, and it was rather confusing. It later led me to formulate Transition 1 in terms of simply accepting treatment and not diagnosis.

Emergent themes: Being diagnosed: Drug psychosis was eliminated. (E 17) Schizophrenia after eliminating drug induced psychosis. (E 17) Known that hashish could give psychosis. (so sceptical to diagnosis) (E 23) Psychiatrists mean something's wrong. (H 27) Schizophrenia means crazy. (H 49) Borderline first diagnosis – she disagreed (M 5) Hospitalised with severe depression, changed to schizophrenia (M 32) Schizophrenia means unintelligent and weak? (N 12) Soon after admission (clear case). (O 3) Voices as symptom. (O 4) Psychosis evidence that he didn't suffer from 'adolescent crisis'. (O 6) Convicted as mentally ill. (O 35) Cognitive impairment – lost skills. (O 113) Obviously psychotic to others. (O 140) Sick means (always?) you're in bed. (O 153) Voices as the symptom. (Ro 5) Drug addiction explains everything. (Ro 12) Didn't want to add voices, too. (Ro 14) Wasn't drug induced psychosis (only) because it last > 30 days. (Ro 14) Schizophrenia included everything and explains everything. (Ro 71) Diagnosis a label or hook (Ro 102) Diagnosis soon after sectioning. (Ru 6) A social, clever guy, he reacted to the diagnosis with disbelief, shame and withdrawal. (Ru 8) **Acceptance or not:** Bad to be called schizophrenic because it means mad or crazy, too. (E 18) Accepted schizophrenia by comparing with others, even if others were more strange. (E 22) Susceptibility a credible cause. (H 1) Schizophrenia as something that comes. (H 14) Psychiatrist didn't explain the diagnosis. (H 20) Diagnosis as relief (ambivalent). (H 28) Psychiatrist just instructed him to take pills. (H 20) Cautious to diagnose. (H 20) Psychiatrist didn't do psychotherapy [diagnosis doesn't mean therapy]. (H 100) Doesn't feel schizophrenic compared with others (M 6) Didn't like schizophrenia, disagreed but has given it up, yielded (M 17) She doesn't think 'schizophrenia' is appropriate for her (identity). (N 12) Cynical to put a diagnosis if you don't agree. (N 77) Things got easier with a diagnosis. (O 47) Paradox of a diagnosis meaning you're not just plain crazy (hope and others like you). (Ro 5) Diagnosis a reasonable cause for him, but just craziness for his friends. (Ro 6) A diagnosis as both positive and negative, (Ro 9) Diagnosis an explanation, not traumatic. (Ro 50) Diagnosis meant great people taking care of him. (Ro 66) Schizophrenia meant not getting treated for depression or anxiety. (Ro 71) He had both depression and anxiety and schizophrenia – believes it is normal. (Ro 71) Diagnosis meant lots of medication. (Ro 74) Diagnosis means you are treated as a case, not a person. Ro, 74 Satisfied to get an explanation (Ro 106) No hope for recovery. (Ro 107).

Sample quotes:

"Because I talked with others in the ward. So I was prepared for it. As I said, I found things became much easier when I got the diagnosis." (O 47)

"Still think schizophrenia is a sinister diagnosis and I didn't agree, either. Now it doesn't matter anymore. They've given me up anyway." (M 17)

"They thought […] would have become ill anyway. But because of sad circumstances it got started earlier." (O 75)

"No, there wasn't much hope (laughs) of getting rid of the illness so I think I will have to live with it, but now I at least have medication and stuff so I'm satisfied." (Ro 107)

B2 Making sense of it

This theme is about attributions, comparisons and turning points.

Emergent themes: Attributions

Believed in telepathy (E 6) The earth ball disappeared into his head, was amazed. (E 7) No trauma. (E 28) Doesn't have TV because they speak with him. (E 31) Difficult to separate reality and phantasy, magic. (E 61) Schizophrenia as something that 'comes'. (H 14) A diagnosis is tiring. (H 88) Got long term psychotherapy. (H 99) No psychotherapy the first 6-9 months. (H 100) Now everybody gets a psychologist. (H 100) Finds it natural to talk with God (M 34) Denies other hallucinations (M 41) Many things that they believe is illness, are for her natural. (N 93) Psychological problems in the family, but they are an artistic family. (N 119) Schizophrenia is just craziness to the non-bearers (stigma). (Ro 6) Bleak prognosis he was told, only medication would help. (Ro 107) Disbelief and different explanations – but you cannot move forward if you don't accept that you're ill. (Ru 8) Parents probably faced with the blaming double bind/mother fault theory. (Ru 13) No schizophrenia in the near family. (Ru 16) Good childhood no trauma, but maybe didn't get enough resistance. (Ru 65) Must have been biologically pre-disposed. (Ru 65) Used half a year to read a book. (Ru 83) Also loses skills in bad periods. (Ru 87) **Myth and comparisons:** Hallucinations take your energy away.(E 17) Yelling and screaming – you wonder if you're next. (E 25) Heard visual h had better prognosis. (H 19) Diagnosis concerns treatment (cure?). (H 28) Less shame but cannot be open about schcizoprhenia (murders). (N 37) Others were even worse. (H 39) There are worse psychosis. (H 39) Parents' divorce, reason for sch. (H 75) Talking with God is hallucinating for the psychiatrists (M 2) Claims to know real from unreal. (N 49) Would never have killed somebody. (N 49) Schizophrenia as a term used as a given rather than discussed. (N 79) Uncle with psychosis in the 50ies, very shameful. (N 119) Schizophrenia permanently destroys your mental abilities ? (Ru 25) **Inisight?** Hoped it would go away. (E 21) Didn't disappear like a common cold. (E 21) Schizophrenia doesn't go away. (E 21) Accepted the diagnosis as he got problems with daily chores. (E 23) Didn't see the need for a psychologist. (H 10) Schizophrenia means crazy. (H 49) Strange thoughts as symptom. (H 75) No childhood trauma. (H 80) No schizophrenia in the family. (H 82) Feels she can override the will of the voices, but never does. (N 12) Doctors don't believe in 'natural' voices. (N 88) Feeling of Jesus walking beside her, as a shadow, talking. (N 98) Thought echoes through TV. (N 102) Commanding him re taking pills. (O 14) Commanding voices: 'Don't need medication' à 'take all'. (O 14) You often believe what voices say. (O 39) Schizophrenia as something you have and that provides explanations. (Ro 6)

Sample quotes:

"But we are an artistic family, you know, you are more sensitive if you're artistic." (N 119)

"I have a theory, that it [his childhood] might have been almost too easy so I couldn't handle adversity." (Ru 65)

B3 Reactions to medication

This is about waiting for relief, about side effects, main effects, compliance and patience. I am aware of the difficulties of what works and not and I was surprised to hear that some had reached the end of the algorithm, viz. klozapin (Leponex/Clozaril).

Emergent themes: Medication helped against anxiety (E 18). Need medication to avoid psychosis (H 49). Medication, a battle you must lose (H 93). Non-compliance because of side effects (H 93). Leponex since 96 doesn't eliminate voices but she [Nicole] sleeps well (N 57, 69). Leponex turned things around (O 1). Vival for emergency, never used (O 21). Very happy with the medication (O 22). No side effects except sleeping one hour more (O 29). Didn't quite understand the need for medication (O 39). Extreme side effects from Trilafon (O 146). Akineton to fix side effects (O 147). Couldn't avoid injection, so 'cooperated' (O 132). A battle (O 135). Pills suppress voice Ro 16). Leponex 'the first real help', now adding Seroquel (Ro 20). Took pills only when he was down (H 20). Take medication or be forced (Ro 22). Voices have told him to not take medication (Ro 23). Dissatisfied – more time with patients, less medication (Ro 74). Often threats of forced medication (Ro 76). Most ill, most rejecting (Ru 33). Cisordinol worked fine but very unpleasant, Haldol terrible (Ru 53). Doesn't like being a zombie (Ro 55). Sedation isn't cure (H 93). Doesn't like sedation (Ru 99).

Sample quotes:

"[I] shivered, salivated, was stiff and walked like I were eighty. Didn't help much against the voices anyway. They continued even if it was a bit better. Anxiety got better." (E 18)

"Heard that I ought to not be drinking while taking medication, in other words for the rest of my life. F… no, I don't want to be only ill." (E 27)

"when you're stuffed with medication you get apathetic – you run around like a zombie." (Ro 55)

"Valium doesn't work and I don't like the feeling of sluggishness. Have probably done for so long that I have built tolerance, don't you think?" (Ru 99)

"It does not remove the voices, but I can at least relax and sleep well and stuff. " (N 57)

"If you absolutely don't want it, if you think it only sedates you." (H 93)

B4 Alliances and power balance

While alliances are helpful and necessary, they are clearly asymmetric and probably biased against the psychiatrist. The participants had lots and lots of comments in this area. My own experience is that compulsory treatment can be necessary and the person usually understands our reasons in hindsight.

In this research I wanted to capture asymmetric social relations; as well as the system/legal side. This includes milieu therapy. Between the lines we can read how the different institutions and wards prioritize their resources and therapies.

My decision to separate system and people is logical: I don't think we are really stopped by the system from treating people with respect, trying to encourage, stand by them and instil hope.

My subsequent analysis is a consequence of my background on the psychiatric floor; other analysts might have combined the two, as they certainly interact.

Emergent themes: No trust, no compliance (H 20). Liked the ward (H 28). Good boy – nor force (H 37). When psychologists start to understand, next they're gone (E 42). Good boy – pays off (H 42). Many psychiatric workers are cynical (N 42). Great people around him in hospital: caring and supporting (Ro 66). You don't open up to people you don't like (N 90). Knows who's very bad, not good, and with whom he could talk (Ru 102). Psychologists make you feel better (H 103). A good and kind psychiatrist (O 150). Praises psychiatrists who have gotten him hospitalise in time (Ru 24). Sectioning often leads to denial: big differences between voluntary and compulsory (Ro 53). Doctors and nurses break human rights frequently (Ro 61). Went down for voluntary but was rejected, one hour later the Police came to his home: biggest humiliation in his life (Ru 66). Police is a punch in the face (H 94). A very nice tone between co-patients (O 155).

Sample quotes:

"When I got Zyprexa the first time, I didn't know […] I just reacted and didn't like being there. […] I didn't take the pills." (H 20) Obviously there was no alliance at the time.

"my main contact – said that it was a relief to get a diagnosis. And I thought of it as a relief but I now realise that it is a box where I may [my underline] belong. It concerns treatment and things I have." (H: 28) Here the alliance was a resource, so it is in two places.

"Had a great psychiatrist. Was interested in us patients and not just the medication. In the neighbouring ward they had an absolutely unusable one. Talked down to everybody." (E 41)

“Those with experience probably don’t want to work with schizophrenics.” (E 42)

“could have saved much medication just by being human.” (Ro 74)

“No I haven’t liked everybody, to put it that way, no. It does feel difficult to open up when you don’t fancy the person.” (N 89)

“If you want help from psychiatry, if that is the best help, then opposing medication the whole time and you will be forced. […] But compulsory things, I don’t see anything good in it. Except if there is a question of life and survival and stuff.” (H 93)

“It is a battle you must lose.” (H 93)

“So I know who is really bad, who are no good, and who are smart and with whom I can have a conversation. But what I think is very sad, is that there are few resourceful enough for me to appreciate talking with.” (Ru 102)

“It isn’t exactly bright people working here. Many have only two years after elementary school, so there is a lot of knitting work going on. […] In Mental Health I can talk with likeminded. Am met with expectations.” (Ru 104)

“But I must say that you cannot get anywhere without accepting that you are schizophrenic.” (Ru 8)

“I am not a criminal who needs handcuffs and don’t hurt others. I was really pissed off and angry. And scared. If four police officers want to take you, then you get scared. Once I tried to escape. Didn’t work out. (laughs).” (E 38)

“I hear it when I talk with people, there is a big difference between compulsory and voluntary. To be taken in by the Police and stuff is traumatic.” (Ro 53)

“doctors and psychiatrists violate human rights in a big way.” (Ro 61)

“Nobody can explain that to me. It is the most aggravating event in my whole life. The worst of it was not to be believed and then two hours later the Police.” (Ru 66

“Yes, you get a punch in the face in the very first meeting with psychiatry because the Police is coming to get you.” (H 94)

“User participation, that you can have more choices. To kind of find yourself and grow – that you can learn from it, that you can decide for yourself what should be.” (H 95)

“…rather be flexible and say: “When you’re out we’re going to give you close monitoring and then you get your chance. As it is now, if your case is dismissed, then you must wait three months.” (Ro 126)

“And I have protested […] because I thought I had a good case. But there are very few I have heard about who are released. I think now that it maybe wasn’t so strange that I didn’t get their approbation.” (O 139)

B5 Hospitalisation and treatment

The general experience of being in a hospital and the psychiatric system. A system has a certain configuration of carers that allows for certain daily activities (B6, B7). The participants criticised the psychiatric system, its rules and constraints rather than the carers; in particular lack of resources, activities, compulsion and the length of their stays.

I decided to separate these categories as they are like circles inside each other. Russell called psychiatry 'a deprived system' for among other reasons that it limits what carers can do in terms of activities for each patient, yet is very generous with money for medication and the duration of hospitalisation.

Of course, I am aware how this resonated with me. Did I influence the participants to criticise more than they would have done otherwise, the old "*isn't it awful*"? This is possible, but I am sure their statements and judgements correlate well with their *concrete* experiences as told with or without my encouragement.

Emergent themes: In 1999 referred to [B], but they are private and do not deal with psychiatry (Ro 4). About 20 hospitalisations before Leponex turnaround (Ro 7). Stayed two years full-time (O 7). Sectioning terrible experience (Ro 21). Admits she’s lazy and that’s been a topic (M 27). Was ‘away’ from 88-90 (Ru 33). Afraid to end up with ‘the really crazy ones’ (H 39). Shorter stays after the first time (E 47). Revolving doors (O 48). Police is traumatic (Ro 53). Too much medication if compulsory (Ro 55). Could be verbally threatening, not physical (Ru 67). Several institutions (N 70). Halfway home two years (N 76). Little if any psychotherapy (N 85). Compulsion should be avoided (H 93).

Wards make you drowsy (O 108). Her room was ‘chaotic’ (N 113). Not enough treatment options (Ro 129). In and out for 12 years (O 144). Should be a ward for young people (O 157).

Sample quotes:

“everybody were nice and ok, but nothing much happened. In any case not in the acute ward, where there was food, medication, sleep and then food again. Every now and then talking with a doctor.” (E 24)

“I am not a criminal who needs handcuffs and don’t hurt others. I was really pissed off and angry. And scared. If four police officers want to take you, then you get scared. Once I tried to escape. Didn’t work out. (laughs).” (E 38)

“a place to store people away, a place for treatment with no treatment." H 50

“I hear it when I talk with people, there is a big difference between compulsory and voluntary. To be taken in by the Police and stuff is traumatic.” (Ro 53)

“Nobody can explain that to me. It is the most aggravating event in my whole life. The worst of it was not to be believed and then two hours later the Police.” (Ru 66)

“Yes, you get a punch in the face in the very first meeting with psychiatry because the Police is coming to get you.” (H 94)

“…rather be flexible and say: “When you’re out we’re going to give you close monitoring and then you get your chance. As it is now, if your case is dismissed, then you must wait three months.” (Ro 126)

B6 Meaningful activities

Meaningful activities, whether therapeutic, leisure or outside the institution. At first I had one category dealing with all daily activities, but then decided to split in two based upon whether they appeared meaningful or desirable; or not meaningful. Budget allocation is partly a value call, but meaningful activities should have a good budget while wasted activities (B7), if at all necessary, should be minimised. I have included ethical, compulsory treatment as 'meaningful' because rather than wasted, they are consequential i.e. a serious reason precedes them.

In contrast, a 'wasted activity' should be abandoned if it is not for some reason necessary.

Emergent themes: Staff nice & kind, but not much going on (E 24). Discovered painting because couldn’t concentrate enough to write (Ru 30). Would have liked more psychotherapy because life can be difficult. (E 42). Psychiatrists did ‘trivia therapy’, not psychotherapy (Ru 42). Isolation as treatment (H 44). Privileges in isolation (H 46). Physical exercise possible in the basement (E 49). Place for treatment with no treatment (sanatorium) (H 50). Physical activity is meaningful (H 51). Trade route to S: Important to demand something of the patient (Ru 68). Appreciated the trade route and Bjorli a lot (Ru 68-69). Should have used time and energy on therapy like group therapy (Ro, 76). One should use people’s resources, not just painting, drawing or guitar (N 84). Very difficult to get paper for painting, so bought his own (Ru 101). There should be an activation scheme for each patient (Ru 102). Physical activity is good e.g. cooking (N 108, 111). Need help to start going (Ro, 124). Very good sessions with the psychologist (O 127). Group therapy didn’t help him much because he was too sick he says (Ro, 132).

Sample quotes:

“I believe the big turning point was cognitive therapy. I think that’s when I understood how ill I was…” (Russell: 40)

“stuffed full with pills so you become apathetic – you run around half wake kind of.” (Ro 55)

“I don’t require that you work all the time, but if you’re up in the mountains we won’t drive you home until the work is done.” Ro 68

“And I thought this was very fair, it could be tough, but I just had to face each new situation. You don’t help a patient if you don’t demand anything.” (Ru 68)

“[After the chaos] activities that appeal to your resources, and not just sitting there to draw or paint, is has to be something more.” (N 84)

“I actually believe that more physical activity would be good. Some tough exercises and stuff. ” (N 108)

B7 Some treatment seem wasted

Treatments and activities that seemed wasted to the participants or that they at least did not enjoy. For further comments see B6.

Emergent themes: Days not really meaningful (O 28). Didn't like the daily routines (M 42). Sick of talking of childhood, says his problems are future not past (E 43). Not so meaningful days (H 50). Asked if morning meetings is therapy? (E 56) Too much passivity and storage (Ru 68). Wasted treatment (expression therapy) (H 72). Expression therapy a waste (H 101). It's easy to get 'loads of theories' (H 73). One round of CBT, remembers little except a triangle of 'feelings, action and stuff' (Ro 78). Morning meetings nonsense (Ro 80). Wasted morning meetings with exercise (N 104-105). Psychiatry sometimes change things that work for you (O 106). Explaining again and again is shameful (N 107). The system created more anxiety (O 110).

Sample quotes:

"And there isn't much to get you up in the morning because there is very little happening." (O 28)

"Ok, year and a half rather. And there things were neither good nor bad, as I remember. Thought that it was a place to store people away, a place for treatment with no treatment." (H 50)

"I feel they gave me up too early. You need help if you want a job and a normal life." (M 58)

"But there is too much just keeping. That's my answer." (Ru 68)

"but what I experienced in psychiatry and the acute ward was just keeping us there." (Ro 76)

"[Should be] using their resources […] I find that it has been medication and technical things really." (N 84, 87)

> "I was in the tough group where we were to sit down and solve the problems. It didn't work for me. Because I never came that close to my feelings, so I was placed in another group that did more innocent things." (O 125)

Lifeworld C – Outside schizophrenia

C1 Coping with residuals

Residuals not only in the sense of remitted schizophrenia (Andreasen, 2005) but the late effects and things you must do to avoid relapse. This is where the definition of recovery is made – a huge controversy. My criteria were that remission is a stage in the recovery process and that you are 'outside of schizophrenia' if you live a normal life with or without medication. Russell is an example of this. He was on a mega-dosage of Zyprexa yet hadn't seen a psychiatrist for ten years. His lack of energy could well be caused by sedation and not by schizophrenia as such. (I did say that he needed to see a psychiatrist about this.)

The theme includes intermediate themes such as not having work or friends, living with depression, anxiety or other psychological issues. Residuals can be stigma that leads to unemployment and missing social inclusion; feelings of shame or humiliation that follows from involuntary hospitalisation, as well as depression and suicidal thoughts.

From a reflexivity point of view this call has been excessively difficult, and I had to use parallels in other parts of medicine to eschew the psychiatric construct of 'chronicity' or 'disability'. As with diabetes, many swallow their medication and go to work. They are not stopped from working because they take insulin injections. You don't have a wheel chair illness if you have lost a leg in an accident. In both cases your social functioning is still ok, which means that social exclusion is a wilful and rather reckless exclusion.

Is then schizophrenia different before and/or after symptom remission? Does the amount or type of medication drain them and stop social recovery? Or have they simply given up because they're an out-group? Coping with residuals is what recovery is about and these were the kind of questions I had in mind when mining for answers.

Anyway, I found that this category was crucial for the Discussion.

Initial themes: Contacts: Dosage well controlled (O 21). No psychiatrist for ten years, so not sure medication is ok! (Ru 97) Individual Plan a great help: contacts, goals, consent

(Ro 76, 113). Satisfied with the commune (Ro 121). Hopes to avoid hospitalisation (i.e. fearing relapse) (O 122). Today social workers go on home visits if needed (Ro 125). **Living with voices:** She permits voices to instruct her (N 12). Doesn't have TV because they speak with him (E 31). Finds it natural to talk with God (M 34). Medication all right now, voices almost gone (E 40). Knows how to stop voices and anxiety (from CBT) (Ru 44). Distinguishes between natural and psychotic voice hearing (Ru 45). Tolerates the ambiguity of not knowing if a voice is real (Ru 46). Still has voices every day, but less now (Ru 58). Rarely visual hallucinations (Ru 59). 100% sure that telepathy exists (E 62). The better you feel, the better with voices and all (daycentre is a sanctuary) (N 124). **Psychological:** Experiences 'withholding' when faced with duties and commitments (N 12). Might get anxiety the day after his drinking (E 26). Feels given up now (M 26). Doesn't like to be locked up because of memories. (O 34). Feeling fat and blames medicine (M 40). Cognitive impairment. (O 43). Manages to take self-reference out of paranoid thoughts. (Ru 47). Problems to concentrate, even in simple conversations, but betteer now (Ru 51). Norway isn't tolerant (Ru 77). Worries about what people says about him (Ru 78). Disgusted with those whose basics are not in place, like food, clothing and hygiene (Ru 79). Shame isn't as bad as it used to be, but tiring (O 80). Fine in safe and known surroundings (O 82). Planning plus 1 hour extra sleep = 'full life like everybody else' (O 104). Freedom to choose your daily activities and lifestyle (O 107). Freedom is existential (O 160). Ok medication now (E 40).

Sample quotes:

"And I can use it against anxiety too: 'Ok, so now you come, Anxiety, but I don't have time for you. Come back in 15 minutes instead.' Or if I start to think I'm telepathic while I'm sitting in a meeting or something, right, then I say that 'now I really don't have time to be telepathic, you telepathic voice, so come back in a quarter of an hour and we'll see." (Ru 44)

"Yes, we have somewhat different opinions he and I, but he meets me where I am. […] But no, I exaggerate a bit as to natural voices. There are also healthy people who hear voices. " (Ru 45)

"When I know what happens Monday to Friday and get to sleep the extra hour [due to Leponex], then I have a full life like everybody else." (Oscar 104)

"Have been stable for the last years. It is positive. And then it is great to live in your own apartment and decide your dinner, what I want for dinner, when I want to have it and where. I can eat in my bathroom if I choose to! So I have my freedom!" (Oscar 160)

C2 Living with identity issues

Closely connected with the previous category, but this is about social life/recovery and how they cope/coped with labels after remission and recovery. Even after full recovery the labels and self-stigma will often remain. During the analysis I discovered how they had accepted their fate and identity; looked like they were oblivious to the fact that many recover fully and no longer need medication.

Emergent themes: Treated as a drug addict before diagnosis (Ro 5). Schizophrenia is shameful (E 15). Identity as church attendant (O 30, 120). His master's degree meant a lot (Ru 37). Very disappointed to get compulsory community care (Ru 61). Very satisfied with outcome (H 70). Having schizophrenia doesn't mean you're a child again (don't patronise) (Ro, 100). The system does not consider the individual and her resources enough (Ro 128). Considered moving away because he was talked about as crazy (= even more isolation) (Ro 152). Likes it where he has lived his whole life, he is accepted now (Ro 153). Feels like a complete failure, living in an elderly home already (M 38). Likes it though in the elderly home: can help and worship (M 46). Feels given up too early (M 58).

Sample quotes:

"And when I meet people in the train or on the bus I say that I'm a church attendant." (O 30)

C3 Family support

The contributions of family members became very obvious as they all seemed to lose friends and didn't regard other patients as 'real friends'. I have avoided concepts such as attachment even as sub-category because it would a) be speculative and b) imply certain theories and therefore not phenomenological.

During the interviews I found what I expected from experience i.e. was not surprised that confirmation that recovery is better if you have a VIP (Very Important Person) in your life (Davidson) and the importance of close relations (Seikkula).

Emergent themes: Mother always followed him up (Ro 3). Good relation with sister (H 5, 10). Feels shame toward daughter so little contact, and when then awkward (M 8). Feels shame towards her own foster family – feels like a failure (M 9). Family support and care (H 10). Parents bought her an apartment – thankful (N 12). Parents were scared and reacted with sorrow. Probably thought it would pass (Ru 12). Family were not cared for or explained at the time (Ru 12-13). Mother was there accompanying him (H 14). Thought her family didn't really love her (N 21). Wasn't allowed to be herself and wanted to run away (N 21). Called mother first (H 24). Both mother and father was there after the collapse (H 24). Slept at his mother's place (safe haven?) (H 24). Brother scolded mother – she had to call father many times (N 26). She became very angry and depressed – very dark inside (N 26). Always a good relation with brother, father and mother (E 46, 66). Great childhood, excellent relations with parents (Ru 65). Parents divorced (H 75). Parents still friends (H 75). Family has really supported him (H 86). Lived on his own so mother followed up every day (Ro 92). He disagrees that he is too close to mom (O 93). Mother becoming his only anchor (Ro 97). Very dependent on his mother (Ro 99). Mother treats him as normal (Ro 100). Wrote his father off because he didn't stop his stepmother's harassing him (Ro 101). Dysfunctional family, sided with dad (N 117).

Sample quotes:

"my family has been behind me all the time. Really supported me. My sister and my mother and everybody." (H 86)

"Some say that mom is too close to me, but then is when you maybe need it most. Sometimes you need people to be kind to you, not demanding everything." (O 93)

"My mother [stood by me]. The others were probably so pissed off that they no longer wanted anything to do with me." (Ro 100)

C4 Friends, friendships

Themes concerning friends, friendships, lost friends and new friends. The research here indicates that loss of friends is inevitable; however there is evidence in the literature that early intervention and involvement can protect friendships.

Oscar raised an important and unforeseen consideration that made me think: are others who visit the day care centre really friends? We agreed that they are friends but not close friends. But why is it that you lose most of your earlier friends and they don't come back? Is it age related i.e. moving out, marriage, children, different work, studies? Fear of schizophrenia? Fear of strange behaviours and unpleasant contact? Or simply that schizophrenia changes you so much?

Emergent themes: Daycentre friends are not friends: Too shy to use day centres. (M 44) He doesn't have real friends (O 84). Doing things together doesn't mean you're friends (O 98). Service users are not real friends (O 99). Sweden and Mediterranean without staff. (O 102, 103). Lonely – doesn't have real friends in the day care centre (N 122). Doesn't feel watched in the day centre, so likes it there (N 124). Feeling watched in the streets and shops, as if they know something about her (N 124). **Lost friends:** He expected friends to come back if they knew he had an illness, but they didn't (Ro 6). Suffering without friends for two years (Ro 6). Not married yet, but had a boyfriend (N 8). Withdrew from social life because of shame (Ru 8). People are scared so don't want to deal with you (Ro 9). Friends disappeared in Oslo, but he got many good friends in T incl the professor (VIP) (Ru 17). Girlfriend psychologist for 1 ½ yrs (Ru 22). Wasn't girlish, socially insecure so did as they told her but had no real friends (N 26). Changing friends is natural as you change yourself (H 86). Drug friends are not real friends (H 88). Friends can get tired of you (H 88). Schizophrenic girlfriend in Oslo (Ru 95). Lost contact with best friend because he said no too often (O 116). Friends failed him, so he wrote them off as not worthy of his friendship (Ro 145). Understands why people avoid schizophrenics after reading newspapers (Ro 149). **Real and new friends:** Started his new social life after two years, with Mental Helse (Ro 6). Girl friend since 2002 (E 33). Girlfriend threatens him (E 37). Managed to build a network, even if not always easy. (Ro 47). Drinking beer with old friends (E 65). Some loyal friends despite strange behaviours (H 86). New friends with similar background (H 86). Friends do things together (O 87). Rarely invited somebody (O 97). Enjoys new friends and like-minded in Mental Helse (Ru 104). Doesn't try to make friends – passive (N 122).

C5 Job

Occupational or job type activities, competitive or not. In this area all participants had lived through disappointments – it seems like recovery must be better supported. Work is realistic but going from 0 to 100 is not.

Emergent themes: Unable to work (O 2). Church attendant makes him feel normal (O 151). Cannot work even 1-2 days a week (O 103). She wants to clean even if she could teach instead (N 12). Could no longer be a teacher (N 44). Could work as assistant librarian, but not every day (N 59). Only physical and creative work are valuable to her (N 120). Milieu worker is meaningful and motivates him (H 54, 60). Changed from patient to colleague (H 61). Feeling respected: knowledge and mastery (H 67). Can fill his days if he wants to (milieu worker and carpenter) (H 69). Cannot work 9 to 4 (Ro 42). CC and MH as jobs (Ro 46). 50% as non-skilled worker, but would like office work (Ru 25). Believes he could now work in an office (Ru 83).

C6 Studies

Different comments about levels and timing of studies before and after hospitalisation. I was amazed to hear about Russell's and Harold's studies. I however did not notice that Russell's degree was on a downward slope until actually doing the analysis.

Emergent themes: Completed intro course despite psychosis (H 26). Two months in chemistry despite (H 27). Not allowed to study while in hospital (H 27). Completed as house builder despite diagnosis (H 55). Incomplete studies after grammar school (N 2). Completed grammar school with very good results (N 12). Tried the Academy of Library (N 12, 58). Sociology master cum laude, double the time (Ru 19-20). Needed some special arrangements for his studies (Ru 34). Anxiety the biggest problem for the studies (Ru 34). He was able to master his studies with own office and PC (Ru 34). Surroundings make things possible or impossible! (Ru 36). Teachers shouldn't know (O 10).

4.2 A GRADUAL LOSS OF EXISTENTIAL GROUND

Not knowing what is going on (A1)

None of the participants (0 of 7) recognised any signs of illness, even if all (7 of 7) said they recognised that something had changed. At first the changes were rather subtle:

> *"I didn't want a psychologist. I never had it better I thought. But (laughs) it was quite early. […] At least he wrote a report then, and then the psychologist said that I might have a schizophrenia coming."* (Harold: 14)
>
> *"noticed nothing wrong, only had anxiety and was depressed*". (Mary: 55)
>
> *"The first signs I believe started already in grammar school because I withdrew and didn't want to play football when it was raining."* (Russell: 10) *"very paranoid about South America and those older than me with a beard and stuff – it sounds a bit stupid. I was very paranoid."* (Russell: 3)

Harold's comment attests to the difficulty of insight:

> *"Even if they said I was quite psychotic and confused when I came in, I didn't want to (he hesitates) I was in a way afraid of getting even worse. I was afraid to end up in the other ward where things were much more unsafe and more 'closed' and stuff"* (Harold: 39)

Only Harold seems to have regained his former level of energy and performance. Russell has a post-graduate degree, while Nicole and Eric have graduate degrees. Harold and Ronny have vocational education, while Oscar almost finished his. Only Mary both dropped out at an early stage, she talks about learning problems and loss of concentration.

I took advantage of the interviews to dig deeper into what goes on before the first hospitalisation. It would be easy to conclude that the path is determined by nature and not by psychiatry; although this ignores neuroplasticity. The issue is rather that we still don't know enough about the brain to understand what's going on.

This is an important point. The interviews showed that Harold did not seem to fall so deep as Oscar or Russell; in fact Oscar was a cook but had to start training anew. Mary's functioning was low from childhood so it seemed natural that it wasn't much to fix.

Their general condition seems to have resulted in negative mood changes for all, and this cannot be explained with reference to intruding hallucinations alone:

> "*Because I was often walking alone, muttering. I think I muttered a lot and cried a lot, irrational things*." (Harold: 9)

> "*…it was something, felt so on the outside. Felt so extremely lonely. People everywhere but I felt an extreme loneliness. Indescribable. Felt totally, totally alone*." (Oscar: 67) He then attempted suicide.

> "*I was so angry [at the voice that criticised her] that I bit one of the attendants in the hand. I was mad and crying, so the Police came to get me. And when I said everybody was against me, then my parents didn't understand anything and sent me to a psychiatrist. But I didn't feel unwell so refused treatment. I didn't like him at all*." (Nicole: 81)

Nicole didn't see a need for a doctor – an irrational behaviour (like biting a stranger) did not make her suspect mental illness. Russell jumped out of the window in the psychiatrist's office. These kinds of disconnection seem almost characteristic or at least very frequent in early onset and serves as a clinical warning.

Hallucinations are difficult (A2)

While you might doubt the realness of hallucinations, they often (not always) demand a reaction. They participants said a) that voices tend to come and go as they wish; b) that visual hallucinations are strange; c) that they have confused hallucinations for real events; and d) that they are the centre of their dramas.

I have always found contents and storylines fascinating. Harold knew what was going on with his Buddhas and attributed it to a special gift. He actively managed their 'drama' and gave each a personality – as neurophenomenology this should certainly interest us because the phenomenon appeared on the way from healthy to schizophrenia. The key thing is that he *knew* what he was doing and later this ability went away and he lost control. I thought of these phenomenologically as quasi-hallucinations or pseudo-hallucinations, which are not counted as schizophrenia but must be related and perhaps on the same spectrum?

However, for all participants (7 of 7) voices were intrusive and have mostly been uncontrollable. Most participants (5 of 7) have also had visual hallucinations, which may be a significant characteristic of my research sample. Medication has made it possible for Nicole to live with voices: "*It does not remove the voices, but I can at least relax and sleep well and stuff*." (Nicole: 57)

With hindsight Russell says that insight came with CBT:

> "*I believe the big turning point was cognitive therapy. That's what I think. I got insight into how ill I was*." (Russell: 40)
>
> *"And I can use it against anxiety too: 'Ok, so now you come, Anxiety, but I don't have time for you. Come back in 15 minutes instead.' Or if I start to think I'm telepathic while I'm sitting in a meeting or something, right, then I say that 'now I really don't have time to be telepathic, you telepathic voice, so come back in a quarter of an hour and we'll see."* (Russell: 44)

Nicole sometimes still follows the advice that voices give her. Oscar showed obedience. His first hallucination was a scary experience with people wearing clown masks were coming to get him, and he would later break into a house: *"There were voices telling me which house to break into. And you often believe what they say there and then."* (Oscar: 39)

Nicole actually heard voices as early as 6 or 7, but still differentiates between those natural voices and the later psychotic voices: "*I started to hear voices when I was about 21 I believe, and I was in good shape so didn't think of it as an illness, because I didn't feel the voices take over and I felt in good shape so just lived with it*." (Nicole: 1) She struggles to understand why anybody would kill another person just because of voices, yet she acknowledges the immense power that voices can have over you: "*strange that they don't manage to sort it out, because I do. Sometimes I do as the voices tell me, but they don't command such things and if they did, I wouldn't have killed anybody. But then I don't know how they feel, they might have a lot of chaos in them. I don't know enough about it, but I do wonder a bit*." (Nicole: 49)

It would seem that Mary might obey a commanding voice as she is sometimes convinced that she speaks with God and cannot understand why psychiatrists call God a hallucination.

Visual hallucinations are strange and most (5 of 7) had visual hallucinations. Oscar experienced people with clown faces who wanted to get him and Ronny said that he didn't understand why the psychiatric staff didn't ask him about hallucinations: "*I could be talking with a chair."* (Ronny: 13)

Harold says his lucky because he has heard that the prognosis for recovery is better for those who have visual hallucinations. Harold experienced a special kind of hallucinations when he was looking at a Buddha carpet and found that he could move the many figures independently of each other. They even had a kind of personality and his goal was to set all of them in motion. He was interested in mysticism at the time so became fascinated rather than scared, as a kind of special new age gift. However, his fascination left as he started to experience anxiety and loneliness, culminating in planning a suicide before collapsing in a rage when he destroyed everything in his apartment.

Including Harold most (4 of 7) used super-natural or religious attributions to make sense of hallucinations. Mary believes she hears God talking with her, while Nicole is not so sure:

> *"Then I feel, sense that Jesus is present at my side. As a shadow. But some of the things he says are quite wild. […] But I spoke with a catholic who also hears voices. 'You cannot know that it is Jesus', he said. That has in a way helped me and I've heard that it is dangerous to mix psychiatry and religion and such. So now I try – I know if I pray a lot then there are more voices than if I don't. So then I think it's better not to be so occupied with religion and such. And then I have felt the Devil at my side, too."* (Nicole: 98)
>
> *"I saw the earth ball coming towards me from the horizon once, came closer and closer and at last disappeared into my head. Rather strange, right?"* (Eric: 6). *"Yes. Understand that I mix up reality and fantasies, but it is difficult to know, really, to know what is real and what isn't. That the earth ball cannot come flying towards you when you actually stand on top of it is really logical. But what if there are more dimensions. Have thought a lot about it. Have a friend who had a near-death experience and he looked at himself from above. So it exists."* (Eric: 61) He has also experienced that people on the TV would talk with him, and so decided that he didn't want to watch television.

Both voices and visual hallucinations were self-referential i.e. the research participants were not just on-lookers but actively took part somehow. This is even true for Eric's earth ball experience. Phenomena become integrated in our lifeworlds and apparently created in it (ego-syntonic hallucinations).

Nicole had mostly supportive and understanding voices that then turned against her when she started to feel depressed and out of control in her teaching. The roles they played in these dramas were thus clearly ego-syntonic. Feeling like a victim made Oscar, Russell, Ronny and Nicole fabricate a gallery that seemed congruent with their paranoia. However, both Russell and Nicole talked about mixed galleries of supportive and critical voices.

Russell believes that the turning point came through CBT, where he could start to interpret the hallucinations. At one point he talks about how he deliberately removes this self-reference by saying that when he gets paranoid about something, he convinces himself that it cannot possibly be about him.

Voices tended to be kept secret, too. For all participants (7 of 7) hallucinations were anomalous and distressing, even if Nicole and Harold experienced a benign onset and interestingly therefore attributed their experiences to some special gift. All participants report both known and unknown voices. Importantly all of them say they kept their voices to themselves for a long time:

> *"I would have dared [to talk about it] if I had wanted to because I am naturally open, but believe people would have seen it as craziness, so let it be."* (Nicole: 32)
>
> *"But I never dared to say at psychiatric that I had voices in my head."* (Ronny: 13)
>
> *"That voices were a natural development somehow. So I didn't think much about it. Thought that 'such is life'. […] But I didn't talk about hearing voices."* (Harold: 13-14)
>
> *"…and then I told about the voices in my head. Hadn't told anybody about it. It is one of those things you don't tell because nobody has voices in the head. Didn't know better."* (Eric:15)

Reflexivity is here difficult. It is seriously hard to take hallucinations as real because we know they aren't, but hallucinations are created in our picture and we know they are not dreams. The real-ness makes them important and I was really interested in how the participants made sense of their voices and whether voices could sometimes appear real while at other times not.

Psychiatric treatments aim for 'insight' yet we are condemned to believe what our senses tell us – is psychiatric insight that we shouldn't take perception seriously? An impossible task it seems and one that later stood out in the existential analytic.

In hindsight I can see how I missed an important existential question for my Interview Guide: Are their hallucinations/voices perceived as real or not; and do they have a mixture of such experiences? And equally important, how have they changed over time such as to be on a spectrum?

Crises and collapse (A3)

All (7 of 7) talk about draining of energy, of anger, anxiety, depression and most notably deep loneliness. Only Eric and Russell did not plan or attempt suicide. Russell talks about his love affair that collapsed and threw him into a deep depression: *"it was reactive psychosis […] got* *some pills that I refused taking and then was called to an assessment and voluntary admission because I could understand that I was astray and that was the paranoid part of the diagnosis then."* (Russell: 3) He was allowed to go home, only to be admitted compulsory a few days later. Nicole threw herself in front of a tram and Harold tried to buy a pistol, wanting to shoot himself in his apartment.

We should not be surprised to find crisis and collapse, yet I was sincerely surprised by the intensity of emotions that seemed out of touch with what was really going on. There is so much we don't know.

I would have thought that people who recover have a more benign onset. This is not what I found and found the terms 'onset' and 'first episode' to be very un-phenomenological – hospitalisation is neither onset nor first episode!!

It also raised another important question: what determines the path of schizophrenia? Would a psychiatrist say that they were compliant and this made it? Would a neuro person say that their brains were better to self-repair? Would a psychologist point to protective factors? What about co-morbidity?

At some point I made a crucial decision not to speculate about causes, but simply accept pure phenomenology. The indication was clear that they did not deteriorate overnight, but over years until they collapsed. For many the word 'collapse' is probably more accurate than 'crisis' and the first episode is not really a first episode phenomenologically.

While Oscar and Mary made one suicide attempt each, Ronny made four attempts to overdose before he was finally diagnosed with schizophrenia after five years with bouts of depression and anxiety. He explains his suicide attempts: *"No, first the job went away because of amphetamine and then the family. And you know when you lose job, house, home and family, then I didn't have much to live for."* (Ronny: 86)

Suicide attempts attest to the deep nature of their distress as their lifeworlds seem to dissolve and they get thrown into crisis and collapse:

> *"Yes, I collapsed. I smashed everything in the apartment, I smashed three guitars and lamps and furniture and everything. Then I sprayed – that's maybe not so relevant – but I remember spraying fire extinguisher all over the room. And then I called my mother, too,*

> *who took me home. Then I slept and she explained that she had tidied everything up, and my father was there, too. But by then I had slept for two days and nights, I cannot remember so much, but I was in bed all the time. So – remember actually – that I was awake in between and had something to drink and eat. But yes, I finished the term. I had dropped out of grammar school because of anxiety; I had a lot of anxiety then."* (Harold: 24)
>
> *"Remember when I was 17 I collapsed on the floor, was numb in my whole body and hospitalised first time. […I had] exercised to an extreme extent, went to school and had many painful thoughts. So I was running. Every time I had painful thoughts, I started to run. And slept very little."* (Oscar: 1-2)
>
> *"I was out of work, right, and then I had many voices. And I was angry at a voice that criticised by feelings and my person, when I wanted for the train. Then I became so very angry that I bit an attendant."* (Nicole: 81)
>
> *"Got problems concentrating, wasn't quite as creative as before; was also afraid of failing. We competed on being the best, the most creative, the coolest.."* (Eric: 11)
> *"Sensed that I got more moody, the voices came more often and I didn't sleep as well as before. One day in the office I just collapsed suddenly, was completely blocked and away and didn't manage to work. Went home to never return."* (Eric: 14)
>
> *"Life didn't work for me, had quit grammar school, no friends, no job. Depressed, my life just stopped, didn't get up in the morning, not hungry and then hospitalised with severe depression. That's when they decided [sic!] I had schizophrenia."* (Mary: 32)

Self-image an important factor (A4)

Although the interviews did not go into depth regarding self-views, the participants seem to confirm that the content of hallucinations reflect how they see themselves. Apart from that their backgrounds vary substantially. One interesting feature is that most (5 of 7) have had psychological issues in childhood and so all appeared to have been paranoid to a certain extent.

> *"Because there are things in life that I have never told anybody, that a psychologist may have tried to get me to talk about, but I didn't want to."* (Oscar: 125) He however says about his mother: *"Some say that mom is too close to me, but then it is when you maybe need it most. Sometimes you need people to be kind to you, not demanding everything."*

> (Oscar: 98) In comparison: *"Yes, dad signed a compulsory hospitalisation. That's what he's done for me. (He laughs) Dad has problems with alcohol, and then it may be that he has the same diagnosis as me."* (Oscar: 90)

Self-image was not something I asked about specifically, so in terms of phenomenology implicit. For a lifeworld perspective it is all the more central and it is shaped as an interaction between ourselves and the world around us. My pre-conception is that it plays a huge role in both trusting others, accepting help and the capacity to recover.

Ronny talks about his living with his father and 'a wicked stepmother' for a year until the child welfare agency picked him up and moved him back to his mother. His disappointment was such that he didn't go to his father's funeral and claims he never mourned.

Mary was placed in a foster family as her stepfather treated her badly and her mother was depressed most of the time: *"I was mugged in elementary school because I didn't know my father […] couldn't take friends home because she [her mother] might wear a bathrobe all day. It was very embarrassing."* (Mary: 10) The exception was her best friend, and after moving to the foster family at 13 at least she could invite friends home!

Nicole remembers her childhood as joyless and "*I was very angry and I was very depressed I remember and it was very dark inside me*." (Nicole: 26)

The above are relationships and interactions that were negative, while of course the opposite might have protected Russell, Harold and Eric.

Coming myself from a loving family I must confess that I find some stories in my clinical work hard to digest; not because I don't believe them to be true, but because I don't emotionally understand how somebody can hurt children. Parents and caretakers are there to protect and support – I'm here not talking about a 'dark childhood' as the mood around you, but acts of violence and abuse. I have a hard time accepting that such acts are somehow programmed into parents and outside their means to withstand. The humanistic side of mine accept that I must deal with both sides as a therapist, but hurting others is a personal choice.

During the early analysis only Oscar seemed to be on the severe side – but this was caused by my comparing the participants with patients at locked wards; an unjustified and un-phenomenological judgement. I have later tried to adjust for the bias.

Using drugs is not a good idea (A5)

A majority (4 of 7) have used drugs, but they are unanimous that it was unwise and probably made their problems worse. Their motivation for using illegal drugs varied from peers using it to self-medication:

Ronny had an ecstatic experience with amphetamine but used it regularly to cope with long working hours, so mostly at home. He also used hashish and alcohol, which he continued as self-medication after amphetamine had made a ‘bang in his head’ and the voices appeared. He then quit amphetamine abruptly.

Harold smoked hashish because his friends did, but denies self-medication. Oscar used hashish for about a year even though it made him psychotic and he had to leave school. He then quit the abuse. Eric too used hashish, but stopped, but he doesn’t want to stop drinking beer. He asserts that it doesn’t worsen his psychosis, but helps against his anxiety and is a social anchor between him and old friends from his time in a music band. Mary tried hashish once but decided it wasn’t for her.

4.3 BEING-WITHIN-THE-SYSTEM

Hospitalisation becomes a milestone and change of direction for all. The analysis showed that Ronny accepted the diagnosis as an explanation to start with, while Oscar and Eric accepted the diagnosis after talking with others on the wards. Harold and Russell tolerated the diagnosis as a condition for help, while Nicole and Mary to this day do not recognise themselves as schizophrenic. Yet all of them – without exception – have obviously accepted help and were willing and able to establish treatment alliances.

Interestingly four of the seven (Harold, Nicole, Oscar and Russell) were diagnosed with paranoid schizophrenia, but were (surprise!) not as paranoid as to reject help. Harold might well speak for all with his paradoxical way of saying that he was a good boy and let the doctors do their things.

I discovered that I had a somewhat simplistic view of what they were going through; and this is probably the same with the patients that we have seen at the university hospital. According to the participants a diagnosis does not mean much, nor does it explain much. They simply have to go on with their lives.

You don't need to accept the diagnosis (B1)

Two participants (Oscar and Russell) were compulsorily detained more than once, while Nicole was in compulsory treatment after a suicide attempt but before her schizophrenia diagnosis. Even if all but Harold were at one time or the other formally in for compulsory treatment (§3-3 in the Norwegian Mental Health Act), they see it in hindsight as necessary and quasi-voluntary. But even if they all accepted help *none* of them appear to have asked for it. Instead they had kept their condition to themselves:

> *"But I never dared to say to them [in the psychiatric ward] that I had voices in my head. It had to be somebody [at the drug abuse centre] who one-on-one asked me directly: Do you … she probably could see it. […] I could be talking with a chair so I don't really get it why they didn't react at the hospital [psychiatric ward]." (*Ronny: 13). *"It probably sounds stupid that I was content with a diagnosis, but I had gone* […] *knowing that something was wrong."* (Ronny: 106)

> *"I reacted with disbelief and it was not until many years later that I talked with anybody about it. It took several years it did – it was such a shame there. Very much shame."* (Russell: 8)

> *"I was very much opposed to talk with a psychologist, but when I did, it was all right and the real reason for wanting hospitalisation was a lump in my throat, I still have it – a piece of cloth that comes and goes and it was very much there at the time. Had just gotten it […]. That's why I agreed"* (Harold: 49)

The finding that it is not necessary to accept your diagnosis came as a revelation and I had to think it over and over. Yet it is almost self-evident.

This puts psycho-education and insight into a very peculiar light, an unnecessary paradox that jeopardises recovery. Because if you reject the diagnosis then psycho-education will not make sense: the important thing is that you accept and comply with medication because it helps you, not because you *must* have schizophrenia. This was certainly a key point for the existential analysis as well as my clinical recommendations.

Oscar says he was prepared for the diagnosis when it came: *"Because I talked with others in the ward. So I was prepared for it. As I said, I found things became much easier when I got the* *diagnosis."* (Oscar: 47) Similarly, Eric compared himself to others in the long-term ward: *"If they were schizophrenics, then I must be schizophrenic, too. Remember I was very hesitant."* (Eric: 22)

Mary feels she's different from the others. *"[I] still think schizophrenia is a sinister diagnosis and I didn't agree, either. Now it doesn't matter anymore. They've given me up anyway."* (Mary: 17)

We don't know much about what went on in terms of information around diagnosis, but none remember having been told that it is possible to recover from schizophrenia: "*No, there wasn't much hope (laughs) of getting rid of the illness so I think I will have to live with it, but now I at least have medication and stuff so I'm satisfied."* (Ronny: 107)

In addition, they were confronted with psychiatric theory and folk myth. Russell, who was diagnosed in the late 80ies says that his parents were probably told about the double-bind theory that blamed mothers primarily (Russell: 12-13) and Oscar hints to the same myth: *"Some say that mom is too close to me."* (Oscar: 93) Oscar speculates that his father's alcoholism has in fact camouflaged problems like his own, i.e. genetic. Nicole comes from 'a very artistic family' and such people have in her view more intuition and are more sensitive than others. Voice hearing as such is for her not an illness, although psychosis is.

Russell echoes Harold as they both thought life had been too easy on them i.e. not enough resilience. In line with this Oscar says: *"They thought […] would have become ill anyway. But because of sad circumstances it got started earlier."* (Oscar: 75)

Can diagnosis mean hope? None of the psychiatrists seem to have said (or known?) anything about recovery. But if you cannot offer a cure, then it may be safer to say nothing rather than to create false hope. Only Eric recalls the psychiatrist sitting down to give explanations, while the majority (6 of 7) say the psychiatrists appeared to only urge them to take medication. It should be no surprise that it resulted in periods of non-compliance.

The majority view of diagnosis (5 of 7) instead seems in line with Harold's: *"a relief, a box where I might belong."* (Harold: 28) For him diagnosis meant hope. For Ronny the diagnosis ended a period of five years of being treated as just a drug addict who occasionally would be depressed, anxious and suicidal.

But if you don't agree with the diagnosis, can medication still make sense? Yes. Nicole and Mary represent this position i.e. they believe the diagnosis is false, which means they are treated for the wrong illness. So paradoxically the important thing for recovery is that medication helps – not that you believe the diagnosis is right. As long as medication helps, there is hope.

Trying to make sense (B2)

Throughout I was looking for the psychology in schizophrenia and making sense is a huge part of it. Specifically, this is about their sense-making and their attributions; not mine. This requires a consistent phenomenological attitude or what I have previously coined 'total immersion while holding back'. I found this easy after I split the literature research and parked the psychiatric diagnostics at the side, while concentrated on the subjective experience.

It was evident that the participants had read about schizophrenia and talked with lots of people: there were many traces of folk psychology and they are certainly themselves part of upholding and perpetuating myths, yet of course, they wouldn't be believed if they said anything else!

Some of this analysis happened in the middle of the 22 July court proceedings, where the Norwegian 'experts' did a lousy job. I'm therefore more than a bit upset that evidence seems unable to beat folk psychology, and also that clinicians don't seem to read and certainly don't spread new evidence.

It simply makes social recovery very difficult. Is the only option to change name and move, like homosexuals and other outgroups had to in the past?

Attributions for their experiences changed after their diagnosis and therefore become imbued with psychiatric terms and explanations. For instance, Oscar and Russell both made reference to the double bind theory i.e. the myth that schizophrenia can be caused by a mother confusing the child or being too close to it. Inheritance is another, in particular for Nicole who has heard that artistic people are more likely to get schizophrenia because they are more sensitive and emotional*: "But we are an artistic family, you know, you are more sensitive if you're artistic"*. (Nicole: 119)

Harold and Russell share a vulnerability view, but they also believe that their childhood was too easy: "*I have a theory, that it [his childhood] might have been almost too easy so I couldn't handle adversity."* (Russell: 65)

Even if Harold, Oscar and Ronny make connections between drug abuse and hallucinations, it would appear that the vulnerability/resilience theory stands a good number one. Oscar doesn't want to speak about early experiences and has secrets that he hasn't told anybody, so his case might also support a trauma theory. Unlike Oscar, Eric says that his childhood was fine, but experienced mugging in high school. It seems safe to assume that mugging has contributed to his anxiety and paranoid behaviours, but how much and how if to cause schizophrenia?

They have accepted that worse cognitive skills must be lived with. Russell says he used half a year to read a book and he loses skills in bad periods. He used double the time for his Master's degree, but in the midst of psychotic episodes that is an incredible achievement. Oscar complains about black holes in memory and difficulties to concentrate, he also had to learn to cook again. Nicole failed in her studies and Harold studied with great efforts. Daily functioning declined due to several possible factors, not only medication.

In making sense of their own experiences they were comparing with others. Harold's statement illustrates the comparison: *"Yes I did feel it as a threat, that they could send you down to the ground floor where I heard shouting and screaming, where the really crazy ones were".* (Harold: 39) As in her mind she has control, Nicole cannot understand how anybody would kill someone else and blaming it on voices. Yet she admitted that she doesn't know the chaos that others might be in.

Those worse psychotics on the same ward had frightened Oscar, patients who were destroying furniture and attacking ward personnel. Ronny's view was: *"When you are compulsory then you deny a lot. […] I hear this when I talk with people, there is a big difference between compulsory and voluntary."* (Ronny: 53)

Eric concluded that he was schizophrenic after comparing himself with others and feared getting worse: *"and there is a lot yelling and screaming [in the ward]. Then you wonder if it will one day be your turn."* (Eric: 25)

Denial takes you nowhere, they agree: "*But I must say that it's right: you cannot get anywhere unless you accept that you are schizophrenic, if not you cannot get out of it."* (Russell: 8) Likewise, Harold asserts: *"it is a battle you must lose."* (Harold: 93)

Reactions to medication (B3)

All (7 of 7) participants patiently tried a battery of pills like most others diagnosed with schizophrenia. The same story emerges that you cannot actually tell the effect of medication beforehand, except that you should be prepared for very unpleasant side effects. Oscar reported extreme side effects from Trilafon, for which he was given Akineton. For Russell Cisordinol worked fine but was very unpleasant, while Haldol was terrible. But they also increased his anxiety and only Kemadrin seemed to work against all side effects. For Ronny Zyprexa and Trilafon had too many negative effects, but for both Russell and Harold Zyprexa works fine. For Nicole Trilafon didn't work and she tried Haldol, Orap and Cisordinol before she ended up with Leponex.

Their main sought after effect from medication was to remove hallucinations, which was far from reliable: "*[Leponex] doesn't remove the voices, but at least I can get some rest and sleep well."* (Nicole: 57) The pills give her enough energy to live a meaningful life. Harold doesn't see sedation as a desirable main effect and excuses those that don't want to be sedated: *"If you absolutely don't want it, if you think it only sedates you."* (Harold: 93) Russell agrees: *"Valium doesn't work and I don't like the feeling of sluggishness. Have probably done for so long that I have built tolerance, don't you think?"* (Russell: 99) Ronny talks about people walking around like zombies and Eric finds that medication makes him drowsy and that side effects held him back from meeting friends: *"[I] shivered, salivated, was stiff and walked like I were eighty. Didn't help much against the voices anyway. They continued even if it was a bit better. Anxiety got better."* (Eric: 18) But he refused to stop drinking: *"Heard that I ought to not be drinking while taking medication, in other words for the rest of my life. F… no, I don't want to be only ill."* (Eric: 27)

Importantly, sedation is not a desired effect – it didn't feel normal, lead to apathy and did not restore their perceptual accuracy and cognitive abilities.

The caveat of medication is the implicit promise that it will cure you, and I certainly expected to find the same story about experimentation as we see in the clinic. It shows that psychopharmaceutic therapy is not an exact science; and they were lucky to find something that worked for them.
Medication has clearly been necessary for their recovery.

Alliances and power balance (B4)

This grew to become a very important category. We know that social relations of all kinds are crucial to well-being and personal growth; often we don't understand why our help is rejected. In particular hospital settings are often seen to have asymmetric and fake relationship; we are paid to work there and for many carers it is not even a calling.

It is asymmetric also in the sense that we automatically assume that patients are there because they both need and want help; and this is often not the case in a psychiatric ward. This category generates all kinds of legal, ethical and professional issues; to which I'm sensitised.

All participants accepted their need for help, which would be unlikely in the long run without alliances. Two facets appeared under this theme, namely chemistry and power.

Power is an issue: the participants talk about being ignored and not respected, misunderstood and not heard. The psychiatric setting has an explicit power distance, where compliance is seen as healthy, while non-compliance is seen as proof of no insight and therefore pathology. All of the participants consider themselves luckier than many others, they are grateful that they stood the test of coercion, that they have effective medication and that they are able to live meaningful lives.

They are all (7 of 7) strong advocates of more user participation, one reason for their involvement in Mental Health: *"If you want help from psychiatry, if that is the best help, then opposing medication the whole time and you will be forced. […] But compulsory things, I don't see anything good in it. Except if there is a question of life and survival and stuff."* (Harold: 93) "*User participation, that you can have more choices. To kind of find yourself and grow – that you can learn from it, that you can decide for yourself what should be."* (Harold: 95)

Russell and Harold however also say that power may be unavoidable. You must accept the treatment / medication to get better: *"It is a battle you must lose."* (Harold: 93) *"But I must say that you cannot get anywhere without accepting that you are schizophrenic."* (Russell: 8)

All have been upset about treatment at one time or another. The legal appeals institution and watchdog in Norway is the Control Commission. Oscar provides the typical case*: "And I have protested […] because I thought I had a good case. But there are very few I have heard about who are released. I think now that it maybe wasn't so strange that I didn't get their approval."* (Oscar: 139) This is a tough balance, though, as Ronny from his experience as a patient, member of a control commission, and participation in a treatment research project had to conclude: *"doctors and psychiatrists violate human rights in a big way."* (Ronny: 61) In particular he laments the reliance on medication: *"could have saved much medication just by being human."* (Ronny: 74) He later points to a conservatism in the system: *"…rather be flexible and say: "When you're out we're going to give you close monitoring and then you get your chance. As it is now, if your case is dismissed, then you must wait three months."* (Ronny: 126)

They are all critical to the role of the Police to pick up people who are believed to be psychotic:

> *"Nobody can explain that to me. It is the most aggravating event in my whole life. The worst of it was not to be believed and then two hours later the Police."* (Russell: 66) He had gone voluntarily to the E.R., but was sent home only to be picked up by the Police in his home.
>
> *"I am not a criminal who needs handcuffs and don't hurt others. I was really pissed off and angry. And scared. If four police officers want to take you, then you get scared. Once I tried to escape. Didn't work. (He laughs)."* (Eric: 38)
>
> *"I hear it when I talk with people, there is a big difference between compulsory and voluntary. To be taken in by the Police and stuff is traumatic."* (Ronny: 53)
>
> *"Yes, you get a punch in the face in the very first meeting with psychiatry because the Police are coming to get you."* (Harold: 94)

And Eric recounts a particularly difficult episode when his girlfriend, also a patient, was pregnant with their child. Their parents, and in his version also the doctors, influenced them heavily to abort on grounds that it might inherit schizophrenia from Eric and they would never be able to care for a child.

They found it difficult to tolerate pressure from somebody they didn't like, probably it easily looked like splitting: friendly to those they liked and trusted, while hesitant or even rejecting to others. We are all just human and some have bigger issues long before schizophrenia, but not causing it. Oscar told a story about a primary contact that was especially tough and in his view unreasonable. Nicole certainly speaks for all: "*No I haven't liked everybody, to put it that way, no. It does feel difficult to open up when you don't fancy the person."* (Nicole: 89) She speculated that many mental health workers do not really seem to care about other people.

If there is no trust, there is hardly compliance either:

> *"When I got Zyprexa the first time, I didn't know […] I just reacted and didn't like being there. […] I didn't take the pills."* (Harold: 20)
>
> *"So I know who is really bad, who are no good, and who are smart and with whom I can have a conversation. But what I think is very sad, is that there are few resourceful enough for me to appreciate talking with."* (Russell: 102) "*It isn't exactly bright people working here. Many have only two years after elementary school, so there is a lot of knitting work going on. […] In Mental Health I can talk with likeminded. Am met with expectations."* (Russell: 104)
>
> *"Had a great psychiatrist. Was interested in us patients and not just the medication. In the neighbouring ward they had an absolutely unusable one. Talked down to everybody."* (Eric: 41) His psychiatrist encouraged him to do his own things and he was given freedom.

Psychologists are better, he said, but as soon as they have spent enough time to understand what it's about they are gone. His theory: *"Those with experience probably don't want to work with schizophrenics."* (Eric: 42)

The bottom line seems to be that the participants have had good and bad experiences like anybody else, but they have had at least one good alliance.

Hospitalisation and treatment (B5)

Most participants (6 of 7) seem to have come through their hospitalisations to live active lives. The exception is Mary, who has been placed in the apartment wing of an elderly home where she feels like she's been given up.

Rather than question the relevance of psychiatry as such, all participants recognise the need for acute care and indeed the role of the Police to interfere with dangerous or disturbing psychosis. Eric and Harold however question a sanatorium-like idea of food, rest and fresh air: "*a place to store people away, a place for treatment with no treatment."* (Harold: 50) The acute ward seemed pointless to Eric: *"everybody were nice and ok, but nothing much happened. In any case not in the acute ward, where there was food, medication, sleep and then food again. Every now and then talking with a doctor."* (Eric: 24)

Their first hospitalisation lasted from 1 year to 1½ year (which seems excessive), but they then could successfully transition to something more tailored to their individual needs:

Nicole was transferred to a ‘habitat’ where she lived independently with others although with few activities and few responsibilities, and inhabitants changing on a relatively frequent basis. Many were drug addicts.

Russell had a first acute stay with sectioning, but then continued his master studies. These were so meaningful to him that he locked the door to the office and slept off the psychotic episode. After finishing he had short stays and is now living in a community house that he in fact dislikes. Same as Ronny he enjoys Mental Health because he likes to ‘be challenged’ and take responsibility. After his diagnosis Ronny moved to his own flat and has since had an active life.

Oscar had about 2 years within the acute/intermediate ward system, then followed by 10 years with a total of 12 shorter or longer hospitalisations, some of them sectioning. He now lives in his own apartment and is an avid user of community centre activities.

Harold moved to his own apartment and works full time. Eric lives in his own apartment, but never started to work again.

Figure 5 Arkansas Tuberculosis Sanatorium

I cannot say that I was surprised about their criticism of the hospital system for long-term stays; but it signalled an earlier lack of understanding for what it means to be an in-patient and a lack of vision for what should be possible.

An early picture that occurred before me was one of a veranda in an old, secluded sanatorium. People know about it but never go there.

The sun is shining, the patients are wearing sun-glasses, and they sit in comfortable chairs with blankets packed around them. Nurses look after them in white clothes and doctors have brief visits during the day. It is a silent place for fresh air, food, rest and medication; known to society but hidden from sight. But then this is not 1920 and tuberculosis, and most patients don't need seclusion to protect society. It's just not ethical.

Not enough meaningful activities (B6)

According to almost all, the impact of main and side effects of medication reduced their possibilities for meaningful activity and there are few if any traces of work related, study related or cognitive rehabilitation activities, and no systematic access to external facilities. Harold asked if he could continue his studies, but was not allowed to; while Russell continued his despite psychotic episodes. And what constitutes meaningful activities, in a rehabilitation perspective meaningful enough for the rest of your life? Only Oscar had group psychotherapy.

In fact, psychologists seemed almost absent from the daily routines and then offered scheduled consultations instead of involvement in the ward.

I have heard such criticism repeatedly but mostly in connection with locked wards in acute psychiatry, where limited activity is a given. I was therefore careful and rather wanted to have participants talk about their hobbies and interests, but then not only what was offered but also what they would otherwise have liked to do.

The interviews contained interesting information across all three lifeworlds; enough to agree with Russell that the psychiatric system is too self-contained. Not only did I interview participants who had hobbies and interests of their own, but would have been very happy and able to contribute actively inside and outside community services instead of just 'being serviced'.

As a personal reflection I find the concept of 'community services' a bit strange; maybe a consequence of a fearful society trying to avoid otherness and so rich as to pay for keeping people out of sight.

As I didn’t use a specific checklist of activities, the following is not necessarily complete but indicate their views on what made sense or not:

Even if regarded necessary to get the day going, none of the participants liked morning meetings. Morning meetings were a place where you had dragged people out of their bed; most say that they don’t have any plans for the day, they don’t know if they care to tidy up their room today or tomorrow, they worry about who gets to wash the corridor, and don’t dare to suggest anything because it’s ridiculous anyway. Then the meeting adjourns with poetry, a song or a mild physical exercise maybe half-heartedly led by workers who must take turns because it doesn’t feel like it’s getting anywhere. I have experienced it and so did these participants. The sedating side effect of medication is one major reason why setting goals seems so difficult or even unrealistic. As Ronny says: *"stuffed full with pills so you become apathetic – you run around half wake kind of."* (Ronny: 55)

Most of them (5 of 7) appreciated physical activity. Harold liked football, tai-chi, canoeing, running in the forest and the like – not that he did it a lot, he admits. Nicole says: *"I actually believe that more physical activity would be good. Some tough exercise and stuff.*" (Nicole: 108) Oscar liked outdoor activities a lot and Russell liked the physical challenge of re-building the trade route to Sweden. Their project leader spoke to their resources and self-control: *"I don't require that you work all the time, but if you're up in the mountains we won't drive you home until the work is done." – "And I thought this was very fair, it could be tough, but I just had to face each new situation. You don't help a patient if you don't demand anything."* (Russell: 68-69)

Mary seems to enjoy being passively among people and mentions the trips to shopping malls and eating-places as particularly meaningful. Russell discovered painting because he had problems to concentrate on reading and writing. He had to buy his own drawing/painting paper. There were no musical activities for Harold and Russell, while Eric continued with his.

In fact, Eric seems to have been particularly privileged as the long-term stay seemed closer to a halfway house than a hospital. It offered a gym in the basement, hard work cutting firewood and leisure activities with the other inhabitants. He refused working in the adjacent 'Industry', where they could earn money doing manual work like packaging and shipping. He had instead some house duties collecting garbage, could continue his creative interests, and he could spend time with some old friends who accepted that he was no longer quite the same even if he tried to be. He thus tried to live as normal a life as possible.

For the others (5 of 7) their life interests had been put on hold awaiting the results of the hospitalisation. Nicole's statement is typical: *"[After the chaos] activities that appeal to your resources, and not just sitting there to draw or paint, have to be something more."* (Nicole: 84) Mary didn't seem to have any substantial life interest.

Some treatments seem wasted (B7)

The participants were critical of the length and content of their stays as too long and too passive. They would wish for more participation in their own treatment, more treatment, more activities and more meaningful days in general. In fact the whole purpose of a long stay is unclear to them (and this author from own experience) as they must have been stable on medication and were no threat to either self or others. Except for Eric, their (6 of 7) overall judgement is less encouraging:

> *"Ok, year and a half rather. And there things were neither good nor bad, as I remember. Thought that it was a place to store people away, a place for treatment with no treatment."* (Harold: 50)
>
> *"And there isn't much to get you up in the morning because there is very little happening."* (Oscar: 28)
>
> *"But there is too much just keeping. That's my answer."* (Russell: 68)
>
> *"but what I experienced in psychiatry and the acute ward was just keeping us there."* (Ronny: 76)
>
> *"[Should be] using their resources […] I find that it has been medication and technical things really."* (Nicole: 84-87)
>
> *"I feel they gave me up too early. You need help if you want a job and a normal life."* (Mary: 58)

As for therapy Harold and Ronny say that it was easy to generate loads of theories in therapy, and Harold says about his expression therapy that they found more problems in his paintings that could possibly be his. Russell says he wasn't helped by any of the therapies until CBT turned his life around. Oscar seems to have had a modern and evidence based treatment both milieu therapy[6], personal psychotherapy and group therapy. As for his group therapy, timing was not ideal though: *"I was in the tough group where we were to sit down and solve the problems. It didn't work for me. Because I never came that close to my feelings, so I was placed in another group that did more innocent things."* (Oscar: 125) There are still things in his life that he has never disclosed to anybody.

I asked specifically, and none (7 of 7) could remember that psychiatrists did anything else than medication.

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[6] Defined in this research as the systematic approach to treatment that is not part of psychotherapy or pharmacotherapy.

4.4 OUTSIDE SCHIZOPHRENIA

This super-ordinate deals with residuals and identity issues after hospitalisation, in addition to other aspects that were resources or activities put on hold while under hospitalisation and treatment, such as family, friends, studies and jobs.

I found these categories very interesting because the participants were somewhat looking backwards to chaos and hospitalisation from a 'safe distance'. The term 'outside schizophrenia' does not refer to medication-free and fully recovered – the condition that with contemporary treatment seems possible for only about 1/3. Instead it refers to those 2/3 who recover to live normal lives and enjoy it like all the participants. We cannot know if the participants have recovered fully because they continue medication, but we can say that they live outside the sweaty grip of schizophrenia.

As a clinician I was particularly interested in whatever remained as problems or complaints after successful medication and five years of living outside. This interest does not introduce any bias; any findings would be ok. What I needed was to establish phenomenological categories based upon the interviews.

Their identity issues are clear – both as stigma and self-stigma. They talked about their relationships with friends and families; and how these had changed, come and gone.

Coping with residuals (C1)

This category is not limited to schizophrenia, but covers life in general and almost anything not dealt with underway. I seemed to miss psychotherapeutic treatment for the consequences of schizophrenia, such as depression, anxiety, broken relationships but also side-effects such as sexual problems and anhedonia. It is not really a vague category, but somewhat difficult to explain because it needs to be broad and existentially important rather than specific.

While they were remitted as per their BPRS scores, the degree of well-being and mental health ranged from Harold on the higher end to Mary on the lower.

While Harold lives a fully normal life in terms of activities and Russell works halftime, all the others (5 of 7) have reduced work and/or permanent disability. They report fatigue and concentration problem in particular, which might be due to medication at the same level as when they were released. Harold is actually free of hallucinations and could be in the totally recovered category with medication he doesn’t need, while the others have residual hallucinations. .

Three of the seven struggle with anxiety. Eric seems to be the most affected and Oscar has Vival in his pocket just in case, but says he has therefore never had to use it.

Ronny praises another type of safety net, his Individual Plan, a legal right since 2004. It documents who is his contact person for various needs and all helpers can look up his Individual Plan to see who else is involved, who is the next of kin, what his goals and interests and needs are *et cetera*. It is also used to identify who might need home visits from the mobile team and documents informed consent and preferred treatment should he become incapacitated again.

Only three avail themselves of community day centres. None of them want psychotherapy or other kinds of therapy currently. They just try to live a normal life within their possibilities.

Oscar summarises his third lifeworld nicely as a feeling of freedom:

> *"Have been stable for the last years. It is positive. And then it is great to live in your own apartment and decide your dinner, what I want for dinner, when I want to have it and where. I can eat in my bathroom if I choose to! So I have my freedom!"* (Oscar 160) And he is happy with his life: *"When I know what happens Monday to Friday and get to sleep the extra hour [due to Leponex], then I have a full life like everybody else."* (Oscar: 104)

The others, even Mary, seem to agree that life is ok now.

Living with identity issues (C2)

As they probably cannot get rid of the diagnosis in any other way than adding 'in remission' to their diagnosis, my understanding was that they have accepted the stigma as inevitable. Nicole's rejection of the diagnosis can be seen as also rejecting this inevitable stigma; we did not explore this.

As expected I found examples that the stigma directly affects their assumed 'usefulness' in society. Being sedated ('zombie') was mentioned by several others – the inability to work full days certainly maintains the stigma. Harold was not expected to be useful so had to choose between two alternative educations that others thought out for him but he didn't really like (while finished one!); and Russell who got a master's degree with distinction between psychotic episodes was only offered unskilled manual work. Russell almost certainly had a much too high dosage of Zyprexa, so I advised him to see a psychiatrist which he hadn't for ten years.

Even after considerable reflection I cannot see this as a consequence of schizophrenia itself, but more as a perpetuation of 100 years of psychiatric myth. It is certainly an area where I have strong beliefs that all participants would be capable of much, much more. As the old adage: whether you believe or you don't believe in yourself, you will be right. Russell called this attitude of 'not expecting anything' simply a disservice.

For three of them (3 of 7) the day centre is the place where they let their guards down; outside they are aware of their identity as schizophrenics: different, dangerous, chaotic, unpredictable, mad or crazy. It is thus outside the day centre and in daily life that their identity issues tend to come forward: *"And when I meet people in the train or on the bus I say that I'm a church attendant."* (Oscar: 30) It is not a full-time job, but it gives him a normal identity.

Family support is important (C3)

The role of the family was rather complex. Almost all (5 of 7) appear to have had childhood within the normal. Yet we must take note of that prolonged exposure to stressful events can result in trauma like experiences. There is only weak evidence that this could cause schizophrenia (Larkin & Morrison, 2006).

Mary was placed in a foster home and recalls a bad childhood until she was 12. She however left them when she was 17 and has had minimal contact since. Ronny recalls a period when he was about seven years old, as he was living with his father and was beaten up regularly by his stepmother. He was moved back to his mother never to speak with his father again and did not attend his father's funeral.

Almost all (6 of 7) have had at least one family member who has supported them through their distress:

> *"my family has been behind me all the time. Really supported me. My sister and my mother and everybody."* (Harold: 86)
>
> *"Some say that mom is too close to me, but then it is what you maybe need most. Sometimes you need people to be kind to you, not demanding everything."* (Oscar: 93)
>
> *"My mother [stood by me]. The others were probably so pissed off that they no longer wanted anything to do with me."* (Ronny: 100)

From a lifeworld perspective actively exploring for social relations, family or friends proved to be useful and correct. I demonstrably did this with a phenomenological attitude without assuming a theoretical perspective e.g. attachment theory or psychotherapeutic concepts would have interfered with the phenomenological attitude.

You must make new friends (C4)

They all (7 of 7) lost friends due to the chaos they lived before hospitalisation. Their explanation is that schizophrenia is difficult to explain and is not a shared experience. They changed too much. It became difficult even for Eric and Harold, who managed to keep some contact with friends. They all express sadness and anger about friends who abandon them; friends who didn't care to stand by them when they had problems. Harold's view is that real friends are loyal despite strange behaviours, but when your conditions change so much then they all agree that you need new friends who understand you. Mental Health Norway is such a place, they say.

Their definitions of and need for friendship seem to vary: Nicole doesn't really try to make friends but enjoys her motherly role at the day centre and is not lonely at home. She misses a boyfriend, though, and wonders if she will ever get married. Ronny kept to himself for two years after he'd been open about his diagnosis and saw his friends desert him. Then he joined Mental Health and now has a good network of new friends there. Harold makes the point that it is natural to change friends. And he asserts that 'drug friends' are not real friends – when you turn dry, there isn't anything to share. Russell enjoyed great fellowship during the studies, but then not again until he joined Mental Health and 'met like-minded people'. With his academic achievements and intelligence he simply feels outside when people around him don't even know basic facts and are politically ignorant.

Oscar considers that except his girlfriend he doesn't really have any friends. His definition of friendship is that friends do things together, but to him day centre friends are not real friends, as there they haven't really chosen each other for friends. Mary's identity issues shine through. She enjoys being with the elderly and doing errands, but she does not participate in day centre activities with others in the same situation. Instead she keeps to herself. But then that is her choice.

Meaningful occupation (C5-C7)

What constituted meaningful activities varied according to age and daily functioning. Problems to adjust are usual also when coming back from unemployment and sick leave, so even if able and willing, it seems unlikely that they would be able to go directly back to ‘normal’ jobs. Only Eric, Harold and Ronny have established themselves in work-life, while the others have not.

Two of the participants are not working (Eric, Mary), three (Nicole, Oscar, Russell) have work ranging from a few hours per week to fifty percent, Harold has full-time employment and Ronny works almost full time as ‘unpaid social worker’ (my interpretation).

They all confirmed that the BPRS is their normal daily score and given the information obtained in the interviews (studies/training, interests) they all have the potential to work. However: One never tried (Mary); Two tried and failed so doubt themselves too much (Nicole, Oscar); and Russell would like qualified work but is discouraged from it.

5 DISCUSSION

5.1 Presuppositions and bias | reflexivity

A hermeneutic of empathy (Gadamer, 1995; van Manen, 1990) became my perhaps most important ally to control personal and professional type biases or prejudices. The literature is enormous, theories span a hundred years and not much has been rejected; any *a priori* selection could become a bias. While I did some advance literature search for the PAP Viva, I added a substantial amount later and yet in the end reduced the depth of my psychiatry write-up because I decided that most of it was not needed for my purpose.

I simplified the research considerably when I did not have to worry about the correctness of their diagnosis but could concentrate empathically on exploring their lived experience. Taking their diagnosis *at the time of treatment* for granted meant that I could hold a useful distance to clinical interpretations.

The phenomenology that I decided to follow was hermeneutic rather than descriptive; I wanted to hear their stories rather than symptoms. Usefully, Rulf (2003) discusses three different uses of the word phenomenology, where she calls psychiatric observations an onlooker's version and not phenomenology in our sense here. Clinical interpretations are of course not limited to psychiatrists as I would easily, almost automatically be similarly inclined to follow my own clinical intuition.

For both van Manen and IPA such interpretations flow seamlessly into theory. Like Giorgi and Ricoeur I feel uncomfortable with this 'anything goes' approach to phenomenology. In addition the existential literature seemed too thin, which could mean more of my stuff with little support in other research. So when van Manen (1990) encourages the voice of the author to carry the research, I did not want to do this.

The idea of an (existential) analytic occurred to me when digging for a solution and comparing my issue with Langdridge's (2007) Critical Narrative Analysis. Although his method did not meet my needs, I could build upon Ricoeur's *hermeneutic of suspicion* as an excellent match. Ricoeur (1981) addresses the constructionist nature of psychoanalysis, history, law and religion as interpretations; similarly, schizophrenia is not a reality or medical fact.

I could therefore use empathic hermeneutic circles (explication) followed by theoretical perspectives (interpretation in the form of existential analytic). The following reflexivity is mainly about Findings.

Handling family trees

Bracketing psychiatry

There are important differences between psychiatry and psychology in methodology, paradigms and knowledge. Family trees are a nice way to illustrate that we all have paradigmatic roots, different roles, experiences and discourses across professions. You simply become part of a professional culture – my education is psychology, but I have also worked many years in psychiatric wards. I see medication and psychotherapy as a useful combination rather than alternatives. When you see people sleeping off psychotic episodes with medication and gradually come back from serious psychotic episodes, you cannot but wonder what it was like before antipsychotic medication. And without medication personal disasters and social calamities seem often unavoidable.

This research is not about psychiatric theory but about people with real lives. I decided I could bracket psychiatry, with the exception that psychiatric concepts were part of their stories.

One important thing that could not be bracketed: the meaning of *psychotic* seemed to be different for the participants than for psychiatrists' (Ricoeur: *polysemy*), yet it is hardly noticed in literature. It is in my view a significant difference:

In psychiatry the term *psychotic disorders* is a family of diagnoses purportedly sharing a loss of 'reality' as the common characteristic. In schizophrenia it is assumed to be of a special kind where *acute episodes* are spikes of and underlying mental illness. But there are two difficulties with this.

First, the participants talked about *episodes as psychotic*, phenomenologically different from daily living with schizophrenia. Instead of being afraid of more hallucinations, which is one phenomenon, they were afraid of losing control i.e. disappearing into psychosis, which is not the same. Second, psychotic episodes are rather similar across many other conditions: depressive psychosis, manic psychosis, urinary infection, cancer drugs, post-partum and drug induced psychoses. A corollary from the above could be that anti-psychotic medication works against psychotic episodes and to prevent them by sedation, but it is not really a medication for schizophrenia. Third, we really don't know why anti-psychotic medication doesn't work for everybody with schizophrenia (Leucht *et al*, 2011), as it should.

Inevitably there were some others signs of psychiatric theory in participants' thinking, but of minor importance. I think I have managed to investigate the narrative conscientiously without thinking in terms of diagnostics, symptoms or the dark alleys of one hundred years of psychiatric theory.

The narrative approach

The hospital system is connected to diagnostics; hospital journals do a good job to document illness but not life as such. Concepts such as lived experience, lifeworlds and narratives are not much used in psychiatric research. I believe we must listen more to the persons in schizophrenia – if we want to help, we need to understand personal experience as well as causes. Although I understand and respect the role of medication, I believe psychology is much underestimated in schizophrenia and, as the literature research showed, under-researched.

The Interview Guide asked for experiences before hospitalisation, during hospitalisation and afterwards. Timeline is a natural thing for a narrative. In fact I could have cut the Interview Guide in many other ways e.g. by subdividing into symptoms or other theoretical themes. I became aware how easy it would have been to destroy the phenomenology in the data; clearly my first supervisor did this reflexivity for me when he called it 'excellent'…

As my interest is recovery I was open to anything coming up. Choosing openness was rewarding, as a more focused approach would probably not have led to my emphasis on lifeworlds.

And in hindsight the PAP Viva had been too allowing of an almost impossible topic.

Lifeworlds

A lifeworld perspective is a shift from observation to empathy and imagination. In my own lifeworld I am sure the physical world is represented accurately through my senses; but it took little imagination to realise how we are biologically programmed to rely on our senses and then schizophrenia must be scary.

Using my imagination and empathy was critical in tackling this research; for instance I discovered how difficult it must be when a part of your physical reality is not shared with others as it is supposed to be. Clearly, the psychology in schizophrenia is very different from a disease of the body or even headaches. Recovery must be about mastering your life, hospitals are about curing disease. This is a mismatch of purpose.

Much of this reflexivity went on in parallel with the transcript analysis.

Already the first case showed me how meaning is created in a person-context interaction. For Harold the phenomenon (Buddhas) remained as time went by, but the lived experience changed. At first he felt completely in control and manipulated his Buddhas, then totally lost it and crashed everything in his apartment. It is this loss of control that he later feared – it just happened: it was not (like) him. Something snapped, but what? Hospitalisation and diagnosis changed his world with a whole set of new attributions and more or less helpful explanations. A one-phase model did not ring true from an existential point of view.

From there on the lifeworld concept seemed naturally embedded in the narratives – it was not even latent anymore.

Now the challenge was to control my own process by bracketing what I think psychiatry should have done and instead concentrate on how the participants act in their lives – *being-in-the-system* is a play of words from Heidegger, whose *being-in-the-world* (with a small letter) is about our relations and behaviours rather than identity or attributes. This was another useful trick.

Lifeworlds not only seem existentially valid, but organised the material as lived experience and person-context, while providing a clinical timeline. This step has affected my emergent categories and I argue that lifeworlds are more valid for existential exploration than the one-phase model with the same mental illness and acute episodes.

Personal 'stuff'

Optimism as obligation

In therapy I use my empathy and emotional intelligence to build mutual respect, trust, resilience and motivation. Very often clients/patients don't believe in themselves, so if I don't, then who will? Clinical work makes little sense without optimism and I am paid to help, not feed their doubt. In other words, I regard optimism a useful bias and somewhat of an obligation. It does not mean that I am unrealistic; on the contrary I take precautions to use a Vygotskian approach of sometimes small proximal steps and scaffolding. I program mastery and courage to experiment and live their lives, with or without medication.

Here I must initially have taken for granted that participants would be totally outside of schizophrenia (Davidson, 2003) and that it would be a definitional task. It turned out to be more complex – I have used a lot of time to ponder if effective medication and compliance were really the core factors for the participants. They were all remitted as per Andreasen *et al* (2005) yet psychotherapy seems to have been negligible for four of the seven participants.

This seems like a paradox, at odds with the research that shows psychotherapy so beneficial that it should be routinely offered. It is possible to resolve the paradox by assuming that psychotherapy contributes to the quality of recovery over and above successful medication.

But it is perhaps not necessary for everybody? Individual needs may be covered in therapeutic environments by means of not only formal psychotherapy, but also milieu therapy and simply a supporting environment. This would explain the WHO studies that found a better chance of recovery in developing countries (see 2.3). At least the sanatorium approach seemed counter-productive; it reminded me of tuberculosis where people were secluded, sitting on a veranda with blankets around them, waiting to get better: isolation, food, medicine and rest.

Perhaps not all with schizophrenia need deeper forms of therapy, but it is also likely that the research participants have therefore not achieved their maximum functioning and well-being. Their maximum might be something only slightly better or something dramatically better; but the evidence of psychotherapy for schizophrenia is that it makes a positive contribution. This is indeed what I found in the research from Oscar, Russell and Harold.

So I remain optimistic, evidence in hand.

Impatience

I am more intuitive than detailed/logical; more interested in the big picture than details. In the first attempts I was clearly biased towards this impatience: My supervisor was kind enough to point it out to me in no uncertain terms...

I had to learn the virtues of patience in research by having to rework (yes, van Manen says rework is necessary, but this was of a different kind …). My first attempt at analysis was more of a thematic re-ordering than actually looking behind the words and between the lines. My next attempt was better; Grounded Theory was definitely a more fruitful exercise. However, Grounded Theory was not really a good idea because what I had was not a purposive sample, but a convenience sample. It meant that I would not be able to establish a solid theory.

By then I had learnt new ways of working. I had been too eager to get the job done; too eager to leave the data and interpret. When I slowed down and concentrated on empathic readings (which felt more like excavating than explicating), I found my curiosity increasing and I was impressed at how much data I actually had got. I could also organise it as emergent themes without reference to theory or naïve interpretations.

Milieu therapy experience

Judging from Soteria and other therapeutic environments, I think milieu therapy is a necessary resource for schizophrenia treatment. Milieu therapy respects individual differences and at the basic level applies Rogerian principles i.e. the three characteristics that Rogers' (1957) deemed *necessary and sufficient*: authenticity/congruence, unconditional positive regard, and empathic understanding. A learning effect takes place when you are hearing your own thoughts; and Rogers builds upon willingness and wanting change, motivation to work together and courage to get in touch with own feelings and beliefs as vital motivation. (Thorne, 2002)

A second type will support homework between psychotherapy sessions. Combined it is thought to be enough to influence daily thinking and to change directly and indirectly the content of hallucinations from the usually negative or imperative to something you can live with.

A third type is a Skinner approach as in parenting, and Applied Behavioural Analysis (ABA) – this is more often used in long-term settings as it takes a therapeutic team to implement successfully.

I regard systematic therapeutic interventions as the key to success. In milieu therapy interventions and activities will have a therapeutic rationale; creating an environment conducive to the desired activities.

Coming from the above background it is possible that I think too highly of milieu therapy.

My controlling mechanism was to not interpret in light of milieu therapy but simply look for active components. When activities are listed as 'wasted' this is not my judgment but what the participants say. For instance, participants said things like *"a place for treatment with no treatment"* (Harold: 50), and *"just keeping us there"* (Ronny: 76).

It would be great if psychotherapy and milieu therapy were coordinated: I was disappointed that there was very little of this in the narratives.

Professional biases

Clinical bias | Helpful questions

My training and practice as psychotherapist means a certain bias towards either assessments or helpful questions. Both are habits and would be relatively automatic e.g. wanting to explore specific treatments and go lightly on others; speculating about the absence of therapy; asking about dose-effect, main effects and adverse effects. Or apply my own theory about their well-being and various therapies that they might have had. But it would of course not have worked: how could they say anything valid about a therapy that they hadn't experienced?

I postponed such questions to the Discussion.

My control/bracketing was a running awareness to focus on the lived experience rather than theories.

Of course, with limited time available (interview time, expectations, motivation/fatigue) I did not just sit there listening for free associations, but tried to manage the time such as to get as much data as possible. It means that I went in and out of hermeneutic circles, in the first case within the interviews and when alone with the text. I did not find this difficult. The NSPC emphasis on phenomenology has been very helpful in developing my presence and focus on the person in front of me – we are a conscious vehicle for dialogue.

From the transcripts the interviews seem relatively well rounded off as hermeneutic circles. I achieved the aim of saturation to a sufficient degree: the counts of meaning units by emergent theme (tables 13-15) revealed individual differences for sure, but there was no need for more data.

Of course, a saturated analysis does not mean absence of bias. But clinical biases seem to have been reasonably well controlled, postponing the whole discussion of evidence-based treatment.

Medication – helpful but not sufficient

We actually don't know why medication does not work for all (Leucht *et al*, 2011) and why not the same medication. It is trial and error. Epigenes might be an answer, but it also creates the exciting possibility that anti-psychotic medication works for the episode because the episode is chemical, while the chronic condition is not. (But indeed, why comply if it doesn't seem to help you?)

Second, the wording in DSM-5 is telling: an acute episode is a spike of a habitual chronic condition, which automatically means more antipsychotic medication or anxiolytics. A psychiatrist could say, manual in hand that they were just 'in remission' and might relapse any day.

The research participants had already an advantage that for them medication worked. But I was disappointed that they had not been offered reduction. Medication alone is in many cases, this is my belief, not only unhelpful but a breach of their rights to evidence based treatment. If inadequate voluntary treatment later leads to compulsory hospitalisation it is also a breach of human rights.

Only evidence-based treatments can be ethical.

Diagnostics – not so helpful

We are still years away from understanding the brain correlates that make schizophrenia a medical and/or psychological condition. The neuropsychiatric correlates are speculative to say the least. I had hopes that DSM-5 would live up to its promise as a modernisation and make it easier to include psychology. On the positive side categories have been replaced with dimensions and subtypes are no longer good practice. The cross-tabulation between the American DSM-5 and ICD-10-CM is a first step towards a global system for clinical data and this should be welcome.

The concept of delusions should be and has been weakened to allow for common personal and cultural beliefs, while elimination of subtypes opens even more space for psychologists:

> Oscar had been diagnosed with F20.0 (ICD-10) Paranoid schizophrenia, which corresponds to 295.30 Schizophrenia paranoid type in DSM-IV. In DSM-5 schizophrenia now has a new code, 295.90 Schizophrenia (new to allow it to co-exist with older diagnoses) which maps into F20.9 Unspecified Schizophrenia in ICD-10. This is better because a subtype is unlikely to have brain correlates that other subtypes don’t.
>
> In Norway we do not diagnose personality disorders for those minor of age, but Oscar’s case might suggest F60.0/301.0 Paranoid personality disorder. With DSM-5 we can now use F60.0/301.0 Paranoid personality disorder comorbid to F20.9/295.90 Schizophrenia. It separates the work of psychiatrists and psychologists nicely, and the personality addition is a stronger rationale for psychological treatment.

> Personality no longer appears as an implicit (i.e. subtype) or underlying cause (i.e. axis II). For differential diagnostics I note that Oscar had to re-learn skills, which sounds like cognitive deterioration perhaps caused by schizophrenia (Criterion B).

It would be very interesting to use descriptive phenomenology in schizophrenia – a person's voice could give us more clues to brain functions than brain scans.

By and large DSM-5 failed to meet my expectations. The DSM-5 agenda was supposed to provide state-of-science (Kupfer & Regier, 2002), but I can see little progress and agree with Regier & Kupfer (2013) that DSM-5 contains 'no radical changes' but rather re-classification and clustering. I was disappointed that personality psychology has not been carried over into psychiatry: The tentative personality scales look like Big 5 compatible (I don't know if they are), but we will continue with the old scales and their interviews (e.g. SCID-II).

Although I am very familiar with psychiatric diagnostics, my bias control was to simply take their diagnosis for granted and concentrate on their stories rather. It made my research so much easier.

Genetics and myth

I have a professional bias against the genetic theory for several reasons. Unless you have a relative with mental illness the DNA myth may not be of concern for lived experience, but it is still a stigmatising theory that makes schizophrenia chronic.

In the genome project scientists could not find a common genetic structure that could explain schizophrenia, except for certain paths in early neurodevelopment. Early gene failures (e.g. trisomy and 22qDS) impact the neural crest and brain development; same with hormones and nutrition. But it is not specific and not a marker. Nutrition includes folic acid deficiency, which seems to have been the case in the Dutch and Chinese famines, research to be replicated in Saudi Arabia archives.

I find this research fascinating and important, but it is also a very long way from what actually goes on in schizophrenia. I wonder whether it will actually help anybody and it is far from psychology.

Bentall (2009) calls the genetic theory an axiom and fundamental error of psychiatry (p. 116). He shows the computations that have led to over-estimation. I would add that the case of the Genain quadruple that was hailed as the penultimate genetic proof, was not peer reviewed and the diagnoses were set in a *US Zeitgeist* and at a time when schizophrenia was diagnosed 10-20 times more frequently than now (see 2.2.2). Their symptoms seem correlated with the severity of their childhood suffering – more compatible with traumagenic theory than genetics.

Mental disorders seem to a certain degree to run in families, a kind of social genetics. Traumagenic theory makes this issue even more pressing – if schizophrenia can be a consequence of trauma then it is time to concentrate on the main cause instead of genes!

Way forward – brain correlates

I still believe brain correlates will be useful to triangulate other findings. It will be a way to clean up one hundred years of spurious theory and show the way forward for methods such as cognitive remediation. I was particularly interested in Salience Network and Default Mode Network as consciousness and not improbably the core failure in schizophrenia – whatever the cause.

My first supervisor recommended that I drop it because it is a huge field by itself and more psychiatry than psychology. Yet this felt intuitively wrong and I think cross-functional understanding is necessary. Taking his advice, I instead wrote a more reflective section called *The Problem of Consciousness.* I think it was a correct compromise.

My second supervisor pointed to the fact that I had maybe discarded the possibility of childhood adversities too quickly. The path from childhood trauma and adversity could indeed go via neurodevelopment, which would account for the difference between the phenomena in adults and children. I could indeed see how I had missed clues for three of the seven participants. Mary obviously had a difficult childhood, I had taken Ronny's words of a 'good childhood' for correct, and also Nicole and Oscar had talked about prolonged periods of psychological stress.

I have come to believe that traumagenic theory has the potential to become a new paradigm: it makes a lot of sense that psychological events can have a different impact in an immature brain than in a fully developed. It is likely that resilience and coping strategies can lead to weak synaptic connections that eventually die (Hebb's rule) in the neuronal pruning during puberty. And it does not preclude early brain developments. With neuroplasticity, is it possible that we can reverse schizophrenia? Is neuroplasticity what happens in full recovery and how are these cases different from those who do not recover?

Perhaps finally after one hundred years we can see some light in the tunnel – I would like to note however that much of the above reflexivity was more for interpretation than for explication.

More psychology needed

The person in schizophrenia

I have wanted to concentrate on the person in front of me – I am naturally more curious about people than theories and numbers. For clinical psychology there is no objectivity as such and the person is beyond 'objective' measures. My time should be spent with persons, not diagnoses; with uniqueness, not algorithms. I am not sure I could bracket my clinical interpretation, but I tried to be constantly aware of it.

I believe I succeeded to make psychology more prominent by bracketing medical research and hold a phenomenological psychological perspective. And there was plenty to analyse as the narratives showed differences in personal stories, resources, resilience and coping strategies.

Asymmetric relationships and ethics

We help people who do not want help, people who reject psychiatry because they feel ok and believe they are being plotted against. But is it helpful?

Nicole said she wasn't even sure if social workers actually like people; and all participants had known people they thought were good and some they didn't like. The asymmetry was obvious and not unlike my own experience and observations.

Lauveng (2005, 2006) talks about clever and clumsy hands, hands that know what they're doing and hands that don't care. The positive effect of treating people with respect was mentioned already by Pinel. Patience and respect are important. Long time ago I read an interesting small book about clinical ethics by Guggenbühl-Craig (1983). One of his points is how we as helpers construe our role from the belief that others actually need our help.

We must be prepared for rejection and not automatically assume that we hear mental illness speaking; maybe it is the healthy part that is speaking. I just try to do my best in the situation. Maybe our help is not even needed, perhaps the patient knows what he/she needs.

It is fortunate that we all have a need for social contact; the key to voluntary treatment I think is to gain access to the doubt that I have found in almost everybody with schizophrenia. I was interested in their relations – did they remember helpers as positive and helpful?

I often explain to newcomers that danger to self or others does not automatically mean a right to use force; it must always be commensurate with the situation and it should have a therapeutic rationale. When not a threat to self or others non-compliance may be within the limits of self-determination. The participants saw the use of force as sometimes necessary, also in their own cases. As I have of course myself pressed the alarm button and at other times used force including restraints and forced injections, this was reassuring. We try to be ethical but sometimes we doubt.

Comorbidity expected

Curiously, it is as though psychiatrists often forget Harry Stack Sullivan's (1940/2006) quote: *" We are all much more simply human than otherwise, be we happy and successful, contented and detached, miserable and mentally disordered, or whatever."* (p.7)

The problem continues: *"We now have a plethora of comorbidity—because patients do not usually have only mood, somatic, or anxiety symptoms but tend to come with a mix from multiple symptom groups."* (Regier *et al*, 2009: 645).

My professional view/bias is resolved by seeing comorbidity as not a diagnostic problem to be solved, but evidence that the realities of life surpasses a medical paradigm. If indeed we are more human than otherwise, comorbidity comes as no surprise. I totally agree with Bentall's (2003) advice to work with complaints and not worry about diagnostics labels.

This is also what could be seen in the BPRS, which goes beyond schizophrenia. We all have complaints and problems in life that should not have a diagnosis: social problems and lack of friends are not mental illnesses even if dysfunctional. Stigmatisation and lack of meaningful work are socially created, not a brain failure (psychiatry) – depression may be manifest by not enough serotonin but it is not the root cause.

I have by now quite some experience in clinical assessments, diagnostics and differential diagnostics; to a degree that it was nice to concentrate on the person in front of me without worrying about interventions and treatment strategies. I was responsible only for the interview!

Is existential exploration applicable to my data?

I was surprised that there is not much scientific literature about the existential side of schizophrenia. Here phenomenology has been a great way to assemble data and an existential analytic lets me select critical areas – the weakness is in available literature, where most of the literature was written in the pre-dopamine era. I started to think of it as out-dated and that my idea of existential exploration would not be possible. However, apparently those early researchers were onto something of greater importance.

I saw the importance when I reflected on how we are biologically programmed to trust our senses – *what would happen to me if I could not trust my senses?* This must be central in schizophrenia.

Second, I realised how difficult it must be to explain things that others deny – social interaction is based upon a shared sensory world where Minkowski saw a broken 'intentional arc' and Merleau-Ponty argued that the brain fails to know what it's doing. In both cases the world is not as we expect: an extremely powerful concept. Third, Jean-Paul Sartre and Rollo May both have a notion of existential anxiety that resonates with my empathy. High EE is known to induce psychotic episodes.

Together these aspects are substantial and existentially important enough to combine into an existential analytic that I can apply on my Findings. A hermeneutic of empathy alone cannot take me there.

The key to keeping my findings sound has therefore certainly been Ricoeur's (1981) advice to keep explication empathic and postpone/limit interpretation to your base of theory.

5.2 AN EXISTENTIAL HERMENEUTIC

While the Findings were based on a *hermeneutic of empathy* i.e. interpreting data without any particular theoretical perspective, the Discussion explores the data from an existential point of view. Themes emerge from the participant interviews (parts) to narrative similarities (whole) and back again, whereby the central concept remains as *dasein* (the verb) or *being-in-the-world* (the verb) i.e. their active being and relating with the world – their *being* went through dramatic changes as a consequence of schizophrenia. Compared with recovery research their patterns are similar, although we need to be cautious because my sample is convenience based and participants are selected exactly because they are remitted and stable.

An important diagnostic issue needs to be considered upfront. A sole focus on illness, an organic failure, is an untenable position as there can be no particular way of having schizophrenia that is disconnected from its psychological consequences. Neither can we of course understand schizophrenia by discarding new discoveries in neuroscience and neurodevelopment.

An existential analytic therefore seems clinically important.

Bad cases of schizophrenia seem to de-stabilize the whole *Dasein* (Being-in-the-world) and I agree with Parnas *et al* (2005a) that in those cases *"We simply fail to realize how dramatic these* *complaints are for the patient. […] [Perplexity and self-disorder] jointly reflect a structural transformation of the 'intentional arc' (Minkowski, 1927), the most basic relation between the self and the world."* (p. 266)

Literature research showed that pre-dopamine psychiatry explored psychoses via phenomenology, but that recovery from schizophrenia was deemed impossible until ten to fifteen years after the Strauss & Carpenter (1977) ground-breaking article. You could escape misery by alleged misdiagnosis (Rulf, 2003; Stanghellini, 2010), which spawned research into markers and reliable clinical consensus. But there is another view that is equally compelling. Strauss (2008) and others have repeatedly pointed out that the new concept of schizophrenia does not seem to have a meaningful gestalt (Boyle, 2002; Flanagan, Davidson & Strauss, 2010; Parnas, 2008; Stanghellini, 2010; Strauss, 2008) and in fact misses core phenomenology (Andreasen, 2007; Bürgy, 2008; Davidson, 2003). It seems safe to say that we are confronted with several incompatible assumptions and implicit meanings.

From a hermeneutic point of view, participant experiences are narratives at considerable lived distance from the experiences and thus modified repeatedly, the three lifeworlds. Research puts the magnifying glass on a central paradox, namely that the distress assumption is no longer valid after successful remission. Antipsychotic medication has been of great help (e.g. Leucht *et al*, 2012) to the extent that the residuals are well below the remission threshold as defined by Andreasen *et al* (2005).

An existential hermeneutic might satisfy what Stanghellini (2010) calls structural psychopathology, viz. a sense of underlying deficits and perceptual gap beyond diagnostic symptoms. When the world around you starts to falter, the effect could be as dramatic as Sartre's (1956) nothingness as a negation, a kind of nothingness that can only be nothing if there was something before it. This change from functioning to deficit seems central in schizophrenia and matches the idea of atrophy, too. The very threat of nothingness is central in existential thinking (e.g. Deurzen-Smith, 1997; May, 1977, 1983) and seems to be what both Harold and Oscar talk about as an extreme sense of anxiety, loneliness and despair.

Sartre (1956) describes nothingness as negation, but also as compulsion. He gives us a phenomenon in such a way that we recognise it as principled experience. When you walk a steep path with certain death if you slip, the imagination of slipping can become the foreground. Similarly, the not-there fills Sartre when he expects to meet Pierre in the café and Pierre is not there. This is hyper-reflexivity and can be explained as a pre-occupation to make new meaning (increases dopamine, too). His focus on shame is not alien to persons with schizophrenia, either. So when I describe the first phase as ‘losing your ground’, it reflects an existential meaning.

Key vocabulary in the existential hermeneutic

Schizophrenia, psychosis, consciousness, and many other words appear to have a precise definition, but in reality they have considerable *polysemy* (multiple meanings) and the implicit assumptions need to be made at least somewhat explicit. The *polysemy* can be controlled by naming central terms and sources that have special significance for an existential exploration. **Nothingness** might be seen as a **negation** of something that was, but is now missing or threatened (May, 1977; Sartre, 1956). To some readers this interpretation might seem a bit beyond Sartre's, but then he did not write about schizophrenia. Sartre uses the example of Pierre who is not in the café to show how *not-present* can become an overwhelming foreground, while the café itself cedes into the background as unimportant. The psychological component is strong with Sartre, he talks about expectations of something being replaced by negation. We probably have all felt how the death of a loved one creates a hole in our existence because our expectations are no longer met – these are synaptic connections rather than just imagination. If atrophy is at all a factor in schizophrenia, we should not be surprised if we see such phenomena. We see it cats and dogs too, so it seems part of our bonding.

The term **lifeworld** is useful as the *later* Husserlian meaning of anybody’s particular view of the world from a unique and singular position in it, while Heidegger (1927/1962) distinguishes between a *Dasein* (*Being-in-the-world*, the person) and ***dasein*** **(*being-in-the-world***, a verb) as the ways we are active in, make sense of and handle our lives as a person. The latter has more potential for a thick psychological exploration.

Other useful concepts include Merleau-Ponty’s (1962) **primacy of perception** (our survival in fact depends on the accuracy of our perceptions), **intersubjectivity** (that we are formed through and depend upon our relations with others) and Minkowski’s (1927) **intentional arc** (that our actions depend on the world responding as expected). Last, there is a **centrality of language** because it is the way humans can make sense and formulate thoughts – we easily detect (and perhaps over-analyse) thought disorders (for symptoms see Parnas *et al*, 2005a; Schultze-Lutter & Klosterkötter, 2004).

From an analytical point of view it makes sense to use Deurzen-Smith's (1997) existential dimensions as reference points: **Umwelt** (physical world), **Mitwelt** (social world), **Eigenwelt** (personal world) and **Überwelt** (spiritual world). There are many elaborations (e.g. Binswanger, 1958, 1963; Boss, 1987; Heidegger, 1927/1962, 1989; May, 1983; Deurzen-Smith, 1988; Deurzen & Arnold-Baker, 2005), and I am indebted to **existential philosophy** for checklists of human issues and blessings generally.

Throughout the discussion there are pertinent themes for all four dimensions, but because not all dimensions are present or important at all times, they will be in natural progression rather than headlines.

Consciousness seems to be at the core of schizophrenia but in an existential hermeneutic expanded to *Being-in-the-world* (***Dasein*),** which is broader than consciousness and includes attention, mental acts and cognitive processes. Meaning making is important for how we behave and adjust to our circumstances, denoted by the term *being-in-the-world* or *dasein* (verbs). As seen in the literature research our knowledge of neural development and networking is incomplete, but in this field the alliance between neuroscience and psychology is promising (Andreasen, 2007; Bürgy, 2008; Davidson, 2003, 2004; France & Uhlin, 2006; Maj, 2012; Parnas, 2012; Parnas *et al,* 2005; Stanghellini, 2010; Strauss, 2011).

My initial anchor was Merleau-Ponty's (1962) notion that consciousness fails to know what it is doing. Yet that which appears to be outside control may be neither inaccessible nor outside reach, but instead just outside attention due to not reaching the level of awareness. (Allen & Williams, 2011; Tallon-Baudry, 2012). This in and out was also Husserl's view: *"According to Husserl most of our psychic life unfortunately occurs in this unreflective unconscious mode [i.e. mode rather than place]. Following Husserl's views, there is no need to hypothesise an unconscious: our consciousness itself is only moderately conscious most of the time."* (Deurzen-Smith, 1997:62) Furthermore it is an interpretation coherent with a Sartrean logic of asynchronous agencies (Sartre, 1956; Tantam, 2008), the cumulative influence hypothesis and the working space theory (Allen & Williams, 2011; Kolb & Whislaw, 2003; Martin, 2006; Tallon-Baudry, 2012 and others i.e. *the problem of consciousness*). No research into schizophrenia should ignore these emerging results and indeed it seems schizophrenia in the foreseeable future will be even less of a unitary diagnosis.

The following conceptual framework (after Bloomberg & Wolpe, 2008) reflects the emergent themes and lifeworlds in the Findings section, together with the most relevant discussion points and literature review.

Table 16 Conceptual framework

FINDINGS	DISCUSSION CATEGORIES	LITERATURE REVIEW
	5.2 An existential hermeneutic	
LIFEWORLD A Losing ground		
A1 A2 A5	5.3.1 Consciousness and perception	2.2.3 The problem of consciousness 2.4.1 The nature of psychosis
A3 A4	5.3.2 Crisis & collapse **→ Accepting help, not diagnosis**	2.4.2 The first episode
LIFEWORLD B Being-in-the-system (freedom vs. regression)		
B1 B2	5.4.1 Accepting help, making sense	2.3.1 Freedom and the concept of care 2.3.2 Recovery as a goal
B3	5.4.2 Patience and medication	2.3.3 Effective therapies
B4-B7	5.4.4 Hospital treatment & alliances	2.3.2 Recovery as a goal 2.3.3 Effective therapies
LIFEWORLD C Recovered (existence precedes essence)		
C1	5.5.1 Coping with residuals **→ Existential transition**	2.2.1 Abnormality and diagnosis 2.2.2 Diagnostic stability
C2	5.5.2 A reconstructed self and survivor narrative	2.4.3 A psychology of recovery
C3-C7	5.5.3 Social recovery	2.4.3 A psychology of recovery
	5.5 Completing the hermeneutic	

5.3 GRADUALLY LOSING YOUR GROUND (LIFEWORLD A)

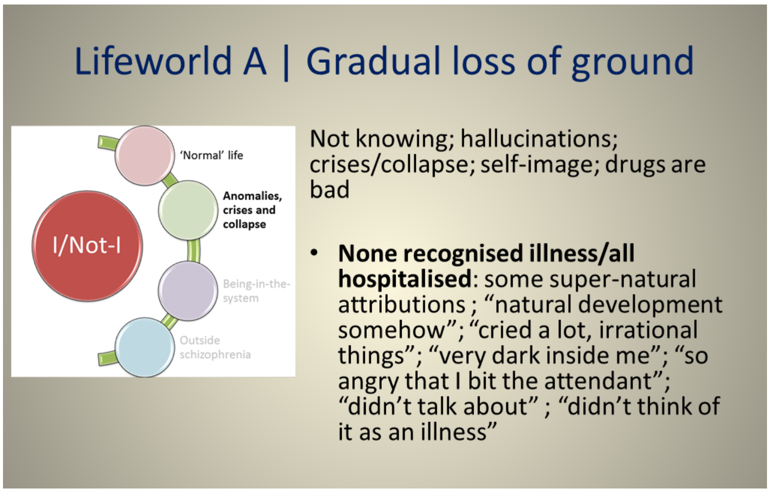
5.3.1 Consciousness and primacy of perception (A1, A2, A5).

The participants confirm that something *was* happening without a prior cause or chain of events. Merleau-Ponty (1962) is in my view right when he says hallucinations arise because consciousness no longer knows what it is doing. He means consciousness in a wider sense that includes attention and awareness.

For reasons that we do not yet understand, some experience hallucinations, others cognitive changes first (e.g. Davidson, 2003). Most (5 of 7) had visual hallucinations and except for Mary seem to have been less affected by negative symptoms. Three of the participants (Harold, Nicole and Ronny) report hallucinations as their first experience, but all had a sense that something was changing and thought/hoped it would pass. Nicole had experienced voices as a child already, but for the others it was alien and strange. The ability to communicate with voices, embedded in a storyline, is a well-known. Other positions involve being talked to (e.g. commanded, threatened) or talked about (running commentaries).

Hallucinations usually have a storyline, but they arise outside of control or attention. For a short while Harold was able to manipulate the Buddha figures, he let them interact, as many as possible, and gave them each a kind of personality. He regarded it as a gift that he had discovered by chance. Later he lost control of the imagery, an interesting phenomenon as it reminds me of the hallucinations vs. pseudo-hallucinations discussion in the Literature Review (2.2.1). Oscar was skiing when he suddenly hallucinated for the first time: threatened by people with scary clown faces coming towards him.

Figure 6 Lifeworld A - synopsis



Lifeworld A | Gradual loss of ground

Not knowing; hallucinations; crises/collapse; self-image; drugs are bad

- **None recognised illness/all hospitalised**: some super-natural attributions ; "natural development somehow"; "cried a lot, irrational things"; "very dark inside me"; "so angry that I bit the attendant"; "didn't talk about" ; "didn't think of it as an illness"

Again the question is inevitably popping up to disturb us: this is not conscious imagery so what makes it suddenly appear from nothing and persist as an illness? It is an obvious change from the seemingly normal baseline. There is no unitary source of failure nor is there a grand theory to explain it. A syndrome approach is not satisfactory as symptoms are most likely systemic manifestations of different (sets of) failures, like fever is a symptom and not the disease.

In *A General Psychopathology*, Jaspers (1963/1913) "*systematically describe all mental and psychological disorders known to psychiatry from a phenomenological perspective, in an attempt to understand rather than merely classify and treat. For the first time, the emphasis is on the subjective experience of patients as he tries to capture the states of consciousness, which are often so mysterious that they are ignored.*" (Deurzen-Smith, 1997:133) He does not question that schizophrenia is a mental illness, although others did in the era before the dopamine theory. The similarity with dreams was investigated by Jaspers already, who conceptualised delusions as a particular state of consciousness. The approach led to classification but neither explanation nor resolution. In line with 'true' phenomenology, Stanghellini (2010) and Parnas (2011, 2012) are both urging us to again focus more on structure.

While clinical symptoms seem too crude for research, the *basic symptoms* approach (e.g. Schultze-Lutter & Klosterkötter, 2004) might have been under-estimated and should be able to contrast pathology with neuroscience research for normal functioning (Edelman, Gally & Baars, 2011; Madl, Baars & Franklin, 2011; Tallon-Baudry, 2012). For instance, we should be interested to explain why sleep deprivation, mania and illegal drugs can lead to hallucinations; if there are discernible markers for vulnerability; and why 22% of the affected (Leucht *et al*, 2012) have insufficient effect from medication. It could be for reasons that have less to do with medication and more with what we don't know about schizophrenia.

After one hundred years of schizophrenia, there are still more questions than answers. My personal belief is that neuroscience is our best bet to piece things together, but for epistemological reasons the overall framework should be psychology and not psychiatry.

Several participants say that it is possible to evaluate hallucinations at least in hindsight, which is important for psychotherapy. Russell simply asks his voices to return later, which they usually don't; Nicole says that "*some of the things he [Jesus] says are quite wild*" (Nicole:98), while Oscar admits "*you often believe what they [the voices] say*" (Oscar:39). Harold described a sense of losing himself, similar to but less harsh than Lauveng's (2005) more poetic descriptions when she is not sure she exists or is part of somebody else. Experiences of depersonalisation are maybe not so common: but in her case the sense of 'I' and 'not-I, the existential anchor, is momentarily lost.

Experiences can become attributed to the spiritual world as well. Mary talks with God; Russell becomes 'telepathic', while Nicole hears famous persons talking to her and senses the Devil in others. She explains that she knows people well (?). Phenomena can be existentially real even if bizarre and not physically possible. Their interpretation depends on a host of factors including culture and religion, beliefs that are often less amenable to change. Ronny did not say that chairs *can* talk, but he talked with a chair as if it did Eric was sure that a famous singer was speaking with him from the TV, but was resilient enough to later stop watching TV rather than continue to believe she was in love with him. Oscar did not feel a physical attack from the clowns, but they were haunting him and he had to flee. Lauveng (2005) describes dangerous wolves inside the hospital, but she did not hallucinate being injured (though she self-harmed).

Stanghellini *et al* (2011) find that insight and scepticism (meta-cognition) is present in non-clinical cases, but this is apparently possible even in clinical cases if then perhaps in hindsight. There may be clues for doubt. Oscar says: *"You often [i.e. not always] believe what they say there and then."* (O:39). Chadwick *et al* (1998) have found that around 80% of voices are believed to be extraordinarily powerful or omnipotent and therefore need weakening: *"…from a psychological perspective the content and theme of delusions and voices would be expected to contain significance and personal meaning and to connect to the individual's wider psychological vulnerability."* (p. xv). They use cognitive-behavioural therapy, which Russell says has worked for him.

Attributions may also be spiritual (Überwelt) such as a special wisdom or a gift. Harold thought his ability to manipulate the Buddha figures was a gift, a special ability due to his becoming an adult. Nicole thought she had a special gift of knowing people, inferred from her observations and borrowing wisdom from important people who speak with her. Russell calls his voices innocuously 'telepathic'. Mary, Nicole and Oscar are all church goers, seeking support through prayers, community, hope, and an acknowledgement that there are many things we cannot explain. We have a pressure to make sense of things and so communicating with voices is phenomenologically different from being commanded, threatened or amused by them.

Attributions to the Überwelt transfer what we cannot know into a causal pattern such as to make sense. Essence follows existence and our existence is interpreted within context and culture: in the Western world our God appears more often than Buddha; and Elvis Presley is believed to live on rather than being reincarnated like a Dalai Lama. Überwelt means that the impossible could be possible, a kind of relative truth that can be difficult to challenge if entangled in despair, anxiety, shame, guilt, loneliness or fear. From this basis truth, reality and imagination are constructions: May (1983) exemplifies this by saying that while it is true that 3+3 unicorns make 6 unicorns, it does not mean that unicorns are real.

The point is that hallucinations may be bizarre and un-understandable, with delusions as attempts to make sense; but the psychology of delusions will tend to be functional or even attractive explanations for experiences originating as Umwelt. For the participants these experiences cascaded into Überwelt, Eigenwelt and Mitwelt. Russell discovered with the help of his therapist 'how sick he was', for him a turning point. Anomalous experiences cascade into strange beliefs, but research shows that such beliefs are often reversible and malleable with the help of psychotherapy or even a good friend. There is also reason to separate delusions caused by a failing sense of reality from those pre-dating the onset. Delusions and personality disorders obviously do not exclude each other, and the latter should by definition not respond to pharmaceutical treatment.

Their psychological stance was reflected from *Dasein*, the position they took in their lifeworld with emotions as compass (Deurzen, 2009:142) to manoeuvre in a world that they discovered as well as created. Their narratives are not about a bad childhood, chaos at home or helplessness. Except for Mary the participants' projects did not collapse, probably a decisive factor for recovery later. Resilience is of the importance. Oscar had an early onset but he had realistic plans for the future. Russell and Harold continued to study, Nicole and Ronny continued to work and Eric worked until the day he quit and walked out.

Still, the participants describe loneliness and emptiness that have the quality of existential anxiety, different from fear and phobia, and different from severe depression or limit situations. A more fitting concept is Sartre's (1956) nothingness as a negation of something that was but is now missing. Because of perceptual, interpersonal and mood changes there are several obvious negations that can gradually build towards crisis and suicide. May (1977) usefully separates awareness (principle 4) from self-consciousness (principle 5) and says about anxiety (principle 6): *"In any case, anxiety is the reaction when a person faces some kind of destruction of his existence [nothingness?] or that which he identifies with it. […] a signal that something is wrong in one's personality and one's human relationships. Anxiety may be viewed as an inward cry for the resolution of the problem."* (p. 364) Whether organic or psychogenic does not matter, he later says: *"It opens up the vast provinces of inner, subjective reality and indicates that such reality may be true even though it contradicts objective fact […] the experiences of rape was as potent even if it existed only in fantasy."* (May, 1983:71)

Their Mitwelt was destabilized. All participants lament their loss of friends, not so strange given the fact that the new world for the affected person becomes partly a non-shared world with strange behaviours and beliefs. Early intervention is important to counter a de-stabilized Eigenwelt, even if only by antipsychotic medication at an early stage. Their unison reluctance to talk about their experience could be the difficulty to express such experience, doubt about their realness and/or early attempts resulting in disbelief or ridicule from people around them. Resilience seems to be characteristic for the participants, a favourable condition for recovery.

All participants now reject and avoid illegal drugs as they are convinced it would be bad – and they don't need it to feel better. Drugs are a social tool as well as a way of compensating for problems in living. Ronny attributes his sudden onset to amphetamine – a 'bang in his head'.

Harold says that he had been using drugs a lot and Oscar says that his smoking hashish made him hallucinate more.

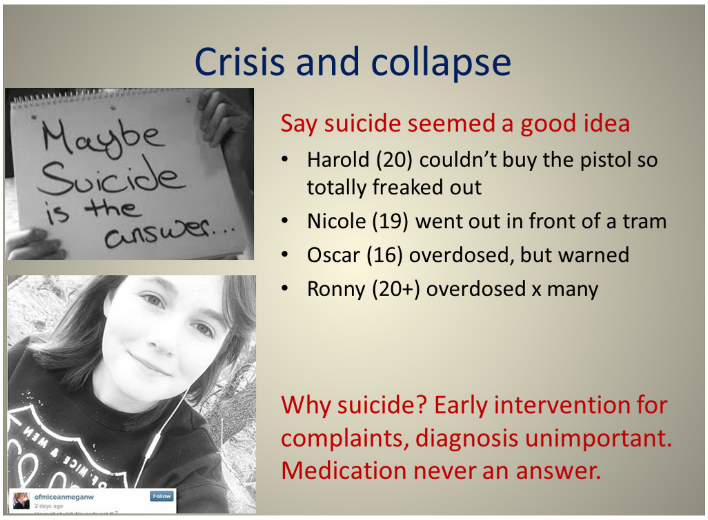
Early intervention can modify the cascade from Umwelt (primacy of perception) to Mitwelt and Eigenwelt. When the world is no longer fully shared, people around you will reject your beliefs, experiences and behaviours. And as you act upon events and beliefs in this non-shared world, others no longer respond as expected. It must be very confusing indeed and my clinical experience confirms it!

It is important to realise that their early problems did not mark schizophrenia, except by an intuition that without a psychological cause something else might be going on. But don't we all have issues in our lives, and in particular when we are young? If asked during an early clinical assessment they would have had disruptions and complaints rather than obvious prodromes: Mary dropped out of school and became increasingly isolated; Oscar was trying to run away from his bad thoughts; Harold kept to himself and cried a lot; Ronny went in and out of hospital with depression and suicide attempts but was not treated for it because he was 'just another drug addict'; and Russell was paranoid and pre-occupied. Many problems, or in Bentall's (2003) terminology complaints, arose in the Mitwelt.

5.3.2 Crisis, collapse and self (A3, A4)

Merleau-Ponty (1962) usefully says: *"It is through my body that I understand other people, just as it is through my body that I perceive things."* (p. 186) Without attention there can be no conscious experience, and we easily become so absorbed when we live an experience that we might be unable to make sense of it just there and then. Lived experience is in his view ambiguous. To Sartre consciousness is an intersubjective body and others are rival consciousness that evoke patterns like dominance, submission or withdrawal.

Figure 7 Reason for early intervention, diagnosis unimportant



Crisis and collapse

Say suicide seemed a good idea

- Harold (20) couldn't buy the pistol so totally freaked out
- Nicole (19) went out in front of a tram
- Oscar (16) overdosed, but warned
- Ronny (20+) overdosed x many

Why suicide? Early intervention for complaints, diagnosis unimportant. Medication never an answer.

Their lifeworld and hence their *dasein* (*being-in-the-world*) changed perhaps imperceptibly and perhaps subconsciously at first, but finally the cascade showed up as manifest confusion and distress.

They had felt increasingly disconnected; they reported emptiness and isolation (intersubjectivity); and their ability to predict the results of their behaviours deteriorated as their world became non-shared.

There seemed to be no obvious cause. Yet how can we know? They did not seek help, but they did show early signs that should have been taken seriously.

Could they have come to treatment earlier? It clearly depends on what one would be looking for. Signs of distress became abundant and could have been taken seriously as such: Oscar tried to run away from his ‘bad thoughts’; Nicole was depressed, felt dark inside and was socially isolated; Russell’s paranoia increased to a degree where he behaved strangely; and several of them had bad childhood experiences in the form of neglect (Mary) and psychological distress (Ronny and Nicole). They do not recognise it as trauma although long-term exposure to adverse conditions can be; in any case the case for trauma as a cause for schizophrenia is very weak. (Larkin & Morrison, 2006).

Davidson (2003) observes that positive or negative symptoms are equally likely to occur first, as was the case here. But by the time that the participants were hospitalised, their behaviours and emotional problems had become so obvious to others that they were brought in. As expected, though a bizarre phenomenon, what is obvious to others was not obvious to the participants. As Merleau-Ponty (1962) points out, reality is embodied and in schizophrenia it is not probably not interpretation that fails, but perceived reality itself.

Eigenwelt issues such as crises of meaning and pre-occupation with new ‘discoveries’ are common in first episodes. Existence precedes essence and the first episodes can be fraught with new implicit meanings and a search for deeper or secret connections –Davidson’s (2003) negative loop.

All seven appear to have followed the same general path consistent with most theory (Bromet & Naz, 2006; Davidson, 2003; Schneider & Deldin, 2001; Yung *et al*, 2006). Of particular importance for recovery, their existence *qua* project stopped at a time in their lives when all others are busy with theirs.

The change from normal life to total immersion is mysterious. It led to dysfunction so serious that they lost control of their existence as such. They talk about lack of energy, of anger, anxiety, depression, and a deep loneliness even amidst people. They felt exhausted and confused, and suicide seemed a good idea for Harold (wanted to buy a gun), Oscar (overdosed), Ronny (several attempts) and Nicole (walked out in front of a tram). It is as though the threshold is lowered, perhaps a kind of 'sickness unto death' (Kierkegaard, 1849) that makes suicide an obvious solution. Or as Sartre (1956) describes, death becomes a real choice when we climb a narrow path and become pre-occupied that we must not stumbleAs we increasingly focus on that which we dread, it might be like when we watch a waterfall and feel drawn towards it. . With less control maybe our normal inhibitation may fail. A psychotic person may lack the necessary impulse control e.g. Nicole found herself suddenly in front of the tram. Only suicide mattered and in her eyes even in hindsight as we talked, she thought her act even demonstrated courage.

Schizophrenia at this stage of severity has been considered a self-disorder (Parnas & Sass, 2003) e.g. a loss of the I vs. not-I distinction and/or intermittent psychotic episodes. May (1977) postulates anxiety as *'the prognostic value of a fever, a sign of struggle and potential disintegration'* (p. 374). Similarly, the metaphor of water under pressure may be useful even if not accurate: anxiety may be the geyser to trigger the dopamine system, which Kapur (2003) poignantly calls *'wind of the psychotic fire'*. Hospitalisation then becomes necessary after a long period of unsuccessful attempts to deal with anomalous experiences in which the participants probably played exactly the ego-syntonic roles they wanted to avoid: harassed, chastised, derogated and criticised. The contents of hallucinations clearly is an object for therapy as even for bizarre hallucinations there is a negative loop from cognitive distortions and disruptions to decline in functioning, delusions, vulnerability, helplessness, withdrawal and isolation.

At this stage the cascade seemed to change direction with behaviours more driven by the de-stabilised Eigenwelt than by reactions to Mitwelt and Umwelt. A trajectory to the outside of schizophrenia (Davidson, 2003) could not be foreseen from the participant narratives. They do not seem particularly benign cases, yet perhaps better than average personal resources.

Trauma can be a pre-disposing or contributing factor (Larkin & Morrison, 2006), yet it seems unlikely that their problems can be attributed to trauma. They seeem outside the ultra-high risk (UHR) category, which has higher conversion from proneness/vulnerability to persistence/schizotypy to impairment. Only about half of UHR convert to psychosis and most people who get schizophrenia do not have an obvious vulnerability even in hindsight. (van Os, 2009).

In the Mitwelt area, their pre-hospitalisation worlds had become increasingly lonely and disconnected. It is a bit scary that even though all had close relatives whom they met regularly, it still took a long time, suicide attempts and existential distress. And it attests to the nature of their experiences, that they did not acknowledge the need for help when it was obvious to everybody else. Perhaps today they would have been picked up as at-risk during a home visit, such as described in the Norwegian TIPS early intervention program (Hegelstad *et al*, 2012). Or perhaps in a developing country they would have lived in the middle of a community who knew them and noticed that something was not right. Major studies have found that social networks are not only important to our mental health, but seem to play an independent role in recovery. (Eack & Newhill, 2007; Jablensky & Sartorius , 2008).

5.3.3 Summary and reflexivity

In my analysis it became clear that the participants typically use psychiatric terms about their experiences, apparently not able or used to do otherwise. After ten years in locked psychiatric wards I had no problems relating to them. There is no evidence that the participants have been better off than others with the same diagnosis who have not remitted and are not on a path to recovery. Instead there is substantial similarity with clinical descriptions of prodromes and onset – a deterioration that may end in suicide ideation and attempts, in chaos and hospitalisation.

In the early stage their problems manifested not as symptoms of schizophrenia, but more normal problems and complaints. They were not in an ultra-high risk category (e.g. family or schizotypy) and their symptoms *per se* did not signal a psychotic state. If anything it seems that the most obvious warning signal was a psychological state out of proportion and connection with anything in their lives. I could almost feel what it must be like to have a sense that something is wrong, yet no apparent cause or chain of events. It is here that it seems appropriate to use Sartre's concept of nothingness, which is coherent with neuropsychological theory of failures as initially local and outside consciousness before they become more pervasive. At an early stage they presented with anxiety, depression and rumination; later with emptiness; although later they would be interpreted more clearly as prodromes.

While we normally succeed to give logical, functional and even attractive explanations to things we experience, they had increasing problems making sense. What is clear from the narratives is exactly the difficulty of making meaning, of increasing doubt and therefore hyper-reflexivity, problems in social life leading to withdrawal and distress. Our survival depends on our senses and we find it excessively difficult and scary, as May (1977) points out, to confront this sense of destruction. Merleau-Ponty (1962) demonstrated how we are anchored also socially in the world through our bodily senses: we are our body. In the worst cases this affects the 'I vs. not I' differentiation and becomes a self-disorder. The participants confirm theory that we must not take symptom severity as a prognostic marker for recovery.

There was a cascade from problems in the perceptual (physical) world – Umwelt – to social withdrawal (Mitwelt) as they became more and more pre-occupied (Eigenwelt). The pressure to make sense entailed also attributions such as wisdom or gift (Harold, Nicole), supernatural phenomena (Russell) or religious experiences (Mary, Nicole). The Überwelt explains what cannot be understood, a kind of projection of that which we do not understand. It lets us believe phenomena that could be true. It is through this lens that we can understand their hypersensitivity, anxiety and the existential loneliness that Oscar conveyed so intensely during the interview.

The changes resulted in a failing intentional arc when unbeknownst to themselves, their world totality became non-shared and their behaviours strange to others. Other people would at least partially no longer make sense, and it is easy to understand both social withdrawal and loss of friends.

At the level of Eigenwelt it seems that the participants, with the possible exception of Mary, were all rather resilient: no childhood trauma (question mark for Ronny and Oscar), no ultra-high risk (except by speculation, Nicole), early abandonment of illegal drugs, at least one VIP in the family *et cetera*. Davidson (2003) concludes how difficult, if not impossible, it is to climb out of the hole that the inside of schizophrenia digs for you. You need help and you need to accept help. This in turn points to another resilience factor, viz. the ability to trust and maintain a relationship with others.

In this sense the participants seem to have had better chances than those less fortunate. Yet, during the course of this early stage the crisis of meaning was growing, resulting in hyper-reflexivity, confusion, exhaustion and despair to such an extent that suicide was a good idea for four of the seven.

Do they then confirm clinical literature? It seems that they do from the vantage point of observed behaviours, clinical notes and basic symptoms. Their stories however also document that *primacy* *of perception* is perhaps the most important factor: we simply have to believe what our senses tell us.

Most notable is the fact that they were not seeking help and were reluctant to accept it. This is not unusual at all, indeed in my clinical experience, the role of a trusted family member is obvious. But importantly, their stories also tell us that they could have been picked up earlier by paying attention to phenomenology and the apparent absence of a cause or chain of events for their ailments – if they had come forward instead of hiding their problems, that is.

5.4 BEING-WITHIN-THE-SYSTEM (Lifeworld B)

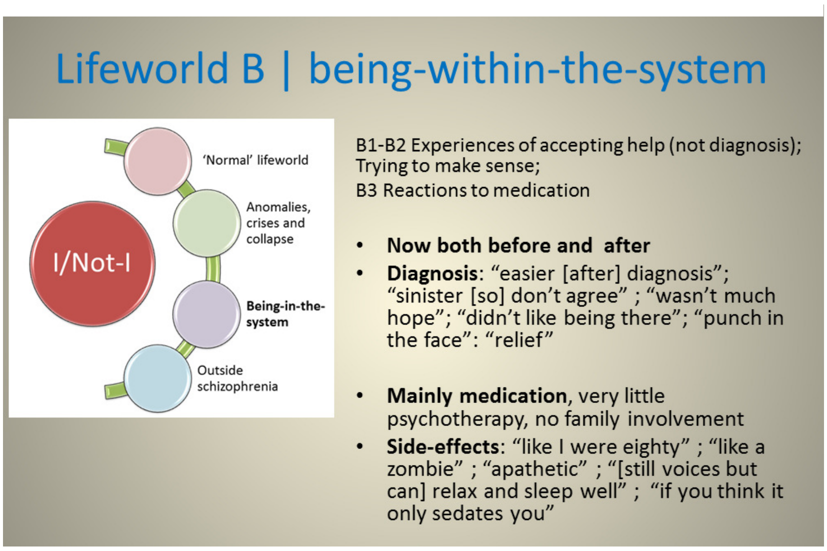
> *Even the most beautiful rosebush looks like a thorny nothing in January. That's how roses are; only we must remember not to take important decisions or measure its value just then.* (Lauveng, 2005: 71, my transl.)

5.4.1 Accepting help and making sense (B1, B2)

Hospitalisation meant an end to loneliness and involvement with Mitwelt, but also chances to make sense of what had happened to them and rewrite a narrative of chaos and distress. It meant validation of their experiences and a change from isolation, collapse and chaos to at least a sense of comfort and security. All of them accepted help more or less voluntarily, but four (4 of 7) did not accept the diagnosis, perhaps not surprisingly since still believed to be 'chronic, lifelong, irreversible and hopeless'.

As *clinically* Nicole or Mary have lacked insight by not accepting schizophrenia, my research indicates that acceptance of schizophrenia (T2) is not necessary for recovery. Arnhild Lauveng (2006) makes a similar point that she did not believe in the prognosis because: "*They said it was a chronic, maybe genetic disorder that I might have to live with for the rest of my life. To buy this 'insight' I would have needed to pay with*

Figure 8 Lifeworld B - synopsis 1



Lifeworld B | being-within-the-system

B1-B2 Experiences of accepting help (not diagnosis);
Trying to make sense;
B3 Reactions to medication

- **Now both before and after**
- **Diagnosis**: "easier [after] diagnosis"; "sinister [so] don't agree" ; "wasn't much hope"; "didn't like being there"; "punch in the face": "relief"
- **Mainly medication**, very little psychotherapy, no family involvement
- **Side-effects**: "like I were eighty" ; "like a zombie" ; "apathetic" ; "[still voices but can] relax and sleep well" ; "if you think it only sedates you"

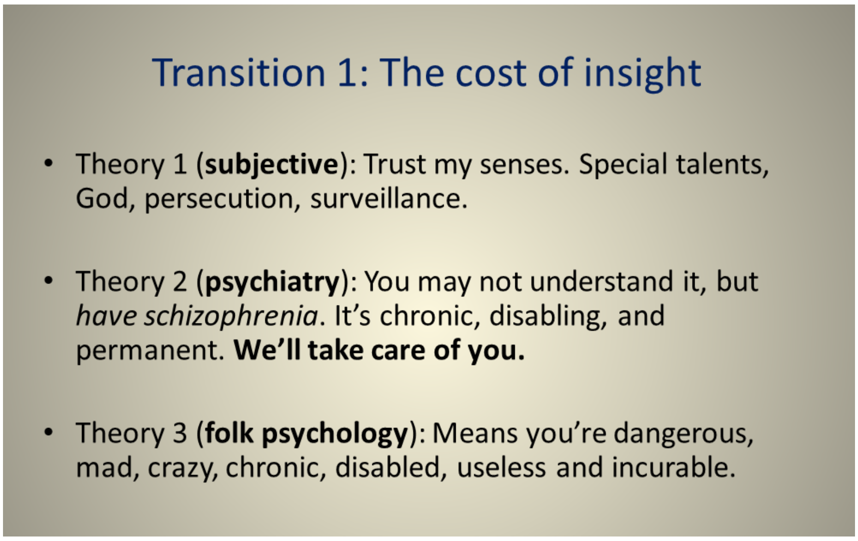
my hope. I didn't want it then, and I still think that the price is too high." (p. 98 my transl.). Arnhild recovered completely from what certainly was schizophrenia as per diagnosis and severity.

We always try to make sense of what happens to us. They certainly had their own personal theories (T1's) that were suddenly confronted with a schizophrenia theory (T2) or in folk psychology madness (T3). In this light it is not so strange that they would reject T2, but at the same time they did not want to return to the chaos that brought them in. Interestingly Ronny says that diagnosis disconfirmed madness (T3), and Harold remembers: *"my main contact – said it was a relief to get a diagnosis. And I thought of it as a relief, but I now realise that it is a box where I may belong. It concerns treatment and things I have."* (Harold: 28)

From an Eigenwelt sense of crisis, they all accepted help and were able to build the necessary alliances. Psychotherapy would have helped, but Nicole and Ronny cannot remember any psychotherapy. Eric and Mary had 'some', while Harold, Oscar and Russell had most of theirs as outpatients and found it very helpful. During hospitalisation experiences were worked through, but probably without reaching the levels possible with psychotherapy (Davidson, 2003; France & Uhlin, 2006; Gonçalves *et al*, 2002; Naudin *et al*, 1999). The lack of early psychotherapy is not really surprising as Norwegian psychiatry was firmly medical, despite the utility of psychotherapy in 1) learning to interpret anomalous experiences to keep expressed emotion down and avoid psychotic episodes, and 2) (re-)constructing narratives.

None of the participants had physical restraints and, contrary to my expectation, none say the diagnosis was traumatic. Harold escaped compulsion by imagining that he needed help with something that felt like *'a cloth in his throat'*. He was *'a good boy'* and *'let the doctors do their thing'*. Whether you are met with respect, or power and coercion, it will resonate with your past and probably

Figure 9 Transition 1 - acceptance



Transition 1: The cost of insight

- Theory 1 (**subjective**): Trust my senses. Special talents, God, persecution, surveillance.
- Theory 2 (**psychiatry**): You may not understand it, but *have schizophrenia*. It's chronic, disabling, and permanent. **We'll take care of you.**
- Theory 3 (**folk psychology**): Means you're dangerous, mad, crazy, chronic, disabled, useless and incurable.

decide the path. Surprisingly, four of the seven were diagnosed with paranoid schizophrenia, yet were not so paranoid as to reject help and once inside, none of them tried to run away or cause problems – at least not that they remember.

Rather than say that they accepted the facts of a diagnosis, it is more correct to say that they tolerated the diagnosis in return for help. A sensible interpretation is that social life must have been a relief after much suffering and loneliness, and there was enough respect and empathy for a working alliance. On a personal note, I stress that our job as helpers is not based upon diagnostics, but based on ‘a phenomenology of respect’ as coined by Davidson (2003) and others at Yale University. There is a healing factor in human understanding and respect alone that entails not judgement of who will and will not recover, but provision of such ethical and evidence-based treatment that maximizes the chance and hope of recovery.

5.4.2 Patience and medication (B3)

All participants have tolerated medication, are compliant and convinced that medication prevents psychotic episodes. Leucht *et al* (2012) confirm in their meta-analysis that antipsychotics reduce the risk of relapse, though there are clear disadvantages such as weight gain, sedation and motor disturbance. Of 62 studies documenting relapse numbers only 14 included metrics on improvement, even though medication cannot prevent relapse and so improvement is more relevant from a recovery and indeed well-being point of view.

Not surprisingly the participants complained about side-effects at some stage. All except Harold report fatigue and concentration problems; three fight against anxiety; and Russell has struggled his way out of the diabetes risk zone. Sedation seems to have been the main effect, but for none of them the desired effect. While only the most anti-psychiatry would insist that medication should not be used, the view of critical psychiatry (e.g. Bentall, 2009; Cullberg, 2006; Szasz, 1973, 2008) is that prescribed quantities are often excessive, unnecessary and harmful, while at the same time medication does not solve the underlying psychological issues. It is easy to agree with Ross & Read (2004): *“I argue that many of these treatments are nowhere as powerful as is often believed, and that their effects have been exaggerated by skilful pharmaceutical marketing.”* (p. xiv) *“Overall, the findings do not suggest that patients’ lives have been transformed by the introduction of new psychiatric treatments.”* (p.17) and *“Some patients are more harmed than helped by them and they should therefore be used cautiously.”* (p.24) Now NICE CG82, the guideline for schizophrenia, also calls for caution and cooperation towards smaller doses. Ethical practice clearly favours minimal possible dosage and informed consent. Contrary to earlier claims there is no evidence that smaller doses increase the risk of relapse (Cullberg, 2006; Leucht *et al*, 2012; NICE CG82) and there is no convincing evidence for neurotoxicity (McGlashan, 2006). If there is no acute psychotic episode there is no harm in waiting with medication.

Leucht *et al* (2012) show another benefit of medication viz. that the risk of violence is reduced from 12% in the placebo samples to 2% in the medicated samples. This is a great benefit, but may not necessarily mean that un-medicated psychosis is more dangerous, but requires skilled helpers. In contrast, Lauveng (2005) said of her own experiences: "a *tired staff with many young, unskilled workers and not enough supervision and support*". (p. 86, my transl.).

Concerning medication, they seem to just accept what is. Only those on clozapine have been followed up regularly but then only for blood counts. Russell seems to be on an exceptional level of olanzapine, but has not been referred by his GP to a psychiatrist for possible adjustment after his release from hospital more than six years ago.

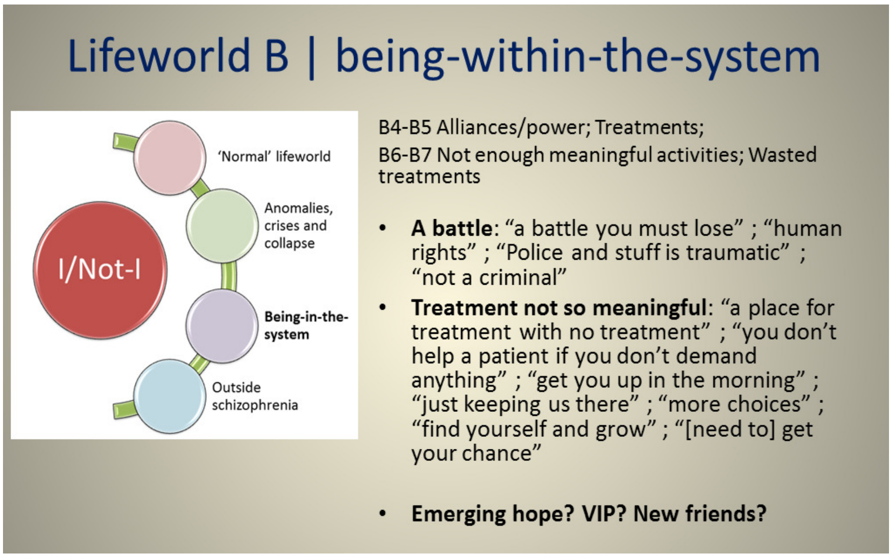
5.4.3 Hospital treatment and alliances (B4, B5)

Hospitalisation means that people no longer are judged capable of looking after themselves. The participants spent some time in acute psychiatry and were then transferred to long-term wards, adding up to around one year. They are critical of the length and content of their hospitalisation, but admit that they had been severely distressed and incapable of looking after themselves on admission. Ronny uses words like 'plain crazy' and 'dizzy' about his psychotic episode. He says he is still sometimes unsure about what is reality or not. Harold says *"they said I was quite psychotic and confused when I came in."* (Harold: 39) and later confirms *"…realised that I needed [medication] to avoid becoming psychotic again."* (Harold: 49) Eric agrees. *"I know that I confused reality and fantasy, but it is difficult."* (Eric: 61) Oscar protested against involuntary treatment and thought he had a good case, yet: *"I think now that it maybe wasn't so strange that I didn't get their acceptance."* (Oscar: 2)

Except for short morning meetings that they neither enjoyed nor found useful, they cannot remember any group work. Hardly surprising though as group therapy in Norway until recently was psychoanalytic and excluded psychotic disorders, very different from Yalom's (2006) here-and-now demonstration that interpersonal group therapy is beneficial for actively psychotic in-patients.

They were not offered CG82 evidence based treatments as CBT, family interventions or art therapy. Six of the seven might have enjoyed the latter: Russell paints and writes; Harold plays music; Eric plays music and enjoys drawing; Oscar trained as cook; Nicole has embroidery, knit work and cooking as hobbies; and Mary liked dancing before she gained too much weight and now eats chocolate instead.

Figure 10 Lifeworld B - synopsis 2



Lifeworld B | being-within-the-system

B4-B5 Alliances/power; Treatments;
B6-B7 Not enough meaningful activities; Wasted treatments

- **A battle**: "a battle you must lose" ; "human rights" ; "Police and stuff is traumatic" ; "not a criminal"
- **Treatment not so meaningful**: "a place for treatment with no treatment" ; "you don't help a patient if you don't demand anything" ; "get you up in the morning" ; "just keeping us there" ; "more choices" ; "find yourself and grow" ; "[need to] get your chance"
- **Emerging hope? VIP? New friends?**

If nobody believes in you, you stop believing in yourself and you lose hope. US President Bush voiced a typical criticism against psychiatry in The President's [Bush] New Freedom Commission on Mental Health (2003) when they concluded that the mental health system *"is not oriented to the single most important goal of the people it serves – the hope of recovery"* (p. 3).

Psychiatry is hard work and most will experience a number of turbulent years before life stabilises in a reconstructed form (Davidson, 2003; Lysaker *et al*, 2010; Wilkens, 2007). Knowing that the course of recovery is a long one in schizophrenia, systems that are based upon waiting for 'normality' to return seem inefficient and uneconomic. Instead the participants would have liked fewer pastimes in exchange for more interest based and vocational activities, which with better medication and psychotherapy would be very realistic and different from the asylum ideas of the past. Basically, they ask for systemic change.

Russell marks a turning point long after his last hospitalisation: *"I believe the big turning point was cognitive therapy. I think that's when I understood how ill I was…"* (Russell: 40) What if he had gotten the insight ten years earlier? The quality and assumptions in psychotherapy are crucial, as pointed out by Harold and Oscar, and Lauveng's (2005) summarises this nicely:

> I have had several therapists, with totally different methods and perspectives. The first ones used the classical I-follow-you-where-you-want-to-go-method, they were relatively passive during the consultation and let me take control and decide the direction. The problem was only that I usually

> went very wrong […] I wanted a therapist who actively helped me to see what I did and who also could show me better alternatives. (p. 51, my transl.).

Psychotherapy in compulsory settings can be ethical only if it is evidence-based, ref also the Madrid declaration (WPA, 2005). So what might they have had? They all underline co-construction and it is likely that such work requires special therapeutic skills including a phenomenological approach. In my experience calm, trust and respect are things that skilled workers develop early in an alliance; they are able to work with appropriate good humour, get to know people easily and are not easily scared. Unskilled workers can be either too cautious or don't know how to get out of trouble and conflict. Bellion (2007) says about help during psychotic episodes:

> A suitable helper is someone whose presence is not generally felt disquieting, who is in good form at the time and can stay calm for a long time. The most important task of a helper is to provide a pleasantly calm atmosphere, confidence and self-assuredness, while kindly standing by." (p.80)

Lauveng (2005) differentiates between 'clever, safe and firm hands' and 'untrained, clumsy or reckless hands'. Several participants remember the latter, a finding that agrees with Bentall (2003):

> Good relationships, it seems, are a universal therapeutic good, and may yet turn out to be the single most important ingredient of effective psychiatric care. Efforts to improve therapeutic relationships are therefore likely to result in substantial benefits for everyone concerned. (p. 260)

Expectations of cure are difficult as relapse is usual on the way to recovery. Getting back to people you know may be a safe haven: *"Rather than describing the hospital as a place to be avoided, participants described many attractions to the hospital that made it a place they appreciated being able to return to when needed. These attractions include safety, respite, food, privacy, and, most importantly, the personal attention they experienced there."* (Davidson, 2003: 179)

Participants say they were told there was little if any hope for recovery. This relationship is both paradoxical and ambivalent, in fact a Jungian analyst, Guggenbühl-Craig (1983), points out that the shadow of being a helper is that we treat people as if they need help: medication, hospitalisation, community care and welfare. The healer psychiatrist defends decisions on grounds that there is hope of improvement, while the doubt may be more honestly communicated to the family than to the patient. Anyway the patient gets to know that something is not being communicated. Being honest about struggle, relapse and hope can be a delicate balance of counter-transference, the author says.

And you behave, the participants agree, to keep your privileges and not end up in worse places or restraints. Or you deny the whole thing and woe never to return, but then you do. The participants have found it particularly difficult to tolerate messages (and pressure) from someone they do not like, which undoubtedly sometimes result in accusations of splitting when it is far from it. The risk of power language is in these cases probably substantial – e.g. Harold decided to simply be 'a good boy'.

5.4.4 Daily activities (B6, B7)

What is the incremental impact that we would be looking for in daily activities? A worthwhile life needs something that gets you up in the morning. Quality of life goes up and down with periods where they had energy to work and enjoy social life, and periods where they needed to rest or were simply depressed, anxious or psychotic. This needs to be considered and respected on an individual basis.

Yet daily activities were also activities that did not bring insight into life and did not necessarily contribute to either a feeling of mastery or a sense of well-being.

It is clear from all narratives that they have had good and bad periods during the course of hospitalisations and outside. Interestingly, Fredrickson (2001, 2009) with her broaden-and-build model has been able to show how well-being is caused by a long term ratio exceeding 3 times as many positive emotions as negative. The question is if the hospital ward is able to deliver this ratio, and if not will they get worse? In any case, the participants say there was '*too much just keeping them there'* and they received little if any psychotherapy to help them interpret and master hallucinations, prevent delusions, set reasonable goals, encourage the healthy side and provide scaffolding for experiments in daily living.

Cognitive-behavioural therapy would have been helpful, standalone (Chadwick *et al*, 1998, 2007; Morrison *et al*, 2007; Young, 1999), combined with existential therapy (Corrie & Milton, 2004) or including group therapy (Roder *et al*, 2006). Vygotsky's concept 'zone of proximal development' comes to mind as a useful metaphor for a strength driven rather than problem oriented therapy. In this light a hospital ward can totally lack meaningful activity. It can also be scary. Both Oscar and Harold were afraid of others on the ward; and afraid of getting worse and placed 'one floor down where people were shouting and screaming'. Mary and Nicole felt similarly uncomfortable at times. Just by watching others they have been sitting in a corner afraid of coercion and violence on the ward; of injections, holding, and isolation; and fearing that it one day would be them.

It's a tough world and they concur that their long-term hospitalisation was not meaningful from a recovery perspective as they were removed from friends, family and favourite activities. In Harold's words 'a place for treatment with no treatment' and the participants seem unanimous that they should have had more choice and more authority over their own activities.

5.4.5 Summary and reflexivity

While the first lifeworld was about losing existential grounding and culminated in chaos and collapse, this second lifeworld is a chance to gain a new perspective and transition to something better. The participants tolerated medication that gave them side effects and they related to people they didn't like. These are signs of resilience and functioning, but also that the alternative was nastier and that hope of recovery goes through accepting help. As helpers we must bear hope and with today's treatments we have justifiable reason to be optimistic. The participants said the message they got at the time was in contrast one of little if any hope, and it was a message that they rejected.

Conflicts are unavoidable and usually about medication, misunderstandings, unacceptable behaviours or threats. Husum *et al* (2010) in a comprehensive review found that acute ward practices in Norway are local to the thirty-two hospitals and vary in the degree of implementations of central evidence-based guidelines. Most participants have had compulsory treatment, and they have all felt coerced. Treatments for schizophrenia vary both within Norway and internationally, as do the legal systems ruling psychiatry. Covering eleven countries with different legislation and psychiatric practice the EUNOMIA project (Kallert *et al*, 2011) found little difference between compulsory hospitalisation and feeling coerced in voluntary hospitalisation. They discuss:

> On average patients show significant but limited symptom improvements after coerced hospital admission, possibly reflecting the severity of the underlying illnesses. Social factors, but not the psychiatric diagnosis,

> appear important predictors of outcomes. Legally voluntary patients who feel coerced may have a poorer prognosis than legally involuntary patients and deserve attention in research and clinical practice. (Abstract)

In other words dilemmas inasmuch as the reason for any coercion is at the same time the rationale for locked wards: they offer compulsory services and control with medication.

Alternative treatments were not on offer except for Nicole, who lived in a kind of halfway house for a year, with drug abusers and others with whom she had little in common. She didn't feel well there.

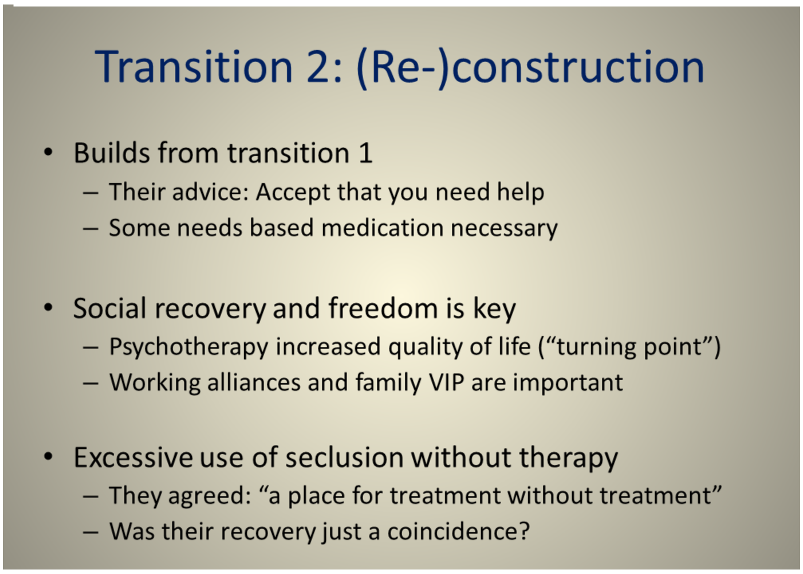
In contrast Soteria (e.g. Aderhold *et al*, 2007) is a voluntary model, based upon 'critical ingredients' defined by Loren Mosher and Luc Ciompi, with minimal and need-based use of neuroleptics. Stastny & Lehmann (2007) discuss communities and halfway houses to conclude they are based on similar principles with a belief that people can be capable and resilient given the right supporting resources. Calton (2008) reviews the Soteria paradigm and concludes that it holds considerable promise, yet has typically not been subject to randomised controlled trials and meta-analyses so are under-researched. He only found three studies good enough for meta-analysis. A subject for later discussion, remission and recovery are also different processes even if they overlap.

Another criticism from the participants is that they stayed in hospital-looking places that offered little except nature, food and whatever few activities people felt motivated for. Visits were occasional, after a few months hardly at all. Compare this with Finnish researchers Seikkula *et a*l (2007) who did in practice what they asked rhetorically: *"Can you imagine a psychiatric practice, in which concerning a psychotic or other severe crisis in the family, the first meeting is organized within one day after the contact; in which both the patient and family members are invited to participate in the first meeting?"* (p.223)

According to the WHO studies, social involvement is also more common in collectivistic countries where psychiatry has less money. Hospitals are artificial and sterile environments, not meant for lengthy stays doing nothing. With stays in the range of a full year or more, the participants are unison in their judgement that the content was meagre or in Harold's words: "a place for treatment with no treatment".

One key finding is that accepting the diagnosis is not necessary for either of compliance, remission or recovery. Accepting help seems to be the only precondition for compliance with medication – and this seems to have little to do with insight per se, but rather resilience, prior attachments and personality. After all you are required to comply with medication for which you may have been offered little or misleading information, which amounts to saying yes to side-effects every day. Non-compliance and protests must be seen in this light. While the participants seem robust, others in a less fortunate state may well react differently to the hospitalisation.

Figure 11 Transition 2 - hope and commitment



Transition 2: (Re-)construction

- Builds from transition 1
  - Their advice: Accept that you need help
  - Some needs based medication necessary
- Social recovery and freedom is key
  - Psychotherapy increased quality of life ("turning point")
  - Working alliances and family VIP are important
- Excessive use of seclusion without therapy
  - They agreed: "a place for treatment without treatment"
  - Was their recovery just a coincidence?

People often feel coerced even in voluntary hospitalisations (e.g. Kallert *et al*, 2011). They all felt coerced and could hardly avoid being drawn into the 'us versus them' view of many with a longer career as in-patients.

But it must have given the participants at least some sense of comfort and safety instead of isolation, collapse and chaos. Importantly, the participants seem to have had few psychotic episodes, perhaps a differentiator for this sample.

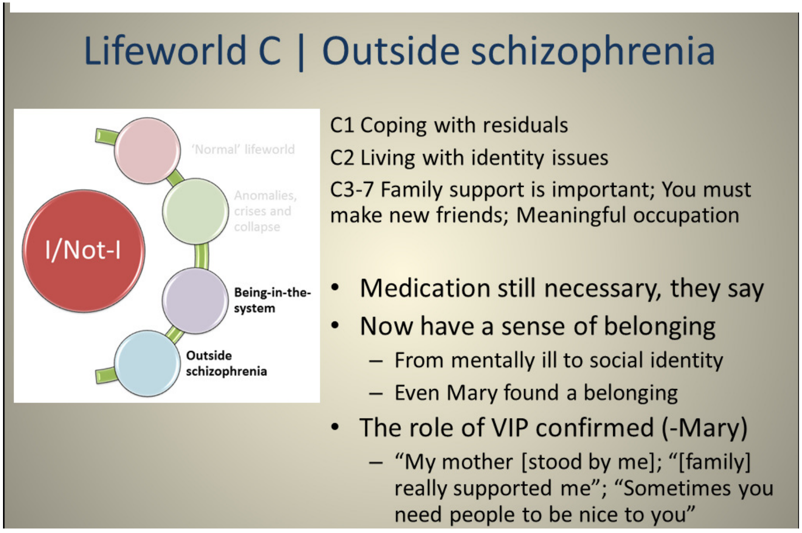
Psychotherapy could have offered opportunities for co-constructing meaning, handling/preventing delusions and misunderstandings, creating hope, providing support, clarifying relationships, mastering and interpreting hallucinations, setting reasonable goals and encouraging a healthier life. Their narratives have changed and we cannot know much about their early cooperation. Their reason for cooperation vary from Harold's 'being a good boy and let them do their things', to others accepting strong side-effects that they would probably not have accepted except by informed consent. Of course, compliance is not an ethical goal for psychotherapy, although informed consent and cooperation are. In the case of the participants, psychotherapy was missing, symptomatic of a biological psychiatry.

The environment offered minimal psychotherapy and none of those in NICE CG82 while they were there. The fact that all have remitted and to a substantial degree recovered despite this, could mean that the main benefit of psychotherapy is for well-being and recovery, not remission. More specifically: Oscar, Harold and Russell say that psychotherapy has validated their experiences, even if for all it was mainly offered years after their initial hospitalisation.

5.5 OUTSIDE SCHIZOPHRENIA (Lifeworld C)

This third phase is not attainable for everybody. The participants thought that long-term hospitalisation was not so helpful, but they agreed that effective medication was a precondition for recovery. Psychotherapy and social support can further lift a person to recovery, but full recovery seems to be tightly connected to a deeper sense of direction, maybe akin to the Sartrean concept of finding your project. From a recovery perspective I shall therefore use the term residuals instead of remission, as residuals are not limited to symptoms but purvey the whole meaning of what happened. Residuals, survival, identity, belonging and recovery are at the same time of existential significance. In comparison, remission may be necessary for transition out of schizophrenia, but not sufficient and maybe not even a sensible goal for society’s treatment of schizophrenia. Well-being, meaning and hope are so important!

Figure 12 Lifeworld C - synopsis



Lifeworld C | Outside schizophrenia

C1 Coping with residuals
C2 Living with identity issues
C3-7 Family support is important; You must make new friends; Meaningful occupation

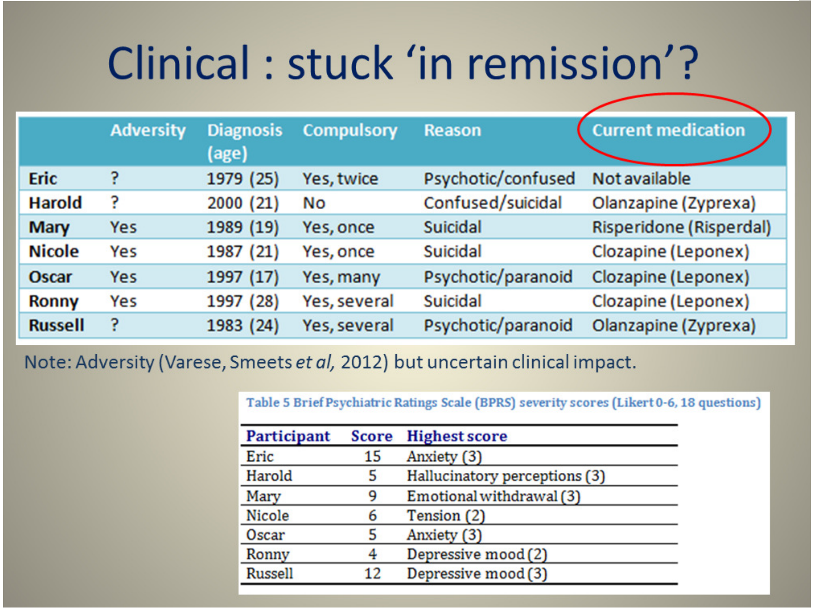
- Medication still necessary, they say
- Now have a sense of belonging
  - From mentally ill to social identity
  - Even Mary found a belonging
- The role of VIP confirmed (-Mary)
  - “My mother [stood by me]; “[family] really supported me”; “Sometimes you need people to be nice to you”

5.5.1 Coping with residuals (C1)

The participants had not relapsed for a minimum of the latest six years (an inclusion criterion) and are thus reasonably stable and partially recovered. All seven are at least ‘in remission’, and they have found a balance that works for them and has enabled a way forward. Most report fatigue and concentration problems, probably due to medication, but they have regained a sense of purpose and future despite a self-stigma as still ‘mentally ill’ and incurable.

This shows significant ambivalence even if *on the way to recovery*, using a gestalt term, symptoms should therapeutically cede into background, with instead subjective dimensions of recovery in the foreground: *"the subjective appraisal of life circumstances"* and *"the subjective experience of oneself as an individual human being"*. (Lysaker *et al*, 2010). The research suggests that they see themselves as survivors, but incapable of full recovery. This seems in turn – at least for them – like the self-stigma that Foucault describes as introjected from society and psychiatry. The lack of psychotherapy seems to have stopped a Sartrean sense of a purpose – a life project – and indeed, hope of social recovery.

Figure 13 Clinically, can you ever get out of 'in remission'



Clinical : stuck 'in remission'?

	Adversity	Diagnosis (age)	Compulsory	Reason	Current medication
Eric	?	1979 (25)	Yes, twice	Psychotic/confused	Not available
Harold	?	2000 (21)	No	Confused/suicidal	Olanzapine (Zyprexa)
Mary	Yes	1989 (19)	Yes, once	Suicidal	Risperidone (Risperdal)
Nicole	Yes	1987 (21)	Yes, once	Suicidal	Clozapine (Leponex)
Oscar	Yes	1997 (17)	Yes, many	Psychotic/paranoid	Clozapine (Leponex)
Ronny	Yes	1997 (28)	Yes, several	Suicidal	Clozapine (Leponex)
Russell	?	1983 (24)	Yes, several	Psychotic/paranoid	Olanzapine (Zyprexa)

Note: Adversity (Varese, Smeets *et al*, 2012) but uncertain clinical impact.

Table 5 Brief Psychiatric Ratings Scale (BPRS) severity scores (Likert 0-6, 18 questions)

Participant	Score	Highest score
Eric	15	Anxiety (3)
Harold	5	Hallucinatory perceptions (3)
Mary	9	Emotional withdrawal (3)
Nicole	6	Tension (2)
Oscar	5	Anxiety (3)
Ronny	4	Depressive mood (2)
Russell	12	Depressive mood (3)

Formally, Andreasen *et al* (2005), The Remission in Schizophrenia Working Group (RSWG), define 'in remission' not as complete absence of symptoms, but *"a low-mild symptom intensity level, where such absent, borderline, or mild symptoms do not influence an individual's behavior."* (p. 441) Remission is seen as necessary towards recovery: *"For a disorder such as schizophrenia complete recovery implies the ability to function in the community, socially and vocationally, as well as being relatively free of disease-related psychopathology."* with symptoms at a level *"below the threshold typically utilized in justifying the initial diagnosis"* (p.442)

Remission is defined in terms of symptoms relief to an extent where schizophrenia is no worse than many other diagnosable disorders. As part of the research protocol I used BPRS to rule out acute psychosis, and BPRS is one of the scales used to measure remission. Using the guideline of mild severity as < 4 on a scale 1-7, most (4 of 7) had all scores in the very low range. Eric scored a 4 for anxiety, Russell a 4 for depressive mood and Mary 4 for emotional withdrawal; but none of these are in the proposed 7 remission criteria for BPRS. Consequently, by definition they are all remitted.

Leucht *et al* (2012) in their big meta-analysis do not cover remission for individual symptoms, as it is usually missing from pharmaceutical research. It is generally assumed that negative symptoms respond less to pharmaceutical treatment, a key problem that was discussed in Chapter 2. The control groups are very variable, from no treatment to other kinds of treatments. Schneider *et al* (2011) confirm an overall lack of research for specific symptoms such as hallucinations, but as expected their mini-study (N=133/n=28) suggests that there is an early significant decrease of frequency and loudness of voices, thereby also distress. They caution however that the decrease may be at least partly due to general sedation and lower expressed emotion. On the other hand, lessening the pressure from hallucinations and hyper-reflexivity increases well-being and the GAF scores improve. Notably though, this effect can also come from illegal drugs. Dual disorders are common. There are also no positive social effects from antipsychotic medication alone and the side effects may create a new set of very real problems such as obesity and reduced libido.

Residuals thus include a lot more than remission and in this area it seems that the participants have been resilient and had luck with few side effects.

5.5.2 A reconstructed self | Identity and Eigenwelt (C2)

The residuals do not seem to restrict daily functioning and the dominant narrative is that participants enjoy their freedom and independence. With medication they say life is not much different from everybody else's. They try to live a normal life within their possibilities and have accepted their past: *"When I know what happens Monday to Friday and get to sleep the extra hour, then I have a full life like everybody else."* (Oscar: 104) Except for Harold, this does not mean full social participation with occupation, money and daily activities; and certainly personality factors play a role in their lifestyle. But, they are aware that their identity as 'schizophrenics' make them more accepted than socially included. Ronny mentions specifically that it would be difficult to return if he became psychotic again and lost control. Local people know day centres are a place for people with problems. For Eric and Mary their address give away their stigma, and so inviting people home similarly reveals their stigma. In the local community they cannot and do not hide, unlike people who chose to deny their condition and seek anonymity in the cities.

A reconstructed self must include a normal identity, first in the Eigenwelt and then confirmed in Mitwelt as Oscar does when he is travelling: he is a church attendant and the conversation that follows is then inconspicuous. A major Danish study finding an average age of first hospitalisation about 27 years (Byrne *et al*, 2002), with first episodes preceded by years of distress, failure and often unemployment . In most countries people with schizophrenia are excessively poor with virtually no rights as the adult earning lives stopped before they had started. This is confirmed also by Davidson (2003), Wilkens (2007) and others. Existentially it would be more correct to speak about constructing rather than re-constructing a suitable lifeworld. Eigenwelt must balance Mitwelt, as existentially we are defined through our relations with others. This is where the WHO studies show that developing countries offer less medication but more social inclusion and therefore probably better chances for full recovery. In a similar vein, Davidson (2003) points out that we need a VIP to help us out of the vicious circle: the most important person in the lives of the participants was mother.

This research confirms that relationships are crucial to recovery, but what is a reconstructed lifeworld? First of all, they regard themselves as 'survivors' where others do not survive. Secondly, they have accepted a sense of thrownness similar to birth and death: *"No, there wasn't much hope (laughs) of getting rid of the illness so I think I will have to live with it, but now I at least have medication and stuff so am satisfied."* (Ronny: 107) What is important here is to note that the participants live with their residuals and social limitations without being overwhelmed by hopelessness or helplessness or falling prey to paranoid ideas. While not a fair world, an acceptable world. Even if not particularly helpful in this research, there is a considerable existential literature concerned with givens of life e.g. Kierkegaard's (1849) *Sickness unto Death*, May's (1977, 1983) treatment of anxiety; Tillich's (1952) *Courage to Be*; and Yalom's (1980) existential philosophy.

Rufer (2007) points to the alternative outcome or essence – the sick identity. He points out the danger of powerlessness and helplessness in what he calls 'forced regression': *"Only by accepting the role of a patient – in other words, having insight into their illness – are they able to gain some measure of attention and recognition from those at whose mercy they find themselves."* (p. 387) *"Diagnoses such as 'schizophrenia' or 'mania' imply social death. The unique person with its potential for further development is essentially lost. At the same time he or she emerges anew – with a sick identity."* (p. 390). Such existential helplessness can become a major issue for recovery therapy.

My research does not confirm this key role of 'insight' as sufficient. Indeed, a positive narrative was not the result of 'insight'; to the contrary several participants say that insight kills hope.

There is good evidence that recovery is a path to the outside of schizophrenia whereby the *sick identity* is left behind, in fact Davidson (2003) pre-supposes as much.

In this perspective, the proposal to call schizophrenia a disability might not be helpful. Residuals below the remission threshold have by definition mild impact, so re-categorising to disability would be more appropriate for those above rather than below the threshold. In fact the participant narratives reflect neither *a sick identity* nor *a disabled identity*, but there are themes like social impairment, unfairness, stigma, discrimination and powerlessness. It is arguably a remaining *social identity* firmly connected to ‘schizophrenic’ i.e. not madness, but potential madness. Recovery becomes social doubt rather than mental illness – and a reconstruction of self must accommodate everything. Instead it seems that the hospitals left them to find their own way out.

My research here shows that we need to take complaints of any kind more seriously; as pointed out by many others (Bentall, 2003; Davidson, 2003; Wilkens, 2007). They are not just ups and downs of the schizophrenia package; and we need to remember that a compliant patient is not necessarily healthier than one who protests and subsequently labeled paranoid. I once remarked to a patient that by following her to make sure she did not harm herself, was I not feeding her paranoid thoughts? She was in the sick role and Sartre would probably have said that I pretended to be helpful. Russell says that we should expect patients to take responsibility for their own lives.

5.5.3 Social recovery (C3-C7)

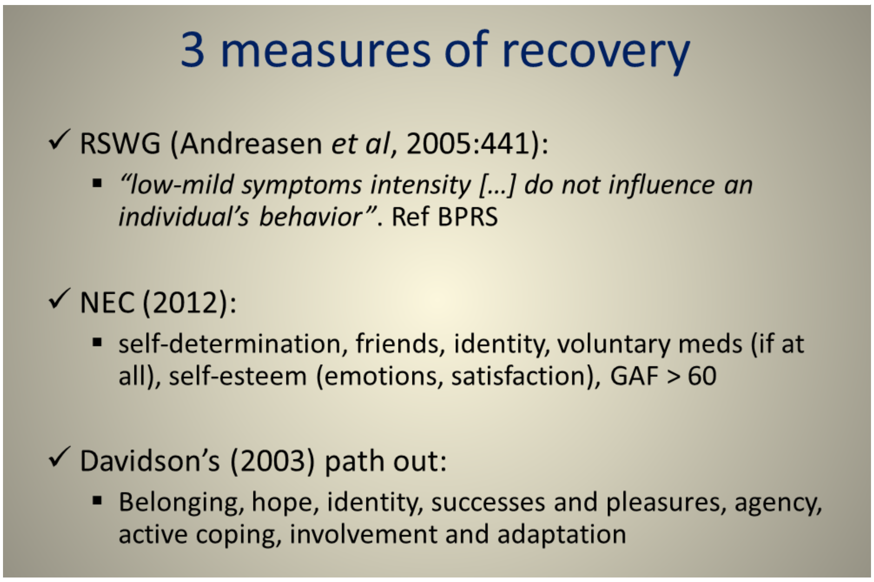
Recovery is an intersubjective process mediated by social inclusion. Read & Haslam (2004) have researched stigma and public opinion. In one experiment subjects were watching different videos of persons explaining their psychotic experiences with the result that bio-genetic explanations significantly increased perceptions of dangerousness and unpredictability, and explanations in terms of life-events reduced the perceptions slightly. A German public campaign backfired and increased the percentage of people who would not accept a neighbour with schizophrenia.

Oscar aptly points out that his work title identifies him as somebody rather than nobody i.e. it is not just an identity, but it defines his relation with other persons. It de-stigmatises him as he can avoid difficult conversations and is not a schizophrenic, outsider or potentially dangerous. Without social inclusion we must expect that recovery will probably plateau. In addition schizophrenia often occurs in the vulnerable phase between education and work, between independence and an own family. The project is not to reconstruct but actually to construct a meaningful life: Eric, Nicole and Ronny had started their adult career, while the others became stuck before they could enter work life. Only two have significant paid work, while the others (5 of 7) have reduced work and/or permanent disability. Norway is rich enough to afford it, but it may be neither fair nor ethical to those it concerns. Only Harold has full-time competitive employment and Russell who could have had more sensible work says it is ‘wrong not to expect more’.

In terms of friends and being stuck inside the schizophrenia vicious circle Oscar exemplifies Davidson’s (2003) path exactly, as he says life would have been unrealistic without a very important person (VIP) and trusted supporter. Except for Mary all had at least one such VIP family member. Scaffolding or hand-holding should not be regressive (too much protection and care, and too little courage), but empathic and realistic to live with and to some extent avoid experiences of failure, stigma and rejection. Families and friends are so important in therapy; schizophrenia may have brain organic causes but is definitely not only intra-psychic. Being somebody (identity) rather than nobody achieves belonging, brings hope and becomes a platform for recovery.

Friends seemed notoriously unfaithful, but the participants admit that they did not feel like keeping contact for several reasons. All lost friends due to the chaos they lived before hospitalisation, and most of them are still somewhat bitter about it. Only Eric was able to continue friendships to a certain degree. It is worth noting that their definitions and need for friendship seem to vary. To some extent they also mourn a ‘normal’ job and ‘normal’ life possibly with children.

Figure 14 Three measures of recovery



3 measures of recovery

- ✓ RSWG (Andreasen *et al*, 2005:441):
  - *“low-mild symptoms intensity […] do not influence an individual’s behavior”*. Ref BPRS
- ✓ NEC (2012):
  - self-determination, friends, identity, voluntary meds (if at all), self-esteem (emotions, satisfaction), GAF > 60
- ✓ Davidson’s (2003) path out:
  - Belonging, hope, identity, successes and pleasures, agency, active coping, involvement and adaptation

For three of the participants the day centre is the place where they let their guards down; outside they are aware of their identity as schizophrenics: different, potentially dangerous, chaotic, unpredictable, mad or crazy. Does it matter that they are active in an organisation like Mental Health? It has given them a social arena and a cause, and for Ronny local leadership has given him a social identity. Russell lives in a community apartment with some shared facilities. Neither his neighbours nor those who look after them have much intellectual resource, he says, so Mental Health is an opportunity to socialise with like-minded. Nicole considers herself stronger and more intelligent than most others with schizophrenia. Eric plays in a band and Harold lives an active life except for his olanzapine in the morning. Most (5 of 7) are engaged socially in a meaningful way not funded by community welfare.

In NEC (2012) the survivor view is more focused on outcome such as quality of life, well-being and belonging with a survivor based definition using seven characteristics: Self-determination without mental health professionals (all participants); A meaningful and fulfilling network of friends (-Mary); Achieved a major social role/identity (-Mary); Voluntary medication if needed (all); Ability to manage emotions (all); A Global Assessment of Functioning (GAF) above 60 (all); and A satisfactory sense of self (-Mary). Of the participants it seems that all but Mary are significantly recovered according to the NEC criteria.

Emphasising recovery the Davidson's (2003) model was derived from phenomenological research and its steps are recognisable (p.45ff): Redefining self; Accepting illness; Overcoming stigma; Renewing hope and commitment; Resuming control and responsibility; Exercising citizenship; Managing symptoms; Being supported by others; and Being involved in meaningful activities and expanded social roles.

Recovery is more than remission and concerned with quality of life rather than symptom control – the assumptions are totally different (see 5.5). There is no doubt that the participants are by definition remitted. This is further underlined by the BPRS at the time of the interview, where I asked if their state there-and-then were also their habitual ones, and if not how they differed. They all said they were stable, with no more than the normal ups and downs. More important, according to the NEC and Davidson models, for these participants there is little left of the distress, emotional chaos, strange behaviours and problems of daily living that led to one year or more of hospitalisation.

5.5.4 Summary and reflexivity

While the second lifeworld was constricted by the psychiatric system, the participants have made their way out of it and live independent lives. There is a sense of paradox in that they are on the one hand survivors of schizophrenia and recovered to the extent that society allows them; yet on the other still medicated as if they would otherwise be sure to relapse. Existentially it means that it is psychological factors, not symptoms that hold them back; yet they are considered chronically ill and incapable of full participation in the normal world. For these participants the process has not achieved its potential. Of the seven, not all have had psychotherapy (!) and their potential for recovery has not been fulfilled (or else it would mean that evidence-based psychotherapy would not be effective, which of course we know it is). In one sense they are therefore remitted, in another sense marked for life and excluded.

They are undoubtedly victims of the chronicity paradigm. It seems safe to assume that their quality of life would increase with less medication and it underlines the need for psychiatrists (and everybody else) to be up-to-date on current research. Best practices medication should be at minimal dosage (they are not aware that a lesser dosage is possible and routinely comply with the last prescription from hospital). It could mean they have gotten used to sedation and because dopamine is a driver for goal-oriented behaviours and motivation, less able to pursue goals or feel pleasure attaining them.

While the main issue in the first lifeworld was confusion in an Umwelt/Mitwelt sense, this third lifeworld is mostly about Mitwelt (social participation) and Eigenwelt (self-stigma). The narratives reveal a certain sense of self-stigma (Augoustinos & Walker, 1995; Foucault, 1965) along with an acceptance of Heideggerian ‘thrownness’. The WHO studies (e.g. Jablensky & Sartorious, 2008), EUNOMIA (e.g. Kallert *et al*, 2011), Davidson (2003) and other recovery research indicate that self-stigma is a direct consequence of the chronicity paradigm. Between 1930 and 1950 there even was a sense of ‘wasted people’ not only in Nazi Germany but in the whole Western world well within processes of prejudice and marginalisation described by Foucault (1965) and Staub (1989).

Their being-in-the-world is closer to disability than a sickness identity, they are "survivors" but do not live in a fully recovered sense even as they would be able to participate much more fully in normal activities. It seems safe to say that it is society, not schizophrenia that stops them. If nobody believes in you, you stop believing in yourself. Harold seems to be the only one who is not held back by these limitations.

Recovering from schizophrenia is a long journey and includes setbacks. The path from the inside stickiness of schizophrenia to the outside, is a difficult one. The odds are not bad with optimal treatment and today's evidence-based standards – provided we kill the myths and update clinical practice.

It seems safe to conclude that the participants have not reached what might be possible for them.

5.6 COMPLETING THE HERMENEUTIC

5.6.1 Narratives and temporality

It is of course accepted that the experience of schizophrenia is not the same for everybody or across time. A clinical journal includes a patient's own information and views to some extent, but the ultimate judge is the mental health professional who interprets and documents words and behaviours as symptoms of illness. Rulf (2003) and others have usefully reviewed literature and pointed to three versions of so-called phenomenology – my own literature research concluded with three perspectives: the psychiatric, the psychological and the subjective. In addition we have found three subjective lifeworlds or personal universes probably unique to schizophrenia.

A lifeworld can be conceptualised hermeneutically as our unique perspectives even though we share horizons with others. Our participation in the world (being-in-the-world) is thus in relation to the real, which reacts as we expect; and to the imaginary, which also reacts as we expect. Experiences in schizophrenia impact our expectations and thereby the world we belong in. Attempts to make sense of the gaps have been described in the literature in terms of perplexity and hyper-reflection; while spiritual attributions are a way to explain the uniqueness of experience also for the participants.

Intersubjectivity seems under-estimated and largely ignored in mainstream schizophrenia research, with exceptions such as Germany because of continental philosophy, and Yale University with Strauss, Davidson and more recently Lysaker (see 2.4.3).

Hospitalisation led them from their own theory (T1) to a confrontation with psychiatric theory (T2) and the threat of madness. This process is clearly under-researched specifically, but it is easy to think about the confrontation in terms of cognitive dissonance theory. If the distance between the perspectives is too far, then rejection is likely. The participants all accepted treatment, but the majority rejected T2 initially and some still do. Rejecting T2 has the advantage of also 'avoiding' the implications of T3. A survivor narrative accommodates T2 as something that was but no longer is, thus modifying T1 and putting the threat of T3 behind.

After hospitalisation they cooperated, so it is quite probable that they were predisposed to trust others and therefore able to build alliances. Davidson (2003) formulates this as the need to have a VIP on your side, while Seikkula *et al* (2007) have demonstrated the positive effects of involving family and friends early on. The Mitwelt domain was for the participants restricted to occasional contacts with the outside world – they lost most of their friends and normal activities – instead their second stage became a 'being-within-the-system'.

In the third lifeworld (C, 'outside' schizophrenia) a very different set of assumptions appear, viz. the hope for a better life. In the third lifeworld both the naïve and the clinical assumptions are fading. Thus the narratives must change at an interpretive level in order to accommodate the lived experience – in line with Ricoeur (1981) we can say that their memories already have distance by several interpretations.

They seem victims of a cultural lack of full social inclusion and work opportunities. This is Foucault's (1965, 1977) notion of dividing practices (out-group) and scientific classification (schizophrenia), and to a considerable degree an internalised role (Foucault's third mode: subjectification).Schizophrenics cannot become fully recovered unless we also allow them to belong in a fully shared society; it is thus not just a question of being-in-the-world but of belonging too, as Ricoeur (1981) says.

If the emergent themes point to similarities between the participants, they are also very different. Harold is the closest to a fully 'normal' identity with work as a pre-dominant theme. Mary is apparently the opposite when she talks about being given up by others (and herself) so just surviving by the day with the occasional depression. They all have positive feelings towards themselves and it feels like they have found a space that is theirs – a meaningful existential narrative that for instance Oscar uses when he avoids difficult questions or indeed the silence that follows when people get to know he is schizophrenic. He does not deny his diagnosis or the residuals. He is authentic.

Social connectedness links with frequency of relationships, while agency and social worth links with quality. A narrative makes sense of the world and Lysaker *et al* (2010, 2010a) points to impoverished self-narratives and lowered self-esteem. Loss is a prominent theme in first person accounts, and theirs are no exception. Their dominant tone is for all their survival *in spite of the system and their condition*, in contrast to a victim narrative stuck in an externalising belief '*of something stopping them'*.

Importantly, while both narratives can be critical to psychiatry, the participants are clear that you cannot survive schizophrenia if you do not accept help. Existentially, it is the basis for transition from the second to the third lifeworld. Their stories are largely consistent with survivor literature and recovery research as accounted for in the Literature review, including Davidson (2003), Lysaker *et al* (2010), Rulf (2003) and Wilkens (2007).

5.6.2 Other perspectives and 'ideologies'

Observations and narratives are interpreted into patterns that we recognise as knowledge; we see what we have been trained to see. Thus psychiatry has illness, not recovery, as the ideologically dominant perspective. The idea of schizophrenia as organic failure substantially ignores the influence of psychological factors including our own will, actions and meaning making.

Ideological perspectives that I have not explored include anti-psychiatry (incl. denial), critical psychiatry (incl. human rights and better treatments) and naïve folk psychology (incl. madness and fear).

The word *psychotic* deserves a comment. While schizophrenia is classified as a psychotic disorder, the participants use the word 'psychotic' only for episodes where they somehow lose connection with the world or lose control over their behaviours. As discussed in the literature review this seems to be where the diagnosis collapses and makes schizophrenia knowable only by its duration and assumed permanent damage. Several factors have contributed to this dominant paradigm, in particular the belief that 'real schizophrenia' is not psychological and that the brain cannot repair itself.

Reformulating the participants' discontent with the length and content of their hospital treatments, I argue that remission and recovery need to be parallel goals rather than sequential. Remission seems vital for the quality of recovery, but remission does not guarantee recovery nor must remission be complete before recovery can start. I have documented overwhelming support for such views from the survivor literature, from the recovery literature, from critical psychiatry, and from the WHO studies.

Psychotherapy had a minimal role in their second lifeworld, but for four of them an important role in the transition to the third. Their recovery – conceptualised as positive changes in how they think about and experience themselves e.g. strengths, independence mastery, self-respect, self-worth, choices, future and hope (e.g. Davidson, 2003; Lysaker *et al*, 2010, 2010a) – was neither a uniform process nor a clear goal. Although the participants seem no different from others in terms of severity and pervasiveness, they had a positive outcome. They are not haunted by delusions and psychotic episodes, and their residuals are below the Andreasen *et al* (2005) remission threshold and with medication they are satisfied with their lives.

5.7 FINAL REFLEXIVITY

About reflexivity: general points

The research has presented a series of challenges, perhaps as it should but perhaps more so because of the subject matter. Schizophrenia is one of the most researched, yet probably the least understood of the diagnoses. Its definitions have changed over the years and in clinical practice it overlaps with bipolar disorder, schizoaffective disorder and personality disorders. There are many myths and it is difficult to treat.

In 2002 I found myself working in a locked ward in Akershus University Hospital. My experience formation is mostly on the floor helping in-patients to get through their rounds as they unfold and document their development and insight. I have come to know a fair amount of detail that is not in the journals.

I was not blank when the research started. I have never had a psychotic episode but when I created the interview guide it felt like I already knew something about what I would hear: different life stories, critical views and few similarities. The search for possible meanings and themes leads to recognition and association, which should be followed by an inner dialogue unhindered by pre-conceived and perhaps paradigmatic ideas. This I judge as the most difficult aspect of my early stages of analysis and it has required considerable effort. I have dealt with my assumptions, theories and reactions as best I could through bracketing, deep listening, looking for alternatives beyond the obvious, and shifting between whole and parts. In the later analysis I have gone from one narrative in depth to another, comparing across the cases.

Langdrige (2007) says about reflexivity: *"conscious of and reflective about the ways in which their questions, methods and very own subject position […] might impact on the psychological knowledge produced in a research study."* (p.59). Similarly, for constructionist grounded theory, Charmaz (2006) says: *"own scrutiny about how interests, positions, and assumptions influenced inquiry. A reflexive stance […] conducts, relates, represents"* (p.188-189).

Staying close to the phenomenological attitude, van Manen (1990) emphasizes that research from a phenomenological point of view *"is always to question the way we experience the world, to want to know the world in which we live as human beings."* (p. 5). To this I have added Ricoeur's (1981) separation of explication and interpretation.

For the overall outcome Bloomberg & Volpe (2008) emphasize the ultimate synthesis between the researcher and the research project:

> "Once you have established patterns [The Findings], they need to be explained. In this regard, you need to draw on your own experience and intuition. In addition, you once again consult the literature and consider your pattern findings in light of previous research and existing theory." (p.131)

Not only do our own experience and intuition inevitably lead to some bias, but there is considerable controversy about the place, scope and usage of literature research. To show such 'own experience and intuition' Langdridge's (2007) says: *"This information must be sufficient for a reader to be able to tune into the particular position of the researcher and the ways in which this position might have influenced the findings."* (p.61)

Research bias and pre-understanding

Experience formation

I have worked in clinical settings since April 2002, with out-patients for psychotherapy and in-patients with psychosis, mania and life-threatening conditions such as attempted or planned suicide, eating disorders, early onset dementia *et cetera*. My interest has not been in the symptoms or diagnosis, although I know the manuals well enough for differential diagnosis, but the whole person's being-in-the-world and specifically coping with schizophrenia as a phenomenon.

Clinical experience has given me a different pre-understanding compared with academic research, reading journals or interviewing staff. For this research I had no access to journals and am of course aware that interviews are not necessarily accurate. Indeed narratives adjust with the purpose and some people will have little recollection of what they have been through. Still I am inclined to believe what people claim as their reality. At least there could be no doubt that the participants had suffered from schizophrenia and had spent a long time in hospital.

The concept of survivors started to fascinate me when I read Arnhild Lauveng's (2005) fight against 'helpers' who advised her against the unavoidable disappointment should she continue to dream about becoming a psychologist. They said to her that it would be impossible. Interestingly one of my participants (Russell) achieved a master's degree despite his schizophrenia while Arnhild is fully recovered (no medication) and indeed a clinical psychologist. Her story was as fascinating as Greene's (1974) *I Never Promised You a Rose Garden*. Later reading Davidson (2003) and seeing Hornstein's (2007) 30 pages reference list of 'survivor literature' made me think that the toxicity, chronicity and disability assumptions might be scientifically incorrect.

As for the emotional side I don't think it is possible to be 'neutral' or 'objective' when you encounter serious conditions like schizophrenia. You need a strong psyche. For the sufferer it can be an absorbing experience of more or less losing the world around you, while as an on-looker you lose some or all contact with the person. I am however almost always able to reach through the fog by reading body expressions and moods, and communicate effectively both verbally and non-verbally. Similarly, you cannot see or hear or smell hallucinations, but you know its importance and direction from the intensity and combination of emotions and body language. It may seem totally irrational to the on-looker, but it makes sense to the person there-and-then and so I can use a normal vocabulary and work with their lived experience. It is respectful and invites trust. I do tell them though that I cannot see what they see, hear what they hear or smell what they smell.

Recently somebody pointed to a cat under the sofa. So I plainly said: "I cannot see it so please describe it for me?" With another I had sufficient trust that we could talk about a rather frightening psychotic episode by referring to emotions first, which opened up to talking about the experience. Sometimes I can use humour, paradoxical comments, reassurance or references to. Interventions like these I have found to create a kind of common experience that you don't get in psychotherapy alone.

In my mind interventions are important to avoid unwittingly reinforcing delusions: one has to do with agreeing with even apparently small hallucinations; the second is when you avoid something that needs to be talked about. Both close the window on joint exploration, because doubt is a necessary condition for insight. Of course, anti-psychotic medication can reduce hallucinations, but I agree with the participants that insight is necessary to stay on medication and away from illegal psychoactive drugs.

Existential exploration is a whole-person undertaking, and the lifeworld structures seemed to emerge very naturally. Structuring the analysis around symptoms, even the German 'basic symptoms', appeared illogical in comparison, even if the normal case in psychiatric research. Beliefs are seldom bizarre (Schneider) or un-understandable (Bleuler) these days, maybe because we hold hallucinations down with antipsychotics.

This is the essence of milieu therapy for psychosis: A psychotic person reacts to both shared ('real') and non-shared ('psychotic') elements – it is of course perfectly possible to have normal psychological reactions to abnormal perceptual experiences. Exploration is no longer regarded as collusion and milieu therapy is a resource for psychologists. The problem is that unskilled workers can of course do harm and the wards these days have mainly unskilled labour.

If still on medication, as all were, is then the term 'survivors' not a contradiction of terms? I dare use it with the following rationale: We cannot know that they are all fully recovered i.e. can be taken off medication, but we know from research that such full recovery is possible. If in remission (Andreasen *et al,* 2005) without symptoms, you have in an existential sense survived schizophrenia as a condition. Like their use of the word 'psychotic', this is a different definition from medical science but certainly no less valid.

Such deliberations were partly based upon literature and partly just logical. There were far too many of them to include all in the Discussion. I believe hermeneutic phenomenology kept it reasonably in place and that my critical voice is in line with contemporary evidence.

Milieu therapy

I don't know where the head psychiatrist in my first employment had learnt about 'milieu therapy', but without it/him it is unlikely that I would have kept enough interest to stay in psychiatry or even pursue a DPsych in counselling. Milieu therapy aims at activating resources, not as social buddies but on the back of behavioural therapeutic ideas and perhaps a Vygotskian '*zone of proximal development'* because in psychosis you can become vulnerable and anxious. He believed that you need special skills to make daily and social activities sticky (therapeutic) and not just trivial social contact.

Who is skilled or un-skilled in psychiatry? I have worked with police students, security personnel and prison attendants who understand therapeutic behaviours while many nurses do not. We know that it works in practice, but it costs some training to make it consistent as behavioural therapy.

With people trained in basic applied behaviour analysis, milieu therapy complements other therapies as 'homework' and daily practicing. Milieu therapy can handle complaints such as coping with side-effects, anxiety, sleep/wake regulation, low self-esteem (creates negative self-talk in hallucinations), hopelessness, social issues, family issues, medical problems *et cetera*.

It is under-utilised but I have seen how there can be a big therapeutic difference between skilled and unskilled workers: in the way they tackle an angry patient, respect personal boundaries and ethics; how they can provide successful learning and mastery; how they understand when to be just a container for difficult emotions; and how they become a trusted VIP rather than just another nice person or pseudo-parent. Such skills make you see dysfunctional beliefs and behaviours that sometimes lure people into good guy and bad guy games.

All of this goes on in the back of my head as associations when I analyse the transcripts and what some of them describe as rather useless treatment: sleep, food, medication, some light exercise and television. Was it right to stay in a hospital setting for more than a year?

Personal/professional attitudes

As a clinical practitioner you must develop a set of professional and ethical principles. Psychosis is a bad experience and I can see a rationale for early intervention. Yet I am watchful rather than neutral, such as to side with the rights of the weak party. It does not mean that I protest against necessary medication, as in many cases a small injection is more humane and less invasive than days in straps with blood thinners to prevent clots or holding people down with sweaty body odours. From clinical experience I therefore accept medication as a good thing to restore control and get necessary rest when the going is too tough without. We have a duty to care for those who have become a direct danger to themselves or others; or have such problems with daily living that they endanger their very existence.

For me an important premise is that only evidence based treatments can be ethical treatments, in particular if compulsory. It is a balancing act: praxis often precedes evidence yet must then also be informed by evidence. For the patient the only evidence is that it works. Telling the truth is ethically important but also worth the effort because it generates trust and resilience. The Internet is too full of information, stories and warnings to take truth lightly. Yes, promises may work initially but do not lead to informed consent and a good alliance for the bad days. It of course does not mean that it is more ethical to prepare patients for a long list of side-effects that normally do not occur.

Most patients are in and out of self-control – all intervention and lack of such must be defended therapeutically and ethically. Somewhat paradoxically a psychotic episode may lead to compulsory injection, with an informed consent to cooperate. The end result is from a medical point of view the injection and cooperation is of course not really voluntary – but they will have preserved their dignity and see us as helpers rather than adversaries.

It has been inevitable to speculate that 'therapeutic environments' must be a significant factor for differences in involuntary days in hospital within Norwegian regions and between countries. This was indeed one point where a Grounded Theory approach would have been appropriate and I am conscious that my Conclusions are not as fully developed as I had hoped for.

Journaling

Reflexivity was at the strongest during the detailed analysis inspired by the format in Smith *et al* (2009) and when writing the early focused memos on lifeworlds (Charmaz, 2006). A systematic approach is necessary and I have been dealing with my assumptions and theories such as to bracket my assumptions; include alternative interpretations; match parts with wholes and *vice versa*; compare cases for similarities and differences; and following Ricoeur's (1981) advice to separate the explication of phenomenology from the subsequent existential exploration, one perspective among several possible ones.

I should perhaps have been (even) more disciplined. Gadamer (1975) usefully regards hermeneutics as questions to open up and keep open possibilities for 'truthful' interpretation; for Ricoeur (1981) such possibilities – including reflexivity – extend to constructionist perspectives, beyond the 'thing itself'. In my next (if ever?) research project I will want to be more careful to formulate and keep track of specific questions. Reflections should be in one workbook rather than as notes and memos in several places. Re-working the material several times you can easily end up with a loose audit trail.

Literature research

Valid research questions

Over the years I have read widely and tried to validate theory with my own observations at work. Where co-students may find a lack of research literature in their field, I knew this would not be the case for schizophrenia. The number of different concepts and theories however continues to surprise me and led to splitting the literature review according to epistemology. It illustrates how bodies of research may be incompatible, outdated and speculative, in this case more than one hundred years of different *Zeitgeist*, definitions and treatments.

Schizophrenia does not have a sense of a unitary mental illness for me, even if a gradual breakdown of a functional neurocircuitry is a likely common basis. One metaphor would be similar to electrical circuits with weak points – the lights go out or flicker, but it isn't necessarily power failure (dopamine). Of course, flickering does not preclude weaknesses such as genetic copy failures or hormonal disturbances in the development of the unborn child. And even though the dopamine hypothesis didn't explain schizophrenia, I am fascinated how antipsychotics can help even in cases where 'pure madness' has been no exaggeration.

I have been open to many directions of research. My biggest disappointment was my failure to triangulate with brain research, but it led to useful knowledge for the future and the discovery that cognitive remediation software seems to work for restitution, learning and neuroscience also in schizophrenia. This is potentially huge: If we can 'circumvent' schizophrenia via neuroplasticity, it must mean that the brain is indeed capable of self-repair.

I was interested in the state of psychiatric research; in the concepts and evidence for therapeutic environments; and lived experience with psychotic episodes as a special phenomenon. My curiosity led me in many directions with few definitive answers, from which I finally had to make a difficult selection based upon experience and epistemology.

An existential hermeneutic

This was difficult as I wanted to connect the research with psychotherapy rather than just phenomenology. Some substantial concepts from pre-dopamine psychiatry helped me, first Rollo May's (1983) comments about psychogenic and somatic schizophrenia, and then the realisation that the world originates through our senses and events therefore likely to be reacted upon as 'real' even when it is not. This primacy of perception is biologically more important and therefore stronger than language, even though meaning is constructed through language as well as influenced and constrained by it.

Gradually during my research and after the lifeworld concept I realised that Merleau-Ponty (1962) could be extended not only to hallucinations, as he discusses, but primacy of perception must be a primordial mechanism because it is *biologically necessary to believe your senses*. This is our 'natural attitude' and our belonging in the world – when it becomes heavily disturbed with hallucinations the sense of *'not shared'* must create confusion and withdrawal. I intuitively connected this with a lifeworld concept where there is both shared and non-shared content.

In fact, there must be a difference between initially not having a clue; then being hospitalised and told you're sick; and then coming through with insight. While the three lifeworlds may have emerged more or less as a necessity for existential exploration, it was also quickly substantiated by the emergent themes. As van Manen (1990) points out there are sometimes 'magnets' that seem to draw emergent themes together into main themes!

This perspective is different from schizophrenia viewed as an illness. Patients are more or less able to cope with their experiences and illness as such did not seem to be an anchor for ontology, rather meaning was. Inter-subjectivity then goes wrong because it is difficult to live with a person who suffers from psychotic episodes, but non-shared 'realities' create an additional lived distance from those around you. Schizophrenia has meaning for ontology also through belonging e.g. "*We are never but an aspect, an element, a part of a wider context. Relationship is essential to our very survival and inspires everything we do."* (Deurzen, 1997: 95). Unfortunately, with schizophrenia these relationships become difficult.

The fundamentals for an existential hermeneutic I decided would also need to be behavioural i.e. a being-in-the-world as acting, reacting and participating in the world, yet the world seems unreliable and no longer reacts as you expect. The seminal idea I think came from Minkowski's term 'intentional arc' – your intentions and predictions will fail if you mistake hallucinations for real perceptions. For such confusion to be possible, brain research in fact suggests that the secondary perceptual areas are involved in creating the imagery or voices, unbeknownst the origin. Our knowledge seems to stop here - schizophrenia can be 'anywhere in the brain' and I very reluctantly accepted my supervisor's advice to drop neuroscience as outside the scope of my research.

It was at this point in my research that I decided to rewrite the literature review by epistemology and eliminate almost half of the psychiatry research including neuropsychology. My research library had by then grown to thousands and thousands of pages, overwhelming and much longer than the references.

Method

I initially found qualitative research rather vague even if interesting and valuable for exploration and emergent theory. This is partly because I am better with math and liked multivariate analysis in my master thesis at Stockholm University and my doctorate courses in Oslo. Drawing conclusions from very few cases still seems to me counter-intuitive, and I felt drawn towards grounded theory. However, I also wanted to limit my data collection as far as my research interest would allow and b) as a 'foreign' student in Norway I had to rely on a convenience sample through a mental health user organisation. I could not get formal support from either the University Hospital or from Oslo University, their reason was that they knew neither my supervisor nor my curriculum and there was no money in the system for supervising students matriculated in another country. It is difficult to argue that my convenience sample could have led to valid purposive sampling; while hermeneutic phenomenology can lead to a grounded theory approach (e.g. Smith *et al*, 2009). In hindsight it might have been easier for me to change to English participants with everything done in the UK, because I ended up very lonely in my research.

Have I been able to keep tongue-in-cheek and know what I was doing? While the interview guide was solid enough, for my initial analysis my skills were insufficient and my impatience a liability. It was too shallow to represent the content of the interviews: more a re-ordering than actual analysis, more a thematic frequency count than search for meaning. A second and more promising attempt used Charmaz (2006) as I seriously considered Grounded Theory for method. I still have photos of my desk covered by focused memos!

I thought I would have no problems with the analysis (I was wrong) as I am used to work with narratives in my clinical practice and the interviews had similarities with clinical assessments. But in psychotherapy your understanding grows with the client or patient in front of you, a co-creation of meaning that I found painfully missing.

If I compare this with others who have basically stood by a carefully defined method such as IPA (Smith *et al,* 2009), my psychology doctorate (Oslo, Stockholm, London) has been a long learning curve indeed.

Analysis and findings

The core data: interviews

I think my interviews are fair interpretations of what the participants wanted to say, but was I perhaps gullible? Did I get too much relief from confirmation? Do they have 'insight' i.e. how well are they really and how suspicious should I be?

Clinical material is not just any material. The participants had a need to be understood or at least listened to. Nicole said that I had listened better than anybody else she had met: she felt understood. I have pondered how a research position is perhaps more different from clinical work than I thought: no problems to solve, nothing that they had told nobody before, no difficult feelings to contain, no homework, no next time *et cetera*. Of course I tried to avoid bias, I am not a judge of their truth and I checked towards the end of the interviews that I had covered the ground to make the interview 'complete'. When listening to the tapes I realised that I had been conversational, probably for better (more data, better connection) but maybe with a downside risk (interviews differing in direction or focus). You want to avoid leading questions, while engagement and curiosity are critical ingredients in a good interview. Several of them could hardly stop talking, as if they usually didn't have somebody listening.

I think my emotions were reasonably under control. There was little nervousness in the room and as 'survivors' they were reasonably high on well-being and optimism – they gave me little reason for pity and they were not angry or paranoid. To the best of my recollection they did not tempt me into a game of 'is-it-not-awful'. They were simply nice, everyday people who had come to accept life as it had become for them and struggling more with stigma than with schizophrenia. This could have been different. Some people blame psychiatry for having created their problems.

I am always thankful that my own two children are very healthy and resourceful. Especially with young people my fatherly side comes forward – they are often so lost and alone. When their family come to visit you often see uncertainty, distance, and a lack of warmth and care. This is not to be taken automatically as a symptom of family dysfunction, as it can be partly a reaction to atrocious problems connected with the conditions and also when otherwise normal families are treated as outsiders instead of resources. As late as 2004 we had an old psychiatrist who never talked with parents because 'they are always part of the problem'. Psycho-education was rare if any, and then general and illness-directed. Advice on how to treat their particular son or daughter was equally rare, except perhaps referring to the 'expressed emotion' research. The patient thereby not only *had* a mental illness (schizophrenia) but *became* the illness (schizophrenic) with no resources and no responsibility for own behaviours. Ethically speaking, if I as a professional would not accept a certain treatment for my children (and in many cases I would not!) then am I ethical in accepting it for others?

One paradox in the interviews was the fact that these participants had accepted what they had been through – i.e. an existential acceptance – but they lacked a framework or reference of what it might have been with a different therapeutic environment, one that believed in their possibilities and pushed them forward instead of treating schizophrenia as an irreversible, chronic, disabling and lifelong mental illness. Ironically we perhaps still fail to recognise that psychiatry is an old political invention as much as a medical specialty. If hospitals are to only treat illness then psychiatrists will in the future have a more limited role as doctors.

At a systems level these are complex issues, yet interestingly most of the patients recognise the short-comings of the system: they feel like the system isn't really helpful and that we don't understand them. These are in my mind warning signs that we must take seriously, rather than blaming it on lack of insight or ingratitude or dual disorders. The latitude for speculation and criticism that is not based on personal lived experience is one difference between descriptive and hermeneutic phenomenology, yet for it to be phenomenology such criticism should be anchored in personal experience and not just an opinion. Harold's comments about his new role as milieu worker reflect how he does for others what he believes works, while Ronny's comment about human rights does not reflect his own lived experience. Within the scope of the interview Harold's comments can be pursued, Ronny's should not; yet arguably both of them will be sure to have influenced their narratives – great examples of Ricoeur's (1981) *distanciation*.

The narratives are individual accounts and I cannot document as a finding that their lives would have been better with a different treatment or less stigma, but Norwegian psychiatry at the time of their hospitalisation and after-care was in need of the changes that followed. Now new changes are on their way and my understanding of the Norwegian system (past, present, and future) will have coloured my work, yet more in line with evidence than personal bias.

The findings

The analysis proper concentrated on lived experience and narratives, without speculating about how things might have been. Except for evidence-based criticism I have had no axe to grind. I have asked myself if the findings are strong enough and whether I have exaggerated or generalised too easily – *post hoc* my work seems to be on the safe side. I would have liked to go back for more data in areas such as psychotherapy because the usefulness of psychotherapy for schizophrenia is contested. There is a conflation perhaps between the symptoms and the person – psychotherapy does not kill hallucinations, but can definitely influence the content and intensity of hallucinations, improve self-esteem, help you cope and adjust, give you hope, and act as a safety valve against anxiety. A therapist can become a VIP for difficult times – Davidson (2003) resonated very strongly with my experience, training and beliefs.

A nice feature of hermeneutic phenomenology is the possibility to explore the lifeworld with consecutive hermeneutic circles e.g. whole/part, now/past, illness/normality, and epistemologically based interpretations. The lifeworld finding helped me to imagine the difference between their current narrative and how it would have been at the other time.

I consider that a lifeworld view fits the data as a natural framework, but the emergence of three different contexts by way of shared/non-shared reality was surprising at first. Yet our place in life is of course socially constructed. I see people as agents who create their own lives through relations, beliefs, activity and inactivity – it is true even when we become victims of illness. My entire training has of course primed me for this as I already in Stockholm encountered person/context interactions as their dominant research area.

I wanted to stay close to the data. For this particular kind of narrative it is easier said than done so I re-read van Manen (1990) and additionally consulted Smith *et al* (2009) and Ricoeur (1981). In keeping with Ricoeur (1981) I decided to stay close to the lived experience in my Findings, but then extend the Discussion. I understand that it led to repetitions for which I apologise.

Interestingly, I discovered how the participants have to a large extent adopted psychiatric vocabulary even though their definitions may differ (Ricoeur's polysemy).

Discussion and conclusions

I have become satisfied with the final literature review and the themes leading up to the Discussion. My idea was to stay close to the data tables and I remembered the context easily because my emergent themes were worded carefully. I seem consistent in taking first a participant point of view (Findings) coherent with a phenomenological attitude and Gadamerian principles, while trying to postpone interpretations until the Discussion. In Ricoeur (1981) terms the Findings have become an 'explication', while the existential hermeneutic is one possible 'interpretation' i.e.

a particular perspective with some assumptions connected to it that makes it different from other perspectives.

The findings can be used for other psychology based interpretations, i.e. the data are re-usable if I later want to add them in a Grounded Theory. In many ways this part was the more interesting as big picture assembly and synthesis is more commensurate with my personality. In fact, it was easier for me to deal with the complexity of my research perspectives than with the *bricolage* of theories and outdated assumptions that I had hoped to cut through with neuroscience and neuropsychology.

At a point during the literature research I was optimistic about a conceptualisation of the term consciousness, as its failure seemed central to the experience of schizophrenia. It is more than a mechanistic active representation in a neural network, on which we cast our light or come to our attention through an N400 ERP spike. We are able to manipulate our inner and outer world as no other creature on this planet. If we don't understand consciousness as an experience (psychology) rather than just a neural representation (neuroscience), we probably will not be able to understand the nature of schizophrenia. I think the subject deserves much more attention and a far better definition – in this context the quest was simply too big an undertaking.

Final learning points

What have I learnt? How have I changed? What didn't change? In the beginning this was just another piece of the doctorate but has underway become a deep learning experience into research methodology and a comfortable knowledge base for further clinical work and supervision. I have been surprised at the depth of analysis possible from what initially looked like just – interviews.

A doctorate is a humbling experience that only half of us finish. I can understand why – it is a demanding, frustrating and lonely project. The New School of Psychotherapy and Counselling has in addition several challenges that seem to have been under-estimated by everybody, in particular the system of distance supervision. I am sure it would have been faster to take the interview material to London and be part of the NSPC/Middlesex culture. It could have meant working on the dissertation for a sabbatical year instead of spending endless time trying to do things in parallel to earning a living. Taking ten minutes with your supervisor over an idea is way more intelligent than shuffling e-mails and waiting for an answer. When nobody is looking over your shoulders, it is too easy to let the work slip from one day to the other. Of course I cannot blame NSPC for my decision not to live in London for a half a year.

The more literature research, the more references and theories you need to keep track of – in the end I removed a substantial portion of my writing, collapsed neuropsychology into a small chapter about 'the role of consciousness' and decided to rewrite/re-assemble the material under three epistemological headings. Might I have known this beforehand? Should an academic supervisor have been able to see that I was wasting my time? I think it would be demanding too much – a dissertation is not only proof of competence but also a project where you mature with both research competence and knowledge of a particular specialist area.

In this sense I believe this is one end of the road and the beginning of a new one as a competent practitioner-scientist.

5.8 LIMITATIONS AND CONSIDERATIONS

Data integrity is important. Using a semi-structured questionnaire the interview itself was rather conversational and allowing good space to remember, yet also making sure that it covered all areas.

Some limitations need to be mentioned. The participants constituted a convenience sample. Their lived experiences are recounted with retrospective and interpreted content. The disordered thoughts appearing in the transcripts can be attributed to an effort to remember something distant in time, or maybe there was a residual of schizophrenia. It would take a clinical assessment to find out.

Anyway, the narratives are not about how it was at the time of the phenomena or events, but how the phenomena appear to them in hindsight. We make sense of our personal history by chaining events and experiences into meaningful patterns that we later modify. In this case their initial experiences lay two lifeworlds and more than ten years back. It is important to note that the dominant paradigm at the time of their hospitalisation was still one of chronicity and no hope, a major change that makes it easier to believe in recovery and work towards social and vocational restitution.

The narratives are survivor narratives that have not been compared with people who have other kinds of narratives. We cannot even infer that their histories are representative for survivor narratives, although there is good reason to believe that taken together they are. It does not feel like adding more participants would add useful data – in this sense the analysis is rather saturated as far as survivors go.

Langdridge (2007) calls Yardley (2000) *"a very useful set of guidelines for judging the validity of qualitative research from a variety of different methodologies."* (p. 156). She has four topics.

The first is sensitivity to theoretical context. This has been a major challenge because literature is all over the place. Initially critical psychiatry seemed important, while I have in the end almost discarded its proponents because they operate within the psychiatric paradigm rather than recovery. A further interest took me into neuroscience and neuropsychology, to some extent a detour but necessary to appear reasonably informed in clinical knowledge. You cannot work in a psychiatric setting and expect to change praxis without being up-to-date with psychiatric research and taxonomy. The eventual result was the chapter The Problem of Consciousness, but stating at the same time that my research interest is over and above consciousness as such. It is the lived experience and the meaning connected with it that I was after, and he existential hermeneutic was constructed to cover an integrated set of existential concepts. The alternative was to resort to pre-dopamine psychiatry and psychoanalytic ideas, but these are typically not taken to depth with schizophrenia and thus I instead extracted the basic existential concepts. This changed the hermeneutic to something worthy of a doctoral dissertation.

Her second topic is commitment and rigour. I have worked in psychiatric locked wards part-time and sometimes full-time for more than ten years. My commitment has been strong and my curiosity has brought me to considerable depth in clinical literature and theory, only to discover that the well of theory is bottomless. It has thus been a difficult endeavour that has taken a lot of commitment. The danger is that the breadth has at times out competed the depth of analysis, and it has certainly become a much, much bigger project than I ever imagined. Hopefully, this version is on safe ground. Rigour is better judged by the reader.

The third is transparency and coherence. The basic approach, a semi-structured questionnaire with a transcribed conversation is as transparent as it can get. By however making sure that no part of the questionnaire is missing, the picture also becomes coherent. Coherence does not guarantee depth or even completeness, thus there are limitations that would have been interesting for a grounded theory approach.

Fourth, there is impact and importance. Is this really useful research? My aim was to let important findings emerge from stories that these survivors tell about their lives, in way of what is existentially important enough to become a framework for psychologists caring for the whole person and leading cross-functional teams. While not perfect, the findings seem many enough and robust enough to make a difference, at least for my own good and that of supervisees and patients.

As for ethical concerns there was no harm or incidents during the interviews. The protocol was followed including pre-interview information and verbal consent, a telephone call the day before, a BPRS before the interview to rule out an active psychotic episode, the signature on the consent sheet thereafter, and a semi-structured, conversational interview that encouraged the participants to speak freely, yet cover the ground. My own safety was at no time in jeopardy nor did I feel threatened.

5.9 ADHERENCE TO BPS ETHICAL GUIDELINES

The following refers to the most recent BPS Code of Human Research Ethics (BPS, 2015) downloaded from www.bps.org.uk with publication date 2014. The Research Ethics Committee has approved the research documents and the design has not been changed, ref. Appendix 1-4.

I shall first consider whether the participants are in a vulnerable position, then continue with the specific items and at length comment on the 4 general principles.

Vulnerable population

The Code mentions as such *"target populations, some of which are vulnerable, lack full competence to consent or are otherwise associated with heightened risk"* (p.6); and *"children aged under 16; those lacking capacity; or individuals in a dependent or unequal relationship"* (p.13).

While such vulnerability was improbable given their independent living and no re-hospitalisation for at least 6 years, I needed to rule out a psychotic episode. None of the participants showed any sign of psychotic behaviours, utterings or ideation during their interview. For the sake of a valid consent BPRS (table 6) was used immediately before signing the consent.

Notwithstanding the above people with schizophrenia can be regarded vulnerable, which is considered below.

Assessment of risk (items 3 and 8)

The *a priori* risk assessment was accepted by the REC. My research targeted people who had recovered and able to consent – indeed a need to involve or consult stakeholders would have disqualified them as participants. As they would be in control of what they want to say and talk about, there was no reason to expect more than their normal day risk of talking about their life conditions.

However, there is always a risk of the unexpected such as particularly sensitive topics and the interview process was kept as emotionally neutral as possible. I took care to follow where they went, not go into areas that would be private or awkward, and abstain from questions that might raise the risk of harm such as re-traumatisation.

I also watched their well-being during the interview and would have taken time-out to make sure they were ok. I was also prepared to refer on to a psychologist, if necessary.

I did not see any reason to doubt my own safety – after working 13 years on the floor in acute locked wards I recognise potential danger long before it becomes dangerous.

For each of them a short debriefing was included after interview. Both body language and what they said was positive, several remarked that it had been a very good interview; Nicole even said it was her best conversation ever…

Even so, I made sure they had my office telephone number (forwarded to my mobile) in case something happened or they needed to talk. Nobody called.

Valid consent (item 4)

The protocol was adhered to and the consent sheets were signed and filed securely. There was no cognitive or literacy issues. Special care is necessary because participants although recovered still might have been psychotic while giving their consent. BPRS was therefore performed *immediately before* the consent sheet was read again by the participants and signed by both of us.

Each participant was also given a Participant Information Sheet covering everything necessary for informed consent (appendix 1, as approved by REC), of which the Norwegian version is an accurate translation. Compared with the listing on pages 18-19 all items have been covered except there was no recompense, no special insurance necessary and no planned debriefings beyond a short 'how has this been for you'.

We read the Consent Form to make sure that each participant understood the meaning of their right to *"during the data gathering phase, freely to withdraw or modify their consent, including ask for destruction of all or part of the data that they have contributed."* (p.15) Fortunately for me and the research, no such withdrawal occurred.

The question is if the above procedure would be enough for the participants to understand what they were asked to do? Basically it was about telling their story and I opened by naming the three headlines (before diagnosis, hospitalisation and after hospitalisation). We did not discuss recovery or any other concept that could be confusing; I asked if it was ok and left it up to them to start.

Throughout they could ask questions.

Confidentiality (item 5)

First of all, the interviews were held in a private setting. Confidentiality was further secured by keeping audio recordings in a strongly encrypted format (PC TrueCrypt).

All participants were given pseudonyms that are known only by me and the participant. Elements that could identify the person were omitted from the transcript. Names of persons and places have been omitted throughout thus without compromising the quality of the content.

A full transcript contains a life story and if read as a whole can easily reveal the person's identity. To be on the safe side, I have chosen to not append transcripts to the dissertation. Instead, if anybody *needs* to see one or more transcripts, this can be done on an individual basis within a controlled distribution and therefore a negligible risk.

Reading quotes and statements in the dissertation might of course lead to second guessing, but would in comparison not be conclusive.

Other considerations (items 6-8)

I did not give any advice and was not asked to give any; nor did I see or hear anything that suggested that advice or referral would be necessary. (6) There was no deception involved. (7) Debriefing was taken into consideration as a precaution, and I closed each interview by asking about reactions and how they felt.

A debriefing (8) was undertaken after the interview had ended, where we talked about how it had been and where I repeated again that I would be available on the given telephone number if they needed to talk. All of them were in a positive mood when I left them. Nobody called.

Overall adherence to The Principles (item 2)

Underlying principles ensure that researchers don't just follow the letter, but adhere to the spirit of all relevant documents including the Society's Code of Ethics and Conduct. These were deemed sufficient to cover interviews with Norwegians in Norway i.e. *"appropriate to local customs, legal frameworks and cultural expectations"*. (p.16)

The following responds to each of the four principles:

Throughout, did I show "*Respect for the autonomy, privacy and dignity of individuals and communities*"?

As a psychologist the answer should be a given although we must never cease to reflect on our contribution, power and ethical behaviours; in addition to BPS guidelines I have several handbooks on my shelf (e.g. Bond, 2000; Tribe & Morrissey, 2005).

As for autonomy I did not pressure them to give answers in any way and they were free to terminate the interview if they got tired. Only one did: I had travelled far and the interview lasted 1 ½ hours. Participation was entirely voluntary, we followed the Interview Guide and there was no pressure to disclose. I was also willing to explain the nature of the research.

As for dignity, I always handle patients and interviewees as equals. I don’t deny that I sometimes show off, but the interviews were conversational and focused on their stories. Once in a while they would be curious about me and I of course answered. There was no reason to fear for my own privacy (as can be the case in clinical practices) and I respected theirs. For instance, I did not ask questions like ‘who’ or challenging with ‘why’ – these were their narratives.

I appreciate that the participants were polite and would feel bad if letting me down there and then – I did not take advantage of this and was careful to treat them with respect and good listening skills. I simply trusted that things that were important to them would come up during a one plus hours interview. Of course, I did 'sell' the potential importance of the research although it would hardly benefit them directly.

I did not encounter any special needs for protection due to either psychological or social reasons, yet it is not difficult to imagine that talking about their lives could bring up issues such as discrimination and sensitive memories. Hence, respect for their autonomy and dignity was demonstrated by simply listening attentively and patiently to their stories. This put them in a collaborative position.

Did I secure "*Scientific integrity*"?

The code says: *"Research should be designed, reviewed and conducted in a way that ensures its quality, integrity and contribution to the development of knowledge and understanding*." (p. 9)

Certainly, passing the REC is not enough. I should demonstrate throughout that the protocol and design were adhered to or deviated from only for a good reason; that the research followed an appropriate method with a sound rationale; and the whole undertaking should be reflected upon continuously from both a quality and utility point of view.

I believe all these aspects have been fulfilled even if I have not always been able to document my reflexivity in chronological order; it became apparent in particular during the write-up how important this is as a research practice.

Sometimes it felt like I should go back and listen to my own thoughts again – the results of thought processes can be very clear while the ideas and thoughts that you rejected go lost. Only the itinerary remains. You don't travel the same road twice and reflexivity can easily lose the extra information. I learned the hard way that reverse engineering is not the same as reflexivity *in vivo…*

Did I show "*Social responsibility*"?

The research should alongside other such research be fulfilling of: *"The aim of generating psychological knowledge should be to support beneficial outcomes."* (p.11) Recovery should clearly be of public interest and in the interest of the public. As psychiatry is known to change very slowly, research should at least have a quality to benefit future generations.

As shown both in Recommendations and Conclusions the research has achieved more than I could expect. The research recommends that an existential formulation is possible and that it will help guide recovery; it could become an additional tool for coordinators and psychologists.

Encouraging better and more optimistic treatments in sync with evidence is clearly a social responsibility; as is the pointing out that recovery from schizophrenia is not only possible, but in fact the rule. In this sense there is at least an indirect and considerable benefit from even small-scale research.

Does my research "*Maximise benefits and minimise harm*"?

It is difficult to know if even 'worth wile projects' will achieve anything. The participants appreciated their involvement and seemed to get a sense of satisfaction from it, yet the findings will hardly be of direct benefit. As for harm, no risk was expected beyond what the participants do every day, but as a pre-caution I asked each participant how it had been and how they felt.

As a clinical judgment I could not see any harm, nor was I approached later. This should mean that the condition was ok.

The bigger benefits would however appear at a higher level. Davidson (2003): *"It has been our experience that the area of overlap between these two interests, that is, qualitative psychological research and serious mental illness, is relatively small and only sparsely inhabited by a few rare, but resilient, birds."* (p.1)

The research was designed to investigate existential themes. Traumagenic theory is gaining evidence and DSM-5 has failed to sync with research; this and other developments has further weakened the concept of schizophrenia. Unfortunately it does not mean that the agony and suffering will also disappear. So if my research can be a small contribution towards better treatment, then this will indeed be the maximum possible benefit.

6 CONCLUSIONS

6.1 Introduction

The purpose of this research has been to investigate recovery from schizophrenia as a subjective, lived experience. Through the collaboration of Mental Helse (Mental Health), by far the largest voluntary mental health organisation in Norway, the research has used a sample of seven persons who have had and still formally have schizophrenia, but remitted as per the criteria in Andreasen *et al* (2005). They are also among the 78% for whom anti-psychotic medication statistically is beneficial (Leucht *et al*, 2012).

Four of the participants have had involuntary hospitalisation and all have at times felt like coerced. The use of involuntary hospitalisation in Norway is among the highest in the world, with a ratio per 100.000 inhabitants on average about five times higher than the UK (Salize *et al*, 2002) and with considerable systematic variation from 180 days in the South to 350 days in the North (Bremnes *et al*, 2008; NOU, 2011).

The criteria for inclusion in the research were: a) formally diagnosed with schizophrenia, b) long-term stay(s) in hospital for one year or more (indicator for severity), and c) remitted and stable with no hospitalisation for at least six years (indicator of recovery). The Brief Psychiatric Rating Scale (BPRS) was used to rule out an on-going psychotic episode at the time of the interview and the participants were also asked to indicate whether this was their habitual condition. The interviews lasted for 1 – 1 ½ hours and were recorded electronically.

The literature review used a structure that more or less follows stakeholder interests/epistemology, in line with Davidson (2003), Foucault (1965), Rulf (2003) and others who are critical of the limitations of the natural science paradigm. Indeed, there is abundant clinical research yet little consensus concerning treatments. A particular complication for research is the fact that central phenomena such as psychotic episodes, negative symptoms, delusions and hallucinations are not restricted to schizophrenia. Triangulation against neuroscience has not yet been successful, as reflected upon in section 2.5. So far it is the complexity, recurrent episodes and chronic nature that characterises schizophrenia, not any unique marker.

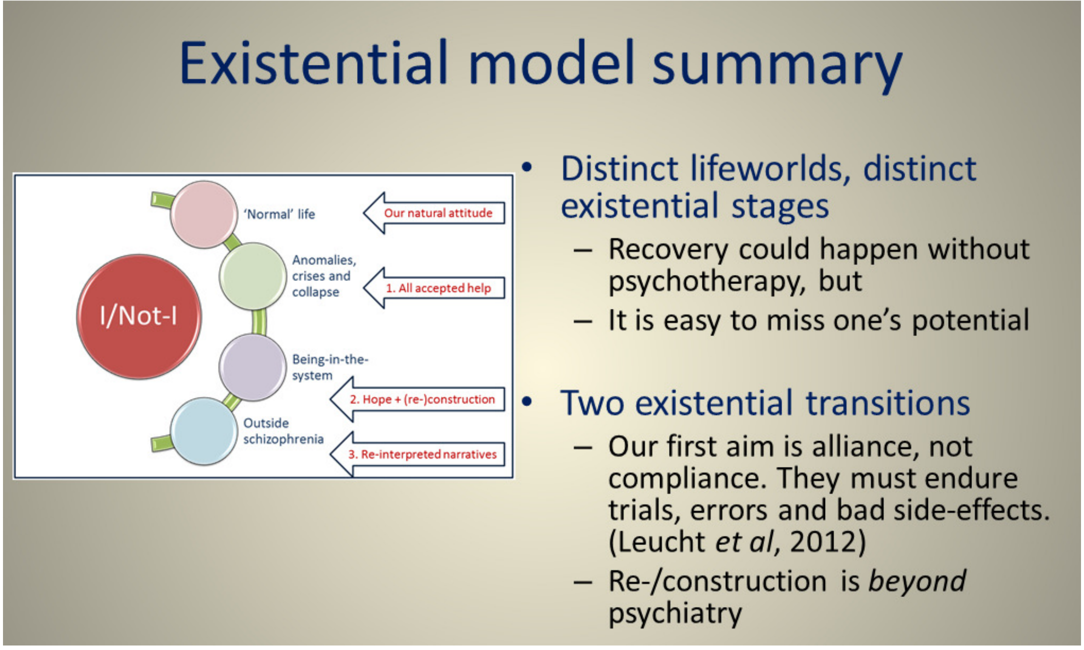
6.2 Emergent and main themes

Existential exploration is a non-medical perspective and a crossroads between psychology and phenomenology. The research is concerned with lived experience and van Manen (1990) proved a good choice for method, which has also been used for similar research (lifeworld, schizophrenia) in the past. Ricoeur's (1981) *hermeneutic of suspicion* was added as it differentiates interpretation from analysis (explication). Phenomenology requires emergent themes to become the results of a *hermeneutic of empathy* (Gadamer, 1995) without recourse to clinical concepts. The emergent themes and the overall sense of the narratives thus converged towards temporality (one of several possible *hermeneutic circles*) conceptualised as three different *lifeworlds*.

Conceptually the research leans heavily on Gadamer's (1995) sharing of horizons – by definition schizophrenia introduces a non-shared world or at least an unreliable world. Arguably, experiences are not fixed as narratives, but become re-interpretations. Importantly, while diagnosis provided an explanation, it was only later that the narratives changed from sick role to survival: they talked about their life as well-being instead of victimisation, persecution or confusion. Their position changed from apparently normal functioning to confusion and/or hallucinations before hospitalisation; to the sick role that goes along with being an in-patient for an indeterminate amount of time, possibly forever; to now survivor narratives. Survival is a subjective rather than objective measure.

The term lifeworld is somewhat ambiguous, but here used in a sense similar to a personal mid-point in a universe of things and people. It lent itself nicely to four existential worlds (Deurzen, 1997; Deurzen & Arnold-Baker, 2005) as an existential analytic. Importantly, as human beings we rely on perception to connect with the world around us (primacy of perception or natural attitude) and Merleau-Ponty (1962) argues that hallucinations are possible only if consciousness fails – whereby he uses consciousness in the psychological sense as an active agency rather than just the neural network. All participants experienced considerable confusion. In bad cases the existential position as mid-point can become so blurred that some are unsure if they exist, or may feel like being somebody else.

Figure 15 Existential model summary



Existential model summary

- Distinct lifeworlds, distinct existential stages
  - Recovery could happen without psychotherapy, but
  - It is easy to miss one's potential
- Two existential transitions
  - Our first aim is alliance, not compliance. They must endure trials, errors and bad side-effects. (Leucht *et al*, 2012)
  - Re-/construction is *beyond* psychiatry

6.3 Main finding: lifeworlds

Their grounding in a previously shared physical and psychological world was failing to various degrees and led to confusion and hospitalisation.

Losing your ground (lifeworld A). Our natural attitude (primacy of perception) results in the perceived world being taken for granted. Failures here become more visible to others than to the affected persons. It is possible to analyse hallucinations in retrospect, but they are often ego-syntonic as self-talk and not likely to be dismissed at this stage. As Oscar points out: *"You often believe what voices say."* (Oscar: 39)

The participants experienced a major change in daily functioning and the main themes were: Not knowing what is going on (A1); Hallucinations are difficult (A2); Crises and collapse (A3); Self-image as important factor (A4); and Using drugs is not a good idea (A5).

Crucially, a so called 'first episode' in medical journals is rather the end point of a gradual worsening of life conditions that ends in hospitalisation. For some participants hallucinations appeared first, and for all a sense that something must be wrong. There is considerable variation but participants had tales of new experiences, confusion and anxiety with attempts to figure out what was going on. Oscar and Harold spoke about their crisis and eventual collapse as including 'indescribable emptiness', perhaps a threat of nothingness that creates anxiety, hyper-reflexivity and confusion (May, 1977; Parnas *et al*, 2005; Sartre, 1956) – a pre-occupation with what is no longer there (nothingness as negation).

This initial phase has been heavily researched as prodromes. Although these do not mark impending schizophrenia, *post hoc* they strengthen the diagnosis and the participants seem to have been no less affected than many others. It is important that complaints and problems in living be taken seriously without referring to schizophrenia (e.g. Bentall, 2003), yet paradoxically not any of the participants sought help.

Being-within-the-system (lifeworld B). This second lifeworld followed after hospitalisation, as a change of environment. They were labelled with mental illness (Theory 2) and placed in a sick role where they must comply with institutional rules and become *Beings-within-the-system*: potentially limited by law in their freedom and at any case subjected to a power hierarchy with rules and controls. The participants belong to those who have been helped by medication and seem to have avoided recurrent psychotic episodes, but they complained about an excessively long time in hospital with a lack of meaningful activities.

The main themes were: You don't need to accept the diagnosis (B1); Trying to make sense (B2); Reactions to medication (B3); Alliances and power balance (B4); Hospitalisation and treatment (B5); Not so meaningful activities (B6); and Some treatments seem wasted (B7).

As psychotherapy was not a core treatment for the participants, we are led to believe it is not a *necessary* treatment. However, an alternative interpretation is more logical: Psychotherapy for schizophrenia has proven efficacy and can change the meaning and even the content of hallucinations, change narratives, and increase the probability for work and social inclusion. Importantly, psychotherapy should increase the odds for recovery if it indeed has the effects that evidence suggests.

Outside Schizophrenia (lifeworld C). The participants confirm a pattern that is also found in the literature research, viz. that remission is the most frequent outcome (e.g. Leucht *et al,* 2012), which in turn means that failing recovery might be more of a problem with society than with schizophrenia itself.

However, we must not forget that some people do not remit from schizophrenia or have intolerable side-effect from medication, that suicide rates are high, and that some simply refuse the help they are offered. For those who accept help (alliance) like the participants did, we can afford to be more optimistic about recovering from schizophrenia or at least living with minimal symptoms.

The themes were: Coping with residuals (C1); Living with identity issues (C2); Family support is important (C3); You must make new friends (C4); and Meaningful activities (C5-C7).

Davidson (2003) and others confirm the research findings: a route out of schizophrenia is helped on a daily basis by anti-psychotics, but hindered by a focus on pathology instead of resources, hope and social life. The WHO studies (Jablensky & Sartorius, 2008), EUNOMIA (in particular. Fiorillo *et al*, 2011; Kallert *et a*l, 2011) and others have shown that psychiatry, as a medical system, is not sufficient and perhaps not even necessary for recovery. The more positive view of recovery as per this research is promising and hopeful – promising because there is evidence that recovery is possible and it makes our work as helpers easier; and hopeful that those affected will be able to follow the path of thousands before them.

Lifeworld C was facilitated by remission and followed by a transition to the outside of schizophrenia. The participants are not angry or rejecting; and they consider themselves survivors and not victims of persecution or injustice. There was no going back to what used to be, though, as schizophrenia meant losing friends as well as social and occupational opportunities – they seemed to regard schizophrenia a one way street where your place/belonging in the world changes and the new lifeworld has elements of both reconstruction and construction. Crucially, the participants had the resources and environment to become un-stuck and enter this third phase, *Outside of schizophrenia*, a term that with effective medication gets an important existential rather than medical connotation.

After remission the need for psychotherapy changes and I conclude: "*Psychotherapy could have offered opportunities for co-constructing meaning, handling/preventing delusions and misunderstandings, creating hope, providing support, clarifying relationships, mastering and interpreting hallucinations, setting reasonable goals and encouraging a healthier life.*"

The (re-)constructed lifeworld meant narrative changes to integrate psychotic experiences as survivors rather than stuck, sick, or victims. Fortunately the participants managed the transition with little help. There are remaining identity issues but they agree that even though not a fair world, at least for them it is an acceptable world.

6.4 Main finding: Two transitions

While lifeworlds describe experience, two major decisions were pre-conditions for the participants' recovery:

(1) Accepting help, although it was not necessary to accept the diagnosis.
(2) Existential (re-)construction including integration of experience rather than denial or rejection.

Accepting help (1). All participants describe a difficult time before hospitalisation. They seem to have felt increasingly disconnected and alone, exhausted and confused to the extent that suicide seemed "a good idea" for at least three of them.

Their eventual hospitalisation seems to be a combination of a) the family encouraging or taking control; b) a degree of self-doubt, later strengthened by talking with other patients; and c) a need for a break from chaos and despair. Hospitalisation offered help, safety, food, privacy, attention, and maybe hope for explanation and resolution. Non-acceptance and non-compliance would probably have paved the way for a very different prognosis.

Crucially, while the research suggests that it is NOT necessary to accept the diagnosis, an alliance leading to acceptance of help is. A trusting relationship was difficult initially, a fact mentioned by all participants; this is underestimated in clinical literature that instead focus on controlling symptoms. Accepting the diagnosis however also means potentially accepting the madness identity that goes along with schizophrenia, even if it is today not so much madness as potential madness (dangerousness). The message at the time of their hospitalisation, according to them, was that schizophrenia is chronic, irreversible, life-long and without hope of recovery.

Existential (re-)construction (2). Their hospitalisation started at 16 to 24 years of age, which makes it more appropriate to talk about treatment as constructing rather than re-constructing a life after hospitalisation. This second transition can become a missed opportunity if it is not supported by psychotherapy. Of the seven, three said that psychotherapy had been very useful, while the others were neutral or could not remember having had regular appointments with a psychologist – signs of a weak treatment regime. In contrast, Lysaker *et al* (2010) conclude that going forward takes a subjective appraisal of life circumstances and the experience of oneself. A deeper sense of direction (a Sartrean project?) becomes available through psychotherapy. Remission, narrative change and recovery become according to Davidson (2003) possible when there is a VIP, a very important person, who continues to believe in you and helps you up from the hole. The participants in fact confirmed such a central role of a family member, in most cases a mother. A psychologist should ideally play an equally important role.

The participants' symptoms have remitted and from an existential vantage point the issue no longer is symptoms, but a relative lack of social inclusion and meaningful occupation. If the dissertation supports a main hypothesis, it is that recovery must be actively supported or else it might not happen.

6.5 Recommendations

The participants say they mostly enjoy their freedom and independence and don't think of themselves as much different from others. My research confirms that the participants judge themselves capable of far more than is made available as opportunities in a community care system. When remission is more the rule than ever, we have a duty to help avoid unnecessary stigma, self-stigma and isolation.

The fact that so many are helped to remission by antipsychotic medication strongly points to recovery and meaningful daily activities as sensible goals for psychotherapy. Remission is the minimum goal of psychiatric treatment, but is not enough for well-being and social integration. The psychologist role would need to be more focused on strengthening the healthy side of the person. The research highlights the need for long-term emphasis on adjustment, well-being and social functioning. Admittedly, this sounds paradoxical for a mental illness that is traditionally regarded as one of the most severe and chronic conditions. However, the participants confirm research literature that schizophrenia is no longer a life sentence nor disability.

Unemployment followed by community services is difficult to escape and the research points to a need for psychologists in at least three major roles. The first major role is in selecting treatment options aimed at recovery and customised for the individual. Because involuntary treatment can lead to vicious circles, it should be avoided, if possible, and research could answer how psychotherapy leads to accepting help (transition 1) and paves the way for a more optimistic outlook (transition 2).

Second, psychologists should choose psychotherapies that accommodate meaningful personal growth, adjustment, scaffolding and existential reconstruction (ref. section *2.3 Therapeutic environments).*

A third major role is supervision. Schizophrenia has unique features and problems, which means that supervisors should have training in neuropsychology and phenomenology. Psychologists are ideally situated at the crossroads of psychiatry and existential adjustment – supervision should replace the focus on symptoms for well-being and narrative change.

6.6 Limitations

The dissertation has limitations and strengths due to being qualitative research. The data are detailed and saturate the main themes, but the participants have self-selected and the sample is thus biased. They deny early childhood trauma that could have damaged a developing brain; they avoid illegal drugs; they are compliant; and they all had at least some solid family relations. It is unclear whether their claims of no trauma are accurate, but it is taken generally not to be an important cause for schizophrenia even though it is for dissociation.

Their extensive period of staying as in-patients provide evidence that they have not been light cases of schizophrenia. More in-depth questioning, assessments or journal reading would have been useful.

A lifeworld theory must cover also cases with worse outcomes, such as not accepting help, denying problems or self-medicating with tranquilizers or illegal drugs. This should lead to re-hospitalisation and lack of transition into lifeworld C. This should also be expected for those who are not among the 78% who according to Leucht *et al* (2012) have effective medication. International studies however indicate that considerable variation in outcomes between treatment regimes is important – in this case everybody were inside one system.

Even if the transition points are probably strong conditions for therapeutic progress, further conceptualisation is needed to verify a lifeworld model for treatment purposes e.g. via grounded theory as an adjunct to IPA. For instance, Charmaz (2006) is specifically recommended by Smith *et al*, 2009).

The failure to triangulate against neuropsychology was at one level disappointing, but on the other not central to my research interest. There are still more questions than answers; in particular, the psychotic experience as a phenomenon is different from 'daily schizophrenia' and has in common with many other conditions that it is responsive to medication and thus covered by the dopamine theory. Here consciousness seems to be central – probably both distorted representation of physical or imagined objects in neural networks and disturbed awareness, attention and focus.

I have only superficially reviewed genetics and epidemiology. I believe much of the on-going research can be helpful in the future, but do not see how it will benefit those affected until the theories can be confirmed in brain research and, more importantly, as neuropsychology.

The research suggests the importance of systemc factors, but I have not discussed this in depth (e.g. institutions, alternative treatments, community programs, funding or training) nor critical psychiatry as a movement. The research deals with phenomena that are real even if not finally conceptualised. Cognitive remediation seems promising and confirms neuroplasticity.

Using Ricoeur's (1981) *hermeneutic of suspicion* has led to a certain duplication of content and argumentation between Findings (explication) and Discussion (interpretation), and perhaps some inconsistencies for which the author apologises.

Hopefully, the participants will recognise themselves, their stories and their horizons; if so, I will have fulfilled a major interest, which was to find out how psychologists can be more helpful to persons with schizophrenia. The research has shown that we can these days afford to be more optimistic about schizophrenia.

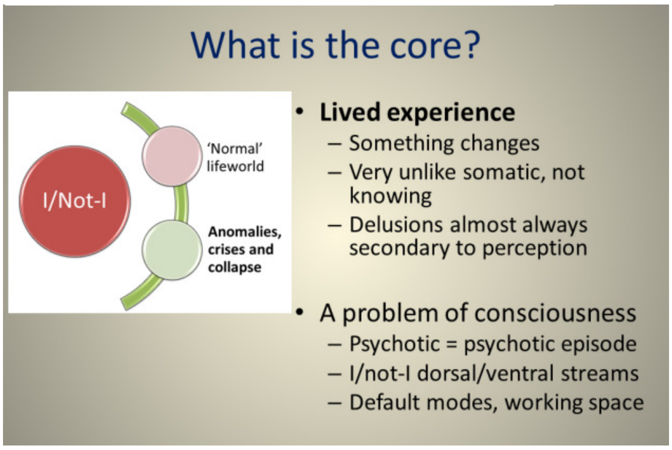
CHAPTER 7 CLINICAL IMPLICATIONS: AN EXISTENTIAL APPROACH

7.1. Findings and Rationale

After almost 100 years of medical theory we still have no reliable markers of schizophrenia and no reliable prognostic indicators for remission. Research into genetics, epidemiology, brain correlates or psychological patterns indicate that in order to make sense of schizophrenia, the concept itself will fall apart.

As psychotic episodes often result in inadequate social behaviours and difficulties for the affected person, early intervention is important. Not to stop schizophrenia (it is typically progressive, but not neurotoxic) but to avoid negative social consequences.

Figure 16 What is the core change



What is the core?

- **Lived experience**
  - Something changes
  - Very unlike somatic, not knowing
  - Delusions almost always secondary to perception
- A problem of consciousness
  - Psychotic = psychotic episode
  - I/not-I dorsal/ventral streams
  - Default modes, working space

My recommendations are based upon the findings and supported by literature research: the two transitions serve as focal point for treatment: (1) acceptance that you need help and (2) the hope for recovery and a better life.

A baseline lifeworld

Personality plays as big a role in schizophrenia as in any person's life and clinical experience attests to the many that in hindsight seem to have had complaints and prodromes (not the same thing) for years prior to the onset of schizophrenia. There is no evidence that paranoia is a specific sick place in the brain. For instance, both hallucinations and paranoia are relatively frequent. Even for the ultra-high risk category (UHR, schizotypy) only 1 in 2 persons convert from prodromes to schizophrenia (van Os, 2009); and even bizarre hallucinations (Schneider's criterion) have been dropped because insufficient to diagnose schizophrenia.

Mental health workers seem to focus on early complaints and problems, but at the expense of seeing personal resources; points of strength, interest and bright spots; resilience or best functioning. Without doubt this is a heritage from the catharsis paradigm, which leads away from those elements that are the most important for recovery and resilience.

The baseline is what we should consider as a relatively normal existence for a particular person. What used to be everyday functioning will be a realistic measure for successful remission. Clinical journals tell us little about how they lived their lives or what they would be capable of doing with motivation, energy, determination, support and a suitable environment.

Exploring the baseline existentially would mean that we wouldn't put everything into shallow (neo-)Kraepelinian categories. Surely physical damage in the brain can lead to vigilance, suspicion and paranoia (as with dementia), but research says we should also look for a traumatic background (see 2.4.4) following which a pattern of vigilance and paranoia is a normal rather than abnormal development.

In any case paranoia is still dysfunctional, but would be better understood as a personality disorder (DSM axis II core beliefs) and not a brain deficit.

We must consider that the conceptualisation of personality disorders in DSM-5 is still not aligned with psychological research, such as dimensional personality scales and the use of axis II and co-morbidity. An existential formulation should use evidence-based concepts wherever the diagnostic system is not up to date.

What we are interested in is simple: those things in a person's lifeworld that are important assets and liabilities for recovery and (re-)construction. The baseline is an ethical imperative: the baseline person did not have a schizophrenia diagnosis!

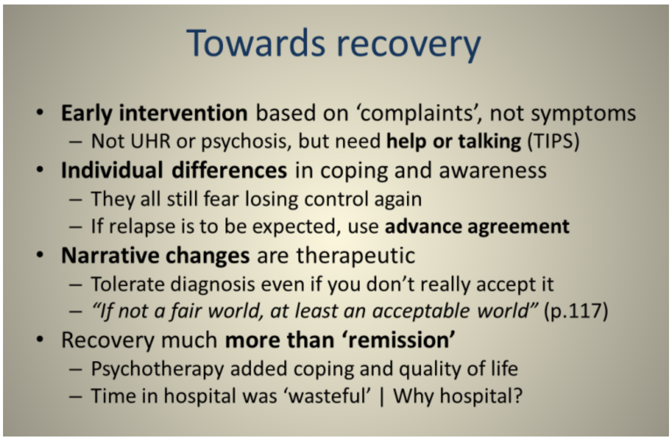
Early intervention in lifeworld A, when gradually losing your ground

Our lens becomes different when the person starts to change behaviours and clinicians start to see the signs that we recognise as prodromes; in an early phase it is not unusual to release a patient but be almost sure he or she will come back later.

Early intervention is difficult, though. Offers of help after release are often rejected and within an acute ward there is not enough time; Transition 1 (acceptance of help) gets delayed. Instead of hospitalisation the TIPS project in Stavanger () uses an early intervention referral system that does not imply madness; this should accelerate Transition 1 (furthering understanding and acceptance of help).

Diagnostics is difficult at this stage. Psychiatrists argue that diagnostics have become more reliable, but such consensus is likely a result of education and training (see section 2.2.2 Diagnostic reliability or lack thereof). With similar backgrounds we often look for and find the same things – this type of reliability is often mistaken for validity.

Figure 17 Recovery is more than remission



Towards recovery

- **Early intervention** based on 'complaints', not symptoms
  - Not UHR or psychosis, but need **help or talking** (TIPS)
- **Individual differences** in coping and awareness
  - They all still fear losing control again
  - If relapse is to be expected, use **advance agreement**
- **Narrative changes** are therapeutic
  - Tolerate diagnosis even if you don't really accept it
  - *"If not a fair world, at least an acceptable world"* (p.117)
- Recovery much **more than 'remission'**
  - Psychotherapy added coping and quality of life
  - Time in hospital was 'wasteful' | Why hospital?

Instead it is important to take any psychological or somatic complaint seriously, without speculating. Early intervention can be effective if the person can then avoid troubling emotional, psychological and social consequences. All research participants had such negative experiences.

The complaints and issues in this period should not be under-estimated. Even for the participants, who have remitted and recovered, this period was seriously disturbing. It is an ethical obligation to educate both public and doctors that schizophrenia does not equal lifelong misery, madness and a stranded life: such myths delay help seeking. The participants say this in hindsight, but it is less clear if this was a factor in their first phase.

Supported recovery in lifeworld B

The participants accepted that they needed help and also accepted the help being offered (transition 1). Ideally transition 1 should follow from an early intervention that saves social relations and avoids disruptions. Two risk factors: some will already be on illegal drugs, while 22% will have little effect from antipsychotic medication (Leucht *et al*, 2012). The participants confirmed that a 'trial and error' period is likely while using the medication algorithms – we need to be open to this fact.

Fortunately things have changed to make recovery more realistic than ever. Research confirms beyond reasonable doubt that there is an outside of schizophrenia for most affected. Mental health workers should say this consistently, because it paves the way for transition 2 later (hope of recovery and a future). As seen in the recovery research and from the participants in this study, optimism is not unfounded.

The rule of thumb is that 2/3 will get better. The problem is that we don’t know for whom and when full recovery will be possible; response to medication is only one predictor.

Despite the potential for collaboration, Norway has kept a world record in forced treatments and the participants received few of contemporary evidence-based interventions and environments. This reliance on biological psychiatry cannot continue: only evidence based treatment can be ethical. It is a breach of human rights to force treatment that is not evidence based, no matter the intention. Psychiatry has a dark history and its excesses must be kept in check by the law.

In this phase it becomes clear that *recovery as a treatment goal* requires more than absence of symptoms; an existential approach to recovery creates an environment conducive to a whole set of activities outside of a hospital setting.

Many patients are coming from bad backgrounds and struggle with severe distress to the extent of existential anxiety, dissociation and loss of proprioception; traces of this could be inferred for Harold, Nicole and Oscar in particular. Really what we're saying here is to get deeply into a person's lifeworld, which probably calls for a psychologist.

Self-managed recovery in lifeworld C

Both of the transitions (first acceptance, then hope and hard work) are targets for treatment in lifeworld B. Hospitalisation should be no longer than necessary while the system must continue to offer support. The goal should be independent living whenever possible. Unfortunately, my participants were considered unable to do anything much with their lives. They had accepted this, which brought my thoughts to self-stigma: If you don’t believe you can do something, you usually can’t.

Getting into or back to working life may take time and a staged approach. Both Nicole and Oscar tried going from 0% to 100%, which was not only naïve in hindsight but appears a predictable and unnecessary failure.

Paradoxically the Norwegian system used enormous resources on hospitals (they all stayed for a year or more); while underestimated their personal resources and failed to offer job training/support relevant to their education and level of functioning. The social world is so important that exclusion from working life leads to social isolation. On the road some may need halfway housing and some will simply continue to live in a collective house such as a farm. And if you never had a family then halfway houses are a way of living that is both independent and meaningful. You can earn money for yourself while learning to cope. Why indeed should everybody be 'normalised' and live in apartments?

Not only should this be a phase of social recovery and personal choice, but the goal is simply independent living and mastery of life itself. If it doesn't work then the person will likely remain in Lifeworld B, learning hopelessness and being taken care of by a system for the rest of their lives.

My belief, supported by this research: we should treat schizophrenia actively not according to symptoms, but according to where people are in their remissions and recovery. Remission criteria (Andreasen *et al*, 2005) are implicit in recovery, but it seems that remission without well-being (e.g. too much medication) impedes recovery.

7.2 Clinical elements and principles

A review of some important elements would now be useful.

People, not symptoms

Whether we accept schizophrenia as a construct or not the phenomena that we call schizophrenia are disturbing to the degree that they lead to hospitalisation and fundamentally change the direction of your life project as well as your position in it.

While it should be obvious to put the people in the centre of their own treatments, the participants said they were not. We as psychologists should understand both the baseline and the three stages: I found it very useful to introduce the term lifeworld as a metaphor for the subjective totality of a person's experience: past, present as well as perceptual and cognitive.

Recovery is a whole-person journey that can be facilitated by different kinds of interventions. Here we would recommend a dose-respondent approach for all medication, psychotherapy and social/clinical support. For most it seems that recovery entails both co-creating hope and future, although it seems the new life will be with new friends for most. This means new meeting places independently of community services. The participants were clear that it meant good-bye to illegal drugs and unhealthy friendships.

An existential formulation can match, embrace and support the notion of recovery.

Dealing with ethical issues

Self-determination is a superior goal, yet informed consent does not resolve all problems.

For those who refuse treatment the criterion *'danger to oneself or others'* is usually sufficient for compulsory detention and treatment. In Norway the law has added a *'decay criterion'* that seem to have followed from the neuro-toxicity assumption. Schizophrenia simply seems to take a path that medication can alleviate but not stop.

Leucht *et al* (2012) find that 22% have little or no benefit from antipsychotic medication. If a small dosage does not work, a larger dosage is unlikely to be better (e.g. Bentall, 2009; Romme, 2012). And when it works after the usual trial and error (aka algorithm), it should be reduced to a minimum: instead of the long-term sedative level that Big Pharma and Wall Street love, a contemporary approach consists of clinical staging, *ad hoc* or low dosage medication plus psychotherapy.

In Norway a major public report (NOU, 2011) concluded that we must allow more room for self-determination and less compulsory treatment. Even as nothing much has happened since and we are still world leaders in compulsory hospitalisation (table 2) the report is very much in line with my research. Action needs to follow.

The ethical use of medication

Research and clinical experience show that medication is helpful in psychotic episodes and that a small maintenance dosage can be useful. The rationale for using medication is often spurious:

Antipsychotic medication rests upon the dopamine theory and has all the limitations of other 'resetting' theories that also include SSRI, painkillers, anxiolytics and ECT.Antipsychotic medication seems to affect hallucinations primarily, while leaving other symptoms more or less unaffected. When SSRI reduces pleasure as well as pain; antipsychotic medication seems to reduce both avoidance (bad thoughts) and approach (producing lethargy, which interestingly is a negative symptom) – it simply weakens the reward system.

Most people with hallucinations are non-clinical and do not get a diagnosis; those who do will continue to carry theirs even when remitted and recovered: once schizophrenic, always schizophrenic. This attitude is neither ethical nor evidence based.

Dopamine cannot explain schizophrenia but Kapur (2003) captures its role nicely with the phrase *'dopamine as the wind of psychotic fire'*.

Medication leaves us with a serious ethical problem: Is antipsychotic medication perhaps just that and not a medication for schizophrenia? Antipsychotic medication seems to be effective with all kinds of psychosis and while it seems to reduce EE, anxiety and hallucinations, it might also aggravate negative symptoms. Too much medication gives a zombie-like, unpleasant condition and for some even loss of control over voices, so should be avoided.

The role of psychotherapy

A clear clinical implication of this research is to add the two transitions as treatment goals. A treatment theory without psychotherapy can hardly be defended and the independent role of psychotherapy is clearly anchored in clinical guidelines.

Literature research seems to indicate that many are critical of psychiatry and attribute success to factors outside psychiatry. This is at least partly correct e.g. the role of Davidson's (2003) Very Important Person – somebody who stays with you no matter what, a person you can trust to be honest and supportive when your senses fail. Interestingly, psychotherapy did not in my research seem to be necessary for recovery.

Yet this might not be accurate, depending on the role of psychotherapy. If we assume Rogerian factors in their environment and all but Mary had a VIP for emotional support; and nurses/milieu therapists that they liked and trusted; then very much is achieved already in terms of a therapeutic environment. Also, four of them in fact had psychotherapy at one time or the other if not in hospital, then in the follow-up.

Another important point is that we usually think of psychotherapy as a private or group session – yet it is possible to have similar interventions *in vivo*. Perhaps psychologists would do better to participate where social interactions happen instead of relying on stories.

What it probably means is that therapy for schizophrenia must be tailored in each case; it is a pervasive condition as such and it changes your life. Although medication might be the first line defence and successful at keeping hallucinations at a tolerable level, psychotherapy might be necessary for the quality of recovery and well-being; and that it increases resilience, coping and therefore the quality of recovery. It should therefore be routinely offered as ethical practice and according to NICE CG82.

Notably, recent findings in traumagenic theory suggest that brain changes could follow from early trauma and enduring distress. This would be compatible with neuro-developmental theory and the phenomenon of dissociation. Psychiatrists that I met recently hypothesised epi-genetic changes in the brain schizophrenia: heritability is now unlikely.

Guidelines and evidence favour CBT, art therapy, family involvement and groups (e.g. NICE CG82); with traumagenic theory now adding to the need for such therapy. It contrasts with what Harold called a *'place for treatment without treatment'* (Harold:50), which sounded more like a perpetuation of the sanatorium idea with rest, food, fresh air and medication.

Coping and meaning is central in recovery for schizophrenia, and much more important than medication. What they fear is the psychotic episode, their definition of 'being psychotic'. This distinction is therapeutically and phenomenologically very important.

Milieu therapy

Milieu therapy is a term used rather broadly about the daily life in psychiatric, childcare or elderly institution; or more narrowly about a regime of therapeutic interventions. Read *et al* (2006) agree with Mosher (2004) and others who have shown *"that 'schizophrenia' is more effectively treated by ordinary human beings in ordinary homes than by medications in hospitals."* (p.46)

Milieu therapy in this recommendation understood as therapeutic interventions reinforcing motivational and therapeutic goals – a sense of coaching to nudge, motivate, encourage and reinforce sometimes very modest changes. Do celebrate successes in the right direction.

Milieu therapy in a hospital is not the same as in halfway houses. As we have seen, the need for assistance/coaching with daily living varies with the individual, the stage you're in, background, severity and what we might simply call personal resources.

Milieu therapy supports therapeutic goals and is different from befriending. Milieu therapy activates personal resources and interests with the view of creating fundamental, willing change. You can add various activities incl. mastering daily chores, handling personal finances, homework, cooking, writing skills, or simply getting up in the morning. Sometimes it may require considerable support and encouragement, such as working with self-esteem, getting new friends, learning a craft or regaining skills. The Vygotskian term 'zone of proximal development' or ZPD is useful when thinking about milieu therapy; the ZPD is individual and here-and-now.

Sometimes the patient needs scaffolding, sometimes a container for bad experiences, lowering expressed emotions (EE), preventing aggression or simply feeling helpful and being appreciated. If we take positive psychology (e.g. Fredrickson, 2009) seriously, in order to grow well-being we all need more than 3 positive experiences to outweigh 1 negative. This ratio is rare in hospital settings and is an argument to limit the time there and also to introduce meaningful activities throughout. Harold seemed to speak for thousands of people who spend time in psychiatric wards – a place to store people away.

As Davidson (2003) asserts – to get out of slippery holes we need both stamina and help. Activities can be external such that milieu therapy is more about simply encouraging participation in groups for voice hearers, reading groups, sports, meditation, yoga *et cetera.* There is a whole array of possibilities that can work alongside hospitalisation, in a halfway house or in independent living.

When remitted and stable, narratives change to stories of mastery and they should be recognised and celebrated.

Assisted social recovery

Interestingly, WHO (e.g. Jablonsky & Sartorius, 2008) and other studies identify social environments as an independent resource for recovery, albeit certainly also a cause of vulnerability and delusional content in the first place. Recovery is more than absence of symptoms i.e. remission. It is an independent process with seemingly different 'lifeworlds' in terms of self-centre, phenomena, reactions and ways of coping.

Psychotherapy can hardly work without an amenable daily environment.

What works? Soteria (Bola & Mosher, 2003) based environments seem to work very well with their own Ciompi’s affect logic model (Ciompi & Hoffmann, 2004). This is a form of milieu therapy as are other approaches such as cognitive milieu therapy, Vygotskian (theory of mind, zone of proximal development) and applied behaviour analysis (ABA). A choice must be made as to the balance between systemic and individual level interventions.

Importantly, in milieu therapy we often try to protect a person – a patient who maintains the bonds with family and friends will clearly have a better resource for social recovery later on.

Coordination and supervision

Perhaps the most important task of the psychologist will be continuity and coordination. Typically you get to talk with so many people as to be confused, and it is virtually impossible to document everything reliably. A psychologist who reads an existential formulation will easily remember, and a new coordinator can pick up quickly and avoid the usual silly questions.

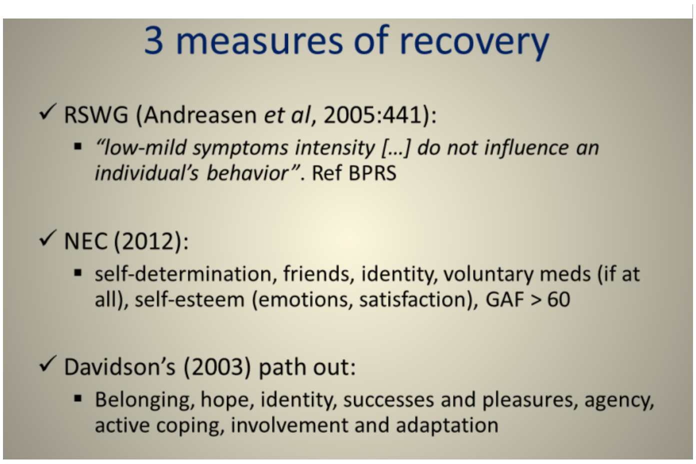
An existential formulation should be shared with the person, family and friends as it a life story rather than diagnostic judgement.

7.3 Existential formulation – a key recommendation

The funding of medicine and psychiatry is organised around diagnoses. This will hardly change, so an existential formulation does not replace other journals. It is meant to document needs and resources, and it must be realistic and therapeutic. It will continuously be reviewed and changed. The focus must be on the current lifeworld, not pathology or irrelevant history.

As needed, the existential formulation might lead to psychotherapy as a planned series or available in response to complaints; this would break with a standard plan based upon a diagnosis. Such formulations will need to counter what Harold called *'a place for treatment without treatment'* – staying for a full year in a system led by doctors seems unnecessary, excessively expensive and not the best way to meet participant needs.

Figure 18 Measuring recovery



3 measures of recovery

- ✓ RSWG (Andreasen *et al*, 2005:441):
  - *"low-mild symptoms intensity [...] do not influence an individual's behavior"*. Ref BPRS
- ✓ NEC (2012):
  - self-determination, friends, identity, voluntary meds (if at all), self-esteem (emotions, satisfaction), GAF > 60
- ✓ Davidson's (2003) path out:
  - Belonging, hope, identity, successes and pleasures, agency, active coping, involvement and adaptation

Together with a coordinating psychologist the person herself should be the active party in describing what life is like. After transition 1 and stable medication, the possibility of halfway houses should be routinely discussed. If a person needs vocational training or a part-time employment, this can more easily be offered with base in halfway house.

The formulation is particularly important in early intervention because there is no 'standard schizophrenia'; I deliberately chose the term *'gradually losing your ground'* because this is what the participants were telling; they were not experiencing 'prodromes' or symptoms. They gave their experiences a meaning, albeit in hindsight a 'sick' one that was later corrected. Crucially, the phenomenon then and now are not the same; which means that an existential formulation is like writing a biography. In contrast to a clinical journal, we are automatically interested in a biography of our lives. In the hands of a psychologist it easily becomes an agreed treatment plan.

The slide shows the kinds of concept that goes into an existential formulation, and below a 4x4 matrix that includes Deurzen's (1997) four existential dimensions.

Table 17 Existential matrix, journaling

	Baseline	**Lifeworld A**	**Lifeworld B**	**Lifeworld C**
Physical (comfort, food, drugs, sex, things, money)	Describe how it used to be, what was pleasant and not, energy, friends, what you dreamt about, what you believed etc. This also shows interest and respect	How you changed	Et cetera	Et cetera
Social (friends, family, work, partner, helpers, children)				
Personal (self-esteem, body esteem, confidence, acceptance, motivation, projects, acceptance, emotions, guilt, shame)				
Spiritual (meaning, religion, beliefs about life, hopes, dreams, sense of purpose)				

For reasons of ethics and effectiveness alike, the affected person should own his or her own life narrative and treatments. The recommendations should lead to a person-based formulation, first started by the coordinating psychologist and then increasingly owned by the client and the psychologist together. This secures integrity and correct formulation while avoids speculations and omissions. It does not need to be part of the journal, although the therapy rationale should be in both places.

Lifeworld A: Gradually losing your ground.

Main topics for lifeworld A could be as found in the research:

- Not knowing what goes on (A1)
- Tackling hallucinations (A2)

- Crises and collapses (A3)
- Changes in self-esteem and self-image (A4)
    - Positives/protective: trust, resilience and optimism
    - Negatives: loneliness, trauma/re-traumatisation, shame
- Using drugs (not a good idea) (A5)

When they were interviewed they had accepted and integrated what their families, friends and carers had observed and thought about them. They were at ease and had accepted help (transition 1), their symptoms had partly remitted and they had gained hope for the future (transition 2). Later this comes up as narrative distance; stories that change as we go.

Possible schizophrenia must be taken seriously so the goals of treatment in lifeworld A:

- Offer psychotherapy for complaints incl. existential formulation according to clinical intuition
- Explore consciousness and primacy of perception (A1, A2, A5) – e.g. exploring with help of the Maastricht Hearing Voices interview
- Prevent or deal with crisis, collapse and self-issues (A3, A4) – with the goal to avoid aggressive behaviours, suicide attempts and involuntary hospitalisation

This phase is the window for early intervention but the language of prodromes may make no sense to the affected person and many of them will not convert to full blown psychosis and even fewer to schizophrenia (van Os, 2009). The subject matter should therefore be on complaints (Bentall, 2003) and phenomenology; keeping it to lived experience instead of speculations from either side.

Psychiatrists should not talk as if it were schizophrenia in the coming because we cannot know; and the affected person should be encouraged to be specific and experience oriented rather than speculating about monitoring, implanted chips or some spiritual phenomenon.

Lifeworld B Living within the system.

When clients are inside the system, an exploration *should* be easier. It is probably not, however, as exploration will be different from the idea of 'objective observations' and the psychiatric definition of phenomenology as an 'on-looker's version'. Exploration needs to be a facilitation and co-exploration, perhaps as taken from my research:

- You don't need to accept the diagnosis (B1)
- Trying to make sense (B2)
- Reactions to medication (B3) – trials, errors and frustration
- Alliances and power balance (B4)
- Hospitalisation and treatment (B5)
- Not enough meaningful activities (B6)
- Some treatments seem wasted (B7)

Note that B1 is controversial because psychiatry sees 'insight' as necessary for compliance. The goals of treatment in Lifeworld B are:

- Accepting help and making sense (B1, B2)
- Patience and medication (B3) – stabilisation with or without medication
- Hospital treatment and alliances (B4, B5) – including milieu therapy, homework, habit changes, existential formulation and protection of resources and relationships; multiple, flexible, evidence based therapy
- Daily activities (B6, B7) – getting on track with normal life again; avoiding stigma and instilling hope

Lifeworld C Outside schizophrenia again

The issues to be formulated would include

- Coping with residuals (C1) – incl. those in BPRS, minimum dosage
- Fixing and/or living with identity issues (C2)
- Family support (C3)
- Making new friends (C4)
- Meaningful occupation (C5-C7)

The goal of treatment in this phase is

- Coping with residuals (C1) - daily living with minimal medication; avoiding relapse, including low threshold self-admittance
- A reconstructed self | Identity and Eigenwelt (C2) – psychotherapy available for life issues, without referring to schizophrenia

- Social recovery (C3-C7) – belonging, occupation, get up in the morning, new friends

The two transitions become therapeutic milestones; after each transition the therapy will certainly change in character and contents. Such formulations can begin with the psychologists already in the first meeting and as part of journal notes. Discussing complaints was better and more existential than speculating about diagnoses and comorbidity.

Rather than clippings from new or outdated journals, the existential formulation should be up-to-date and relevant for where the patient is currently. The existential formulation should be modified such as to cover well-being, social inclusion and the ability to function in normal daily life:

- Developmental background, including asking for early trauma
- Resources and maximum daily functioning (baseline) as a goal for recovery
- Lifeworld A – gradually losing your ground ('what do you think of it now')
- Lifeworld B – being-within-the-system i.e. acceptance, reactions, coping and complaints
- Lifeworld C – Outside schizophrenia i.e. healthy behaviours and resources with the goal to encourage and strengthen them through positive psychology and psychotherapy

Psychotic episodes can never be ruled out completely. They can come and go along the way, so therefore adequate signals and responses need to be planned for and coping techniques trained. Fear of particular emotions ('affect phobia') should be addressed such as to reduce the psychosis and anxiety; which in turn will reduce the need for medication.

Depression, anxiety and other issues that are not symptoms of schizophrenia should not be seen as a consequence of schizophrenia; general practitioners should be better educated.

The participants had not received optimal treatment from an existential point of view. It should be noted that they are remitted (BPRS) and since living independently with good daily functioning their GAF would be around 70-80. Generally speaking they are satisfied with life, which is what they want for themselves. (This is fine. Speaking for myself I have probably only touched GAF 100 in an over-optimistic, unrealistic state such as being in love – and others are probably no better). A GAF of 70 is a great therapeutic goal.

7.4 Clinical strategies

The purpose of an existential formulation is to capture what emerges as important to a person, starting with background and complaints; then inviting to a collaborative exploration. As most people get tired of telling the same story again and again, this is also a chance to explore life with one person, the psychologist coordinator. People who come and go cannot expect the necessary trust and confidence. It has to be an authentic interest and collaboration – taking the time.

Table 18 Layers to recovery

<table>
<tr><td colspan="4">Recovered and living a normal life to the maximum of your ability</td></tr>
<tr><td colspan="4">Hope as transition 2 | Remitted and halfway</td></tr>
<tr><td>Normal life, homework</td><td>Medication</td><td>Psychotherapy</td><td>Milieu therapy</td></tr>
<tr><td colspan="4">Co-operation as foundation for treatment (transition 1)</td></tr>
<tr><td colspan="4">Existential formulation as psychological framework</td></tr>
</table>

Strategy 1: Psychologist as coordinator | a change of thinking

A first hospitalisation is confusing and difficult not the least because like the participants many will have kept disturbing episodes to themselves. They might talk about complaints and depression, but 'forget' to talk about voices and feelings of being misunderstood. The participants had been hiding their suffering, anxiety and confusion from friends and family, often understood just as social isolation and withdrawal. Considerable shifts in behaviours should always be taken seriously.

Crucially, 'being psychotic' had a different definition from that of psychiatry; it was directly connected with the fear of losing control. Therefore perhaps *psychotic episodes should be regarded as a distinct phenomenon rather than ongoing 'mental illness'.*

The vocabulary of recovery is different from medical symptoms and psychiatry. The nature of psychosis leads to inadequate behaviours described in everyday language, as if things really are as they appear. This is very important for the language of exploration, but it is also phenomenologically really true. My existential analytic is phenomenological and to re-iterate some of the main elements:

- primacy of perception – when we doubt our senses or hallucinations interfere with our daily life to such a degree that we cannot function
- intentional arc – when our actions are no longer understood by others and they become unpredictable such that we can no longer function socially

- centrality of language – when we describe things that others don't see or hear (non-shared objects) and they comment that we talk gibberish and un-understandable
- existential anxiety – when we become afraid of the world and liable to misinterpretations, biased thinking and attributions

I take psychotherapy for granted and propose some specific principles:

- Use a whole person view (existential formulation) in addition to (inevitable) diagnostics.
- Recognise that experiences can be pervasive, adverse and traumatic, requiring special interventions
- Take traumagenic theory seriously when making sense of contents.
- Also consider a) the fact that people can recover fully and b) experiences with cognitive remediation as indications that neuroplasticity should not be under-estimated in treatment
- Offer psychotherapy early for complaints, without assuming prodromes. For instance depression and anxiety are separate diagnoses and not symptoms of schizophrenia, and there is no such thing as a schizophrenic personality.
- Define and treat psychotic episodes as episodic psychological content, not just as chemical spikes
- Realise that schizophrenia is a social disease because the stigma stays even after full remission

An existential formulation takes into account the person's resources and environment, consistent with the three lifeworlds and the two transitions. The deeper analysis of the period of best functioning sets a baseline – this can serve as the maximum functioning after full recovery. This can be seen most clearly in the case of Russell, who managed to take a master's degree while at the same time coping with hallucinations. It makes no sense to use the same treatment for him as for somebody with a dual disorder who refuses to take medication.

We know that brain changes can follow from early trauma and enduring distress (see the comments on synaptic growth and pruning, plus the section on traumagenic theory: *The impact of childhood trauma and adversity*). The catharsis idea does not have evidence for schizophrenia – which means that psychoanalytic treatments are contra-indicated. This is consistent with recommendations for trauma treatment.

A warning is necessary. Psychosis can be so complex as to warrant special skills and a team approach. This is the case for catatonia, dissociation, cognitive deterioration, confusion and loss of proprioception. The same phenomenon can have several sources – we will probably always need psychiatry for differential diagnosis.

Usually there is not much doubt about the situation and the coordinating psychologist should make sure that milieu therapy is coordinated and relevant for the person's stage of lifeworld, such that it can be continuous in and out of treatment settings including Soteria and half way houses, low threshold self-referrals and occupational rehabilitation. Research in low-income countries with almost no medication is that our hospital systems may be necessary to curb psychotic episodes in a Western lonely world where we don't know our neighbours and life is too fast for many, while recovery seems to be environmental and societal.

Strategy 2: Early intervention

In the clinic many will have lost many of their daily skills temporarily and it is easy to think that low IQ and GAF 40 is their normal level. We should never make judgement about a rosebush in a cold month.

It was easy, deceptively so, to accept what the participants said about their childhood as normal. By looking closer however, there were traces of enduring distress for half of them, even if perhaps no recall of traumatic experiences. We cannot say whether they were on the traumagenic continuum, but many with schizophrenia have experienced unusual adversity, traumatic events, aberrant behaviours, poverty, and street violence; they have simply been under the radar and should have received help in childhood.

When schizophrenia is suspected, Romme (2012) asserts that early interventions should explore and normalise, and we should be interested in lived experience and the underlying core beliefs. The Maastricht Hearing Voices Interview (Romme 1990; Romme & Escher, 2000) can be used for a lifeworld analysis of voices as social objects without referring to them as symptoms of mental illness: (1) Nature of the experiences; (2) Characteristics of the voices; (3) The history of hearing voices; (4) What triggers the voices; (5) What do the voices say; (6) How do you explain the origin of the voices; (7) What impact do the voices have on the way you live; (8) The balance of the relationship; (9) Coping strategies; (10) Childhood experiences; (11) Treatment history; (12) Social network; and (13) Other questions.

In the early period we are often sure that a person will return with a full-blown psychotic episode but we have no legal right to keep the person from leaving. Our clinical intuition should thus not be put aside, only the belief that we can predict the course. Even a full blown psychosis cannot be used to diagnose schizophrenia until after six months, and Schneider's criterion of bizarreness is no longer sufficient. None of the symptoms of schizophrenia are reliably as such, and they do neither explain the past nor predict the future.

Strategy 3: Spending less time within the system

All seven participants accepted help, but recovery did not require acceptance of the diagnosis. This is logical. Three of them did not accept the diagnosis, but accepted help. The diagnosis as such is obviously less important than the treatment.

Transition 1 is the tricky point – simply accepting help goes a long way to avoiding relapse. Involuntary hospitalisation furthers paranoia, while medication furthers helplessness. Both create unfortunate external attributions; I avoid relapse because of medication, not because of me. Respectively: medication makes me sick, it is poisonous.

With transition 1 voluntary treatment, experimentation, new habits and collaboration become possible.

Notably, existential formulation is possible even when help is rejected. Almost everybody is interested to talk about their lives and a good psychologist should master ways to develop a suitable relation. Personal chemistry is a major factor with this group, whether you call it transference or something else.

Lifeworld B: within-the-system.

After onset and the first hospitalisation the need for help was obvious to others, but not to the participants. It is difficult to write an existential formulation without the cooperation of the affected person, but it is possible through teamwork. It shows respect and interest – most people will get naturally curious about their own biography in the making.

Less medication.

Medication is not a panacea: *"As a broad conclusion we can state that if a low dose doesn't work then neither will a high dose."* (Romme, 2012: 95). We have all seen the calming effects of medication. It means a manic person can get much needed sleep and a psychotic person may calm her voices and get some rest. But what and how much are important considerations (Bentall, 2009; Leucht *et al*, 2012; Morrison *et al*, 2009; Larkin & Morrison, 2006; Romme, 2009).

However, a contrarian effect is also known from person narratives:

> "Quite a lot of voice hearers, whose voices remain, report a decreased ability to control their voices under high dosages of antipsychotics, when for instance some of their voices turn into omnipotent, haunting and nagging demons, which make them suffer, in addition to undergoing negative side-effects of the medication." (Hoffmann, 2012:21)

Add massive side-effects that include decreased control, feeling like zombies and disconnected from themselves, sexual problems, tremors, speech problems, over-eating, incontinence *et cetera*. Of course we would all like to remove all symptoms, yet there is convincing evidence that this can be a futile goal.

Regulating voices. Voices are self-talk so if you feel like a loser, this is what your voices will tell you. Other voices may disagree; a drama as if they were real persons. Medication can influence the frequency and intensity of voices, but cannot control their content. Milieu therapy and psychotherapy can, which provides a great rationale for therapy as more important for recovery than medication.

From hope to recovery. Transition 2 is not just *hope* of recovery, but also a choice. Davidson (2003) asserts that recovery can be almost impossible without a VIP: your mother, your partner, a best friend or the psychologist. Russell, Harold and Oscar are clear that psychotherapy contributed to their self-insight and recovery.

Seikkula and others work to strengthen those relationships with the involvement of trusted others (family, friends) immediately after hospitalisation. Practical matters can be taken care (like clothes, money, sick leave forms); the situation can be described and explained; what needs to happen next discussed and agreed. Their research finds that this maintains bonds and makes for earlier dismissal and better functioning outside.

Psychotherapy with inpatients is a golden opportunity as nowhere else is the extra cost lower and the options better than when a patient is there all the time. So many lost opportunities.

Recovery can happen without psychotherapy as it did for some of the participants, but a corollary emerges: Positive effects from psychotherapy should translate into faster and better recovery with more psychotherapy.

Strategy 4: Halfway houses, independence and meaningful lives

Best practices would mean halfway housing instead of prolonged hospital stays – Harold called it *"a place for treatment with no treatment'*. The NOU (2011) recommended steps in this direction, but nothing much seems to happen. In Norway there are few halfway houses, otherwise schizophrenics often share housing with drug addicts (!). The responsibility for housing is now being put on the communes, the majority of which have from 500 to 8.000 inhabitants. Intermediate housing is sometimes available, but not the competence needed to run them.

Lifeworld C – Outside schizophrenia. The participants had all remitted. Coordination no longer needs a psychologist (the person is stable and remitted) but still a good level of experience and competence to monitor and prevent relapse, and also continuing with the life narrative which will continue to unravel as a life project (borrowing the definition from Sartre of course). This is particularly important for those who were affected early and recovered slowly: often they never had a job but wish to work; they lost all their friends and now wish for new friends and hopefully a life partner.

7.5 Recovery as a goal – summary

Despite evidence the belief that there is 'an outside' to schizophrenia is not yet generally shared. First of all, this needs to change. Somewhat as a surprise, my research showed that 4 of 7 remitted without or with only minimal psychotherapeutic treatment (they couldn't remember) and they were quite satisfied with their dosage regimes to protect against relapse. It seems to provide a safety net, as do low threshold hospitalisation to deal with periods of elevated expressed emotion (EE). With newer antipsychotic medication the effect is almost immediate and thus *ad hoc* usage could be sufficient.

Over and above medication NICE CG82 says that psychotherapy should be routinely offered and this research does not disagree: psychotherapy has been proven to help understanding and coping; and it effects social recovery in positive and protective ways. Unfortunately, psychotherapy has not been routinely offered to the research participants so we cannot know if the positive evaluation would also have applied to the others. It is little reason to expect that it would not be the case.

One main finding is the need for a journal that is not a medical journal, but a narrative collaboration between a psychologist and the patient (as it were). It considers where the patient is and what the next steps towards recovery should be; small steps if needed, big steps if possible.

For such joint planning and doing the Vygotskian concept *'zone of proximal development'* is as useful for adults in psychotherapy as it is for child rearing. For it to be realistic and tied into psychotherapy, it calls for a psychologist as coordinator, which is clinical strategy number one below.

The existential formulation takes into account different aspects of life (physical, social, personal and spiritual) matched with what we know as challenges when going through the three lifeworlds and the two transitions. As time goes the formulation is reviewed, noticing what have changed and celebrating progress.

It is important to formulate a baseline of what life used to be like before lifeworld A and its problems; this is where medical journals are severely lacking for the purpose of recovery. While it may take years to achieve the same level, more than this level can be unrealistic and life is going to change dramatically anyway: medication, new friends, new interests, changes in family relations *et cetera*.

The research also formulates four clinical strategies.

First, **psychologists** should be used in a coordinating role for recovery i.e. both before and after remission. Psychiatrists are trained in the medical profession and geared towards symptoms and remission. Psychologists would be the natural specialists for recovery and psychotherapy. To compare, psychiatrists are not nurses and they are not clinical psychologists.

Notably a coordinating psychologist is not somebody who comes and goes, but perhaps the psychologist who has the best chemistry, similar interests. This is because if medication works and the symptoms are managed, emotional support and positive psychology needs to be part of the treatment.

Second, **early intervention**: the research confirms the phenomenology of losing your ground as well as destroying social relations by strange behaviours. Such early intervention should however not speculate in schizophrenia prodromes and not set any diagnosis, even tentatively, too early. Complaints and problems in living should be addressed irrespective of diagnosis, and notably what appears to us as dysfunctional and abnormal might be dysfunctional but a normal reaction to adverse real-life conditions. We know trauma and war generate paranoid behaviours that are not illness in a particular part of the brain; and depression and anxiety are separate diagnoses, not by themselves prodromes.

Hence, early intervention is all about taking complaints and problems seriously while showing respect and encouraging cooperation. This paves the way for a good transition into hospital if necessary.

Third, the research shows clearly that the participants could have spent much less time in the hospital following their transition to accept help. This leads to further;

Fourth, **halfway houses, independence and meaningful lives** in what I have called Lifeworld C. The participants had been too long in a hospital and left more or less alone in their recovery. Halfway houses create a much different environment that facilitates social recovery; a hospital does not.

These recommendations have recovery as a goal. This is still new but hopefully, treatment for schizophrenia five years from now will have changed.

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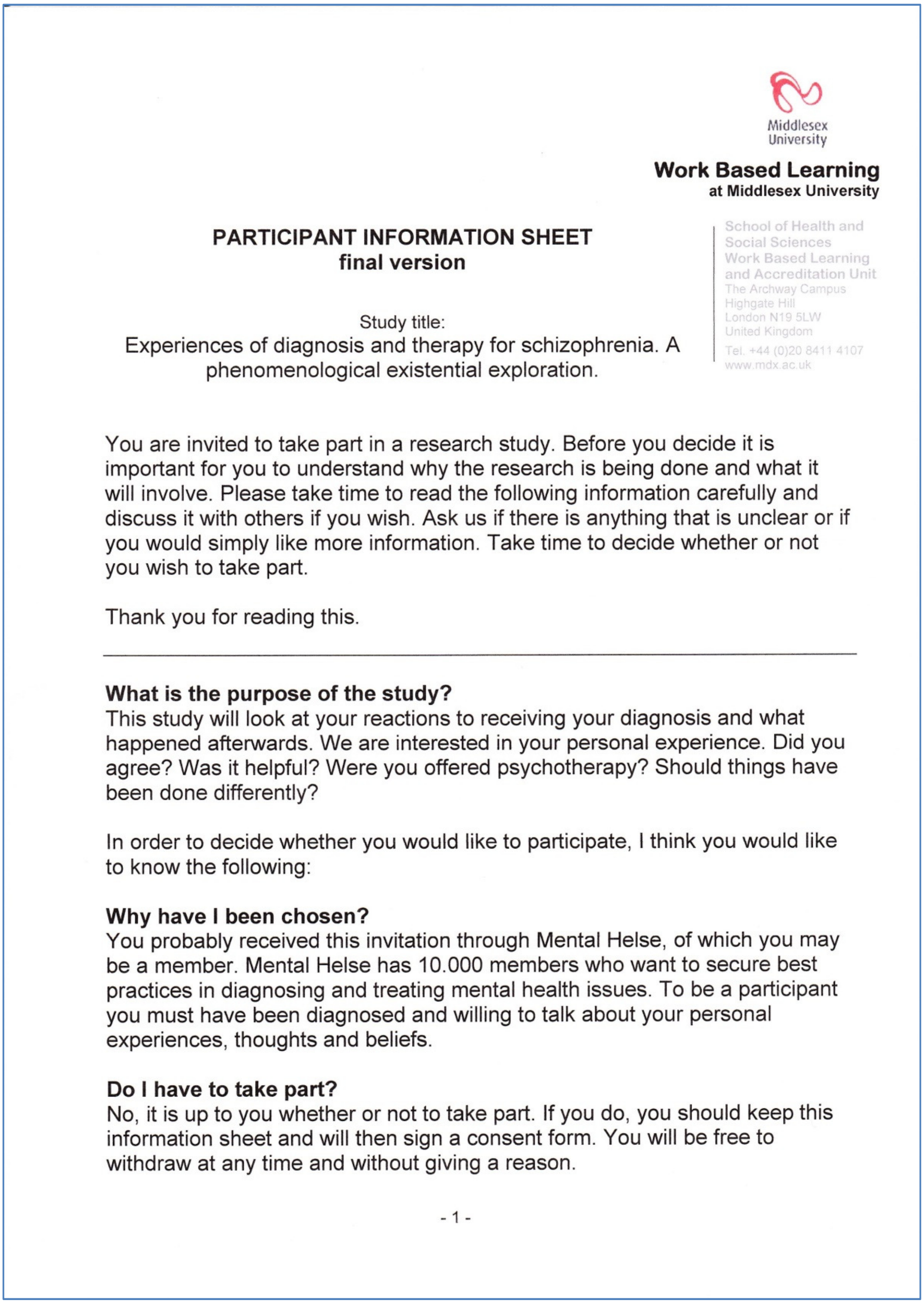
Appendices

Appendix 1 – Personal information sheet



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PARTICIPANT INFORMATION SHEET
final version

Study title:
Experiences of diagnosis and therapy for schizophrenia. A phenomenological existential exploration.

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is unclear or if you would simply like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study will look at your reactions to receiving your diagnosis and what happened afterwards. We are interested in your personal experience. Did you agree? Was it helpful? Were you offered psychotherapy? Should things have been done differently?

In order to decide whether you would like to participate, I think you would like to know the following:

Why have I been chosen?

You probably received this invitation through Mental Helse, of which you may be a member. Mental Helse has 10.000 members who want to secure best practices in diagnosing and treating mental health issues. To be a participant you must have been diagnosed and willing to talk about your personal experiences, thoughts and beliefs.

Do I have to take part?

No, it is up to you whether or not to take part. If you do, you should keep this information sheet and will then sign a consent form. You will be free to withdraw at any time and without giving a reason.

- 1 -

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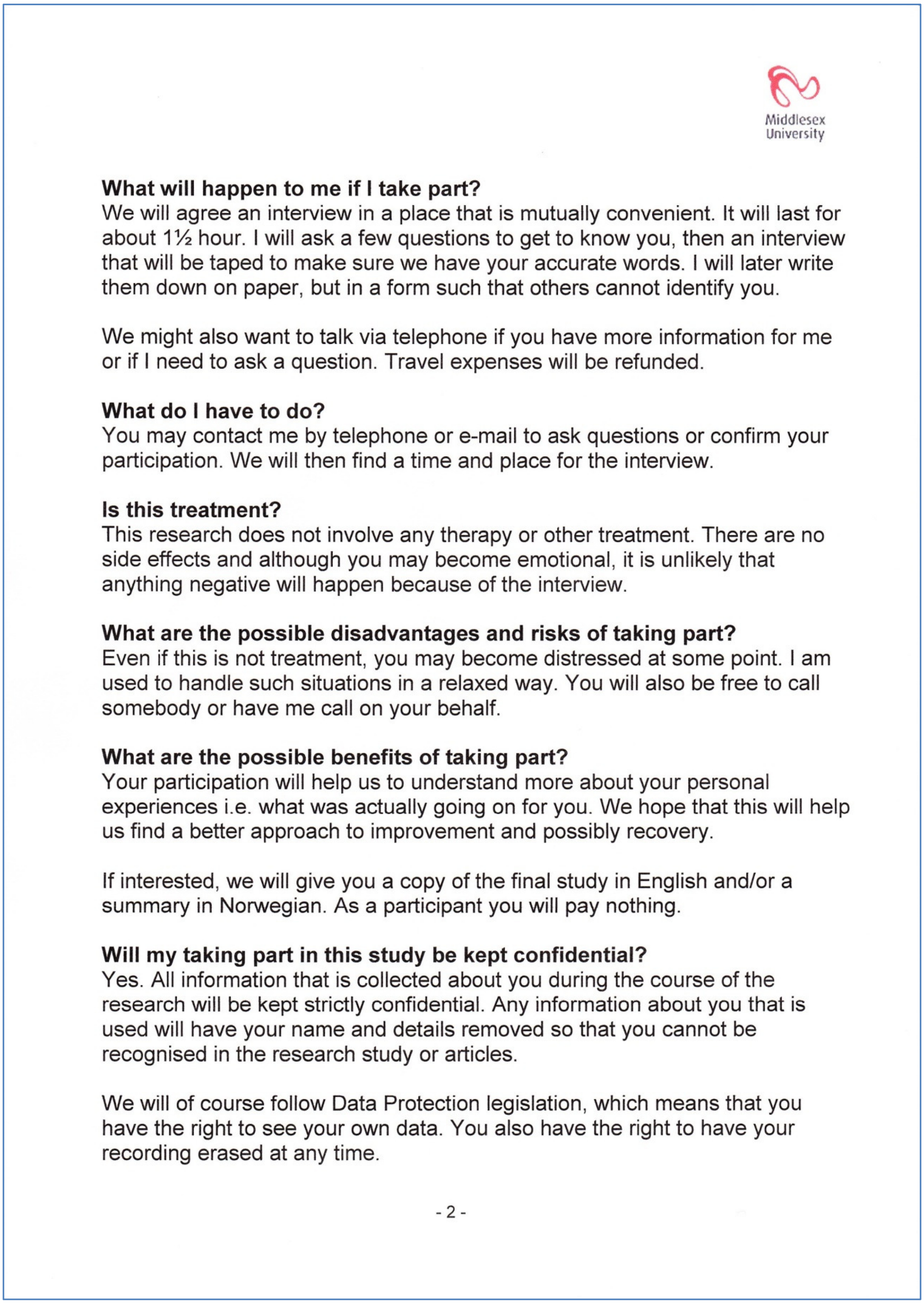

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What will happen to me if I take part?
We will agree an interview in a place that is mutually convenient. It will last for about 1½ hour. I will ask a few questions to get to know you, then an interview that will be taped to make sure we have your accurate words. I will later write them down on paper, but in a form such that others cannot identify you.

We might also want to talk via telephone if you have more information for me or if I need to ask a question. Travel expenses will be refunded.

What do I have to do?
You may contact me by telephone or e-mail to ask questions or confirm your participation. We will then find a time and place for the interview.

Is this treatment?
This research does not involve any therapy or other treatment. There are no side effects and although you may become emotional, it is unlikely that anything negative will happen because of the interview.

What are the possible disadvantages and risks of taking part?
Even if this is not treatment, you may become distressed at some point. I am used to handle such situations in a relaxed way. You will also be free to call somebody or have me call on your behalf.

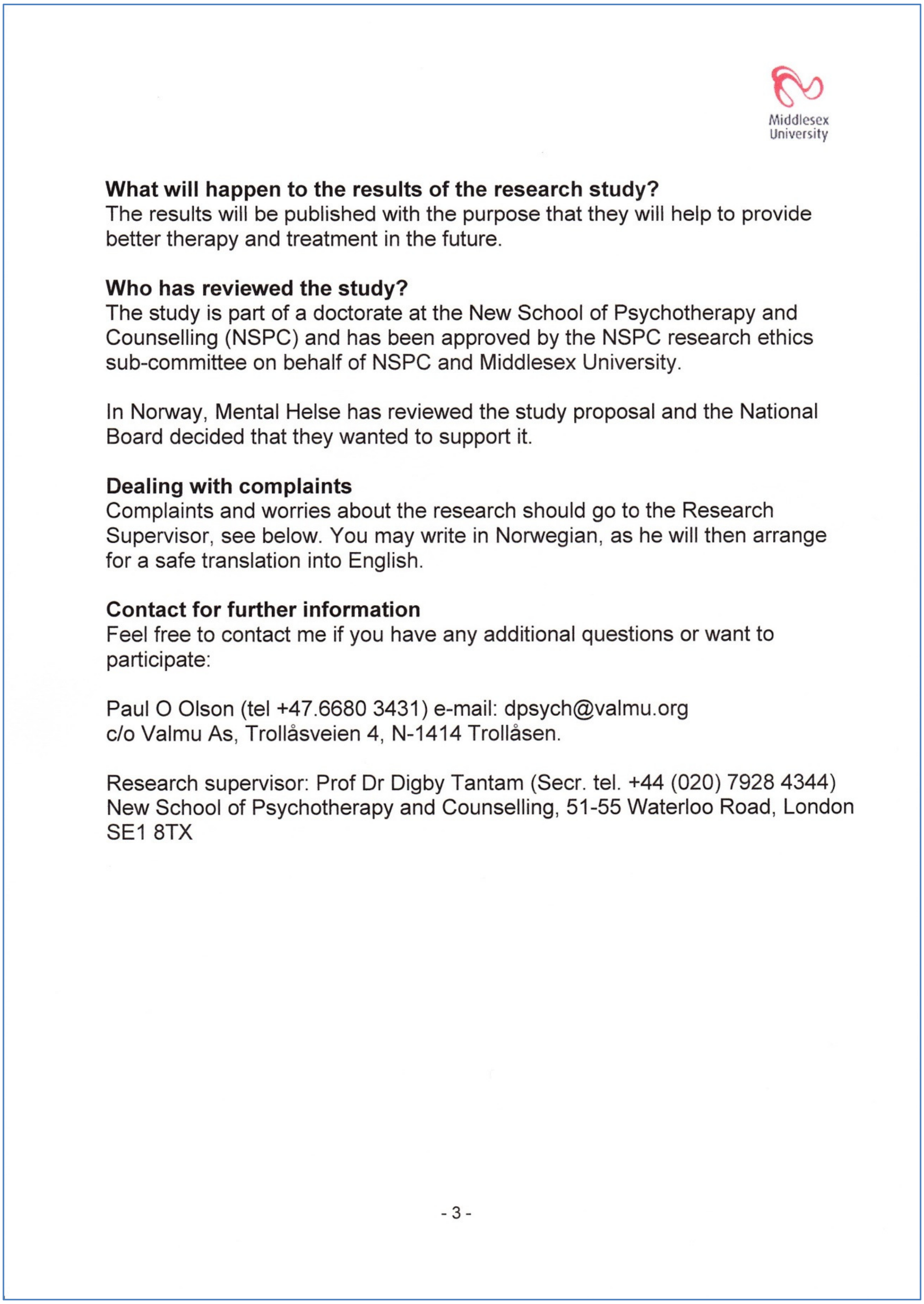
What are the possible benefits of taking part?
Your participation will help us to understand more about your personal experiences i.e. what was actually going on for you. We hope that this will help us find a better approach to improvement and possibly recovery.

If interested, we will give you a copy of the final study in English and/or a summary in Norwegian. As a participant you will pay nothing.

Will my taking part in this study be kept confidential?
Yes. All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that is used will have your name and details removed so that you cannot be recognised in the research study or articles.

We will of course follow Data Protection legislation, which means that you have the right to see your own data. You also have the right to have your recording erased at any time.

- 2 -



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What will happen to the results of the research study?

The results will be published with the purpose that they will help to provide better therapy and treatment in the future.

Who has reviewed the study?

The study is part of a doctorate at the New School of Psychotherapy and Counselling (NSPC) and has been approved by the NSPC research ethics sub-committee on behalf of NSPC and Middlesex University.

In Norway, Mental Helse has reviewed the study proposal and the National Board decided that they wanted to support it.

Dealing with complaints

Complaints and worries about the research should go to the Research Supervisor, see below. You may write in Norwegian, as he will then arrange for a safe translation into English.

Contact for further information

Feel free to contact me if you have any additional questions or want to participate:

Paul O Olson (tel +47.6680 3431) e-mail: dpsych@valmu.org
c/o Valmu As, Trollåsveien 4, N-1414 Trollåsen.

Research supervisor: Prof Dr Digby Tantam (Secr. tel. +44 (020) 7928 4344)
New School of Psychotherapy and Counselling, 51-55 Waterloo Road, London
SE1 8TX

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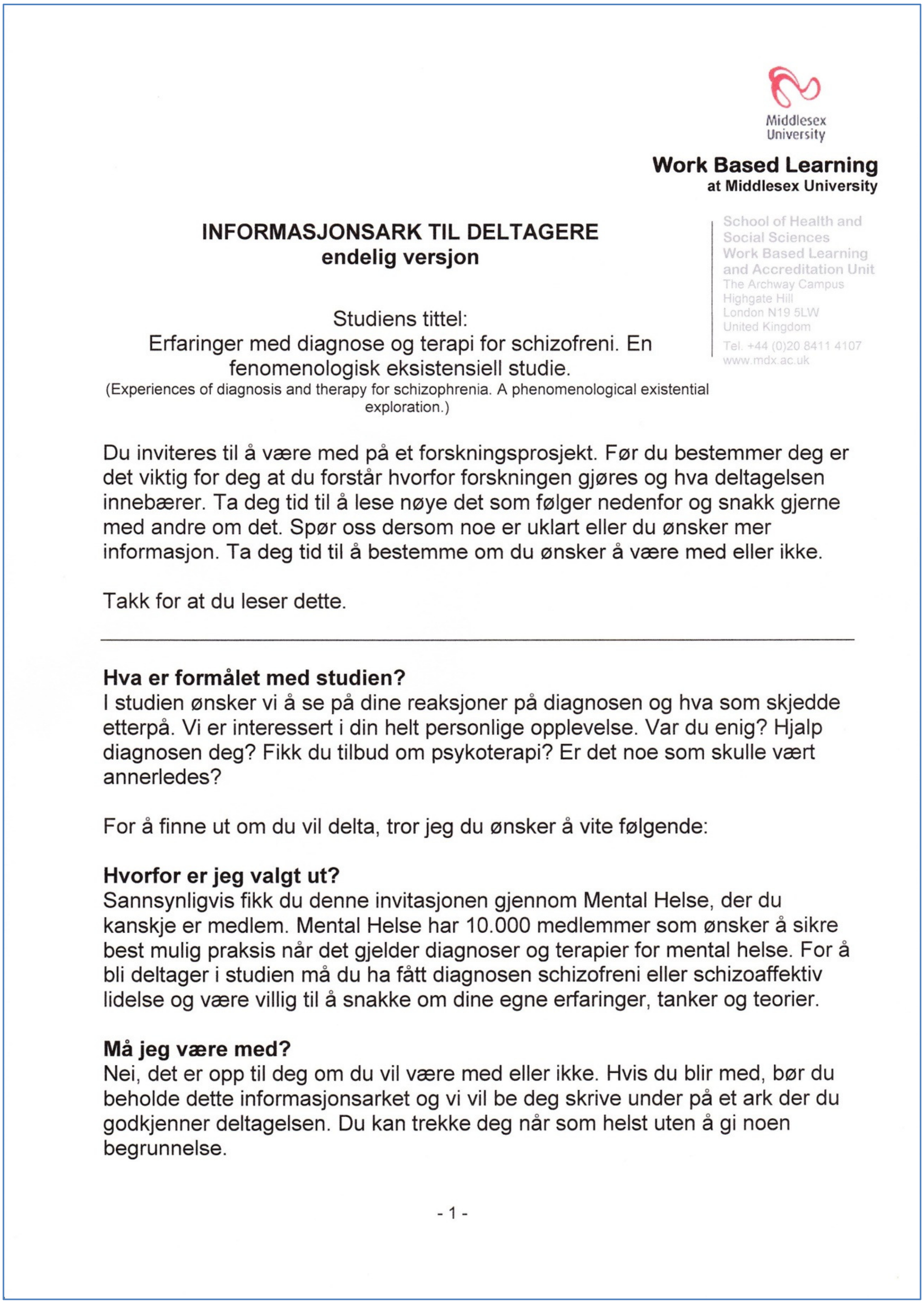

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INFORMASJONSARK TIL DELTAGERE
endelig versjon

Studiens tittel:
Erfaringer med diagnose og terapi for schizofreni. En fenomenologisk eksistensiell studie.
(Experiences of diagnosis and therapy for schizophrenia. A phenomenological existential exploration.)

Du inviteres til å være med på et forskningsprosjekt. Før du bestemmer deg er det viktig for deg at du forstår hvorfor forskningen gjøres og hva deltagelsen innebærer. Ta deg tid til å lese nøye det som følger nedenfor og snakk gjerne med andre om det. Spør oss dersom noe er uklart eller du ønsker mer informasjon. Ta deg tid til å bestemme om du ønsker å være med eller ikke.

Takk for at du leser dette.

Hva er formålet med studien?
I studien ønsker vi å se på dine reaksjoner på diagnosen og hva som skjedde etterpå. Vi er interessert i din helt personlige opplevelse. Var du enig? Hjalp diagnosen deg? Fikk du tilbud om psykoterapi? Er det noe som skulle vært annerledes?

For å finne ut om du vil delta, tror jeg du ønsker å vite følgende:

Hvorfor er jeg valgt ut?
Sannsynligvis fikk du denne invitasjonen gjennom Mental Helse, der du kanskje er medlem. Mental Helse har 10.000 medlemmer som ønsker å sikre best mulig praksis når det gjelder diagnoser og terapier for mental helse. For å bli deltager i studien må du ha fått diagnosen schizofreni eller schizoaffektiv lidelse og være villig til å snakke om dine egne erfaringer, tanker og teorier.

Må jeg være med?
Nei, det er opp til deg om du vil være med eller ikke. Hvis du blir med, bør du beholde dette informasjonsarket og vi vil be deg skrive under på et ark der du godkjenner deltagelsen. Du kan trekke deg når som helst uten å gi noen begrunnelse.

- 1 -

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Hva skjer med meg som deltager?
Vi vil bli enige om et intervju et sted som passer oss begge. Intervjuet vil vare cirka 1 ½ time. Jeg kommer til å stille deg noen spørsmål for å bli kjent med deg, deretter vil selve intervjuet bli tatt opp på lydbånd slik at vi har dine helt nøyaktige ord. Senere vil jeg overføre intervjuet til papir, men jeg utelater alt som kan gjøre at noen kan identifisere deg. Reiseutgifter vil bli refundert.

Det er mulig at vi senere vil snakke med hverandre på telefon dersom du har mer du vil fortelle, eller jeg må stille et spørsmål.

Hva må jeg gjøre?
Du kan kontakte meg på telefon eller e-post for å stille spørsmål eller bekrefte at du vil delta. Vi vil så finne tid og sted for intervjuet.

Er dette behandling?
Nei, denne studien innebærer ingen terapi eller annen behandling. Det er ingen bivirkninger og selv om det kan være ubehagelig å fortelle om visse ting, så er det usannsynlig at noe negativt vil skje som resultat av intervjuet.

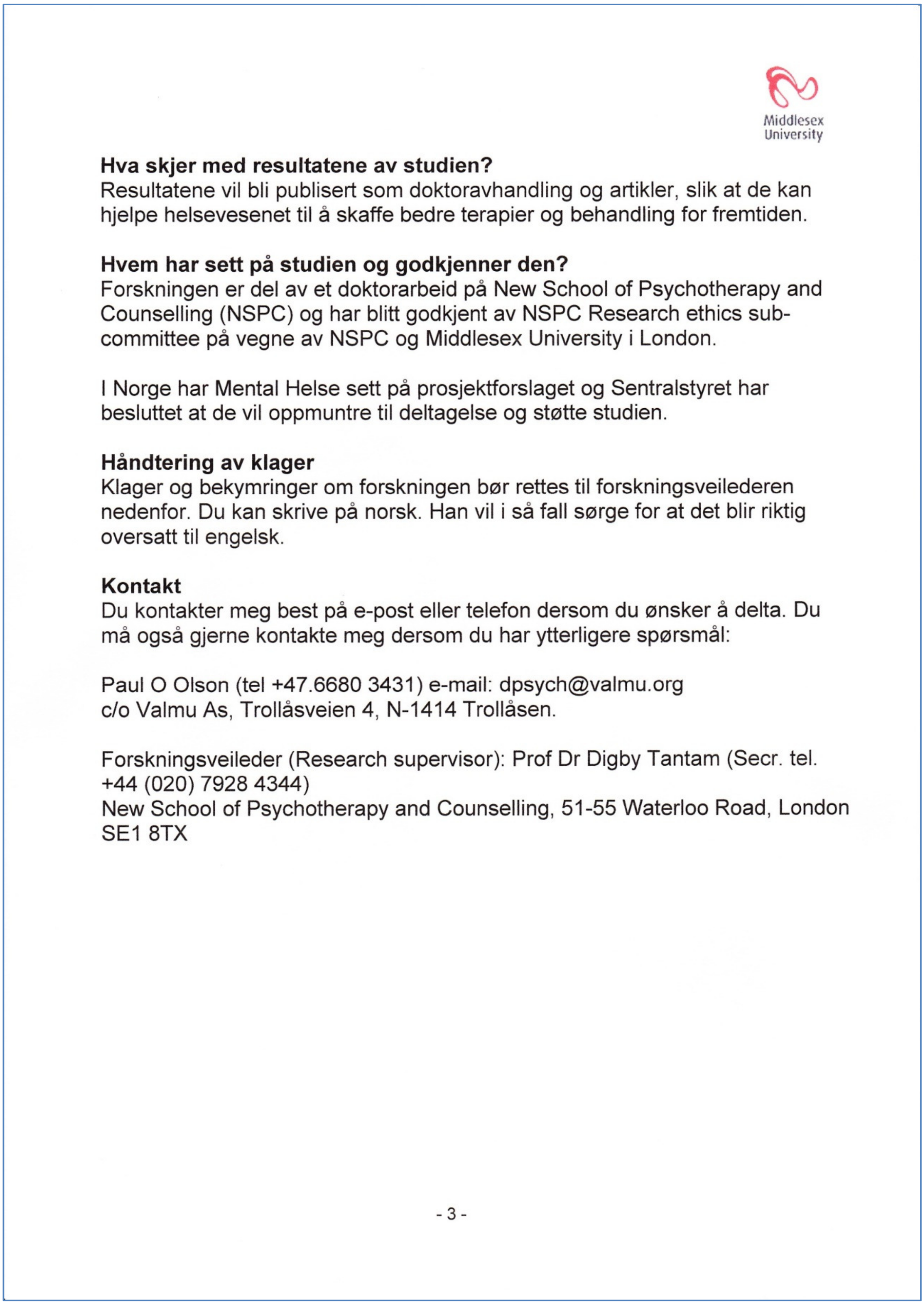
Hvilke er mulige ulemper og risikoer hvis jeg deltar?
Selv om dette ikke er behandling, kan du komme til å føle noe ubehag i løpet av intervjuet. Jeg er vant til å håndtere slike situasjoner på en avslappet og god måte. Om nødvendig må du gjerne ringe noen du kjenner eller be meg om å ringe på dine vegne.

Hvilke er mulige fordeler hvis jeg deltar?
Din deltagelse vil hjelpe oss å forstå dine personlige erfaringer dvs. hva skjedde egentlig slik du ser det. Vi håper dette vil hjelpe oss å finne bedre måter å hjelpe på.

Hvis du er interessert, vil vi sende deg et eksemplar av den ferdige studien på engelsk eller en oppsummering på norsk. Som deltager er dette gratis.

Vil min deltagelse være konfidensiell?
Ja. All informasjon som samles om deg vil være helt konfidensiell. Navn og andre ting som kan fortelle hvem du er, vil bli fjernet slik at du ikke kan gjenkjennes verken i studien eller i artikler senere.

Vi vil selvsagt følge lover og regler, hvilket også betyr at du har rett til å se dine egne data. Du har også rett til når som helst å få dine data slettet.



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Hva skjer med resultatene av studien?
Resultatene vil bli publisert som doktoravhandling og artikler, slik at de kan hjelpe helsevesenet til å skaffe bedre terapier og behandling for fremtiden.

Hvem har sett på studien og godkjenner den?
Forskningen er del av et doktorarbeid på New School of Psychotherapy and Counselling (NSPC) og har blitt godkjent av NSPC Research ethics sub-committee på vegne av NSPC og Middlesex University i London.

I Norge har Mental Helse sett på prosjektforslaget og Sentralstyret har besluttet at de vil oppmuntre til deltagelse og støtte studien.

Håndtering av klager
Klager og bekymringer om forskningen bør rettes til forskningsveilederen nedenfor. Du kan skrive på norsk. Han vil i så fall sørge for at det blir riktig oversatt til engelsk.

Kontakt
Du kontakter meg best på e-post eller telefon dersom du ønsker å delta. Du må også gjerne kontakte meg dersom du har ytterligere spørsmål:

Paul O Olson (tel +47.6680 3431) e-mail: dpsych@valmu.org
c/o Valmu As, Trollåsveien 4, N-1414 Trollåsen.

Forskningsveileder (Research supervisor): Prof Dr Digby Tantam (Secr. tel. +44 (020) 7928 4344)
New School of Psychotherapy and Counselling, 51-55 Waterloo Road, London
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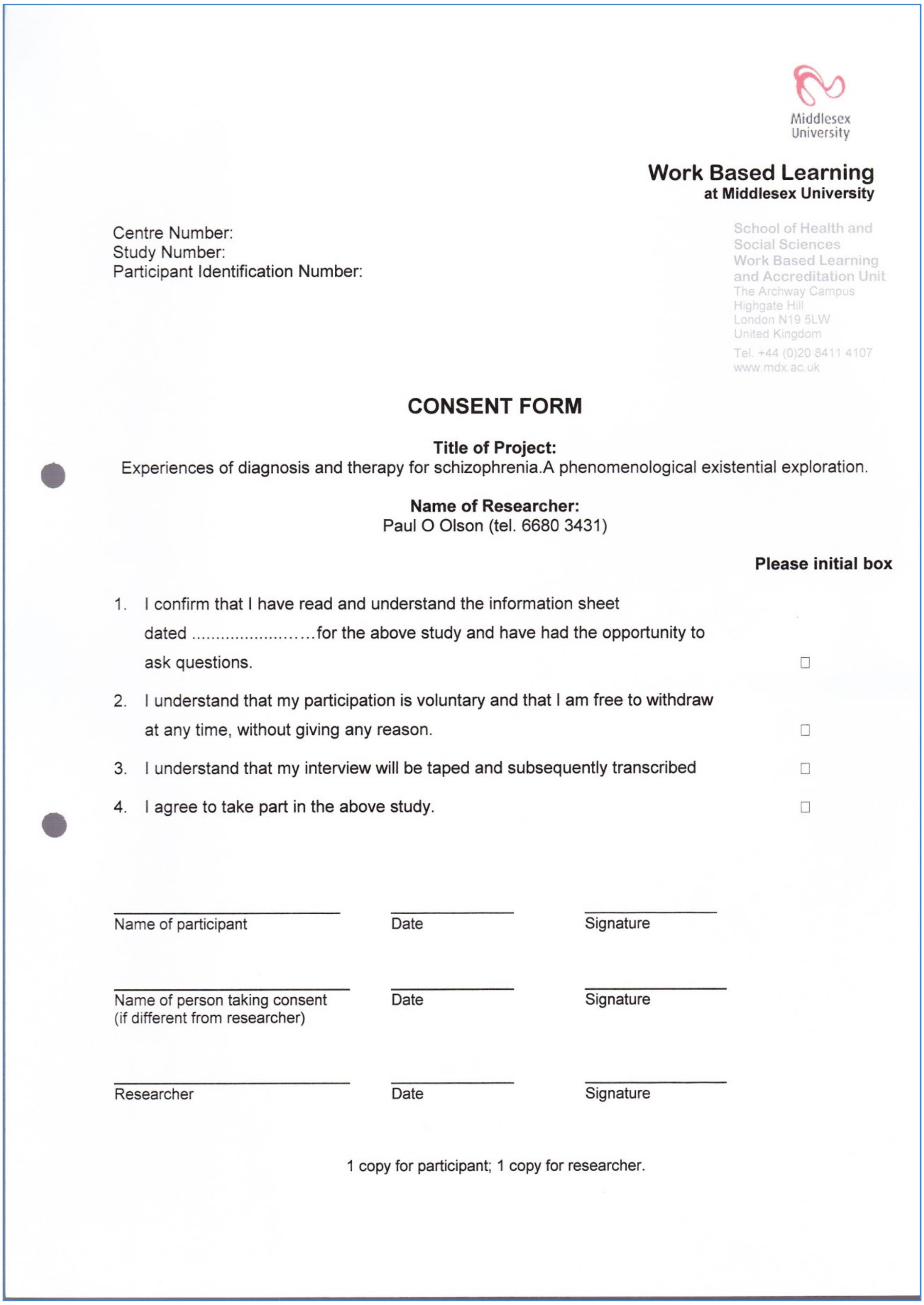
Appendix 2 – Consent form



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Centre Number:
Study Number:
Participant Identification Number:

CONSENT FORM

Title of Project:
Experiences of diagnosis and therapy for schizophrenia.A phenomenological existential exploration.

Name of Researcher:
Paul O Olson (tel. 6680 3431)

Please initial box

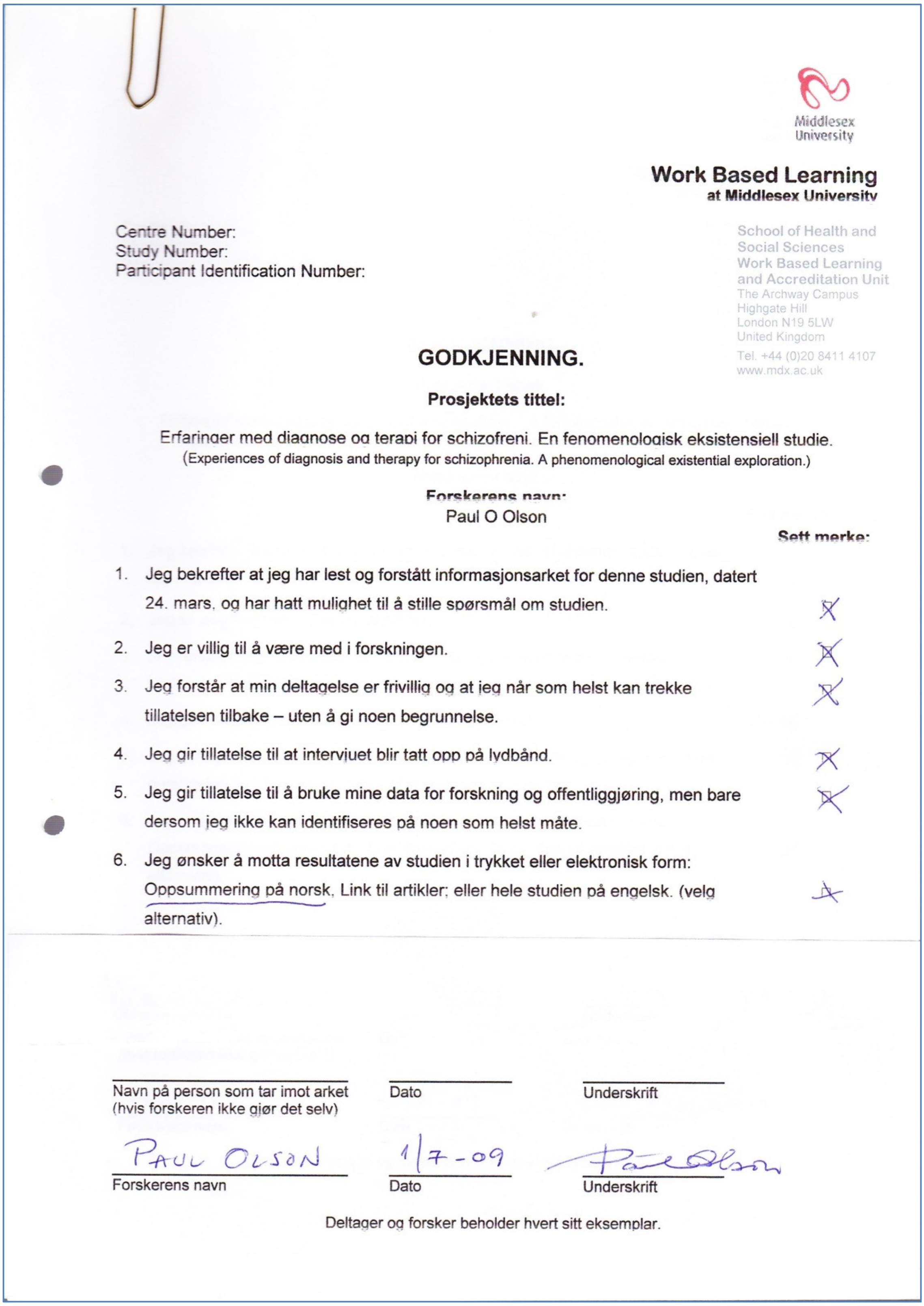
1. I confirm that I have read and understand the information sheet dated ……………………for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that my interview will be taped and subsequently transcribed ☐
4. I agree to take part in the above study. ☐

Name of participant ______ Date ______ Signature ______

Name of person taking consent (if different from researcher) ______ Date ______ Signature ______

Researcher ______ Date ______ Signature ______

1 copy for participant; 1 copy for researcher.



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Centre Number:
Study Number:
Participant Identification Number:

GODKJENNING.

Prosjektets tittel:

Erfaringer med diagnose og terapi for schizofreni. En fenomenologisk eksistensiell studie.
(Experiences of diagnosis and therapy for schizophrenia. A phenomenological existential exploration.)

Forskerens navn:
Paul O Olson

Sett merke:

1. Jeg bekrefter at jeg har lest og forstått informasjonsarket for denne studien, datert 24. mars, og har hatt mulighet til å stille spørsmål om studien. X
2. Jeg er villig til å være med i forskningen. X
3. Jeg forstår at min deltagelse er frivillig og at jeg når som helst kan trekke tillatelsen tilbake – uten å gi noen begrunnelse. X
4. Jeg gir tillatelse til at intervjuet blir tatt opp på lydbånd. X
5. Jeg gir tillatelse til å bruke mine data for forskning og offentliggjøring, men bare dersom jeg ikke kan identifiseres på noen som helst måte. X
6. Jeg ønsker å motta resultatene av studien i trykket eller elektronisk form: [✓ Oppsummering på norsk], Link til artikler; eller hele studien på engelsk. (velg alternativ). X

Navn på person som tar imot arket (hvis forskeren ikke gjør det selv) / Dato / Underskrift

PAUL OLSON
Forskerens navn

1/7-09
Dato

Paul Olson
Underskrift

Deltager og forsker beholder hvert sitt eksemplar.

Appendix 3 – BPRS and Interview Guide

:

BRIEF PSYCHIATRIC RATING SCALE (BPRS)

Patient Name ______________________ Today's Date ____________

Please enter the score for the term that best describes the patient's condition.

0 = Not assessed, 1 = Not present, 2 = Very mild, 3 = Mild, 4 = Moderate, 5 = Moderately severe, 6 = Severe, 7 = Extremely severe

Score

☐ 1. SOMATIC CONCERN
Preoccupation with physical health, fear of physical illness, hypochondriasis.

☐ 2. ANXIETY
Worry, fear, over-concern for present or future, uneasiness.

☐ 3. EMOTIONAL WITHDRAWAL
Lack of spontaneous interaction, isolation deficiency in relating to others.

☐ 4. CONCEPTUAL DISORGANIZATION
Thought processes confused, disconnected, disorganized, disrupted.

☐ 5. GUILT FEELINGS
Self-blame, shame, remorse for past behavior.

☐ 6. TENSION
Physical and motor manifestations of nervousness, over-activation.

☐ 7. MANNERISMS AND POSTURING
Peculiar, bizarre, unnatural motor behavior (not including tic).

☐ 8. GRANDIOSITY
Exaggerated self-opinion, arrogance, conviction of unusual power or abilities.

☐ 9. DEPRESSIVE MOOD
Sorrow, sadness, despondency, pessimism.

☐ 10. HOSTILITY
Animosity, contempt, belligerence, disdain for others.

☐ 11. SUSPICIOUSNESS
Mistrust, belief others harbor malicious or discriminatory intent.

☐ 12. HALLUCINATORY BEHAVIOR
Perceptions without normal external stimulus correspondence.

☐ 13. MOTOR RETARDATION
Slowed, weakened movements or speech, reduced body tone.

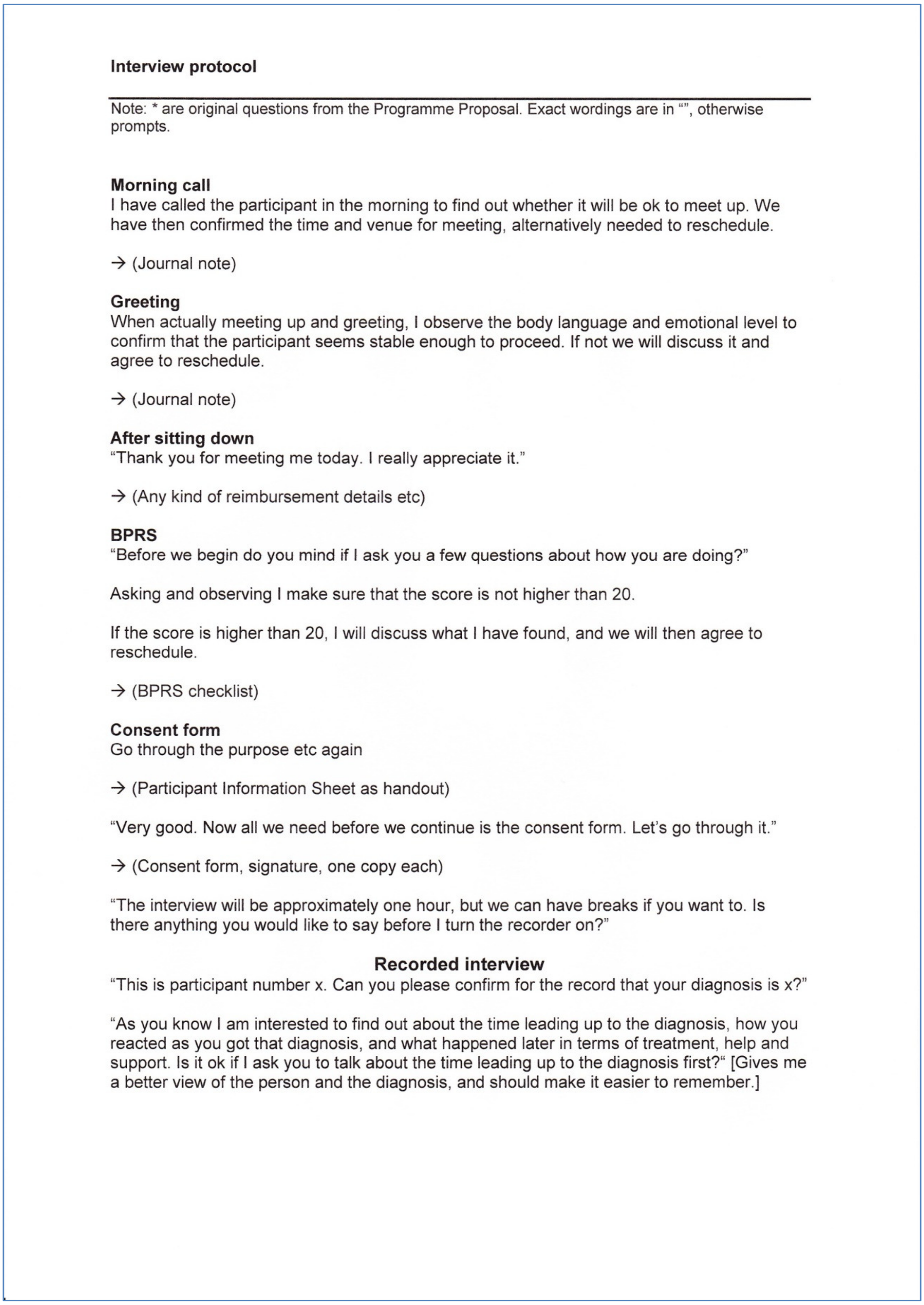
☐ 14. UNCOOPERATIVENESS
Resistance, guardedness, rejection of authority.

☐ 15. UNUSUAL THOUGHT CONTENT
Unusual, odd, strange, bizarre thought content.

☐ 16. BLUNTED AFFECT
Reduced emotional tone, reduction in formal intensity of feelings, flatness.

☐ 17. EXCITEMENT
Heightened emotional tone, agitation, increased reactivity.

☐ 18. DISORIENTATION
Confusion or lack of proper association for person, place or time.



Interview protocol

Note: * are original questions from the Programme Proposal. Exact wordings are in “”, otherwise prompts.

Morning call

I have called the participant in the morning to find out whether it will be ok to meet up. We have then confirmed the time and venue for meeting, alternatively needed to reschedule.

→ (Journal note)

Greeting

When actually meeting up and greeting, I observe the body language and emotional level to confirm that the participant seems stable enough to proceed. If not we will discuss it and agree to reschedule.

→ (Journal note)

After sitting down

“Thank you for meeting me today. I really appreciate it.”

→ (Any kind of reimbursement details etc)

BPRS

“Before we begin do you mind if I ask you a few questions about how you are doing?”

Asking and observing I make sure that the score is not higher than 20.

If the score is higher than 20, I will discuss what I have found, and we will then agree to reschedule.

→ (BPRS checklist)

Consent form

Go through the purpose etc again

→ (Participant Information Sheet as handout)

“Very good. Now all we need before we continue is the consent form. Let’s go through it.”

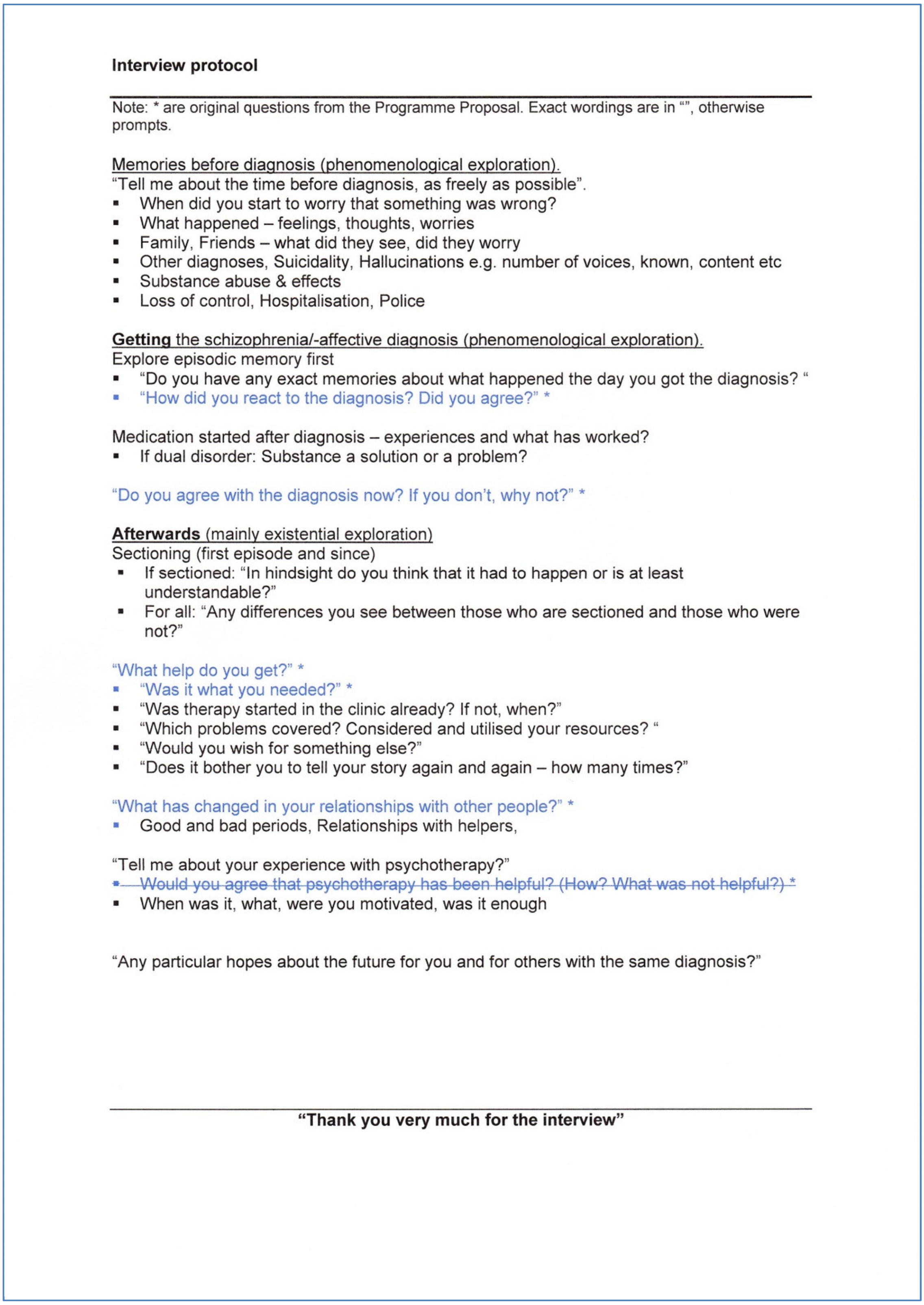
→ (Consent form, signature, one copy each)

“The interview will be approximately one hour, but we can have breaks if you want to. Is there anything you would like to say before I turn the recorder on?”

Recorded interview

“This is participant number x. Can you please confirm for the record that your diagnosis is x?”

“As you know I am interested to find out about the time leading up to the diagnosis, how you reacted as you got that diagnosis, and what happened later in terms of treatment, help and support. Is it ok if I ask you to talk about the time leading up to the diagnosis first?“ [Gives me a better view of the person and the diagnosis, and should make it easier to remember.]



Interview protocol

Note: * are original questions from the Programme Proposal. Exact wordings are in "", otherwise prompts.

Memories before diagnosis (phenomenological exploration).
"Tell me about the time before diagnosis, as freely as possible".
- When did you start to worry that something was wrong?
- What happened – feelings, thoughts, worries
- Family, Friends – what did they see, did they worry
- Other diagnoses, Suicidality, Hallucinations e.g. number of voices, known, content etc
- Substance abuse & effects
- Loss of control, Hospitalisation, Police

Getting the schizophrenia/-affective diagnosis (phenomenological exploration).
Explore episodic memory first
- "Do you have any exact memories about what happened the day you got the diagnosis? "
- "How did you react to the diagnosis? Did you agree?" *

Medication started after diagnosis – experiences and what has worked?
- If dual disorder: Substance a solution or a problem?

"Do you agree with the diagnosis now? If you don't, why not?" *

Afterwards (mainly existential exploration)
Sectioning (first episode and since)
- If sectioned: "In hindsight do you think that it had to happen or is at least understandable?"
- For all: "Any differences you see between those who are sectioned and those who were not?"

"What help do you get?" *
- "Was it what you needed?" *
- "Was therapy started in the clinic already? If not, when?"
- "Which problems covered? Considered and utilised your resources? "
- "Would you wish for something else?"
- "Does it bother you to tell your story again and again – how many times?"

"What has changed in your relationships with other people?" *
- Good and bad periods, Relationships with helpers,

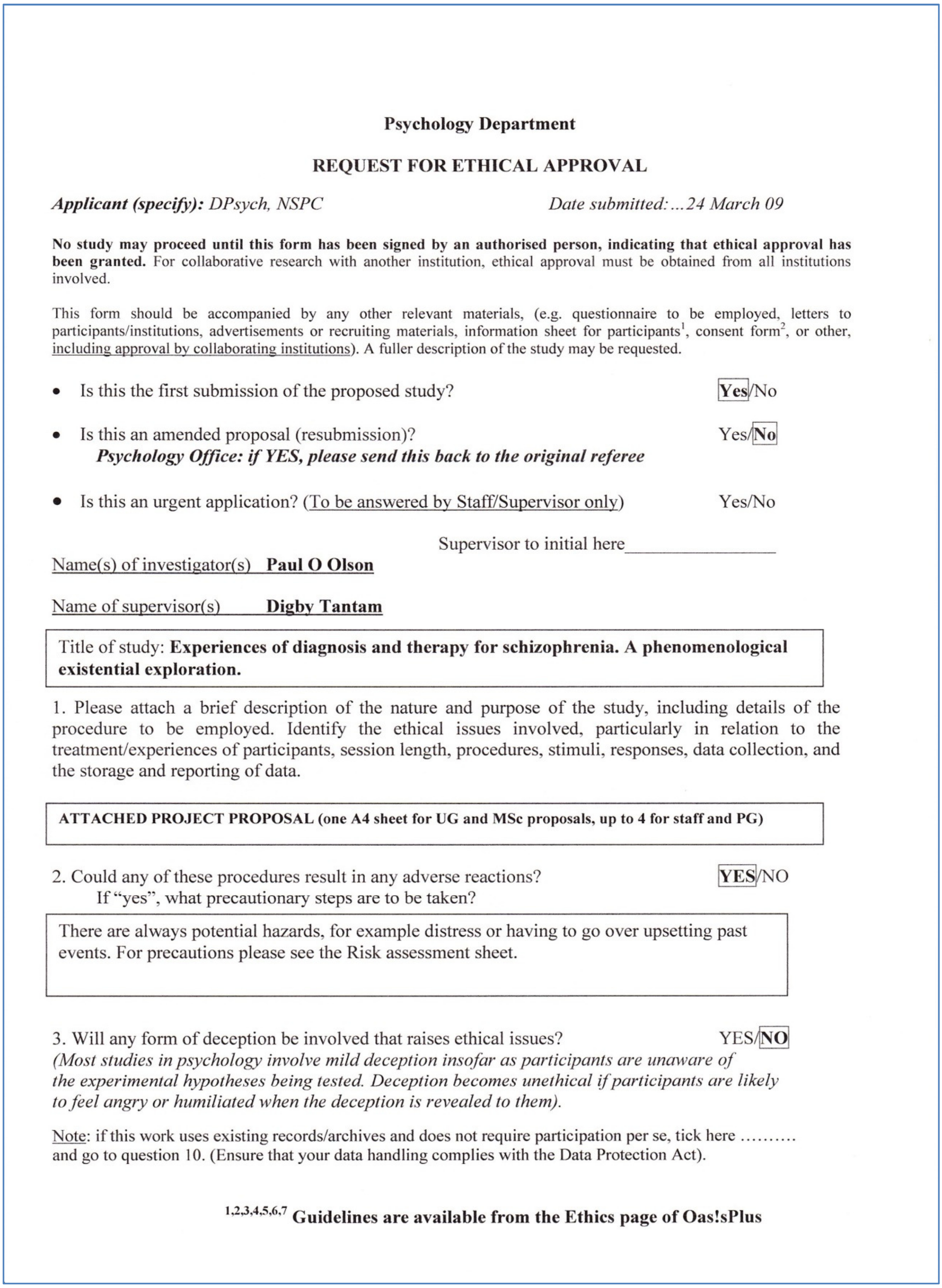
"Tell me about your experience with psychotherapy?"
- ~~Would you agree that psychotherapy has been helpful? (How? What was not helpful?) *~~
- When was it, what, were you motivated, was it enough

"Any particular hopes about the future for you and for others with the same diagnosis?"

"Thank you very much for the interview"

Appendix 4 – Ethical approval and Risk assessment

:



Psychology Department

REQUEST FOR ETHICAL APPROVAL

Applicant (specify): *DPsych, NSPC* *Date submitted: ...24 March 09*

No study may proceed until this form has been signed by an authorised person, indicating that ethical approval has been granted. For collaborative research with another institution, ethical approval must be obtained from all institutions involved.

This form should be accompanied by any other relevant materials, (e.g. questionnaire to be employed, letters to participants/institutions, advertisements or recruiting materials, information sheet for participants[1], consent form[2], or other, including approval by collaborating institutions). A fuller description of the study may be requested.

- Is this the first submission of the proposed study? [✓ Yes]/No
- Is this an amended proposal (resubmission)? Yes/[✓ No]
  Psychology Office: if YES, please send this back to the original referee
- Is this an urgent application? (To be answered by Staff/Supervisor only) Yes/No

Supervisor to initial here________________

Name(s) of investigator(s) **Paul O Olson**

Name of supervisor(s) **Digby Tantam**

Title of study: **Experiences of diagnosis and therapy for schizophrenia. A phenomenological existential exploration.**

1. Please attach a brief description of the nature and purpose of the study, including details of the procedure to be employed. Identify the ethical issues involved, particularly in relation to the treatment/experiences of participants, session length, procedures, stimuli, responses, data collection, and the storage and reporting of data.

ATTACHED PROJECT PROPOSAL (one A4 sheet for UG and MSc proposals, up to 4 for staff and PG)

2. Could any of these procedures result in any adverse reactions? [✓ YES]/NO
If "yes", what precautionary steps are to be taken?

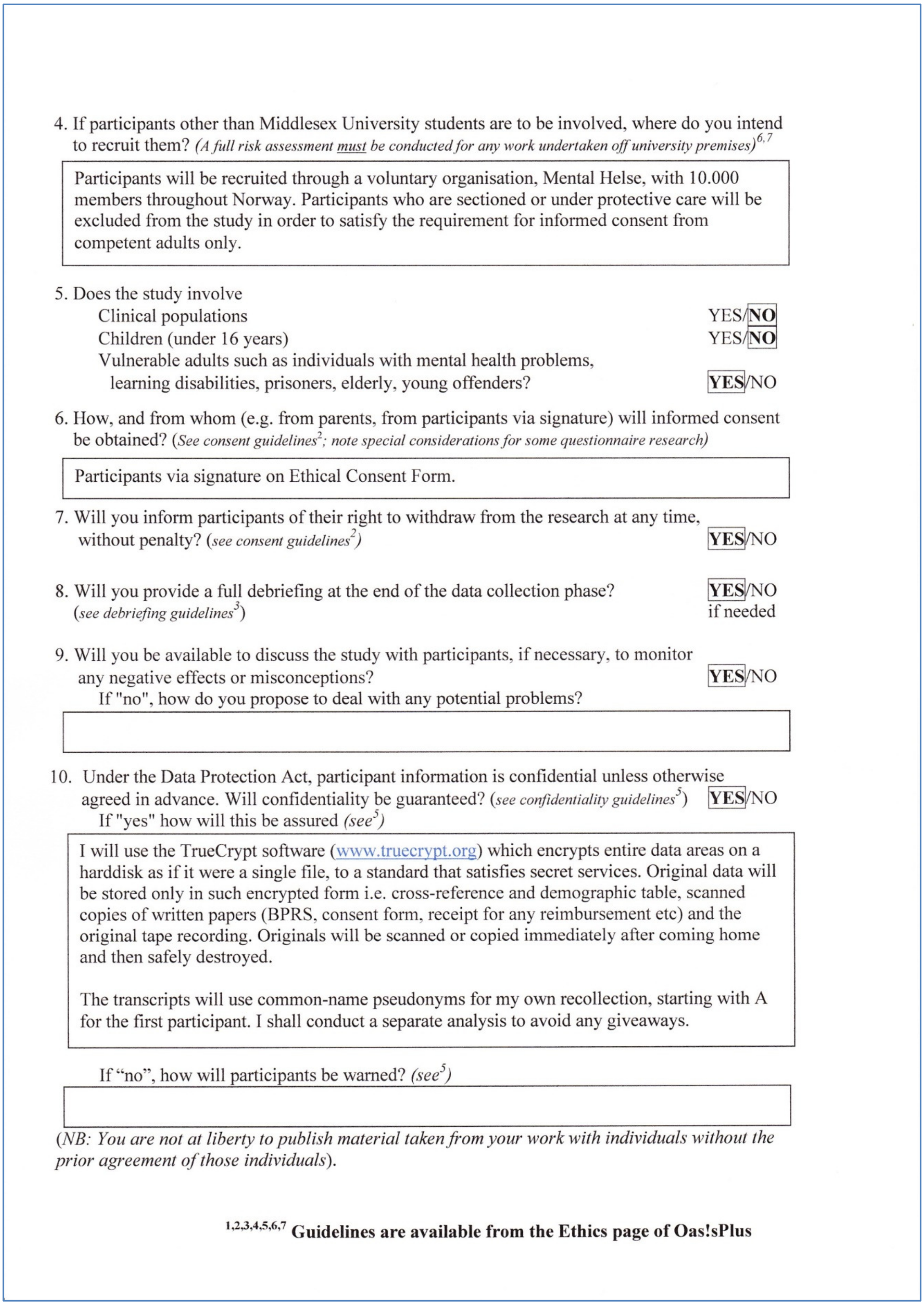
There are always potential hazards, for example distress or having to go over upsetting past events. For precautions please see the Risk assessment sheet.

3. Will any form of deception be involved that raises ethical issues? YES/[✓ NO]
(Most studies in psychology involve mild deception insofar as participants are unaware of the experimental hypotheses being tested. Deception becomes unethical if participants are likely to feel angry or humiliated when the deception is revealed to them).

Note: if this work uses existing records/archives and does not require participation per se, tick here ……… and go to question 10. (Ensure that your data handling complies with the Data Protection Act).

[1,2,3,4,5,6,7] **Guidelines are available from the Ethics page of Oas!sPlus**

:



4. If participants other than Middlesex University students are to be involved, where do you intend to recruit them? *(A full risk assessment must be conducted for any work undertaken off university premises)*[6,7]

Participants will be recruited through a voluntary organisation, Mental Helse, with 10.000 members throughout Norway. Participants who are sectioned or under protective care will be excluded from the study in order to satisfy the requirement for informed consent from competent adults only.

5. Does the study involve

Clinical populations	YES/[✓ **NO**]
Children (under 16 years)	YES/[✓ **NO**]
Vulnerable adults such as individuals with mental health problems, learning disabilities, prisoners, elderly, young offenders?	[✓ **YES**]/NO

6. How, and from whom (e.g. from parents, from participants via signature) will informed consent be obtained? (*See consent guidelines*[2]*; note special considerations for some questionnaire research)*

Participants via signature on Ethical Consent Form.

7. Will you inform participants of their right to withdraw from the research at any time, without penalty? (*see consent guidelines*[2]*)* [✓ **YES**]/NO

8. Will you provide a full debriefing at the end of the data collection phase? (*see debriefing guidelines*[3]) [✓ **YES**]/NO if needed

9. Will you be available to discuss the study with participants, if necessary, to monitor any negative effects or misconceptions? [✓ **YES**]/NO

If "no", how do you propose to deal with any potential problems?

10. Under the Data Protection Act, participant information is confidential unless otherwise agreed in advance. Will confidentiality be guaranteed? (*see confidentiality guidelines*[5]) [✓ **YES**]/NO

If "yes" how will this be assured *(see*[5]*)*

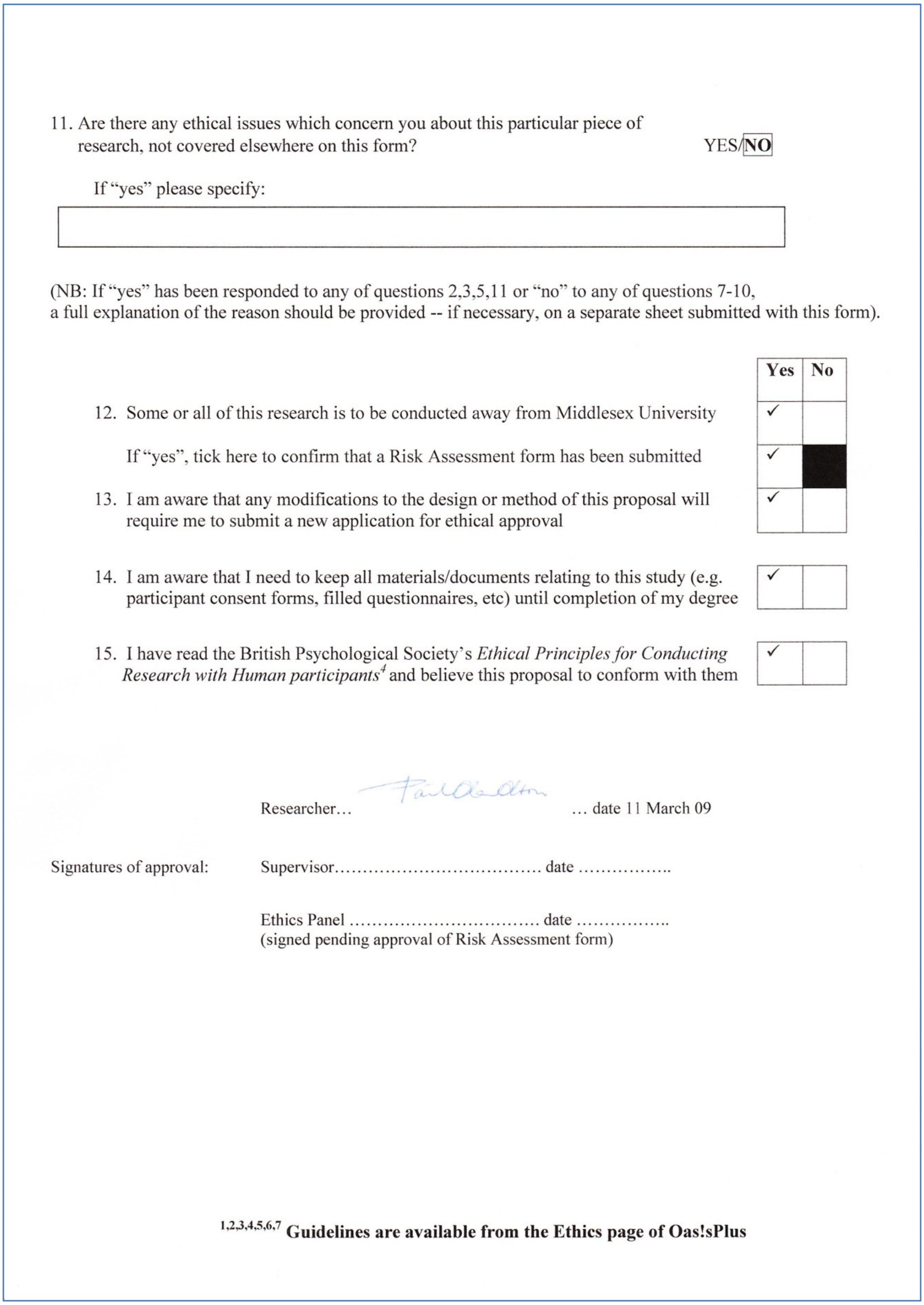
I will use the TrueCrypt software (www.truecrypt.org) which encrypts entire data areas on a harddisk as if it were a single file, to a standard that satisfies secret services. Original data will be stored only in such encrypted form i.e. cross-reference and demographic table, scanned copies of written papers (BPRS, consent form, receipt for any reimbursement etc) and the original tape recording. Originals will be scanned or copied immediately after coming home and then safely destroyed.

The transcripts will use common-name pseudonyms for my own recollection, starting with A for the first participant. I shall conduct a separate analysis to avoid any giveaways.

If "no", how will participants be warned? *(see*[5]*)*

(NB: You are not at liberty to publish material taken from your work with individuals without the prior agreement of those individuals).

[1,2,3,4,5,6,7] **Guidelines are available from the Ethics page of Oas!sPlus**



11. Are there any ethical issues which concern you about this particular piece of research, not covered elsewhere on this form? YES/[✓ NO]

If "yes" please specify:

(NB: If "yes" has been responded to any of questions 2,3,5,11 or "no" to any of questions 7-10, a full explanation of the reason should be provided -- if necessary, on a separate sheet submitted with this form).

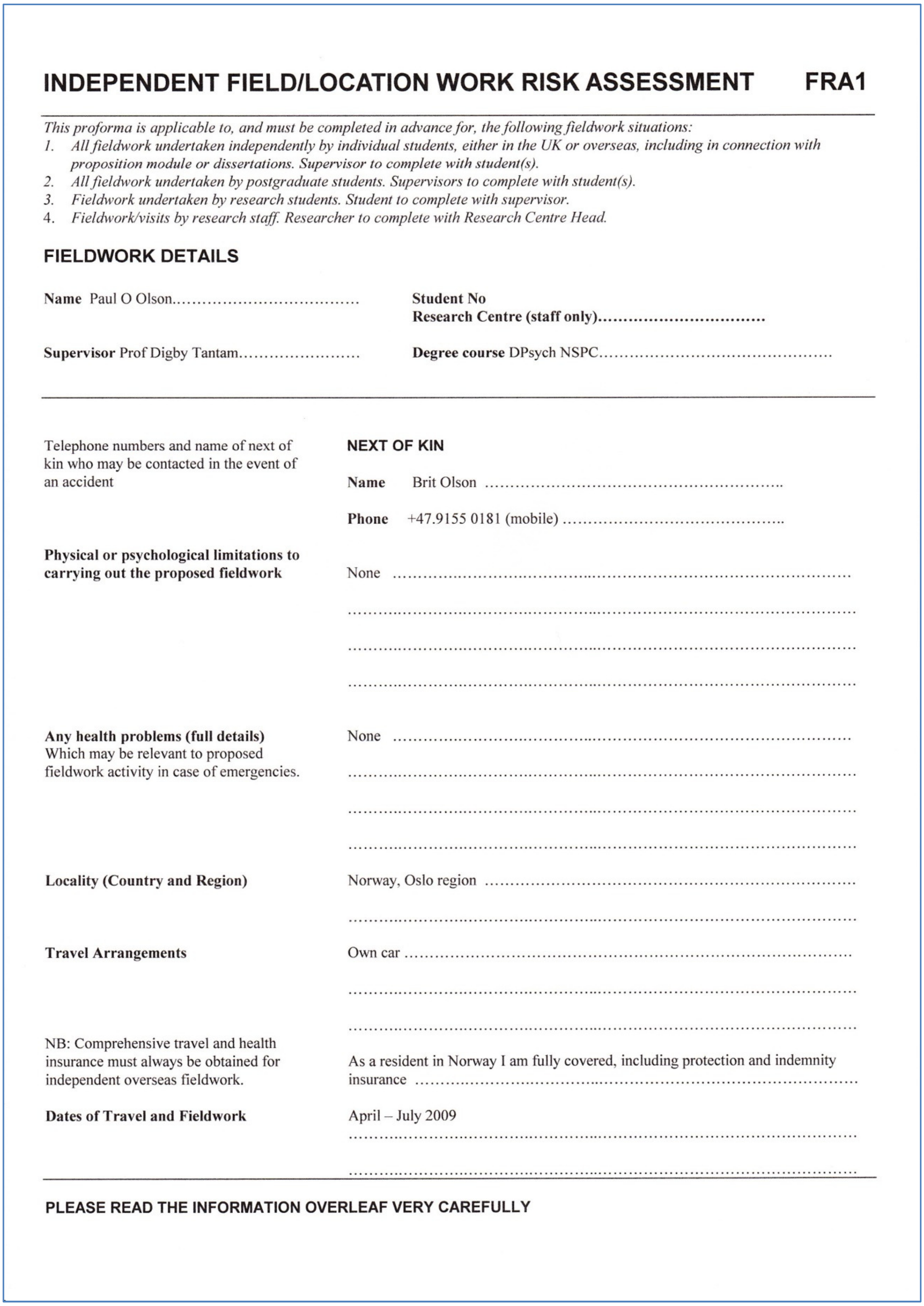
	Yes	No
12. Some or all of this research is to be conducted away from Middlesex University	✓	
If "yes", tick here to confirm that a Risk Assessment form has been submitted	✓	■
13. I am aware that any modifications to the design or method of this proposal will require me to submit a new application for ethical approval	✓	
14. I am aware that I need to keep all materials/documents relating to this study (e.g. participant consent forms, filled questionnaires, etc) until completion of my degree	✓	
15. I have read the British Psychological Society's *Ethical Principles for Conducting Research with Human participants*[4] and believe this proposal to conform with them	✓	

Researcher… Paul O Olson … date 11 March 09

Signatures of approval: Supervisor……………………………… date ……………..

Ethics Panel …………………………… date ……………..
(signed pending approval of Risk Assessment form)

[1,2,3,4,5,6,7] **Guidelines are available from the Ethics page of Oas!sPlus**



INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following fieldwork situations:

1. *All fieldwork undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).*
2. *All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).*
3. *Fieldwork undertaken by research students. Student to complete with supervisor.*
4. *Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.*

FIELDWORK DETAILS

Name Paul O Olson………………………………

Student No

Research Centre (staff only)……………………………

Supervisor Prof Digby Tantam……………………

Degree course DPsych NSPC………………………………………

Telephone numbers and name of next of kin who may be contacted in the event of an accident

NEXT OF KIN

Name Brit Olson …………………………………………………..

Phone +47.9155 0181 (mobile) ……………………………………..

Physical or psychological limitations to carrying out the proposed fieldwork

None ………………………………………………………………………………

Any health problems (full details) Which may be relevant to proposed fieldwork activity in case of emergencies.

None ………………………………………………………………………………

Locality (Country and Region)

Norway, Oslo region ………………………………………………………………

Travel Arrangements

Own car ……………………………………………………………………………

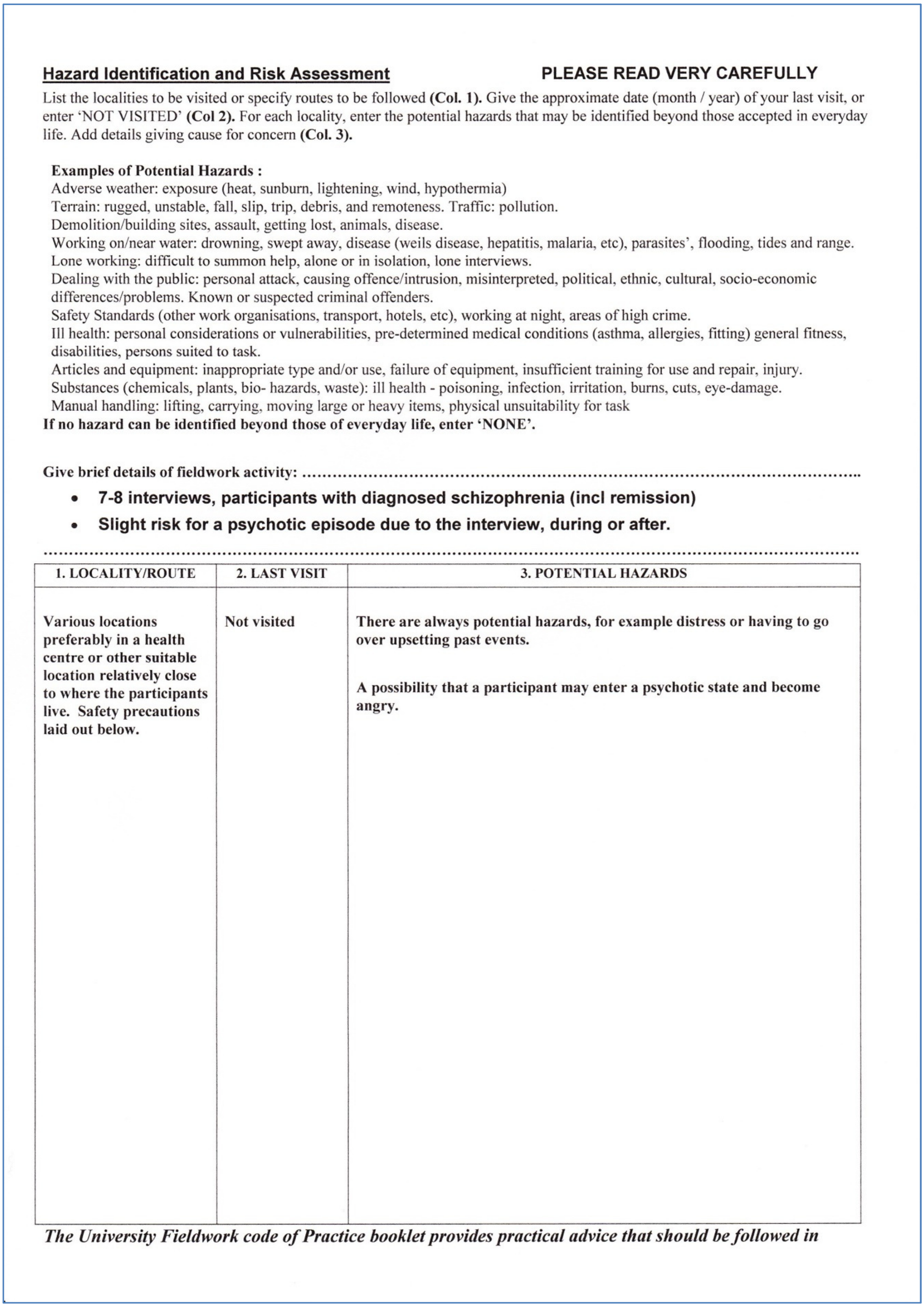
NB: Comprehensive travel and health insurance must always be obtained for independent overseas fieldwork.

As a resident in Norway I am fully covered, including protection and indemnity insurance ………………………………………………………………………

Dates of Travel and Fieldwork

April – July 2009

PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY



Hazard Identification and Risk Assessment **PLEASE READ VERY CAREFULLY**

List the localities to be visited or specify routes to be followed **(Col. 1).** Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' **(Col 2).** For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern **(Col. 3).**

Examples of Potential Hazards :
Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)
Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.
Demolition/building sites, assault, getting lost, animals, disease.
Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.
Lone working: difficult to summon help, alone or in isolation, lone interviews.
Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders.
Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.
Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.
Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.
Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.
Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

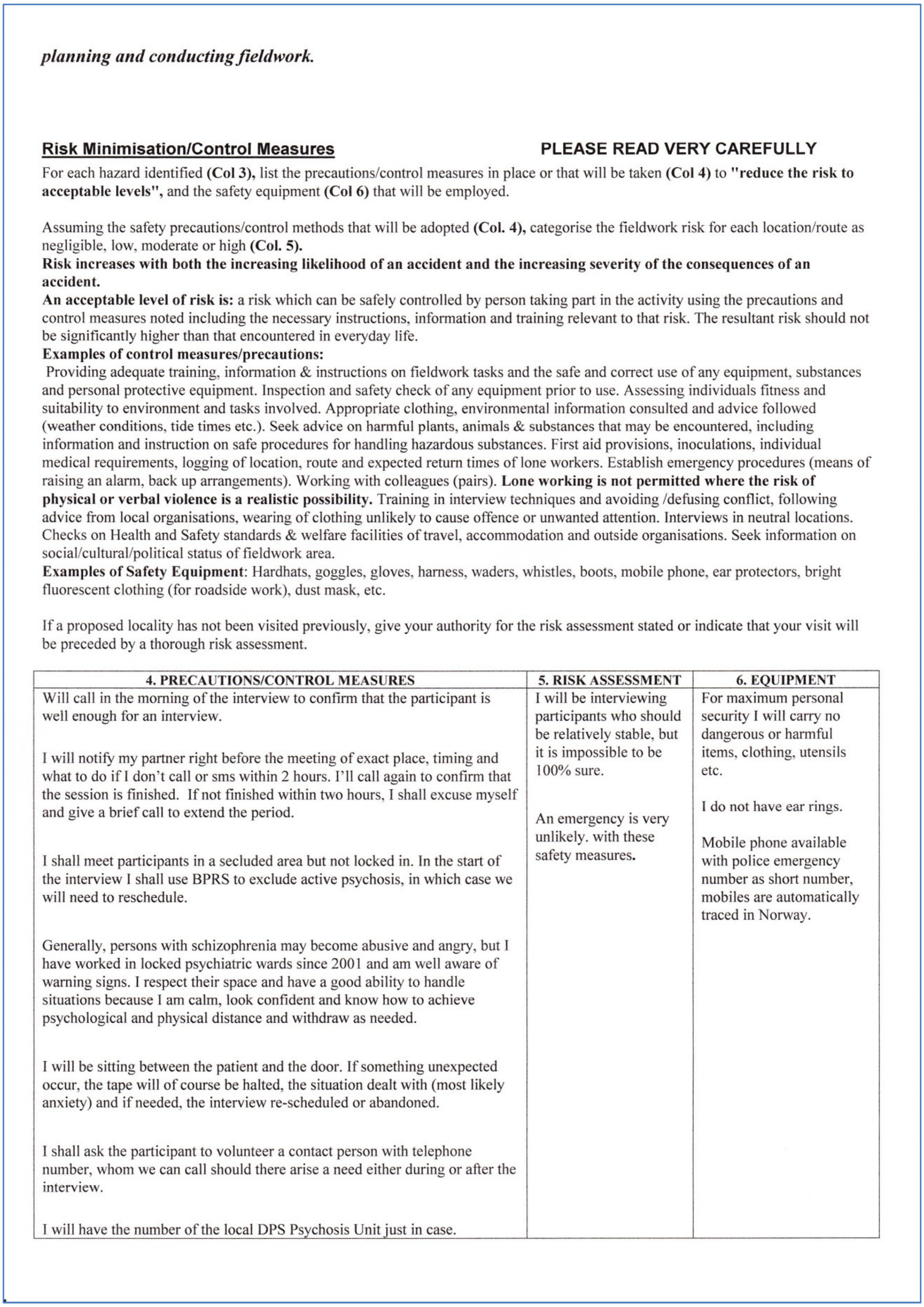
Give brief details of fieldwork activity: ……………………………………………………………………………………………..

- **7-8 interviews, participants with diagnosed schizophrenia (incl remission)**
- **Slight risk for a psychotic episode due to the interview, during or after.**

……

1. LOCALITY/ROUTE	2. LAST VISIT	3. POTENTIAL HAZARDS
Various locations preferably in a health centre or other suitable location relatively close to where the participants live. Safety precautions laid out below.	**Not visited**	**There are always potential hazards, for example distress or having to go over upsetting past events.** **A possibility that a participant may enter a psychotic state and become angry.**

The University Fieldwork code of Practice booklet provides practical advice that should be followed in



planning and conducting fieldwork.

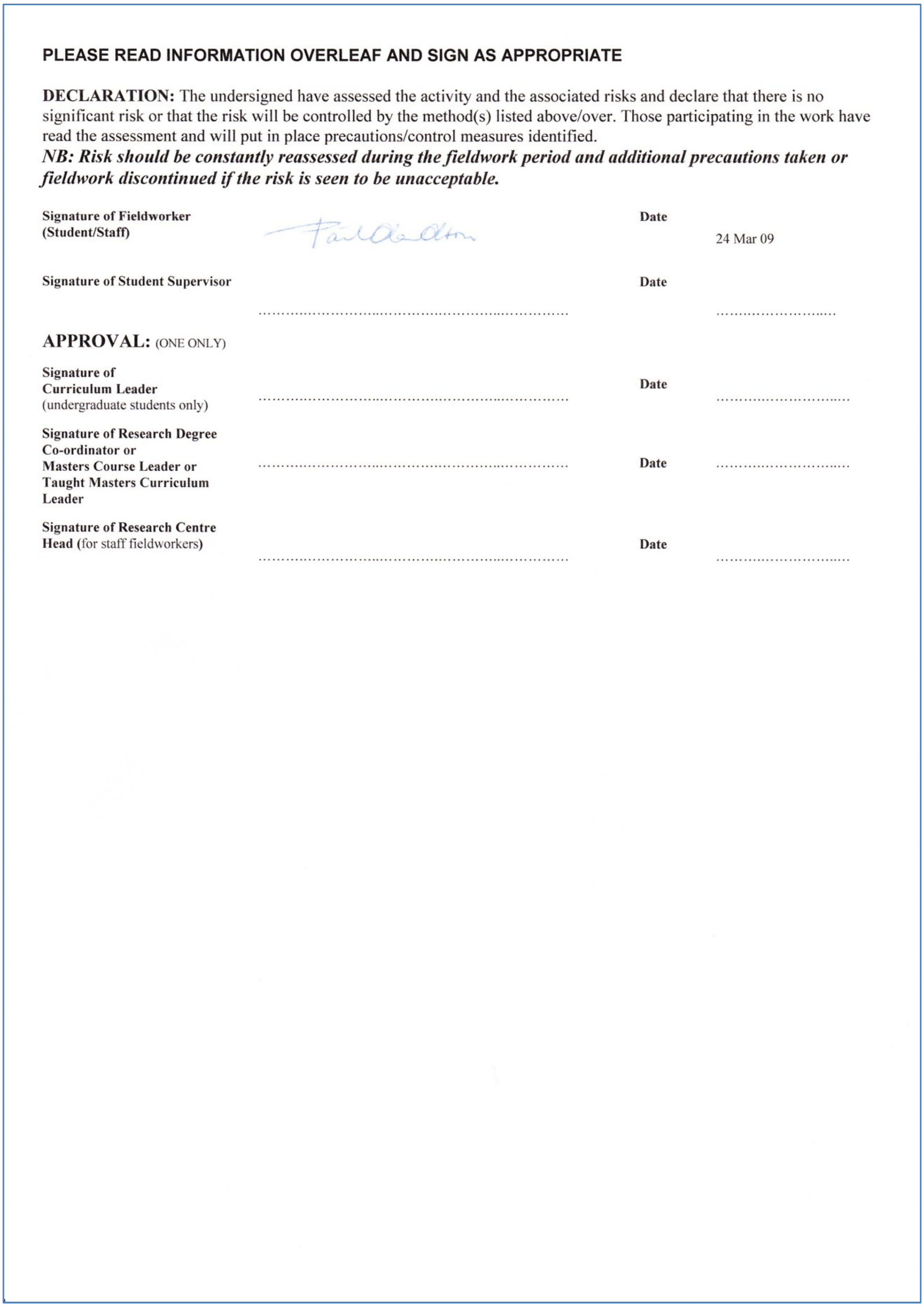
Risk Minimisation/Control Measures **PLEASE READ VERY CAREFULLY**

For each hazard identified **(Col 3),** list the precautions/control measures in place or that will be taken **(Col 4)** to **"reduce the risk to acceptable levels",** and the safety equipment **(Col 6)** that will be employed.

Assuming the safety precautions/control methods that will be adopted **(Col. 4),** categorise the fieldwork risk for each location/route as negligible, low, moderate or high **(Col. 5).**
Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.
An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.
Examples of control measures/precautions:
Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs). **Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility.** Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.
Examples of Safety Equipment: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/CONTROL MEASURES	5. RISK ASSESSMENT	6. EQUIPMENT
Will call in the morning of the interview to confirm that the participant is well enough for an interview. I will notify my partner right before the meeting of exact place, timing and what to do if I don't call or sms within 2 hours. I'll call again to confirm that the session is finished. If not finished within two hours, I shall excuse myself and give a brief call to extend the period. I shall meet participants in a secluded area but not locked in. In the start of the interview I shall use BPRS to exclude active psychosis, in which case we will need to reschedule. Generally, persons with schizophrenia may become abusive and angry, but I have worked in locked psychiatric wards since 2001 and am well aware of warning signs. I respect their space and have a good ability to handle situations because I am calm, look confident and know how to achieve psychological and physical distance and withdraw as needed. I will be sitting between the patient and the door. If something unexpected occur, the tape will of course be halted, the situation dealt with (most likely anxiety) and if needed, the interview re-scheduled or abandoned. I shall ask the participant to volunteer a contact person with telephone number, whom we can call should there arise a need either during or after the interview. I will have the number of the local DPS Psychosis Unit just in case.	I will be interviewing participants who should be relatively stable, but it is impossible to be 100% sure. An emergency is very unlikely. with these safety measures.	For maximum personal security I will carry no dangerous or harmful items, clothing, utensils etc. I do not have ear rings. Mobile phone available with police emergency number as short number, mobiles are automatically traced in Norway.



PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

DECLARATION: The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.
NB: Risk should be constantly reassessed during the fieldwork period and additional precautions taken or fieldwork discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker (Student/Staff) **Date** 24 Mar 09

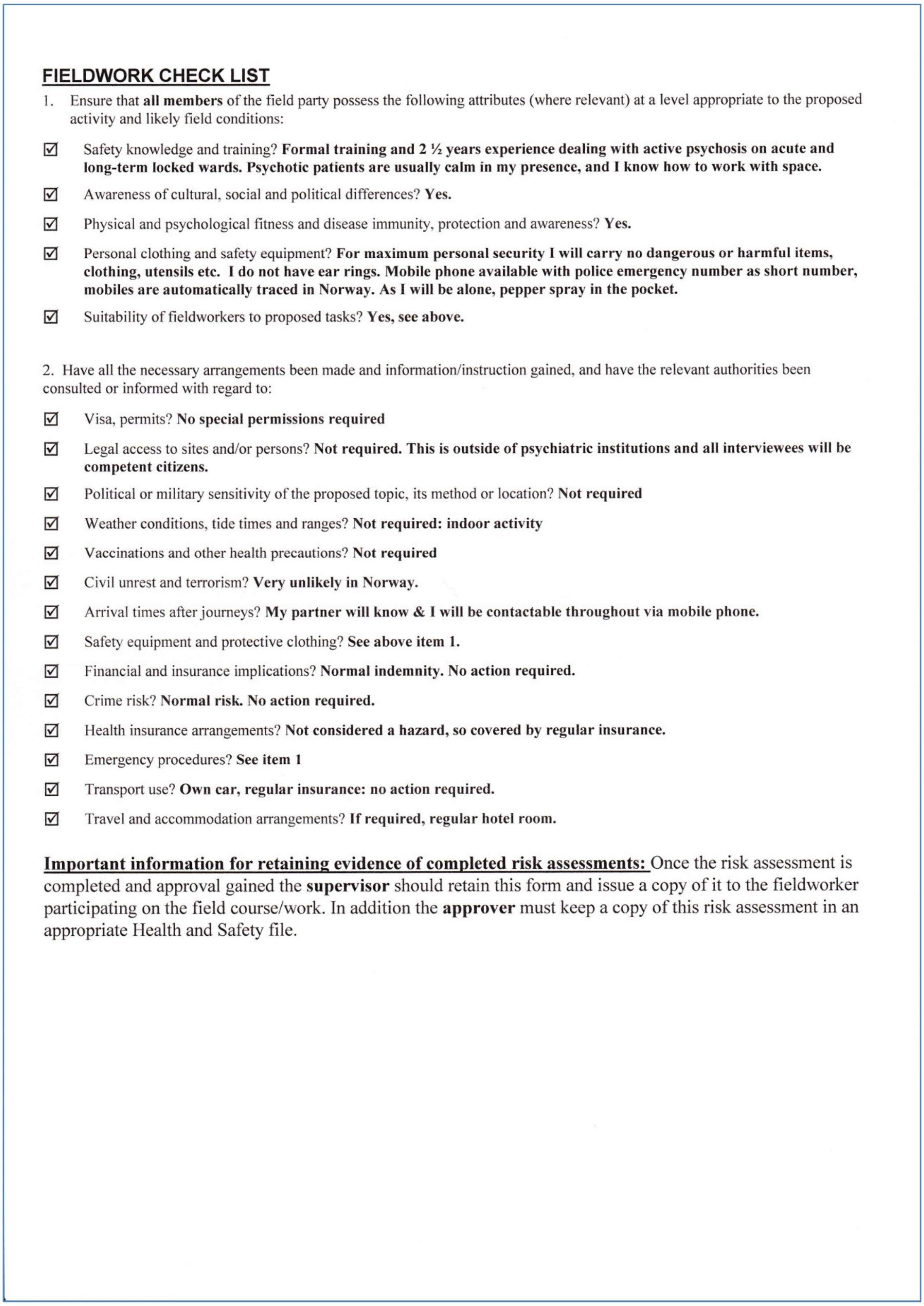
Signature of Student Supervisor ………………………………………………………… **Date** ……………………

APPROVAL: (ONE ONLY)

Signature of Curriculum Leader (undergraduate students only) ………………………………………………………… **Date** ……………………

Signature of Research Degree Co-ordinator or Masters Course Leader or Taught Masters Curriculum Leader ………………………………………………………… **Date** ……………………

Signature of Research Centre Head (for staff fieldworkers) ………………………………………………………… **Date** ……………………



FIELDWORK CHECK LIST

1. Ensure that **all members** of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:

☑ Safety knowledge and training? **Formal training and 2 ½ years experience dealing with active psychosis on acute and long-term locked wards. Psychotic patients are usually calm in my presence, and I know how to work with space.**

☑ Awareness of cultural, social and political differences? **Yes.**

☑ Physical and psychological fitness and disease immunity, protection and awareness? **Yes.**

☑ Personal clothing and safety equipment? **For maximum personal security I will carry no dangerous or harmful items, clothing, utensils etc. I do not have ear rings. Mobile phone available with police emergency number as short number, mobiles are automatically traced in Norway. As I will be alone, pepper spray in the pocket.**

☑ Suitability of fieldworkers to proposed tasks? **Yes, see above.**

2. Have all the necessary arrangements been made and information/instruction gained, and have the relevant authorities been consulted or informed with regard to:

☑ Visa, permits? **No special permissions required**

☑ Legal access to sites and/or persons? **Not required. This is outside of psychiatric institutions and all interviewees will be competent citizens.**

☑ Political or military sensitivity of the proposed topic, its method or location? **Not required**

☑ Weather conditions, tide times and ranges? **Not required: indoor activity**

☑ Vaccinations and other health precautions? **Not required**

☑ Civil unrest and terrorism? **Very unlikely in Norway.**

☑ Arrival times after journeys? **My partner will know & I will be contactable throughout via mobile phone.**

☑ Safety equipment and protective clothing? **See above item 1.**

☑ Financial and insurance implications? **Normal indemnity. No action required.**

☑ Crime risk? **Normal risk. No action required.**

☑ Health insurance arrangements? **Not considered a hazard, so covered by regular insurance.**

☑ Emergency procedures? **See item 1**

☑ Transport use? **Own car, regular insurance: no action required.**

☑ Travel and accommodation arrangements? **If required, regular hotel room.**

Important information for retaining evidence of completed risk assessments: Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the fieldworker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

Appendix 5 - Trade names vs. generic names

Akineton – biperiden

Cisordinol – zuklopentixol

Haldol – haliperidol

Kemadrin -

Leponex – klozapin

Melleril – no longer sold (N05A C02)

Orap – no long sold (N05A G02)

Risperdal – risperidone

Seroquel – quetiapin

Trilafon – perfenazin

Valium – diazepam

Vival – diazepam

Zyprexa – olanzapin