JYU DISSERTATIONS 207

Tomi Bergström

# Life after Integrated and Dialogical Treatment of First-Episode Psychosis

## Long-Term Outcomes at the Group and Individual Level

UNIVERSITY OF JYVÄSKYLÄ
FACULTY OF EDUCATION AND
PSYCHOLOGY

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# Life after Integrated and Dialogical Treatment of First-Episode Psychosis

## Long-Term Outcomes
## at the Group and Individual Level

Esitetään Jyväskylän yliopiston kasvatustieteiden ja psykologian tiedekunnan suostumuksella
julkisesti tarkastettavaksi yliopiston vanhassa juhlasalissa S212 syyskuun 19. päivänä 2020 klo 12.

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in building Seminarium, auditorium S212, on September 19, 2020, at 12 o'clock noon.

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# ABSTRACT

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This research (comprising studies labeled *Study I, Study II, and Study III)* aimed to evaluate the long-term outcomes of the family-oriented and need-adapted Open Dialogue approach (OD) in the treatment of first-episode psychosis (FEP). Quantitative and qualitative data, based on an average follow-up time of 19 years, were derived from the *Western Lapland research cohort;* this included all persons (N=108) who received treatment for FEP over three inclusion periods within the catchment area in which OD was regionally implemented. Study I used case note-based information to analyze specific patterns in the use of mental health services under the OD treatment system (N=65), in the decades following FEP. For Study II, the mortality rates and long-term use of services among the cohort members (N=108) were gathered from national registers. The results were compared with a matched comparison group, comprising all Finnish FEP patients with a 19−20 year follow-up whose treatment was initiated *outside* the catchment area (N=1763). Study III included information gathered via in-depth life-story interviews with 20 members of the cohort. Thematic narrative analysis was used to interpret how the people themselves viewed mental crises and OD as part of their life stories. The results indicated that the practice in the catchment area had followed the principles of OD, even if there was variety in long-term treatment patterns. Compared to other FEP treatments, OD was associated with a significantly decreased need for mental health services, and with better maintained work capability at a 19-year follow-up. The standardized mortality ratio was lower under OD, but in both groups, the premature mortality rate was high, and there were no significant differences in suicide rates. The service users themselves emphasized support from their close networks, and also their own actions in the gradual process of surviving, thus reflecting a tendency to associate mental crises with actual life events. The results of this thesis suggested that with gradual developmental efforts towards collaborative treatment approaches at the community level, it is possible to help people to maintain their agency and social functioning, accompanied by a decreased need for mental healthcare, decades after FEP. However, due to the observational nature of the study, more research is still needed on the effectiveness and transferability of OD.

*Keywords:* antipsychotics, cohort study, disability allowance, family therapy, long-term follow-up, open dialogue, psychosis, psychosocial treatment, qualitative study, schizophrenia

# TIIVISTELMÄ (FINNISH ABSTRACT)

Bergström, Tomi
Elämä ensipsykoosin integroidun ja dialogisen hoidon jälkeen: pitkän aikavälin hoitotulokset yksilö- ja ryhmätasolla
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Tämän kolmesta osatutkimuksesta koostuvan väitöskirjan tavoitteena oli arvioida verkostokeskeisen ja tarpeenmukaisen avoimen dialogin hoitokäytännön (AD) pitkän aikavälin hoitotuloksia ensipsykoosin hoidossa. Laadullista ja määrällistä tietoa kerättiin valtakunnallisista rekistereistä keskimäärin 19 vuoden seuranta-ajalta, sekä haastattelemalla AD tutkimuskohorttiin kuuluneita. Kohortti käsitti kaikki Länsi-Lapin alueellisten tutkimus- ja kehityshankkeiden aikana ensipsykoosin vuoksi hoidossa olleet potilaat (N=108). Ensimmäisessä osatutkimuksessa selvitettiin mielenterveyspalveluiden käyttöä AD palvelujärjestelmässä vuosikymmenten aikana (N=65). Toisessa osatutkimuksessa tutkittiin kaikkien kohorttiin kuuluneiden (N=108) kuolleisuutta ja palveluiden käyttöastetta vertailemalla tuloksia kaltaistettuun vertailuryhmään, joka muodostettiin kaikista Suomessa 19-20 vuotta aiemmin tutkimusalueen ulkopuolella hoidossa olleista ensipsykoosipotilaista (N=1763). Kolmannessa osatutkimuksessa kohortin jäseniä (N=20) pyydettiin kertomaan oma elämäntarina. Temaattisen narratiivisen analyysin avulla selvitettiin, miten psykoosiksi määritetty kriisi koettiin, ja millaisia merkityksiä sen dialogiselle hoidolle annettiin vuosikymmenten jälkeen. Tulosten perusteella alueellinen hoitokäytäntö noudatti AD:n periaatteita, joskin pidemmässä seurannassa hoitokäytännöissä oli havaittavissa vaihtelua. Verrattaessa muunlaiseen ensipsykoosin hoitoon, AD oli yhteydessä vähentyneeseen tarpeeseen käyttää mielenterveyspalveluita sekä paremmin säilyneeseen työkykyyn koko 19-vuoden seuranta-ajan. Vakioitu kuolleisuussuhde oli vertailuryhmässä korkeampi, mutta molemmissa ryhmissä ennenaikainen kuolleisuus oli muuta väestöä korkeampaa, eikä ryhmien välillä havaittu tilastollisesti merkitseviä eroja itsemurhissa. Hoidossa olleet korostivat sekä lähipiirin että oman toiminnan merkitystä kriisistä selviytymisessä, joka heijasteli taipumusta esittää mielenterveyskriisi erottamattomana elämäntapahtumista. Kaikkiaan tulokset antoivat viitteitä siitä, että palvelujärjestelmän asteittainen kehitystyö kohti yhteisöllisempää hoitokäytäntöä voi olla yhteydessä toimijuuden säilymiseen ja vähentyneeseen mielenterveyspalvelujen käyttöasteeseen vuosikymmeniä ensipsykoosin jälkeen. Tutkimuksen observoivan luonteen vuoksi tarvitaan kuitenkin kontrolloidumpaa näyttöä AD:n vaikuttavuudesta ja siirrettävyydestä.

*Avainsanat:* antipsykootti, kohorttitutkimus, työkyvyttömyyseläke, perheterapia, pitkän ajan seuranta, avoimen dialogin malli, psykoosi, psykososiaalinen hoito, laadullinen tutkimus, skitsofrenia

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Tornio, 23.2.2020
Tomi Bergström

# LIST OF ORIGINAL PUBLICATIONS

I Bergström, T., Alakare, B., Aaltonen, J., Mäki, P., Köngäs-Saviaro, P., Taskila, J. J., & Seikkula, J. (2017). The long-term use of psychiatric services within the Open Dialogue treatment system after first-episode psychosis. *Psychosis*, 9(4), 310-321.

II Bergström, T., Seikkula, J., Alakare, B., Mäki, P., Köngäs-Saviaro, P., Taskila, J. J., Tolvanen, A., & Aaltonen, J. (2018). The family-oriented Open Dialogue approach in the treatment of first-episode psychosis: nineteen-year outcomes. *Psychiatry Research*, 270, 168-175.

III Bergström, T., Seikkula, J., Holma, J., Mäki, P., Köngäs-Saviaro, P., & Alakare, B. (2019). How do people talk decades later about their crisis that we call psychosis? A qualitative study of the personal meaning-making process. *Psychosis*, 11(2), 105-115.

Taking into account the instructions and comments given by co-authors and supervisors, the author of this thesis wrote the original research plan, acquired research permissions, coordinated the collection of quantitative and qualitative data, collected most of the quantitative data and all of the qualitative data, conducted all parts of the qualitative and quantitative analyses, and wrote the original publications.

## FIGURE

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# CONTENTS

# 1 INTRODUCTION

This dissertation concerns the lives of individuals who have experienced a life crisis characterized by experiences that most of us would find unusual, and even terrifying. It has gained impetus from efforts made in a small region in northern Finland, where people have collaborated to find new ways of helping those who are suffering from these experiences. In many societies such experiences – which are often seen as involving difficulties in distinguishing what is real from what is not – are called *psychoses*. They are usually viewed as a symptom of some of the most severe mental disorders, including *schizophrenia*.

Nevertheless, we still do not know what schizophrenia and other psychoses truly are, or what causes them. It is notable that people diagnosed with psychosis can manifest very different kinds of backgrounds, experiences, and outcomes. Moreover, in the literature, schizophrenia and other psychoses encompass a clinically and prognostically heterogeneous group of mental and social phenomena (Alanen, 2009). The multifaceted nature of the phenomena has proved challenging for the development of optimal treatment strategies (Borchers, 2014), and recent long-term follow-ups indicate that the treatment outcomes of schizophrenia-spectrum psychoses remain unsatisfactory (Volavka & Vevera, 2018), with only one out of seven individuals meeting the criteria for recovery, in terms of manifesting persistent improvements in clinical and social domains (Jääskeläinen et al., 2013). Thus, even though the estimated lifetime prevalence of schizophrenia is less than 1% (e.g. Saha, Chant, Welham, & McGrath, 2005), the burden associated with these disorders has remained substantial for individuals, their close networks, and society as a whole (Charlson et al., 2018).

To address this challenge, there have been increasing attempts to develop strategies for early intervention and integrative treatment (see Bird et al., 2010). The aim has been to combine different treatment methods before the symptoms develop into a more severe and chronic form. In line with this, there has been renewed interest in psychological treatments (see Bird et al., 2010; Bradshaw, 2000), and in psychosocial understandings of psychosis, that would underline the dimensional and inseparable nature of “unusual” and “normal” mental phenomena (Cooke et al., 2017), and further, the ways in which the phenomena are embedded in life-course events (see Beards et al., 2013; Read, van Os, Morrison, & Ross, 2005; van Os, Kenis, & Rutten, 2010).

One example of an integrated and psychotherapeutically-oriented model of care is the *Need-Adapted Approach* (NAA), plus its subsequent modifications. This model has been systematically developed and implemented in the Finnish healthcare system since the late 1960s (Alanen, 1997). The primary goal in the original implementation projects was to create a comprehensive model of treatment within the psychiatric public health system, within which different methods would be combined to meet the therapeutic needs of each individual patient, closely integrated with their social networks (Alanen, 2009). Since then, NAA has moved in more network-oriented and dialogical directions, in line with the *Open Dialogue* (OD) approach. Here, the primary goal is to promote reciprocal open dialogues between patients, persons in their closest networks, and mental health workers. The setting is one of open meetings in which efforts are made to create a collaboratively shared understanding of each situation (Seikkula, Aaltonen, Alakare, Haarakangas, Keränen, & Lehtinen, 2006).

Currently OD is defined as a *holistic and person-centered model of mental healthcare,* in which the emphasis is on *the mobilization of resources within patients and their close networks,* with the aim of *increasing their sense of agency from early on* (Razzaque & Stockmann, 2016). The premise in such a dialogical way of working is that every perspective is accepted, unconditionally. Instead of interpreting the problem and coming up with an intervention or solution, the professionals focus on creating a safe space where everyone can be heard (Olson, Seikkula, & Ziedonis, 2014). As a result, each person in the dialogue can construct and reconstruct their understanding, using their own voice (Razzaque & Stockmann, 2016). Thus, the aim is not to treat the patient's symptoms *per se*; rather, attention is given to the relations between people who are connected within a constantly changing life situation (Piippo, 2008). To a large extent, this endeavor can be viewed as an alternative to conventional mental healthcare (Buus, Bikic, Jacobsen, Müller-Nielsen, Aagaard, & Rossen, 2017), in which care is usually delivered purely at the level of the individual (Razzaque & Stockmann, 2016).

Outcome studies have been conducted on both NAA and OD approaches. These indicate that with low-threshold and integrated family-oriented treatment of first-episode psychosis there is a decrease in both the long-term need for mental health treatment and the incidence of residual psychotic symptoms (Lehtinen, Aaltonen, Koffert, Räkköläinen, & Syvälahti, 2000; Seikkula, Alakare, & Aaltonen, 2011). In naturalistic studies, OD has been associated with increased social functioning (Buus et al., 2019) and maintained work capability (Seikkula et al., 2006). Nevertheless, in the absence of controlled trials, the effectiveness of the approach has had to be viewed as inconclusive (Freeman, Tribe, Stott, & Pilling, 2019). Moreover, earlier research on the long-term outcomes of other integrated early-intervention practices has indicated that the improved treatment and symptom outcomes may not be sustained after longer periods of time, as compared to treatment as usual (Gafoor et al., 2010; Secher et al., 2015). There is also a lack of knowledge on how the individuals themselves view different treatment strategies and their own personal coping throughout the years, following the initial need for mental healthcare.

This thesis presents long-term outcomes from the integrated and dialogical treatment of first-episode psychosis. It encompasses both quantitative and qualitative information. It is based on research which had two main aims:

1. to evaluate the stability of the treatment outcomes of first-episode psychosis – treatment that commenced under a regional mental healthcare system in which a family-oriented Open Dialogue approach was gradually developed and implemented;
2. to study the kinds of meanings given by individuals themselves, i.e. people who had experienced psychosis, and who had been treated under the Open Dialogue system. The meanings could encompass both the treatment given and the actual experience of mental crisis, years or even decades from the first onset of the crisis.

A point of departure for the research was the view that such a study of the long-term course of life, conducted at both group and individual levels, could illuminate the multifaceted and complex phenomena currently categorized under the psychosis umbrella. It would thus have the potential to guide the development of more valid and effective research and treatment practices.

## 1.1 The concept of psychosis

### 1.1.1 Group-level conceptualizations of psychosis

There is no clear consensus on definitions of psychosis (see Therman, 2014). From a medical perspective it is defined as an abnormal condition of the mind, characterized by difficulties in distinguishing what is real from what is not (Arciniegas, 2015). This is considered to be manifested in the form of certain symptoms, notably delusions, hallucinations, and/or disorganized behavior including incoherence in speech, thoughts, and more generally in interaction with others (Arciniegas, 2015; American Psychiatric Association, 2013). Diagnostically these symptoms can be grouped under the heading of schizophrenia spectrum and other psychotic disorders, so long as (1) there is no known somatic condition that would cause them, including the use of intoxicating substances, and (2) the observable phenomena differ significantly from local social and cultural expectations (American Psychiatric Association, 2013; World Health Organization, 2004).

Schizophrenia and other non-affective psychoses are often considered to be the most impairing form of psychopathology, associated with significant suffering for patients and their close networks (van Os & Kapur, 2009). Hence, with a view to developing preventive and more effective treatment practices, there have been significant efforts to increase understanding on the etiology of non-affective psychoses (see Klosterkotter, Schultze-Lutter, Bechdolf, & Ruhrmann, 2011). Despite this, the etiology and pathophysiology of schizophrenia and other psychoses have remained elusive (Jablensky, 2010).

Usually, the etiology of schizophrenia is presented as multifactorial, being associated with the combined effect of both biological and psychosocial risk factors (van Os & Kapur, 2009), ranging from genetic vulnerability (Ripke et al., 2014; Lichtenstein et al., 2009) to a variety of life adversities (Beards et al., 2013; Croft et al., 2019; Varese et al., 2012). However, current polygenic models (see Rammos et al., 2019) appear to have low explanatory power plus weak clinical utility (Torrey & Yolken, 2019), and the same seems to be true of other proposed biomarkers for diagnoses of the schizophrenia group (Fusar-Poli & Meyer-Lindenberg, 2016). It is also recognized that even though life-adversities increase the risk of developing psychosis, their occurrence is not a necessary factor (Luhrmann et al., 2019); conversely, not all people with traumatic life-experiences develop psychotic manifestations (e.g. Bentall, Wickham, Shevlin, & Varese, 2012).

The challenges in finding underlying causal mechanisms behind severe mental problems seem to reflect the (problematic) theoretical assumption that observable symptoms are caused by underlying disorders with discrete mechanisms (see also Borsboom, Cramer, & Kalis, 2018; Girgis, Zoghbi, Javitt, & Lieberman, 2019). In reality, most conceptualized mental disorders are massively multifactorial, and are always dependent on some form of intentionality, in the sense that they cannot be understood without referring to the content of mental states (Borsboom, Cramer, & Kalis, 2018). It has also been noted that even though the use of phrases such as “psychosis” and “schizophrenia” gives an impression of stability of definition, the developmental history of diagnostic categories shows that the movement towards these conceptualizations has not been straightforward (see Berrios, Luque, & Villagrán, 2003; Kendler, 2016). Indeed, it can be argued that the phrases used to describe abnormal mental states are always dependent on the boundaries of current cultural and historical contexts (Berrios, Luque, & Villagrán, 2003).

Diagnostic co-morbidities (Buckley, Miller, Lehrer, & Castle, 2009; van Os, & Kapur, 2009) and the fact that clinical features show a high degree of variability between and within individuals (see Jablensky, 2010), give grounds to question the idea that current diagnostic concepts describe discrete and natural disease entities with common causes (see Borsboom, Cramer, & Kalis, 2018; Isvoranu et al., 2017). In practice, this means that psychoses that are currently grouped under the schizophrenia spectrum can be clinically and prognostically so heterogeneous that markedly different patients may come to be categorized as suffering from the same disorder (Alanen, 2009).

As Heinimaa (2008) has demonstrated, *psychosis* is a clinical term that should be viewed as dependent on local conditions of understanding. For example, in the clinical context, the term *psychosis* in itself refers to something “incomprehensible” (Heinimaa, 2008); thus it emerges in interactional situations that somehow challenge common sense and conventional ways of interacting, with resulting emotional uncertainty in both the observer and the experiencer (Borchers, 2014). This, together with the fact that there is no clear consensus on the core symptoms of schizophrenia-spectrum disorders (see Parnas, 2011), could explain research findings indicating that both the psychosocial risk factors and genetic underpinnings of severe mental disorders do not follow current diagnostic boundaries (Cuthbert & Inseln, 2013; van Os & Kapur, 2009). Attempts to operationalize mental disorders by mainly focusing on observable symptoms may indeed have increased the reliability of diagnostic procedures, but both the validity and the clinical utility of current conceptualization efforts can be questioned (e.g. Allsopp, Read, Corcoran, & Kinderman, 2019; Borsboom, Cramer, & Kalis, 2018; Cuthbert & Inseln, 2013; First et al., 2004). From such considerations, alternative models for understanding mental distress have been proposed and studied (e.g. Borsboom, Cramer, Schmittmann, Epskamp, & Waldorp, 2011; Cuthbert & Inseln, 2013; Isvoranu et al., 2017; Johnstone & Boyle, 2018; Read, Mosher, & Bentall, 2004).

Systemic and other family therapeutic approaches have placed a particular emphasis on the relational nature of psychosis, paying close attention to the reciprocal associations within family, social and cultural contexts, rather than seeking mechanical explanations of causalities (Ingamells, 1993). From a more social perspective it has been recognized that narratives about psychosis are not born in a vacuum; rather, they are co-created within a range of social and cultural contexts (e.g. France & Uhlin, 2006). These include everyday social interactions with family members, with the professionals giving treatment, and with other persons connected to people in distress (Holma & Aaltonen, 1997; 1998). In line with this, Holma & Aaltonen (1997) have demonstrated how the culturally dominant stories likely to be preferred by significant others and by mental health workers can marginalize alternative stories, such as might provide other ways of understanding the experiences in question. This may well lead to a diminished sense of agency. Extending the argument, Lysaker & Lysaker (2017) have noted that current conceptualization efforts themselves possess the risk of defining persons with schizophrenia as wholly subjected to both biological and social forces.

Even if we are drawn to accept a reductionist view that would consider all experiential phenomena to be epiphenomena of other processes, the reduced entity must first be properly described and understood (Nelson, Yung, Bechdolf, & McGorry, 2008). In the domain of psychiatry and in clinical psychology, subjective experiences are usually the primary target of research and treatment (Parnas & Zahavi, 2002). This being so, an adequate and valid conceptualization of schizophrenia and psychoses will encompass approaches that take into account lived experiences, and hence the subjective dimensions of mental distress (Sass & Parnas, 2003). One avenue in addressing these issues can be found in the phenomenological research tradition (Sass & Parnas, 2003; Keller, 2008), with its aim of grasping the essential structures of human existence (Parnas & Zahavi, 2002).

### 1.1.2 Individual-level research on psychotic experiences

From a phenomenological perspective, psychoses are usually described as disturbances or other abnormalities in the self-experience itself, sufficient to have profound consequences for the interpersonal and intersubjective dimensions of existence (Sass, Borda, Madeira, Pienkos, & Nelson, 2018). Pursuing a phenomenological analysis, this self-disturbance is associated with hyper-reflexivity (in which aspects of oneself are experienced as akin to external objects) and with the diminution of self-affection (Sass & Parnas, 2003). According to Sass & Parnas (2003) these phenomena are necessarily accompanied also by some alterations in how figures and meanings emerge in different contexts.

According to Lysaker and Lysaker (2002), our self consists of a group of internalized positions which are in dialogue; the alteration of this dialogical structure of the self is a characteristic feature of psychosis, one that has dramatic consequences for to ability to interact with others, and to act in the world. Correspondingly, Longden, Madill, and Waterman (2012) have proposed that voice-hearing experiences can be most appropriately understood as involving dissociated components of the self, resulting from interpersonal stressors and traumas.

It has been found that people with a prolonged psychiatric condition tend to produce less integrated representations of themselves and others (Hasson-Ohayon et al., 2015). Lysaker, Lancaster, and Lysaker (2003) have observed similar incoherences in the self-narratives of people diagnosed with schizophrenia. Such narratives have been associated with internalized stigma (Lysaker, Tsai, Maulucci, & Stanghellini, 2008), and with more general deficits in metacognitive abilities (Lysaker et al., 2008; Lysaker & Lysaker, 2017).

In other studies, people experiencing early psychosis were found to be aware of their mental changes. They attempted to incorporate their experiences within familiar self-narratives, even if they did not recognize what these experiences signified, or how to response to them (Judge, Estroff, Perkins, & Penn, 2008). Overall, it has been recognized that people with a schizophrenia-spectrum diagnosis actively interpret their self-experiences (Lysaker & Lysaker, 2017), and research on narrative and psychosis has revealed the complex and multifaceted ways in which people give meanings to and make sense of their personal experiences (e.g. Roe, Hasson-Ohayon, Kravetz, Yanos, & Lysaker, 2008).

Because phenomenological approaches provide a perspective on the impact of genetic risk and of adverse events on processes of basic self-experience, they have been viewed as compatible with current dimensional models of psychosis (Sass et al., 2018). In these models, psychotic experiences are usually presented as a continuum, ranging from peculiar and bizarre experiences, to more crippling symptomatologies, such as fulfill the clinical criteria for psychotic disorder (see DeRosse & Karlsgodt, 2015; Therman, 2014; van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009). At the same time, experiences interpretable as psychoses have been seen as approaching the continuum of normal human experience (Lindgren, 2015). Such a view is in line with findings that psychotic-like experiences are common in the general population (e.g. Nuevo et al., 2012), with only a selective minority of those who experience them proceeding to receive treatment and thus a diagnosis. Nevertheless, as Keller (2008) and Seikkula (2019) have noted, most phenomenological studies focus on the ways in which psychosis differs from normality, rather than on what remains very similar in all varieties of human existence.

Service user/survivor-led research has had a particular role in renewing the conceptual basis of mental health research, by underlining the importance of collectively-produced knowledge, and further, the problems inherent in narrow conceptualizations (Rose, 2017). In recognition of this, there has been increasing research on the personal meanings that individuals ascribe to psychosis (e.g. Boydell, Stasiulis, Volpe, & Gladstone, 2010; Dudley, Siitarinen, James, & Dodgson, 2009; Jones & Shattell, 2016; McCarthy-Jones, Marriot, Knowles, Rowse, & Thompson, 2013). This work has confirmed and increased our understanding of the multifaceted nature of experiences that are often categorized under the psychosis umbrella. For example, it seems that for some persons these experiences – such as hearing voices or having unusual beliefs – can be extremely painful, whereas for others, certain aspects of experiences diagnosable as psychosis can be meaningful and valuable (Borchers, 2014; Romme, Escher, Dillon, Corstens, & Morris, 2009; Woods, Jones, Alderson-Day, Callard, & Fernyhough, 2015). Moreover, it seems that such experiences can be understood and interpreted in vastly differing ways, depending on the cultural context. Thus, they may be given paranormal and spiritual explanations, or else deemed to be normal and understandable reactions to certain situations (Longden, Madill, & Waterman, 2011).

Overall previous studies on first-person accounts have revealed that for persons with lived experiences of psychosis, the phenomena under the psychosis umbrella are usually more than just hallucinations and/or delusions (McCarthy-Jones et al., 2013). In fact, they are often presented as closely enmeshed with people's real-life experiences and everyday life contexts (Gullslett, Kim, & Borg, 2014; Winness, Borg, & Kim, 2010). Jones & Shattell (2016) noted that people with lived experiences of psychosis actively give meanings to their experiences. They may use a variety of explanatory models, generally struggling to explain them with available terms and constructs. Moreover, in service user-led studies, people with psychosis did not point to a specific point of onset; rather, they presented a continuity of themes and preoccupations from many years prior to the actual onset (Jones et al., 2016).

In other studies, persons with severe mental problems have not experienced the crisis or recovery as a single event or linear process (Gullslett, Kim, & Borg, 2016), and it have been noted that many of the experiences diagnosable as psychotic can make sense in the context of a person's life history (Corstens & Longden, 2013). For example, Irarrázaval & Sharim (2014) found that the assessment of life stories embedded descriptions of symptoms and other challenges within real-life worlds. In another study, people with the lived experience tended to attribute their experiences to external causes. These ranged from spiritual origins to childhood traumas, demonstrating the gap as compared to current medical views on the etiology of schizophrenia (Araten-Bergman, Avieli, Mushkin, &

Band-Winterstein, 2016). On a general level it has long been recognized that patients themselves favor psychosocial explanations over biological ones (Angermeyer & Klusmann, 1988).

Despite this, there has been relatively little research on how people view their initial mental health crisis after a longer period of time. In one study, Shepherd et al. (2012) found that people with a schizophrenia diagnosis came in time to view the symptom onset in terms of "feeling different," in association with a chaotic social environment and life-adversities. Many of them also experienced social withdrawal and loneliness as part of their life course (Shepherd et al., 2012). Earlier studies on ageing people with schizophrenia have reported cumulative suffering, experiences of loss, and loneliness (Araten-Bergman et al., 2016), but also hope, and opportunities for the normalization of personal experiences (Mushkin, Band-Winterstein, & Avieli, 2018). Overall, research on personal experiences of psychosis up to the present seems to reflect the complexity and variety of the phenomena currently categorized under the concept.

## 1.2 Treatment of psychosis

### 1.2.1 Current treatment strategies and long-term outcomes

The multifactorial and heterogeneous nature of the phenomena categorized as schizophrenia or other psychoses challenges the development of effective treatment practices. The current Finnish treatment guidelines (Schizophrenia: Current Care Guidelines, 2015) have attempted to take account of this heterogeneity by emphasizing both biological and psychosocial treatments, and further, by recognizing the importance of long-term confidential relationships, combined with individualized treatment methods.

The activism of users of mental health services has been a particular factor in shaping treatment guidelines over the years. They have challenged the conventional idea of a serious mental disorder as purely a deteriorative condition, placing an emphasis rather on psychosocial approaches and – increasingly – a "recovery-orientation" (Piat & Sabetti, 2009). In terms of psychosocial treatments, the strongest evidence base for the treatment of schizophrenia and other severe psychoses (see Schizophrenia: Current Care Guidelines, 2015) is thought to include cognitive and other behavioral therapies (Sarin, Wallin, & Widerlöv, 2011), and also (family) psychoeducational therapies (Buchkremer, Klingberg, Holle, Schulze Mönking, & Hornung, 1997).

It should nevertheless be noted that, due to the lack of a known etiology, the main treatment goals have focused mainly on the reduction of symptoms. Moreover, according to previous studies, the treatment still relies largely on neuroleptic medication (Kiviniemi, 2014; Nykänen et al., 2016). In the short term, neuroleptics seem to be effective in reducing the positive symptoms (e.g. hallucinations and delusions) during acute psychosis, and in preventing relapses (Correll, Rubio, & Kane, 2018; Leucht, Barnes, Kissling, Engel, Correll, & Kane, 2003;

Leucht, Corves, Arbter, Engel, Li, & Davis, 2009; Lewis et al., 2006); however, their specific "antipsychotic" mechanisms are unknown. Some authors have pointed out that the observed suppression of psychotic agitation could be due to more general neurological restrictions, bearing in mind that sedation and a decrease in agitation in general are expected to follow from the blockage of dopaminergic pathways (see Moncrieff & Cohen, 2009). Similar non-specificity in the treatment of mental disorders is observable with other types of drugs, and the same applies to a range of psychosocial treatments (Cuthbert & Inseln, 2013).

Despite the fact that neuroleptic medication is often continued for significant periods of time, there is not much evidence on its benefit after the first years of onset (Correll, Rubio, & Kane, 2018; Leucht et al., 2012). Current evidence comes mainly from retrospective register data, in which moderate maintenance treatment of schizophrenia with neuroleptics appeared in some cases to prevent rehospitalization (Tiihonen et al., 2017) and premature mortality (Tiihonen et al., 2009). On the other hand, higher exposure to neuroleptic medication has been associated with an increased risk of cardiovascular death (Torniainen et al., 2015). Criticism has been expressed regarding some of these studies, due to the fact that – in addition to other potential sources of bias – there are multiple uncontrolled confounders which could affect both the outcomes and usage trends from certain types of neuroleptics (e.g. De Hert, Correll, & Cohen, 2010; Moncrieff & Steingard, 2019).

In longitudinal studies in which the same individuals have been followed over decades, it has been found that neuroleptics do not reduce the frequency of psychosis in schizophrenia (Harrow, Jobe, & Faull, 2014), and that the overall long-term clinical and social outcomes have been better with less medicated samples (Harrow, Jobe, Faull, & Yang, 2017; Moilanen, 2016). High doses of neuroleptics have been associated with cognitive deficits (Husa et al., 2014), and in one trial with a seven-year follow-up, maintenance treatment was associated with poorer outcomes as compared to early dose reduction or to a discontinuation of neuroleptics (Wunderink et al., 2013).

Neuroleptics have also been found to cause other negative side effects, including weight gain, cardiovascular effects, and metabolic syndromes (Young, Taylor, & Lawrie, 2015), in addition to a potential reduction in gray matter volume (Fusar-Poli et al., 2013) and to other brain morphology changes (Ho, Andreasen, Ziebell, Pierson, & Magnotta, 2011). These findings indicate that at least some of the observed physiological changes that were previously associated with schizophrenia could be due to medication rather than to the underlying disease entity (van Erp et al., 2018). Despite this, the current lack of data, together with significant sources of bias, makes it difficult to systematically review whether or not long-term treatment with neuroleptics is harmful (Sohler et al., 2016).

There are, nevertheless, indications that the proportion of recovered or remissive cases in schizophrenia has not increased, despite the different treatment options followed (Jääskeläinen et al., 2013). For example, in a Northern Finland cohort with a 10-year follow-up, the re-hospitalization rates were 60% for a 2-year follow-up, and 81% for a 10-year follow-up (Miettunen, Lauronen, Veijola, Koponen, Saarento, & Isohanni, 2006). According to meta-analyses, symptomatic remission at long-term follow-up ranged from 16.4% to 37.5% (Volavka & Vevera, 2018). In 20-year follow-up studies, a steady worsening of both negative and positive symptoms was observed after first-episode psychosis (Kotov et al., 2017). Although the overall prognosis presents substantial variability, research overall has found poor long-term social outcomes in schizophrenia-spectrum disorders (Velthorst et al., 2017). The mortality gap in people with schizophrenia and other psychoses has also remained significantly high in long-term follow-ups (Doyle et al., 2019; Kiviniemi, 2014; Simon et al., 2018)

Despite the above, over a long period of time, a significant proportion of people with a schizophrenia diagnosis do achieve a more favorable outcome (Harrison et al., 2001), and there is no evidence that functional psychoses are themselves neurotoxic mental states (Bora, Yalincetin, Akdede, & Alptekin, 2018), nor that they automatically follow a progressive deteriorating course (Lally et al., 2017). Moreover, in one 20-year follow-up a significant proportion of people personally defined themselves as recovered, even if stricter criteria for recovery would indicate that there are limited gains in clinical recovery over the long term (O'Keeffe et al., 2019). In sum, studies so far indicate (1) that there are always persons who have recovered from psychosis (Harrison et al., 2001), but also (2) that the recovery rates and responses to treatment have not improved over time (Jääskeläinen et al., 2013; Lally et al., 2017), and further, (3) that the mortality gap between people with schizophrenia and the general population appears to be widening (Hayes, Marston, Walters, King, & Osborn, 2017; Lee, Liu, Tu, Palmer, Eyler, & Jeste, 2018).

### 1.2.2 A critical review of current treatment strategies

There are some potential explanations for the challenges described above. First of all, the multifaceted nature of the phenomena grouped under the category of severe mental disorders affects the validity of well-defined clinical trials, thus challenging fulfillment of the main premises for evidence-based medicine (EBM) (see Girgis et al., 2019; Cuthbert & Inseln, 2013). For example, empirical findings on the validity and reliability of psychiatric diagnoses indicate that the EBM framework for understanding mental health difficulties can neither improve scientific knowledge nor treatment outcomes in clinical practices (Timimi, 2014). In addition to validity problems, Thomas, Bracken, and Timimi (2012) have demonstrated that EBM – insofar as it attempts to frame mental health work as a series of mechanistic interventions targeted at specific malfunctions – misleadingly decenters non-technical aspects. These include the subjective, relational, and cultural factors which (following the logic of EBM itself) seem to be of prime importance in seeking to understand and treat complex human experiences.

According to van Os, Guloksuz, Vijn, Hafkenscheid, and Delespaul (2019), mental disorders may be especially difficult to capture via analysis of treatment-induced symptom reduction at the group level, since the mental difficulties represent such variable clusters of trans-syndromal symptom dimensions that they cannot be reduced to diagnostic categories. As a result, the likelihood ratios for etiology, treatment responses, and prognoses in current diagnostic categories are too low to be considered useful for current EBM (van Os et al., 2019). Correspondingly, Leichsenring (2004) has noted that randomized controlled trials (often viewed as the gold standard of EBM) mainly test laboratory modifications of therapy. The empirical evidence derived from these cannot be transferred directly to the field in the absence of evidence obtained via more naturalistic research designs.

According to Alanen (2009) there is a danger that only those psychosocial treatment strategies that are most readily researchable via methodologies fulfilling certain epistemological ideals may be accepted as evidence-based treatments, and thus selected in official treatment guidelines. This may be problematic in the context of mental health treatment since (according to the common factor perspective) there are overlapping and unspecific dynamic processes, such as empathy and trust, which are effective in all psychological interventions, irrespective of the specific methodology (Laska, Gurman, & Wampold, 2014). There is also empirical support for the view that manualized treatment methodologies are not superior to other kinds of psychological treatments (Truijens, Zühlke-van Hulzen, & Vanheule, 2019); indeed, it has been pointed out that highly structured and mechanistic approaches can narrow our ways of approaching the complexities of human suffering (Alanen, 2009).

In line with this, a recent large-scale meta-analysis (Jones et al., 2018) has indicated that cognitive therapies (and similar manualized behavioral therapies) are not more effective in the treatment of schizophrenia-group psychoses than other kinds of psychosocial interventions, i.e. procedures that may well be cheaper and more easily implemented in every clinical practice. Along similar lines, Mulder et al. (2018) have observed limitations relating to randomized controlled trials in developing treatment guidelines. They point out that for practicing clinicians, such trials do not provide information on whether or not the treatment will work for their particular patients.

More practical challenges can arise in implementing technical and structured programs within everyday clinical practices (Atkins, Rusch, Mehta, & Lakind, 2016). First of all, such programs are often developed in an academic setting that may possess resources unavailable in the everyday clinical field (Atkins et al., 2016). Secondly, there is no consensus on the outcome criteria, given that it is unclear how recovery from mental distress is to be defined, and hence operationalized (see Woods, Hart, & Spandler, 2019). In fact, research on service users has emphasized multiple ways in which people narrate or conceptualize their personal recovery. These frequently differ from the conventional variables that are used in clinical studies (e.g. Jose et al., 2015).

Jones et al. (2019) found that service providers emphasized the importance of therapeutic relationships rather than specific treatment techniques; on the other hand, macrolevel factors (including the resources available, plus the increasing mechanization of services with an overreliance on manualized approaches) were seen as barriers to service improvements. The findings were presented as a reminder that, as opposed to the narrow implementation of a specific intervention, there is a need to strengthen the capacity of providers to work more comprehensively across settings (Jones et al., 2019). People with lived experiences have also emphasized the need for survivor-led and recovery-oriented approaches, such as would value personal experiences and give more emphasis to peer support (e.g. Brosnan, 2018; Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014). Finally, it has been noted that mental health treatments have usually focused on the characteristics of the individual, even if the more relevant targets for intervention might well be social and structural in nature (see Jones, 2019; van Os et al., 2019).

To sum up, even though there is some consensus on the benefits of more integrative, person-centered, and recovery-oriented models of treatment, there are still challenges in delivering and implementing such approaches within everyday clinical practices. The challenges are bound up with the issues described above, and also factors relating to current treatment paradigms, which to some extent remain disease-focused and paternalistic (Frost et al., 2017). Moreover, as Yrjö Alanen (2009) has noted, the global atmosphere has not been favorable to the development of more integrated and comprehensive treatments, insofar as such treatments will be based on gradual development, starting from the recognition of local culture and resources, and with an associated need for constant on-the-job training and supervision activities. One example of this kind of a systematic developmental work can be found in the Need-Adapted Approach (NAA) and its later modifications.

### 1.2.3 The Need-Adapted Approach (NAA)

The basis of NAA was formed in several research projects that were initiated in the late 1960s and during the 1970s in Turku, Finland. The initial aim was to integrate psychoanalytic and family therapeutic treatments of schizophrenia-group psychoses within the public healthcare sector (Alanen, Lehtinen, Räkköläinen, & Aaltonen, 1991; Lehtinen & Räkköläinen, 1989). The development and nationwide implementation of such psychotherapeutically-oriented treatment strategies continued into the 1980s as part of the *Finnish national schizophrenia project* (Tuori et al., 1998). In association with continuous observation of the optimal treatment strategies for schizophrenia-group psychoses, the following elements were defined as the main goals in the treatment (Alanen, 2009):

1. Therapeutic activities should be planned and carried out flexibly and individually in each case
2. Examination and treatment should be dominated by a psychotherapeutic attitude.
3. Different therapeutic activities should supplement each other.
4. Treatment should become and remain a continuing process.
5. Follow-up is important, at the individual level, and in the development of treatment system as a whole.

To address the heterogeneous nature of schizophrenia-spectrum psychoses, the NAA underlined the importance of integrating various treatment modalities, based on the changing needs of both patients and their close networks (Alanen, 1997). This meant that instead of focusing only on observable symptomatology (and thence diagnosis), the main intention would be to emphasize the people themselves, plus the personal experiences of their close networks; this would apply to both the planning and implementation of the treatment (Alanen, 2009; Seikkula & Alakare, 2004; Seikkula et al., 2006). At this point, the psychotic behavior was viewed as a relational phenomenon, one that both occurred in and brought about mutual effects within a certain type of social network (Alanen, 2009.) In order to bring all relevant people from these networks together, joint network therapy meetings became the most central forum of the treatment processes. These were presented as serving three different functions: informative, diagnostic, and therapeutic (Alanen, 1997).

Alongside the implementation projects, academic research was applied in a continuous manner, seeking to evaluate different modifications of the model and to reach optimal treatment strategies, adaptable in different settings and situations (Alanen, 2009; Tuori et al., 1998). The investigations were defined as naturalistic action research, as they used a range of patient cohorts and data, gathered at different time frames from actual clinical practices (Alanen, 2009). For example, as part of the *Turku Schizophrenia Project*, it was noted that the inclusion of joint treatment and an overall increase in family-oriented activities was associated with a better outcomes (Alanen, Lehtinen, Räkköläinen, & Aaltonen, 1991; Lehtinen, 1993). For its part, the *National Schizophrenia Project* gave further confirmation that the treatment of schizophrenia-group psychoses can often be conducted in outpatient settings, within which the main tenets of NAA are followed, leading to more favorable treatment outcomes (Tuori et al., 1998).

Further evaluation on the effectiveness of NAA was conducted within the Finnish *Acute Psychosis Integrated Project* (API), which was commenced in six psychiatric hospitals in Finland in the early 1990s (Aaltonen, Koffert, Ahonen, & Lehtinen, 2000; Lehtinen et al., 2000). One of the main goals in this project was to evaluate the outcomes of first-episode psychosis treatment when immediate neuroleptization was avoided (Alanen, 2009; Lehtinen et al., 2000). The 2-year outcome of the group treated via NAA integrated with a more selective use of neuroleptics showed equal or somewhat better results than the control group (Lehtinen et al., 2000). Subsequently, NAA and its modifications have presented similar treatment outcomes in both observational (Bouchery et al., 2018; Cullberg, Levander, Holmqvist, Mattsson, & Wieselgren, 2002; Cullberg et al., 2006) and more controlled research settings (Granö, Karjalainen, Ranta, Lindgren, Roine, & Therman, 2016). The term *integrated care* has become one way to describe such family-oriented approaches, in which the aim is to combine different services and treatment strategies with a view to improving mental health systems more generally (Holmesland, 2015).

### 1.2.4 Western Lapland projects

Over the years, NAA has further evolved from individual therapy towards more systemic, narrative, and (eventually) dialogical and network-oriented approaches (Borchers, 2014). In one catchment area in particular, consisting of the western parts of Finnish Lapland, systemic family therapeutic practices, in conjunction with the other main tenets of NAA, have been systematically implemented in everyday clinical practices, commencing prior to and continuing after the API study (Seikkula et al., 2006). When local implementation projects in Western Lapland indicated that conventional family-based and other psychotherapeutic approaches were often too objectifying and narrowing in addressing the changing and complex needs of patients and their families, more flexible and open ways of organizing therapeutic treatment meetings were tested and eventually adopted in the entire regional mental healthcare system (Seikkula & Olson, 2003).

In local research projects (Haarakangas, 1997; Keränen, 1992; Seikkula, 1991) it was observed that a more open and unstructured way of working led to situations in which patients and their families were more actively involved in both the process of understanding the problem and planning the care. It was no longer possible for staff to follow their conventional roles, including the planning and subsequent conduct of specific interventions (Seikkula, 2011). The notions of dialogism presented by Bakhtin (1984), in addition to other constructivist perspectives, were applicable in understanding the phenomena that arose from the new practices. Language and communication were viewed as primarily constitutive of social reality, and the co-evolving processes of listening and understanding created a shared language for difficult experiences (Seikkula & Olson, 2003). According to Seikkula and Olson (2003), the other central frameworks in developing new practice included ideas on reflecting teams (Andersen, 1987), and also the collaborative language systems approach of Anderson and Goolishian (1988).

The main premise in such a dialogical approach is the idea that involvement in mutual and dialogical responses is the central core of human existence; the dialogues begin from early interaction between infant and parent, and continue throughout human life in relations with others (Seikkula, 2011). From this perspective, the term *psychosis* refers to a temporary and often terrifying alienation from these shared communicative practices (see Holma & Aaltonen, 1997); in such a situation, individuals do not have a language for their difficult experiences other than, for example, hallucinations and delusions (Seikkula, Alakare, & Aaltonen, 2011). This implies that behavior diagnosable as psychosis emerges mainly in relationships that do not guarantee adequate responses, and further, that they cannot then be described as a categorical or pathological phenomenon, associated with the characteristics of a single individual (Seikkula, 2019).

According to Seikkula (2019), recovery from psychotic behavior can occur if dialogical responses in acute crises are guaranteed. Guidelines for this kind of response were drawn up as a part of the systematic development and research work conducted in the Western Lapland area. For example, based on systematic case note analyses, it was observed that a successful treatment process – one that enables the dialogism associated with favorable outcomes – consists of several elements. These came to be codified as the seven main principles of the Open Dialogue (OD) approach (which is the term used henceforth in this thesis) (Seikkula, Alakare, & Aaltonen, 2011). The central elements encompass both the structural and the therapeutic principles of OD (Table 1).

While the primarily focus in OD is on promoting dialogue in order to increase the sense of agency in the lives of patients and their families (see Holma & Aaltonen, 1997), the shared understanding of each situation that emerges during the process simultaneously enables a more person-centered and flexible integration of existing treatment methods. The intention is that these should address the real and constantly-changing needs of individual patients and their families. In this sense the term *open dialogue* does not refer to a specific therapy method (see Seikkula, 2011); rather, it encompasses (1) the dialogical way of working with patients and their families, and at the same time, (2) guiding principles for the entire system of psychiatric practice that can make this kind of dialogical and need-adapted response possible.

In Western Lapland, this meant that the entire regional treatment system was gradually rearranged over the decades, with a view to providing intensive network-centered treatment for *all* psychiatric patients within a community-based setting (Aaltonen, Seikkula, & Lehtinen, 2011). During the 1980s, all public mental health outpatient clinics, plus the psychiatric hospital in the region, set up case-specific, mobile, and multi-professional outpatient teams, with the aim of operating across organizational boundaries (Aaltonen, Seikkula, & Lehtinen, 2011). Eventually, a more specialized crisis unit was established in Keropudas hospital to coordinate all treatment in the region (Aaltonen, Seikkula, & Lehtinen, 2011). Since any of the clinical staff members in the region could be called upon to participate in crisis teams across the municipalities, and since one of the primary aims was to promote continuity of treatment and a dialogical response to life crises, regardless of the defined problem or diagnosis (Seikkula et al., 2003), an appropriate training program became necessary. Thus, basically the entire mental care staff in the region participated in systemic three-year family therapy on-the-job training programs influenced by need-adapted and reflective approaches, the general orientation being towards horizontal aspects of expertise instead of vertical, authority-emphasizing aspects (Aaltonen, Seikkula, & Lehtinen, 2011). Following a period of continuous development and regional research projects, the new system of treatment became established in the 1990s. It eventually covered the entire hospital district of Western Lapland, and thus every new case of psychiatric crisis in the region of about 72 000 habitants (Aaltonen, Seikkula, & Lehtinen, 2011).

TABLE 1 The seven organizational/therapeutic principles and twelve fidelity elements of Open Dialogue (OD)[1]

| **Organizational principles of OD** | **Key elements of fidelity to dialogic practice**[2] |
|---|---|
| Immediate help | Two (or more) therapists |
| A social network perspective | Participation of family and network |
| Flexibility and mobility | Use of open-ended questions |
| Responsibility | Responding to clients' utterances |
| Psychological continuity | Emphasizing the present moment |
| **Therapeutic principles of OD** | Eliciting multiple viewpoints |
| Tolerance of uncertainty | Use of a relational focus in the dialogue |
| Dialogue | Responding to problematic discourse in a matter-of-fact style |
| | Emphasizing the clients' own words, not symptoms |
| | Conversation among professionals within meetings (reflection) |
| | Being transparent |
| | Tolerating uncertainty |

[1] Also in von Peter et al., 2019

[2] Olson, Seikkula, & Ziedonis, 2014

### 1.2.5 The Open Dialogue approach (OD)

As in NAA, the basic format of the Open Dialogue is the treatment meeting. In psychotic crises, this should occur within 24 hours of the first contact made by anyone who has concerns (Seikkula et al., 2011). Referrals or diagnoses are not needed, and no-one is turned away. If more specific expertise is needed, professionals from other disciplines can be invited to be part of the network (Seikkula & Alakare, 2004). The crisis is viewed as opportunity for change, and the primary goal is to bring together all important people connected to the situation as soon as possible, so that they openly share their ideas on the situation. The aim in this is to create a new kind of an understanding and to integrate outpatient treatment with the patient's daily life (Seikkula et al., 2006).

The responsibility for mobilizing the team and for arranging the first meeting rests with the professional first contacted, and the meeting should take place wherever the participants themselves feel safe enough. Thereafter, those team members who participate in the first meeting have to ensure the psychological continuity of the process, meaning that at least some members of the team remain in contact throughout the entire treatment process (Seikkula & Alakare, 2004; Seikkula et al., 2011). To guarantee this psychological continuity there must be at least two clinicians participating in the initial meetings, and all staff members, irrespective of their professional background, are equally responsible for the treatment (Razzaque & Stockmann, 2016).

To promote a more collaborative approach to the crisis, attempts are made to redress power imbalances by emphasizing transparent meaning- and decision-making processes; hence, all discussion, plans, and decisions about care take place within the network meeting, in the presence of the patient and of relevant members of his/her close networks (Seikkula & Olson, 2003; Razzaque & Stockmann, 2016). The main premise in approach is based on the acceptance of a polyphony of multiple voices, within which – in contradiction to the conventional systemic approach – the focus is not on the intervention *per se*, but on the creation of a shared language that will permit the meanings of the person's suffering to emerge (Seikkula et al., 2011; Razzaque & Stockmann, 2016). Because the "system" is constantly being created in every new dialogue, there is no longer a need to focus on the family system or dynamics; rather, the focus is on all the individuals involved in current situation (Seikkula & Olson, 2003). In this way OD allows every person to enter the conversation in his or her own way, and every voice is valued as a crucial part of the dialogue (Razzaque & Stockmann, 2016). The therapeutic ingredient is hypothesized to come from the effect of dialogism on the social network, as new words enter the common discourse, meaning that what is inexpressible (interpreted as a psychosis) can be given voice along with the important others (Seikkula, 2019).

In order to guarantee such a dialogical response, preliminary treatment decisions and interpretations should be avoided at the early stage of the process. According to Seikkula, Alakare, and Aaltonen (2011), this kind of a tolerance of uncertainty requires that all parties can feel safe enough in the joint process, and therefore that meetings should be arranged frequently enough to generate an adequate sense of security. Because the participants in the dialogue are viewed as co-creators of the shared reality, the aim is to follow the themes and the manner of speaking that the family- and network-members are accustomed to (Seikkula & Olson, 2003). Thus, the idea of listening to and being with clients is viewed as more important than the process of interviewing. The first questions should be as open as possible, to give the opportunity for family members to raise the issues that are most relevant to them at that moment (Razzaque & Stockmann, 2016).

Within the meetings, all the participants are recognized as relational beings who live within joint, embodied experiences that take place mostly outside spoken language (Seikkula, 2011). Hence, the approach shares similarities with other approaches underlining moment-to-moment connectivity (Razzaque & Stockmann, 2016). With regard to such processes, Seikkula (2008) has hypothesized that in therapy, the clients and therapists live within a joint embodied experience before any words emerge. Later empirical evidence has supported this via observations of a kind of embodiment synchrony, observable on the level of autonomic nervous system activity between participants in therapeutic dialogues (Karvonen, 2017). There are indications that such attunement often constitutes a complex dyadic or triadic phenomenon that changes over time (Karvonen, 2017; Seikkula, Karvonen, Kykyri, Kaartinen, & Penttonen, 2015).

### 1.2.6 Long-term outcomes from the integrated treatment of psychosis

Due to the gradual and regional development of the approach, it was not possible to conduct rigorous tests on OD by means of RCTs (Buus et al., 2017). Instead, the effectiveness of the Open Dialogue approach in the treatment of first-episode psychosis has been studied within three naturalistic research projects, conducted in the Western Lapland area in the 1990s as part of everyday clinical practices (Seikkula, Alakare, Aaltonen, Holma, Rasikangas, & Lehtinen, 2003; Seikkula et al., 2006; Seikkula, Alakare, & Aaltonen, 2011). The first inclusion period formed part of the nationwide *Acute Psychosis Integrated* (API) project (1992–1993). In 1994–1997 the project was continued at local level in Western Lapland, within the *Open Dialogue Approach in Acute Psychosis* (ODAP 1) project. Here, the primary aim was to evaluate the effectiveness of OD in its more systematic implementation. The third research period (ODAP 2) ran from 2003 to 2005. It aimed to replicate earlier designs and thus confirm the earlier findings. The studies included all people whose treatment had commenced in the region, who had received their first non-affective psychosis diagnosis at the time of the three inclusion periods, and who were aged 16–50 at onset (Seikkula, Alakare, & Aaltonen, 2011). The information was gathered via interviews, questionnaires, and medical records (Seikkula et al., 2006).

According to the main findings, at the 2-year follow-up in the API and ODAP 1 studies the overall re-admission and neuroleptic usage rates were significantly lower than in a comparison group (Seikkula et al., 2003). In a historical comparison, it was found that the ODAP 1 group had fewer hospital days, and that the duration of untreated psychosis had declined (Seikkula et al., 2006). At the 5-year follow-up (Seikkula et al., 2006), 82% of patients did not have residual psychotic symptoms, 86% had returned to their studies or a job, and 14% were receiving disability allowances. According to the findings, 29% had used neuroleptic medication at some phase of the treatment (Seikkula et al., 2006). The findings from the replication (on ODAP 2), conducted by Seikkula, Alakare, and Aaltonen (2011), were in line with the findings obtained from the original studies, and further showed a decrease in the total incidence of schizophrenia in the region. No favorable effect on the overall suicide rate was observed in any of the studies (Seikkula, Alakare, & Aaltonen, 2011; Seikkula et al., 2006).

Preliminary information obtained from outside the Western Lapland area has suggested that the approach described here may be associated with a favorable treatment outcome (Buus et al., 2019; Gordon, Gidugu, Rogers, DeRonck, & Ziedonis, 2016), although a number of methodological issues need to be taken into account (Freeman et al., 2019). It is worth noting also that, especially in other parts of Scandinavia, there have been reports on the implementation of OD, including its modifications, in a range of contexts. Promising outcomes and experiences have been reported, but as yet there have been no rigorous trials to evaluate the effectiveness of the approach (Buus et al., 2017).

Overall, even though naturalistic studies could provide more valid information on real-life events, evidence on OD generally and on dialogical practices in particular remains limited (Freeman et al., 2019). A number of problematic factors apply here. In the first place, most of the data and findings have been collected from the same region and the same patients, with the possibility that there could be unreachable confounding factors simultaneously affecting the outcomes. Furthermore, the lack of randomization challenges further evaluation of the aspects of the intervention that may or may not be significant, and of how different factors may affect the outcomes.

From a research perspective, one challenge is that there are no standardized definitions of what OD actually *is*, since neither the treatment principles nor the fidelity criteria are designed to be manualized or otherwise used in standardized ways – an absence reflecting the attempt to emphasize personal experiences in the dialogue (Buus et al., 2017), and to maximize the flexibility of need-adapted care (Alanen, 2009). As a result there is bound to be continuous tension between the dialogical stance towards human experiences and the scientific need for simplification (Buus et al., 2017). On a general level, it is far from clear how such complex treatment approaches can be studied via RCTs (see van Os et al., 2019).

Despite these limitations, there does exist evidence on the efficacy of need-adapted treatment, and confirmation that many individual elements of OD are effective in the treatment of severe mental problems (Pavlovic, Pavlovic, & Donaldson, 2016). These include the early-intervention (Correll et al., 2018) and the family- and network-orientation (Pharoah, Mari, Rathbone, & Wong, 2010), including dialogism (Haram, Fosse, Jonsbu, & Hole, 2019; Haram, Jonsbu, Fosse, Skårderud, & Hole, 2018). By these means, more collaborative, equal, and empathic interactions are achieved, which are seen as beneficial in the treatment of mental distress, irrespective of the specific methodologies (Laska, Gurman, & Wampold, 2014). In addition, the avoidance of preliminary treatment decisions, including the more selective use of neuroleptic medication, seems to be associated with better functional outcomes in several longitudinal studies (Bola, Lehtinen, Cullberg, & Ciompi, 2009; Harrow, Jobe, & Faull, 2014; Moilanen et al., 2016; Wunderink et al., 2013).

Personalized, comprehensive, and integrative early-intervention practices have also been associated with better treatment outcomes in other kinds of treatment approaches (Bertelsen et al., 2008; Bola, 2006; Thorup et al., 2005; Uzenoff, Penn, Graham, Saade, Smith, & Perkins, 2012). One early example of such approaches is the *Soteria* model, developed in the 1970s by Mosher et al (1975; 1979; 1996), which emphasized collaborative and compassionate ways of being with clients in preference to intervening in their lives, hence differing from the more authoritarian medical models of the time. The characteristic features included the 24 hours-per-day application of interpersonal interventions by non-medical staff in a home-like environment. Efforts were made to minimize the use of neuroleptics and coercive methods, emphasizing instead the subjective meanings given to experiences of psychosis (Bola & Mosher, 2002). Both the original model (Bola & Mosher, 2003; Mosher, Vallone, & Menn, 1995) and its later replications (Ciompi, 2017) have presented promising outcomes in the treatment of schizophrenia-group psychoses as compared to standard care. Moreover – despite some methodological limitations – later meta-analyses have found these outcomes to be at least equal and sometimes better as compared to standard treatment (Calton, Ferriter, Husband, & Spandler, 2008).

Later assertive community treatment (ACT), including multidisciplinary teams and integrated care, has demonstrated improved outcomes in the treatment of psychosis (Marshall & Lockwood, 2004). More recent trials have indicated that comprehensive first-episode psychosis programs emphasizing personalized psychotherapeutic approaches and low-dose medications may significantly improve both functional and clinical outcomes (Kane et al., 2016). However, the evidence regarding the long-term outcomes of early- and integrated-intervention practices in the treatment of psychosis is still limited, and there have been some contradictory results. For example, in the Danish OPUS trial (Bertelsen et al., 2008; Secher et al., 2015), and in the Lambeth Early Onset study (Gafoor et al., 2010), the improved treatment and symptom outcomes were not found to be sustained at five years from onset. In sum, there is a need for studies also on the *long-term outcomes of OD* with stronger control for confounders. Such studies have the potential to increase knowledge on both the effectiveness of the approach and the stability of long-term outcomes from the integrated treatment of psychosis.

Moreover, there is limited understanding on how people themselves have experienced OD and NAA treatment. Piippo (2008) reported that from the patient's perspective, the focus on the social network and on an open and co-operating way of working increased trust, autonomy, and safety. On the other hand, patients became distrustful of both NAA and treatment as usual when they encountered (1) overwhelming enthusiasm towards the model, and/or (2) an over-abstract treatment model, diverging from their daily lives. On a general level, patients nevertheless experienced need-adapted and open dialogue treatment in a positive manner as compared to their earlier treatment experiences (Piippo, 2008). In more recent studies on the early implementation of OD, the service users similarly felt that they had been more listened to and better understood (Gidugu, Rogers, Gordon, Elwy, & Drainoni, 2020; Hendy & Pearson, 2020; Tribe, Freeman, Livingstone, Stott, & Pilling, 2019), especially as compared to their earlier care experiences, even if some of them also felt the network treatment meetings to be emotionally overwhelming and strange (Tribe et al., 2019).

Buus et al. (2017) noted in their review that, as currently reported, the criticism of OD from service users has been relatively mild as compared to that of other kinds of mental health treatment. Indeed, according to earlier studies, many patients experienced their mental care as a struggle for dignity in the face of discrimination and rejection (Lilja & Hellzén, 2008). Patients indicated (1) the continuing existence of stigma inherent to the mental healthcare system (Mestdagh & Hansen, 2014), and (2) more general experiences of being misunderstood (Gaillard, Shattell, & Thomas, 2009). In their summary of the qualitative evidence on service users' personal preferences regarding the treatment of psychosis, Byrne, Davies, and Morrison (2010) found that the treatment preferences usually included an increase in more collaborative and person-centered approaches to care, even if qualitative evidence was noted as still remarkably scarce. Overall, given the mixed results and the general lack of knowledge, more information is needed on longer-term outcomes also from service users' perspectives.

## 1.3 Aims of the research

The research reported here attempted to address the issues presented above. The primary goal was to provide knowledge on the long-term outcomes from the integrated and network-oriented Open Dialogue treatment of first-episode psychosis, at both group and individual levels. More specifically, the aim was to evaluate the long-term stability of previously reported treatment outcomes from the Western Lapland region, in which a family-oriented Open Dialogue approach had been applied in the treatment of first-episode psychosis. The second goal was to add to the literature on the kinds of meanings people with lived experiences ascribe to Open Dialogue treatment and to severe mental crises, decades after the initial need for treatment. More specific research questions were framed for the three sub-studies (here referred to as Study I, Study II, Study III), as follows:

1. How were psychiatric services used under the Open Dialogue treatment system within the decades from first-episode psychosis, and how were the clinical and demographic baseline characteristics associated with the long-term treatment patterns? (Study I)
2. How stable are the treatment outcomes of the Open Dialogue approach over a long period of time, and how do these outcomes compare to those from first-episode psychosis treatment commenced under other treatment systems? (Study II)
3. How do people themselves view their mental crisis, and the treatment of it that commenced under OD, as part of their life stories, decades from the onset? (Study III)

# 2 METHODS

## 2.1 Theoretical background

Since the primary aim of this thesis was to evaluate the real-world outcomes of a need-adapted (and thus multi-level) treatment approach covering the public mental health services of an entire region, a naturalistic study design was adopted. This means that the studies conducted, and the reporting of the studies, aimed to encompass the phenomena as they occurred in real life, and in actual clinical practices. To further increase real world comparability, in Study III phenomenological research strategies (e.g. Keller, 2008) were used, and the main emphasis was on the subjective and interrelated nature of experiences. However, in line with Georgaca's (2013) discussion of qualitative research on psychosis, Study III can be viewed more as a qualitative empirical study, differing from conventional phenomenological approaches insofar as it did not aim to arrive at the "core essences" of experiences. Overall, it was deemed appropriate to avoid excessive interpretations at all phases of the study, and to emphasize the phenomenological status of both the real-world treatment outcomes and the subjective experiences of people.

Several more specific assumptions were adopted. *Non-affective psychosis* was understood as a clinical term indicating that a certain threshold of both distress and worry was exceeded in specific contexts and interactive situations. As descriptive terms, schizophrenia and other psychoses were assumed to reflect certain symptom expressions, courses, and clinical outcomes, not underlying disease entities with common causes *per se*.

The term *neuroleptic* was preferred to *antipsychotics* as there is no clear consensus on their actual mechanism or treatment targets. Even though there are observable differences in the mechanism of action and in effectiveness between typical and atypical neuroleptics, all currently-used neuroleptics tend to block dopamine D2 receptors (Howes et al., 2009). It has therefore been hypothesized that hyperactivity of the dopamine receptor neurotransmitters contributes in particular to the positive symptoms of psychosis (Toda & Abi-Dargham, 2007). One recent attempt to describe this is the *integrated sociodevelopmental-cognitive* model, in which early-life adversities and stress are hypothesized as sensitizing dopaminergic systems, increasing the risk of agitation and over-interpretation, especially in emotionally overwhelming situations (Howes & Murray, 2014). However, observable suppression of psychotic agitation can be also described via more general neurological restrictions and sedation following the blockage of dopamine pathways (see Moncrieff & Cohen, 2009), and therefore the term *neuroleptic* more accurately describes the *actual* neurological mechanisms of these drugs.

In Study III, the narration of life stories with constant reconstruction of past, present, and future was considered to be an essential psychological meaning-making process, used to maintain identities (see McAdams, 2001). In line with Shotter's (1993) view, it was assumed that people's responsive understanding of each other is more essential than the absolute or valid match between words and things. In this regard a social constructionist perspective (involving an ontologically pluralistic view with co-constructed realities) was recognized (Gergen, 1994), and conventional clinical language with predetermined assumptions was avoided whenever possible. Nevertheless, in all the sub-studies of this thesis a non-dogmatic epistemological position was maintained, to avoid the challenges associated with relativism (see Boghossian, 2006): it was taken to be the case that there is indeed a world independent of our knowledge and language, even if our knowledge of it remains incomplete and subjective. Following on from the assumption of compatibility with critical realism, qualitative and quantitative research approaches were viewed as working together to address each other's limitations (Shannon-Baker, 2016), i.e. as being capable of providing a more complex understanding of a phenomenon than would be accessible via one approach alone (Creswell & Plano Clark, 2011).

## 2.2 Study design, catchment area, and data collection

The primary data for all the studies in this thesis were obtained within research projects conducted in the hospital district of Western Lapland between 2015 and 2018. The catchment area in question consists of the south-western part of Finnish Lapland, sharing a border with Sweden. The hospital district in the region consists of six municipalities including two towns (Kemi and Tornio). The population of the area has decreased from 72 000 in 1995 to 63 000 in 2015, reflecting the national trend towards urbanization. At the time of the original implementation of OD (see above), the population in the area was both culturally and ethnically homogeneous, with 90% of the population being Finnish-speaking Lutheran Finns (Seikkula et al., 2006).

In 2015 there were seven adult psychiatric outpatient clinics in the catchment area (one in each municipality and one in Keropudas hospital) and one psychiatric hospital (Keropudas hospital, located in Tornio) with 22 beds. The latter is in charge of *all* psychiatric inpatient treatment in the region. There was also a general hospital psychiatric team plus child and adolescent psychiatric teams operating under the hospital district (for more details see Valtanen, 2019).

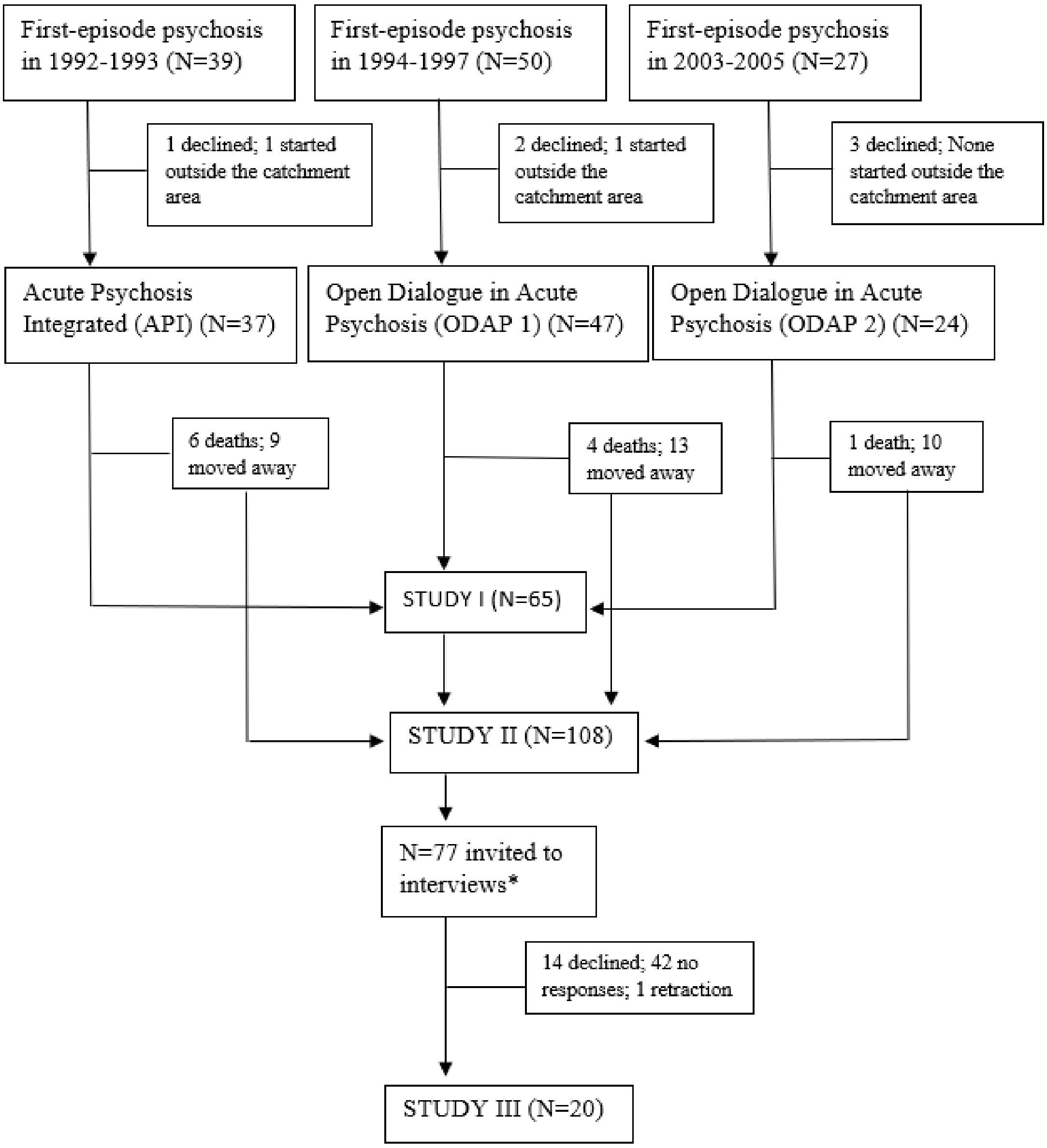
In Western Lapland, as in other parts of Finland, the mental healthcare system is publicly funded, and municipalities are responsible for providing services to all residents. Patients with severe mental health problems are usually referred from municipal primary care to a more specialized secondary healthcare system operating under the hospital districts; however, in the Western Lapland catchment area the treatment process can be initiated by anyone who gets in contact with one of the local mental healthcare workers, without an official referral, and staff from all the mental health units collaborate in teamwork across organizational and municipal boundaries.

At the time of the original implementation of OD in 1980 and 1990, all mental health units in the region participated in the development of treatment, and 90% of all mental health staff (about 150 people) in the region received at least a two-year training in family-therapy, or in related psychotherapeutic approaches (Aaltonen, Seikkula, & Lehtinen, 2011). Despite systematic efforts to implement family-therapeutic approaches within the public mental healthcare system in Finland (Tuori et al., 1998), in the mid-1990s there were no other centers in Finland implementing an OD-like network, or a dialogically-based treatment model covering the entire regional public mental healthcare system.

All the datasets used in this thesis were derived from the Western Lapland research cohort. These included all persons (total N=116) who received treatment for first-episode psychosis in the region of Western Lapland at the time of the original Open Dialogue research projects (Seikkula et al., 2003; 2006; 2011). The projects in question were *API,* running from January 1st, 1992 until December 31st, 1993 (N=39), *ODAP 1*, running from January 1st, 1994 until March 31st, 1997 (N=50), and *ODAP 2*, running from February 1st, 2003 until December 31st, 2005 (N=27).

All the persons in these three research projects were treatment naïve prior to the inclusion period, and were diagnosed with non-affective psychosis (ICD-10 codes: F20–29.1; DSM-IV codes: 295−298). The observation period in the sub-studies of this thesis extended to the end of the year 2015, and therefore ranged from 23 to 10 years, starting from the API study (onsets 1992–1993), and including also ODAP 1 (onsets 1994–1997) and ODAP 2 (onsets 2003−2005). A flow chart (Figure 1) describes how people from the three inclusion periods were included in the three sub-studies of this thesis.

To address the primary aim of this thesis, two separate types of dataset were formed. The first included register-based information only (used in Studies I and II), while the second contained also qualitative information gathered via interviews (used in Study III). For Study II the dataset was further supplemented with a comparison group comprising *all* Finnish FEP patients whose treatment was initiated *outside* the Western Lapland catchment area 19−20 years previously (see below).The data from the local medical registers of Western Lapland healthcare district were gathered during the year 2015, and results based on these were reported in Study I. The data formation from the national registers began in 2016 and was completed in the spring of 2017. The interviews were undertaken between February 2016 and August 2017. These fell within a separate research project conducted in the region (reported in Study III), the aim being to collect user-experiences and feedback on Open Dialogue treatment, and further, to gain new insights on how severe mental crises should be approached and services developed.



*Living in the Western Lapland area, or up to approximately 500 km from it in 2015

FIGURE 1 Flow of cohort members to the three sub-studies

### 2.2.1 Studies I and II (register data)

The data used in Studies I and II were gathered as part of the *Open Dialogue: Long-term outcomes in a naturalistic setting* (ODLONG) project, whose primary aim was to evaluate the long-term stability of previously-reported treatment outcomes from OD, and to compare these with a comparison group (CG). The main data sources in Studies I and II were local medical records and case histories from the Western Lapland healthcare district; these included detailed information on all mental healthcare and medical treatments conducted in the region from onset to the end of the year 2015.

In Study II, further information on both the OD group and the CG group was obtained from the following data sources:

1. The Finnish Care Register of Health Care (CRHC) (formerly Hospital Discharge Register) and the Register of Primary Healthcare (RPHC) provided by the National Institute for Health and Welfare, Finland (THL). These sources together provide information on all hospital admissions in Finland since 1969, all outpatient treatment conducted in specialized healthcare units since 1997, and all treatment conducted in the primary healthcare system since 2011.
2. The register of disability pensions and reimbursed medicine, provided by the Social Insurance Institution of Finland (SII). This source contains information on all medicine reimbursements granted (since 1964), all full or partial disability pensions, and all cash rehabilitation benefits granted due to decreased work capacity caused by schizophrenia or other mental health disorders. It also includes all purchases (since 1995) of reimbursed medicines during the follow-up, on the basis of the Anatomical Therapeutic Classification (ATC).
3. The national cause-of-death register provided by Statistics Finland (SF), which contains information from the death certificates issued by physicians, including the time and cause of death.

The author of this thesis gathered the data from local medical records during 2015. Prior to 2001, all case files concerning both inpatient and outpatient treatment were archived in paper form in the medical archive of Keropudas Hospital. Thereafter, most of the information became available in electronic form. The information from national registers was gathered by each register controller in line with the research protocol. The author of this thesis coordinated the data collection, and combined the data samples gathered from different register sources, using pseudonymized research IDs created by THL.

### 2.2.2 Study III (a qualitative study)

For Study III, people from the Western Lapland research cohort were invited to participate in in-depth interviews. The invitation letters were sent to all candidates who – according to the Finnish Population Center database – were still living in the Western Lapland area, or up to approximately 500 km from it (N=77).

In addition to letters, local healthcare staff were asked to recruit verbally persons who were still receiving some form of treatment (N=18) in 2015 and 2016.

In the letter, people were invited to come to talk about their experience of family-oriented treatment, and to give more comprehensive descriptions of their lives, with a view to increasing understanding of how mental health issues should be approached. To minimize the arousal of negative emotions, the letter avoided the use of diagnostic terms or other reference to medical conditions, making only a general reference to previous service use and to participation in previous research projects.

At the start of the interview, all the participants were encouraged to relate their life stories as precisely as they could. To address more specifically the aims of Study III, all the participants were later asked to describe more comprehensively their personal characteristics, their significant child and adulthood life-events, views as to what had led up to the treatment, what it was like for them, how they survived, and how it had affected their later life course. A semi-structured framework was used at the end of each session to ensure coverage of all of these themes.

All the interviews were conducted by the author of this thesis, usually accompanied by a co-interviewer from either the hospital staff or the research group. One interviewer was responsible for adherence to the thematic content and for asking more specific questions when necessary. The other maintained the discussion with open questions, aiming to follow up topics that were central to the interviewee. All the participants were encouraged to bring a family member or other important person to the interview; however, only one participant took advantage of this opportunity.

The interviews were transcribed verbatim by the author of this thesis. During the process, all identification information was either changed or deleted. The preliminary thematic analyses were conducted during the transcription phase.

The primary aim in the interviews was to obtain feedback on the OD approach. However, due to the relative lack of treatment-related narratives, the focus in Study III was largely on how the crisis and mental treatment under OD were presented as part of the person's overall life story.

## 2.3 Datasets and participants

### 2.3.1 Study I

Study I was an observational study, focusing on long-term treatment patterns under the Open Dialogue treatment system. It aimed to provide more detailed descriptive quantitative and qualitative information, obtained directly from case notes, on (i) treatment processes, and (ii) factors associated with a greater need for mental health services within the OD system over a period of decades.
Because treatment in Finland is bound to the patient's municipality, Study I included only people who had lived continuously in the catchment area (obviating

as far as possible any potential bias resulting from the use of other types of mental health services during the follow-up period). All cohort members were first identified from the archived research registers compiled for the API, ODAP 1, and ODAP 2 studies. For exclusion purposes, the database of the *Finnish Population Center* was then used to detect people from the cohort who had moved away (N=32) or who had died (N=11) within the observational period (1992−2015). In total, Study I included 22 persons from the API group, 30 from ODAP 1, and 13 from ODAP 2 (total N=65). The demographic and clinical characteristics are presented in Table 2.

TABLE 2 Demographic and clinical characteristics of all the samples

| | Partial[1] cohort (Study I) N=65 | Total cohort (Study II) N=108 | Comparison group (Study II) N=1763 | Interviewees (Study III) N=20 |
|---|---|---|---|---|
| Demographics at onset | | | | |
| Age (mean) | 26.5 | 25.3 | 30.5 | 25 |
| Male | 60% | 57.4% | 57.6% | 60% |
| Single | 71% | 75% | NA[2] | 60% |
| Unemployed or passive | 24% | 16.6% | NA[2] | 25% |
| Clinical characteristics | | | | |
| Schizophrenia[3] | 62% | 52.8% | 53.3% | 55% |
| GAS scores (at onset)[4] | 34.8 | 35 | 35 | 38 |
| Neuroleptics at some point | 55% | 54.6% | 97% | 65% |
| Neuroleptics at the end of the follow-up[5] | 34% | 33% | 81% | 35% |
| Disability allowances at the end of the follow-up[5] | 35% | 33% | 61% | 40% |

[1] Includes only persons from OD cohort who had lived continuously in the catchment area
[2] Information was not available
[3] Yes = if there were one or more entries with schizophrenia-group psychosis (F20−20.9) within the first five years from onset
[4] Global Assessment Scale (100 = superior functioning, 1= severe impairments)
[5] Includes only people still alive at the end of the year 2015

### 2.3.2 Study II

The focus in Study II was on evaluating the 19-year outcomes from OD, and on comparing these to the treatment initiated *outside* the Western Lapland catchment area 19−20 years previously. Because psychosis is a rare problem and the catchment area is small, in order to increase the statistical power and reliability of the analyses, the data were complemented (when appropriate) with a group from a later replication (ODAP 2) study with shorter follow-up time. Variation in the follow-up time was controlled in the statistical analyses (see below).

The experimental group (OD) for Study II was thus formed on the basis of the following inclusion criteria:

1. The first treatment contact in the area of Western Lapland with a non-affective psychosis diagnosis (ICD-9 codes=295–295.9 and 297–298.9; ICD-10 codes=F20–29.1) occurred during the three inclusion periods (1992−1993, 1994−1997, 2003−2005) within which OD principles were reported as having been applied in the treatment as part of the original intervention.
2. The individuals had not received mental health treatment prior to the inclusion periods in question.
3. The individuals were aged 16−50 at onset.

From the total research cohort of 116 people, two individuals were excluded because their treatment was initiated outside the catchment area (see Figure 1). Furthermore, the identification numbers for six individuals in the cohort were unobtainable from the research registers, as they had declined participation in the original OD research projects (for more details see Seikkula et al., 2011). Thus, the OD group for Study II was formed from a total of 108 members of the cohort. The follow-up (onset to 2015) varied from 10 to 12 years for people whose first onset occurred in 2003−2005 (20%), and from 18 to 23 years for people whose first onset occurred in 1992−1997 (80%). The average follow-up time was 19 years (MD=20, SD=4).

The comparison group (CG) for Study II was formed from the registers mentioned above. As there are no reliable national registers in Finland detailing primary healthcare prior to 2011, the CG data were obtainable only from FEP patients with one or more hospital admissions. At the time of data collection in 2015, the year 1995 was the first inclusion year for which it was possible to obtain consistent medical data covering a period of 19-20 years from onset; this was due to the limited information on purchases of medicine prior to 1995.

To minimize selection bias, data were first gathered on *all* the people in Finland who had one or more register entries in the CRHC with any non-affective psychosis diagnosis (ICD-9 codes=295–295.9 and 297–298.9; ICD-10 codes=F20–29.1) between January 1, 1995 and December 31, 1996 (N=10 859). This sample was later matched with the Western Lapland research cohorts on the basis of the following inclusion criteria:

1. The individuals had not received any specialized psychiatric healthcare treatment, reimbursement for mental health-related medication, or disability allowance for a mental health disorder prior to the inclusion years.
2. The treatment was initiated and conducted outside the Western Lapland healthcare district area.
3. The individuals were aged 16−50 at onset.

In total there were 1763 people who had received treatment for first-episode psychosis in the period 1995−1996, and who fulfilled the other inclusion criteria.

### 2.3.3 Study III

Study III aimed to evaluate the personal meaning-making processes of persons who had experienced acute or prodromal psychosis. From the total of 77 persons invited, 21 (27%) expressed a willingness to participate in the interview study, 14 (18%) declined, and the remainder (55%) did not respond. One person retracted participation later. All the participants (N=20) completed informed consent forms in which they gave permission to use the information obtained via interviews, and to combine this with the information obtainable from their local medical records. A deficiency analysis based on descriptive statistics indicated that the interviewees were more likely to have received neuroleptics, disability allowances, and a schizophrenia diagnosis than the remainder of the cohort (see Table 1). This was probably due to the more direct recruitments of those who were still receiving treatment.

## 2.4 Measurements in the quantitative studies

### 2.4.1 Study I

In Study I, descriptive information on the long-term use of mental health services under the Open Dialogue treatment system was formed by combining information obtainable from local medical records. All available information on in- and outpatient treatment and on medical treatment from onset to 2015 was gathered. The information included demographics, the date of the first meeting, diagnoses, prescription medicines, hospital admissions, duration of hospitalizations, number of outpatient visits, and the form of outpatient treatment (individual or network meeting).

At the time of the API, ODAP 1, and ODAP 2 studies, all the patients in the cohort were diagnosed with non-affective psychosis. The diagnoses for the API and ODAP 1 studies were based on the *Diagnostic and Statistical Manual of Mental Disorders* (APA, 2000) (DSM-III-R codes: 295.10–295.95 and 297.10–298.90), and for ODAP 2 on DSM-IV (codes 295.10–298.9). Baseline diagnoses were set within the first year from onset, and further evaluations were conducted within one-year (Seikkula, Alakare, & Aaltonen, 2011) 2-year (Seikkula et al., 2003), and 5-year follow-up periods (Seikkula et al., 2006). During the API and ODAP 1 projects the reliability of the diagnoses was further tested by an independent psychiatrist outside the region, on the basis of case histories (Seikkula et al., 2011).

In Study I temporal changes in admissions, hospital days, and outpatient treatment were further analyzed by forming three sum variables covering the total N of treatment events within different measurement points (years 0−5, years 6−10, and years 11−20). The data were complemented with qualitative information gathered from case histories, including (1) reports on threatening and/or aggressive behavior during the initial treatment contact (yes/no), (3) how the treatment contacts were ended, and (2) how medication was used. Treatment was considered to be inactive if it was ended on the basis of (1) joint agreement between patient and staff, or if the treatment has ended because (2) the patient could not engage in contact (i. e. was a dropout), or if the treatment had (3) settled to medication and/or occasional medication controls only. This information was used to calculate the total duration of each treatment contact.

### 2.4.2 Study II

In Study II, the primary aim was to compare long-term outcomes between the Western Lapland cohort and the comparison group, which was drawn from FEP patients treated in other parts of Finland. For the total Western Lapland cohort (N=108) the information on residential history and mortality rates was obtained from the *Finnish Population Register Center* databases. The information on psychiatric treatment was obtained from local medical records (see above) for people who had lived continuously in the area of Western Lapland, and from nationwide registers for people who had moved away or who had died within the follow-up period.

Information concerning disability allowances, medication purchases, and causes of death was obtained from SII and from cause-of-death registers for the entire sample (OD+CG). Gender, age at onset, and *Global Assessment Scale* (GAS) scores were obtained from CRHC for the CG and from local medical records and CRHC for the OD. GAS scores (indicating the extent to which symptoms affected a person's functionality in his or her daily life) were rated at onset by a member of the treatment staff, based on standard procedures used in Finnish hospitals.

Prior to 1996 the diagnoses were set (as a standard procedure by physicians in their daily clinical practice) on the basis of ICD-9. Thereafter, ICD-10 was applied. Nevertheless, even though the ICD classification system was laid down for official use in Finland, the DSM-III-R diagnostic criteria for the diagnosis of mental disorders were used in clinical practices in the 1990s (Isohanni et al., 1997). Within the Western Lapland catchment area, structured diagnostic procedures were used for the sake of precision in the original research projects (see Study I).

Validity problems relating to descriptive diagnoses, and especially subtypes of non-affective psychoses (Korver-Nieberg, Quee, Boos, & Simons, 2011; van Os & Kapur, 2009) were recognized, as was the fact that in a naturalistic sample, the occurrences of particular diagnoses are highly dependent on particular outcomes, and also on the time spent under mental health services (see above). Thus, to minimize selection bias, the main focus in Study II was on the naturalistic observation of *all* people with *any* non-affective psychosis diagnosis made within a specific time frame under public mental health services; this was considered to be an indication that a certain symptom threshold had been exceeded in the clinical context. Nevertheless, previous research has indicated that schizophrenia can be distinguished by severity level from a brief psychotic disorder, and from psychotic disorders not otherwise specified (Korver-Nieberg et al., 2011). Hence, in additional sensitivity analyses the distinction between schizophrenia and other psychoses was used.

Further outcome variables were formed by combining information from all available sources, as follows:

1. > 30 hospital days (yes: total time spent in hospital within the entire follow-up was over one month)
2. Re-admissions (yes: two or more hospital admissions within the entire follow-up)
3. Treatment contact at the end of follow-up (yes: if there were one or more outpatient visits in 2015, or one or more hospital days in 2015)
4. Neuroleptics (1) at onset, (2) at some point of follow-up, (3) at the end of follow-up (yes: if there was any purchased neuroleptic, or any neuroleptic used during hospital treatment, within (1) the first month from onset, (2) at some point of follow-up, (3) in 2015.
5. Disability allowances (1) at some point of follow-up, (2) at the end of follow-up (yes: if there were one or more days spent on a partial or full-time disability allowance granted due to decreased work capability caused by mental health problems (1) at some point of follow-up, (2) in 2015).

To evaluate the temporal changes in the use of services from onset to the end of the follow-up, hospital admissions (N), hospital days (N), and the duration (years) in receipt of disability allowances were compressed into four sum variables matched with specific time frames: (1) during the first five years from onset; (2) in years 6−10; (3) in years 11−15; (4) after 15 years from onset.

## 2.5 Analyses

### 2.5.1 Statistical analyses (Studies I and II)

All the statistical analyses were conducted via IBM SPSS 24 for Windows, and statistical significance was considered to be $p<.05$. First of all, the distributions of the continuous variables were tested with the Kolmogorov-Smirnov test. As no normality could be expected, all further analyses were performed with non-parametric methods. Group differences in continuous variables were tested with the Mann-Whitney U-test. Friedman's ANOVA was used to test differences in the measurement points (sum variables) of the follow-ups. Prior to this, outliers were detected using Tukey's method, with all values higher than Q3 + 1.5(Q3-Q1) (where Q3=upper quartile, Q1=lower quartile) being excluded from the statistical analyses. Group differences in categorical variables were mainly evaluated with the Chi-square test. In Study II, the standardized mortality ratios (SMRs) were calculated for each group against the age and gender-specific risk ratios of death among the general Finnish population.

In Study II, further statistical modeling and effect size estimations were performed to evaluate more specifically how the treatment approach predicted the long-term outcomes when all potential confounders were controlled. Model building was initiated via logistic regression analysis, by first entering all potential confounders (demographic and clinical characteristics at baseline) into the model one by one. At the second phase, the *group variable* (OD/CG) was included, and *omnibus tests* were used to estimate how the inclusion affected the overall fit of the model. Adjusted odds ratios and omnibus tests were used to estimate how treatment commenced outside the OD predicted outcomes, as compared to other potential predictors.

Additional sensitivity analyses with further matched samples were conducted, to see whether the conclusions remained. Because over-matching can reduce the efficiency of a cohort study (see Greenland & Morgenstern, 1990), and because at baseline the OD and the comparison group differed only in age and in the length of the follow-up, matching was first initiated on the basis of these two variables. The follow-up time was matched by excluding the ODAP 2 group from the analyses, and by adjusting the follow-up period of the API group to 19.5 years. Then, six reference (control) individuals from the comparison group were matched for each individual in the remaining OD group. This procedure was in itself sufficient to equalize distributions in baseline variables between the two groups, and it allowed the controls to be chosen at random.

Exclusion was then used to further control for any selection bias that could have caused differences in symptom severity at onset. This was done by including only people with a matched follow-up time, with a schizophrenia diagnosis, and with one or more hospital admissions. Due to the potential difference in diagnostic procedures between the CG and the OD group, and the decrease in the incidence of new schizophrenia patients in the OD cohort in the later inclusion years (Seikkula, Alakare, & Aaltonen, 2011), additional sensitivity analyses were conducted with different cut-off points, these being defined in terms of one or more entries with a schizophrenia diagnosis (1) within the first year from onset, (2) within the first five years from onset, (3) at some point in the follow-up. Finally, all the analyses were re-conducted with both demographically and clinically matched samples.

### 2.5.2 Qualitative analyses (Study III)

Qualitative methods were used in Study III to interpret how people make sense of their experiences decades after the onset. Inductive thematic analysis (Braun & Clarke, 2006) was first used to detect repeated patterns across the dataset, and to distinguish the main themes and sub-themes within and between the stories. Further qualitative analyses were performed via thematic narrative analysis (Riessman, 2008). Here, the aim was to evaluate meaning structures by reconstructing the stories into a more condensed form (Brinkmann & Kvale, 2015). This was done by reading the transcripts multiple times, and by observing how previously coded themes were associated with the stories as a whole. During the process, the validity of the analyses was constantly evaluated and discussed within the study group. At the final phase, *story types* were created by comparing the thematic contents within and between stories. Note that the different categories in Study III were used merely to condense a large amount of data for the purposes of reporting it; also that there were overlaps between the stories, and that none of the themes was presented in an exclusive manner.

## 2.6 Ethical considerations

Because all the datasets used in this thesis contained intimate information on a sensitive and potentially stigmatizing topic, special attention was paid to data protection and to other ethical questions throughout the research projects. Prior to the collection of the data, the research protocols were reviewed and approved by the *North Ostrobothnia Hospital District Ethical Committee*. Further permissions were granted by all the register controllers, including the *Länsi-Pohja (Western Lapland) healthcare district* plus all municipalities in the region; also by the *Population Register Center*, the *Finnish National Institute for Health and Welfare*, the *Social Insurance Institution*, and *Statistics Finland*. Research protocols for all the sub-studies included in this thesis followed both the *Finnish Personal Data Act* and the *Finnish Data Protection Act* (covering the management of personal data). The *Finnish Office of the Data Protection Ombudsman* was consulted and informed prior to any collection of data.

In Studies I and II all identification information was pseudonymized. Personal identification numbers were replaced with research IDs created by THL, and these IDs were used to link data across different registers. The register controllers collected most of the raw material, and the identification information for the comparison group was not provided to the researchers at any point of the research projects. The actual processing of data was conducted only with pseudonymized datasets, and all raw material was stored separately in the archive of Keropudas Hospital. Access to any material used in this study was restricted, being limited only to personnel who signed a confidentiality agreement with the Western Lapland Healthcare District, and with all the register controllers mentioned above. In the register studies, only the general distributions were observed and reported.

In Study III, all the participants completed written informed consent forms, in which they gave permission to use the information obtained via interviews. In line with the Finnish Personal Data Act, it was ensured that throughout the research projects all the information obtained on the basis of participants' informed consent was stored separately from any information obtained from register sources, and also from any information obtained as part of previous research projects on OD. Separate datasets were combined only on the basis of the additional written informed consent. The interviews were transcribed verbatim. During the process all identification information was either changed or deleted. Qualitative analyses were performed with pseudonymized transcriptions.

In the invitation letters and during the interviews, all candidates were informed that the interviews might arouse unpleasant or traumatic memories, and all of them were specifically informed that participation, refusal, or discontinuation of participation would have no influence on their treatment, either now or in the future. All participants were given the opportunity to continue discussions afterwards with experienced clinicians working in local mental units of Western Lapland. All of them were granted the opportunity to review, comment on, and revise transcriptions. Overall, one participant indicated that the interview aroused unpleasant memories, while the remainder viewed the interview as a neutral or positive experience.

# 3 OVERVIEW OF ORIGINAL STUDIES

## 3.1 Study I

In Study I, the objective was to produce detailed descriptive information on how the psychiatric services were used within the Open Dialogue treatment system in the decades following FEP. In addition, group differences between baseline characteristics and long-term treatment patterns were evaluated. First of all, there were indications that people who went through a milder crisis at onset were more likely to have moved away from the catchment area during the follow-up (Table 2). This means that the data presented in Study I relate to the use of services by patients with more severe crises.

As reported previously (Seikkula, Alakare, & Aaltonen, 2011) the yearly incidence rate of non-affective psychosis generally and of schizophrenia in particular declined over the observational year. The high incidence of first-onset schizophrenia patients in Western Lapland prior to the systematic implementation of OD, and the subsequent decline, are described in more detail elsewhere (Aaltonen, Seikkula, & Lehtinen, 2011; Seikkula, Alakare, & Aaltonen, 2011).

From initial contact to the end of the follow-up, in 29% of cases the treatment was carried out entirely in the outpatient setting, while 46% of the patients had been re-admitted to hospital at least once. The average number of hospital admissions over the entire follow-up was 2.6 (SD=3.6), and the median time spent as an inpatient in the entire follow-up was 12 days. The majority of all hospital admissions (61%) occurred within the first five years from onset. From initial contact to the end of the follow-up, 55% received neuroleptics at some point in their treatment, while 12 (18%) people were treated with two or more neuroleptics simultaneously. The average length of neuroleptic use in the whole sample was 5 years, but the variation was high (SD=3 years), and 71% of those who received neuroleptics at onset were still on medication at the end of follow-up. In 18 (28%) treatment processes, there was no need for any psychiatric medication, and in 17% only anxiolytics were used during the acute psychosis.

In all the treatment processes there was at least one network treatment meeting. However, during the follow-up, the ratio of meetings attended by the family or other network members decreased as compared to individual meetings. In the sample as a whole (N=65), 75% of all outpatient visits occurred within the first five years from onset. Thereafter the outpatient treatment rates significantly decreased ($\chi^2$=45.6, $p<.001$). Overall, the average duration of treatment after onset was 4 (SD=2) years. However, because almost half of the patients were redirected to treatment at some point after the initial treatment had ended, the mean time spent as a patient in the entire follow-up period was 6 (SD=4) years. At the end of the follow-up, 12 (18%) people were receiving outpatient or hospital treatment, while for 5 (8%) people the treatment had settled on medication controls only. In 61% of cases, the treatment processes had ended on the basis of a joint agreement, and 13% of the processes had ended due to dropout.

There were no significant group differences in total admission rates and in total length of treatment between males and females, between younger and older people, and between those who were unemployed at onset as compared to those who were working or studying. Even though the average length of treatment was on average longer in the group of people who were rated as suffering more severe functional impairment at onset (GAF<30), the difference was not statistically significant. By contrast, people who were reported as presenting more threatening behavior and/or who were medicated and/or hospitalized at onset had significantly more hospital admissions. They also spent more years in treatment and on neuroleptic medication than others. However, as the potential cofounders were not controlled, caution is advised when interpreting these findings.

## 3.2 Study II

The aim in Study II was to evaluate the long-term outcomes of the entire Western Lapland cohort (OD) by means of a comparison with a comparison group (CG) over a period of approximately 19 years. The comparability of OD and CG was first evaluated by examining group differences in demographic and clinical baseline variables. According to the results, there were no significant differences in gender, GAS scores, annual crude incidence rate of FEP, and main diagnoses (schizophrenia vs. other psychosis) within the first five follow-up years. However, in the OD there was significant variation in both the incidence of psychosis and schizophrenia diagnoses between the inclusion years (see Study I).

Statistically significant differences between the samples were also observed regarding age (see Table 2), and in the way in which the patients were guided to treatment. Thus, patients in the CG were older and more likely to have undergone involuntary admission at onset than those in OD. Due to the inclusion of the 2000s group, there was significantly more variation in total follow-up time in the OD group.

It was recognized that these differences, together with the potential overrepresentation of hospitalized patients in the CG, might cause statistical bias.

Thus, additional sensitivity analyses were conducted with matched samples in order to control this (see 2.5.1.). As the additional analyses did not differ from the main findings obtained with the OD and CG samples as a whole, the focus in Study II remained on naturalistic observation, i.e. how all those people who at some point in their life had exceeded a certain symptom severity threshold, and who were thus interpreted as suffering from acute psychosis in the clinical context, had survived under different treatment systems over the decades.

From onset to the end of the follow-up period, 16.8% patients from the CG and 10.2% patients from the OD died. The difference in mortality was not statistically significant. However, when calculated against the Finnish standard population, the SMR was higher in the CG than in the OD (3.4. vs. 2.9). In the entire sample (OD+CG), suicide emerged as the most common cause of deaths. In the OD group there were on average more suicides, but the observed difference was not statistically significant. Correspondingly, in the CG there were significantly more deaths caused by accidents, though it should be noted that in some cases suicide could not be ruled out. In the CG more people died from natural causes (illness and/or another internal malfunction of the body) than in the OD; however, when adjusted for age this finding was not statistically significant.

From onset to the end of follow-up, a significant decrease ($p<.001$) in hospital admission rates and in hospital days was found, while a significant increase ($p<.001$) in the average duration of disability allowances was observed in both groups. Significantly ($p<.001$) more people from CG received neuroleptic medication over the entire follow-up (97.3% vs. 54.6%). At the end of the follow-up, more patients ($p<.001$) from CG than from OD were still receiving psychiatric hospital or outpatient treatment (49.2% vs. 27.8%), and disability allowances (61% vs. 33%), due to mental health disorders. In addition, the CG showed higher readmission rates over the entire follow-up. Initial administration of treatment outside the OD significantly ($p<.01$) predicted ongoing treatment (adjusted odds ratio (OR)=2.2; 95% CI= 1.3−3.7), neuroleptic medication (OR=7.1; 4.3−11.8), and disability allowances (OR=2.6; 1.6−4.3) at the end of follow-up. These outcomes remained when potential confounders were adjusted, and also when the analyses were conducted with clinically and demographically matched samples.

## 3.3 Study III

The aim of Study III was to interpret how the people from the Western Lapland cohort themselves viewed their mental crisis and treatment decades after the onset. In their life stories, all the participants gave meanings for their experiences. In addition, all of them included a phenomenon diagnosable as psychosis in their stories, although only 7 out of 20 participants actually used the term psychosis. All of them indicated that their life-situation had eased since the time of their first contact with the mental health services, but otherwise there was no single manner in which their experiences were narrated or included within their personal life story.

On the basis of narrative analysis, two types of stories emerged regarding how the crisis was viewed as part of the story. The first group was characterized by contradictions between the narrator's personal expectations of the normative or culturally expected course of life and the way in which the mental health crisis had disturbed this. In the second group the role of traumatic life events occurring from early childhood was emphasized; in these narratives the crisis was presented as a more or less expected culmination of prolonged life adversities. Four stories lacked continuous plots, so the stories were not fitted into either of these story types, even if thematic similarities occurred. When asked directly, the participants in these cases indicated that they had major challenges in remembering or describing life events prior to and after the crisis.

Basically, in all the stories, the crisis was narrated as a direct consequence of multiple distressing life events, cumulative setbacks, or other significant changes in life areas that formed an otherwise central part of the story. Many participants also indicated that they had suffered from a shattered sense of basic security and from other difficulties in social relationships, including bullying and a constant sense of loneliness. Such life adversities were narrated as causing hopelessness and other difficult experiences. Many of the interviewees also indicated that they were sensitive by nature. This, they believed, made them more vulnerable to mental distress and social anxiety.

In some stories, experiences that were diagnosed as a psychosis were presented as a hyper-reaction and an over-interpretation caused by distressing emotions, while in others they were characterized by a loss of self-control and by a temporally distorted sense of reality. Basically, in all the stories, the acute crisis was presented as a thoroughly confusing experience, and many of the interviewees struggled to remember or describe what it was like. Many of them also indicated that during the acute phase they had significant difficulties in interacting with others, because they were often so deep in their own reality and experiences. Nevertheless, basically in all the life-stories there were attempts to integrate the thematic content of the experiences with actual life events that happened at the time, and the overall emotions relating to the situation were described in very general terms.

Because the crisis was thematically linked to actual life events, it was often narrated as easing simultaneously with changing life situations. In addition, many participants emphasized their own actions and other people's roles in the gradual processes of surviving. More generally, in most of the stories, relief was found outside the actual mental health treatment, and in many stories the treatment was mentioned only briefly. Correspondingly, there was basically no specific feedback on the special network-oriented treatment they received, which could partly reflect the fact that at the time, OD was the standard care in the region, so that there was no point of reference. Overall, the people generally viewed the initial OD treatment in a neutral manner. As expected, the treatment-related narratives were more central to people who had needed more mental health services; yet even in these stories, other factors such as support from significant others, were emphasized rather than the treatment.

There were also associations between demographic factors and the thematic contents of the stories. For example, women indicated more often than men that the crisis followed adversities relating to intimate relationships. Men with later onset associated the crisis with challenges in the work environment and more generally, with a sense of inadequacy from being unable to provide support or a livelihood for their families. People with earlier onset expressed more traumatic life events starting from early childhood, and for some of them mental health issues formed a central part of their life story. Many of them also associated the crisis with the contradiction they experienced between what they wanted to do or be and the demands of close networks and of society as a whole. Finally, people who had maintained their work capability and thus better social functioning, as conventionally measured, expressed more internalized stigma relating to the crisis, and also regret concerning why things had not worked out as they expected. People with a higher need for mental services were more likely to find also some positive aspect from the crisis, including opportunities for social bonding and for learning experiences.

# 4 DISCUSSION

The aim of this thesis was to gain both group- and individual-level knowledge of the long-term course of life after the integrated and dialogical treatment of first-episode psychosis (FEP). More specifically, the research had three purposes: to examine the long-term outcomes of a network-oriented Open Dialogue approach in the treatment of FEP (Study I), to compare long-term outcomes with other kinds of treatment of psychosis (Study II), and to evaluate the personal meanings given decades after the onset, as they applied to the treatment of the crisis, and to the experiences diagnosable as psychosis (Study III).

To achieve these goals, the research reported in the thesis used both quantitative and qualitative methods to analyze samples formed from the Western Lapland research cohort. This cohort included all people who, 10−23 years ago, received treatment resulting from first-episode psychosis, under a particular public mental health care system, regionally organized on the basis of the principles of the *Open Dialogue approach*. This approach emphasizes need-adapted, collaborative, and rapid network-oriented interventions, made with a view to integrating treatment with daily life and to generating a shared understanding of difficult experiences, within a dialogical process.

According to the main findings of this thesis, the potential benefits of a network-oriented and dialogical response to an acute psychotic crisis were still observable after a long period of time. The benefits encompassed maintained social functioning and a sense of personal agency, even if significant heterogeneity in both group- and individual-level long-term outcomes was also observed. In the following sub-sections, the main findings on long-term outcomes at both levels will first be presented separately. They will then be summarized together, along with further evaluation of their clinical significance.

## 4.1 Summary of group-level outcomes

As presented in previous studies, the long-term outcome of first-episode psychosis showed great heterogeneity. Overall, it could be considered unsatisfactory, being characterized by high mortality and disability rates, in addition to a frequent and prolonged need for mental health services. As compared to other forms of treatment, the family-oriented *Open Dialogue approach* was associated with a reduced need for treatment and better functional outcomes throughout the roughly 19-year observation period. It should nevertheless be noted (i) that both groups showed a decrease in the total usage rate of psychiatric services over the period, and (ii) that the OD cohort, too, contained a proportion of people who needed more treatment. As observed in previous studies on OD (Seikkula, Alakare, & Aaltonen, 2001), a higher need for services was associated with difficulties in applying the treatment approach, notably regarding the possibilities to implement outpatient treatment, and the selective use of neuroleptics. As inpatient treatment and earlier medication were associated with more threatening behavior at onset, it is possible that in some cases there might have be challenges in applying and maintaining the treatment principles, and/or that not all individuals benefitted from the treatment.

Despite these challenges, the findings from Study I indicated that the practice in the Western Lapland area followed the principles of OD, involving an emphasis on outpatient treatment and the selective use of neuroleptic medication. Families were integrated within the treatment at the initial onset, and the majority of the treatment events were network treatment meetings. However, in longer treatment processes, the ratio between individual and network meetings seemed to become reversed. There are some possible explanations for this pattern, including the possibilities that (1) in maintenance treatment the role of the families was not considered to be as significant as in the acute phase, (2) social networks may not have been motivated to participate in longer treatment processes, or (3) social networks may not have been integrated with the treatment at the initial contact – a factor that itself could be associated with prolonged treatment. The observed variations in both the main outcomes and in the general treatment patterns could also reflect issues pertaining to fidelity; since the implementation took place in everyday clinical practice, it is likely that in some cases difficulties in maintaining the treatment principles occurred independently of patient-related factors. In future all of these issues will require more detailed analysis of the treatment processes, with better control of the various confounders.

The results from Study II showed that as compared to the rest of Finland, the treatment commenced under OD was associated with an overall lower need for psychiatric services, plus a shorter time spent on disability allowances and on neuroleptic medication. The findings remained the same throughout the long follow-up period, and when potential confounders were adjusted. This result was expected, as the 2-year (Seikkula et al., 2003) and 5-year follow-ups (Seikkula et al., 2006) also showed a decrease in the need for treatment and in residual psychotic symptoms, plus high remaining social functioning. In addition, it is also the case that in other national register-based follow-ups on the treatment of first-onset schizophrenia in Finland, the Western Lapland area has presented the lowest adjusted figures for the usage rate of both typical and atypical neuroleptic medication, the shortest durations for hospital treatment (Karvonen et al., 2008), and the lowest incidence of disability pensions granted in the 5-year follow-up period (Kiviniemi, 2014). The results of Study II appear to indicate that relatively good social functioning at an earlier stage could have had a cumulative effect overall, enabling people to maintain a better grip of their lives.

In OD the standardized mortality rate was lower, but the mean suicide rate somewhat higher than in the rest of Finland; however, there were no statistically significant differences when confounders were adjusted. This was observed also in another 5-year follow-up study that included all Finnish first-time schizophrenia patients (Kiviniemi, 2014). Here, the Western Lapland area presented a lower overall mortality rate, while the suicide rate was above the median, but under the highest quartile as compared to all other Finnish hospital districts (Kiviniemi, 2014). In other studies on the overall suicide rates of mental health patients in Finland, the Western Lapland area seemed to present a generally lower suicide rate as compared to other parts of Finnish Lapland (Pirkola, Sund, Sailas, & Wahlbeck, 2009). Nevertheless, the high premature mortality rates and the prolonged need for services in both groups underline the importance of further developing the system, and also of guaranteeing safe treatments and environments for patients and their families.

Overall, the main findings are in line with both existing and emerging evidence on the effectiveness of NAA and OD approaches, and of their later modifications (Buus et al., 2017; Freeman et al., 2019; Lakeman, 2014). For example, in another Finnish study, an NAA- and OD-based treatment model was more effective than standard care in improving functioning, self-reported depression, and hopelessness among adolescents with any psychosis-risk symptoms (Granö et al., 2016). In a US feasibility study on OD, qualitative and quantitative findings suggested that good clinical outcomes and high satisfaction can be achieved with the approach (Gordon et al., 2016). In another US study, peer-staffed crisis services which included elements of NAA and OD resulted in lowered rates of hospitalization and health expenditures, thus indicating an improvement in treatment outcomes (Bouchery et al., 2018).

In a Danish 10-year follow-up study, OD was associated with significantly better social functioning and less use of emergency psychiatric services and general practitioner services as compared to standard care (Buus et al., 2019); however, no reduction in overall psychiatric inpatient treatment days was detected, thus clearly differing from the findings in Study II. As noted by the authors of the Danish study (Buus et al., 2019), the Danish Open Dialogue intervention was brief, and was limited only to adolescent outpatient treatment. Thus, it did not include the kind of extensive integrated care, including also a local psychiatric hospital, that was provided in Western Lapland. As the primary goal in the Western Lapland projects was the reduction of hospitalization, regional resources were directed towards this aim. This could imply that the low hospitalization and re-hospitalization rates observed in Study II might reflect the ways in which treatment was regionally arranged, rather than the outcome of the treatment *per se*. Moreover in the Danish study (Buus et al., 2019) the data were gathered in a transdiagnostic manner, such that the overall admission rates might have remained too low for statistical significances to appear.

Overall, it should be noted that there is still a lack of transdiagnostic observation on total service use in the Western Lapland area, due to the fact that research on OD has focused mainly on the initial psychotic crisis. It is thus not clear how the approach addresses other kinds of life challenges, or whether the approach has spread through the entire system after the various implementation projects. However, considering the overall picture, shorter treatment durations in the region at the time of the original implementation of the approach are observable in the Finnish National Statistical Indicator Bank *Sotkanet.fi* (National Institute of Health and Welfare (THL), 2019). Moreover, in line with the main findings of the present study, Finnish cross-sectional registers on specialized mental healthcare services as a whole indicate that prior to 2010 the Western Lapland area showed the fewer involuntary admissions and treatment days, in addition to a lower mean of coercive practices, as compared other regions (Rautiainen & Pelanteri, 2012; THL, 2019). However, since that time the variables relating to (in particular) hospital treatment and coercion have exceeded the national average. It should also be noted that in contrast with the findings of Study II, the relative proportion of people with reimbursements for neuroleptics and for disability allowances relating to mental health has not differed from the national average, as revealed in cross-sectional registers (THL, 2019).

Even though the National Indicator Bank cannot be used to draw any firm scientific conclusions (since it is not designed for such a purpose), some potential explanations for the observed differences between cross-sectional and longitudinal data deserve mention. First of all, the National Indicator Bank covers the general utilization of services cross-sectionally, on the basis of place of residence (THL, 2019), while in Study II, the *same* people were observed longitudinally, across the municipalities. As presented in Study I, over 30% of the people from the cohort had moved away during the follow-up, reflecting the national trend by which job and education opportunities are centered in the larger cities outside from region. As expected, the functional outcomes of these people seemed to be better than the outcomes of those who stayed in the area; in connection with this, one should bear in mind that the relative proportion of persons with more severe symptomatology and thus a higher need for services has constantly increased in the Western Lapland area.

A second point to note is that there are no indications that the treatment approach itself would *prevent* life-crises and thus decrease the initial need for mental health care. On contrary, in Study I as well as in other studies on OD (e.g. Buus et al., 2019), it seems that the treatment under OD could be more intensive at the onset, and that the observed differences between treatments occur after a longer follow-up on the same individuals. Note also that in a small area, even individual patients' movement from one category to another causes significant variation in cross-sectional registers, leading to high annual variation. In sum, there seems good reason to claim that longitudinal research designs are preferable for evaluating individuals' actual long-term use of mental and social services.

The increase in (for example) admission and coercion rates after the 2010s nevertheless suggests that there could have been challenges in maintaining the regional treatment approach. One can point to the fact that the number of staff with on-the-job training in family therapy has been constantly decreasing in the region, due to generational shifts and to major changes in the Finnish psychotherapist training system. In addition, during the 2000s, most of the outpatient clinics in the area were separated from the hospital district, meaning that the regional treatment system became more decentralized. More research is thus needed on how the approach has been perceived in the area, and on possible obstacles to maintenance of this kind of comprehensive treatment in current society.

The overall results from the register data nevertheless suggest that by investing in long-term and gradual development, in conjunction with integrative treatment practices for first-episode psychosis, it is possible to achieve a long-lasting increase in social functioning, along with a reduction in hospital admissions and in medical treatment. However, the findings also indicate that at the most detailed level, the outcomes of the treatment approach were not clear cut, and that variation occurred in both the treatment practices and the long-term outcomes. Moreover, due to the naturalistic study design, the specific ingredients that might have led to a more favorable outcome could not be determined. For example, it is possible that having the research conducted in everyday clinical settings led to greater treatment efforts via on-the-job psychotherapy training programs and supervision activities, including also constant feedback from both the service users and the service providers.

In future, further cost-analyses on OD will be needed, as the OD approach calls for fairly large resources, in parallel with more intensive treatment at the initial onset as well as appropriate training of the staff. However, it should be noted that the long-term outcomes, which include a reduced need for mental services and better perceived social functioning, could bring about significant savings for society over a long period of time. Furthermore, existing cost analyses on Finnish schizophrenia treatment in the Western Lapland area have already shown the lowest treatment expenses in a five-year follow-up as compared to rest of the Finland (Karvonen et al., 2008). Indications on cost savings have been presented also in other studies on the early implementation of OD and NAA (Bouchery et al., 2018; Buus et al., 2019; Seikkula et al., 2003).

## 4.2 Summary on individual-level outcomes

The multifaceted nature of experiences categorized as psychosis was represented also in first-person accounts. As presented in previous studies on first-person accounts of people with lived experiences of psychosis, there was no single way of narrating these. Nevertheless, there were some recurring themes between and within the stories. First of all, basically all the participants made sense of their experiences by presenting the crisis as an inseparable reaction to actual life events. Most of the stories were characterized by constant disappointments and life adversities, combined with low self-esteem and loneliness. In some stories, the experiences were regarded as hyper-reactions caused by distressing emotions, while others were characterized by a more severe distortion of reality and loosened self-control. Correspondingly, the thematic content and factors that brought relief were associated with real-life events, occurring outside the actual mental health treatment.

The characteristic feature in most of the stories was feelings of guilt and shame, bringing together the contradiction between personal ideals and more general cultural expectations. In some stories, this discrepancy was narrated as the primary cause of the psychosis. Mental health issues were a more central feature in the stories told by participants with an earlier onset. This was to be expected, as they presented a greater need for treatment and thus a longer time spent in the system. Then again, the crisis might have challenged the fulfillment of more conventional developmental tasks, including getting an education and starting a family, with the narrative identity having to be built on a different foundation. In future, further studies would be needed on how contextual factors affect outcomes, and thus the way in which different experiences manifest themselves in a particular time and culture.

The thematic contents reflected similarities to the findings obtained from previous studies on personal narratives (Barker, Lavender, & Morant, 2001; Shepherd et al., 2012). Generally speaking, it seems that people with lived experiences of psychosis do not usually view it as merely representing an illness, or as some otherwise distinct disease entity. Rather, they present the whole experience as inseparable from actual life events. This kind of interweaving of the severe mental crisis with traumatic experiences and other life-course adversities has been presented in previous studies on people with severe mental health crises (Gullslett, Kim, & Borg, 2014). For example, Jones et al. (2016) presented how people with lived experiences of psychosis had challenges in defining the specific point of onset, presenting instead a continuity of themes from many years prior to the treatment. Correspondingly, it has been recognized that for persons with severe mental problems the crisis is not experienced as a single event (Gullslett et al., 2016).

Some differences from previous studies were also observed. For example, as compared to previous studies (e.g. Lilja & Hellzén, 2008; Mestdagh & Hansen, 2014; Thornhill et al., 2004), the initial mental health treatment was presented in a more neutral manner. Indeed, in the majority of stories there was a lack of treatment-related narratives as compared to other themes. This was unexpected, since the invitation to take part had expressed a wish to get feedback on a network-oriented treatment approach. It is possible that this was partly due to the treatment approach itself, since the OD might have shifted the entire treatment process closer to "real-life," by blurring the conventional roles of service users, family members, and service providers, and by shifting the process outside the institutional setting. Because the network-approach usually includes other authorities from e.g. school, work, or social services within joint treatment processes, it is possible that the treatment contact was not always regarded as a psychiatric or mental health form of treatment, if it was not separately defined as such. This, together with the fact that at the time, OD was the standard approach to care in the region, might explain why there were none of the kinds of comparison between OD and other types of mental health treatment that have been expressed in some previous studies (e.g. Piippo, 2008; Tribe et al., 2019).

In addition, most of the stories in Study III lacked the spiritual aspects of personal experiences found in some earlier studies (e.g. Jones, Kelly, & Shattell, 2016; Menezes & Moreira-Almeida, 2010). This could reflect factors related to Finnish culture. It could also relate to the research setting, including potential selection bias. Nevertheless, findings from different studies do reflect the complexity of phenomena currently categorized under the term psychosis, underlining the importance of gaining more insight from people with lived experiences. This can be considered to be especially important in the clinical context, since in Study III participants indicated that they had significant difficulties in expressing themselves during the acute crisis, with a high risk of their experiences being misunderstood by others. Similar difficulties in describing these experiences through existing language have been reported previously (Jones & Shattell, 2016). All of these hypotheses drawn from Study III would require more robust evaluation and testing in future.

## 4.3 Clinical implications

At a point some decades from onset, people did not view their experiences as a symptom of a disorder; rather, the mental health crises were integrated with other life-course events and daily experiences. A similar gap between the medical model and personal explanatory models on the etiology of psychosis has been reported previously (e.g. Bergman-Araten et al., 2016). Sometimes this is interpreted as a lack of insight into the illness, affecting treatment adherence and thus the outcomes of the treatment (Lacro, Dunn, Dolder, Leckband, & Jeste, 2002). However, up to now there have not been many studies that would include first-person accounts from persons who no longer require mental health services or medical treatment.

According to the first-person accounts presented in Study III, it is not necessary to adopt or maintain clinical explanatory models in order to survive from psychosis. In future, more robust research is needed on how – from this perspective – the language and psychoeducational programs that we currently use in clinical practices are actually associated with the long-term outcome. Relevant here is the concern expressed by some authors (e.g. Romme & Escher, 2012) regarding whether voice-hearing experiences and unusual beliefs should necessarily be seen as signs of psychopathology; they have suggested that the adoption of such an approach could handicap the building of a relationship with the person who is affected by the experiences in question, and could discriminate against persons who give other kinds of meanings to them.

In fact, in previous studies, people with the lived experience of psychosis have underlined the importance of exploring their personal etiology, and the meaning of their own experiences (O'Keeffe et al., 2018). The emphasis on people's intentional and active role in meaning-making processes might have potential in developing more person-centered approaches (Corstens et al., 2014). In line with this, a user-led investigation (Jones et al., 2016) has noted the need for approaches which take account of the complex nature of psychosis and of service users' own experiences. Such an approach would go beyond mere symptom reduction or predetermined functional goals.

In sum, one can suggest that the wide range of complex phenomena currently categorized under the psychosis umbrella cannot be comprehensively treated as clear-cut symptoms of particular disease entities, without reference to the patient's social surroundings and other real-life environments. This was also reflected in the first-person accounts in Study III; in these, both the experiences and the factors that brought relief were associated with events and factors that occurred in real life, outside the actual mental health treatment. Although no causal relationships can be established from such qualitative and descriptive data, a network-orientation in OD can be viewed as a one potential option to diminish organizational borders, and thus to increase more collaborative interaction between authorities within local communities, prompting them to take better account of the social and structural factors that increase human suffering.

On the other hand, it is possible that the relative lack of treatment-related narratives simply indicates that the treatment did not in fact have an impact (either good or bad) on the person's life. However, such a view is contradicted by the group-level outcomes. Taken together with the current findings, it can be hypothesized that more collaborative and network-oriented treatment – in which the primary attempt is to integrate the entire treatment process more closely with daily life − might have a favorable impact, not just on the group-level outcome, but also on the way in which different human experiences are subsequently viewed as part of the individual's life story. Viewed in this light, a dialogical response to a crisis may have been beneficial in creating a shared understanding of what the acute crisis was about, from the person's own point of view. This in itself could have helped people to better maintain their sense of agency. From this perspective, the lack of treatment-related narratives could be regarded as an expected and favorable result following the dialogical response to the crisis. Nevertheless, this would merit further studies with firmer controls.

There are also many other individual elements in OD that have already proven to be beneficial in the treatment of psychosis. First of all, there is robust evidence that individualized and integrated early-intervention practices improve outcomes in the treatment of psychosis (e.g. Bird et al., 2010; Bola et al., 2009; Correll et al., 2018; Kane et al., 2016; Srihari et al., 2015). The provision of immediate help and guaranteed continuity of treatment between in- and outpatient settings appears to ease the difficulties that often occur in healthcare systems, when there are breaks in treatment contact and thus in decision- making, with the possibility that the treatment has to be restarted with people who are unfamiliar with the patient's current situation. Such continuity could be beneficial in dealing with life-crises, and with other factors in people's daily lives that are causing distress.

Moreover, a dialogical stance has a strong potential for breaking down the traditional expertise hierarchy, and this can increase the sense of authenticity in the treatment processes (Galbusera & Kyselo, 2018). In this way, the treatment shifts onto a more equal footing, with an emphasis on people's own agency, and thus on personal attempts to create meanings for challenging experiences. This has the potential to lead to more empathic and respectful interactions – an aspect that has been viewed as one of the common factors of all therapeutic processes (Laska, Gurman, & Wampold, 2014). Moreover the shift from a one-way type of interaction to more open dialogues gives opportunities for the creation of a new kind of understanding between staff, patients, and their close networks regarding each situation. There are then increased possibilities for planning the treatment in more need-adapted and personalized manner.

Since OD is, by and large, a non-medicalizing approach which emphasizes mutual respect, equality, and autonomy, it has been viewed as facilitating a contextual and relational understanding of mental wellbeing while also addressing power differentials in a manner aligned with human-right perspectives in global mental healthcare (von Peter et al., 2019). As presented also in first-person accounts, many experiences diagnosable as psychosis can be interpreted as understandable reactions to difficult life situations and to extreme stress, rather than as symptoms of a disorder. In line with the above, traditional views of psychosis as a symptom of a progressive brain disease, or more generally as a representation of underlying disease entities, have been questioned (e.g. Cooke et al., 2017). In parallel with this, some authors have expressed concern that the pathologizing of the experiences in question, and the maintenance treatment of them with neuroleptic medication, can in some cases block the biological (Whitaker, 2004) and mental functioning (Wunderink et al., 2013) that − in the long term – is essential for survival. It is argued that the more selective use, or possible postponement of neuroleptic medication, together with an adequate sense of trust, could help crises to progress along more natural trajectories.

More evidence is still required on the long-term effects of neuroleptics and on the risk-benefit ratio of their use (Correll, Rubio, & Kane, 2018). Nevertheless, the findings in this thesis are in line with other follow-ups, in which it was found that long-term treatment outcomes for the schizophrenia-spectrum population were more favorable with less medicated samples (e.g. Harrow, Jobe, & Faull, 2014; Joukamaa, Heliövaara, Knekt, Aromaa, Raitasalo, & Lehtinen, 2006; Nykänen et al., 2016; Wunderink et al., 2013).

## 4.4 Strengths and limitations

### 4.4.1 Strength and limitations in the quantitative studies

Finnish registers are usually considered to be reliable sources of and valid tools for research information (Kiviniemi, 2014), and as these make it possible to detect *all* the events occurring in specific treatment systems, they can be considered to offer valid information on how services were actually used in the region of Western Lapland in the follow-up period. This means that the external and especially the ecological validity of the quantitative analyses presented in Studies I and II can regarded as good. Moreover, data on the overall use for mental health services and on disability allowances can be considered to provide strong indications on clinical and functional outcomes, given that in Finland, health and social services are guaranteed to the entire population on the basis of statutory national social security provisions.

Nevertheless, there are issues relating to internal validity. For example, in Study I a larger sample size and more comprehensive information on the demographic and clinical characteristics would have allowed more detailed and sophisticated statistical analyses to evaluate causal relationships. Thus, further research is needed on whether or not the observed difficulties in applying the treatment principles are associated with poorer outcomes. In future, more detailed fidelity assessments might also provide clearer insights on how, and from what aspects of the treatment, different people gain benefit.

Other limitations relate more generally to observational and naturalistic register-based studies. First of all, no direct evaluation could be made of the use of medication, the current ability to function, and subjectively-experienced life satisfaction, given that the registers formed the only source of data. The lack of standardization in (for example) the diagnostic procedures that one would find in more experimental settings has further implications for comparability. It should be noted that while in Western Lapland the diagnoses were set as a standardized procedure, in line with the original research projects, in the comparison group they were set as part of everyday clinical practice. Thus, in the latter case, both the threshold and the motivation to apply certain diagnoses might have caused undetected variation, hence affecting the comparability of the samples. Even though a high threshold for application of a schizophrenia-spectrum diagnosis in everyday practice potentially increased sample comparability, in future better controlled research designs will be needed to address issues of this kind. In future also, the register data should be analyzed in more detail regarding the co-morbidity of the diagnoses, plus the types and quantities of neuroleptics (and other medications) used.

In naturalistic studies it is quite possible that selection bias exists, and there could have been undetected variables simultaneously affecting the long-term need for mental health services and the other outcome variables. In Study II in particular, the fact that there were two groups coming from different regions of Finland, with possible regional differences, could have impacted on the findings. In part, this was compensated for by the long follow-up time, with minimal loss of subjects. One should also note that in Finland the variations in e.g. ethnic and socio-economic status are relatively small, and it is therefore unlikely that these factors would cause significant bias in this kind of register study (Kiviniemi, 2014). Furthermore, the use of national registers made it possible to gather information even when individuals had moved away from the catchment area. This – together with the long follow-up time – could have reduced the bias relating to regional differences.

Some of the main limitations were compensated for by the inclusivity of the samples. Since OD covered the *whole* region – and thus *all* the people in the region with first-episode psychosis – there is good reason to argue that the naturalistic study design with a historical comparison does, in this case, offer valid information on the *actual* treatment outcomes of *all* FEP treatment in the region. Correspondingly, in forming the comparison group in Study II, the aim was to include all non-affective FEP patients who were guided to treatment in Finland with a mean similar follow-up time, in order to further reduce the non-randomization bias. According to the results, this goal was achieved: in both groups the observed distributions in age, gender, diagnoses and annual incidence of FEP were in line with earlier studies including first-episode nonaffective psychosis patients in real-world settings (Kirkbride et al., 2009; Lehtinen et al., 2000; Svedberg, Mesterton, & Cullberg, 2001). Moreover, there were no significant differences between the groups regarding most of the demographic and clinical characteristics. The exceptions pertained to age, and the way in which patients were guided to treatment at onset, both of which might have been affected by the treatment approach itself (including earlier detection of the psychosis, combined with mobile and low-threshold treatment aimed at easing service accessibility).

The lack of reliable information on outpatient treatment prior to 2011 nevertheless increases the risk that there was over-representation of hospitalized and medicated patients in the comparison group, even if earlier studies indicated that most patients in Finland did in fact receive hospital and medical treatment during acute psychosis (Kiviniemi, 2014; Perälä, 2013). It can also be argued that the hospital discharge register alone seems to capture effectively persons with diagnosable non-affective psychosis (Perälä, 2013); in earlier studies, only 3% of people with schizophrenia-spectrum diagnosis were found not to be detectable via the hospital discharge register (Isohanni et al., 1997).

Despite this, it is likely that in many cases first-contact with services did actually occur prior to admission, but that in the CG some of these remained undetectable, given the limited information available on outpatient treatment prior to 2011 and medication purchases prior to 1995. This could partially explain the older onset age in the comparison group, and it might have caused undetectable variations in the follow-up times. It should also be noted that in order to increase the statistical power of the analyses, the OD group were complemented with people guided to treatment at different periods of time. This variation in both the onset- and follow-up-times might have increased the risk of a confounding effect on some of the outcome variables. To address these issues, additional sensitivity analyses were conducted, with matched samples, and with stronger control of potential confounders. These analyses did not show any significant differences in the main findings.

Overall, the results from the register studies provided externally valid group-level information on the actual use of mental health services over a long period of time, under different kinds of treatment systems. However, due to limitations relating especially to internal validity, more controlled trials would be required in order to achieve a maximally precise evaluation of the effectiveness of the OD approach.

### 4.4.2 Strength and limitations in the qualitative study

In the first place, it should be noted that the sample in Study III was not random. One has to consider the likelihood of undetectable selection in the recruitment process, notably due to the more direct recruitment of those still in treatment contact, as compared to those who were approached via letters only. Furthermore, the sample size was too small to draw any firm generalizations, although it can be considered to be relatively large for the purposes of an in-depth analysis, and for the primary aims of Study III. Moreover, the participants' clinical and demographic characteristics seemed to be in line with the entire FEP population in the catchment area (see Table 2).

Secondly, the researcher's own preconceptions can affect both the course of the interviews and also aspects of the analysis. For example, it is possible that in researcher-led studies, some essential aspects of personal experiences are downplayed and misunderstood. Furthermore, both situation- and person-related factors might affect participants' decisions as to what they choose to bring up in interviews. In addition, in the present study, it was not possible to systematically review the analyses with participants, since none of them wanted to review the transcriptions or to continue discussion afterwards, even though this option was offered. In future, such opportunities should be given greater emphasis in the initial research protocol, in order to increase the validity of the analyses and to encourage service users to participate in the research and development work.

Some of these issues were compensated for by having a minimally structured interview protocol. This was intended to reduce the possibility of leading questions or other researcher-related factors. Similarly, a semi-structured frame was used after the initial storytelling. Care was also taken that in the analyses the focus would only be on what participants narrated, avoiding any excessive interpretation.

Overall, a qualitative method makes it possible to increase understanding on how people themselves make sense of their experiences. This is essential in studying complex and multifactorial mental and social phenomena such as psychosis, which are always inseparable from the intentional subject and the individual's own meaning-making processes. This kind of information can be used to guide more valid research plus more effective and person-centered treatment approaches, even if the qualitative approach still needs to be complemented with other, more standardized research methods.

### 4.4.3 Author's statement on position and on potential conflicts of interest

Personally, I have not experienced anything that I would call psychosis. Like most of us, I have had life-events that can be interpreted as traumatic, and I have suffered from different degrees of mental distress over my life course. I have had guidance from mental and social services in my childhood, and I have also had experiences that might be called "unusual," though not on a distressing level. Even though these experiences – like all life-course experiences – have influenced my research interests and the way in which I have approached the topic in this thesis, I do not identify myself as a service user, survivor, or peer expert in the sense in which these terms are usually applied.

Alongside my research projects for this thesis, I have continued to work in my daily job as a clinical psychologist in Keropudas hospital, which is charge of all adult psychiatric inpatient treatment in the area of Western Lapland. Overall, I have had over five years of experience of working in the treatment system described in this thesis. This position can be regarded as a strength, since it provides unique insight into the complexities of the actual clinical practice of OD. On the other hand, closeness to both the approach and the research site could make my way of approaching the topic more subjective, and thus more vulnerable to bias.

In my daily job as a clinical psychologist in the Keropudas acute psychiatric ward, I continuously work with people who suffer, or have suffered, from experiences diagnosable as psychosis. After the acute phase I usually continue to work with them in outpatient settings as a member of their network; thus I am often part of their lives over long periods of time. Usually I work with and see patients in their homes, or in other everyday life contexts. I recognize that this way of working has potentially provided perspectives towards the topic of this thesis that affect the way in which I have set the research questions and interpreted the findings. My daily work has also increased my curiosity towards the topic, thus acting as one of the main motivators to start doing the research in the first place.

My current employer has not received any financial benefits from this research, and as a public healthcare organization, its performance is not dependent on the results obtained within any of research projects presented in this thesis. I have conducted the research separately from my clinical work and without any financial support from my hospital district, with the exception of some flexibility permitted in my working hours. At the time of writing this thesis I have worked only in public and non-financial mental-health services, and I have not received any funding or financial benefit from private or other profit-making organizations. As a clinical psychologist, my livelihood or career development is not dependent on my research funding or academic success, and thus not on any of the results presented in this thesis.

I am not part of the original Open Dialogue development team and I had no role in developing or implementing the Need-Adapted or Open Dialogue approaches. Even though my ways of working and interacting with people are characterized by elements from these approaches, I do not call myself a *dialogical practitioner*. Nevertheless, my familiarity with the approach and the shared value-basis will potentially affect the aspects I have focused on in this research. Furthermore, the fact that the study group and the supervisors of this thesis consisted of members from the original development team might further increase the risk of researcher-allegiance bias (i.e. a tendency to find positive results for the treatment favored by the investigators) (Leykin & DeRubeis, 2009). These issues were recognized and openly discussed throughout the project.

At the time of writing the original articles of this thesis, I did not receive any fees for teaching, training, or lecturing on the Open Dialogue or related approaches. I have later received a lecture fee as a private person for presenting the main findings of this study. None of the members of the research group have any financial or other connections with pharmaceutical manufacturers or suppliers. Most of the research phases reported in this thesis were self-funded, and I conducted them alongside my daily job, mainly in my own free time. The only external funding sources were the Finnish State Research Funding (VTR) granted by the Finnish Ministry of Social Affairs and Health to cover the expenses involved in compiling data from the national registers, and personal research funding obtained from the University of Jyväskylä to cover one period of study leave. These funding sources had no involvement in the design of the study, or in the collection, analysis, and interpretation of the data.

## 4.5 Conclusion

The findings of this thesis gave strong indications of the heterogeneous long-term course and multifaceted nature of the experiences categorized under the psychosis umbrella. At the individual level there was no distinct "psychosis" entity with a defined start and end, describable in an "off-on" manner. Rather, the crisis was presented as inseparable from real-life events. Moreover, many of the people did not identify themselves as service users or as patients, and the factors that helped them to survive were often found in aspects of their life outside the treatment. This finding was to some extent in contradiction with the group-level outcomes, in which the network-oriented and dialogical treatment approach was associated with a decreased need for mental health services and with maintained work capacity at the follow-up, which took place at approximately 19 years from clinical onset.

Despite the contradictory aspects noted above, it can be hypothesized that there is in fact a connection between the lack of treatment-related narratives and the treatment approach itself: the dialogical responses, within a real-life context where the emphasis is on personal meaning-making processes, might enable the creation of a shared understanding of a given situation, and thus help people to maintain their sense of personal agency. This would explain why people emphasize their own role in the gradual process of survival, even when the network-oriented open dialogue treatment was associated with a better long-term functional outcome as compared to more conventional treatment strategies. Thus, the fact that people emphasize their own agency rather than treatment can be interpreted as a favorable outcome in itself; however, whether or not this is a typical outcome of Open Dialogue or similar approaches merits further study.

To put this in another way, the question still remains as to whether the long-term outcomes presented in this study are a causal consequence of a specific treatment model, or whether they merely indicate how systematic and local development (aimed at encouraging more reciprocal and equal dialogues between people) improves long-term outcomes in the treatment of severe mental problems. If the latter is true, the findings from this thesis would provide a rationale for smaller-scale regional integration of services (see also van Os, 2019). The aim would be for these to work together in local networks, creating opportunities for more flexible needs-based consultation, and for joint developmental projects in line with local factors, resources, and needs. According to the main findings of this thesis, this kind of gradual and communal development work would have the potential to provide long-term benefits for societies as a whole, even if it requires more resources initially as well as a shift in the paradigm on how mental distress and human suffering in general are to be described, studied, and understood.

Whatever the specific mechanism of change might turn out to be, people with lived experiences guide us to look beyond the specific treatment model and techniques. As underlined also in the *common factor perspective* (Laska, Gurman, & Wampold, 2014), it seems that what is essential for people with severe distress is interaction with others, and a way of responding to human suffering, rather than specific techniques or methods. As Jaakko Seikkula has expressed it (2011): *"Nothing more is needed than being heard and taken seriously and it is this which generates a dialogical relation. And when – after a crisis – we again return to dialogical relations, the therapeutic task is fulfilled because agency is regained."*

# YHTEENVETO (SUMMARY)

## Elämä ensipsykoosin integroidun ja dialogisen hoidon jälkeen: pitkän aikavälin hoitotulokset yksilö- ja ryhmätasolla

Tämä väitöskirja koostui kolmesta osatutkimuksesta, jotka yhdessä kuvasivat ihmisten selviytymistä vuosikymmeniä dialogisen ja verkostokeskeisen ensipsykoosin hoidon jälkeen.

Kirjallisuudessa psykoosi-termillä viitataan inhimillisiin reaktioihin, joille yhteistä ajatellaan olevan todellisuudentajun heikentyminen, ja joita diagnostisesti kuvataan skitsofrenia-ryhmän tyyppioireena. Tämän ryhmän psykooseja pidetään yleisesti oirekuvaltaan ja hoidettavuudeltaan haastavimpina mielenterveysongelmien ryhmänä, ja näistä aiheutuva kärsimys on sekä yksilö- että yhteisötasolla merkittävää.

Koska psykoosien etiologia tunnetaan edelleen puutteellisesti, on näiden hoidossa jouduttu keskittymään lähinnä akuutin oireilun lievittämiseen. Vaikka psykoosioireita pystytäänkin usein eri keinoin lievittämään, ovat pitkän aikavälin hoitotulokset sekä oirekuvan että sosiaalisen selviytymisen kannalta säilyneet epätyydyttävinä. Lisäksi psykoosipotilaiden ennenaikaisen kuoleman riski on muuhun väestöön verrattuna kasvanut viimeisten vuosikymmenten aikana.

Erityisen haasteen psykoosien etiologian ymmärtämisen ja tätä kautta hoitokäytäntöjen kehittämisen kannalta muodostaa psykoosi-ilmiön ja sen määritelmien heterogeenisyys. Viime aikaisten tutkimusten mukaan mielenterveysongelmat ja näiden oireet eivät ole palautettavissa ryhmätasolla määriteltäviin sairausluokkiin, ja myös hoidossa vaikuttavaa on yleensä vuorovaikutuksen laadun kaltaiset ei-spesifit mekanismit. On esitetty, että mielenterveyshoidon kehittämisessä olisi painotettava enemmän ihmisten yksilölliset tarpeet huomioivia integroituja lähestymistapoja. Esimerkki tällaisesta lähestymistavasta on *Tarpeenmukaisen hoidon malli*, jossa skitsofrenian ja muiden psykoosien monitekijäinen luonne pyritään huomioimaan suunnittelemalla hoitoa yhteistyössä potilaan ja hänen lähiverkostonsa kanssa niin, että se vastaisi mahdollisimman joustavasti kunkin yksilöllistä elämäntilannetta.

Eräs tarpeenmukaisen hoitokäytännön alueellisista modifikaatioista pohjautuu Suomessa Länsi-Pohjan sairaanhoitopiirin n. 72 000 ihmisen toimialueella 1980- ja 1990-luvuilla tehtyyn kehitystyöhön, jonka tavoitteena oli koko psykiatrisen palvelujärjestelmän organisoiminen sellaisten periaatteiden mukaan, joiden katsottiin edistävän mielenterveysongelmista kärsivien ja heidän läheisten tarpeenmukaisempaa kohtaamista. Hoitokäytäntö ja sen periaatteet on myöhemmin kuvattu *Avoimen dialogin hoitomallina*, jolla tarkoitetaan samanaikaisesti sekä dialogista tapaa kohdata hädässä oleva ihminen että keinoja organisoida palvelujärjestelmää niin, että tällainen kohtaaminen mahdollistuu. Mallissa korostuu välitön, tarpeenmukainen ja yli organisaatiorajojen jatkuva psykoterapeuttinen hoitokontakti, jonka tavoitteena on potilaan ja hänen lähiverkostonsa omien resurssien tukeminen jaettujen tulkinta- ja päätöksentekoprosessien kautta.

Avoimen dialogin hoitokäytännön vaikuttavuutta ensipsykoosin hoidossa tutkittiin alun alkaen Länsi-Pohjan kehitystyön yhteydessä tehdyissä tutkimuksissa, jotka kuvasivat hoitokäytännön toimivuutta todellisissa kliinisissä olosuhteissa. Näissä tutkimuksissa hoitokäytäntö oli yhteydessä ensipsykoosipotilaiden kohonneeseen psyykkiseen ja sosiaaliseen selviytymiseen. Viime vuosien aikana tuloksia on alustavasti saatu toistettua myös Länsi-Pohjan alueen ulkopuolella. Sekä kontrolloitu että pidemmän aikavälin vertaileva tutkimusnäyttö mallin vaikuttavuudesta on kuitenkin edelleen puutteellista. Lisäksi on epäselvää, kuinka potilaat itse ovat hoitokäytännön kokeneet, ja millaisia merkityksiä he sekä psykoosille että sen dialogiselle hoidolle antavat vuosikymmenten jälkeen.

Tämä väitöskirja ja sen osatutkimukset pyrkivät vastaamaan yllä esitettyihin ongelmiin. Osatutkimusten aineistot muodostettiin pääasiassa Länsi-Pohjan tutkimuskohortin pohjalta, joka käsittää kaikki ensipsykoosin vuoksi Länsi-Pohjan alueella avoimen dialogin mallin implementoinnin (1992-1997) aikana hoidossa olleet potilaat. Tilastollisen selitysvoiman lisäämiseksi aineistoa täydennettiin soveltuvin osin myöhemmän replikaatiovaiheen (2002-2005) aineistolla. Tutkimuksen vertailuryhmä muodostettiin kaikista muualla Suomessa ensipsykoosin vuoksi 1990-luvun puolivälissä hoidossa olleista.

Väitöskirjassa hyödynnettiin monimenetelmäistä metodologiaa, jossa laadullisten ja määrällisten tutkimusstrategioiden katsottiin yhdessä tuottavan monipuolisempaa kuvaa tarkastelun kohteena olleista ilmiöistä siten, kuin ne todellisissa kliinisissä olosuhteissa ilmenivät. Väitöskirjan kaksi ensimmäistä osatutkimusta hyödynsivät pääasiassa valtakunnallisista terveydenhuolto- ja sosiaalirekistereistä kerättyjä tietoja, joita analysoitiin tilastollisin menetelmin. Kolmannessa osatutkimuksessa analysoitiin laadullisten menetelmien avulla niitä merkityksiä, joita hoidossa olleet itse sekä psykoosille että sen hoidolle antoivat vuosikymmeniä avoimen dialogin hoidon jälkeen.

Väitöskirjan ensimmäinen osatutkimus oli kuvaileva seurantatutkimus, jossa tarkasteltiin tutkimuskohorttiin kuuluvien mielenterveyspalveluiden käyttöä 10-23 vuoden seuranta-aikana avoimen dialogin järjestelmässä. Samalla tutkittiin hoidon pitkittymiseen ja palveluiden käyttöasteeseen liittyviä tekijöitä. Aineisto muodostettiin niistä tutkimuskohortin potilaista, jotka olivat yhtäjaksoisesti asuneet Länsi-Pohjan sairaanhoitopiirin alueella koko seurantajakson (1992-2015) ajan (N=65). Sekä numeerista että laadullista tietoa kerättiin suoraan erikoissairaanhoidon ja perusterveydenhuollon rekistereistä.

Tulosten perusteella alueellisessa hoitokäytännössä näyttäytyi etenkin hoidon alkuvaiheessa selektiivinen psykoosilääkkeiden käyttö, avohoitopainotteisuus sekä verkostokeskeisyys. Pidemmissä hoitoprosesseissa yksilö- ja verkostotapaamisten suhde kääntyi päinvastaiseksi. Suurin osa hoitoprosesseista oli päättynyt seuranta-aikana sovitusti, joskin kohortissa oli myös pidempään hoitoa tarvinneita. Enemmän palveluita tarvinneet olivat todennäköisemmin saaneet psykoosilääkettä ja/tai olleet sairaalahoidossa hoidon alussa, ja heidän käyttäytymisensä oli koettu muita uhkaavampana. Tulosten perusteella joissakin hoidon vaiheissa ja/tai tilanteissa dialogisen hoitokäytännön systemaattinen ylläpitäminen voi näin ollen olla haasteellista.

Toinen osatutkimus oli rekisteripohjainen kohorttiseuranta, jossa tarkasteltiin kaikkien tutkimuskohorttiin kuuluneiden potilaiden selviytymistä, ja verrattiin tuloksia muualla Suomessa ensipsykoosin vuoksi hoidossa olleiden vastaaviin tuloksiin. Tarkasteltavia muuttujia olivat kuolleisuus, psykiatristen palveluiden käyttö ja myönnetyt sosiaalituet keskimäärin 19-vuoden seuranta-aikana. Seurantaryhmä muodostettiin valtakunnallisista hoitorekistereistä sisällyttämällä aineistoon kaikki 1990-luvun puolivälissä ensimmäistä kertaa psykoosin vuoksi erikoissairaanhoidossa olleet 16-50 vuotiaat potilaat. Ryhmäeroja tarkasteltiin pääasiassa epäparametrisin tilastomenetelmin. Avoimen dialogin hoidon vaikuttavuutta suhteessa muunlaiseen hoitoon tutkittiin lisäksi logistisella regressioanalyysillä sekoittavat tekijät vakioimalla. Herkkyysanalyyseja toteutettiin sekä demografisesti että kliinisesti kaltaistetuilla aineistoilla.

Tulosten perusteella tutkimuskohorttiin kuuluneilla potilailla oli vertailuryhmää merkitsevästi vähemmän sairaalajaksoja ja hoitopäiviä koko seurannan ajan. Myös psykoosilääkkeiden käyttö oli tutkimuskohortissa vertailuryhmää merkitsevästi matalampaa. Seurantahetkellä mielenterveyssyistä työkyvyttömyyseläkkeellä tai kuntoutustuella oli tutkimusryhmästä 33%, kun vertailuryhmässä vastaava luku oli 61%. Kokonaiskuolleisuudessa tai itsemurhien määrissä ei ollut ryhmätasolla tilastollisesti merkitseviä eroja vertailu- ja tutkimusryhmän välillä, joskin vertailuryhmässä iän ja sukupuolen mukaan vakioitukuolleisuusaste oli korkeampi. Regressiomalleissa hoidon alkaminen Länsi-Pohjan alueen ulkopuolella ennusti tilastollisesti merkitsevästi sitä, että henkilö oli edelleen hoidon piirissä ja/tai työkyvyttömyyseläkkeellä seurannan päätyttyä. Tulokset säilyivät samansuuntaisina kun niihin mahdollisesti vaikuttavat sekoittavat tekijät vakioitiin ja kun analyysit suoritettiin kaltaistetuilla aineistoilla.

Kolmannessa osatutkimuksessa tutkimuskohorttiin kuuluvia kutsuttiin haastatteluihin, joissa heitä pyydettiin ensin vapaamuotoisesti kertomaan oma elämäntarina. Vapaamuotoisen kerronnan jälkeen elämäntarinan temaattista sisältöä tarkennettiin puolistrukturoidun haastattelurungon avulla. Psykoosille ja sen dialogiselle hoidolle annettavia merkityksiä analysoitiin pääasiassa narratiivisen sisällönanalyysin keinoin.

Haastatteluihin osallistuneet (N=20) edustivat sekä demografisesti että kliiniseltä kuvaltaan hyvin koko tutkimuskohorttia. Kaikki osallistujat kertoivat mielenterveyskriisiin johtaneista tekijöistä ja suurin osa (80%) tuotti spontaanisti sisällöllisesti eheän ja kronologisesti etenevän elämäntarinan. Kaikki kertoivat elämäntilanteen rauhoittuneen ensipsykoosin jälkeen. Vain 35% haasteltavista nimesi kokemuksensa psykoosiksi. Lähes kaikissa tarinoissa mielenterveyshoitoa vaatinut kriisi liitettiin todellisiin elämäntapahtumiin ja etenkin kumuloituneeseen sosiaaliseen kuormitukseen. Vastaavasti tilannetta helpottaneet tekijät löytyivät kertomuksissa pääasiassa mielenterveyshoidon ulkopuolelta todellisen elämän tapahtumista, omasta itsestä ja ihmissuhteista. Kolmannen osatutkimuksen tulokset antoivat viitteitä yksilöllisten tulkintatapojen ja näin toimijuuden säilymisestä.

Kaikkiaan verkostokeskeisen ja dialogisen hoitokäytännön positiiviset vaikutukset olivat edelleen havaittavissa vuosikymmeniä ensipsykoosin jälkeen parantuneena sosiaalisena toimintakykynä sekä toimijuuden säilymisenä. Yksilötasolla dialogista ja verkostokeskeistä hoitoa saaneet ihmiset eivät kuvanneet psykoosia muusta elinpiiristä ja sen tapahtumista irrallisena tai kategorisesti määriteltävä sairautena. Sen sijaan psykoosiksi määritetyt kokemukset liitettiin todellisen elämän tapahtumiin, jolloin myös auttavien elementtien kerrottiin löytyneen useimmiten varsinaisen mielenterveyshoidon ulkopuolelta. Tästä huolimatta verkostokeskeinen ja dialoginen mielenterveyshoito oli ryhmätasolla yhteydessä standardihoitoa parempaan sosiaaliseen selviytymiseen ja vähentyneeseen palveluiden käyttöasteeseen 19-vuoden seurannassa.

Rinnakkain tarkasteltuna tulokset viittaavat siihen, että dialoginen ja verkostokeskeinen hoito, jossa korostetaan potilaan ja hänen lähipiirin omia tulkintoja vaikeasta elämäntilanteesta, näyttää integroivan hoitoprosessin lähemmäksi todellisen elämän kontekstia, tukien samalla asianomaisten oman toimijuuden säilymistä ja hankalan elämäntilanteen ratkeamista. Tätä kautta hoitokäytännöllä voi olla tilanteen kroonistumista ehkäisevä vaikutus, joskin tämän todentaminen vaatii vielä lisätutkimuksia.

Sekä ryhmä- että yksilötason pitkän ajan hoitotuloksissa oli havaittavissa runsaasti vaihtelua. Tämä tukee aiempia tutkimuksia psykoosi-ilmiön pitkän aikavälin ennusteen sekä sen määritelmien heterogeenisyydestä. Jatkossa kontrolloidumpaa lisänäyttöä tarvitaan etenkin avoimen dialogin hoitokäytännön vaikuttavuudesta, sillä observoivan tutkimuksen avulla ei voida tehdä luotettavia päätelmiä syy-seuraussuhteista tai niistä mekanismeista, jotka hoidon vaikuttavuutta selittävät. Onkin mahdollista, että tämän väitöskirjan tulokset kuvaavat spesifiä hoitokäytäntöä enemmän systemaattisen ja ihmisten tasa-arvoista kohtaamista edistävän kehitys- ja tutkimustyön myönteistä vaikutusta mielenterveyshoidon tuloksellisuuteen. Löydökset tukevat näkemystä, jonka mukaan mielenterveyshoidossa ja sen kehittämisessä olisi perusteltua liikkua kohti sellaisia yhteisöllisiä kehityshankkeita, joissa pyritään yli organisaatiorajojen ratkomaan inhimillistä pahoinvointia ruokkivia kuormitustekijöitä, ja näin yksilöllisemmin huomioimaan hankalia elämäntilanteita ja näihin liittyviä kokemuksia.

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# ORIGINAL PAPERS

# I

# THE LONG-TERM USE OF PSYCHIATRIC SERVICES WITHIN THE OPEN DIALOGUE TREATMENT SYSTEM AFTER FIRST EPISODE PSYCHOSIS

by

Tomi Bergström, Birgitta Alakare, Jukka Aaltonen, Pirjo Mäki, Päivi Köngäs-Saviaro, Jyri J. Taskila, & Jaakko Seikkula.

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# The long-term use of psychiatric services within the Open Dialogue treatment system after first-episode psychosis

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# The long-term use of psychiatric services within the Open Dialogue treatment system after first-episode psychosis

## ABSTRACT

Open Dialogue is a family-oriented early intervention model for mental health problems developed in the health district of Western Lapland, Finland. In the present study, the aim was to describe how psychiatric services were used in Western Lapland after decades of first-episode psychosis services, and to analyze how baseline characteristics were related to re-admission rates and the total duration of psychiatric treatment in geographical area where Open Dialogue approaches were developed and efforts made to systematically apply them to all psychiatric treatments. The data were obtained from the medical histories of patients who had first-episode psychosis in 1992–2005 and who lived continuously within the catchment area during the observation years (1992–2015) ($N = 65$). From baseline up to 2015, average length of treatment was 6±2 years, and significant decrease ($p < .001$) in total use of psychiatric services was observed. The admission rates and duration of treatment were highest with subjects who behaved aggressively ($U = 270$, $p < .005$), and/or who were hospitalized ($U = 157$, $p < .001$) and medicated ($U = 114$, $p < .001$) at onset. Overall, external aggression at onset emerges as a factor that may challenge the application of the OD treatment principles, being associated with a greater need for hospitalization and longer treatment duration.

KEYWORDS: First-episode psychosis; longterm treatment patterns; open-dialogue approach; need-adapted approach

## Introduction

Over the last four decades, the treatment of people diagnosed with schizophrenia and other psychoses has largely moved from traditional institutional settings to outpatient- and community-based psychiatric systems (Lien, 2002). This trend is soundly based, insofar as psychiatric hospital care has many negative aspects, including (for the patient) disengagement from the social environment, in addition to great costs for society (Miettunen et al., 2006). However, there is no doubt that deinstitutionalization sets major challenges for public health care (Turner, 2004). These challenges are particularly significant in the case of psychotic disorders, in which a person's ability to function may well be severely disturbed, with a concomitant need for a safe and structured environment.

Studies have shown very high re-hospitalization rates for schizophrenia-spectrum disorders, and some authors have argued that deinstitutionalization has led to a "revolving-door" phenomenon (Turner, 2004). In line with this, Mortensen and Eaton (1994) observed that readmission rates stood at 80% within ten years of follow-up. Similar results have been presented in a Finnish study conducted on a schizophrenia-spectrum population; there, the re-hospitalization rates were 60% for a two-year and 81% for a 10-year follow-up (Miettunen et al., 2006). In addition, many negative side effects (Lieberman, 2004; Radua et al., 2012) and increased preliminary mortality rates (Joukamaa et al., 2006) have been associated with the neuroleptic medication used to treat psychosis – this despite the fact that neuroleptics have traditionally been argued to be a means towards deinstitutionalization in the first place.

In response to the challenges noted above, low-threshold psychiatric services have been developed in many Western countries (Cullberg et al., 2006; Srihari et al., 2015). Most of these programs have focused on the early detection of psychosis, the aim being that intervention should be applied before prodromal symptoms of schizophrenia-spectrum disorders evolve into a more severe form. For example, first-episode services developed in the United States have been found to reduce both hospital admission rates (Srihari et al., 2015) and the total length of treatments (Kane et al., 2015). They seem also to be associated with generally improved symptom outcomes as compared to treatment as usual (Dixon et al., 2015; Kane et al., 2015). Similar results have been presented for Danish OPUS treatment, though in a comparison with treatment as usual, it appeared that most of the positive short-term effects had diminished (Secher et al., 2014). From the evidence so far, one can see that the associations between utilization of services and treatment outcomes are complex, and that the use of mental health services is dependent upon many variables (Korkeila, Lehtinen, Tuori, & Helenius, 1998). Thus, there is still a need for more information concerning the long-term requirements for psychiatric services in community-based early intervention systems.

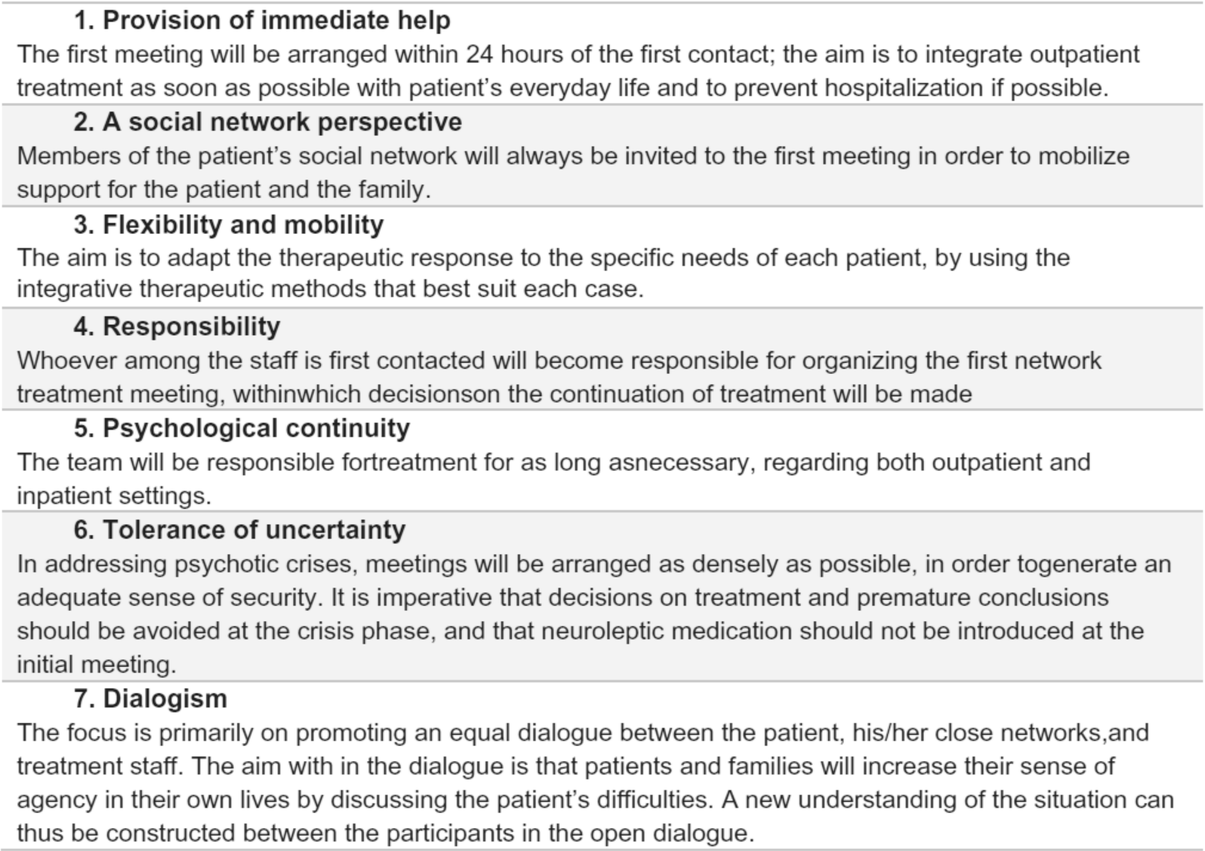
Another example of early intervention practices, developed especially for the treatment of schizophrenia spectrum disorders, is the *Need-Adapted Approach* (NAA) (e.g. Lehtinen, Aaltonen, Koffert, Rakkolainen, & Syvalahti, 2000). NAA began to be developed in Finland in the early 1970s, on the basis of systematic research work conducted by Yrjo Alanen and his colleagues (1986, 1991). The premise of NAA is based on the notion that schizophrenia-spectrum disorders comprise a heterogeneous group of psychotic conditions, implying that the treatment needs of patients should be evaluated on a case-by-case basis. Alanen (2004, p. 5) summarized NAA as "an integrated treatment approach for new patients of the schizophrenia group in which different treating methods are combined with each other so as to meet the therapeutic needs of individual patients as well as their interactional networks."

Since the 1980s, NAA has further evolved towards the *Open Dialogue* (OD) approach. The OD approach is applied in a small Finnish catchment area of 63 000 inhabitants, consisting of the South Western part of Finnish Lapland and the Keropudas hospital region (Aaltonen, Seikkula, & Lehtinen, 2011; Seikkula, Alakare, & Aaltonen, 2011). OD is based on seven treatment principles (Figure 1); these have emerged from a number of research programs (Haarakangas, 1997; Keranen, 1992; Seikkula, 1991) and are aimed at determining optimal treatment processes. In the area of Western Lapland, efforts have been made to apply these principles in all psychiatric crises, regardless of the diagnosis (Seikkula, Aaltonen, Alakare, et al., 2006).

The primary idea behind OD is the provision of psychotherapeutic treatment for all patients within their own interactional and social networks (Seikkula et al., 2006). This is done (i) by integrating the close networks of the patient with the treatment processes, and (ii) by generating a socially shared language and new meanings for difficult experiences, within dialogs with intervention teams, patients, and their families. As in NAA, there are attempts to guarantee the continuity of treatment between inpatient and outpatient settings. The primary emphasis is on outpatient and psychotherapeutic treatment, with careful evaluation – and if possible, postponement – of both hospital treatment and neuroleptic medication.

In the 1990s and early 2000s, the effectiveness of OD in the treatment of acute psychosis was studied in three research projects. The first of these formed part of the nationwide *Acute Psychosis Integrated treatment* (API) project, which was conducted during 1992–1998 (data collection in Western Lapland (1992–1993), under the direction of the National Research and Development Center for Welfare and Health, in conjunction with the Universities of Jyvaskyla and Turku, Finland (Lehtinen et al., 1996, 2000). The API project was conducted in six psychiatric catchment areas. In three of these (including Keropudas hospital, the only psychiatric hospital in Western Lapland) the treatment followed the NAA approach, while in Western Lapland the principles of OD (in addition to NAA) were applied and studied.

In 1994–1997 (i.e. the second research period), the project continued at the local level in Western Lapland, within the *Open Dialogue Approach in Acute Psychosis* (ODAP) project, whose aim as to evaluate the effectiveness of the treatment in its more systematic implementation, i.e. following more strictly the *seven principles of OD* (see Figure 1).



**1. Provision of immediate help**

The first meeting will be arranged within 24 hours of the first contact; the aim is to integrate outpatient treatment as soon as possible with patient's everyday life and to prevent hospitalization if possible.

**2. A social network perspective**

Members of the patient's social network will always be invited to the first meeting in order to mobilize support for the patient and the family.

**3. Flexibility and mobility**

The aim is to adapt the therapeutic response to the specific needs of each patient, by using the integrative therapeutic methods that best suit each case.

**4. Responsibility**

Whoever among the staff is first contacted will become responsible for organizing the first network treatment meeting, withinwhich decisionson the continuation of treatment will be made

**5. Psychological continuity**

The team will be responsible fortreatment for as long asnecessary, regarding both outpatient and inpatient settings.

**6. Tolerance of uncertainty**

In addressing psychotic crises, meetings will be arranged as densely as possible, in order togenerate an adequate sense of security. It is imperative that decisions on treatment and premature conclusions should be avoided at the crisis phase, and that neuroleptic medication should not be introduced at the initial meeting.

**7. Dialogism**

The focus is primarily on promoting an equal dialogue between the patient, his/her close networks,and treatment staff. The aim with in the dialogue is that patients and families will increase their sense of agency in their own lives by discussing the patient's difficulties. A new understanding of the situation can thus be constructed between the participants in the open dialogue.

Figure 1. The seven treatment principles of the Open Dialogue (OD) treatment system (also in seikkula et al., 2006)

The third research period (ODAP-II) was 2003–2005. This project was specifically planned to gather information on first-episode psychotic patients in the daily clinical setting in which OD was applied (Seikkula et al., 2011).

The three study periods included all first-episode psychosis patients between 16 and 50 years of age with non-affective psychosis within the catchment area (based on *Diagnostic and Statistical Manual of Mental Disorders* (APA, 2000) (DSM-III-R codes: 295.10–295.95 and 297.10–298.90) and on DSM-IV for the ODAP-2-period, codes 295.10–298.9).

The outcomes of OD in the treatment of psychosis have been reported in previous studies (Seikkula et al., 2011). The results indicate that when OD is applied there is a decrease in the overall need for psychiatric services, and in the incidence of residual psychotic symptoms (Aaltonen et al., 2011; Seikkula et al., 2011). Moreover, in a two-year follow-up, it was found that 84% of the patients had returned to full-time employment and studies, while only 33% had used neuroleptic medication (Seikkula et al., 2006). Despite these promising results, there is still a lack of information regarding the long-term stability of the treatment outcomes, and on how psychiatric services have been used in the OD system, considered over a longer period of time.

### *Aims of the study*

In this paper, we present the long-term treatment patterns related to first-episode psychosis in the health district of Western Lapland, Finland, i.e. an area in which efforts have been made to apply the principles of OD in all community psychiatric practices.

The first goal was twofold, in that we sought to evaluate (i) the application of the treatment principles in OD (concerning the emphasis on outpatient treatment, and network treatment meetings), and (ii) the selective use of neuroleptic medication in the population of subjects who had lived continuously in catchment area. The second goal was to analyze how different demographic and clinical characteristics might have affected hospital admissions and the total length of treatment under the OD system. The research questions were framed as follows:

(1) How were psychiatric services (hospital, outpatient and medical treatment) used by subjects who had lived continuously (from initial contact to the year 2015) in the OD catchment area, and did hospital admissions, hospital days, and outpatient clinic visits change over time?
(2) Were there differences in re-admission rates and in total durations of treatment between subjects with different baseline demographic and clinical characteristics?

## Methods

### *Study design*

The research data for this retrospective cohort study were gathered as a part of the *Open Dialogue longterm outcomes in naturalistic settings* (ODLONG) research project, conducted in Western Lapland with the cooperations of the University of Jyvaskyla and the University of Oulu. ODLONG was started in 2015. Its primary aim was to evaluate the long-term effectiveness of OD treatment, through quantitative data derived from the *OD research cohorts*. These cohorts included all the first-episode psychotic patients (total *N* = 116) who were treated within the catchment area in question, and who participated in the original research projects in the years 1992–1997 (*N* = 89) (Seikkula et al., 2006), and during the years 2002–2005 (*N* = 27) (Aaltonen et al., 2011; Seikkula et al., 2011).

### *Data collection*

Because the focus in the present paper was only on long-term treatment patterns within a specific catchment area, and because the place of treatment in Finland is linked to the place in which the patient is domiciled, for exclusion purposes the database of the *Finnish population register* were used to detect subjects from the cohort who had moved away from the catchment area (*N* = 40), or who had died (*N* = 11) in the period covered by the study (1992–2015) (total *N* = 51).

After we identified the subjects for the study (*N* = 65), all available data concerning their inpatient and outpatient treatment between the years 1992–2015 were gathered from case notes, and from other medical records. These were sourced from five local outpatient clinics, and from the medical records of Western Lapland Health district. The information included the following:

- date of first meeting (*initial contact*);
- baseline diagnosis (DSM-IV codes = 295.10–298.9, given six months from initial contact);
- GAF scores: rated by the hospital staff at the initial contact; the scores range from 100 (high functioning) to 1 (severely impaired);
- medications prescribed;
- hospital admissions;
- duration of hospitalizations (days);
- number of outpatient clinic visits; and
- form of outpatient treatment (network/individual meetings).

The observational period (see Figure 2) ranged from 10 years for ODAP2 (i.e. the most recent observational period) to 23 years for API.

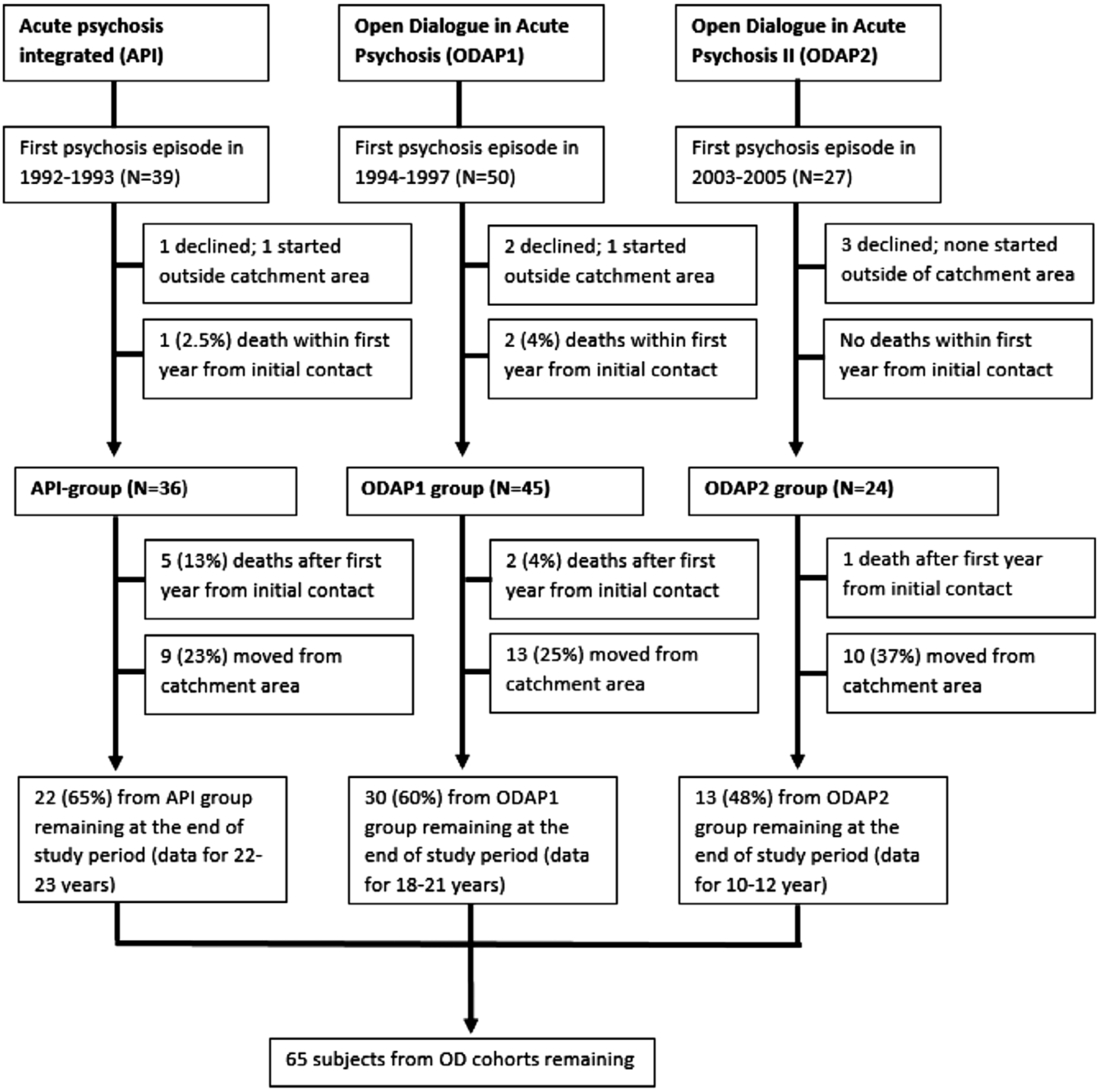


Figure 2. Flow of participants in the OD cohorts from inclusion to the end of the total study period (December 2015)

Note that because inpatient and outpatient case files comprised the only data source used in this study, the specific causes of death and other treatment outcome variables were not obtainable for this study. Hence, further analysis concerning the long-term effectiveness of OD will be implemented later as part of the ODLONG project.

*Analyses*

The group differences in baseline characteristics between subjects who lived continuously in the catchment area and those who had moved away were analyzed with the chi-square test. Information concerning the use of psychiatric services within the complete observational period (1992–2015) was analyzed via descriptive statistics; thus, we calculated the mean ($M$), median (MD), percentage (%) and standard deviation (SD) for hospital admissions, hospital days, medication, and outpatient clinic visits. Temporal changes in admissions, hospital days, and outpatient treatment were further analyzed by forming three sum variables covering the total amount of treatment received in three periods, i.e. (i) treatment in the first five years from initial contact, (ii) treatment in years 6–10, and (iii) treatment for the period following ten years from onset. Statistically significant differences between the sum variables were analyzed using the nonparametric Friedman test.

The total duration of neuroleptic use was calculated from medication lists. If the case note files indicated that the subject had stopped medication even though there was an ongoing prescription, the reported time spent without medication was subtracted from the total duration. Correspondingly, the total duration of treatment was evaluated by combining information from the case files. The treatment contact was determined to be *active* if the subject had one or more upcoming outpatient meetings agreed with the treatment staff, and/or if the subject was receiving hospital treatment. The treatment contact was considered to be *inactive* (i) if the treatment had ended on the basis of a joint agreement between the patient and treatment staff, or (ii) if the treatment has ended because the subject could not engage in treatment contact (=dropout), or (iii) if the treatment had settled on medication only.

Finally, the Mann–Whitney $U$-test was used to compare the group differences in hospital admissions ($N$) and the total duration of treatment (years) between subjects with different demographic and clinical characteristics at baseline. A comparison was made with respect to the following baseline variables:

- gender (*male vs. female*);
- age (<25 *vs.* ≥25);
- employment status (*working or studying vs. unemployed*);
- marital status (*single vs. other*);
- ability to function ($GAF \geq 30$ *vs.* $GAF < 30$);
- aggressive behavior (*yes vs. no; yes = one or more situations with physical aggression at onset reported in the case note files*);
- early hospital admission (*hospitalized within first month: yes vs. no*); and
- early medication (*neuroleptics within first month: yes vs. no*).

Because one subject gave rise to 30% of all hospitalizations ($N = 78$, years 1992−2015), the data for that person were excluded as forming an outlier from the statistical analysis concerning hospital admissions. The level of statistical significance was defined as a $p$ value equal to or less than .05. All the analyses were performed via the SPSS 22 statistical program.

*The sample*

In total, the present study included 22 subjects from the API group, 30 from the ODAP1 group, and 13 from the ODAP2 group (*N* = 65). Table 1 presents the background variables for the subjects included in the study, and for the subjects who had moved away from the health district of Western Lapland.

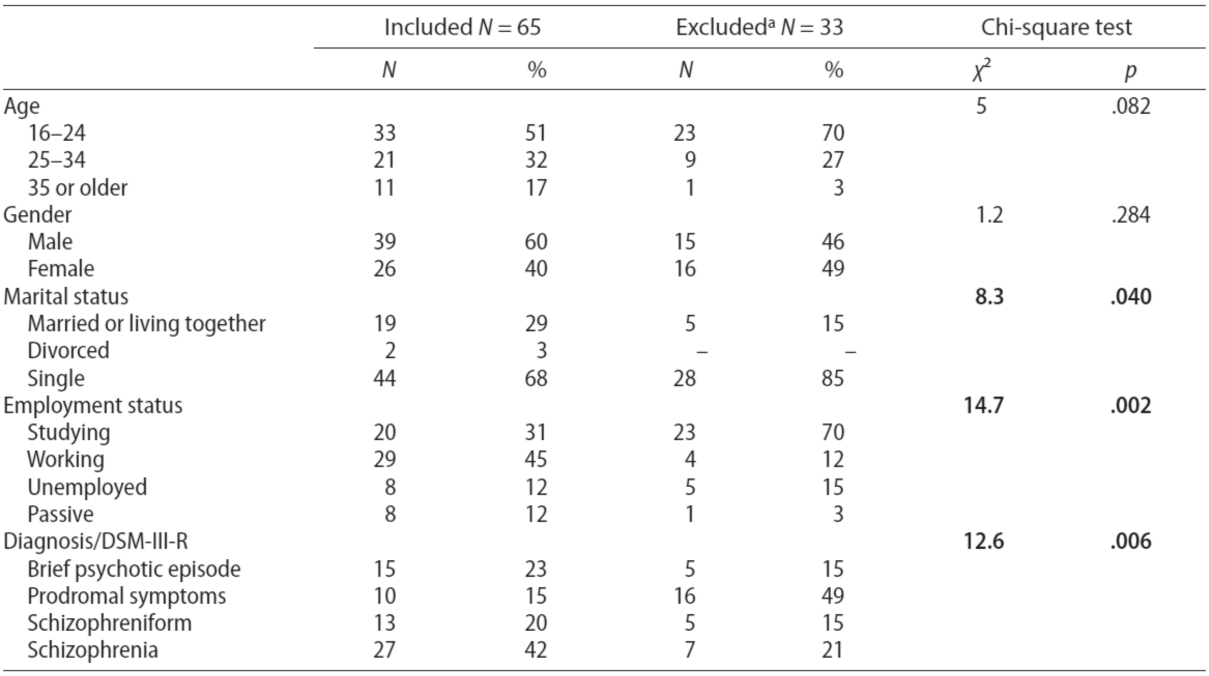
No significant differences were found in age and gender between the included and the excluded subjects. By contrast, statistically significant differences in marital and employment status and in the baseline diagnosis were observed between subjects who had moved, and those who were still living in the area of Western Lapland. It thus appeared that those who were single or studying at the baseline, and those who had been diagnosed with a milder form of psychosis, were more likely to have moved elsewhere during the study period.

## Results

*Hospital admissions*

The use of psychiatric services in the entire study period is summarized in Table 2. Twenty-three percent of the subjects were hospitalized within the first month from initial contact. The average number of hospital admissions from initial contact to the year 2015 was 2.6±1.8. The median time spent as an inpatient in the entire observational period was 12 days.

**Table 1.** Characteristics (at the initial contact) and statistical differences between the included and excluded subjects.



| | Included *N* = 65 | | Excluded[a] *N* = 33 | | Chi-square test | |
|---|---|---|---|---|---|---|
| | *N* | % | *N* | % | $\chi^2$ | *p* |
| Age | | | | | 5 | .082 |
| 16–24 | 33 | 51 | 23 | 70 | | |
| 25–34 | 21 | 32 | 9 | 27 | | |
| 35 or older | 11 | 17 | 1 | 3 | | |
| Gender | | | | | 1.2 | .284 |
| Male | 39 | 60 | 15 | 46 | | |
| Female | 26 | 40 | 16 | 49 | | |
| Marital status | | | | | **8.3** | **.040** |
| Married or living together | 19 | 29 | 5 | 15 | | |
| Divorced | 2 | 3 | – | – | | |
| Single | 44 | 68 | 28 | 85 | | |
| Employment status | | | | | **14.7** | **.002** |
| Studying | 20 | 31 | 23 | 70 | | |
| Working | 29 | 45 | 4 | 12 | | |
| Unemployed | 8 | 12 | 5 | 15 | | |
| Passive | 8 | 12 | 1 | 3 | | |
| Diagnosis/DSM-III-R | | | | | **12.6** | **.006** |
| Brief psychotic episode | 15 | 23 | 5 | 15 | | |
| Prodromal symptoms | 10 | 15 | 16 | 49 | | |
| Schizophreniform | 13 | 20 | 5 | 15 | | |
| Schizophrenia | 27 | 42 | 7 | 21 | | |

[a]Subject have moved from health district of western Lapland during study period.
Statistically significant differences in bold ($p < .05$).

Three subjects spent over one year in hospital (none of them continuously) in the total period (1992–2015), the longest time being 2.4 years. In all, 46% of the subjects had one or more readmissions, whereas in 29% of cases the treatment was carried out entirely in the outpatient setting, with no need for hospitalization. In addition, the results indicated that the majority of hospitalizations (61%) occurred within five years from the initial contact. Thereafter, both hospitalization rates and hospital days significantly decreased (Table 3).

### *Medical treatment*

Neuroleptic medication was started within one month from initial contact with 17 (26%) subjects. In all, 20 subjects (34%) were receiving neuroleptics in 2015. From initial contact to 2015, 55% ($N = 36$) of the subjects received neuroleptics at some point, with 12 (18%) subjects being treated with two or more neuroleptics simultaneously. The average length of neuroleptic use was 5±3 years. About 71% of those subjects who received neuroleptics at the start of initial contact were still on neuroleptic medication in the year 2015. Eleven (17%) subjects were treated only with anxiolytics, and 18 (28%) subjects were treated without any psychiatric medication at all.

### *Outpatient treatment*

The average number of outpatient clinic visits from initial contact to 2015 was 63±31. 75% of these occurred within the first five years from initial contact. Thereafter, outpatient treatment rates decreased significantly (Table 3). In all cases, there was at least one network treatment meeting within one month from initial contact. From initial contact up to 2015, the average number of outpatient meetings attended by family or network members, was 33±15, whereas the average number of meetings attended only by the patient and treatment staff was 30±22. In longer treatment processes, this ratio between network treatment meetings and meetings without the patient's close networks was reversed. Thus, after a period of two years from initial contact, the majority of the treatment meetings (70%) were conducted without any members of the patient's close network in attendance.

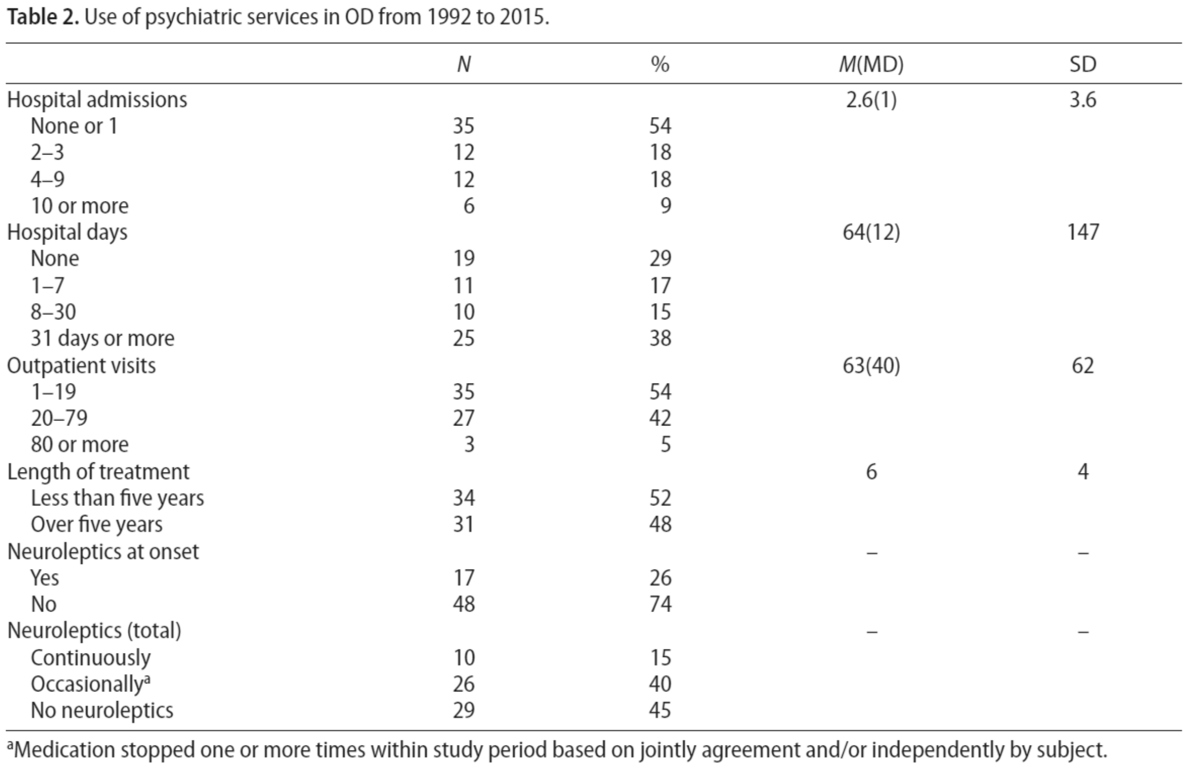


**Table 2.** Use of psychiatric services in OD from 1992 to 2015.

|  | *N* | % | *M*(MD) | SD |
|---|---|---|---|---|
| Hospital admissions |  |  | 2.6(1) | 3.6 |
| None or 1 | 35 | 54 |  |  |
| 2–3 | 12 | 18 |  |  |
| 4–9 | 12 | 18 |  |  |
| 10 or more | 6 | 9 |  |  |
| Hospital days |  |  | 64(12) | 147 |
| None | 19 | 29 |  |  |
| 1–7 | 11 | 17 |  |  |
| 8–30 | 10 | 15 |  |  |
| 31 days or more | 25 | 38 |  |  |
| Outpatient visits |  |  | 63(40) | 62 |
| 1–19 | 35 | 54 |  |  |
| 20–79 | 27 | 42 |  |  |
| 80 or more | 3 | 5 |  |  |
| Length of treatment |  |  | 6 | 4 |
| Less than five years | 34 | 52 |  |  |
| Over five years | 31 | 48 |  |  |
| Neuroleptics at onset |  |  | – | – |
| Yes | 17 | 26 |  |  |
| No | 48 | 74 |  |  |
| Neuroleptics (total) |  |  | – | – |
| Continuously | 10 | 15 |  |  |
| Occasionally[a] | 26 | 40 |  |  |
| No neuroleptics | 29 | 45 |  |  |

[a]Medication stopped one or more times within study period based on jointly agreement and/or independently by subject.

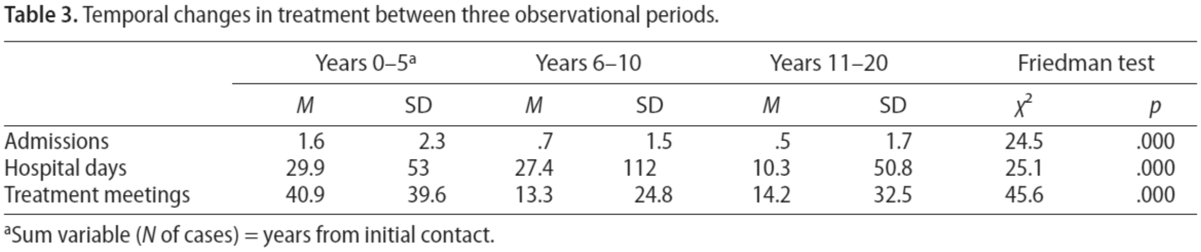


**Table 3.** Temporal changes in treatment between three observational periods.

|  | Years 0–5[a] |  | Years 6–10 |  | Years 11–20 |  | Friedman test |  |
|---|---|---|---|---|---|---|---|---|
|  | *M* | SD | *M* | SD | *M* | SD | $\chi^2$ | *p* |
| Admissions | 1.6 | 2.3 | .7 | 1.5 | .5 | 1.7 | 24.5 | .000 |
| Hospital days | 29.9 | 53 | 27.4 | 112 | 10.3 | 50.8 | 25.1 | .000 |
| Treatment meetings | 40.9 | 39.6 | 13.3 | 24.8 | 14.2 | 32.5 | 45.6 | .000 |

[a]Sum variable (*N* of cases) = years from initial contact.

### *Duration of treatment*

The average length of active treatment in the first instance (i.e. following initial contact) was 4±1 years. However, almost half of the subjects were redirected to treatment at some point after the initial treatment had ended; hence, the mean time spent as a patient in the entire study period was 6±2 years. In 2015, 12 (18%) subjects had received some form of psychiatric treatment (outpatient meetings and/ or hospital treatment). In 2015 the treatment was ended by joint agreement for 40 (61%) subjects, whereas 4 subjects had dropped out from treatment. For 5 subjects, the treatment had settled on medication only in 2015.

### *Group differences in hospital admissions and in durations of treatment*

No significant differences were found in admission rates and length of treatment between males and females, younger and older subjects, or working and unemployed subjects (Table 4). The average length of treatment was one year longer in the group rated as suffering more severe functional impairment (GAF < 30) at initial contact; nevertheless, the difference was not statistically significant. By contrast, subjects who were reported as presenting physical aggression at onset had significantly more hospital admissions ($U = 270$, $p < .005$). They also spent more years in active treatment contact ($U = 257$, $p < .005$) during the study period than non-aggressive subjects.

Here it should be noted that aggressive behavior might, at the same time, have challenged the application of the treatment principles at onset, consistent also with the fact that, according to our analysis, the readmission rates ($U = 157$, $p < .001$) and the time spent in treatment ($U = 280$, $p < .05$) were also higher when early hospitalization occurred. Furthermore, subjects who received neuroleptics at onset showed the highest hospital admission rates ($U = 114$, $p < .001$), and they also received psychiatric treatment for a significantly longer time ($U = 469$, $p < .001$) than subjects who were treated without medication, or whose neuroleptic medication was postponed.

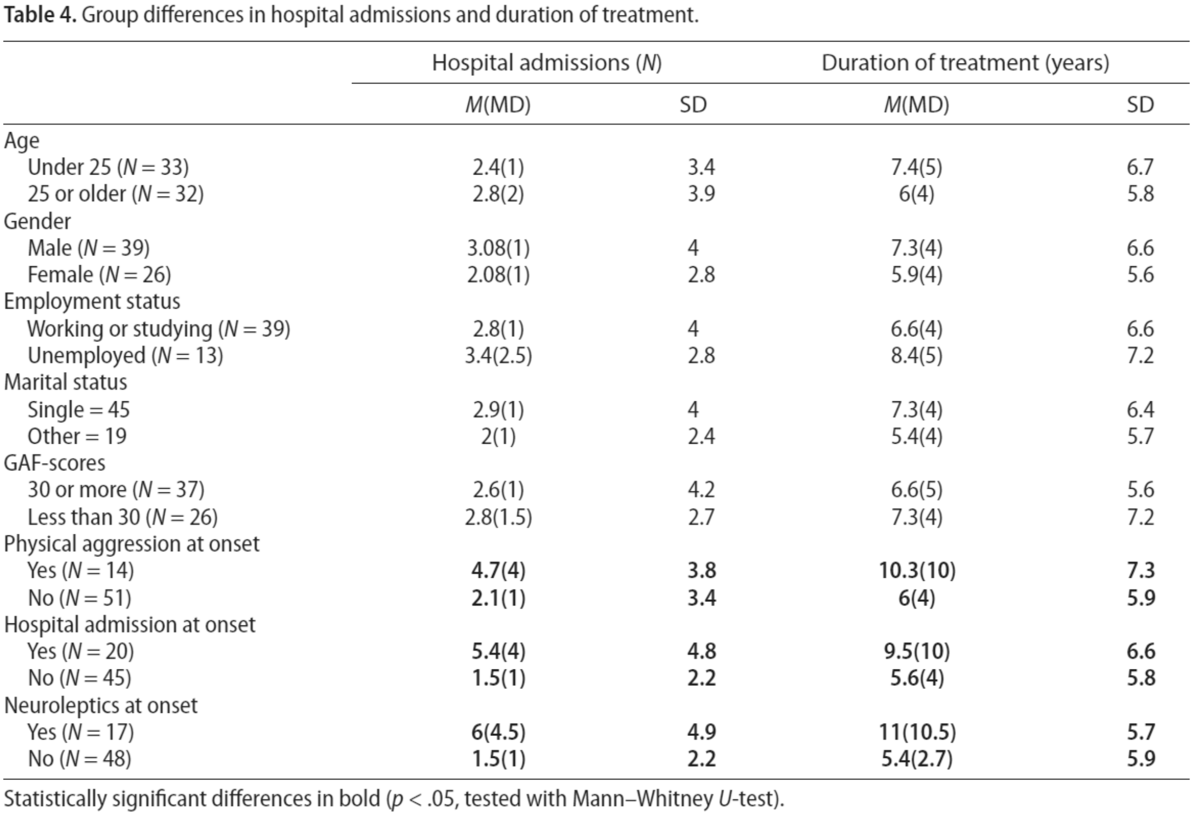


**Table 4.** Group differences in hospital admissions and duration of treatment.

| | Hospital admissions (*N*) | | Duration of treatment (years) | |
|---|---|---|---|---|
| | *M*(MD) | SD | *M*(MD) | SD |
| Age | | | | |
| Under 25 (*N* = 33) | 2.4(1) | 3.4 | 7.4(5) | 6.7 |
| 25 or older (*N* = 32) | 2.8(2) | 3.9 | 6(4) | 5.8 |
| Gender | | | | |
| Male (*N* = 39) | 3.08(1) | 4 | 7.3(4) | 6.6 |
| Female (*N* = 26) | 2.08(1) | 2.8 | 5.9(4) | 5.6 |
| Employment status | | | | |
| Working or studying (*N* = 39) | 2.8(1) | 4 | 6.6(4) | 6.6 |
| Unemployed (*N* = 13) | 3.4(2.5) | 2.8 | 8.4(5) | 7.2 |
| Marital status | | | | |
| Single = 45 | 2.9(1) | 4 | 7.3(4) | 6.4 |
| Other = 19 | 2(1) | 2.4 | 5.4(4) | 5.7 |
| GAF-scores | | | | |
| 30 or more (*N* = 37) | 2.6(1) | 4.2 | 6.6(5) | 5.6 |
| Less than 30 (*N* = 26) | 2.8(1.5) | 2.7 | 7.3(4) | 7.2 |
| Physical aggression at onset | | | | |
| Yes (*N* = 14) | **4.7(4)** | **3.8** | **10.3(10)** | **7.3** |
| No (*N* = 51) | **2.1(1)** | **3.4** | **6(4)** | **5.9** |
| Hospital admission at onset | | | | |
| Yes (*N* = 20) | **5.4(4)** | **4.8** | **9.5(10)** | **6.6** |
| No (*N* = 45) | **1.5(1)** | **2.2** | **5.6(4)** | **5.8** |
| Neuroleptics at onset | | | | |
| Yes (*N* = 17) | **6(4.5)** | **4.9** | **11(10.5)** | **5.7** |
| No (*N* = 48) | **1.5(1)** | **2.2** | **5.4(2.7)** | **5.9** |

Statistically significant differences in bold ($p < .05$, tested with Mann–Whitney *U*-test).

Discussion

*Summary of main findings*

The first aim of this study was to describe the long-term use of psychiatric services in the health district of Western Lapland, and to evaluate how the treatment principles of OD (involving the emphasis on outpatient treatment, network treatment meetings, and the selective use of neuroleptic medication) were applied. According to the results, the general practice was to apply outpatient treatment. The majority of the subjects were treated with only one hospital admission, or with no hospital treatment at all, and 95% had spent less than one year as an inpatient in the entire 10–23 year period. In addition, 74% of the subjects at the initial contact and 45% of the subjects at any point during study period did not receive neuroleptics which would indicate an observable tendency to avoid the automatic use of neuroleptic medication. Finally, the majority of the treatment meetings were conducted with the presence of subject's close networks at the initial contact, and overall the patients' close networks were integrated within the treatment processes at onset. In this regard, the results support the view that treatment in the Western Lapland health district has followed the OD and NAA principles of flexibility, involving an adaptive attitude towards the specific needs of patients and their families.

*The second aim* of this study was to evaluate how different demographic and clinical baseline characteristics affected hospital admission rates and the total duration of treatment under the OD system. According to results, compared to patients whose treatment was conducted in an outpatient setting and without neuroleptic medication at the onset, the patients who were hospitalized and/or treated with neuroleptics within one month from initial contact had more hospital admissions, and also received neuroleptics and other psychiatric treatment for a significantly longer period. However, this could be due more to the severity of the illness, or to other differences in the symptoms, rather than to the treatment per se. For example, the mean and median values in both hospital admission rates and durations of treatment were also higher with patients who presented aggressive behavior at onset. Thus, the results give some indications that there could be an association between aggressive behavior and a higher need for hospital and medical treatment. It should be noted that, at the same time, such a situation challenged the application of OD treatment principles regarding the postponement of hospital and neuroleptic treatment at onset.

Even though there could be difficulties in applying and maintaining the principles of OD when aggressive behavior occurs, the results also indicated that more conventional treatment methods, such as early admissions and/or neuroleptic medication, *do not significantly reduce the risk of re-admissions or prolonged treatment*. On the contrary, in the present study, the majority of the subjects who received neuroleptics at onset were still on neuroleptic medication in the year 2015; moreover, their re-admission rates were higher, and they received psychiatric treatment for longer, than subjects who were treated without neuroleptics, or whose medication was postponed. This finding is in line with another longitudinal comparison of a medicated versus a non-medicated sample; thus, Harrow et al. (2014) found that neuroleptic medications do not reduce the frequency of acute psychosis in schizophrenia, or diminish the severity of post-acute psychosis. However, given that this might be due to indeterminable and/or other unreachable variables, at present all that can be said is that continuous neuroleptic medication, or medication and hospital admission commenced early, does not uniformly reduce the risk of becoming a high-frequency user of psychiatric services.

There were also indications concerning the long-term stability of treatment outcomes reported in earlier studies (Seikkula et al., 2006, 2011). For example, decreasing patterns in both the re-hospitalization rates and outpatient clinic visits were observed, and in 2015 the majority of treatment contacts were ended by joint agreement, which could indicate a reduction in psychotic symptoms. However, this might also be associated with overall, age-related facilitation of psychotic symptoms, something that could in part occur independently of any given treatment. This issue could not be addressed directly in the present study due to the lack of a comparison group.

In parallel with the above, one can detect a decrease in network treatment meetings in comparison with individual outpatient visits over longer treatment processes. There are a number of possible explanations for this pattern, including (i) that in maintenance treatment, the role of the families may not have been thought to be as significant as in the acute phase, (ii) that social networks may not have been motivated to engage in longer treatment processes, (iii) that social networks may not have been as integrated with treatment at the initial contact, and this factor could be associated with more prolonged treatment processes. Overall, the considerations above emphasize the degree to which more information is still needed concerning the role of families in the therapeutic processes of first-episode psychosis.

### *Limitations*

Certain limitations in this study should be addressed. The first disadvantage, present also in earlier studies (e.g. Eaton et al., 1992), is that in naturalistic settings and cohort-based studies there is a lack of the standardization (in for example the diagnosis and other variables) that one would normally find in more experimental research settings; hence, the results obtained may not be entirely comparable with other studies. Furthermore, the comorbidity of the diagnoses, and the types and quantities of neuroleptics, were not taken into account. Secondly, even though case histories and other medical records obtained from various health care institutions could be considered a reliable source of information on typical treatment patterns in a specific area, there is a possibility that not all psychotic episodes may come to the attention of the treatment facilities in question. Thirdly, the small sample size, plus the attrition of data caused by subjects moving away from the area, affected the statistics presented in this study. However, since the information is missing mainly from participants who were diagnosed with a milder form of psychosis, or else who were in a prodromal phase at the start of treatment, one can speculate that the outcome of these participants might have been better overall, with less need of psychiatric services than those participants who are still in the health district of Western Lapland.

### Clinical implications

The results provide new information on how psychiatric services have been organized in a specific early-intervention system, and on how these services were used in the decades following first-episode psychosis. The study also gave some indications that the treatment of first-episode psychoses could, in many cases, be carried out mainly in an outpatient setting over a long period of time, without the need for immediate hospital admission or medication. This aspect would seem to differ from more traditional treatments, in which neuroleptic medication plus inpatient treatment is often applied immediately after psychotic symptomology had been detected.

In addition, the observable decrease in the overall need for psychiatric services seems to indicate the stability of long-term treatment outcomes reported in earlier studies, though the decrease might also be due to other treatment and/or patient related variables, and would merit further study. More comprehensive information is also needed concerning the overall and long-term effectiveness of OD in the treatment of more severe psychoses, and especially when physical aggression occurs; the results here indicate that the need for psychiatric services was higher, and the total length of treatment longer, with patients whose behavior was more threatening, and who were hospitalized and medicated at onset.

Overall, it can be said that at the most detailed level, the advantages of the treatment approaches described here were not clear-cut in every respect. However, there are indications of success in the main, overarching goal, i.e. to develop a comprehensive area culture for the treatment of all severe mental health disorders – one based, as much as possible, on a reciprocal Open Dialogue between patients, the persons in their closest network, and mental health workers.

## Disclosure statement

No potential conflict of interest was reported by the authors.

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## II

# THE FAMILY-ORIENTED OPEN DIALOGUE APPROACH IN THE TREATMENT OF FIRST-EPISODE PSYCHOSIS: NINETEEN-YEAR OUTCOMES

by

Tomi Bergström, Jaakko Seikkula, Birgitta Alakare, Pirjo Mäki, Jyri J. Taskila,
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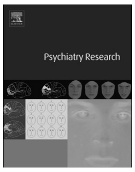

# The family-oriented open dialogue approach in the treatment of first-episode psychosis: Nineteen–year outcomes

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ABSTRACT

*Open Dialogue* (OD) is a family-oriented early intervention approach which has demonstrated good outcomes in the treatment of first-episode psychosis (FEP). Nevertheless, more evidence is needed. In this register-based cohort study the long-term outcomes of OD were evaluated through a comparison with a control group over a period of approximately 19 years. We examined the mortality, the need for psychiatric treatment, and the granting of disability allowances. Data were obtained from Finnish national registers regarding all OD patients whose treatment for FEP commenced within the time of the original interventions (total $N = 108$). The control group consisted of all Finnish FEP patients who had a follow-up of 19–20 years and who were guided to other Finnish specialized mental healthcare facilities ($N = 1763$). No difference between the samples was found regarding the annual incidence of FEP, the diagnosis, and suicide rates. Over the entire follow-up, the figures for durations of hospital treatment, disability allowances, and the need for neuroleptics remained significantly lower with OD group. Findings indicated that many positive outcomes of OD are sustained over a long time period. Due to the observational nature of the study, randomized trials are still needed to provide more information on effectiveness of approach.

## 1. Introduction

Schizophrenia and other psychoses represent a complex phenomenon, characterized by a wide variety of phenotypic expressions, courses, and outcomes. The heterogeneous nature of psychoses has challenged the development of optimal treatment strategies (Alanen, 2009). In response to this challenge, recent decades have witnessed more studies on preventive early intervention and integrative treatment practices (Bird et al., 2010). One example of such practices is the psychotherapeutically-oriented *needs-adapted approach* (NAA), developed in the context of the Finnish *Turku project* and *National Schizophrenia project* (Alanen et al., 1991). In these projects, the treatment of schizophrenia group psychoses was seen as a continuous process in which different treating methods are combined to meet the therapeutic needs of each individual patients as well as their social networks (Alanen, 2009).

NAA has since been applied and studied in several multi-center programs, including the national *Acute Psychosis Integrated Treatment* project (API), conducted in six Finnish psychiatric catchment areas in the early 1990s (Lehtinen et al., 2000). In one catchment area, consisting of the western parts of Finnish Lapland, the NAA was further modified. Constant on-the-job psychotherapy training was included within it; moreover, there were several research programs which had commenced before API (Keränen, 1992; Seikkula, 1991), and which continued locally thereafter, namely the *Open Dialogue in Acute Psychosis* (ODAP I and ODAP II) projects (see Seikkula et al., 2011). By the mid-1990s, a process of gradual development had led to a new way to organize the entire psychiatric treatment system within the area, based on seven principles (Fig. 1) (Aaltonen et al., 2011; Seikkula et al., 2011). The model is hereafter referred to as the *Open Dialogue* approach (OD).

The primary goal in the NAA and OD programs has been to create a comprehensive, psychotherapeutically- oriented model of treatment within the psychiatric public health sector, to address the real and

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**1. Immediate help**. The first meeting will be arranged within 24 hours of the first contact; the aim is to integrate outpatient treatment as soon as possible with the patient's everyday life, and to prevent hospitalization if possible. In addition to this, a 24-hour crisis service will be set up.

**2. A social network perspective.** Family members and other relevant members of the patient's social network will always be invited to the meeting, in order to mobilize support for the patient and the family. In addition to families, key members of the patient's social network can include other authorities, fellow workers, neighbors, or friends.

**3. Flexibility and mobility.** The aim is to adapt the therapeutic response to the specific needs of each person, using the therapeutic methods that best suit each situation. The first meeting will often be organized at the patient's home.

**4. Responsibility.** Whoever among the staff is first contacted will become responsible for organizing the first network treatment meeting, within which decisions will be made on the continuation of treatment and on the case-specific team responsible. The team will take charge of the entire treatment process.

**5. Psychological continuity.** The team will be responsible for treatment for as long as necessary, in both the outpatient and the inpatient setting.

**6. Tolerance of uncertainty.** In addressing psychotic crises, meetings will be arranged in as quick succession as possible, in order to generate an adequate sense of security for the joint process. It is imperative that decisions on treatment and premature conclusions should be avoided at the crisis phase; also that neuroleptic medication should not be introduced at the initial meeting, and should only be started if other efforts prove insufficient. In psychotic crises, efforts should be made to arrange meetings every day, at least for the first 10–12 days, in order to avoid premature conclusions and treatment decisions.

**7. Dialogue.** The focus in the treatment should be on promoting an equal dialogue between the patient, his/her close networks, and treatment staff. The aim within the dialogue is primarily for patients and families to increase their sense of agency in their own lives, and secondarily, to induce change in the patient or in the family. A shared understanding of the situation can thus be constructed between the participants within an open dialogue. All issues should be discussed openly, in the presence of all persons.

**Fig. 1.** The seven treatment principles of Open Dialogue approach (OD).

changing needs of (in particular) first-contact schizophrenia patients, plus their families (Aaltonen et al., 2011). In Western Lapland, attempts have also been made to apply the NAA and the principles of OD in all psychiatric treatment conducted in the region, regardless of the diagnosis. The primary aim has been to create low-threshold- and family-oriented treatment system which promotes the reciprocal open dialogues between patients, the persons in their closest networks, and mental health workers, seeking thus to ease the accessibility of mental health services and to create a shared understanding of each situation (Seikkula et al., 2006).

Outcome studies on both OD (Seikkula et al., 2006; Gordon et al., 2016) and NAA (Lehtinen et al., 2000) indicate that with low-threshold- and integrative family-oriented treatment of first-episode psychosis, the total recovery rates are often better than those with treatment-as-usual. For example, two- and five-year non-randomized follow-up studies conducted in Western Lapland showed that with OD there is a decrease in both the overall need for psychiatric treatment and the incidence of residual psychotic symptoms (Seikkula et al., 2011). In addition, after two years from onset, only 33% of the patients were using neuroleptics, and 84% had returned to full-time employment or studies (Seikkula et al., 2006).

However, in the absence of controlled trials, it remains unclear which aspects of the intervention are significant, given that OD integrates diverse elements that have been proven to be potentially beneficial in the treatment of psychosis (Pavlovic et al., 2016). These include, for example, early-stage family interventions (Marshall and Rathbone, 2011), with a shortened duration of untreated psychosis (Farooq et al., 2009), and increased therapeutic alliance (Laska et al., 2014). Improved treatment outcomes have also been observed in other early and comprehensive intervention systems (Cullberg et al., 2006; Kane et al., 2015; Granö et al., 2016). Nevertheless, regarding the *long-term outcomes* of early intervention practices in the treatment of psychoses, research has been limited, and contradictory results obtained. For example in the Danish *OPUS* trial (Secher et al., 2015), and in the *Lambeth Early Onset* study (Gafoor et al., 2010), the improved treatment and symptom outcomes were not found to be sustained at five years from onset.

In the present register-based cohort study, the aim was to evaluate the stability of OD outcomes in the treatment of first-episode non-affective psychosis (FEP), at an average of 19 years from onset. The more specific aims were: (i) to compare mortality rates and causes of deaths between the Western Lapland research cohort (Open Dialogue group (OD)) and a control group (CG), the latter being formed from patients whose treatment commenced in all other public sector psychiatric catchment areas; (ii) to compare the use of psychiatric services and disability allowances granted from the times of onset to the end of the follow-up; and (iii) to compare and evaluate OD and CG with regard to temporal changes in the need for hospital treatment and disability allowances over the entire follow-up period.

## 2. Methods and material

### 2.1. Design and context

The research data for this study were collected as part of the project called *Open Dialogue long-term outcomes in a naturalistic setting (ODLONG)*. The primary aim in the project was to evaluate the long-term outcomes of OD treatment with reference to Finnish national registers. Finland is a northern European country with a population of 5.5 million in 2017. The population has been considered to be both culturally and ethnically homogeneous (see Hovatta et al., 1997). During the 1990s roughly 90% of the population were Finnish-speaking Lutheran Finns. The figures were similar within the Western Lapland catchment area.

#### 2.1.1. The Finnish healthcare system

The healthcare system in Finland is publicly funded, and municipalities throughout the country are responsible for providing healthcare to all residents. Patients with severe mental health problems, including psychosis, are usually guided from primary care to a more specialized secondary healthcare system provided by 21 regional hospital districts. Hence, acute psychosis is usually treated in a hospital setting, with neuroleptics as the cornerstone of treatment in both acute and maintenance treatment (Kiviniemi, 2014).

Even though there have been attempts to integrate family therapeutic interventions with the Finnish public healthcare system, it appears that in the mid-1990s there were no other centers implementing an OD-like network-based treatment model, with 24-h low-threshold mobile crisis intervention teams, and guaranteed continuity of treatment between in- and outpatient clinics, covering the entire regional public healthcare system. Note also that the dialogical stance in treatment meetings has been viewed as a more collaborative way of working than that which would occur in most clinician-patient interactions (Razzaque and Stockmann, 2016). It should nevertheless be borne in mind that there could have been both resource- and culture-related differences in treatment practices between and within Finnish hospital districts (see Pirkola et al., 2009); hence, the control group in this study represents on merely a general level how treatment was initiated outside the Western Lapland catchment area.

### *2.1.2. Western Lapland catchment area*

The Western Lapland catchment area consists of the south western part of Finnish Lapland. The population of the area has fallen from 72,000 in 1995 to 63,000 in 2016, reflecting the national trend whereby education and job opportunities have been centered in the larger cities. The hospital district in the area consists of five municipal outpatient clinics and one psychiatric hospital (Keropudas hospital), which is in charge of all psychiatric inpatient treatment in area. At the time of the original implementation of OD in the 1990s, all mental health units in the area participated in the development of treatment by setting up case-specific mobile crisis intervention teams. In addition, 75% of the staff in the area participated in three-year on-the-job training in family therapy, or in psychodynamic individual psychotherapy.

Since then, the figure has fallen, due to generational shifts and changes in the Finnish psychotherapist training system. In addition, during the 2000s most of the outpatient clinics in the area were separated from the hospital district, operating now under the municipalities, which has decentralized the regional treatment system. Since these changes might have challenged the maintenance of a comprehensive treatment system over the whole region, this paper focuses only on the long-term outcomes of psychosis treatment that commenced under OD at the time of its original implementation.

### *2.2. Cohorts and data sources*

The *Western Lapland research cohorts* used in this study consisted of FEP patients who were guided to in- and outpatient specialized mental healthcare units operating in the Western Lapland healthcare district within two specific research inclusion periods. The projects in question were *API* (from January 1st, 1992 until March 31st, 1993), and *ODAP I* (from January 1st, 1994 until March 31st, 1997). In forming the *control group*, the aim was to include all Finnish non-affective FEP patients with a similar follow-up of 19–20 years, whose first psychiatric treatment commenced outside the OD catchment area (meaning that the FEP treatment commenced outside the area within which a family-oriented Open Dialogue approach has been systematically developed and extensively applied).

Because psychosis is a rare problem and the Western Lapland catchment area is small, movement of even a single patient between categories may affect statistical significance. In order to increase the statistical power and reliability of the analyses, the Western Lapland research cohort was supplemented by data from a third research inclusion period with a shorter follow-up (ODAP-II: from February 1st, 2003 until December 31st, 2005 ($N = 27$)).

The information was obtained from the following data sources:

1. The Finnish *Care Register of Health Care* (CRHC), and *the Register of Primary Health Care Visits* (RPHCV) provided by the *National Institute for Health and Welfare, Finland* (THL). The first of these (the formerly Finnish Hospital Discharge Register) consists of information on all hospital admissions since 1969, plus outpatient treatment conducted in Finnish specialized healthcare units since 1998. The second provides information on all treatment given in the primary healthcare system since 2011, including municipal mental healthcare units.
2. *The register of disability pensions and reimbursed medicines,* provided by the *Social Insurance Institution of Finland* (SII). This register contains information on all disability allowances (full or partial disability pensions, and cash rehabilitation benefits granted due to decreased work capacity caused by schizophrenia and/or other psychoses); it also states all purchases for reimbursed medicines (based on Anatomical Therapeutic Chemical (ATC) classification).
3. *The national cause-of-death register* provided by *Statistics Finland* (SF). This register contains information obtained from the death certificates issued by physicians, including the time and specific cause of death.
4. *Local medical records* (LMR). This information can be obtained from the specialized healthcare units of Western Lapland healthcare districts, and from the five municipal mental healthcare outpatient clinics operating in the area. They contain everyday clinical notes and case histories, including specific information on all treatment conducted in the Western Lapland catchment area, from baseline to 2015.

The study design was reviewed and approved by the ethical committee of the North Ostrobothnia hospital district. Further permissions were granted by Länsi-Pohja healthcare district (including five municipalities), Finnish National Institute for Health and Welfare, The Social Incurance Institution and Statistics Finland. All identification information was replaced with personal identification numbers, which were also used to link data across registers. Note that more comprehensive and detailed descriptions concerning the OD and the interventions applied to cohorts are presented elsewhere (Aaltonen et al., 2011; Seikkula et al., 2011).

### *2.3. Samples and inclusion criteria*

### *2.3.1. The experimental group (OD)*

The experimental group (OD) for this study was formed from research cohorts of the *Western Lapland catchment area*. The following inclusion criteria were applied:

(i) The first treatment contact in the area with non-affective psychosis diagnosis (ICD-9-codes = 295–295.9 and 297–298.9; ICD-10-codes = F20–29.1), occurred during the three inclusion periods (1992–1993, 1994–1997, 2003–2005), within which OD principles were reported has having been applied in the treatment, as part of the original intervention studies.
(ii) The individuals had not received any mental health treatment prior to the inclusion period in question.
(iii) The individuals were aged 16–50 at onset.

From the original research cohort of 116 people, three individuals were excluded from this study because they had received psychiatric treatment before the inclusion period; furthermore, the identification numbers for five individuals were unobtainable. Thus, the experimental group for this study was formed from a total of 108 people from the Western Lapland research cohorts. The observational period (onset to 2015) was from 10 to 12 years for people whose first onset occurred in 2003–2005 (20%), and from 18 to 23 years for people whose first onset occurred in 1992–1997 (80%). The average follow-up time was 19 years (MD = 20, SD = 4).

After identification of the persons to be included in the study, their residential history and mortality rates were obtained from the *Finnish Population Register Center* databases. The information concerning psychiatric treatment was obtained from LMR for people who had lived continuously in the area of Western Lapland ($N = 60$), and from CRHC and RPHCV for people who had moved away ($N = 37$), or who had died ($N = 11$) within the follow-up period (1992–2015). Information concerning disability allowances, medication purchases, and cause of death was obtained from SII and from cause-of-death-registers for the entire experimental group ($N = 108$).

#### 2.3.2. The control group (CG)

The control group (CG) for this study was formed from the registers mentioned above, on the basis of the following inclusion criteria:

(i) The first treatment contact in the Finnish public specialized healthcare system with non-affective psychosis diagnosis (ICD-9 codes = 295–295.9 and 297–298.9; ICD-10 codes = F20–29.1), occurred between January 1, 1995 and December 31, 1996.
(ii) The individuals had not received any psychiatric specialized healthcare and medical treatment or disability allowances for a mental health disorder prior to 1995.
(iii) The treatment was initiated and conducted *outside* the Western Lapland healthcare district area.
(iv) The individuals were aged 16–50 at onset.

There were 1763 people who had received treatment for first-episode psychosis in the period 1995–1996, and who fulfilled the other inclusion criteria. After identification of persons for the CG, information from the CRHC register was obtained concerning their demographic and diagnostic characteristics, and their use of psychiatric services, from the start of 1995 to the end of 2015. Information was obtainable on the outpatient treatment conducted in primary healthcare centers only from 2011 to the end of 2015 (RPHCV, see above). Information on disability allowances, medication purchases, and cause of death for the period 1995–2015 was obtained from the SII and cause-of-death registers.

### 2.4. Outcome variables

#### 2.4.1. Demographics

Gender, age at onset, and GAS *(Global Assessment Scale)* scores were obtained from CRHC for CG, and from LMR for OD. GAS scores were rated and registered at onset by a member of the treatment staff, following a standard procedure used in Finnish healthcare units. Diagnostic information was obtained from the CRHC, SII, and LMR registers. For comparative purposes, the diagnosis was determined to be schizophrenia (i.e. prolonged and more severe psychosis), if the individual was noted as having one or more entries with a schizophrenic psychosis (ICD-9 codes: 295–295.9; ICD-10 codes: F20–20.9) within the first year from onset. The diagnoses were set (as a standard procedure by physicians in their everyday clinical practice) on the basis of the ICD-9 criteria prior to the year 1996. Thereafter, the ICD-10 criteria were applied. In the API and ODAP I projects, the reliability of the diagnosis was further evaluated by an independent psychiatrist ($K = 0.453$, $p = .002$).

#### 2.4.2. Clinical characteristics

The clinical characteristics in the two samples, from onset to 2015, were analyzed by combining information from all the registers. The following outcome variables were formed:

1. *>30 hospital days* (According to the CRHC and LMR registers, the total time spent in hospital within the follow-up was over one month.)
2. *Re-admissions* (*yes* = two or more hospital admissions within the entire follow-up, according to the CRHC and LMR registers. The total number of hospital admissions that occurred within the follow-up period, and the length of each admission, were obtained from either the CRHC or the LMR register. New entries caused by hospital transfers were combined with the initial admission.
3. *Treatment contact at the end of follow-up* (*yes* = one or more outpatient visits in 2015 to a specialized or primary mental healthcare clinic, or one or more hospital days in 2015, according to the CRHC, RPHCV, and LMR registers).
4. *Neuroleptics at (a) onset, (b) at some point, (c) at the end of follow-up* (*yes* = one or more purchased neuroleptics according to SII, or neuroleptics used during hospital treatment, according to the CRHC and LMR registers (a) within the first month from onset, (b) at some point, (c) in 2015).
5. *Disability allowance at (a) some point, and (b) at the end of follow-up* (*yes* = according to SII, one or more days spent on a partial or full-time disability allowance granted due to decreased work capability caused by mental health problems, (a) at some point, (b) in 2015. From SII we obtained the start and end dates for each disability allowance (a full or partial disability pension, or a cash rehabilitation allowance) granted within the follow-up for mental health problems (meaning that according to the medical certificate the individual's work capacity was determined to be partially or fully decreased due a diagnosed mental health disorder). The total time spent on disability allowances within the observation period was calculated by summing the differences between the start and end date for each entry.

To evaluate the temporal changes in the use of psychiatric services and in disability allowances from onset to 2015, hospital admissions (*N*), hospital days, and the duration of the disability allowance (years) were each compressed to four sum variables matched with specific time frames (the first five years from onset, years 6–10, years 11–15, and after 15 years from onset).

### 2.5. Statistical analysis

The differences in mortality rates and causes of death between the groups were analyzed via Pearson's chi-square test, and by calculating the standardized mortality ratios (SMRs) for each group against the age and gender-specific risk ratios of death among the general Finnish population (obtained from the SF public register). The group differences in categorical variables between OD and CG were analyzed using cross-tabulation and Pearson's chi-square test. Temporal changes in hospital admissions, hospital days, and the duration of disability allowances were analyzed using the nonparametric Friedman test (the data were positively skewed). The Mann Whitney *U test* was then applied in order to analyze the differences between OD and CG. Prior to the analyses, outliers were detected using Tukey's method; hence, all values higher than $Q3 + 1.5(Q3 - Q1)$ (where Q3 = upper quartile, Q1 = lower quartile) were excluded from the statistical analyses (see Table 3). The level of statistical significance was defined as a *P* value equal to or less than 0.05.

## 3. Results

### 3.1. Demographic characteristics and group differences at onset

The annual crude incidence rate* of FEP which required specialized public healthcare treatment, and which met the other inclusion criteria averaged 17.9/100 000 persons for OD and 17.5/100 000 persons for CG. There were no significant differences in gender, diagnoses (schizophrenia vs. other psychoses), and GAS scores at onset (Table 1). In this regard, the two groups can be considered comparable with each other.

However, there were statistically significant differences in age, and in the way in which the patients were guided to treatment. Thus, the

**Table 1**
Demographic and clinical characteristics at onset.

| | OD[a] ($N = 108$) | CG[b] ($N = 1763$) | Statistics | $p$ |
|---|---|---|---|---|
| Age (years) | | | $U = 57,812$ | **0.00** |
| M | 25.3 | 30.5 | | |
| MD | 25 | 30 | | |
| SD | 7.1 | 8.8 | | |
| GAS scores | | | $U = 75,920$ | 0.75 |
| M | 35.09 | 35.04[c] | | |
| MD | 35 | 35 | | |
| SD | 11.5 | 12.1 | | |
| Gender | | | $\chi^2 = 0.001$ | 0.98 |
| Male | 57.4% | 57.6% | | |
| Diagnosis | | | $\chi^2 = 0.001$ | 0.92 |
| Schizophrenia | 52.8% | 53.3% | | |
| Start of treatment | | | $\chi^2 = 23.4$ | **0.00** |
| Involuntary[d] | 26% | 50% | | |

[a] Open Dialogue -group.
[b] Control group.
[c] Missing $N = 162$.
[d] Treatment commencing as involuntary was based on involuntary referral (by a doctor independent of the hospital).

patients in the CG were older and more likely to have undergone involuntary admission at onset than those in OD (see Table 1). Another issue was that basically all the patients in the CG were admitted to hospital at least once, whereas in the OD, 30% underwent all treatment in an outpatient setting. This possible selection bias was associated with the data sources: concerning outpatient treatment, there are no reliable national registers in Finland prior to the year 2011. This means that the CG data were obtainable only from FEP patients with one or more admissions, in which case overall symptom severity at onset might have been higher in CG than in OD.

It was recognized that these differences—as well as the variations in the length of follow-up – might cause statistical bias. To address these issues, additional analyses were conducted via demographically (samples matched randomly with age- and the length of follow-up) and clinically (only persons with a schizophrenia diagnosis, and one or more hospital admissions included) matched samples. The potential effect of confounding variables was further evaluated via logistic regression analysis.

Because the results from the additional analyses did not differ from the results obtained from the samples as a whole (see online data supplements), and because all of these aspects (i.e. a lower threshold, earlier detection of psychosis, and emphasis on outpatient treatment) might in part be a consequence of the early-intervention practice itself, in the following paragraphs the outcomes are reported with reference to the complete CG and complete OD samples.

**N* of new cases/year divided by the population of Western Lapland in 1992–2005 ($N = 72,000 - 65,000$) for OD and population of rest of Finland in 1995–1996 ($N = 5,044,826–5,060,320$) for CG.

### 3.2. Mortality

296 (16.8%) patients from CG, and 11 (10.2%) patients from OD died within the follow-up period. The difference in mortality was not statistically significant (Table 2), although when calculated against the Finnish standard population, the SMR was slightly higher in CG than in OD (3.4 vs. 2.9). In the entire sample (OD + CG), most of the deaths (55%) occurred within ten years from onset, with suicide emerging as the most common cause (31.4% of all deaths). In CG, accidents comprised the second most common cause of death (16.7%), followed by cardiovascular diseases (14%), and cancers (12%). In OD, cancer was the second most common cause of death (18% of all deaths). No significant difference was observed in the total suicide rates between the two groups (Table 2). In CG, more people died from natural causes (illness and/or another internal malfunction of the body) compared to OD, though when adjusted for age, the finding was not statistically significant (see online data supplements).

**Table 2**
Mortality.

| | OD[a] ($N = 108$) | CG[b] ($N = 1763$) | Statistics | |
|---|---|---|---|---|
| | % | % | $\chi^2$ | $P$ |
| Deaths (Total) | 10.2 | 16.8 | 3.24 | 0.07 |
| Suicides | 7.4 | 4.8 | 1.44 | 0.23 |
| Natural causes | 2.8 | 9.2 | 5.3 | **0.02** |

[a] Open Dialogue -group
[b] Control group

**Table 3**
Clinical characteristics from onset to the end of the follow-up.

| | ODtotal[a] ($N = 108$) (%) | ODhospital[b] ($N = 75$) (%) | CG[c] ($N = 1763$) (%) | Statistics[d] | |
|---|---|---|---|---|---|
| | | | | $\chi^2$ | $p$ |
| Treatment patterns | | | | | |
| >30 hospital days | 18.5 | 54.5 | 94.4 | 32.4 | 0.00 |
| *Re*-admission(s) | 45.4 | 63.6 | 90.5 | 201.4 | 0.00 |
| Treatment contact at the end of follow-up[e] | 27.8 | 35.3 | 49.2 | 5.1 | 0.02 |
| Neuroleptics | | | | | |
| At onset | 20.4 | 25 | 70.1 | 305.1 | 0.00 |
| At some point | 54.6 | 63.6 | 97.3 | 217.8 | 0.00 |
| At the end of follow-up[e] | 36.1 | 47.1 | 81.1 | 47.8 | 0.00 |
| Disability allowances | | | | | |
| At some point | 41.7 | 53.2 | 78.8 | 28.5 | 0.00 |
| At the end of follow-up[e] | 33 | 44.1 | 61 | 6.7 | 0.01 |

[a] Open Dialogue –group, includes all persons from the OD cohort.
[b] Includes only persons from the OD cohorts with one or more admissions.
[c] Control group.
[d] Comparison: OD(hospital) and CG.
[e] Only people still alive in 2015 included ($N = 1564$).

### 3.3. Clinical characteristics from onset to the end of the follow-up

Significantly more people from CG received neuroleptic medication at onset and spent over one month in a hospital over the entire follow-up (Table 3). Almost all the patients in the CG group (97.3%) received neuroleptics at some point in their treatment. By contrast, in the OD group, 46% were treated completely without neuroleptics, with 36% on medication at the end of the follow-up as compared to 81% in CG. At the end of follow-up, more patients from CG than from OD were still receiving psychiatric hospital or outpatient treatment, and also disability allowances due to mental health disorders. In addition, the CG group showed higher re-admission rates from baseline to the end of follow-up. Further statistical modeling indicated that initial administration of treatment *outside* the OD significantly predicted ongoing treatment (adjusted odds ratio ($OR$) = 2.2; 95% $CI$ = 1.3–3.7), neuroleptic medication ($OR$ = 7.1; 4.3–11.8), and disability allowances ($OR$ = 2.6; 1.6–4.3) at the end of follow-up. The results remained statistically significant when potential confounders were adjusted (see online data supplements).

### 3.4. Temporal changes in hospital treatment and disability allowances, from baseline to the end of follow-up

In both groups, there was a significant decrease in hospital

**Table 4**
Temporal changes in hospital treatment and disability allowances.

| Years from onset | 0–5 $N = 1775$[a]<br>*M*(SD) | 6–10 $N = 1703$[b]<br>*M*(SD) | 11–15 $N = 1622$[c]<br>*M*(SD) | 16–20 $N = 1544$[d]<br>*M*(SD) | Total $N = 1871$[e]<br>*M*(SD) |
|---|---|---|---|---|---|
| Hospital admissions (N)[f] | | | | | |
| Open Dialogue | 1.9(3.2) | 0.9(1.9) | 0.3(1.2) | 0.2(1.2) | 3.2(4.7) |
| Control | 3.8(3.1) | 1.9(2.9) | 1.1(2.4) | 0.8(1.9) | 7(6.5) |
| Hospital days[g] | | | | | |
| Open Dialogue | 27.4(49) | 36.9(123.2) | 11(64) | 6.1(40.9) | 63.1(131) |
| Control | 202.1(231) | 69.2(136) | 48(112) | 33.7(100) | 340.4 (359) |
| Disability allowance (years)[h] | | | | | |
| Open Dialogue | 0.5(1.2) | 0.8(1.7) | 1(1.5) | 1.4(2.4) | 3.4(5.5) |
| Control | 1.7(1.8) | 2.5(2.3) | 2.7(2.4) | 3(2.1) | 9.7(8.1) |

[a] Excludes persons dead within years 0–5 ($N = 96$).

[b] Excludes persons dead within years 0–10 ($N = 168$).

[c] Excludes persons dead within years 0–15 ($N = 229$), and from the OD group persons with first onset in 2002–2005 ($N = 20$).

[d] Excludes persons dead within years 0–20 ($N = 307$), and from the OD group persons with first onset in 2002–2005 ($N = 20$).

[e] Includes all persons.

[f] Excludes outliers = $N > 38$ (hence $N = 52$ from CG and $N = 1$ from OD are excluded).

[g] Excludes outliers = $N > 1800$ (hence $N = 64$ from CG are excluded).

[h] Average time spent on full or partial disability allowances granted due to decreased work capability caused by mental health problems; no outliers detected.

admission rates ($x^2 = 2341, p < .001$) and in hospital days ($x^2 = 2469, p < .001$) over the four time periods (Table 4). By contrast, in both groups there was a significant increase in the average duration of disability allowances ($x^2 = 760.6, p < .001$). The admission rates ($U = 44{,}140, p < .001$), time spent in hospital ($U = 24{,}538, p < .001$), and the durations of disability allowances ($U = 46{,}849, p < .001$) were significantly lower in OD than in CG for all the time periods.

## 4. Discussion

The aim of this cohort study was to evaluate the long-term outcomes of the family-oriented Open-Dialogue approach (OD) in the treatment of first-episode non-affective psychosis. This was done by comparing OD treatment's outcomes with first-episode psychosis treatment initiated outside the OD catchment area 19–20 years ago, with reference to mortality rates, and the need for psychiatric services and disability allowances. The results indicated that with treatment commenced under OD as compared to controls, the overall need for hospital and neuroleptic treatment, and also the time spent on disability allowances, was significantly lower in a follow-up of approximately nineteen years. These findings are in line with earlier studies on OD (Seikkula et al., 2006; 2011), and also with another register-based study with 5-year follow-up, which included all Finnish first-onset schizophrenia patients between 1995 and 2003 (Kiviniemi, 2014). In that study the Western Lapland catchment area presented the lowest figures for the durations of hospital treatment and disability pensions when compared to other Finnish healthcare districts.

As both groups showed a reduction in hospital treatment and an increase in the average time spent on disability allowances, it is important to note that within the OD cohorts, too, some people needed more psychiatric treatment than others. In a previous study it was observed that when more threatening behavior occurred, there could be difficulties in maintaining the dialogical approach and in applying the OD treatment principles favoring outpatient treatment and the selective use of neuroleptics (Bergström et al., 2017). The association between poorer outcomes and difficulties in organizing OD treatment has been reported previously (Seikkula et al., 2001). Note that since OD implementation took place in everyday clinical practice, it is possible that in some cases, difficulties in applying and maintaining the open dialogue occurred independently of patient-related factors.

Another issue concerns suicide rates, which were high in both groups. Overall, the results indicated that the suicide rate under the OD condition remained at a high level; in fact, it was the only variable in which no favorable change occurred when compared to controls. This was also observed in another Finnish study where the suicide rates of schizophrenia patients in Western Lapland whose treatment commenced in 1995 were above the median, while total mortality remained below the median (Kiviniemi, 2014). Then again, in one study it seemed that overall suicide rates in area remained below the median when compared to other parts of Finnish Lapland (Pirkola et al., 2009). Nevertheless, the figures underline the importance of developing treatment systems in such a way as to guarantee a safe environment.

Even though the treatment outcomes were not always clear-cut, there are some indications that long-term outcomes were more favorable with OD. Due to the observational nature of the study, it is not possible to directly evaluate the causal relations, or the specific elements in the OD treatment that might have brought about more favorable outcomes. Nevertheless, some possible factors deserve mention. In the first place, it is possible that the systematic provision of immediate help in psychotic crises, plus the guaranteed continuity of treatment between in- and outpatient settings, are beneficial in dealing with life-crises and other acute stress factors. The measures taken in OD could ease the difficulties that occur when there are breaks in treatment contact and in decision making, or when the treatment is restarted with staff who are unfamiliar with the patient's specific situation. The results here are in line with other studies, in which better treatment outcomes have been observed in integrative early-intervention systems for acute psychosis (Lehtinen et al., 2000; Cullberg et al., 2006; Granö et al., 2016).

Secondly, the OD principles concerning the tolerance of uncertainty, and of having open dialogues (see Fig. 1) between staff, patients, and their close networks, could tend to break down the traditional expertise hierarchy, within which mental health professionals are led to provide treatment in an objectifying manner. In this way, OD could hypothetically shift the entire treatment process onto a more equal footing, with an emphasis on the patient's own agency and subjective expertise regarding the situation. In some cases this could encompass possibilities to approach psychotic crises in an more empathic and respectful manner—which has been proposed as one of the common factors in all psychotherapeutic processes (Laska et al., 2014). In addition, the shift from a traditional one-way type of interaction to more open dialogues gives opportunities for the creation of a new kind of understanding between staff, patients, and their close networks concerning the current situation. This makes it possible to plan the treatment in such a way as to meet the case-specific needs of each patient, and may itself reduce psychotic symptoms by increasing mutual trust (Aaltonen et al., 2011), and by offering a shared language and meanings for difficult experiences within the patient's natural networks and environments (Holma and Aaltonen, 1998; France and Uhlin, 2006).

Thirdly, in recent decades, traditional views of psychosis as a symptom of underlying or progressive brain disease have been questioned (Cooke et al., 2014), with new evaluations of the role of psychosis in wider social contexts and in a variety of life crises (Beard et al., 2013; Lindgren et al., 2017; Mansueto and Faravelli, 2017). Viewed in this light, many psychotic states can be interpreted as reactions to difficult life situations and/or traumatic events rather than as symptoms of biological disorders (Holma and Aaltonen, 1998; Read et al., 2005). In line with this, some authors have proposed that in certain cases neuroleptic medication could block biological (Whitaker, 2004) and mental (Wunderink et al., 2013) functions that are essential for remission. In OD, the more selective use, and possible postponement of neuroleptic medication may give opportunities for the psychotic crises to progress along a more natural trajectory with an adequate sense of mutual trust and security, and this might have a favorable impact on the outcome. Our results are in line with other follow-ups, in which it was found that long-term treatment outcomes for the schizophrenia-spectrum population were more favorable with samples receiving less medication (Joukamaa et al., 2006; Wunderink et al., 2013; Harrow et al., 2014; Nykänen et al., 2016; Harrow et al., 2017). However, there are still lack of randomized trials on long-term use of neuroleptics.

Finally some limitations in the study should be addressed. First of all, the residual psychotic symptoms, the use of medication and the patients' current ability to function could not be directly evaluated, since the registers formed the only source of data. Moreover, both samples covered mainly non-affective psychoses, occurring among persons who were guided to the specialized healthcare system. On a more general level, the issues here apply to observational and naturalistic study designs as a whole. It is possible that selection bias could have existed, and/or that there could have been other unreachable variables affecting the course of psychosis, and the need for psychiatric services. Moreover, the lack of the kind of standardization (in for example the diagnosis) that one would find in more experimental settings has implications for comparability. It should be noted that even though register-based cohort studies can in some cases offer more generalizable information concerning real-world outcomes (Saturni et al., 2014), standardized and randomized trials are still needed to evaluate the causalities and effectiveness of a given practice.

In the present study, the fact that there were two groups coming from different regions of Finland, with possible regional differences could have impacted the findings. It can be argued that this was compensated by the long follow-up time, with minimal loss. On a general level the long follow-up of the same individuals reduce the probability that observed differences are consequence of cultural-, regional- or time-related factors. Furthermore the use of national registers made it possible to gather information even when individual had moved away from OD catchment area within the follow-up, which potentially have reduced the bias followed by the regional differences. It has also been noted that in Finland the variations in racial and socio-economic status are very small, and it is therefore unlikely that these factors will cause significant bias to this kind of a register studies (Kiviniemi, 2014).

Some of the limitations were compensated by the inclusivity of the samples. As implementation of OD covered the whole regional area and thus all people with first-onset psychosis, the aim was to include *all* non-affective FEP patients who were guided to treatment in Finland within a specific time frame in order to reduce the non-randomization bias. The results indicated that this goal was at least partly achieved: there were no significant differences between the samples regarding the annual incidence of FEP, or in demographic and clinical baseline characteristics including both the diagnoses and the social, occupational, and psychological functioning evaluated with GAS. Exception to this was age and the way in which patient were guided to treatment at onset, both of which might have been due to the earlier detection of FEP, as is typical in OD-like early-intervention systems where goal is to provide low-threshold and mobile treatment in order to ease the accessibility of health services and decrease the need of hospitalization. As these differences, and especially the over-representation of hospitalized patients in the CG might still cause statistical bias, additional analyses were conducted with matched samples and with stronger control of confounding variables.

Overall, the results gave some indications that by investing in long-term and gradual developmental efforts, in conjunction with integrative and psychotherapeutically-oriented interventions for first-episode psychoses, it is possible in some cases to achieve a long-lasting and stable reduction in hospital admissions and in medical treatment, in addition to better preserved work capability. Nevertheless, due the naturalistic study design, the specific ingredients that might have led to more favorable outcomes could not be determined with certainty. Furthermore, the present study does not indicate how far the treatment culture has been preserved in the area since the original interventions—the point here being that one cannot know how the research projects (conducted in the 1990s and early 2000s) themselves led to more favorable outcomes. It is possible that the research conducted in everyday clinical settings encouraged staff to observe their own work more closely, and there could have been benefits from greater treatment efforts, on-the-job psychotherapy training programs, and constant supervision activities. In the future, the aim would be to have better standardization of the different intervention and treatment variables, with more precise evaluations of outcomes.

## Funding

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## Declaration of interests

None.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.psychres.2018.09.039.

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# III

# HOW DO PEOPLE TALK DECADES LATER ABOUT THEIR CRISIS THAT WE CALL PSYCHOSIS? A QUALITATIVE STUDY OF THE PERSONAL MEANING-MAKING PROCESS

by

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*Psychosis, 11, 105-115.*

# How do people talk decades later about their crisis that we call psychosis? A qualitative study of the personal meaning-making process

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## Abstract

*Psychosis* refers to a severe mental state that often significantly affects the individual's life course. However, it remains unclear how people with the lived experiences themselves view these phenomena, as part of their life story. In order to evaluate this personal meaning-making process we conducted in-depth life-story interviews with 20 people who had been diagnosed with non-affective psychosis 10 to 23 years previously in one catchment area. 35% of them were still receiving mental health treatment, and 55% of them were diagnosed with schizophrenia. Only a minority named their experiences as psychosis. On the basis of narrative analysis, two types of stories appeared to encompass how mental health crises and/or related experiences were presented as part of the life story: (i) crisis as a disruptor of the normative course of life ($N$=9), and (ii) crisis as an expected reaction to life adversities ($N$=7). In the majority of the stories the mental health crisis was associated with cumulative life adversities in a central life area. Correspondingly, most of the factors that brought relief were narrated as inseparable from social and other real-life environments. We discuss the need for more person-centered and collaborative models of research and treatment.

Keywords: First-person account, Schizophrenia, Autobiography, Qualitative research, Open Dialogue, Long-term follow-up

## Introduction

The term *psychosis* is often used to categorize a wide range of mental states characterized by difficulties in distinguishing what is real from what is not. From the clinical and the scientific perspective, challenges derive from the multifaceted nature of the phenomena, and from the variety of conceptions that can be applied (Borchers, 2014). Thus, for many people the term is associated with significant suffering, whereas for others the hearing of voices, or other experiences categorized as belonging to psychosis, can be meaningful and valuable. As Louisa Putnam (2018, p.2) has noted: “many co-constructed spaces from which to see and respond to psychosis—culturally, relationally, psychologically, and neurologically—may be multiple facets of the same reality.”

The dominant clinical language can sometimes disregard people’s subjective experiences (Borchers, 2014), making it more difficult for clinicians to understand the phenomena they encounter, and to interact with people who have experienced them. Especially the service user/survivor-led research has overhaul the conceptual basis of psychiatry by underlying both the importance of collectively produced knowledge and the challenges relating to the singular conceptualisations (e.g. Rose, 2017). In recognition of this, there has been a growth in research on individuals’ experiences of psychosis (McCarthy-Jones et al., 2013; Boydell et al., 2010). Since humans make sense of their own experiences via stories (McAdams, 2001), one possibility to increase understanding of the matter is to research the life stories of people with the lived experiences.

In this study, in-depth life-story interviews were conducted with people who, about twenty years ago, had for the first time received mental health treatment for a severe mental crisis. The primary aim was to explore (i) how people themselves give meanings to experiences which, in the clinical context, are often interpreted as psychosis, and (ii) how these experiences are included in life stories.

## Methods

### *Theoretical approach*

We applied a phenomenologically-based methodology, with an emphasis on the subjective and interrelated nature of experiences. The design nevertheless differed from traditional phenomenological research, as we did not aim to arrive at the “core essences” of the experiences. In line with Georgaca’s (2014) presentation on research trends in qualitative studies of psychosis, our study can be viewed as a qualitative empirical study, within which narrative and dialogical approaches were also applied to interpret the material.

The narration was regarded as a psychological meaning-making process, capable of providing unity to human lives. By constantly reconstructing the past, present, and future, individuals can be viewed as maintaining their identities via life stories (McAdams, 2001). As experiences interpreted as psychosis have frequently been associated with a disruption in the sense of self, and thus with a loosened ability to maintain coherent inner dialogues (Lysaker & Lysaker, 2002; Roe & Davidson, 2005), narrative inquiry could provide a useful framework for research on these phenomenon. For example, Lysaker (2002) has argued that alteration of the dialogical structure of the self is the primary feature of psychosis, since it has dramatic consequences to ability to interact with others and act in the world. Moreover, research on narratives and psychosis have been consistent with the idea that people make sense of their problems via life stories, and they have shown the multifaceted ways on how people narrate and understand their experiences (Roe et al., 2008).

In socially oriented approaches it has been recognized that the culturally dominant stories, preferred usually by significant others, might marginalize the alternative stories that are providing other ways of understanding the experiences, eventually leading to the diminished sense of agency (Holma & Aaltonen, 1997). In line with this, many of the phenomena categorized as psychotic can be seen as a person’s attempts to make sense of difficult experiences that do not have a language to express them, other than, for example, hallucinations and delusions (Seikkula et al., 2001). According to this dialogical perspective, psychosis is emerging in relationships that do not guarantee adequate responses. Psychosis cannot thus be viewed as a categorical or pathological phenomena, but instead a understandable way to respond in extreme stress, similarly associated to embodied and relational mind as any other affective arousals (Seikkula, in press).

From a more social constructionist point of view the narratives about psychosis are always co-created within social systems (France & Uhlin, 2006). Even though we share this view and thus attempted to avoid conventional medical language with pre-determined assumptions concerning, for example, the aetiology of phenomena, in the present study more moderate epistemological position was adopted: it was recognized that there’s also world independent from of our knowledge and language, even if our knowledge from it remains incomplete and subjective.

### *Participants and recruitment*

The participants for in-depth interviews were recruited from the *Western Lapland* research cohort (N=108). This included all persons treated for first-episode psychosis in the area of Western Lapland healthcare districts, Finland, within three inclusion periods (Seikkula et al., 2011). At onset, all persons within the cohort were treatment-naïve, and were diagnosed with non-affective psychosis (ICD-10 codes: F20–F29). Individual follow-up extended from 10 to 23 years. All the persons in cohort were initially treated in accordance with the principles of the Open Dialogue approach (OD) (Seikkula et al., 2011), in which a primary goal is to collaboratively support the person and their social networks in the co-creation of a shared understanding for the difficult experiences they are undergoing. More detailed descriptions concerning the catchment area, research cohort, diagnostic procedures, and the treatment, are presented elsewhere (Bergström et al., 2018; Seikkula et al., 2011). The research plan was reviewed and approved by the North Ostrobothnia hospital districts ethical committee.

The invitation letters were sent to all candidates (N=77) who were still living in the Western Lapland area, or up to approximately 500 km from it. In addition to the letters sent out, the local healthcare staff in Western Lapland area were asked to recruit verbally persons from this group who were still receiving treatment (N=18). In the letter, people were invited to come and talk about their experiences of treatment, and to give more comprehensive descriptions of their lives, with a view to improving understanding how mental health issues should be approached. In order not to arouse negative emotions, the letter avoided the use of diagnostic terms, or other references to medical conditions, making only a general reference to an earlier need for mental health services. From the total of 77 invited people, 21 (27%) expressed their willingness to participate, 14 (18%) declined, and the remainder (55%) did not react. One person subsequently retracted participation.

All participants (N=20) completed informed consent forms, in which they gave permission to use information obtained via interviews, and to combine this with register information obtained from local medical records. Due to the sensitive nature of the topic, all the participants were given the opportunity to continue the discussions afterwards with experienced clinicians. One participant indicated that the interview aroused unpleasant memories, while the remaining interviewees viewed the interview as neutral or positive experience.

### *Interviews*

At the start of the interview, all participants were encouraged to relate their life stories as precisely as they could. To address the more specific aims of this study, all the participants were later asked to describe more comprehensively (i) their own personal characteristics, (ii) significant child- and adulthood life-events, (iii) views as to what (the term used by a participant) had led up to the treatment, (iv) what was it like for them, (v) how they survived, and (vi) how it affected their later life course. Even though the interviews focused on the participants' own experiences, and on what was relevant for them, a semistructured frame was used to ensure coverage of all the themes mentioned above. The interviews were transcribed verbatim. During the process all identification information was either changed or deleted. The average length of the interviews was 97 minutes (min=52, max=157). The total duration of the data amounted to 33 hours.

### *Analyses*

First of all, inductive thematic analysis (Braun & Clarke, 2006) was performed to detect repeated patterns across the dataset, and to distinguish the main themes and sub-themes within and between the stories. The validity of themes was tested by constantly matching them with the entire dataset. Further analyses were performed using thematic narrative analysis (Riessman, 2008). In this procedure the aim is to evaluate meaning structures through the reconstruction of stories into more condensed forms (Brinkmann & Kvale, 2015). The primary goal was to synthesize the data, and to identify core narrative elements. This was done by reading the transcripts multiple times, and by observing how previously coded themes- and sub-themes were associated with each other and with the stories as a whole. At the final phase, *story types* were arrived at by integrating the thematic contents of the stories, and by comparing the stories with each other. In all the analyses we attempted to maintain the phenomenological status of the participants' narratives by emphasizing their own experiences, and by avoiding excessive interpretations.

## **Results**

All the life stories included a phenomenon which, in the clinical context, was interpreted as either acute or prodromal psychosis. However, only 7 out of 20 participants actually used the term *psychosis*. Instead, they talked about a life crisis or a mental crisis. Other frequently used terms were *burnout*, *distress*, *mental health problem*, and *collapse*. All the participants indicated that their life-situation had eased since the time of their first contact with the mental health services. More specific demographic and clinical variables at the onset and at the time of the interview are presented in Table 1.

Table 1. Demographic and clinical characteristics at onset and at the time of the interview

| Participants (N=20) | |
|---|---|
| **Demographics** | |
| Age at baseline (MD/SD) | 25/9 |
| Age at the time of the interview (MD/SD) | 45/11 |
| Gender, male (%) | 60 |
| Marital status | |
| Single at baseline (%) | 60 |
| Single at the time of the interview (%) | 70 |
| Employment | |
| Unemployed at baseline (%) | 25 |
| Unemployed at the time of the interview (%) | 50 |
| **Clinical characteristics** | |
| GAS at baseline (MD/SD)* | 38/15 |
| Diagnosis at baseline** | |
| Schizophrenia (%) | 55 |
| Other non-affective psychosis (%) | 30 |
| Prodromal (%) | 15 |
| Neuroleptics | |
| At some point (%) | 65 |
| At the time of the interview (%) | 35 |
| Treatment contact at the time of the interview (%) | 35 |
| Disability allowances at the time of the interview (%)*** | 40 |

*Rated at onset by a member of the treatment staff
**Diagnosis was made as the part of the Open Dialogue- research projects (see Seikkula et al., 2011)
***Disability allowances granted due to decreased work capability caused by mental health problems

Based on the analyses, two types of stories emerged regarding how the crisis was included in the individual’s life story: (i) *crisis as a disruptor of the normal life course* (N=9), and (ii) *crisis as an expected reaction to life adversities* (N=7). Four stories lacked continuous plots; hence, these stories were not fitted into either of the story types, even if thematic similarities occurred (see online supplements). When asked directly, these participants indicated that they had difficulties in remembering events prior and after the crisis.

Note that the type stories in this study were used mainly to condense large amounts of data, and thus to act as an aid in reporting the data; hence, there were overlaps between the stories, and none of the themes were presented alone, or in an exclusive manner.

### *Crisis as a disruptor of the normal life course*

In these stories, the crisis was narrated as disrupting a plot that otherwise followed culturally normative or expected paths, including getting a job and starting a family. There were no singular traumatic events in childhood or before the onset, although many participants indicated that they were sensitive by nature, and that this had made them vulnerable to distressing emotions. The crisis was often viewed as a consequence of multiple distressing life events, cumulative setbacks, or of significant changes in central life areas, breaking into the desirable life course:

> *There were constant disappointments in our relationship and then that divorce thing happened. It affected my self-confidence, leading to other failures and disappointments. It was as if the house of cards that we had carefully built suddenly collapsed.*

Many participants said that prior to the crisis they had faced changes or other forms of distress in their relationships. These included also the death of a parent and other losses. In two stories the crisis was linked to childbirth (both participants having been diagnosed with postpartum psychosis). This was narrated as due to difficulties in adopting the mother’s role. Another frequent sub-theme included adversities faced within intimate relationships. In women’s stories in particular this was experienced as a threat, involving both physiological and psychological abuse:

> *Back then my husband’s nerves were constantly on edge and I and my children had to be afraid when he started yelling at us. I couldn’t say anything or express my own thoughts. It was like a continuous stalemate situation, where we couldn’t communicate. Finally I collapsed. I couldn’t sleep and I started to feel that everybody wanted something bad for me.*

More often than women, men presented the crisis as a reaction to work-related disappointments, associated with constant stress, in addition to the fear of losing both the source of livelihood and the social respect of others:

> *Prior my collapse, I worked so hard and I was sure that I'd get that promotion. However, they decided to hire another guy for that position, going right past me. It was horrible. I felt that they had mistreated me, and I started to think it was all just some kind of strange game.*

Life adversities were narrated as causing hopelessness and the fear that other people wanted to cause harm. Thus, beliefs interpretable as psychosis were often linked to actual life events, though in most of the stories, the attribution of someone's wish to harm was now regarded as an over-interpretation of circumstances, caused by distressing emotions. As a consequence the crisis was narrated as a thoroughly confusing experience, characterized by a loss of control combined with the anxiousness and agitation.

On the other hand, even though these experiences were generally described as a distressing reaction to a hopeless life-situation, some participants viewed the sudden burst of energy in a more positive manner, when the experiences that followed it were more difficult to tolerate:

> *In psychosis you really can't control your own actions and therefore you easily mess things up, but after that, I mean when you come back to this reality, it can be quite depressing. I started to sort of miss that psychosis: at least then I felt much lighter.*

As the mental health crisis was thematically linked to actual life events, it was narrated as easing simultaneously with changing life situations. Many participants also emphasized their own actions in the gradual process of surviving. Other factors that brought relief were also often found outside the actual mental health treatment, especially in relationships with significant others:

> *Of course some people might benefit from treatment, I mean medication and stuff like that, but for me the most important thing was my friends and my family. It's just that someone listens to you, is interested in you, and is present.*

Overall, in these stories, life continued after the crisis. Most of the participants were able to continue with their jobs and to maintain other important life aspects. However, most of them also expressed regret, in that there was no going back to the time before the crisis, and that things had not worked out in their lives as they had expected:

> *I imagined my life was going to be good, or at least normal, or something like that. You get a job, you have friends, but for me things didn't work out that way. Of course you still wish you could be a herd animal like others, but for some reason I always had those difficulties.*

In many stories there was observable conflict between one's personal experiences and the way things should have been, or the way they are presented in general cultural narratives. Many participants also felt that they had become more vulnerable to psychological distress, and this had made them more cautious, especially in stressful life situations.

### *Crisis as an expected reaction to life adversities*

The stories in this category were characterized by significant life adversities occurring from early childhood. In many stories these were associated with the social environment with a constant sense of divergence, and they were narrated as having had a significant impact on psychological wellbeing and on the participant's life course, years before any actual need for treatment. Given that such experiences had been recurrent from early childhood, the mental health crisis was presented as merely a peak representing dynamic processes of long duration. For example, some participants indicated that they had suffered from insecurity and a shattered sense of basic trust, related to their childhood environment:

> *My father was very impulsive and short-tempered. I remember that there was this constant fear, and it lasted throughout childhood up to adolescence.*

Another frequent theme was *difficulties with peers*, which included bullying and other negative phenomena within close relationships. Many participants mentioned that bullying had had a negative impact on their psychological wellbeing, and in some stories it was attributed as the primary cause of psychosis:

> *In elementary school I was bullied constantly. So much that I wanted to kill myself. I think my psychosis started then, though nobody realized it. I started to hear their voices and I often saw those figures in the forest near our house, but when I got closer there was no one there.*

The bullying was mainly psychological, such as name-calling and exclusion from groups. In women's stories bullying was viewed as having had a severe impact on self-esteem, whereas in the men's stories aggression and the need to defend one's own rights were emphasized:

> *I was bullied quite severely, and I think my mind somehow got stuck in the school premises. Eventually that led to a feeling that everything was a kind of a theater, and everybody was just faking and hiding some secrets from me. I developed those violent fantasies and I started to hear multiple voices, some were familiar and some were not. My mind was like a public toilet where all the townsfolk were shitting.*

The experiences interpreted as a psychosis were associated directly with the adversities that occurred in the current social environment, here operating in a somewhat similar manner to the previous stories. In some stories, the disappointments faced in the social world were narrated as negatively affecting self-esteem, making interaction with others even harder.

Some participants created meaning for their difficulties by viewing their personal characteristics as retarding their ability to gain independence, with the onset of the crisis narrated as a developmental crisis. Hence, there was no specific onset of crisis; instead, the entire shift from youth to adulthood was narrated as causing psychological suffering, due especially to uncertainty regarding one's own identity and the future:

> *I didn't know what I wanted to be or do, and I felt everybody else was making decisions for me. Those feelings and other difficulties were on a collision course, and I was driven to a stalemate situation, in which I didn't know what to do or how to react. Eventually that contradiction led to some kind of collapse of the mind.*

These stories were characterized by a distorted sense of reality, and some participants indicated that they were still not certain as to what was real and what was not. Many participants also indicated that during the acute phase of psychosis they had significant difficulties in interacting with others, since they were so deep in their own reality:

> *That psychosis was like you were sinking into some kind of a darkness where you couldn't find your way out. Like someone was pulling you down. I don't know what it really was.*

As described in the sample, such mental states were characterized by terror, though some participants viewed this as in some sense a relieving state of mind, warding off an even more horrifying reality:

> *Of course it's scary when you constantly see those characters flying around you and hear those voices. But on the other hand it was a constant fight with my parents about what was real and what was not, as they attempted to wake me up to the real world, even though the real world was precisely what I was afraid of.*

Overall, in these stories it seemed to be more difficult to get a grip of life after the crisis. In many stories the experiences were repeated and strengthened, especially under stress, or in major life transitions. For these participants such experiences – and mental health issues in general – seemed to form a more or less central element in their life story. Such an emphasis was understandable, given that the need for treatment and the time spent in mental health services in this group was higher, and that the age at onset was younger (see online data supplements).

As mental health issues were such a central part of these stories, it also seemed to be more challenging for the participant to evaluate how these had affected their life course. However, as compared to the previous stories, there were more attempts to view the consequences of the mental crisis in a relatively positive manner:

> *Maybe without it (the psychosis) I wouldn't have those friends that are so important for me, but on the other hand, there are those negative things; I don't have a job, no education and, well, the coin always has two sides, right?*

## Discussion

In this study people with lived experiences of severe mental crisis were actively given meanings to their experiences decades later of the initial need of treatment. In line with the earlier studies on narratives and psychosis, there was no single way of including these experiences within personal life stories, and further, basically, all the participants provided extensive narratives on how and why the crisis occurred, what it was like, and how it had affected their life course.

Despite the variety of narratives, many commonalities and recurring themes were found within and between the stories. For example, the majority of the stories were characterized by constant disappointments that had taken place in social environments, combined with sensitivity and low self-esteem. In some stories, the crisis was narrated as a combination of difficult emotions and over-interpretations, whereas in others it was characterized by the distortion of reality, and loosened self-control. People often seemed to make sense of such phenomena by linking them to a life-crisis, which formed an expected and inseparable reaction to actual life-events. Also the factors that brought relief were narrated as deriving from real life, outside the actual treatment.

Some themes seemed to be linked to participants demographic characteristics. For example, in the women's stories, integrity was often insulted, while men with later onset presented the crisis in terms of a sense of inadequacy at being unable to provide a livelihood for the family. Participants with earlier onset seemed to build their identities more specifically around their mental health crisis. Even though this might reflect symptom severity, and thus a higher need for treatment, it might also be consequence of the earlier onset itself. Thus, the crisis might have challenged the fulfillment of more traditional developmental paths, including education, getting a job and starting a family, with narrative identity then having to be built on a different foundation. Further studies would be needed how such contextual factors affect the ways in which different experiences, including mental health issues, manifest themselves at particular times and within particular cultures, and how the experiences are interpreted.

There were also thematic unities in frequent themes. These manifested similarities to findings obtained from earlier studies on personal narratives (Barker et al., 2001;Judge et al., 2008;Shepherd et al., 2012), and studies in which there was an emphasis on the role of adult and childhood traumatic experiences (Isvoranu et al., 2017;Beards et al., 2013; Bentall et al., 2012; Read et al., 2005; Sheperd et al., 2012), as well as personal sensitivity (Dudley et al., 2009). The enmeshed nature between the mental health crises and people's life experiences, and thus the need for more contextual perspectives, has been reported earlier (Gullslett et al., 2014). As in our study, Jones et al. (2016b) found that people with lived experiences of psychosis had sometimes challenges in defining the specific point of onset, presenting rather a continuity of themes and preoccupations from many years prior to the actual onset.

In addition, previous studies have emphasized the importance of moving away from distressing life events (Tan et al., 2014), and the role of significant others (Tan et al., 2014; Pitt et al., 2007) in the gradual processes of survival. Overall, it has been recognized that for persons with severe mental problems the crisis is not experienced as a single event or linear process (Gullslett et al., 2016).

Some differences from previous studies emerged. For example, in this study the experiences towards the initial treatment was presented more neutral manner than have been reported in some studies (Thornhill, 2004). The relative lack of the treatment-related narratives was somewhat unexpected, as the wish to get feed-back on network-oriented treatment approach was expressed in the invitation. This might be partly due to the treatment approach itself, as it might have shift the whole initial treatment process closer to “real-life”. Moreover, dialogical response to crisis might itself be beneficial (Seikkula, in press), enabling also the creation of shared understanding and helping people to maintain their sense of agency (Holma & Aaltonen, 1997). Although the maintained sense of agency might partly explain why many participants in this study emphasized their own actions in survival, this issue merits further study. More information would also be needed on whether or not different roles adopted in the clinical contexts could increase the risk of a self-fulfilling situation,

In addition, most of the stories in this study lacked the spiritual aspects of personal experiences presented in some earlier studies (e.g. Jones et al., 2016a). There are some possible explanations for this: in the first place, this could reflect factors related specifically to Finnish culture. It could also relate to the interview situation and the research setting as a whole, including potential selection bias. Nevertheless, the findings from different studies reflect the complexity of phenomena currently categorized under the term psychosis, underlining the importance of gaining more insight from people with lived experiences. This is especially important in the clinical context, as the participants indicated that they had had significant difficulties in expressing themselves during the initial crisis, with the major risk of their experiences being misunderstood by others.

Overall, in this study, people who had experienced a crisis diagnosable as psychosis commonly attempted to create meaning for their experiences by integrating the crisis with other life-course experiences; thus, they did not view it merely as a representation or symptom of a disorder. A similar gap between medical models and personal perspectives on the aetiology of psychosis has been reported previously, in studies on aging individuals with a schizophrenia diagnosis (Ogden, 2014; Bergman-Araten et al., 2016). This is despite the common assumption that if a mental illness is viewed as similar to any other medical condition – a perspective often associated with an insight into the illness – this can help the patient to understand the nature of the disease and thus improve adherence to medication (e.g. Lacro et al., 2002), with an eventual improvement in the outcome. However, it is notable that so far there have not been many studies including first-person accounts from persons who have *not* required mental health services or medication decades after the onset.

As one can presume that the stories might differ between persons who actively need and do not need treatment, in the present study the inclusion of both might have increased the validity of the findings. It should also be noted that, as compared to our earlier study (Bergström et al., 2018), the participant’s clinical and demographic characteristics seemed to be representative of the entire FEP population in the catchment area in question. However, the high loss indicates that there was an selection, and more direct recruitment of those still in treatment could have increased the representation of people with who had experienced more severe crises (see table 1).

There were also some other limitations. It is possible that the researchers’ own preconceptions could have affected the course of interviews, and also the aspects focused on in the analysis. Even though all the participants were given the opportunity to review the transcriptions and to continue discussions afterwards, none of them wanted to use this opportunity, and it was therefore not possible to systematically review the analyses with them. In future, such opportunities should be given greater emphasis in the initial research protocol, in order to increase the validity of the analyses and to encourage service users to participate in the research and development of clinical practices. Here one should consider the possibility that in a researcher-led study of this kind some essential aspects of personal experiences were downplayed or simply misunderstood. One should further bear in mind that there are always both situation- and person-related factors affecting participants’ decisions as to what they choose to bring up in interviews.

We attempted to compensate for some of these factors. Thus, we used a minimally structured interview protocol in order to reduce the possibility of leading questions, or other researcher-related factors. In the analysis itself, the focus was only on what the participants themselves narrated, and excessive interpretation was avoided. It should be noted that all the participants were initially treated by following the principles of need-adapted and open dialogue approaches which emphasized their personal experiences, and this might have affected how their experiences were narrated. For example, it might have diminished the effect of treatment-related external factors including the traditional clinical or psychoeducational language on developing narratives. Finally it is important to note that even though in interviews a semi-structured frame was used after the initial informal storytelling, causal relationships cannot readily be drawn from such data.

## Clinical implications

The use of a qualitative method makes it possible to increase understandings of how people themselves make sense of the psychosis phenomenon. This has potential in developing more person-centered treatment approaches that emphasize peoples' intentional and active role in meaning-making processes (see Corstens et al., 2014), with possibilities for more beneficial treatment. For example, there are indications that needs-adapted and network-oriented treatment approaches – in which it is possible to collaboratively create and maintain the personal meanings of experiences – are associated with promising long-term outcomes in the treatment of psychosis (Bergström et al., 2018). A user-led investigation (Jones et al. 2016b) has also noted the need for approaches which take into account the complex nature of psychosis and that will emphasize the service user's own agency and experiences, rather than merely focus on symptom reduction and on pre-determined functional goals.

Overall, it is possible that a wide range of complex phenomena, currently categorized under the term psychosis, cannot be comprehensively treated as clear-cut symptoms of a particular disease entity, without reference to the context, including the patient's social and other "real-life" environments. In addition, an increased awareness of the contextual and relative nature of experiences categorized as psychotic could offer more valid paths for research. In future, more robust studies are needed to obtain more generalizable knowledge on these issues.

Disclosure Statement

No potential conflict of interest was reported by the authors.

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