

Personal Recovery and Satisfaction Among Service Users with Psychosis



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Summary

The main theme in this thesis is the personal recovery of people with psychosis and their satisfaction with mental health services. More specifically, the following areas of investigation were examined: the perceived importance and support for personal recovery (paper I), the relationship between personal and clinical recovery (paper II) and the relationship between satisfaction with services and personal recovery (paper III).

In the first paper, we examined whether personal recovery was considered important for service users with psychosis, and their perceived support from clinicians for personal recovery. The overall aim of the first paper was to address the question of whether personal recovery is considered to be of importance for service users regardless of their level of symptoms and psychosocial function. We also wanted to find out how supported they felt and factors associated with that support. We investigated this by using The INSPIRE Measure of Staff Support of Personal Recovery (Williams et al., 2015) in a cross-sectional sample of 321 service users with psychosis. The results showed that the great majority of this large, heterogeneous sample of service users with psychosis across several clinical units reported that personal recovery was important to them and that there were no differences between service users who rated personal recovery as less important and those rating it as more important. The results also showed that higher self-reported depressive symptoms, lower GAF-S score, and male gender were significantly associated with lower levels of perceived support. Among health service characteristics, we found that having received Illness Management and Recovery (IMR) treatment, having gained knowledge about coping with stress and illness, and having a plan for early detection and prevention of relapse over the past six months were associated with higher perceived support. These findings indicate that recovery-oriented treatments are relevant for most service users with psychosis in various mental health services, and that participation in IMR-treatment, and related themes, such as help for coping with stress and illness and having a plan for early detection and prevention of relapse, were associated with people with psychosis feeling supported in their personal recovery process. The results also indicate that

specific attention should be given to service users with high general level of symptoms and self-reported depression because these service users felt less supported, even though personal recovery was considered equally important for them.

The second paper examined the relationship between personal recovery reported by service users and clinical recovery rated by both clinicians and service users. The relationships between different subdomains of clinical recovery and personal recovery were also assessed. The aim was to contribute to shed light on the relationship between these two forms of recovery and reveal areas of clinical importance. The investigation was through a cross-sectional sample of 318 mental health service users with a psychosis diagnosis and their clinicians from 39 sites across Norway, who completed standardized questionnaires of personal recovery, clinical symptoms and psychosocial functioning. The results showed that clinical recovery was positively associated with personal recovery, both when rated by service users and by clinicians, but more strongly when rated by service users. Among clinical recovery subdomains rated by the service users, we found that personal recovery was associated with lower levels of depression, self-harm and problems with relationships. Among subdomains rated by the clinicians, personal recovery was associated with less problems with relationships and higher aggressiveness. These findings suggest that affective symptoms are more strongly associated with personal recovery than are psychosis-specific symptoms such as hallucinations and delusions, suggesting the need for greater focus on treatment for depression among people with psychosis. However, problems with relationships appeared significant when reported by both clinicians and service users. This finding indicates that improving social connection is important for personal recovery, and that this might be an important treatment area for clinicians and service users.

The aim of the third paper was to investigate the relationship between satisfaction with services and personal recovery. This was examined by a linear mixed model assessing the relationship between satisfaction with mental health services among service users with psychosis in Norway and self-reported outcome measures on personal recovery, perceived support for personal

recovery and quality of life. Cross-sectional data from 292 service users diagnosed with psychosis, from 39 clinical sites across Norway, were analyzed, and satisfaction with services was assessed using the Client Satisfaction Questionnaire-8. The results showed that satisfaction with services was positively associated with perceived support for personal recovery, but not associated with the actual level of personal recovery or quality of life. In addition, we found that service users under a Community Treatment Order (CTO) were significantly less satisfied than those who were not under this order. The results indicate that those who felt supported in their personal recovery were more satisfied with the care they received. However, because satisfaction with services was not related to service user-rated quality of life or level of personal recovery, follow-up studies are needed. The lower satisfaction of service users placed under CTOs shows the importance of targeted interventions to improve satisfaction with services among this group.

Collectively, the studies in this thesis contribute to the literature on personal recovery by showing that personal recovery is important for many service users with psychosis regardless of their clinical level of symptoms and functioning. In addition, it shows that clinical and personal recovery are associated, but more strongly through affective symptoms and social connection than psychosis-specific symptoms. Finally, it shows that satisfaction with services is associated to perceived support for personal recovery.

List of papers

The current thesis is based on the following three papers:

I. Skar-Fröding, R., Clausen, H. K., Šaltytė Benth, J., Ruud, T., Slade, M., & Sverdviik Heiervang, K. (2021). The Importance of Personal Recovery and Perceived Recovery Support Among Service Users With Psychosis. *Psychiatric Services*, 72(6), 661–668.

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Abbreviations

Ahus	Akershus University Hospital
BASIS-24	Behavior and Symptom Identification Scale)
CGI	Clinical Global Impressions Scale
CHIME	Connectedness, hope, identity, meaning and purpose, and empowerment
CRPD	Convention on the rights of persons with disabilities
CSQ-8	Client Satisfaction Questionnaire
CTO	Community treatment order
GAF-S	Global Assessment of Functioning split version
GAF-F	Global Assessment of Functioning split version
HoNOS	Health of the Nation Outcome Scale
ICC	Intraclass correlation coefficients
IMR	Illness management and recovery
INSPIRE	INSPIRE measure of staff support of personal recovery
MANSA	Manchester Short Assessment of Quality of Life
NIMH	National Institute of Mental Health
PROMs	Patient-reported outcome measures
QoL	Quality of life
QPR	Questionnaire about the Process of Recovery
REK	Regional Committee for Medical and Health Research Ethics
SD	Standard deviation
WHO	World Health Organization

1. Background

The recovery concept arose from the civil rights movement in the 60s and through the voices of former psychiatric patients (Davidson, Rakfeldt, & Strauss, 2011). The concept has since sparked significant discussions about what recovery means, how it is experienced, how it can be measured, and how professionals and services can deliver Recovery-oriented support in practice (Frese III, Knight, & Saks, 2009; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Slade, 2012). A lot of the research had its focus on what personal recovery is and how it could and should be defined. This eventually led to some key questions with which the research became preoccupied. The first is whether the focus on personal recovery is relevant for all people with psychosis, regardless of the severity of clinical symptoms and functional level. This area inevitably overlaps with the second key question; whether and how personal recovery and the more traditional focus on clinical recovery (reducing symptoms and increasing function) are related. The aim of this thesis is to contribute to knowledge on these two key questions. The first paper in this thesis examined the question of whether personal recovery is considered important by a large and heterogeneous group of service users from several different clinical units and how much perceived support for personal recovery the service users experienced. The second paper examined whether personal and clinical recovery is related and, if so, which clinical subdomains specifically affect this relationship. The third paper examined the concept of satisfaction with services, exploring whether satisfaction with mental health services is related to personal recovery. This theme is related to the two key questions described above; it touches on the importance of patient-reported outcome measures in addition to clinical outcome measures when evaluating the quality of mental health services.

In the following sections of the Background chapter, key themes, including serious mental illness, recovery and satisfaction with services are, described from a theoretical and historical perspective. Furthermore, the key research findings and frontiers in the field that are relevant to the

research questions in this thesis are presented. Finally, some important concepts relevant to the thesis and its included papers are mentioned.

1.1 Serious Mental Illness and Psychosis

1.1.1 Serious Mental Illness

The term “serious mental illness” has been in use for several decades, especially in reference to schizophrenia and associated diagnoses (Spaulding, Silverstein, & Menditto, 2017). There is no clear Norwegian or international definition of the criteria required for serious mental illness (Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000). In the US, the National Institute of Mental Health (NIMH) has defined serious mental illness as “a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities”. In Norway, although there is no clear definition, it usually refers to diagnoses such as schizophrenia, bipolar disorder, severe depression and some personality disorders (Folkehelseinstituttet, 2009).

1.1.2 Psychosis

Psychosis is a clinical term that includes schizophrenia, delusional disorders, schizoaffective disorders, substance-induced psychosis and acute and transient psychosis (Store Norske Leksikon, 2021). In the ICD-10, the diagnosis of psychosis are described in the F20-29 (Schizophrenia, schizotypal and delusional disorders) section (World Health Organization, 1992). The symptoms of a psychosis are often a mixture of so-called positive symptoms, such as delusions and hallucinations, and negative symptoms, such as withdrawal, lack of motivation, and apathy. Hallucinations involve having a sensory experience without stimulation of the sensory organ. Hallucinations may be auditory (hearing voices no one else hears), olfactory (smelling things no one else can smell), gustatory (tasting things that others in the environment do not taste) or tactile (feeling movement or touch sensations on the skin). Auditory hallucinations are the most frequent hallucination in people with a psychotic disorder. A delusion is defined as a perception that does not correspond to reality and is not shared by others. To be considered a delusion, the perception must

represent a firm conviction that cannot be corrected by others. The most common delusion is that of being persecuted (persecution) (Store Norske Leksikon, 2021). Negative symptoms are characterized by symptoms including psychomotor slowing, underactivity, blunting of affect, passivity, poor self-care and social performance (World Health Organization, 1992). The lifetime prevalence for psychosis is assumed to be between 0.5-3% (Store Norske Leksikon, 2021). Psychosis may be continuous or episodic, and it is also highly variable in quality and severity across individuals and within individuals over time (Spaulding et al., 2017).

1.2 Recovery

1.2.1 What is Recovery

In the Oxford Dictionary (Stevenson, 2010) recovery is defined as “the process of becoming well again after an illness or injury” or “the process of improving or becoming stronger again”. In mental health research and clinical practice, recovery has evolved into a concept with diverse possibilities regarding understandings, knowledge and practices. The two main definitions of recovery are personal and clinical recovery (Slade, Amering, & Oades, 2008), also described as subjective vs objective recovery (Leonhardt et al., 2017), and recovery from illness (i.e., outcome) vs being in recovery (i.e., process) (Davidson & Roe, 2007). Clinical recovery is the definition traditionally used in mental health services with a focus on symptom reduction and increased functioning (Slade et al., 2008). For example, a widely used definition of clinical recovery is that it comprises full symptom remission, full- or part-time work or education, independent living without supervision by informal carers and having friends with whom activities can be shared, all sustained for a period of two years (Lieberman, Kopelowicz, Ventura, & Gutkind, 2002). The personal recovery concept has its roots in the user movement and differs from the clinical conceptualization. Personal recovery has often been described as a process that refers to changes in one’s attitude to life and the illness, with emphasis on hope and the establishment of a meaningful life (Anthony, 1993; Slade et al., 2008). More recently, a systematic review identified key themes of the personal recovery concept: connectedness, hope, identity, meaning and purpose, and empowerment, which

was provided the acronym CHIME (Leamy et al., 2011). Personal recovery has been widely used in literature to describe the patient-based definition of recovery (Slade, 2009), and is the intended definition when policies or services refer to having a recovery approach or being recovery-oriented (Slade, Oades, & Jarden, 2017). In this thesis, I use the term recovery as synonymous with personal recovery, unless specified otherwise.

1.2.2 Roots of The Personal Recovery Concept

The personal recovery concept has evolved from the 1960s as part of the civil rights movement in the USA. Recovery is a concept with diverse descriptions and definitions such as an approach, a model, an experience-based field of knowledge, a philosophy, a paradigm, a movement and a vision (Borg, 2017). The development of recovery ideology and practice has had its main focus within psychosis, and the research conducted has been primarily connected to serious mental illness (Slade et al., 2014). The recovery movement grew out of the activism of former psychiatric patients, who criticized the violation of human and civil rights of psychiatric patients. Eventually, the recovery movement spread throughout Australia, New Zealand, countries in Europe and the Scandinavian countries (Borg, 2017). The concept also evolved alongside a new optimism regarding recovery from schizophrenia, based on new data emerging from longitudinal studies such as the Vermont longitudinal study (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987) which showed remarkably higher recovery rates for people with schizophrenia than had been generally assumed at the time. It is considered that these two things, the new data and the voices from the user movements, contributed to the evolution of the recovery concept (Bellack, 2006). Since then, the recovery concept has had a considerable impact on mental health care policies in many English-speaking countries, including England, Australia, Ireland, New Zealand and the United States and German-speaking European countries such as the Netherlands and Germany (Slade et al., 2008). In the Nordic countries, there has been a growing emphasis on recovery, but the impact of mental health policies has been minimal compared with the above-mentioned countries (Schön & Rosenberg, 2013). At a more global level, the World Health Organization's (WHO) mental health

action plan for 2013-2020 (World Health Organization, 2013) has indicated that the central issues for mental health care is to expand the work with and understanding of recovery.

1.2.3 Recovery in Norway

In Norway, the recovery concept in research and practice has evolved over the last 25 years, a rather short period of time compared to the international recovery history (Borg, 2017). The Norwegian user organization Mental Helse was funded in 1978 and has since the start become a strong voice for people with mental health problems. After this, several other mental health peer support organizations (We shall overcome (WSO), Aurora, Hvite ørn), relatives and families organizations (Landsforeningen for Pårørende innen Psykisk helse, Voksne for Barn) and substance abuse peer support groups (Rusmisbrukernes interesseorganisasjon, A-larm) have occurred. The Norwegian Council for Mental Health (Rådet for psykisk helse) is also an umbrella organization (Borg, 2017). The political roots of the evolvement of recovery in Norway, has developed through different political documents, committees and decisions over the past 40 years such as *Opptrappingsplanen for psykisk helse* (plan for stepping up mental health) from the Ministry of Health and Care Services in 1998 and *Sammen om mestring* (together about coping) from The Norwegian Directorate of Health in 2014 (Borg, 2017). More recently, guidelines from the Ministry of Health and Care Services emphasized a more user-centered mental health service (Helse- og omsorgsdepartementet, 2017), and reforms of the Patient and User Rights Act have taken place to strengthen the patients' autonomy and consent (Helsedirektoratet, 2017b) and user-involvement in mental health care (Helsedirektoratet, 2017a). Some recovery-oriented treatments and practices are now being implemented in Norway, including illness management and recovery (IMR) (Egeland et al., 2017), recovery colleges (Sønstebø, 2019), individual placement and support (IPS) (Sveinsdottir et al., 2020), shared decision making (Kasper et al., 2017), and assertive community treatment (ACT) and flexible assertive community treatment (FACT) teams (Helsedirektoratet, 2015a).

In the Norwegian national guidelines for treatment for people with psychosis, personal recovery is mentioned in addition to the clinical form of recovery (remission). Although it is not

included as a specific treatment method it is mentioned under the *General principles for good practice* chapter and described as “an attitude that promotes hope and belief in opportunities for the individual to live a meaningful and fulfilling life, even with a serious mental illness” (Helsedirektoratet, 2013).

1.2.4 *The Difference Between Personal and Clinical Recovery*

The clinical recovery concept has emerged from professional-led research and clinical practice. The personal recovery concept has emerged from mental health service users and the survivor movement, and differs from clinical recovery. On a general level, clinical recovery can be seen as meaning recovery from mental health difficulties, and personal recovery as recovery with mental health difficulties (Slade, 2009). The main features that differentiate these two concepts (Slade et al., 2017) are presented in Table 1 below:

Table 1.

Clinical and Personal Recovery

Clinical recovery	Personal recovery
An outcome or state, generally dichotomous —a person is either “in recovery” or “not in recovery”	A process or continuum
Observable—in clinical language, it is objective, not subjective	Subjectively defined by the person themselves
Rated by the expert, not the patient	Rated by the person experiencing the mental health difficulties, who is considered the expert on his or her recovery
Definition of recovery does not vary between individuals	Recovery means different things to different people, although there are aspects that many people share

For mental health services, clinical recovery has traditionally been the primary goal in the treatment of people with psychosis. This involves medication and psychosocial interventions to increase functioning and reduce symptoms (Slade, 2009). However, support and focus on personal recovery has become an increasingly important aspect of mental health services in many countries (Schrank & Slade, 2007; Van Eck, Burger, Vellinga, Schirmbeck, & de Haan, 2018). A recovery-focused mental health system is oriented toward supporting people's life goals (Slade, 2012). It involves focusing on people's own personal decision-making about all aspects of their own recovery process, including the desired goals and outcomes, as well as the preferred services to reach those goals (Farkas, Gagne, Anthony, & Chamberlin, 2005).

1.2.5 The Relationship Between Personal and Clinical Recovery

A growing number of studies have explored whether and how clinical recovery and personal recovery are related, with inconsistent findings. Some studies have found no relationship between symptom severity and self-reported personal recovery (Macpherson et al., 2016). Other studies have shown that these two concepts are related, but most markedly by the impact of affective and anxiety symptoms (Jørgensen et al., 2015; Law, Shryane, Bentall, & Morrison, 2016). The most recent meta-analysis of the relationship between personal and clinical recovery showed an overall small-to-medium association between clinical and personal recovery, with psychotic symptoms showing a smaller correlation than affective symptoms with personal recovery (Van Eck et al., 2018). One of the important future areas in this field is to understand the complexity of these two concepts, such as whether some subdomains of personal and clinical recovery are associated with each other. This has been considered in Paper II in this thesis. In addition, research on the relationship between personal and clinical recovery has often reflected the dichotomized view of recovery, with clinicians rating clinical recovery aspects and service users reporting their personal recovery. In a study examining whether there were separate constructs of clinical recovery and personal recovery dimensions of the outcome, exploratory factor analysis identified three rather than the supposed two

factors: patient-rated personal recovery, patient-rated clinical recovery and staff-rated clinical recovery. The authors argue that although staff and patients may differ in their perceptions of the mental health illness, there is some overlap, and it is meaningful to consider the patient's own view of their illness and their stage of recovery. They suggest that it might be meaningful to assess both service user and staff perspectives on clinical recovery alongside service user-rated assessments of personal recovery in mental health research (Macpherson et al., 2016). Hence, in Paper II, we wanted to investigate whether and how self-reported clinical domains alongside clinician-rated clinical recovery were associated with personal recovery because this could reveal important aspects for personal recovery. We thought that examining the role of service user-rated clinical symptoms in relation to personal and clinical recovery could help shed light on the relationship between these two concepts and reveal new areas of clinical importance.

1.2.6 Are Clinical and Personal Recovery Compatible?

Despite some fundamental differences between the two recovery perspectives, there have been proposals that the two forms should be complementary rather than mutually exclusive (Roe, Mashiach-Eizenberg, & Lysaker, 2011; Van Eck et al., 2018), and they reflect somewhat different consequences of illness and criteria for disability and improvement. It has been argued that from the perspectives of scientists, clinicians, society and families, it would be untenable to ignore symptoms and functional disability. Conversely, the user movement has pointed out that other mechanisms, such as hopelessness, dependence, loss of control over one's life and sense of self, can be more painful than symptoms and impaired functioning (Bellack, 2006). Integrative approaches to defining and measuring recovery have been proposed, such as that by Lysaker, Yanos, and Roe (2009) who suggest that recovery can be understood in terms of externally observable objective outcomes and two distinct subjective outcomes (the subjective appraisal of one's life circumstances and opportunities and the subjective experience of oneself as an individual human being). This conceptualization could help the understanding of recovery as a complex process in which life events and the meaning-making of these events influence the experience of illness and wellness.

Others have argued that a primary focus on clinical recovery is incompatible with a primary focus on personal recovery because it can hinder personal recovery when it comes to promoting hope about the future and meaning-making of the illness, and because of its excessive focus on symptom reduction (Slade, 2009). The question of the compatibility between these two perspectives is intertwined with whether and how personal and clinical recovery are related, and is important because it will influence how mental health services should be organized.

1.2.7 Is Personal Recovery Applicable for Everyone?

A question that arises from the research on personal recovery is whether a personal recovery approach is applicable for all people with severe mental illness. Some studies have proposed that the fundamental difference between the two recovery concepts is that they apply to two different populations; the clinical recovery concept refers to symptom remission and restoration of functioning in people who have recovered from psychosis, and that the personal recovery concept only makes sense within the context of enduring disability, and refers to people who continue to have an illness (Davidson, Lawless, & Leary, 2005). Conversely, other studies have suggested that service users with more clinical symptoms and lower functioning levels prefer clinical recovery goals, such as reducing symptoms and confusion (Rosenheck et al., 2005), or that personal recovery is more of a self-realisation concept, in accordance with Maslow's pyramid (Henwood, Derejko, Couture, & Padgett, 2015; Maslow, 1943), where more basic needs must be met before self-realisation can occur (Clarke, Oades, & Crowe, 2012; Lofthus et al., 2018). More recent studies indicate that the concept has been broadened to include such diagnoses as depression and first-episode psychosis (Stuart, Tansey, & Quayle, 2017), and that people with psychosis can participate in working toward personal recovery regardless of their clinical and functional competence (Chan, Mak, Chio, & Tong, 2017). We considered that one important step in answering the question of whether personal recovery is applicable to everyone was to examine whether people at different stages and with different illness-related situations considered personal recovery to be important to them. Hence, one aim of this thesis was to clarify whether personal recovery was considered

relevant to a large heterogeneous group of service users with psychosis. This has been addressed in Paper I of the thesis.

1.2.8 Recovery-Oriented Mental Health Services and Practices

Although there are some key elements that constitute recovery-oriented practices, such as basing decisions less on professionally defined goals and more on listening to and acting on the service user's wishes (Slade & Hayward, 2007), there is a lack of clarity regarding best practice (Lakeman, 2010). A practice framework was developed to guide recovery practices, by systematically analyzing and synthesizing 30 recovery guidance documents from six countries. Four overarching levels of practice were identified: supporting personally defined recovery, working relationship, organizational commitment and promoting citizenship. These domains were considered equally important and can be seen as applying to different levels of practice. The first two involve the content and process of care and include terms such as individuality, informed choice, peer support, strengths focus, holistic approach and the importance of the therapeutic relationship. The third level is aimed at the organizational level, with the promotion of a service culture that gives primacy to recovery and focuses on and adapts to the needs of people rather than those of services. Terms such as recovery vision, workplace support structures, quality improvement, care pathway and workforce planning are included in this practice domain. The fourth domain is about services having a core aim of supporting people who live with mental illness to reintegrate into society and to live as equal citizens. Terms such as seeing beyond "service user," service user rights, social inclusion and meaningful occupation are included in this practice domain (Le Boutillier et al., 2011). Others have differentiated between two types of strategies for recovery-oriented mental health services; a comprehensive change of the entire organization based on recovery understanding (paradigm shift) versus recovery models that are used together with various other treatment and rehabilitation options, where a paradigm shift or a fundamental reorganization is not necessarily an issue (NAPHA, 2013). Although there is still no consensus about recovery and its implications for the policy and practice of mental health services, there is a significant growing

evidence base for recovery-oriented approaches. A review identified 10 evidence-based recovery-oriented practices that support recovery by targeting key recovery processes as described by the CHIME framework. These were: peer support workers, advance directives, wellness recovery action planning, illness management and recovery, REFOCUS program, strengths model, recovery colleges or recovery education programs, individual placement and support, supported housing, and mental health dialogues (Slade et al., 2014).

1.2.9 Illness Management and Recovery (IMR)

Illness Management and Recovery (IMR) is a standardized psychosocial intervention based on the stress-vulnerability model. The aim of IMR is to help people with serious mental illness better manage their illness and achieve personally meaningful goals (Mueser et al., 2006). IMR was developed during the National Implementing Evidence-Based Practices (NIEBP) project in the USA, a program aimed at incorporating empirically supported illness self-management strategies into a single program (Bond, Drake, McHugo, Rapp, & Whitley, 2009).

The IMR programme is based on five strategies: psychoeducation to improve knowledge of mental illness, relapse prevention to reduce relapses and rehospitalisation, behavioural training to improve medication adherence, coping skills training to reduce the severity and distress of persistent symptoms, and social training to strengthen social support. (Egeland et al., 2017). IMR is organized into 11 modules, covering the following topics: recovery, practical facts about mental illness, the stress-vulnerability model, building social support, using medication effectively, drugs and alcohol, reducing relapses, coping with stress, coping with persistent symptoms, getting your needs met in the mental health system, and living a healthy lifestyle. IMR can be delivered in a group or an individual format over approximately six months to one year (McGuire et al., 2014). IMR is considered to be one of the recovery-oriented treatments with the strongest evidence-base (Slade et al., 2014)

1.2.10 A Human Rights Based Definition of Recovery

The recovery movement has been described by some as being first and foremost a civil rights movement, and only second a movement that has implications for mental health systems practice and policy (Davidson et al., 2011). The shift in mental health services from a paternalistic to a patient-centered approach has evolved with the increased focus on human rights for people with psychiatric disabilities. One important hallmark for this increased attention came with the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2007. A human rights-based approach to recovery expands the concept to examine society as a whole, rather than limiting it to particular individuals within society (Forrest, 2014). This means expanding the scope from looking at what happens in the consulting room to consider how organizations work and how views of people are taken into consideration in health and social care policy and wider society (Gask & Coventry, 2012). Studies have shown that people with comparable severity of psychopathology may differ in their real-life functioning because of differences in personal resources (Ritsner et al., 2003). In this way, recovery can be seen as resuming one's position and opportunity conditions as a citizen, not as a "mentally ill" person or "addict" (Borg, 2017). In Norway, the CRPD was ratified in 2013. However, in 2015, the Equality and Anti-Discrimination Ombud in Norway criticized the Norwegian politics and legislation for not being in accordance with the CRPD, with human rights for people with disabilities in Norway often and systematically violated (Likestillings og diskrimineringsombudet, 2015).

1.2.11 Critics of Recovery

The personal recovery concept in serious mental illness took on its modern form in the 1980s as a part of the user movement that reacted to reductionist medical models that had come to dominate mental health services (Deegan, 1988; Treichler et al., 2019). However, critics of the recovery movement have claimed that it is embedded within the sociocultural values of neoliberalism (Braslow, 2013), because it places responsibility for recovery to a large extent on the individual and de-emphasizes structural social injustice causes of, and collective responses to, distress (Harper & Speed, 2014). Some service users have expressed fears that the individual-

empowerment aspect of recovery might provide health service providers with an excuse to make cuts in support (Roberts & Boardman, 2013; Stuart, Tansey, & Quayle, 2017). This critique has made representatives of recovery-oriented practices react and argue that recovery-oriented practices is not a valid justification for service cuts (Slade et al., 2014). Other organizations, such as Recovery in the Bin, claim that the basic principles of recovery, such as autonomy and self-determination, have been colonized by mental health services and politics that in fact undermine them, and that the principle of recovery can never be assembled into in a “one-size-fits-all” method or measure (Recovery in the Bin, n.d.).

1.3 Satisfaction

1.3.1 The Satisfaction Concept

Patient satisfaction with mental health care (also termed treatment satisfaction, service satisfaction or consumer satisfaction), has been used as a quality indicator and process variable in mental health care since the 1960s. There is no consensus on exactly how patient satisfaction should be measured and numerous scales have been developed to measure patient satisfaction with mental health care (S. Priebe & Miglietta, 2019). A recent systematic review showed that scales vary significantly in their structure, length, focus and quality (Miglietta, Belessiotis-Richards, Ruggeri, & Priebe, 2018), but identified four scales that have been used in more than 15 studies and may therefore be regarded as more established. These were the Client Satisfaction Questionnaire (CSQ-8) (Attkisson & Greenfield, 1996), the Self-Rating Patient Satisfaction Questionnaire (SPRI) - inpatient version (Hansson & Höglund, 1995), The Verona Service Satisfaction Scale – European Version (VSSS-EU) (Ruggeri, Lasalvia, et al., 2000), and the Client Assessment of Treatment (CAT) (Priebe & Gruyters, 1995). Using patient satisfaction is important because patients have a unique perspective on health services, without which, service evaluation would be biased toward a clinician or provider view (Smith et al., 2014). Evidence has emerged showing that patient-rated satisfaction is a more reliable indicator of service quality than other measures, and even more sensitive to differences in quality of care between different services and different parts of services

than clinician ratings (Shipley, Hilborn, Hansell, Tyrer, & Tyrer, 2000). Satisfaction is seen as an important outcome variable because various studies have shown that more satisfied patients are more adherent to treatment and benefit more from care than less satisfied patients (S. Priebe & Miglietta, 2019).

1.3.2 Satisfaction Among Service Users with Psychosis

Although satisfaction with mental health services has been increasingly used as an important quality indicator since the 1960s (S. Priebe & Miglietta, 2019), satisfaction with mental health services among service users with psychosis has for a long time been disregarded due to a belief that these patients lacked the insight and ability to evaluate mental health services (Ruggeri et al., 2003). Nowadays, satisfaction with services is regarded as an important quality indicator among service users with psychosis (Reininghaus & Priebe, 2012). Research has shown that higher satisfaction rates among service users with psychosis are associated with clinical outcome benefits, such as reduction in positive psychotic symptoms at follow-up (Vermeulen, Schirmbeck, van Tricht, de Haan, & investigators, 2018), and that lower satisfaction rates have been associated with more involuntary admissions, more severe psychopathology and more unmet needs (Ruggeri et al., 2003).

When it comes to the general mental health population, satisfaction with services has been consistently associated with self-reported outcomes, such as quality of life (S. Priebe & Miglietta, 2019). However, the relationship between satisfaction and self-reported outcome measures among service users with psychosis is inconclusive and underexplored. One study has found a significant association between dissatisfaction with care and lower self-reported quality of life (Ruggeri et al., 2003), whereas another showed positive associations between satisfaction and quality of life at baseline but not at follow-up (Vermeulen et al., 2018). Another study, on treatment satisfaction among people with schizophrenia, found that treatment satisfaction was high even though life satisfaction was low (Koivumaa-Honkanen, Honkanen, Antikainen, Hintikka, & Viinamäki, 1999). When summing up the literature, it seems apparent that although the objective clinical benefits of

high service satisfaction among service users with psychosis seem robust, studies show varying associations between satisfaction with services and other self-reported outcomes, such as quality of life and life satisfaction. Furthermore, no studies have investigated the relationship between satisfaction with services and self-reported personal recovery, although some have investigated satisfaction with recovery-related topics, such as shared decision-making (Aimola et al., 2019) and empowerment (Barrett et al., 2010). The study by Barrett et al. (2010) showed a strong positive relationship between recovery orientation of treatment and satisfaction with services, which was mediated through empowerment, an important component of recovery. Aimola et al. (2019) found that more patient involvement in decisions about care and having a care plan that was developed in collaboration with the service user was associated with higher patient satisfaction with care. The relationship between satisfaction with services and self-reported outcome measures was the main aim of the third paper in this thesis, which examines the relationship between service user satisfaction and perceived support for personal recovery, personal recovery and quality of life.

1.4 Important Concepts

1.4.1 PROMs

The term PROMs stands for “patient-reported outcome measures” and has become increasingly popular in the care of service users with psychosis since the 1960s (Reininghaus & Priebe, 2012). PROMs has been described as “the systematic assessment of mental health aspects of service users, through the use of standardized measures, to ascertain the impact of treatment in routine clinical practice” (Gelkopf, Mazor, & Roe, 2020, p.2). In contrast to concerns that the validity of PROMs might be impaired by the influence of psychiatric symptoms and cognitive deficits among service users with psychosis, research has shown that it is valid as an independent outcome measure (Reininghaus & Priebe, 2012). The use of PROMs is important for several reasons; some treatment effects are known only by the patient and hence cannot be measured by observers. Patients also provide a unique perspective on treatment effectiveness, which is particularly important when improvements in clinical measures may not correspond to

improvements in how the patient functions or feels. Another benefit of patient-reported instruments is that they might be more reliable than observer-rated measures because they eliminate interrater variability. Perhaps the most important aspect of patient-reported measures is that they reflect patients as active partners in care, whose views and opinions matter (Priebe, Kaiser, Huxley, Röder-Wanner, & Rudolf, 1998).

1.4.2 Quality of life

The WHO defines Quality of Life (QoL) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 2021). QoL in people with schizophrenia is significantly lower than in healthy controls, and QoL scales have increasingly been used as major outcome measures in the treatment of schizophrenia (Dong et al., 2019).

1.4.3 Service User and Patient

In this thesis, the terms service user and patient are used interchangeably to refer to the person who is using mental health services. However, the three scientific papers included in this thesis use only the term service user. According to Norwegian official guidelines, a service user is “a person who is in need of or makes use of mental health or substance abuse services” (Helsedirektoratet, 2017a). In the Norwegian Patients and User Rights Act, a patient is a person who is offered or given help from health services (including involuntary help), or who is requesting help from health services (Helsedirektoratet, 2015b).

2. Aims and Research Questions

The main theme in this thesis is the personal recovery of people with psychosis and their satisfaction with mental health services. As described in the Background chapter, there are some key questions with which the research area has been preoccupied. One of these is whether the focus on personal recovery is relevant for all people with psychosis, regardless of the severity of their clinical symptoms and functional level. The second key question is whether and how personal recovery and the more traditional focus on clinical recovery are related. The aim of this thesis was to contribute to knowledge on these key questions about recovery and to examine the relationship between satisfaction with mental health services and personal recovery.

2.1 The Perceived Importance of and Support for Personal Recovery

To address the question of whether personal recovery is applicable for everyone, we wanted to find out if people at different stages and with different illness-related situations considered personal recovery to be of importance to them. We also wanted to find out how supported they felt by their mental health clinician and which factors were associated with that support. This was addressed in the first paper through the following research questions:

Research question 1: Is personal recovery as defined by the CHIME framework considered important for service users with psychosis?

Research question 2: Are there any differences between service users with different levels of rated importance?

Research question 3: How much perceived support for personal recovery do the service users receive?

Research question 4: What covariates are associated to perceived support?

2.2 The Relationship Between Personal and Clinical Recovery

We wanted to examine if personal and clinical recovery were related but also whether some of the clinical subdomains are specifically related to personal recovery, which we thought could help to disentangle the complex relationship between these two forms of recovery. However,

because most research that has aimed to investigate the complex relationship between personal and clinical recovery has only included clinician or researcher-assessed clinical symptoms (Jørgensen et al., 2015; Rossi et al., 2018; Van Eck et al., 2018) we also wanted to examine the role of service user-rated clinical symptoms in relation to personal recovery. We thought that this could shed new light on the relationship between these two concepts, and reveal areas of clinical importance. Hence, the aim of the second paper was to examine the relationship between personal recovery reported by service users and clinical recovery rated by both clinicians and service users. We proposed the following research questions:

Research question 1: Is there a relationship between personal recovery and clinical recovery rated by clinicians?

Research question 2: Is there a relationship between personal recovery and clinical recovery rated by service users?

Research question 3: Is there a relationship between personal recovery and different subdomains of clinical recovery when rated by clinicians and by service users?

2.3 The Relationship Between Personal Recovery and Satisfaction with Mental Health Services

In the third paper, we wanted to examine the level of satisfaction with services among service users with psychosis across Norway, and the relationship between the service users' satisfaction with mental health services and other PROMs, such as personal recovery, perceived support for personal recovery and QoL. Although satisfaction with services is associated with beneficial clinical outcomes among individuals with psychosis, its relationship with QoL or life satisfaction has generated inconsistent findings. Furthermore, we found no studies had investigated the relationship between satisfaction with services and personal recovery. Hence, we proposed the following research questions:

Research question 1: How satisfied are service users with psychosis in Norway with the mental health services they receive?

Research question 2: What is the relationship between satisfaction with services and perceived support for personal recovery?

Research question 3: What is the relationship between satisfaction with services and personal recovery?

Research question 4: What is the relationship between satisfaction with services and quality of life?

Research question 5: Are service users on a community treatment order (CTO) less satisfied with services?

We hypothesized that higher quality of life and more perceived support for personal recovery would be positively associated with higher satisfaction with services. We also expected that service users who are highly satisfied with services would report higher levels of personal recovery. Finally, we hypothesized that users in a Community Treatment Order (CTO) would be less satisfied with their care.

3. Method

3.1 Research Design and Setting

This study has a multicenter cross-sectional design. It is part of the Norwegian research project A Pairwise Randomized Study on Implementation of Guidelines and Evidence-based Treatments of Psychoses (ClinicalTrials NCT03271242). The research project examines the extent to which knowledge-based practices recommended in guidelines for psychosis treatment have been implemented in mental health care, whether implementation is improved through implementation support, and whether patient satisfaction and patient outcomes are related to the degree of implementation. Six health authorities (Akershus University Hospital, the Hospital Innlandet, Sørlandet Hospital, Stavanger University Hospital, Health Fonna and the University Hospital of Northern Norway) are collaborating partners in the project. A total of 39 clinical units and hospital departments with outpatient clinics, day units, mobile teams, and inpatient wards participated in the project. A patient outcome substudy of the main project was conducted in which data from 325 service users with psychosis and their clinicians from the 39 clinical units were collected. The present PhD study is part of the patient outcome substudy (N = 325), and is based on quantitative data from questionnaires and rating scales completed by patients and clinicians at baseline (June 2016 to March 2017). All three papers included in this thesis have a cross-sectional design and are based on the baseline data from this project. The PhD study was funded by the Southeastern Norway Regional Health Authority (Helse Sør-Øst) (Grant number 2015106).

3.2 Philosophical Underpinnings

In this section, the philosophical underpinnings of this thesis and the challenges and importance of researching personal recovery from a quantitative approach, are described.

3.2.1 *Epistemological, Ontological and Axiological Assumptions*

Quantitative approaches emerge from the positivist paradigm. A positivist paradigm approach encompasses the study of research questions or hypotheses that identify the prevalence

and characteristics of concepts, test relationships, assess cause and effect relationships between variables and test for intervention effectiveness (Polit & Beck, 2008). The philosophical underpinnings of this thesis are founded in the post-positivistic philosophical position of critical realism. Critical realism is usually associated with the works of the British philosopher Roy Bhaskar (1944–2014) (Khanna, 2019). Critical realism holds on to an ontological realism (i.e., the existence of a real world, independent of our perceptions), and at the same time accepts epistemological constructivism and relativism (i.e., the understanding of the reality is a function of our perspectives). Hence, it combines ontological realism with constructivist epistemology (Khanna, 2019). Epistemological constructivism is the belief that our knowledge of this reality is a construction we shape from a perspective. That is, we cannot reach absolutely objective knowledge because our knowledge will at all times be marked by our perspective. From a critical realism approach, one will claim that all knowledge is “theory-laden,” but that this knowledge at the same time refers to a reality that exists independently of our knowledge of it (Maxwell, 2012). Hence, a critical realist approach corresponds to the purpose of the thesis and the methods used because this project investigates personal recovery from a quantitative approach with the aim of assessing relationships between variables and the prevalence of concepts. At the same time, I acknowledge that personal recovery is only accessible by the person themselves. In addition, although a positivist quantitative approach, by definition, is aimed at accessing some kind of objectivity, I acknowledge, in line with a critical realist approach, that my background will have influenced the interpretations of the findings in this study. With regard to my standpoint as a clinical psychologist, I have tried to let curiosity and having an open mind guide me in the research process. However, it is realistic to assume that this standpoint will have to some degree affected the interpretation of the findings. A person with user-experience would come from another standpoint, having experienced the role of patient and as a user of mental health services. However, people with user experience have been involved in the design of the main project, in the development of questionnaires to patients and clinicians, in the decisions regarding data collection, and discussions of the results in this thesis

results in the project group meetings. Hopefully this has contributed to a good balance of perspectives in this study.

3.2.2 A Quantitative Method Approach to Recovery

Personal recovery has traditionally been examined through a qualitative research approach, but in the last decade, more quantitative research has been conducted. Quantifying recovery as a subjective process is complicated because personal recovery, by definition, is a unique and deeply personal process that can only be derived from the person itself. Concerns about the compatibility of researching personal recovery with quantitative methods stem, in part, from epistemological issues; it is common to equate quantitative methods with a positivist epistemology and qualitative methods with a social constructionist epistemology (Slade, 2009). This leads to a fundamental tension between nomothetic (objective) and idiographic (subjective) knowledge. However, as described by Slade (2009) neither nomothetic nor idiographic knowledge in isolation are sufficient for clinical practice. In relation to mental health systems, this tension is exemplified by the dilemma of, on the one hand, solely relying on observable, empirical data when providing care, which might be an inadequate approach for addressing human problems, and, on the other hand, exclusively relying on idiographic knowledge, which might lead to several weaknesses or blindness to different areas (Slade, 2009). The use of PROMs creates a similar challenge because the measures are supposed to reflect individual experiences (interpretivism) but ultimately yield a numeric score on a scale representing a predefined construct (positivism) (Neale & Strang, 2015). However, I believe that using a quantitative research method on personal recovery is an important aspect for the development of recovery-oriented mental health services because, as Slade (2009) argues, if we cannot define a construct or its constituent elements in a way that most people understand and agree on, it will be difficult or impossible to measure. The value of quantitative research is that the results gained from it allow for comparisons between persons and across data over long time periods. It also creates the ability to replicate research and compare studies or similar populations (Babbie, 2020). For example, in the research on recovery, quantitative approaches are needed to evaluate

interventions that support recovery and to understand the relationship between changes in personal and clinical recovery. In addition, the use of PROMs provides a unique perspective on treatment effectiveness, which is particularly important when improvements in clinical measures do not reflect how the patient functions or feels. It also reflects the patients as active partners in care, whose views and opinions matter (Priebe et al., 1998).

3.3 Sample and Recruitment

A total of 325 mental health service users from six health authorities across Norway were recruited. Clinicians at the participating mental health units recruited eligible service users who were in contact with the clinic during the study period, and newly referred service users assessed to have psychosis. Clinicians were instructed to include patients in the diagnosis groups F20–29 of the ICD-10 (World Health Organization, 1992), as well as those cases where the patient did not have a definitive diagnosis yet but was treated in accordance with the psychosis guidelines. Both patients with a newly discovered psychotic disorder and patients with a longer course of treatment were included. Inclusion criteria were mental health service user aged 16 years or older with psychosis. Only participants who were capable of giving written and informed consent were included. Assessment of capacity to consent was made by the responsible clinician. Signed consent forms were sent to the project coordinator who ensured their proper storage. Exclusion criterion was inability to read or understand Norwegian. The recruitment period lasted from June 2016 until March 2017.

The original sample in the project consisted of 325 service users. However there are different sample numbers in the three papers, and in different analyses within the papers. This is due to differences in missing data on the different measures used. Sociodemographic information of the original sample of 325 service users is presented in table 2.

Table 2.*Sociodemographic Characteristics of participants (N=325)*

Characteristics	n	%
Gender		
Female	133	41
Male	191	59
Ethnicity		
Norwegian	281	88
Other	39	12
Age (M ± SD)	40.0 (12.7)	
Diagnosis		
Schizophrenia	161	54
Schizoaffective disorder	60	26
Other	79	20
GAF subscale (M ± SD)		
Symptom	52.6 (13.0)	
Function	50.4 (11.4)	
Community Treatment Order (CTO)	43	14
Time in mental health care		
< 6 months	20	7
6 – 23 months	28	9
2 – 5 years	50	16
6 – 10 years	66	21
> 10 years	147	47
Living situation		
Alone	204	65
With married/partner	53	17
Alone with children	10	3
With parents/family	40	13
With friends	6	2
Educational level		
Did not complete primary school	9	3
Primary school	96	31
Upper secondary school	82	26
Vocational education	54	17
Higher education 1-3 years	40	13
Higher education 4-6 years	23	7
Other	10	3

3.4 Data Collection and Procedure

Data were collected from service users and clinicians from the 39 mental health clinical units of the six health authorities that participated in the project. Questionnaires were administered to the service users by the secretary or other clinic personnel. The service users were either provided with

a place to sit in the clinic to complete the administered questionnaires or took them home. When finished, the questionnaire was sealed in an envelope and returned to the clinic. The responsible clinician was instructed to complete the clinician-rated measures about the patient and the treatment together with the treatment team, and was responsible for sending the forms to the project coordinator as agreed upon in each unit. The project coordinator ensured the proper storage of the submitted forms. Instructions were that the completion of the clinician and service user forms should take place within the same 14-day period.

3.5 Measures

3.5.1 Patient-reported measures

The *INSPIRE* measure of staff support of personal recovery (*INSPIRE*) is a 27-item self-report questionnaire that measures perceived staff support for personal recovery (Williams et al., 2015). It consists of two subscales: support (20 items) and relationship (7 items). The 20-item support subscale was used to examine the importance of personal recovery (Paper I) and to assess experienced support for personal recovery from the mental health clinician (Papers I and III). The relationship subscale was not included in the main project. Each subscale item was first rated by the participant on whether it is important for the participant's recovery; for example, "An important part of my recovery is ... feeling hopeful about my future," with response options of yes/no (Paper I). If yes, the participant rates the support they receive from their health service provider for this item ("I feel supported by my worker with this") on a five-point Likert scale from 0 (Not at all) to 4 (Very much). A total support score is calculated for each participant as described in the *INSPIRE* scoring instruction guide (Institute of Mental Health Recovery Research Team, n.d) and ranges from 0 (low support) to 100 (high support). The number of "yes-important" responses was used as a variable to examine whether personal recovery was considered important (Paper I). The support score was used as a variable to examine perceived support for personal recovery (Papers I and III). Psychometric evaluation of the *INSPIRE* in the current sample showed a one-factor solution, with good internal consistency (Omega coefficient = .96).

The *Questionnaire about the Process of Recovery* (QPR) (Neil et al., 2009) was used to examine the level of personal recovery (Papers II and III). The QPR is a 15-item self-report measure of recovery developed in collaboration between clinicians and service user researchers, with adequate psychometric properties (H. Law, Neil, Dunn, & Morrison, 2014). Items are rated on a five-point Likert scale (0 = Disagree strongly, 1 = Disagree, 2 = Neither agree nor disagree, 3 = Agree, 4 = Agree strongly). The total sum score ranges from 0 (Low recovery) to 60 (High recovery). Psychometric evaluation of the QPR in the current sample showed a one-factor solution with high scale reliability (Cronbach's alpha = .91).

The *Client Satisfaction Questionnaire-8* (CSQ-8) (Paper III) is an eight-item questionnaire used to measure patients' global satisfaction with services (Attkisson & Greenfield, 1996). It has shown good psychometric properties (De Wilde & Hendriks, 2005). The CSQ-8 measures general satisfaction on eight scaled items from 1 (Poor) to 4 (Excellent) resulting in a total score range of 8–32. The level of satisfaction is classified as low (8–20), intermediate (21–26) or high (27–32) (Larsen, Attkisson, Hargreaves, & Nguyen, 1979). Psychometric evaluation of the CSQ-8 in the current sample showed high scale reliability (Cronbach's alpha = .91).

The Behavior and Symptom Identification Scale (BASIS-24) (Papers I, II and III) is a brief service user self-report measure of psychopathology and functioning that was developed to assess mental health treatment outcomes. It consists of 24 items assessing six symptoms and functioning domains: depression/functioning, interpersonal relationships, self-harm, emotional lability, psychosis and substance abuse. The scale has shown good validity and reliability for assessing mental health status and functioning from the perspective of service users (Cameron et al., 2007). Scores were calculated as described in the BASIS-24 instruction guide (BASIS-24 Instruction Guide, 2006), providing a score between 0-4, with higher scores indicating more severe problems.

In Paper I, the depression/functioning and substance abuse domains were included. The substance abuse domain was transformed into a dichotomous variable (substance abuse/no substance abuse). Abuse was defined as a score of 3 (Often) or 4 (Always) on any of the items in

the domain. Item 22 (Did anyone talk to you about your drinking and drug use?) was excluded because it was considered irrelevant. In Paper II, all six domains were included as clinical recovery subdomains, and the sum scores of all six domains were included as the main measures of service user-rated clinical symptoms. In Paper III, the depression/functioning domain was included.

The Manchester Short Assessment of Quality of Life (MANSA) (Papers I and III) (Priebe, Huxley, Knight, & Evans, 1999) was used to assess QoL by using a single item of the scale (Item 1, Life as a whole: “How satisfied are you with your life as a whole?”), which was rated on a seven-point scale from 1 (Couldn’t be worse) to 7 (Couldn’t be better). The variable was named Satisfaction with life in Paper I and QoL in Paper III. The MANSA item 1 (Life as a whole) has been shown to correlate strongly with item 1 (Life as a whole) in the Lancashire Quality of Life Profile (LQoLP) (Pearson correlation coefficient = .832, $p < .001$) (van Nieuwenhuizen, Janssen-de Ruijter, & Nugter, 2017).

Overall experience in getting help to manage life and illness (Paper I) was measured by the level of agreement with six statements about patients’ overall experiences in getting help to manage their lives and their illness for the past six months. The statements were rated on a five-point scale (1 = Strongly disagree; 5 = Strongly agree), with an additional option of answering “not relevant.” The six statements were as follows:

Setting goals: “I have been well trained in setting goals and working to achieve them.”

Increased knowledge: “I have gained useful knowledge about stress, vulnerability and social support.”

Coping: “I have gained useful knowledge about coping with stress and illness.”

Health service use: “I have gained useful knowledge about how to use health services better.”

Medication: “I have gained useful knowledge about the medicines I use.”

Early detection and prevention of relapse: “I have prepared a plan for the early detection of any signs of aggravation, and what should be done then.”

IMR experience (Paper I) was measured using participants' response to a question asking whether they had received IMR treatment during the past 6 months (yes/no).

3.5.2 Clinician-rated Measures

The *Health of the Nation Outcome Scale* (HoNOS) (Paper II) is a 12-item staff-rated measure of mental health and psychosocial functioning (Wing et al., 1998). Each item is rated on a 5-point severity scale from 0 (no problem) to 4 (severe to very severe problem). The scale was developed to measure outcomes routinely for adults with mental illness. It has been regarded as adequate for assessing outcomes in different service user groups on a range of mental health-related constructs, and for routinely monitoring outcomes (Pirkis et al., 2005). In Paper II, the total score (0–48) of all 12 items was included as the main measure of clinician-rated clinical recovery, whereas nine of the 12 items were included as clinical recovery subdomain variables. Three items (physical illness or disability problems, problems with living conditions, problems with occupation and activities) were excluded because they were considered to measure somatic health and actual access to resources rather than clinical recovery.

The split version of the *Global Assessment of Functioning Scale* (S-GAF) (Papers I, II and III) was used by clinicians to rate the level of functioning (GAF-F) and severity of service users' symptoms (GAF-S) on a scale of 1–100 (Pedersen, Hagtvet, & Karterud, 2007), with higher scores indicating fewer symptoms and higher levels of functioning (Goldman, Skodol, & Lave, 1992). The split version of the scale is highly generalizable (Pedersen & Karterud, 2012).

The *Clinical Global Impressions Scale* (CGI) (Paper I) was originally developed for use in NIMH-sponsored clinical trials (Guy, 1976). In Paper I, the CGI-Severity (CGI-S) component, in which clinicians rate the severity of service users' mental illness in the past seven days on a seven-point scale (1 = Normal, not at all ill, 7 = Among the most extremely ill patients), was included (Busner & Targum, 2007).

Service user demographics (Papers I, II and III) were measured by means of clinician-reported age, gender, ethnicity, CTO and mental health care history.

3.6 Data Analysis

Statistical analyses were performed with the Statistical Package for Social Science version 25 (IBM Corp., Armonk, NY, USA). In all three papers in this thesis, a suitable regression analysis was used. In Papers I and II, linear regression models were used. In Paper III, a linear mixed model was estimated. All tests were two-sided, and results with p values $<.05$ were considered statistically significant.

3.6.1 *Imputation of Missing Data*

Missing values were imputed for the GAF scales, the MANSA item, the QPR scale, the CSQ-8 scale and the Overall experience scale. The number of missing values among scale items for each case was calculated. Imputation was performed for cases with fewer than 50% missing values in the following way. The empirical distribution for each item in the scales was determined. A random number was drawn from that distribution and used to replace the missing value. The process was repeated until all missing values were imputed. This approach mimics the bootstrap method (Efron & Tibshirani, 1994), and was used because this study is part of a large randomized trial study that collected data at baseline, and three follow-up points (6, 12 and 18 months). To avoid the imputation being performed for each substudy in the main project separately, and thereby producing somewhat different sets of variables every time they were used, imputation of the missing values was performed before any analyses were initiated. Although multiple imputation would have been a preferred technique, this approach would have produced numerous datasets, which may be difficult to handle in certain types of analyses (e.g., multilevel analysis). The method described in this thesis does not alter the empirical distribution and is a suitable approach when the number of missing values is relatively small.

In Paper I, missing values were imputed for the GAF-S ($n = 40$), GAF-F ($n = 40$), the MANSA item ($n = 7$) and the Overall experience scale ($n = 28$). In Paper II, missing values were imputed for the GAF-S ($n = 39$), the GAF-F ($n = 39$) and the QPR ($n = 24$). In Paper III, missing

values were imputed for the GAF-S (n = 34), the GAF-F (n = 34), the MANSA item (n = 6), the QPR (n = 21) and the CSQ-8 (n = 6).

3.6.2 Descriptive Analyses

In all three studies, dichotomous and categorical variables were presented as frequencies and percentages. Continuous variables were described by means and standard deviations (SD).

3.6.3 Multiple Regression Analyses

The main statistical analysis method used in this study is regression analyses. In paper I and II, linear regression models were estimated. In paper III, a linear mixed model was estimated. Multiple regression analysis is an appropriate choice when one has multiple variables, and want to understand their contribution to a desired outcome variable. Multiple regression analysis is the most common way to determine association or create predictive models with several variables assessed simultaneously (Momeni, Pincus, & Libien, 2018).

Paper I. In this paper, we used bivariate and multiple regression models to assess the characteristics associated with the number of “yes-important” responses and with the total support score from the INSPIRE measure of staff support. We did this in two steps. First, models with prechosen participant characteristics (age, gender, ethnicity, CTO status and mental health care history), participant-rated measures (depression functioning, satisfaction with life and substance abuse) and clinician-rated measures (GAF-S, GAF-F and CGI-S) were estimated. Second, covariates on service users’ overall experiences in managing their life and illness (overall experience statements) and whether they had participated in IMR (IMR experience) were added. Because participants were recruited to the study by different units, a hierarchical structure (implying cluster effect on unit level) could have been present in the data. Hence, before performing the linear regression analyses, the cluster effect on the unit level was assessed by an intraclass correlation coefficient (ICC). We found that there was essentially no cluster effect in outcome variables (ICC = .001 for the number of yes-important answers and ICC = .01 for support score). Hence, no adjustment for within-unit correlations was needed. Correlation analysis did not identify any

multicollinearity issues among covariates. Residuals were inspected graphically to assess the normality and homoscedasticity assumptions of the linear regression model, but no significant deviations were identified. Both bivariate and multiple models were estimated for cases with no missing values on covariates.

Paper II. In the second paper, we calculated Pearson's correlations among the sum/total scores and subdomain scores of BASIS-24 and HoNOS, finding low-to-moderate correlations. Five linear regression models were estimated to assess the association between personal recovery (QPR) and service user-rated clinical recovery (BASIS-24) and clinician-rated clinical recovery (HoNOS). The sum score of BASIS-24 and the BASIS-24 subdomain scores were included in Model 1 and Model 2 (Table 3 in paper II), respectively. The HoNOS total score and the nine prechosen items of HoNOS were included in Models 3 and 4 (Table 4 in paper II), respectively. The sum and subdomain scores of the two measures were analyzed in separate models because including them in the same model would imply multicollinearity issues. Finally, the sum score of BASIS-24 and the HoNOS total score were included in Model 5 (Table 5 in paper II). GAF-symptom, GAF-function, age and gender were entered in all the models as covariates. The ICC was estimated to assess the degree of clustering due to data collection from different mental health units. Because no cluster effect was identified, no adjustment was needed. Model assumptions were tested in the same way as in Study 1.

All regression models were estimated for service users with no missing values on included covariates. Because of many missing values ($n = 72$), those included and not included in the regression analyses were compared. The differences between continuous variables (the QPR, BASIS-24 sum score, GAF-S, GAF-F and age) were assessed by an independent-sample t test, whereas categorical variables (gender, diagnosis, ethnicity and being under CTO) were compared using the χ^2 test.

Paper III. In this paper, the ICC showed a noticeable cluster effect on the clinical sites level (ICC = .125) and health authority level (ICC = .041). Hence, unadjusted and adjusted linear mixed

models with random effects for clinical sites nested within health authorities were estimated to assess the association between service satisfaction (CSQ-8) and three covariates (QPR, INSPIRE, MANSA), controlled for confounders (GAF-S, GAF-F, depression/functioning, CTO, age and gender). Multicollinearity was assessed by inspecting correlations among covariates, but no multicollinearity issues were found. Standard residual diagnostics were performed to assess assumptions of normality and homoscedasticity of residuals. As an exploratory analysis, the interactions between being under a CTO and QoL (MANSA) and personal recovery (QPR) were entered into the model, to determine whether the CTO variable moderated their relationship with CSQ-8.

3.7 Ethical considerations

This thesis is part of the Norwegian research project *A Pairwise Randomized Study on Implementation of Guidelines and Evidence-based Treatments of Psychoses* (ClinicalTrials NCT03271242). The study was approved by the Regional Committee for Medical and Health Research Ethics (REK Sørøst B 2015/2169), and followed the principles of the Declaration of Helsinki. The data used in this thesis are part of the patient outcome substudy, and are based on quantitative data from questionnaires and rating scales completed by patients and clinicians at baseline. Clinicians at the participating mental health units were instructed to recruit all service users who met the inclusion criteria. However, it is possible that not all eligible service users were asked to participate, which is ethically problematic because perhaps not everyone was given the opportunity to participate.

Only participants who gave written informed consent were included, and they were informed that they could withdraw their consent at any time. There are some ethical issues worth discussing regarding informed consent. The main rule is that consent must be informed, voluntary, expressed and documented. People with a psychotic disorder are a vulnerable group, and several of the participants were in a nonvoluntary relationship with the mental health services. At the same time, such a vulnerability may not be enough to collectively deprive a group of people of the

opportunity to promote their own views. It is reasonable to assume that some patients relevant to the study may have had reduced consent competence when they met the condition for compulsory mental health care. However, it is assumed that although people with psychotic disorders may at times have a reduced ability to make autonomous decisions, they mainly have consent competence in the vast majority of areas. Although patients may be quite affected by their psychotic disorder, they are usually fully able to assess their participation in various contexts.

In addition, although the questionnaires in this study were not considered to be obtrusive, we cannot exclude the possibility that some of the participants might have found the questionnaires too personal or exhausting.

4. Summary of findings

This chapter briefly summarizes the aims and findings of the three papers included in the thesis. The findings are presented in accordance with the proposed research questions described in the Aims and Research Questions chapter.

4.1 Paper 1 - The Importance of Personal Recovery and Perceived Recovery Support Among Service Users With Psychosis

In this study, we examined whether personal recovery, as defined by the CHIME framework, was considered important for service users with psychosis, and their perceived support from clinicians for personal recovery. The aim was to contribute to answering the question of whether personal recovery is of importance to service users regardless of their level of symptoms and illness-related situation. We also wanted to find out how supported they felt and which factors were associated with that support. This was investigated using INSPIRE in a cross-sectional sample of 321 service users with psychosis. Bivariate and multiple linear regression models were used to assess variables associated with rated importance and support.

We found that the great majority of this large, heterogeneous sample of service users with psychosis across several clinical units reported that personal recovery was important to them (Research question 1). Ten (3%) participants rated all 20 INSPIRE items as not important. A total of 167 participants (52%) gave an “important” rating to 17–20 items (Figure 1 in Paper I).

A linear regression model (Table 3 in Paper I) showed no significant differences between service users who rated personal recovery as less important and those who rated it as more important (Research question 2). When investigating the perceived support for personal recovery, we found that service users experienced moderate support for personal recovery from their mental health clinician (Research question 3). On average, the service users reported levels of support from 2 (Somewhat) to 3 (Quite a lot) (Table 2 in Paper I). A multiple linear regression model examining variables associated with experienced support (Table 4), showed that among the chosen covariates on service user characteristics, service user-rated measures and clinician-rated measures, higher

self-reported depressive symptoms, lower GAF-S score and male gender were significantly associated with less perceived support. Among the chosen covariates on health service characteristics, we found that having participated in IMR groups, having gained knowledge about coping with stress and illness, and having a plan for the early detection and prevention of relapse for the past six months were significantly associated with higher perceived support (Research question 4).

4.2 Paper III – Associations Between Personal Recovery and Service User-Rated Versus Clinician-Rated Clinical Recovery, a Cross-Sectional Study

This study examined the relationship between personal recovery reported by service users and clinical recovery rated by both clinicians and service users. The relationships between different subdomains of clinical recovery and personal recovery were also assessed. The aim was to shed light on the relationship between these two forms of recovery and reveal areas of clinical importance. A cross-sectional sample of 318 mental health service users with a psychosis diagnosis and their clinicians from 39 sites across Norway completed standardized questionnaires of personal recovery, clinical symptoms and psychosocial functioning. Five regression models were used to investigate the relationship between personal and clinical recovery with subdomains.

We found that overall, clinical recovery was positively associated with personal recovery, both when rated by service users (Table 3 in Paper II) and by clinicians (Table 4 in Paper II) (Research questions 1 and 2). When compared, the results showed that clinical recovery reported by service users was more strongly related to clinical recovery than clinician-rated clinical recovery (Table 5 in Paper II). Among clinical recovery subdomains rated by the service users, we found that personal recovery was associated with lower levels of depression, self-harm and problems with relationships (Table 3 in Paper II). Among subdomains rated by the clinicians, personal recovery was associated with fewer problems with relationships and higher aggressiveness (Table 4 in Paper II) (Research question 3).

4.3 Paper III - Relationship between satisfaction with mental health services, personal recovery and quality of life among service users with psychosis: a cross-sectional study

The third study in this thesis investigated the relationship between satisfaction with mental health services among service users with psychosis in Norway and self-reported outcome measures on personal recovery, perceived support for personal recovery and QoL. This was examined using cross-sectional data from 292 service users diagnosed with psychosis from 39 clinical sites across Norway. Satisfaction with services was assessed using the CSQ-8. A linear mixed model was estimated to explore the relationship between satisfaction with services and preselected covariates, and to control for confounding factors.

We found that a large majority of the participants (89%) reported moderate-to-high levels of satisfaction (Research question 1), which are higher satisfaction levels than found in similar international studies. The mean (SD) CSQ-8 score was 25 (4.7), indicating an average of intermediate satisfaction. Thirty participants (10%) reported low satisfaction, 141 (49%) reported intermediate satisfaction and 121 (41%) reported high satisfaction. A linear mixed model (Table 3 in Paper III) showed that satisfaction with services was positively associated with perceived support for personal recovery (Research question 2) but not associated with the actual level of personal recovery (Research question 3) or QoL (Research question 4). As anticipated, we found that service users under a CTO were significantly less satisfied than those who were not (Research question 5).

5. Discussion

The aim of this thesis was to contribute to knowledge on personal recovery and satisfaction with services among service users with psychosis. This chapter discusses the findings in the papers in relation to the perceived importance of personal recovery and the perceived support for personal recovery (Paper I), the relationship between personal and clinical recovery (Paper II) and the relationship between satisfaction with services and personal recovery (Paper III). In addition, findings across the papers, and their relevance to literature and themes described in the Background section, are discussed. Strengths and limitations of the findings from the three papers and the methodological considerations that arise from these studies are also discussed.

5.1 Discussion of findings

5.1.1 *The importance of personal recovery and perceived support for personal recovery*

The main finding in Paper I was that the great majority of a large, heterogeneous group of service users with psychosis across several clinical units reported that personal recovery was important to them, regardless of age, ethnicity, symptomatology, functioning, CTO status and time in mental health care. There were no differences between service users who rated personal recovery as less important and those who rated it as more important. This finding indicates that personal recovery is a concept that can apply to service users regardless of their level of clinical severity because it seems to be of great importance. This is consistent with previous studies suggesting that service users with psychosis can work toward personal recovery regardless of their clinical and functional competence (Chan et al., 2017).

Although the great majority of participants reported personal recovery to be of high importance, they experienced only a moderate degree of personal recovery support from their mental health clinician. Several factors can influence the level of experienced support for recovery, such as the degree to which various clinicians and various mental health units are recovery-oriented. In this study, we examined participant characteristics, participant-rated measures, clinician-rated measures and health service characteristics in relation to perceived support. We found that higher

self-reported depressive symptoms, lower GAF-S score and male gender were significantly associated with less perceived support. Previous research has shown that affective symptoms seem to be more closely linked than psychotic symptoms to personal recovery and related themes, such as QoL (Priebe et al., 2010; Van Eck et al., 2018). Our finding that a higher level of self-reported depression was related to less perceived support is in accordance with previous findings of an association between affective symptoms and personal recovery among service users with psychosis. Among health service characteristics, we found that previous experience with IMR and related themes, such as knowledge about coping with stress and illness and having a plan for early detection and prevention of relapse, were significantly associated with higher perceived support. This suggests that recovery-oriented treatments, such as IMR and related themes, may be effective in helping people feel supported in their process of personal recovery, a result consistent with a recent meta-analysis showing greater improvement in personal recovery outcomes when service users were involved in recovery-oriented mental health treatment compared with standard care or other types of treatment (Thomas, Despeaux, Drapalski, & Bennett, 2018). It is important to point out that the mental health service characteristics explained a much larger proportion of the variance in the regression models than those variables related to service user characteristics. This suggests that there is great potential for mental health services to influence and affect perceived support for personal recovery. IMR seems to be a treatment related to perceived support for personal recovery, although we cannot draw conclusions regarding causality among these associations. In general, our results point to the importance of providing support for personal recovery, even (or especially) among service users with high levels of general symptoms and depression.

5.1.2 The relationship between personal and clinical recovery

In the second paper, we found that personal recovery was significantly associated with clinical recovery, as rated by both service users and clinicians. These results support the findings from previous studies showing a connection between the two concepts (Jørgensen et al., 2015; Van Eck et al., 2018). We also investigated the relationship between different clinical subdomains and

personal recovery. The results showed that among the service user-rated clinical subdomains, fewer depressive symptoms and everyday coping (depression/functioning), being able to manage social situations and having other people to turn to (problems with relationships) and fewer suicidal thoughts/thoughts about self-harm (self-harm) were related to higher personal recovery. These findings show that when service users rate their own clinical symptoms, more affective symptoms and related themes, such as suicidal thoughts, are associated with lower levels of personal recovery, whereas psychotic symptoms, such as hallucinations and delusions, are not. This finding is consistent with previous studies that show that affective symptoms are more strongly associated with personal recovery than are other psychosis-specific symptoms, such as hallucinations and delusions (Van Eck et al., 2018). This is further supported by the finding that no clinician-rated subdomain of psychotic symptoms showed any significant associations with personal recovery. When service users report on this, it seems that the subdomains regarding depression and related themes, such as self-harm and suicidal thoughts, play an important role in personal recovery; this does not appear when rated by clinicians. This could be due to an underestimation of affective symptoms and the fact that affective symptoms are seldom given enough consideration in clinical treatment. Depression among people with psychosis is largely underresearched and has traditionally been considered as secondary to or comorbid with the more specific psychotic symptoms (Upthegrove, Marwaha, & Birchwood, 2017). Although the relationship between clinical and personal recovery is complex, as shown across studies, results do seem to point to emotional distress being related to subjective appraisals of recovery. It is also worth mentioning that among subdomains rated by the clinicians, higher personal recovery was associated with higher aggressiveness. Although this result could be a sign of overestimation in the regression model (as pointed out in paper II), a speculation is that this finding could reflect a higher level of assertiveness, which in turn could be associated to an ability for mobilization and inner strive for a better life.

Our study showed that reports by clinicians and service users on the importance of different clinical subdomains for personal recovery differed. However, one important finding of this study is that problems with relationships appeared significant when reported by both clinicians and service users. This is in accordance with previous research, which has demonstrated the importance of social support for personal recovery (Leamy et al., 2011; Lysaker, Ringer, Maxwell, McGuire, & Lecomte, 2010). Our results show that improving social relationships might be an area of great relevance for personal recovery because it is supported by findings from both clinicians and service users. Improving social connections might be an area where clinicians and service users can meet and find agreement on important treatment goals. The importance of other people, the social environment and society for personal recovery has been a topic of discussion, with some defining it as a separate kind of recovery, termed “social recovery” (Topor, Borg, Di Girolamo, & Davidson, 2011), whereas others define it as a part of personal recovery or even as a part of clinical recovery in terms of functioning. Regardless of how it is conceptualized, improving social connections seems to be an important area for mental health services to focus on to strengthen the personal recovery of service users with psychosis. It is also worth mentioning that social support has proven to be related to both subjective and objective markers of recovery (Thomas, Muralidharan, Medoff, & Drapalski, 2016). Improving social connections can be aimed at the individual level, such as strengthening the individuals’ relations to friends and family, and also at a more structural level, such as being part of the society. For example, reducing conflict and strengthening social support from family members as an intervention for people with psychosis has a strong evidence base when it comes to clinical recovery (Bighelli et al., 2021; Pharoah, Mari, Rathbone, & Wong, 2010), and our results suggest that improving social relations might also be of importance for personal recovery. However, the implementation level of structured family interventions for people with psychosis is poor, both in Norway (Hestmark et al., 2021), and internationally (Bucci, Berry, Barrowclough, & Haddock, 2016). People with psychosis still face considerable societal challenges, and psychiatric diagnoses can often constitute an obstacle to social rights such as full-time work, education or access to

housing (Bradshaw, Kemp, Baldwin, & Rowe, 2004). There is a significant, growing evidence base for recovery-oriented treatments aimed at increasing social inclusion at a structured level, such as the individual placement and support approach to employment (Bond, Drake, & Becker, 2012) and the recovery colleges education initiative (King & Meddings, 2019).

The division between personal and clinical recovery seems to exist because there are two different people assessing it, the outside person and the subjective person, and they are concerned about different things. Therefore, when discussing whether personal and clinical recovery are related, it is also important to discuss what they have in common. It has been suggested that clinicians and researchers must reject paternalism and the idea that wellness only results from medication and treatment adherence, but at the same time, it is important not to reject the expertise that clinicians offer their service users (Leonhardt et al., 2017). For example, a person “lacking in relationships, resources, or any fulfilling life roles who denies any problems” (Leonhardt et al., 2017, p 1126) would not seem to be moving toward subjective recovery. The research and treatment offered to individuals with psychosis seem to struggle with offering care in a way that balances expertise and still supports personal choice and mastery in the life of the individual. Leonhardt et al. (2017) has suggested that the resolution to working with this balance is a recovery-oriented approach to treatment that balances the power structure between provider and service user. van Weeghel, van Zelst, Boertien, and Hasson-Ohayon (2019) make a similar conclusion and suggest that because addressing both clinical and personal recovery is challenging, the resolution of this tension necessitates a personalized approach. The challenge is that the treatment aimed at symptom reduction may not always be consistent with the personal recovery concept, and interventions aimed at facilitating a sense of meaning may not always be consistent with clinical recovery (van Weeghel et al., 2019). Several studies support this by showing that there is often a discrepancy between patients’ own personal goals, including their desired outcome from the help they receive, and clinicians’ treatment goals (Andresen, Caputi, & Oades, 2010; Bridges et al., 2013).

5.1.3 Satisfaction among service users with psychosis and its relation to personal recovery

The main aim of Paper III was to investigate the relationship between satisfaction with services and PROMs, such as perceived support for personal recovery, personal recovery and QoL. We also investigated the level of satisfaction among services users with psychosis in Norway. Our results showed that 89% of the service users rated their satisfaction as intermediate to high, which is a higher satisfaction rate than those reported in similar international studies. Comparisons between studies are difficult because different samples, recruitment methods and different satisfaction measures have been used. Compared with the results of a Dutch study that used the CSQ-8 among 654 service users with psychosis, and had similar recruitment methods (Vermeulen et al., 2018), our results are somewhat more positive. This result could, however, be explained by the fact that their sample included many service users with first-episode psychosis, and hence their sample was younger, which is often associated with less satisfaction. In Norway, there have been efforts to make mental health care policy more patient centered (OECD, 2014), and Norway spends the largest share of its total health budget on mental health among the European countries (Helsedirektoratet, 2015c). However, our study shows that there is room for improvement, given that 11% of our participants reported low satisfaction rates.

In line with the research literature on satisfaction rates among service users on a CTO (S. Priebe & Miglietta, 2019), we found low satisfaction scores among service users under a CTO in our study. This supports and adds further evidence for the importance of interventions aimed at improving satisfaction with services within this group. We also found that service users who experience higher perceived support for personal recovery from their health care provider are more satisfied with the health care that they receive. This, and the finding of low satisfaction among service users under a CTO, are in line with research concluding that among service characteristics, only coercive treatment and a perceived negative therapeutic relationship consistently influence satisfaction with care (S. Priebe & Miglietta, 2019; Smith et al., 2014). This shows that service-related factors important for the general mental health population are also relevant to service users with psychosis.

It is interesting that although satisfaction with services was positively associated with perceived support for personal recovery, there was no significant association between service satisfaction and personal recovery or QoL. This could perhaps reflect that the perceived support for personal recovery more directly measures the service users' experience with the mental health services, whereas the actual level of personal recovery measures more broadly the general life situation of the person. Personal recovery and QoL are concepts associated with many aspects of the life and community of the person, and hence are probably also dependent on factors other than satisfaction with mental health services. On the other hand, it is important for services to have a holistic focus on the service users' actual life situation. If satisfaction is a good quality indicator and process variable in mental health care, this should also be reflected in subjective outcome measures, not just on clinical outcome measures. In general, our findings are in line with the previous research literature (Koivumaa-Honkanen et al., 1999; Ruggeri et al., 2003; Vermeulen et al., 2018), in that there are inconsistent findings in the relationship between satisfaction and subjective outcome measures, such as personal recovery and QoL. Our results are somewhat inconsistent because we showed that perceived support for personal recovery but not personal recovery or QoL, was associated with satisfaction with services. However, this is a cross-sectional study and hence, we do not have information on whether these concepts are related to satisfaction with services over time. Longitudinal studies on the relations between satisfaction with services and self-reported outcomes among service users with psychosis are scarce and more follow-up studies measuring change over time are needed.

5.1.4 Discussion of Findings Across Papers

Findings across papers show that depressive symptoms seem to be important for both perceived support for personal recovery (paper I) and for actual level of recovery (paper II). Depression among people with psychosis has a history of being neglected in treatment (Upthegrove et al., 2017), and seem to be rarely mentioned as a specific topic in the literature on personal recovery. Perhaps an increased focus on depression, or more importantly the underlying

mechanisms or reasons for why the person is depressed, could help to identify important treatment goals. This is in line with recovery-oriented practices' focus of listening to and acting on the service user's individually defined goals. The finding that personal and clinical recovery were associated, support the notion that the two concepts are compatible rather than conflicting. This is further supported by the finding that both recovery-oriented treatments such as IMR, and related themes such as having gained knowledge about coping with stress and illness, and having a plan for early detection and prevention of relapse, were associated to perceived support for personal recovery (paper I). Having received knowledge about coping with stress and illness, and having a plan for early detection and prevention of relapse are elements in line with the focus of some recovery-oriented practices, but it is also themes incorporated in the traditional clinical treatment for people with psychosis. The compatibility between personal and clinical recovery is also supported by the finding of the importance of social connection for personal recovery (paper II), as social support has been proven to be related to both subjective and objective recovery (Thomas et al., 2016).

There has been a growing focus on human rights aspects for and societal factors regarding personal recovery for people with serious mental illness. Although this thesis does not investigate environmental or social factors for personal recovery, the finding that satisfaction with services was not related to actual level of personal recovery, speak towards the importance of other aspects that might impact the possibility for personal recovery. This is further supported by our finding of the importance of social connection for personal recovery (paper II). As the framework regarding guidance for recovery practices by Le Boutillier et al. (2011) proposes, recovery can be supported at different levels, such as supporting personally defined recovery, working relationship, organizational commitment and promoting citizenship. Mental health services might have the ability to support and strengthen the personal recovery of people with psychosis, but it is also important to acknowledge the importance of interventions aimed at a structural level of society.

5.2 Methodological Considerations

5.2.1 Study Design

This study was a multicenter cross-sectional study and is therefore subject to potential confounders. In addition, because all variables were measured at the same time, we were only able to report associations between variables and could not draw conclusions on causalities.

5.2.2 Study Population – Representativity and Generalizability

Unlike studies starting from a series of patients, cross-sectional studies often need to select a sample of subjects from a large and heterogeneous study population. Thus, they are susceptible to selection biases, such as sampling bias. In general, random sampling methods are preferred in cross-sectional studies because they are considered to be more accurate and rigorous. However, in applied clinical research, this is often not feasible (Wang & Cheng, 2020). The only exclusion criterion in the current study was the inability to understand Norwegian, and the aim was to include a representative sample of Norwegian service users from the psychosis population. However, although the 39 participating clinical sites were considered representative of psychosis treatment in the Norwegian mental health care system, participants were not randomly selected; thus, they may not accurately represent the population with psychosis in Norway. In addition, although the clinicians that recruited the participants were instructed to ask all eligible service users to participate, we do not have information on the actual numbers of participants who were approached. Hence, this sample might be a convenience sample, which limits the generalizability of the findings.

5.2.3 Measurements – Reliability and Validity

Most of the measurements used in this study were standardized and validated instruments with good psychometric properties, but none of the instruments used had previously been validated in a Norwegian sample. Some issues need to be discussed.

5.2.3.1 Clinician-rated measures

We did not examine the interrater reliability of any of the clinician-rated scales, which is a limitation of the study. The clinicians did not receive any training on the instruments for the study. However, the use of the GAF scales was mandatory in Norwegian mental health clinics at the time of inclusion, and each clinic was responsible for training their clinicians in using this instrument.

The clinicians did not receive any training on the CGI scale, but the instruction manual was included in the questionnaire. An instruction manual was also available for the HoNOS scale, and clinicians had access to an Internet-based training course.

5.2.3.2 Patient-reported measures

In recent decades, patient-reported outcomes have become increasingly important for the evaluation of treatment of people with schizophrenia. However, there is a potential bias worth mentioning when it comes to patient-reported outcome measures. The common rater effect is a known potential bias when including several measures from the same respondent. This bias refers to any artifactual covariance between the predictor/covariates and outcome variable produced by the fact that the respondent providing the measure of these variables is the same (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003). For example, there is a risk of positive and negative ratings being incorrectly attributed to the outcome measured when they actually reflect a general appraisal tendency of patients for positive or negative ratings across measures designed to assess different PROM concepts (Priebe et al., 1998). However, the selected covariates in the three papers in this thesis showed only low-to-moderate correlations in the correlation analyses that were performed before the regression analyses, which speaks against such bias.

The selected PROMs used in this thesis were validated measures with good psychometric properties. However, none of them had been validated using a Norwegian sample. We performed psychometric evaluations of the CSQ-8 and the QPR. The CSQ-8 in the current sample showed high scale reliability (Cronbach's alpha = .91). Psychometric evaluation of the QPR in the current sample showed a one-factor solution with high scale reliability (Cronbach's alpha = .91).

However, it is worth mentioning that a psychometric evaluation of the support subscale of the INSPIRE measure in the current sample (Šaltytė Benth, Skar-Fröding, Ruud, Clausen, & Heiervang, 2021) did not support the five-factor solution found in previous international studies (Schön, Svedberg, & Rosenberg, 2015; Williams et al., 2015). In addition, the paper showed that the five-factor solution in previous studies was the result of confirmatory factor analyses being

performed without first performing explanatory factor analyses. This makes it questionable whether the INSPIRE measure consists of the five CHIME domains (Šaltytė Benth et al., 2021).

In addition, although MANSA is a well-known and validated instrument showing satisfactory psychometric properties (Priebe et al., 1999), we only used a single item from the scale to measure QoL, and we do not know how well this single item correlates with the full MANSA scale.

5.3 Strengths and limitations

In this section, I summarize the general strengths and limitations of this thesis, and some limitations and strengths from each paper.

The major strength of this study is the broad heterogeneous group of participants with psychosis that were recruited from “real-world” clinical practice in 39 different units, representing both rural and urban areas. This increases the generalizability of the results, and enabled us to answer the research question of whether personal recovery is a concept that is applicable and considered important for service users, regardless of their level of clinical recovery and across several different units (Paper I).

The study has some limitations. First, selection bias was a potential risk. Because this is a naturalistic, observational study, the participants were not randomly selected. Hence, they may not accurately represent the overall Norwegian population of individuals with psychosis. In addition, although the clinicians that recruited the participants were instructed to ask all eligible service users, we do not have information on the actual number of participants that were asked to participate. Hence, the sample might be a convenience sample, and our results should therefore be interpreted with caution. However, it is worth mentioning that although the actual level of representability of the sample in this thesis is unknown, our results might be more generalizable than studies conducted in highly controlled randomized studies, which often have more specific inclusion and exclusion criteria.

Other important limitations were the cross-sectional nature of the study, which prevented conclusions on causality, and the lack of assessment of interrater reliability between the clinician-rated measures. In addition, in paper II we used two different measures to assess clinical recovery, which might have introduced some uncertainty in our comparisons.

Paper III have some strengths and limitations worth mentioning. One of the major strengths of this paper is that we had access to and adjusted scores for common confounders. This minimized the risk of positive and negative ratings being incorrectly attributed to service satisfaction when they actually reflected general tendencies of certain service users with specific characteristics (e.g., depressive symptoms), which can serve as a “mood-dominated” general tendency toward more positive or negative appraisals of one’s situation across various self-reported constructs (McCabe, Saidi, & Priebe, 2007). The common rater effect, a known potential bias when including several measures from the same respondent, could be a potential limitation. However, our selected covariates showed only low-to-moderate correlations, speaking against such bias. Further, although CSQ-8 is among the most widely regarded scales for measuring service satisfaction, it is a scale that measures the general level of satisfaction and not specific aspects of the care provided. The scale also includes some questions that some might consider unsuitable for those on a CTO, such as for example “Did you get the kind of service that you wanted?”

6. Conclusion and implications

In general, this thesis shows that personal recovery is important for many service users with psychosis (paper I), that clinical and personal recovery are associated (paper II), and that satisfaction with services is associated to perceived support for personal recovery (paper III).

Part of the thesis aim was to clarify whether personal recovery was considered relevant to a large heterogeneous group of service users with psychosis because the concept's applicability has been debated. The first study contributes to answering this question by showing that the great majority of a large, heterogeneous group of service users with psychosis across several clinical units reported that personal recovery was important to them, regardless of age, ethnicity, symptomatology, functioning, CTO status and time in mental health care. This indicates that recovery-oriented treatments are relevant in clinical practice for service users with psychosis in various mental health services. This implication is further supported by the finding that recovery-oriented treatments such as IMR, and related themes, such as help for coping with stress and illness and having a plan for early detection and prevention of relapse, were associated with the service users feeling more supported in their personal recovery process. Another important implication from this study is that clinicians should be attentive to service users with high levels of general symptoms and depression because these service users experienced less support for personal recovery, even though it is regarded as equally important to them.

The second paper showed that clinical recovery and personal recovery are related both when rated by clinicians and by service users, but more strongly when rated by service users. The results differed when clinicians and service users reported on the clinical subdomains. Among clinical subdomains, service user-reported depression and related themes, such as self-harm and suicidal thoughts, were associated with personal recovery, which did not appear when rated by clinicians. In addition, neither service user-rated nor clinician-rated psychotic symptoms showed any significant associations with personal recovery. This indicates that affective symptoms play a greater part in

personal recovery than the traditional symptoms of psychosis such as hallucinations and delusions, a finding that is in accordance with the previous research literature. This has clinical implications, showing that there is a need for more focus on treatment for depression among people with psychosis. In addition, more problems with relationships were associated with lower personal recovery, both when reported by clinicians and by service users. This indicates that improving social connections might be an area where service users and clinicians can meet and find important tasks for treatment, to strengthen the personal recovery of service users with psychosis. For mental health services, these results mean that it is important to facilitate the building and maintenance of a strong social support system for individuals with psychosis.

The results from Paper III showed that satisfaction levels among service users were higher than in similar, international studies. Service users who felt supported in their personal recovery were more satisfied with the care they received, which supports the implementation of recovery-oriented practices for service users with psychosis. For mental health clinicians, this means having an increased focus on recovery aspects, such as the personal goals of the individual service user, and emphasizing hope and empowerment when providing care for service users with psychosis. This finding also indicates that it is important to support service users with psychosis in their personal recovery. However, satisfaction with services was unrelated to quality of life or the actual level of personal recovery. Because this was a cross-sectional study, we did not have information on whether these concepts were related to satisfaction with services over time. Studies on the relations between satisfaction with services and self-reported outcomes among service users with psychosis are scarce and more follow-up studies measuring change over time are needed. As anticipated, service users on a CTO were significantly less satisfied with services. The low satisfaction reported by these service users adds further evidence for the importance of targeted interventions to improve satisfaction with services.

This thesis has some implications for future research. First, affective symptoms seem to play an important role both for personal recovery (Paper II) and experienced support for personal

recovery (Paper I). Therefore, the role of depression as a potential mediating variable behind factors related to personal and clinical recovery among service users with psychosis should be further investigated. Second, because participation in IMR treatment was associated with more perceived support for personal recovery (Paper I), and service users who felt more supported were more satisfied (Paper III), it would be interesting for future research to find out whether service users who receive IMR treatment are also more satisfied with services. Third, longitudinal studies investigating the relationship between the actual level of personal recovery, satisfaction with services and perceived support for personal recovery are needed. Such studies should also include clinical outcomes, to better explain how these constructs interact.

To sum up, personal recovery is important for people with psychosis. They need to live a good and meaningful life independent of severe and sometimes persistent symptoms. Focus on recovery, treatment of depression and strengthening of social support seem to be of importance. Providing recovery-oriented treatments may help clinicians support service users more actively in their recovery process. There is not necessarily a conflict between clinical, personal and social recovery, and mental health services should strive to strengthen all of them.

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The Importance of Personal Recovery and Perceived Recovery Support Among Service Users With Psychosis

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Objective: More knowledge is needed about whether personal recovery, as defined by the CHIME framework (connectedness, hope, identity, meaning and purpose, and empowerment), is considered important by service users with psychosis. This study examined the importance of personal recovery for a large, heterogeneous group of service users with psychosis and their perceived support from clinicians for personal recovery.

Methods: This cross-sectional study used baseline data from 321 service users with psychosis from 39 clinical units across Norway. The INSPIRE Measure of Staff Support for Personal Recovery (based on CHIME) was used to examine personal recovery and perceived support provided for recovery. Twenty support-for-recovery items were each rated on importance (yes or no) and on the extent of support received (5-point scale). Bivariate and multiple linear regression models assessed variables associated with rated importance and support.

Results: Most service users rated personal recovery items as important, regardless of their symptomatology and functioning. Previous experience with Illness Management and Recovery, knowledge about coping with stress and illness, and having a plan for early detection and prevention of relapse were significantly associated with higher perceived support. Higher self-reported depressive symptoms, lower score on the Global Assessment of Functioning symptom subscale, and male sex were significantly associated with less perceived support.

Conclusions: Most service users with psychosis found personal recovery important, regardless of symptomatology and functioning, which has implications for clinical practice and provides empirical evidence that recovery-oriented treatments are relevant for most service users with psychosis in various mental health services.

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Personal recovery refers to changes in one's attitude to life and illness, with emphasis on hope and the establishment of a meaningful life (1–3). Connectedness, hope, identity, meaning and purpose, and empowerment have been identified as key themes in the personal recovery concept—and have provided the acronym CHIME (4). Personal recovery has been contrasted with clinical recovery, where symptom reduction and increased functioning are the main treatment focus (2).

There has been debate over the relationship between personal recovery and the traditional clinical recovery goal of reduced symptomatology and improved functioning (5). This has important clinical implications. Some studies have shown that people with psychosis can participate in working toward personal recovery regardless of their clinical and functional competence (6), whereas others have shown that service users with more clinical symptoms and a lower functioning level prefer clinical recovery goals, such as reducing symptoms and confusion (7). Some have argued that personal recovery is more of a self-realization concept, in accordance with Maslow's pyramid (8, 9), and that for some

service users, more basic needs must be met before self-realization can occur (10, 11). Because CHIME is widely endorsed in the recovery literature (12), more knowledge

HIGHLIGHTS

- This study examined the importance of personal recovery for a large and heterogeneous group of service users with psychosis and their perceived support from mental health clinicians for personal recovery.
- Most participants rated personal recovery as important, regardless of their level of symptoms and functioning.
- Previous experience with Illness Management and Recovery was significantly associated with higher perceived support for recovery, whereas high levels of general symptoms and depression were significantly associated with less perceived support.
- The findings have implications for clinical practice, providing empirical evidence that recovery-oriented treatments are relevant for most service users with psychosis in various mental health services.

about the applicability of the framework is needed. An important step toward increased knowledge is to clarify whether personal recovery, as conceptualized by the CHIME framework, is considered relevant to most people with psychosis. A better understanding of this issue can help inform mental health services and the development of recovery-oriented practices. A few studies have used qualitative data to investigate the applicability of the CHIME framework, and results have supported the category structure (13, 14) but have also suggested an expanded conceptualization of recovery, in which experienced difficulties are more prominent (14). However, no studies have quantitatively examined the applicability of the framework.

Support of and focus on personal recovery have become increasingly important aspects of mental health services in many countries (5, 15). Lately, several recovery-oriented interventions have been developed and implemented in mental health systems internationally (16). For example, Illness Management and Recovery (IMR) treatment (17) aims to improve the ability of individuals with severe mental illness to better manage their illness in areas such as symptomatology, functioning, knowledge, progress toward goals, and hope (18, 19). However, one of the biggest obstacles to the implementation of recovery-oriented practices is the lack of knowledge about how recovery can be best supported (20). More knowledge about factors associated with perceived support for personal recovery is important for improving treatment and health service development and bridging the gap between the personal recovery vision and clinical practice.

This cross-sectional study aimed to answer the following research questions: Is personal recovery as defined by the CHIME framework considered important for service users with psychosis? Are there any differences between service users with different levels of rated importance? How much perceived support for personal recovery do the service users receive? And what covariates are associated with perceived support?

METHODS

Design

The study had a cross-sectional design, with baseline data from a Norwegian research project—a randomized trial of implementation of the Norwegian national clinical guidelines for treatment of psychosis (ClinicalTrials NCT03271242: “A pairwise randomized study on implementation of guidelines and evidence based treatments of psychoses”). The study was approved by the Regional Committee for Medical and Health Research Ethics (REK Sørøst B 2015/2169), following the principles in the Declaration of Helsinki.

Sample and Setting

Inclusion criteria were mental health service user, age ≥ 16 , and *ICD-10* diagnosis of psychosis (F20–29) (21). Exclusion criteria were an inability to understand and answer the questionnaires in Norwegian. A total of 325 service users participated in the project. Service users ($N=4$) with

missing data on the INSPIRE measure were excluded from analysis in this study. A total of 39 clinical units and hospital departments with outpatient clinics, day units, mobile teams, and inpatient wards from six health authorities across Norway participated, including three university hospitals.

Measures

Service user-rated measures. The INSPIRE Measure of Staff Support for Personal Recovery was used to examine the importance of personal recovery and to assess experienced support from a mental health clinician. The INSPIRE is a 27-item self-report questionnaire that measures perceived staff support for personal recovery (22). It consists of two subscales: support (20 items) and relationship (7 items). The relationship subscale was not completed in this study. The support items cover five domains: connectedness, hope, identity, meaning and purpose, and empowerment, which were identified through a systematic review and given the acronym CHIME (4). Participants first rate each support item for whether they consider it important for their recovery (e.g., “An important part of my recovery is: Feeling supported by other people”—yes or no). If yes, participants rate the extent of support they experience from their mental health clinician (“I feel supported from my worker with this”) on that item on a 5-point Likert scale (0, not at all; 1, not much; 2, somewhat; 3, quite a lot; and 4, very much).

The number of “yes-important” responses was used as the dependent variable to examine whether personal recovery was considered important and whether any differences existed between service users with different levels of rated importance. The support score was used as the dependent variable to examine perceived support for personal recovery and covariates associated with perceived support.

The Behavior and Symptom Identification Scale (BASIS-24) is a brief self-report measure of six domains of mental well-being and functioning, with good validity and reliability for assessing mental health status from a service user perspective (23, 24). Two of the six domains were used. The depression-functioning domain was included as a measure of the level of participants’ depressive symptoms. The substance abuse domain was also included and was transformed into a dichotomous variable (substance abuse versus no substance abuse). Abuse was defined as a score of 3 (often) or 4 (always) on any of the items in the domain. Item 22 (“Did anyone talk to you about your drinking and drug use?”) was excluded because it was considered irrelevant. Subdomain scores were calculated as described in the BASIS-24 instruction guide (25), providing a score between 0 and 4, with higher scores indicating more severe problems.

Participants’ satisfaction with life was assessed with one item from the Manchester Short Assessment of Quality of Life (MANSA) (26). “How satisfied are you with your life as a whole?” was rated on a 7-point scale (1, couldn’t be worse; 7, couldn’t be better).

Participants also rated six statements about their overall experience with getting help to manage their lives and their

illness for the past 6 months. The six statements pertaining to overall experience were named as follows. Setting goals: “I have been well trained in setting goals and working to achieve them.” Increased knowledge: “I have gained useful knowledge about stress, vulnerability, and social support.” Coping: “I have gained useful knowledge about coping with stress and illness.” Health service use: “I have gained useful knowledge about how to use health services better.” Medication: “I have gained useful knowledge about the medicines I use.” Early detection and prevention of relapse: “I have prepared a plan for the early detection of any signs of aggravation, and what should be done then.” The questions were rated on a 5-point scale (1, strongly disagree; 5, strongly agree), with an additional option of answering “not relevant.”

The participants also reported whether they had participated in IMR groups during the past 6 months (yes or no). This variable was named IMR experience.

Clinician-rated measures. The Clinical Global Impressions Scale (CGI) was originally developed for use in National Institute of Mental Health–sponsored clinical trials (27). This study included the CGI severity component (CGI-S), in which clinicians rate the severity of service users’ mental illness in the past 7 days on a 7-point scale (1, normal, not at all ill; 7, among the most extremely ill service users) (28).

The Global Assessment of Functioning Scale (GAF) is a standardized assessment of impairment caused by mental factors (29) in which clinicians rate the level of functioning and severity of service users’ symptoms on a scale from 1 to 100. Lower scores indicate more severe symptoms and lower levels of functioning. The split version of the scale used in this study has two subscales: symptom (GAF-S) and functioning (GAF-F) (30).

First, we identified covariates on service user characteristics (age, gender, ethnicity, community treatment order status, and mental health care history), service user–rated measures (depression–functioning, satisfaction with life, and substance abuse), and clinician-rated measures (GAF-S, GAF-F, and CGI-S). These were chosen on the basis of prior research as described above and were factors that we hypothesized might affect or mediate the outcomes in the study.

Second, because of the small part of the variation explained by these variables in the regression models, we included data on health service characteristics, such as the six statements pertaining to overall experience (overall experience) and IMR experience variables, to determine whether this explained more of the outcome. We hypothesized that experience with IMR and related recovery themes (overall experience) might increase both level of importance and perceived support.

Procedures

Clinicians at participating clinical units recruited service users and performed the clinical ratings. Questionnaires were administered to service users by the secretary or other personnel at the clinics. Service users were provided a place

to sit to fill out the questionnaires or took the questionnaire home with them. When the service user was finished, the questionnaire was put in an envelope, which was closed and returned to the clinic. Recruitment began in June 2016. Eligible service users already in contact with the clinic at the time and newly referred service users assessed to have psychosis were asked to participate. Recruitment continued until March 2017. Only participants who gave written informed consent were included.

Analysis

To assess the characteristics associated with number of yes-important answers and with the total support score, bivariate and multiple linear regression models were estimated. First, models with participant characteristics (age, gender, ethnicity, community treatment order status, and mental health care history), participant-rated measures (depression–functioning, satisfaction with life, and substance abuse), and clinician-rated measures (GAF-S, GAF-F, and CGI-S) were estimated. Next, covariates on service users’ overall experiences in managing their life and illness (overall experience statements) and whether they had participated in IMR (IMR experience) were added. Because participants were recruited to the study by different units, a hierarchical structure (cluster effect on unit level) could have been present in the data. Assessment by an intraclass correlation coefficient (ICC) found that there was essentially no cluster effect in outcome variables (ICC=0.001 for number of yes-important answers and ICC=0.01 for support score). Hence, no adjustment for within-unit correlations was needed. Correlation analysis did not identify any multicollinearity issues among covariates. Residual diagnostics did not show any significant deviations from linear regression model assumptions. Both bivariate and multiple models were estimated for cases with no missing values on covariates. Results with *p* values below 0.05 were considered statistically significant. The analyses were performed with SPSS, version 25.

Imputation of missing values on the GAF (N=40), the MANSA (N=8), and the overall experience (N=25) scales was performed by first generating the empirical distribution for each variable. A random number was drawn from that distribution and used to replace the missing value. The process was repeated until all missing values were imputed. Missing values on demographic variables were not imputed.

RESULTS

Sample Characteristics

The characteristics of the 321 participants are shown in Table 1.

Importance of Personal Recovery

The 321 participants rated the 20 INSPIRE support items as important or not important to their recovery. The percentages who gave a rating of important to each item ranged from 66% to 91% (Table 2). Ten (3%) participants rated all 20 items as not important. A total of 167 participants (52%)

TABLE 1. Characteristics of 321 participants with psychosis

Characteristic	Missing	N	%
Female	1	133	41
Ethnicity	5		
Norwegian		277	88
Other		39	12
Age (M±SD) ^a	11	40±12.7	97
Diagnosis	25		
Schizophrenia		158	53
Schizoaffective disorder		59	20
Other		79	27
GAF subscale (M±SD) ^b			
Symptom		53±13	100
Functioning		51±11.3	100
Under a community treatment order	7	42	13
Time in mental health care	14		
<6 months		20	7
6–23 months		28	9
2–5 years		50	16
6–10 years		64	21
>10 years		145	47
Education	11		
Did not complete primary school		9	3
Primary school		96	31
Upper secondary school		81	26
Vocational education		53	17
Higher education		62	20
Other		9	3
Satisfaction with life (M±SD) ^c	0	4.5±1.4	
Overall experience (M±SD) ^d			
Setting goals	1	3.4±1.1	
Increased knowledge	2	3.3±1.2	
Coping	2	3.3±1.1	
Health service use	1	3.2±1.1	
Medication	1	3.5±1.1	
Early detection and prevention of relapse	2	3.1±1.3	
Illness Management and Recovery experience	4	98	31

^a Range, 16–77.

^b The Global Assessment of Functioning (GAF) split version assessed symptom severity and psychosocial functioning. Possible scores range from 0–100, with higher scores indicating less severe symptoms and better functioning. Scores in the sample ranged from 26 to 90 on the symptom subscale and 20 to 85 on the functioning subscale.

^c Assessed with one item from the Manchester Short Assessment of Quality of Life. Possible scores range from 1 to 7, with higher scores indicating a greater satisfaction.

^d Possible ratings on receipt of help to manage life and illness in the six indicated areas range from 1 to 5, with higher ratings indicating more help.

gave an “important” rating to between 17 and 20 items. Figure 1 further illustrates participants’ ratings of items as important to personal recovery.

Differences Between Service Users With Different Levels of Rated Importance

A multiple linear regression model examined characteristics associated with ratings of important (Table 3). The model explained 4.8% of the total variation in the number of ratings of important. When covariates on service users’ overall experience with managing their life and illness for the past 6 months (the six statements) and information on participation in IMR groups for the past 6 months (IMR experience) were included, the model explained 8.1% of the total

variation. No significant associations were found in the multiple linear regression model.

Support for Personal Recovery

Participants rated the level of support they had experienced from their mental health clinician in terms of the 20 IN-SPIRE support items. The ratings per item ranged from 2.27 to 2.83 (Table 2), showing that, on average, the service users reported levels of support from somewhat (rating of 2) to quite a lot (rating of 3).

A multiple linear regression model examined characteristics associated with experienced support (Table 4). The model explained 14.8% of the total variation in experienced support. When covariates on service users’ overall experience with managing their life and illness for the past 6 months (the six statements) and information on participation in IMR groups for the past 6 months (IMR experience) were included, the multiple linear regression model explained 31.1% of the total variation in experienced support. In the multiple model, lower GAF-S score, higher depression-functioning score, and male sex were significantly associated with lower levels of perceived support. Also, higher scores on the coping statement (“I have gained useful knowledge about coping with stress and illness”) and the statement about early detection and prevention of relapse (“I have prepared a plan for the early detection of any signs of aggravation, and what should be done then”) were significantly associated with higher perceived support, as was having participated in IMR groups during the past 6 months (IMR experience).

DISCUSSION

This study showed that most service users with psychosis considered personal recovery, as operationalized with the CHIME framework, to be important. The study found no differences between service users who rated personal recovery as less important and those rating it as more important. Overall, service users experienced only moderate support for personal recovery from their mental health clinician. Higher self-reported depressive symptoms, lower GAF-S score, and male sex were significantly associated with less perceived support. Having participated in IMR groups, having gained knowledge about coping with stress and illness, and having a plan for early detection and prevention of relapse for the past 6 months were significantly associated with higher perceived support.

The main finding was that the great majority of a large, heterogeneous group of service users with psychosis across several clinical units reported that personal recovery was important to them, regardless of age, ethnicity, symptomatology, functioning, community treatment order status, and time in mental health care. This finding has implications for clinical practice, providing empirical evidence that recovery-oriented treatments are relevant for most service users with psychosis in various mental health services.

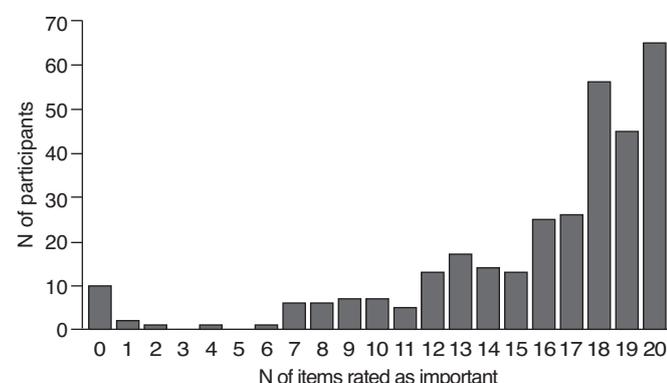
TABLE 2. Ratings by participants with psychosis of items related to support for personal recovery from the INSPIRE Measure of Staff Support for Personal Recovery

Domain and item	Importance to recovery				Perceived support from mental health clinician											
	Not important		Important		Rating ^a		Not at all		Not much		Somewhat		Quite a lot		Very much	
	N	%	N	%	M	SD	N	%	N	%	N	%	N	%	N	%
Connectedness																
Feeling supported by other people	37	11	284	89	2.83	.85	1	<1	16	6	78	28	125	44	64	22
Having positive relationships with other people	30	9	290	91	2.73	.89	4	1	22	8	73	25	140	48	51	18
Having support from people who use services	98	31	217	69	2.61	.92	5	2	12	6	84	39	78	36	38	17
Feeling part of my community	74	23	246	77	2.62	.99	4	2	33	13	61	25	103	42	45	18
Hope																
Feeling hopeful of my future	58	18	259	82	2.61	1.02	7	3	25	10	87	33	83	32	57	22
Believing I can recover	40	12	280	88	2.79	.96	6	2	16	6	80	29	107	38	71	25
Feeling motivated to make changes	68	21	250	79	2.62	1.02	9	4	22	9	73	29	96	38	50	20
Having hopes and dreams for the future	51	16	268	84	2.62	1.06	6	2	34	13	80	30	83	31	65	24
Identity																
Feeling I can deal with stigma	91	30	214	70	2.27	1.12	19	9	27	13	74	34	66	31	28	13
Feeling good about myself	70	22	247	78	2.59	.98	5	2	26	11	83	34	85	34	48	19
Having my spiritual beliefs respected	99	32	215	68	2.61	.96	7	3	16	7	67	31	89	41	36	17
Having my ethnic, cultural, racial identity respected	105	34	207	66	2.71	1.11	11	5	16	8	53	26	70	34	57	27
Meaning and purpose																
Understanding my mental health experiences	63	20	251	80	2.73	.10	8	3	18	7	65	26	102	41	58	23
Doing things that mean something to me	34	11	285	89	2.74	.91	3	1	24	8	75	26	125	44	58	20
Rebuilding my life after difficult experiences	52	16	264	84	2.78	.98	5	2	19	7	74	28	98	37	68	26
Having a good quality of life	40	13	278	87	2.69	.99	6	2	25	9	82	30	102	37	63	23
Empowerment																
Feeling in control of my life	55	17	262	83	2.70	1.03	8	3	26	10	63	24	104	40	61	23
Being able to manage my mental health	37	12	281	88	2.80	.94	4	1	20	7	72	26	117	42	68	24
Trying new things	104	32	216	68	2.53	.10	5	2	25	12	77	36	69	32	40	18
Building on my strengths	46	14	271	86	2.61	.98	9	3	20	7	89	33	102	38	51	19

^a Rated on a 5-point Likert scale (0, not at all; 4, very much).

However, although the great majority of participants reported personal recovery to be of high importance, they experienced only a moderate degree of personal recovery support from their mental health clinician. Several factors can influence the level of experienced support for recovery,

FIGURE 1. Number of items on support for personal recovery rated as important by 321 study participants with psychosis^a



^a Items were from the INSPIRE Measure of Staff Support for Personal Recovery.

not the least being the degree to which various clinicians and various mental health units are recovery oriented. Our findings show that previous experience with IMR and related themes, such as knowledge about coping with stress and illness and having a plan for early detection and prevention of relapse, were significantly associated with higher perceived support. This suggests that recovery-oriented treatments such as IMR and related themes may be effective in helping people feel supported in their process of personal recovery, a result in line with a recent meta-analysis showing greater improvement in personal recovery outcomes when service users were involved in recovery-oriented mental health treatment versus usual care or other types of treatment (31). Future research should examine perceived support and IMR treatment in relation to the different CHIME domains.

In addition, we found that higher self-reported depressive symptoms, lower GAF-S score, and male sex were significantly associated with less perceived support. This finding is of clinical importance. That is, it is important not to be blinded by high levels of general symptoms or depression, because these service users nevertheless believe that personal recovery is important. Although we cannot draw conclusions regarding causality among these associations, our results point

TABLE 3. Linear regression model of variables as associations of the number of items rated as important to personal recovery by 275 participants with psychosis^a

Variable	Bivariate model			Multiple model		
	Coefficient	95% CI	p	Coefficient	95% CI	p
Global Assessment of Functioning symptom subscale	-.01	-.06, .03	.515	-.02	-.09, .04	.471
Global Assessment of Functioning functioning subscale	-.00	-.05, .05	.862	-.01	-.08, .06	.799
Clinical Global Impressions Scale severity component	-.16	-.55, .24	.436	-.13	-.64, .38	.622
Service user-rated depression-functioning	-.62	-1.22, -.03	.040	-.56	-1.34, .23	.165
Service user-rated satisfaction with life	.29	-.12, .69	.161	-.14	-.64, .37	.596
Age	.02	-.03, .06	.410	.03	-.03, .08	.368
Female (reference: male)	1.00	-.12, 2.13	.081	.71	-.51, 1.93	.252
Other ethnicity (reference: Norwegian)	-.10	-1.84, 1.65	.915	-.42	-2.29, 1.45	.660
Under community treatment order (reference: no)	.84	-.78, 2.46	.307	1.00	-.74, 2.74	.259
Time in mental health care (reference: >10 years)						
<6 months	-.29	-2.67, 2.09	.812	.49	-2.05, 3.03	.705
6-23 months	.50	-1.59, 2.59	.637	1.26	-.97, 3.49	.267
2-5 years	1.09	-.49, 2.67	.177	1.42	-.35, 3.19	.116
6-10 years	-.83	-2.33, .66	.273	-.61	-2.28, 1.05	.469
Substance abuse (reference: no)	-.84	-2.46, .78	.308	-.24	-2.01, 1.53	.789
Overall experience						
Setting goals	.51	-.01, 1.04	.054	.34	-.34, 1.02	.325
Increased knowledge	.33	-.15, .81	.173	.11	-.78, 1.00	.806
Coping	.30	-.22, .81	.255	-.24	-1.13, .66	.216
Health service use	.06	-.46, .57	.831	-.42	-1.10, .25	.057
Medication	.60	.09, 1.11	.021	.58	-.02, 1.17	.253
Early detection and prevention of relapse	.38	-.07, .83	.100	.33	-.24, .90	.617
Illness Management and Recovery experience (reference: no)	-.53	-1.76, .70	.400	-.35	-1.73, 1.03	.617

^a The final sample was reduced to 275 because of missing values.

TABLE 4. Linear regression model of variables as associations of the sum of ratings of perceived support for personal recovery by 264 participants with psychosis^a

Variable	Bivariate model			Multiple model		
	Coefficient	95% CI	p	Coefficient	95% CI	p
Global Assessment of Functioning symptom subscale	.19	.03, .35	.021	.22	.01, .43	.039
Global Assessment of Functioning functioning subscale	.23	.04, .42	.017	-.06	-.29, .17	.617
Clinical Global Impressions Scale severity component	-.93	-2.41, .55	.218	.88	-.77, 2.52	.295
Service user-rated depression-functioning	-4.82	-7.01, -2.64	<.001	-3.79	-6.37, -1.21	.004
Service user-rated satisfaction with life	2.75	1.27, 4.22	<.001	-.21	-1.85, 1.43	.800
Age	.12	-.05, .28	.180	.07	-.11, .24	.473
Female (reference: male)	6.86	2.69, 11.03	.001	5.15	1.18, 9.11	.011
Other ethnicity (reference: Norwegian)	2.75	-3.78, 9.28	.408	2.87	-3.23, 8.96	.355
Under community treatment order (reference: no)	.65	-5.35, 6.65	.830	1.57	-4.03, 7.17	.582
Time in mental health care (reference: >10 years)						
<6 months	-5.35	-14.40, 3.70	.245	-3.28	-11.62, 5.05	.438
6-23 months	-6.04	-13.91, 1.84	.133	-2.99	-10.29, 4.30	.420
2-5 years	-3.34	-9.20, 2.53	.263	-3.06	-8.77, 2.66	.293
6-10 years	-1.07	-6.75, 4.62	.712	.21	-5.48, 5.52	.994
Substance abuse (reference: no)	-3.19	-9.17, 2.80	.295	4.33	-1.39, 10.05	.137
Overall experience						
Setting goals	5.67	3.81, 7.54	<.001	1.71	-.51, 3.93	.131
Increased knowledge	4.85	3.17, 6.52	<.001	.06	-2.82, 2.93	.969
Coping	6.33	4.58, 8.08	<.001	3.91	1.03, 6.80	.008
Health service use	4.39	2.56, 6.22	<.001	.86	-1.36, 3.07	.446
Medication	3.62	1.74, 5.49	<.001	.55	-1.37, 2.47	.572
Early detection and prevention of relapse	4.55	2.93, 6.17	<.001	2.13	.26, 4.00	.025
Illness Management and Recovery experience (reference: no)	.09	-4.55, 4.72	.971	4.62	.08, 9.16	.046

^a The final sample was reduced to 264 because of missing values.

to the importance of providing support for personal recovery, even among service users with high levels of general symptoms and depression. Future research should examine how patterns of importance ratings change over time and how perceptions of support are influenced by treatment.

Previous research has shown that affective symptoms seem to be more closely linked than psychotic symptoms to personal recovery and related themes, such as quality of life (5, 32, 33). Our finding that a higher level of self-reported depression was related to less perceived support underlines the important notion of an association between affective symptoms and personal recovery among service users with psychosis.

A major strength of this study was the broad group of participants with psychosis and the many different units that participated, which allowed us to gain information that can be generalized to a range of mental health services for service users with psychosis. A limitation of the study was the lack of data on the representativeness of the sample. Because participants were not randomly selected, they may not accurately represent the overall Norwegian population of individuals with psychosis. Other important limitations were the cross-sectional nature of the study, which prevented conclusions regarding causality, and that interrater reliability between the GAF scales and the CGI scale was not assessed.

CONCLUSIONS

This study showed that the great majority of a large, heterogeneous group of service users with psychosis across several clinical units reported that personal recovery was important for them, regardless of age, ethnicity, symptomatology, functioning, community treatment order status, and time in mental health care. This finding has implications for clinical practice, providing empirical evidence that recovery-oriented treatments are relevant for most service users with psychosis in various mental health services. Recovery-oriented treatments such as IMR, and related themes, such as help for coping with stress and illness and having a plan for early detection and prevention of relapse, appeared to help people with psychosis feel supported by clinicians in their personal recovery process. Specific attention should be given to service users with high levels of general symptoms and depression, because these service users experienced less support for personal recovery, even though personal recovery was equally important for them.

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Title: Associations between personal recovery and service user-rated versus clinician-rated clinical recovery, a cross-sectional study.

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Abstract

Background: This study examined the relationship between service user-rated personal recovery and clinician-rated and service user-rated clinical recovery. The relationships between different subdomains of clinical recovery and personal recovery were also assessed.

Methods: In total, 318 mental health service users with a psychosis diagnosis and their clinicians from 39 sites across Norway completed standardized questionnaires regarding personal recovery, clinical symptoms and psychosocial functioning. Regression models were used to investigate the relationship between personal and clinical recovery.

Results: Overall, clinical recovery was positively associated with personal recovery, when rated both by service users and by clinicians. Personal recovery was associated with lower levels of depression, self-harm and problems with relationships when rated by the service users. Among the subdomains rated by the clinicians, personal recovery was associated with fewer problems with relationships and higher aggressiveness.

Conclusions: These findings suggest that affective symptoms are associated with personal recovery, indicating the need for greater focus on depression treatment among people with psychosis.

Improving social connections is of importance for personal recovery, and might be an area where clinicians and service users can meet and find agreement on important treatment goals.

Key words: Psychosis, Personal recovery, Clinical recovery, PROM

Introduction

The recovery concept originates from two different traditions: the user movement and clinical practice (1). This duality has resulted in two opposing definitions, known as personal recovery and clinical recovery (2). Clinical recovery is the definition that has traditionally been the main focus of mental health services, with a focus on symptom reduction and increased functioning (3). The personal recovery concept as defined by service users differs from this medical conceptualization, and refers to changes in one's attitude to life and the illness with emphasis on hope and the establishment of a meaningful life (3-5). Connectedness, Hope and optimism, Identity, Meaning and Empowerment (given the acronym CHIME) have been identified as key processes supporting personal recovery (6).

Over the past decade, there has been a growing body of research on the relationship between personal and clinical recovery, with inconsistent findings. Several studies have found either a desynchronized (7), or no relationship (8) between symptom severity and self-reported personal recovery. One study found that although there were no significant correlations between personal recovery and symptom assessments, personal recovery seemed to serve as a protecting factor by moderating the relationship between positive symptoms and social functioning (9). Other studies have shown significant correlations between symptom severity and personal recovery (10, 11), and have suggested that even though clinical and personal recovery is not the same, the different concepts of recovery are complementary to each other (8, 10). A recent meta-analysis on the relationship between personal and clinical recovery found a small to-medium association between overall symptom severity and personal recovery (12). Insight into this association is important because it may inform mental health services what treatment strategies to provide.

As empirical research on the two concepts is growing, the complexity of the relationship between them has become more evident. For example, among different subdomains of clinical recovery,

affective symptoms have been shown to play a significant role in relation to personal recovery (10, 13) and subjective quality of life (14, 15), a concept closely related to personal recovery. In the meta-analysis of personal and clinical recovery, affective symptoms were shown to play a more important role for personal recovery than positive or negative symptoms (12). More research is needed to gain a better understanding of whether the attainment of some elements of recovery is dependent on the attainment of others, and if so, to identify important factors that affect the process of personal recovery. This will have implications for the future development of recovery-oriented practices.

However, research on the relationship between personal and clinical recovery often reflects this dichotomized view of recovery, with clinicians rating clinical recovery aspects and service users reporting their personal recovery. It has recently been argued that it might be meaningful to assess both service user and staff perspectives on clinical recovery alongside service user-rated assessments of personal recovery in mental health research (7). Investigating if and how self-reported clinical domains are associated with personal recovery could reveal important aspects for personal recovery. Service users and clinicians have independent perspectives on clinical recovery, and service users have differing perspectives on clinical and personal recovery (7, 16), a complexity that needs to be reflected in health service research design. Most research that has aimed to disentangle the complex relationship between personal and clinical recovery has only included clinician- or researcher-assessed clinical symptoms (10, 12, 17). Examining the role of service user-rated clinical symptoms in relation to personal and clinical recovery is relevant and could shed light on the relationship between these two concepts, thereby revealing new areas of clinical importance.

The aim of this study was to examine the relationship between personal recovery reported by service users and clinical recovery rated by both clinicians and service users. To that end, we addressed the following research questions: Is there a relationship between personal recovery and clinical recovery as rated by clinicians? Is there a relationship between personal recovery and clinical recovery as

rated by service users? Is there a relationship between personal recovery and different subdomains of clinical recovery when rated by clinicians and service users?

Methods

Design

This cross-sectional study used baseline data from the Norwegian research project *A pairwise randomized study on implementation of guidelines and evidence-based treatments of psychoses* (ClinicalTrials NCT03271242). This project is a cluster randomized trial focusing on the current implementation of the Norwegian national clinical guidelines for the treatment of psychosis, and on how the implementation of evidence-based treatments can be improved. The study was approved by the Regional Committee for Medical and Health Research Ethics (REK Sørøst B 2015/2169), and followed the principles laid down in the Declaration of Helsinki.

Setting and sample

A total of 325 mental health service users from six health authorities across Norway, including three university hospitals, were recruited. Thirty-nine clinical units and hospital departments with outpatient clinics, day units, mobile teams, and inpatient wards participated. The inclusion criteria were mental health service user aged 16 years or older and diagnosed with psychosis (ICD-10 F20-29) (18). The exclusion criterion was the inability to read or understand Norwegian. Service users with missing data (n = 7) were excluded, reducing the final study sample to N = 318.

Measures

Service user-rated personal recovery

The outcome measure used in this study to examine personal recovery was the *Questionnaire about the Process of Recovery (QPR)* (19), a 15-item self-report measure of recovery with adequate psychometric properties developed in collaboration between clinicians and service user researchers (20). QPR is one of the most widely used measures of personal recovery, and one of the measures with strongest evidence base (21). Items are rated on a 5-point Likert scale (0, “disagree strongly”; 1, “disagree”; 2, “neither agree nor disagree”; 3, “agree”; 4, “agree strongly”). The total sum score ranges from 0 (low recovery) to 60 (high recovery). Psychometric evaluation of the QPR in the current sample showed a one-factor solution with high scale reliability (Cronbach’s alpha 0.91).

Service user-rated clinical recovery

The Behavior and Symptom Identification Scale (BASIS-24) is a brief service user self-report measure of psychopathology and functioning that was developed to assess mental health treatment outcomes. It consists of 24 items assessing the following six symptoms and functioning domains: “depression/functioning”, “interpersonal relationships”, “self-harm”, “emotional lability”, “psychosis”, and “substance abuse”. The scale has shown good validity and reliability for assessing mental health status and functioning from the perspective of service users (22, 23). The BASIS-24 is one of the most frequently used patient-reported instruments to evaluate mental health and psychosocial functioning (24), which also incorporates symptoms of psychosis. The six domains were included as clinical recovery subdomains and the sum scores of all six domains were included as main measures of service user-rated clinical symptoms. Scores were calculated as described in the BASIS-24 instruction guide (25), providing a score between 0-4 with higher scores indicating more severe problems.

Clinician-rated clinical recovery

The Health of the Nation Outcome Scale (HoNOS) (26) is a 12-item staff-rated measure of mental health and psychosocial functioning. Each item is rated on a 5-point severity scale from 0 (no problem) to 4 (severe to very severe problem). The scale was developed to measure outcomes routinely for adults with mental illness. It is a widely used routine outcome measure in mental health services in many countries (27), and has been regarded as adequate for assessing outcomes for different service user groups on a range of mental health-related constructs, and for routinely monitoring outcomes (28). The total score (0-48) of all 12 items was included as the main measure of clinician-rated clinical recovery, while nine of the 12 items were included as clinical recovery subdomains variables. The three items not included (physical illness or disability problems, problems with living conditions and problems with occupation and activities) were excluded because they were considered to measure somatic health and actual access to resources rather than clinical recovery. The clinicians were instructed to complete a net-based training course of the HoNOS scale and the instruction manual was included in the questionnaire.

The Global Assessment of Functioning Scale (GAF) is a standardized measure assessing impairments caused by mental factors (29). Clinicians rate the level of functioning and severity of service users' symptoms on a scale between 1-100 with lower scores indicating more severe symptoms and a lower level of functioning. The split version of the scale used in this study has two subscales: symptom (GAF-S) and function (GAF-F) (30). It was mandatory to use the GAF scales in the participating mental health clinics at the time of the study, and each clinic were responsible for training their clinicians.

Covariates

Age and gender were included as covariates in the analyses.

Procedure

Service users were recruited by clinicians working at the participating mental health units. Eligible service users already in contact with the clinic at the time, and newly referred service users assessed to have psychosis, were asked to participate. Only participants who gave written informed consent were included. All participants were evaluated to be capable of giving informed consent.

The clinician providing the treatment/case manager performed the clinical ratings, and questionnaires were administered to the service users by the clinicians or other personnel at the clinics. Service users were given a place to sit and fill out the questionnaire or took it home with them. When finished, the questionnaires were placed in a sealed envelope, and returned to the clinic. The recruitment period lasted from June 2016 to March 2017.

Analysis

The sociodemographic and clinical service user characteristics are presented as frequencies and percentages or means and standard deviations (SDs), as appropriate (Table 1). Pearson's correlations among the sum/total and subdomain scores of BASIS-24 and HoNOS were calculated to assess the extent to which these scales correlated (Table 2).

Five linear regression models were estimated to assess the association between personal recovery (QPR) and service user-rated clinical recovery (BASIS-24) and clinician-rated clinical recovery (HoNOS). The BASIS-24 sum and subdomains scores were included in Model 1 and Model 2, respectively (Table 3). The HoNOS total score and the nine pre-chosen HoNOS items were included in Model 3 and Model 4, respectively (Table 4). The sum and subdomains scores of the two measures were analysed in separate models, since including them in the same model would imply multicollinearity issues. Finally, the BASIS-24 sum score and the HoNOS total score were included in Model 5 (Table 5). GAF-symptom, GAF-function, age and gender were entered as covariates in all the models. Bivariate and multiple models were estimated. The intra-class correlation coefficient was

estimated to assess the degree of clustering due to data collection from different mental health units. As no cluster effect was identified, no adjustment was needed in the regression models. All tests were two-sided, and results with p-values ≤ 0.05 were considered statistically significant.

Imputation of missing values on the GAF-S (n = 39), GAF-N (n = 39) and QPR (n = 24) was performed by first generating the empirical distribution for existing values. A random number was drawn from that distribution and used to replace the missing value. The process was repeated until all missing values were imputed. All regression models were estimated for service users with no missing values on the included covariates.

Due to many missing values, mainly in the HoNOS scale (N = 65), those included and not included in the regression analyses were compared. The differences between continuous variables (QPR, BASIS-24 sum score, GAF-S, GAF-F and age) were assessed by independent sample t-tests, while categorical variables (gender, diagnosis, ethnicity and being under a Community Treatment Order) were compared by χ^2 -tests.

Results

Sample characteristics

The mean age of the 318 participants was 40 years (SD = 12.7) and 41% (n = 130) were female. The majority of the participants were Norwegian (n = 274, 88%), and 53% (n = 145) had a diagnosis of schizophrenia. A more detailed description of the participants' sociodemographic characteristics is shown in Table 1.

Table 1. Sociodemographic characteristics of the participants (N = 318)

Characteristics	
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Gender N (%)	
Female	130 (41)
Male	187 (59)
Ethnicity N (%)	
Norwegian	274 (88)
Other	39 (12)
Age (years) mean (SD)	40 (12.7)
Diagnosis N (%)	
Schizophrenia	145 (53)
Schizoaffective disorder	54 (20)
Other	74 (27)
Community Treatment Order N (%)	
Yes	42 (13)
No	269 (87)
GAF symptom mean ^a (SD)	52 (13.0)
GAF function mean ^a (SD)	51 (11.4)
QPR total score mean ^b (SD)	41 (10.3)
BASIS-24 total score mean ^c (SD)	1.21 (0.66)
Emotional lability mean (SD)	1.55 (0.90)
Psychosis mean (SD)	1.05 (1.04)
Depression/functioning mean (SD)	1.31 (0.94)
Relationships mean (SD)	1.60 (0.98)
Self-harm mean (SD)	0.34 (0.65)
Substance abuse mean (SD)	0.43 (0.68)
HoNOS total score mean ^d (SD)	7.67 (4.83)
Aggressiveness mean (SD)	0.35 (0.61)
Non-accidental self-injury mean (SD)	0.17 (0.51)
Problem drinking or drug-taking mean (SD)	0.36 (0.88)
Cognitive problems mean (SD)	0.85 (0.80)
Hallucinations and delusions mean (SD)	1.08 (1.16)
Depressed mood mean (SD)	0.87 (0.90)
Other mental and behavioural problems mean (SD)	1.33 (1.15)
Problems with relationships mean (SD)	1.58 (1.10)
Problems with activities related to daily living mean (SD)	1.09 (0.97)

- a) The Global Assessment of Functioning Scale (GAF) split version
b) Questionnaire about the Process of Recovery (QPR)
c) The Behavior and Symptom Identification Scale (BASIS-24)
d) Health of the Nation Outcome Scale (HoNOS)

Correlations between BASIS-24 and HoNOS total scores and subdomains

Pearson's correlations assessing the association between the BASIS-24 and HoNOS scales are presented in Table 2. The results showed weak to moderately strong correlations (ranging from -.01 to .60).

Table 2. Correlations between BASIS-24 and HoNOS total score and the subdomains

Correlations	Basis-24 sum score	Substance abuse	Self-harm	Depression/functioning	Psychosis	Emotional lability	Relationships
HoNOS total score	.52	.26	.31	.49	.40	.28	.22
Aggressiveness	.21	.15	.01	.17	.12	.18	.08
Non-accidental self-injury	.27	-.03	.37	.23	.15	.22	.06
Problem drinking or drug-taking	.13	.60	.04	.05	.16	-.01	.07
Cognitive problems	.20	.05	.19	.19	.22	.09	.10
Hallucinations and delusions	.34	.08	.18	.28	.50	.19	.11
Depressed mood	.40	.08	.26	.40	.21	.24	.18
Other mental and behavioral problems	.41	.11	.24	.43	.28	.25	.10
Problems with relationships	.36	.16	.15	.35	.18	.12	.27
Problems with activities related to daily living	.34	.07	.20	.34	.19	.19	.19

Relationship between personal recovery and service user-rated clinical recovery

Table 3 shows the results from the regression analyses assessing the association between personal recovery and service-user rated clinical symptoms. In the multiple model, a higher general level of service user-rated clinical recovery (lower BASIS-24 sum score) was significantly associated with higher personal recovery (higher QPR score) (Model 1). Among the clinical subdomains, lower scores on depression/functioning and self-harm and fewer problems with relationships were significantly associated with higher personal recovery (Model 2).

Table 3

Relationship between personal recovery and clinician-rated clinical recovery

Table 4 shows the results from the regression analyses assessing the association between personal recovery and clinician-rated clinical symptoms. In the multiple model, higher clinician-rated clinical

recovery (HoNOS total score) was significantly associated with higher personal recovery (Model 3). Among the clinical subdomains, fewer problems with relationships and higher aggressiveness were significantly associated with higher personal recovery (Model 4).

Table 4

Relationship between personal recovery and service user-rated vs clinician-rated clinical recovery

In the bivariate analyses (Table 5), personal recovery seemed to be associated with both clinical recovery when reported by service users and clinicians. However, personal recovery was more strongly related with service user-rated clinical recovery than with clinician-rated recovery, as shown in the multiple analysis. This was also supported by standardized regression coefficients (not shown).

Table 5

No significant differences were found between the dropouts and the remaining participants when compared by independent sample t-tests and χ^2 -tests.

Discussion

The present study examined the relationship between personal recovery and clinical recovery and its subdomains, as rated by clinicians and service users. The results revealed that personal recovery was significantly associated with clinical recovery, as rated by both service users and clinicians.

Among the service user-rated clinical subdomains, fewer depressive symptoms and everyday coping (depression/functioning), being able to manage social situations and having other people to turn to (Problems with relationships), and fewer suicidal thoughts/thoughts about self-harm (Self-harm) were related to higher personal recovery. Neither the service user- nor clinician-rated subdomain of psychotic symptoms showed any significant associations with personal recovery. This finding is

consistent with previous studies showing that affective symptoms are more strongly associated with personal recovery than are other psychosis-specific symptoms, such as hallucinations and delusions (12). However, it has been suggested that psychotic symptoms may increase distress, which in turn, has a negative influence on personal recovery (31). Therefore, the role of depression as a potential mediating variable behind factors related to personal and clinical recovery among service users with psychosis should be further investigated. This finding also has clinical implications, providing further support for the already highlighted need for more investigation and treatment for depressive symptoms among people with psychosis (32). As depression among people with psychosis has been consistently and robustly linked to insight (33), the role of insight in the relationship between depression and personal recovery should be further investigated.

Among the clinician-rated clinical subdomains, fewer problems with relationships and higher aggressiveness were significantly associated with higher personal recovery. Our study shows that the results differ when clinicians and service users report on the importance of different clinical subdomains for personal recovery. When service users report on this, it seems that the subdomains regarding depression and related themes such as self-harm and suicidal thoughts play an important role in personal recovery; this does not appear when rated by clinicians. This could be due to an underestimation of affective symptoms and the fact that affective symptoms often are seldom given enough consideration in clinical treatment, as highlighted by previous research on the role of depression in schizophrenia (32). However, problems with relationships appeared significant when reported by both clinicians and service users. This finding supports previous research, which has demonstrated the importance of social contact for personal recovery (6, 34). It is also clinically relevant, emphasizing the need for health-care services to facilitate the building and maintenance of a strong social supportive system for individuals with psychosis. Improving social connections can both be aimed at the individual level such as strengthening the individuals' relations to friends and family, and at a more structural level such as being part of the society. For example, reducing conflict and strengthen social support from family members as an intervention for people with psychosis have a

strong evidence-base when it comes to clinical recovery (35). However, the implementation level of structured family interventions for people with psychosis are poor, in Norway (36) as well as internationally (37). Other interventions with a significant evidence base worth mentioning are Individual Placement and Support approach to employment and the development of Recovery Colleges (38). Our results show that improving social relationships might be an area of great relevance for personal recovery, as it is supported by findings from both clinicians and service users. The importance of other people, the social environment, and society for personal recovery has been a topic of discussion, with some defining it as a separate kind of recovery, termed “social recovery” (39), while others define it as a part of personal recovery, or even as a part of clinical recovery in terms of functioning. Regardless of how it is conceptualized, improving social connections seems to be an important area for mental health services to focus on to strengthen the personal recovery of service users with psychosis. In addition, social support has proven to be related to both subjective and objective markers of recovery (40).

The finding that clinician-rated higher aggressiveness was significantly associated with higher personal recovery, was surprising and unexpected. Although the finding could be a sign of overestimation in the regression model (as pointed out in the limitation section), it could also be a reflection of a high level of assertiveness in the person, which in turn could be associated to an ability for mobilization and a strive for a better life. Another surprising finding is that problems with alcohol or drugs did not appear to be significantly related to personal recovery in our sample, which should be further investigated.

Our findings suggest that personal recovery is more strongly related to service user-rated clinical recovery than to clinician-rated recovery. However, the service-user domains of importance are primarily social relations and depressive symptoms. This is of clinical importance, as it shows that from the user perspective, these two aspects are more important for personal recovery than are typical psychosis-specific symptoms such as hallucinations and delusions.

Strengths and limitations

A major strength of this study is the broad group of participants with psychosis that were recruited from “real-world” clinical practice in many different units, which increases the generalizability of the results. However, as the study participants were not randomly selected, the sample might not be representative of the Norwegian population of individuals with psychosis. Therefore, our results should be interpreted with caution. One possible limitation of the study is the common rater effect, a known potential bias when including several measures from the same respondent. However, correlation analysis between QPR and BASIS-24 total score showed only a moderate correlation, speaking against such bias. In addition, two different measures were used to assess clinical recovery were used, which might have introduced some uncertainty in our comparisons. In addition, the unexpected significant finding of the “aggressiveness” subscale might be a sign of overestimation in the model; this should be taken into consideration. Finally, given the cross-sectional nature of this study, no casual interpretations were possible.

Conclusions and implications

Clinical recovery was significantly associated with personal recovery when rated by both clinicians and service users, but more strongly when rated by service users. The results differed when clinicians and service users reported on the clinical subdomains. Service user-reported depression and related themes such as self-harm and suicidal thoughts were associated with personal recovery; this association did not appear when rated by clinicians. In addition, neither service user-rated nor clinician-rated psychotic symptoms showed any significant associations with personal recovery. These findings suggest that affective symptoms are more strongly associated with personal recovery than are psychosis-specific symptoms such as hallucinations and delusions. This finding has clinical

implications, suggesting the need for greater focus on treatment for depression among people with psychosis. However, problems with relationships appeared significant when reported by both clinicians and service users. This finding indicates that improving social connections might be an area of clinical importance when it comes to strengthening the personal recovery of service users with psychosis, and that it is important for mental health-care services to facilitate the building and maintenance of a strong social support system for individuals with psychosis.

Declarations

Ethics approval and consent to participate

The study was approved by the Regional Committee for Medical and Health Research Ethics (REK Sørøst B 2015/2169), and followed the principles of the Declaration of Helsinki. Participation was voluntary and based on written informed consent. All participants were evaluated to be capable of giving informed consent.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request

Competing interests

The authors declare that they have no competing interest.

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Authors' contributions

The study was planned and conducted by HKC, KSH, and TR. JSB carried out the analysis, and RSF, HKC, KSH and TR analyzed and interpreted the data. RF drafted the manuscript, and HKC,KSH,TR,JSB,MS and RF revised and approved the final manuscript

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Table 3. Results of linear regression models for the association between personal recovery (QPR) and service user-rated clinical recovery (BASIS-24)

Variables	Model 1, N = 295						Model 2, N = 305					
	Bivariate models			Multiple model			Bivariate models			Multiple model		
	Regr. coeff	95% CI	p	Regr. coeff	95% CI	p	Regr. coeff	95% CI	p	Regr. coeff	95% CI	p
BASIS-24 sum score	-8.51	-10.31;-6.99	.001	-8.47	-10.12;-6.83	.001						
Emotional lability							-3.01	-4.26;-1.75	.001	0.67	-0.67;2.01	.325
Psychosis							-2.85	-3.91;-1.78	.001	-0.12	-1.21;0.97	.829
Depression/functioning							-5.36	-6.46;-4.27	.001	-3.89	-5.31;-2.47	.001
Relationships							-4.34	-5.41;-3.27	.001	-3.00	-4.06;-1.95	.001
Self-harm							-5.61	-7.41;-3.82	.001	-2.61	-4.41;-0.82	.004
Substance abuse							-1.70	-3.35;-0.05	.044	-0.53	-2.01;0.95	.481
Age	0.02	-0.07;3.09	.558	-0.01	-2.05;2.03	.993	0.04	-0.06;0.13	.444	-0.02	-0.10;0.06	.577
GAF-symptom	0.11	0.02;0.20	.015	-0.02	-0.13;0.08	.662	0.10	0.01;0.19	.024	-0.01	-0.11;0.09	.803
GAF-function	0.19	0.09;0.29	.001	0.05	-0.07;0.17	.446	0.19	0.09;0.29	.001	0.03	-0.09;0.15	.620
Gender												
Male-ref	0						0			0		
Female	0.71	-1.67;3.09	.558	-0.01	-2.05;2.03	.993	0.81	-1.53;3.15	.497	-0.74	-2.80;1.32	.482

Table 4. Results of linear regression model for associations between personal recovery (QPR) and clinician-rated clinical recovery (HoNOS)

Variables	Model 3, N = 246						Model 4, N = 246					
	Bivariate models			Multiple model			Bivariate models			Multiple model		
	Regr. coeff	95% CI	p	Regr. coeff	95% CI	p	Regr. coeff	95% CI	p	Regr. coeff	95% CI	p
HoNOS total score	-0.66	-0.91; -0.40	.001	-0.57	-0.89; -0.25	.001						
Aggressiveness							-0.19	-2.41; 2.02	.864	2.41	0.08; 4.74	.043
Non-accidental self-injury							-3.23	-5.60; -0.86	.008	-1.38	-3.90; 1.14	.283
Problem drinking or drugtaking							-0.93	-2.39; 0.54	.216	-0.24	-1.73; 1.25	.750
Cognitive problems							-1.92	-3.48; -0.35	.017	-0.39	-2.13; 1.36	.665
Hallucinations and delusions							-1.79	-2.88; -0.69	.002	-0.83	-2.10; 0.43	.195
Depressed mood							-2.60	-3.98; -1.22	.001	-0.82	-2.52; 0.87	.340
Other mental and behavioral problems							-1.63	-2.73; -0.52	.004	0.13	-1.34; 1.59	.865
problems with relationships							-3.11	-4.21; -2.00	.001	-2.28	-3.69; -0.87	.002
problems with activities related to daily living							-2.16	-3.46; -0.87	.001	-0.19	-1.81; 1.43	.818
Age	0.04	-0.06; 0.13	.479	-0.01	-0.11; 0.09	.858	0.04	-0.06; 0.13	.479	0.03	-0.08; 0.13	.611
GAF-symptom	0.13	0.03; 0.23	.009	-0.06	-0.21; 0.09	.425	0.13	0.03; 0.23	.009	-0.05	-0.21; 0.11	.508
GAF-function	0.20	0.10; 0.31	.001	0.12	-0.05; 0.29	.174	0.20	0.10; 0.31	.001	0.11	-0.08; 0.29	.259
Gender												
Male-ref	0			0				0			0	
Female	1.64	-0.93; 4.20	.209	0.90	-1.61; 3.41	.482	1.64	-0.93; 4.20	.209	0.76	-1.82; 3.34	.562

Table 5. Results of linear regression model for associations between personal recovery (QPR), clinician-rated clinical recovery (HoNOS) and service user-rated clinical recovery (BASIS-24).

Variables	Model 5, N = 235						
	Bivariate models			Multiple model			
	Regr. coeff	95% CI	P	Regr. coeff	95% CI	p	
BASIS-24 sum score	-8.16	-9.90; -6.43	.001	-7.87	-9.97; -5.77	.001	
HoNOS total score	-0.64	-0.91; -0.38	.001	-0.07	-0.39; 0.26	.688	
Age	0.01	-0.09; 0.12	.795	-0.04	-0.13; 0.05	.386	
GAF-symptom	0.15	0.05; 0.25	.005	-0.03	-0.17; 0.12	.714	
GAF-function	0.21	0.10; 0.32	.001	0.04	-0.12; 0.20	.635	
Gender							
Male-ref	0			0			
Female	1.43	-1.23; 4.08	.291	0.28	-2.07; 2.64	.813	

RESEARCH ARTICLE

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Relationship between satisfaction with mental health services, personal recovery and quality of life among service users with psychosis: a cross-sectional study

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Abstract

Background: Mental health policy internationally emphasizes patient centredness and personal recovery. This study investigated the relationship between satisfaction with mental health services among service users with psychosis in Norway, and personal recovery, perceived support for personal recovery, and quality of life.

Methods: Cross-sectional data were collected from 292 service users diagnosed with psychosis from 39 clinical sites across Norway. Satisfaction with services was assessed using the Client Satisfaction Questionnaire-8. A linear mixed model was estimated to explore the relationship between satisfaction with services and preselected covariates, and to control for confounding factors.

Results: A large majority of participants (89%) reported moderate-to-high levels of satisfaction. Satisfaction with services was positively associated with perceived support for personal recovery, but not with personal recovery or quality of life. In addition, service users under a Community Treatment Order (CTO) were significantly less satisfied than those who were not.

Conclusions: Satisfaction levels among service users were higher compared with similar, international studies. Those who feel supported in their personal recovery were more satisfied with the care they receive, which support the need for implementation of recovery-oriented practices for service users with psychosis. However, satisfaction with services was not related to service user-rated quality of life or level of personal recovery; thus, more follow-up studies are needed. The lower satisfaction of service users placed under CTOs shows the importance of targeted interventions to improve satisfaction with services among this group.

Trial registration: NCT03271242, date of registration: 5 sept. 2017.

Keywords: Service satisfaction, Mental health service user, Personal recovery, Quality of life, Community treatment order

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Background

Satisfaction with services is widely regarded as an important process variable and quality indicator in mental health care [1, 2]. In general, satisfied service users are more adherent to treatment and benefit more from care [1], while those who are less satisfied have poorer treatment outcomes [3]. Satisfaction with services can be influenced by user characteristics and by treatment and services aspects [4]. Among socio-demographic characteristics the only feature consistently linked with satisfaction with care has been service user age, with higher age associated with higher satisfaction. Clinical characteristics and self-reported outcome measures have shown more substantial correlations. Higher symptom level (especially more depressive symptoms), personality disorder diagnosis, and lower self-reported quality of life have been found to be associated with less satisfaction with care [5]. Among service characteristics, only coercive treatment and a perceived negative therapeutic relationship have been consistently found to impact satisfaction with care [1, 3]. Coercion appear to have a key role in ratings of satisfaction [4]. Overall, when evaluating satisfaction with services, the identified confounders are age, legal status of treatment, and severity of illness or symptoms, particularly depressive symptoms [1].

Satisfaction with services is also an important quality indicator among services users with psychosis [5]. Among service users with psychosis, higher satisfaction rates have been associated with clinical outcome benefits, such as reduction in positive psychotic symptoms at follow-up [6], and lower satisfaction rates have been associated with more involuntary admissions, more severe psychopathology, and more unmet needs [7].

Satisfaction rates for service users with psychosis seem to differ between countries. A previous study of 654 Dutch service users with psychosis showed satisfaction rates with mental health services ranging among low (19.4%), intermediate (48.9%), and high (31.7%) [6]. A total of 125 Israeli service users with psychosis reported themselves as dissatisfied (16.8%), barely satisfied (45.6%), moderately satisfied (25.6%), or highly satisfied (12%) [8]. Among 130 Kuwaiti service users with schizophrenia, the dissatisfaction rate was 21.5% [9], consistent with rates from a multisite European study showing dissatisfaction ranging from 26 to 42.2% among service users with psychosis at five sites [7].

Although satisfaction with services has been consistently associated with self-reported outcomes such as quality of life among the general mental health population [1], among service users with psychosis the relation between satisfaction and self-reported outcome measures is inconclusive and underexplored. One study showed a significant association between dissatisfaction with care and lower self-reported quality of life [7], while

another showed positive associations between satisfaction and quality of life at baseline but not at follow-up [6]. In addition, another study among people with schizophrenia found that treatment satisfaction was high even though life satisfaction was low [10]. In sum, while objective clinical benefits of high service satisfaction seem apparent among service users with psychosis, studies show varying associations between satisfaction with services and other self-reported outcomes, such as quality of life and life satisfaction.

Furthermore, no attempts have been made to examine satisfaction with services and its relationship with self-reported personal recovery, although some studies have investigated satisfaction with recovery-related topics such as shared decision-making [11] and empowerment [12]. As healthcare systems in developed countries evolve from a paternalistic to a patient-centred approach [13] concepts like quality of life and personal recovery have received increased attention. The personal recovery concept originates from the user movement [14], and focuses on prioritizing more personal and subjectively meaningful treatment goals [15]. It is often contrasted to clinical recovery, the definition traditionally used in mental health services, which focuses on symptom reduction and increased function [16]. While clinical recovery has traditionally been the primary goal in the treatment of people with psychosis, supporting and focusing on personal recovery has become a key aim in mental health services in many countries [17] and has had a considerable impact on health care policy. The World Health Organization's Comprehensive Mental Health Action Plan 2013–2020 [18], promotes a recovery orientation in mental health systems, emphasizing that the central issue for mental health services is to expand the understanding and knowledge of promoting recovery. In Norway, recent central political guidelines from the Ministry of Health and Care Services (Helse- og omsorgsdepartementet), have placed emphasis on developing more patient-centred care [19], consistent with requests from user organizations [20]. In the Norwegian national guidelines on assessment and treatment of persons with psychoses (2013), a recovery approach is emphasized as a general principle for good practice [21], and recent years have seen an increase in implementation of development recovery-oriented practices in Norway such as Illness Management and Recovery (IMR) [22] ACT/FACT –teams [23] and Individual Placement and Support (IPS) [24]. A previous study showed that a great majority of Norwegian service users with psychosis reported that support for personal recovery were important for them (article in press).

To sum up, while satisfaction with services is associated with beneficial clinical outcomes among individuals with psychosis, studies investigating the relationship

between satisfaction and quality of life or life satisfaction have generated inconsistent findings. Furthermore, no study to date has investigated the relationship between satisfaction with services and personal recovery. If personal recovery and patient centeredness are to be the focus of mental health services policy, then examining their relations to user satisfaction with services is necessary. This has important clinical implications for mental health services since satisfaction with services should impact these important aspects of the lives of those with psychosis, in addition to more traditional clinical outcomes like reduced hospitalization and symptoms.

The aims of this study were to examine the level of satisfaction with services among service users with psychosis across Norway, and to examine the relations between satisfaction with services and personal recovery, perceived support for personal recovery and quality of life. Based on existing findings on quality of life and the importance of the therapeutic relationship for satisfaction with services, we hypothesized that higher quality of life and more perceived support for personal recovery would be positively associated with higher satisfaction with services. We also expected that service users who are highly satisfied with services would report higher levels of personal recovery. Finally, we hypothesized that users in a Community Treatment Order (CTO) would be less satisfied with their care.

Methods

Design

This is a cross-sectional study, analyzing baseline data from the Norwegian research project A Pairwise Randomized Study on Implementation of Guidelines and Evidence-based Treatments of Psychoses (ClinicalTrials NCT03271242). The study was approved by the Regional Committee for Medical and Health Research Ethics (REK Sørøst B 2015/2169), and followed the principles of the Declaration of Helsinki.

Setting and sample

A total of 325 mental health service users from six health authorities across Norway, including three university hospitals, were recruited. Thirty-nine clinical units and hospital departments with outpatient clinics, day units, mobile teams, and inpatient wards participated. Further details about the participating units are available in the study protocol (ClinicalTrials NCT03271242). Inclusion criteria were: mental health service user diagnosed with psychosis (ICD-10 F20–29) (World Health Organization, 1992), and aged 16 years or older. The only exclusion criterion was being unable to understand and answer the questionnaires in Norwegian. Thirty-three service users with missing data were excluded, reducing the final study sample to $N = 292$.

Measures

Outcome measure

The Client Satisfaction Questionnaire-8 (CSQ-8) (Table 1) [25] is an eight-item questionnaire used to measure patient's global satisfaction with services, which has shown good psychometric properties. The CSQ-8 measures general satisfaction on eight scaled items from 1 (= poor) to, 4 (= excellent) resulting in a total score range of 8–32. Level of satisfaction is classified as low [8–20], intermediate [21–25], or high [26–30]. Psychometric evaluation of CSQ-8 in the current sample showed high scale reliability (Cronbach's alpha 0.91).

Covariates

The Questionnaire about the Process of Recovery (QPR) [27] was used to examine personal recovery level. The QPR is a 15-item self-report measure of recovery developed through collaboration between clinicians and service user researchers, which has shown adequate psychometric properties [28]. Items are rated on a five-point Likert scale from 0 (Disagree strongly) to 4 (Agree strongly). Total sum score ranges from 0 (low recovery) to 60 (high recovery). Psychometric evaluation of QPR in the current sample showed a one factor solution with high scale reliability (Cronbach's alpha 0.91).

Perceived support for personal recovery was examined using the 20-item support subscale from the *INSPIRE* measure of staff support of personal recovery [29]. Each service user-rated subscale item is first rated on whether it is important for the participant's recovery (e.g. "An important part of my recovery is ... feeling hopeful about my future", (Yes/No). If yes, the participant rates the support they receive from their health service provider for this item ("I feel supported by my worker with this") on a five-point Likert scale from 0 (Not at all) to 4 (Very much). A total support score is calculated for each participant as described in the *INSPIRE* scoring instruction guide (<http://www.researchintorecovery.com/INSPIRE#s12>) and ranges

Table 1 Items of the Client Satisfaction Questionnaire (CSQ-8) (Range 8–32)

1. How would you rate the quality of service received?
2. Did you get the kind of service that you wanted?
3. To what extent has our program met your needs?
4. If a friend were in need of similar help, would you recommend our program to him or her?
5. How satisfied are you with the amount of help you have received?
6. Have the services you received helped you to deal more effectively with your problems?
7. In an overall, general sense, how satisfied are you with the service you have received?
8. If you were to seek help again, would you come back to our program?

from 0 (low support) to 100 (high support). Psychometric evaluation of the INSPIRE in the current sample showed a one factor solution, with a good internal consistency (Omega coefficient 0.96) [30].

Quality of life was assessed using a single item (Item 1, Life as a whole) from the *Manchester Short Assessment of Quality of Life (MANSA)* [31]: “How satisfied are you with your life as a whole?” which was rated on a seven-point scale from 1 (Couldn’t be worse) to 7 (Couldn’t be better). The variable was named Quality of life. MANSA item 1 (Life as a whole) has been shown to correlate strongly (Pearson correlation coefficient .832, $p < .001$) with item 1 (Life as a whole) in the Lancashire Quality of Life Profile (LQoLP) [32].

Confounders

User and service characteristics that have been considered as potential confounders in studies on satisfaction with services, such as illness severity, depressive symptoms, age, and legal status of treatment [1], were included.

Illness severity was assessed using the Global Assessment of Functioning Scale (GAF) [33]. Level of functioning and severity of service users’ symptoms are rated by clinicians on a scale (1–100), with lower scores indicating more severe symptoms and lower levels of functioning. The split version of the scale used in this study has symptom (GAF-S) and function (GAF-F) subscales [34].

Depression was assessed using the ‘depression/functioning’ domain of the Behavior and Symptom Identification Scale (BASIS-24). BASIS-24 is a brief service user self-report measure of psychopathology and functioning, which was developed to assess mental health treatment outcomes. This 24-item scale assesses six symptom and functioning domains: Depression/functioning, Interpersonal relationships, Self-harm, Emotional lability, Psychosis, and Substance abuse. BASIS-24 has shown good validity and reliability for assessing mental health status and functioning from the perspective of service users [35, 36]. Scores were calculated as described in the BASIS-24 instruction guide [37], providing a score between 0 and 4 with higher scores indicating more severe problems.

Information on whether participants were on a CTO (Yes/No) at the time of participation in the study, gender, and age were also included as confounders.

Procedure

Clinicians at the participating mental health units recruited eligible service users who were in contact with the clinic during the study period, and newly referred service users assessed to have psychosis. Clinicians performed clinical ratings and questionnaires were

administered to service users by the secretary or other clinic personnel. Service users were either provided with a place to sit in the clinic to complete the questionnaires, or took them home. When finished, the questionnaire was sealed in an envelope, and returned to the clinic. The recruitment period lasted from June 2016 until March 2017, and only participants who gave written informed consent were included.

Analysis

As participants came from different clinical sites nested within different health authorities, a hierarchical structure may have been present in these data. Intra-class correlation coefficient (ICC), representing a proportion of total variance that is between the sites and/or health authorities, was used to assess possible cluster effects. Because of noticeable cluster effect within clinical sites (ICC = 12.5%) and health authorities (ICC = 4.1%), unadjusted and adjusted linear mixed models with random effects for clinical sites nested within health authorities were estimated to assess the association between service satisfaction (CSQ-8) and three covariates (QPR, INSPIRE, MANSA) controlled for confounders (GAF-symptoms, GAF-Function, Depression/functioning, CTO, Age, and Gender). Multicollinearity was assessed by inspecting correlations among covariates, but no multicollinearity issues were found. Standard residual diagnostics was performed.

As an exploratory analysis, the interactions between being on a CTO and quality of life (MANSA) and personal recovery (QPR) were entered into the model, to determine whether the CTO-variable moderated their relation with CSQ-8. All tests were two-tailed, and results with p -values below 0.05 were considered statistically significant.

Imputation of missing values on the GAF ($n = 34$), MANSA ($n = 6$), QPR ($n = 21$) and CSQ-8 ($n = 6$) were performed by generating the empirical distributions for each variable and drawing a random number from that distribution to replace the missing value. The process was repeated until all missing values were imputed. Missing values on demographic variables were not imputed.

Results

Clinical and sociodemographic characteristics of participants

The mean age of the 292 participants was 40 years (Standard deviation (SD) = 12.7). Forty-two per cent were female. The majority of the participants ($n = 277$, 88%) defined themselves as Norwegian, and 15 (12%) were from other ethnic backgrounds. Fifty-three per cent had a diagnosis of schizophrenia and 13% were under CTO. Further details on sociodemographic and clinical

characteristics of the 292 participants are shown in Table 2.

Service satisfaction amongst Norwegian service users with psychosis ($N = 292$)

The mean (SD) CSQ-8 score was 25 (4.7), indicating an average of intermediate satisfaction. The distribution was 30 (10%) reported low satisfaction, 141 (49%) reported intermediate satisfaction and 121 (41%) reported high satisfaction.

Associations between satisfaction with services and personal recovery, perceived support for personal recovery and quality of life

Table 3 shows the results of the linear mixed model analysis performed to assess the associations between satisfaction with services (CSQ-8) and covariates. In the adjusted model, higher perceived support for personal recovery (INSPIRE) was associated with higher service satisfaction. Neither personal recovery (QPR) nor Quality of life (MANSA) showed significant associations with service satisfaction. There was an association with one

Table 2 Participants ($N = 292$) sociodemographic and clinical characteristics

Characteristics	
Gender N (%)	
Female	122 (42)
Ethnicity N (%)	
Norwegian	255 (88)
Other	34 (12)
Age Mean (SD)	40 (12.7)
Diagnosis N (%)	
Schizophrenia	145 (53)
Schizoaffective disorder	54 (20)
Other	74 (27)
GAF symptom ^a Mean (SD)	53 (13)
GAF function ^b Mean (SD)	51 (11.3)
Community treatment order N (%)	
Yes	40 (14)
Depression (BASIS-24) ^c Mean (SD)	1.3 (0.92)
Personal recovery (QPR) ^d Mean (SD)	41 (10.2)
Perceived support (INSPIRE) ^e Mean (SD)	66 (17.6)
Quality of life (MANSA) ^f Mean (SD)	41 (10.2)
Satisfaction with services (CSQ-8) ^g Mean (SD)	26 (4.7)

^aRange from 0 to 100, higher scores indicate less severity

^bRange from 0 to 100, higher scores indicate higher function

^cRange from 0 to 4, higher scores indicate more severe symptoms

^dRange from 0 to 60, higher scores indicate higher level of personal recovery

^eRange from 0 to 100, higher scores indicate more perceived support

^fRange from 1 to 7, higher scores indicate higher quality of life

^gRange from 8 to 32, higher scores indicate higher satisfaction

confounder: service users on a CTO were significantly less satisfied than those not on a CTO.

The interactions between CTO status and quality of life (MANSA) and personal recovery (QPR) were not significant, and therefore not included in the regression models. Hence, CTO status did not account for the absence of association between CSQ-8 and either MANSA or QPR.

Discussion

This cross-sectional study assessed the level of satisfaction with services, and its associations with self-reported outcome measures, among 292 service users with psychosis. Most (89%) of the service users rated their satisfaction as intermediate to high. Satisfaction with services was positively associated with perceived support for personal recovery, while personal recovery and quality of life were not significantly associated with service satisfaction. In addition, service users in a CTO were significantly less satisfied than those who were not.

Overall, our results showed higher satisfaction rates than those reported in similar international studies. Compared with the Dutch study [6], which also used the CSQ-8, covering 654 service users with psychosis, our results are somewhat more positive. However, despite somewhat similar samples and recruiting methods, their sample included many users experiencing their first episode of psychosis, and hence their sample were younger, which is often associated with less satisfaction. Results in our study, however, did not show age to be significantly related to satisfaction level. Compared with the studies from Israel [8], Kuwait [9] and the multi-site European study [7] our satisfaction scores seemed markedly higher. However, these other studies used different satisfaction scales, making adequate comparisons difficult.

Among European countries, Norway spends the largest share of its total health budget on mental health and has a significant element of tax financing for these services. Most health services are in the public sector, and deductibles are low [38]. In addition, significant efforts have been made to improve mental health care by increasing resources, and by making mental health care policy more patient centered and more highly prioritized [39]. However, our study shows that there is room for improvements, given that 11% of our participants reported low satisfaction rates. In particular, the low satisfaction scores among service users in a CTO adds further evidence for the importance of interventions aimed at improving satisfaction with services within this group.

As anticipated, our results show that service user who experience higher perceived support for personal recovery from their health care provider are more satisfied with the health care that they receive, and that those on

Table 3 Linear mixed model results for associations between satisfaction with services (CSQ-8) and quality of life (MANSA), perceived support for personal recovery (INSPIRE), and personal recovery (QPR)

Covariates	Bivariate models			Multiple models		
	Regression coefficient	95% CI	p	Regression coefficient	95% CI	p
Personal recovery (QPR) ^a	0.12	0.07; 0.17	<.001	0.03	-0.03; 0.09	.354
Perceived support (INSPIRE) ^b	0.13	0.10; 0.15	<.001	0.11	0.08; 0.14	<.001
Quality of life (MANSA) ^c	0.56	0.18; 0.94	.004	0.07	-0.34; 0.47	.741
GAF-Symptom ^d	0.05	0.01; 0.10	.012	0.02	-0.03; 0.07	.440
GAF-Function ^e	0.05	0.005; 0.10	.031	-0.001	-0.06; 0.06	.962
Depression/functioning (BASIS-24) ^f	- 0.97	- 1.55; -0.40	.001	- 0.24	-0.88; 0.40	.460
CTO, yes	- 2.45	-3.96; -0.96	.002	-2.20	-3.57; -0.81	.002
Age	- 0.001	-0.05; 0.04	.692	-0.02	-0.06; 0.02	.263
Gender, female	1.45	0.38; 2.52	.008	0.98	-0.007; 1.96	.052

^aRange from 0 to 60, higher scores indicate higher level of personal recovery

^bRange from 0 to 100, higher scores indicate more perceived support

^cRange from 1 to 7, higher scores indicate higher quality of life

^dRange from 0 to 100, higher scores indicate less severity

^eRange from 0 to 100, higher scores indicate higher function

^fRange from 0 to 4, higher scores indicate more severe symptoms

a CTO are less satisfied. These findings are consistent with research concluding that among service characteristics, only coercive treatment and a perceived negative therapeutic relationship consistently impact satisfaction with care [1, 3]. This tells us that service-related factors important for the general mental health population are also relevant to service users with psychosis.

Support for personal recovery among service users with psychosis is associated with higher satisfaction, which is clinically important. For mental health clinicians, this means having an increased focus on recovery aspects such as the personal goals of the individual service user and finding out what matters most to them in their lives. Furthermore to strongly emphasize hope and empowerment when providing care for service users with psychosis. This finding also indicates that it is important to support service users with psychosis in their personal recovery, which calls for increased implementation of recovery-oriented practices. The question for mental health care services on how to target and improve quality of life and personal recovery of service users with psychosis is of great importance. Our previous study did show that recovery-oriented treatment (i.e., Illness Management and Recovery), is associated with higher perceived support for personal recovery (article in press), and another study has shown that service users enrolled in Assertive Community Treatment (ACT) programs are highly satisfied with the care they receive, including those being on a CTO [40]. Other interventions with a significant evidence base to support recovery include 19 randomised controlled trials of peer support work [41], 27 randomised controlled trials of the Individual Placement and Support approach to employment [42] and the development of education initiative called Recovery Colleges in 22 countries [43].

We did not find that satisfaction with services was related to quality of life or actual level of personal recovery. Perhaps this reflects that the perceived support for personal recovery more directly measures the service users' experience with the mental health services, while actual level of personal recovery measures more broadly the general life situation of the person. Personal recovery and quality of life are concepts associated to many aspects in the life and community of the person. This is also why recovery-oriented interventions aimed at social inclusion such as Individual Placement and Support (IPS) [42] and Recovery colleges [43] has been developed and implemented.

However, as this is a cross-sectional study we do not have information on whether these concepts are related to satisfaction with services over time. Studies on the relations between satisfaction with services and self-reported outcomes among service users with psychosis are scarce; thus more follow-up studies measuring change over time are needed. These will be especially important since patient centeredness and personal recovery are the growing policy foci for mental health services. Such studies should also include clinical outcomes, to better explain how these three constructs interact. A mixed-methods study involving qualitative exploration of the experience of recovery support could also help develop an understanding of this process and inform the future development of more targeted interventions.

Strengths and limitations

One of the major strengths of this study is that we adjusted scores for common confounders. This minimized the risk of positive and negative ratings being incorrectly

attributed to service satisfaction when they actually reflect general tendencies of certain service users with specific characteristics (e.g., depressive symptoms), which can serve as a “mood-dominated” general tendency toward more positive or negative appraisals of one’s situation across various self-reported constructs [44].

One limitation is the common rater effect, a known potential bias when including several measures from the same respondent. However, our selected covariates showed only low-to-moderate correlations, speaking against such bias.

Selection bias was another potential risk. Although the 39 participating clinical sites are considered representative of psychosis treatment in the Norwegian mental health care system, participants were not randomly selected; thus, their satisfaction levels may not accurately represent the population with psychosis in Norway. In addition, although the clinicians that recruited the participants were instructed to recruit/ask all eligible service users, we do not have information of actual numbers of participants that were asked to participate. Hence, this sample might be a convenience sample which limits the generalizability of the findings and could explain the high satisfaction levels. Further, although CSQ-8 is among the most widely regarded scales for measuring service satisfaction, it does not cover all aspects of care. The scale also consist of questions of which some might be considered unsuitable to those on a CTO. Finally, as with all cross-sectional studies, it is not possible to draw any conclusions about causality.

Conclusion

Satisfaction levels among service users were higher compared with similar, international studies. Service users who feel supported in their personal recovery were more satisfied with the care they receive, which calls for increased implementation of recovery-oriented practices for service users with psychosis. However, satisfaction with services was unrelated to quality of life or level of personal recovery. The low satisfaction reported by service users on a CTO emphasizes the importance of targeted interventions to improve satisfaction with services among this group.

Abbreviations

CTO: Community Treatment Order; IMR: Illness Management and Recovery; FACT: Flexible Assertive Community Treatment; IPS: Individual Placement and Support; ACT: Assertive Community Treatment

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Authors’ contributions

The study was planned and conducted by HKC, KSH, and TR. JSB carried out the analysis, and RSF, HKC, KSH and TR analyzed and interpreted the data. RF

drafted the manuscript, and HKC, KSH, TR, JSB, MS and RF revised and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the Regional Committee for Medical and Health Research Ethics (REK Sørøst B 2015/2169), and followed the principles of the Declaration of Helsinki. Participation was voluntary and based on written informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interest. Mike Slade acknowledges the support of Center for Mental Health and Substance Abuse, University of South-Eastern Norway and the NIHR Nottingham Biomedical Research Centre. Torleif Ruud is a member of the editorial board (Associate Editor) of this journal.

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