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Eirik Roos

Community 24/7 residential services for persons with severe mental illness effect and experiences

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NTNU Norwegian University of Science and Technology

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# Eirik Roos

# Community 24/7 residential services for persons with severe mental illness – effect and experiences

Thesis for the Degree of Philosophiae Doctor

Trondheim, October 2018

Norwegian University of Science and Technology Faculty of Medicine and Health Sciences Department of Public Health and Nursing



# NTNU

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Trondheim, June 2018

Eirik Roos

# Norsk sammendrag

# Kommunale døgnbaserte tjenester for personer med alvorlige psykiske lidelser – effekt og erfaring

#### **Bakgrunn**

Samarbeid mellom sykehus i psykisk helsevern og primærhelsetjenesten er vesentlig for å sikre optimal behandling og tjenester til personer med alvorlige psykiske lidelser. Dette inkluderer optimal utskrivning fra sykehus og best mulige kommunale tjenester. Det er imidlertid få studier som har undersøkt erfaringer med kommunal etterbehandling umiddelbart etter utskrivning fra psykiatrisk sykehus for å finne riktige nivå på kommunale tjenester og tilrettelagte boliger med ansatte tilsted hele døgnet med høy grad av selvstendighet for brukerne.

#### Mål

Hovedmålet med denne avhandlingen var derfor å undersøke bruk av kommunale døgntjenester som vektlegger høy grad av selvstendighet for personer med alvorlige psykiske lidelser. De spesifikke målene var å undersøke erfaringer og effekt av utskrivning til etterbehandling i kommunalt helsehus og erfaringer med å bo i tilrettelagte bofellesskap med egen fult utstyrt leilighet.

#### Metode

For å besvare forskningsspørsmålene ble det gjennomført en åpen randomisert studie (RCT) med 41 pasienter og to kvalitative studier med 13 pasienter med erfaring fra kommunal etterbehandling og 14 pasienter bosatt i tilrettelagte bofellesskap.

#### Resultat

Pasienter som ble randomisert til å bli utskrevet til kommunal etterbehandling hadde total kostnadsbesparelse på 38.5 % av spesialist- og kommunale tjenester i løpet av 12 måneder sammenlignet med ordinært forløp, men estimatet var upresist. Pasientene beskrev at oppholdet i den kommunale etterbehandlingen var likt det å bo på et hotell, med at de kjedet seg fordi det ikke var tilbud om organiserte aktiviteter inne i helsehuset. Flere fortalte at de ikke var informert på forhånd om filosofien ved helsehuset før oppholdet. De måtte derfor selv finne aktiviteter utenfor helsehuset og de sa de fikk aktiv støtte og hjelp til dette fra de ansatte. Pasientene som bodde i tilrettelagte bofellesskap med egen fullt utstyrt leilighet fortalte at de følte trygghet på grunn av tilgang til ansatte døgnet rundt. Det å ha en egen leilighet å trekke seg tilbake til ble sagt å bidra til å redusere konflikter med de andre

beboerne. De fortalte om kontakt med de andre beboerne i fellesrommene, men sa de hadde liten kontakt med personer utenfor bofellesskapet.

#### Konklusjon

Overføre utskrivningsklare pasienter fra psykiatrisk sykehus til kommunal etterbehandling i helsehus kan potensielt redusere det totale forbruket av psykiske helsetjenester og kostnader. Trolig er årsaken at omfang av tjenester ble vurdert i en mer hjemlig situasjon, fordi situasjonen i helsehuset førte til at pasientene var mer selvstendige. Til tross for vektlegging av selvstendighet både ved etterbehandling i helsehuset og i bofellesskapet, var tilstedeværelse av ansatte døgnet rundt veldig vesentlig for at pasientene følte seg trygge og derfor være i stand til å opptre selvstendig.

# Summary in English

# Community 24/7 residential services for persons with severe mental illness – effect and experiences

#### **Background**

Collaboration between mental health hospitals and primary care is essential to provide optimal care and services for persons with severe mental illness (SMI). This includes optimal discharge from hospitals and best possible services in primary care. However, few studies have addressed experiences with residential aftercare immediately after discharge from hospital to identify the appropriate level of primary care services and provision of sheltered housing with a high degree of independence for the users.

#### Aim

The overall aim of this study was to investigate the use of 24/7 residential community mental health services that emphasise a high degree of independence for persons with SMI. The specific aims were to investigate the experience and effect of discharge to community residential aftercare, and experience of living in sheltered housing consisting of fully equipped private apartments.

#### Methods

To answer the research questions, an open parallel group randomised controlled trial (RCT) with 41 participants and two qualitative studies with 13 persons with experience from a community residential aftercare and 14 persons living in sheltered housing were conducted.

#### Results

Patients with SMI randomized to be discharged to community residential aftercare (CRA) had a total cost saving of 38.5% on specialised and primary health care use compared to usual care for 12 months, but the estimate was imprecise. Patients stated that their stay at the CRA was similar to living in a hotel, but that they were bored due to the lack of organized in-house activities. Further, they generally stated they were not informed about the philosophy of the CRA before the stay. They had to come up with activities outside the CRA and said that they got active help from the staff to do so. In addition, persons living in a private fully equipped apartment in sheltered housing said they felt safe due to the access to

the in-house staff 24/7. Having a private apartment to retire to, reduced conflicts with other residents. They mentioned contact with the other residents in the common rooms but said that they had little contact with people outside the sheltered housing.

#### **Conclusions**

Transferring patients ready for discharge from hospital to community residential aftercare has the potential to reduce total consumption of health care services and costs. The likely mechanism is that the level of services was determined in a more home-like setting, as the setting led the patients to be more independent. Despite the emphasis on independence in both the aftercare and sheltered homes, the presence of the staff 24/7 was very central to make the patients feel secure and, thus, able to act more independently.

# **Abbreviations**

CMHC Community Mental Health Centre

CRA Community Residential Aftercare

GP General Practitioner

MMH Mental Health Hospital

RCT Randomized Controlled Trial

SDT Self-determination Theory

SMI Severe Mental Illness

STC Systematic Text Condensation

TAU Treatment as Usual

# List of included papers

This thesis is based on following three papers. Each paper is referred to by Roman numerals. The papers in their full format are attached as appendices at the end of the thesis.

- I. Roos, E., Bjerkeset, O., Steinsbekk, A.: Health care utilisation and costs after discharge from a mental hospital: an RCT comparing community residential aftercare and treatment as usual. Resubmitted after review.
- II. Roos, E., Bjerkeset, O., Svavarsdóttir, M., Steinsbekk, A.: Like a hotel, but boring: users' experience with short-time community-based residential aftercare. BMC Health Services Research. 2017 Dec 16;17(1):832. <a href="https://doi.org/10.1186/s12913-017-2777-z">https://doi.org/10.1186/s12913-017-2777-z</a>
- III. Roos, E., Bjerkeset, O., Søndenaa, E., Antonsen, D.Ø., Steinsbekk, A.: A qualitative study of how people with severe mental illness experience living in sheltered housing with a private fully equipped apartment. BMC Psychiatry. 2016 Jun 6;16:186. <a href="https://doi.org/10.1186/s12888-016-0888-4">https://doi.org/10.1186/s12888-016-0888-4</a>

# 1 Background

The topic of this thesis is 24/7 residential community services for persons with severe mental illness (SMI). The PhD project was inspired by changes in the provision of services the last two decades and in particular the experience of operating a community residential aftercare (CRA) in the municipality of Trondheim, Norway.

The background section begins with a brief introduction to mental health problems before a more detailed presentation of severe mental illness. This includes treatments typically offered to persons with SMI and provides an overview of the type of services available, mostly independent of setting. The last part discusses hospitalisations, followed by the discharge process, and leads to community services and a specific focus on 24/7 residential services in the community.

#### 1.1 Mental Health Problems

Approximately 14% of the global burden of disease has been attributed to depression and other common mental health disorders, alcohol-use and substance-use disorders, and psychoses (Prince et al., 2007). This has drawn attention to the importance of mental disorders for public health and how the quality of care can be improved for persons with these problems.

Common mental health problems encompass a range of conditions relating to low mood and anxiety, which can affect people's ability to work, study, or maintain relationships. However, the term mental disorder is only used when specific diagnostic criteria are met. Mental disorders range from simple phobias, mild anxiety, and depressive disorders to severe illnesses such as schizophrenia (Reneflot A, 2018). Aspects that are common to all mental disorders is that they affect thoughts, feelings, behaviour, and interactions with others. Mental disorders are associated with risk factors for chronic diseases such as smoking, reduced activity, poor diet, obesity, and hypertension (Prince et al., 2007).

Mental disorders often begin at an early age. A study of lifetime prevalence of mental disorders of adolescents from the US (Merikangas et al., 2010) found that the overall prevalence of mental disorders with severe impairment and/or distress was 22.2%. Overall, anxiety disorders were the most common condition (31.9%), followed by behaviour disorders (19.1%), mood disorders (14.3%), and substance-use disorders (11.4%).

A study in six European countries described the 12-month and lifetime prevalence rates of mood, anxiety, and alcohol disorders among adults older than 18 years of age (Alonso et al., 2004). The study found that 14% reported a lifetime history of mood disorder, another 14% anxiety disorder, and 5% alcohol disorder. The 12-month prevalence was 6% with anxiety disorder, 4% with mood disorder, and 1% with alcohol disorder. Major depression and

specific phobia were the most common single mental disorders. Women were twice as likely as men to suffer 12-month mood and anxiety disorders, while men were more likely to suffer alcohol abuse disorders (Alonso et al., 2004).

In Norway, a study on the occurrence of a wide variety of mental disorders found the following aspects to hold true (Kringlen, Torgersen, & Cramer, 2006):

- Lifetime prevalence, the proportion of the population who will have a mental disorder during their lifetime, ranges from 25% to 52% for different disorders. The average prevalence is around 40%.
- The proportion of the population who has had a mental disorder in the last 12 months ranges from approximately 10% to 33% for different disorders.

In another Norwegian study, it was found that more women than men suffer from mental illness, but the gender differences vary between the different types of disorders (Mykletun A, 2009). Eating disorders occur almost exclusively among women, and there is also a much higher incidence of anxiety and depression among women than among men. However, the results vary somewhat for personality disorders and schizophrenia. Only substance abuse-related disorders are more common among men than among women in Norway (Mykletun A, 2009).

#### 1.2 Severe Mental Illness (SMI)

In this thesis, the focus is on persons with severe mental illness (SMI). SMI includes schizophrenia, bipolar disorder, schizoaffective disorder, and major depressive disorder (Hert et al., 2011). People with SMI have an increased mortality rate, which is two or three times as high as that in the general population, with life expectancy shortened by between 13 and 30 years (Hert et al., 2011). Approximately 60% of this is due to physical (somatic) illness (Vreeland, 2007). In patients with SMI, as in the general population, obesity is associated with not only with lifestyle factors which can negatively affect health—for example, lack of exercise, poor diet—but also with illness-related (negative, disorganized, and depressive symptoms) and treatment-related factors, including weight liability of certain psychotropic agents (Hert et al., 2011). The risk of obesity in persons with SMI is higher than that in the general population and varies by diagnosis. People with schizophrenia have a 2.8 to 3.5 increased likelihood of being obese and those with major depression or bipolar disorder have a 1.2 to 1.5 increased likelihood of being obese (BMI ≥ 30) (Coodin, 2001).

There is also an increased risk of suicide among persons with SMI. A meta-review of 1.7 million patients found that suicide mortality for patients with borderline personality disorder, depression, bipolar disorder, opioid use, and schizophrenia, as well as anorexia nervosa and alcohol use disorder in women, had substantially increased rates (greater than 10 times) compared with the general population (Chesney, Goodwin, & Fazel, 2014).

The consequences of stigma, discrimination, and social exclusion related to mental illness—such as reduced access to housing, healthcare, and employment—are of substantial concern (Griffiths, Carron-Arthur, Parsons, & Reid, 2014). Public stigma is stigma towards people with mental illness by members of the public who do not have mental illness (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012). Public stigma has been described as three interrelated problems: problems of knowledge (ignorance), attitudes (prejudice), and behaviour (discrimination) (Corrigan et al., 2012). Not surprisingly, direct social contact with people with mental illness has the strongest evidence for reducing stigma (Thornicroft, Brohan, Kassam, & Lewis-Holmes, 2008).

A qualitative five-year longitudinal study (72 focus groups interview) among persons with SMI living in congregate housing units of between 6 and 18 apartments with no live-in professional support found that stigma and discrimination were perceived as problems to which participants remained eternally vigilant, taking various preventive measures (Whitley & Campbell, 2014). Most notable among these measures was a concerted and self-conscious effort to behave and look 'normal' through dress, appearance, conduct, and demeanour.

#### 1.3 Care and Treatment for Persons with SMI

There are a range of services and interventions aimed at supporting and helping people with SMI. Housing and social engagement is often targeted, as it is an essential factor in peoples' life. A quality study including 113 homeless persons (50% with SMI) in the US found that those who lived in independent housing (individual paid rent for residence) had the largest positive and significant improvements in satisfaction with overall quality of life and with housing, leisure, and money compared with obtained dependent housing for the homeless (the individual did not pay rent for residence) (Wolf, Burnam, Koegel, Sullivan, & Morton, 2001). A qualitative study among 27 adults with SMI found that endorsed preventive strategies included accessing social support and engaging in activities/hobbies (Yanos & Rosario, 2014). Participants tended to have a less positive mood at the end of the day on days where either no, or more passive, strategies were used.

Psychoeducational approaches have been developed to increase patients' knowledge of, and insight into, their illness and its treatment. It is assumed that increased knowledge and insight will enable people with schizophrenia to cope with their illness in a more effective manner, thereby improving prognosis. A review on interventions to improve the experiences of caring for people with SMI found that psychoeducation in supported groups had a benefit on psychological distress more than six months later (Yesufu-Udechuku et al., 2015). Furthermore, according to a Cochrane review, psychoeducation appears to reduce relapse, readmission, and encourage medication compliance, as well as reduce the length of hospital stay (Xia, Merinder, & Belgamwar, 2011).

Anti-psychotic therapy is the main treatment for schizophrenia, and helps in reducing psychotic symptoms and preventing relapses (de Paiva Barretto et al., 2009). Research on

cognitive behaviour therapy (CBT) in schizophrenia has grown from simple case studies to large randomized controlled trials in subsequent decades. Irrespective of the symptoms of the patient, two factors are crucial for the CBT therapist: 1) motivation and engagement, not only in early sessions but throughout the entire treatment period and 2) to work on the patients' low self-esteem. A recent review on psychosocial treatments for adults with schizophrenia found that most psychosocial interventions improved functional outcomes, quality of life, and core illness symptoms, and several reduced relapse compared with usual care (McDonagh et al., 2017).

A systematic review from treatment for individuals with both schizophrenia and substance-use disorders, found that programs must integrate psychosis and substance-use treatments and ongoing monitoring of both substance use and patterns and symptoms (Crockford & Addington, 2017). The best outcomes were achieved with combined use of antipsychotic medications and addiction-based psychosocial interventions. A review of exercise interventions in schizophrenia found no significant effect on body mass index, but psychiatric symptoms were significantly reduced by interventions using approximately 90 minutes of moderate-to-vigorous exercise per week (Firth, Cotter, Elliott, French, & Yung, 2015).

Disengagement from mental health services can lead to devastating consequences for individuals who require ongoing treatment for schizophrenia and other serious mental illnesses. A review suggested that engagement strategies should specifically target these high-risk groups, as well as high-risk periods (Kreyenbuhl, Nossel, & Dixon, 2009). Interventions to enhance engagement in mental health treatment found in the review ranged from low-intensity interventions, such as appointment reminders, to high-intensity interventions, such as assertive community treatment (ACT). A review from 2007 found that ACT offered significant advantages over standard case management models in reducing homelessness and symptom severity in homeless persons with severe mental illness (Coldwell & Bender, 2007). A review on the effect of intensive case management for persons with SMI found that it reduced the time in hospital care (Burns et al., 2007).

As mentioned above, people with SMI are at higher risk of ill physical health (particularly diabetes, and cardiovascular and respiratory disease); thus, focusing on these aspects could help reduce the associated excess morbidity and mortality (Hoang, Goldacre, & Stewart, 2013).

Despite severe mental illness, some patients are able to live a normal life living in ordinary residences, are well educated, and have a job. However, most persons with SMI need support to manage a job. A review among persons with SMI found that individual placement and support is an effective intervention across a variety of settings and economic conditions and is more than twice as likely to lead to competitive employment when compared with traditional vocational rehabilitation (Modini et al., 2016).

Not only are patients themselves affected by SMI, their family is affected as well, as they usually provide a greater part of the care, frequently without any training (Aschbrenner, Greenberg, & Seltzer, 2009). A study found a correlation between improved knowledge to family caregivers and decline in burden (Weiss, Hadas-Lidor, Weizman, & Sachs, 2017). Providing non-professional caregivers with professional 'know-how' appeared to lead to reduced burden for the caregiver, thereby contributing to maintaining well-being of the family caregiver population. Examples of content in courses for the next-of-kin of people with SMI includes lectures on what SMI is, workshops, home assignments and exercises, reading of material, viewing and analysing documentary films on recovery concepts, and writing and analysis of meaningful interactional life episodes (Weiss et al., 2017).

#### 1.3.1 Hospital treatment and the discharge process

Having SMI is associated with increased treatment costs and hospitalisations. A review from the US found that length of stay in general hospitals has been reduced for psychiatric patients but remains longer than that for physical disorders (Tulloch, Fearon, & David, 2011). This review also found that inpatient costs resent 16% of total health spending (Tulloch et al., 2011).

Rehospitalization is also common in people with SMI, as a study found that 86% were rehospitalized over a seven-year follow-up period and 73% were readmitted in the first year after discharge (Irmiter, McCarthy, Barry, Soliman, & Blow, 2007). Nevertheless, a review found a reduction in readmission between 14% and 37% due to pre- and post-discharge patient psychoeducation, structured needs assessments, and inpatient/outpatient provider communication (Vigod et al., 2013). This indicates that patients with SMI are in need of aftercare (Mojtabai et al., 2009). Patients with SMI have reported that they see social malaise as an explanation for being readmitted (Duhig, Gunasekara, & Patterson, 2015), and a qualitative study from the US suggested a history of frequent psychiatric hospitalizations, non-adherence to aftercare treatment, and substance misuse as possible risk factors for readmission (Mgutshini, 2010).

Delayed discharge (occasionally called delayed transfer or bed blocking) refers to the situation where a patient is deemed to be medically well enough for discharge but where he/she is unable to leave hospital because arrangements for continuing care have not been finalized (Bryan, 2010). A survey covering one week in 2004 in the UK found high levels of delayed discharges, reporting 4% to 16% of beds affected and up to 2366 bed days lost depending on specialty (Lewis & Glasby, 2006).

A study in Norway from 2013 estimated that 7% of patients in mental health hospitals were ready to be discharged (Ose, 2013). The main reason for delayed transfer was that hospital staff assessed that the patients needed sheltered housing with in-house staff 24/7.

#### 1.3.2 Discharge process from hospital to community

A collaborative process between patients with SMI, hospital staff, and primary care staff is needed to ensure that the most important services are in place immediately after discharge. However, these services are difficult to obtain, as the discharge process between inpatient units and communities are complex (Mikkelsen, Petersen, Kaae, & Petersen, 2013). Staff and management experiencing cross-sector problems of collaboration point to ineffective coordination of services and lack of mutual understanding of how systems other than one's own work (Fredheim, Danbolt, Haavet, Kjønsberg, & Lien, 2011; Mikkelsen et al., 2013).

A review of the discharge planning process in mental health care found that communication between health professionals, consumers, and their families was important to maximise the effectiveness of this process (Nurjannah, Mills, Usher, & Park, 2014). A review from 2013 found that the efficacy of interventions designed to improve the transition from in-patient psychiatric units to outpatient care to reduce readmission were medication education, telephone follow-up, home visits, and peer support as well as a transition manager and timely communication between in-patient staff and community service providers during the transition (Vigod et al., 2013). Further, a review of qualitative studies on users' experience of progress and recovery from critical psychiatric illness during the first month after discharge suggests that patients and their families have a desire for more autonomous control over their own recovery (Bench & Day, 2010).

#### 1.4 Community Mental Health Services and 24/7 Residential Services

In the past decades, most western countries have shifted more of the care for persons with mental disorders from hospital to community-based settings (Kunitoh, 2013). There are many reasons for this change; and one of the most important ones is that service user preferences, recovery orientation, and services can be cost-effective.

In the UK, around one-third of the people with SMI are treated solely in primary care (Reilly et al., 2012), and are in long-term contact with primary care services more often than the general population (Kai, Crosland, & Drinkwater, 2000). There are a number of interventions used in primary care to help patients with mental health illness after inpatient stays, such as brief motivational interviews (Pantalon, Murphy, Barry, Lavery, & Swanson, 2014), peer support, and a good therapeutic relationship (Cheryl Forchuk, MARTIN, Chan, & Jensen, 2005; Lawn, Smith, & Hunter, 2008), self-referral inpatient treatment (Rise et al., 2014), crisis homes (Aagaard, Freiesleben, & Foldager, 2008) and care management (Bennewith et al., 2014; Griswold et al., 2008; Keogh, Callaghan, & Higgins, 2015; Svedberg, Svensson, Hansson, & Jormfeldt, 2014). Furthermore, employment, partnership, and a sheltered living situation are important services in the community after inpatient stays for persons with SMI (Frick et al., 2013).

Other services that can help persons with SMI to become more independent are selfmanagement programs with focus on medical management (e.g. teaching people how to follow through on treatment), role management (e.g. encouraging healthy behaviours), and emotional management (e.g. learning how to monitor symptoms and identify early warning signs of relapse) (Corbin & Strauss, 1988).

There exist different forms of 24/7 residential community services, ranging from short stay residential (inpatient) services to long-term sheltered housing. The short stay residential services can be classified according to the point in the patient trajectory at which the services are offered (K. A. Thomas & Rickwood, 2013):

- Step-up residential services are appropriate for persons who are not currently severely
  unwell or in a crisis situation but who are at high risk of experiencing a crisis. Step-up
  services are used to avoid or occasionally replace acute hospitalisation.
- Step-down residential services are designed for persons recovering from a worsening of their condition, where the services are used as a transition from, for example, hospital inpatient stay to community living. Step-down services can also be termed aftercare.

This thesis is concerned with step-down aftercare and sheltered housing. Briefly, the research on step-up services shows promising results (Borge et al., 2008; Byford et al., 2010; Fenton, Hoch, Herrell, Mosher, & Dixon, 2002; M. Slade et al., 2010; K. A. Thomas & Rickwood, 2013). A review by Thomas & Rickwood (2013) concluded that acute residential services offer a cost-effective alternative to inpatient psychiatric units that can alleviate pressure on inpatient beds for patients whose symptoms do not require the specialist services of inpatient units. Such services admit only voluntary patients who have been assessed as being able to function with some independence and who are not severely unwell and do not present a threat to their own or others' safety. Lengths of stay in most acute residential services ranged from a few days to a few weeks, whereas the treatment period or length of stay in subacute services was up to six months. They provided accommodation, therapy (or access to therapy), peer support, and access to clinical staff.

### 1.4.1 Community residential 24/7 aftercare (step-down)

Most of the literature on aftercare concerns various follow-up services such as outpatient or ambulant services (Taylor et al., 2014; Tulloch, Khondoker, Thornicroft, & David, 2015). There are only few studies on community-based services in the form of residential aftercare (step-down) (Majer, Chapman, & Jason, 2016; K. Thomas, Rickwood, & Bussenschutt, 2015; K. A. Thomas, Rickwood, & Brown, 2017; Zarzar, Sheitman, Cook, & Robbins, 2017). At step-down units, the staffs assess patients' needs of services and prepare patients for community living by focusing on independence and self-care. This is done by offering individual support to find suitable housing, develop vocational and domestic skills, and built community connections (K. A. Thomas & Rickwood, 2013).

An observational study among 24 patients from Australia examined the changes in patients' symptoms and functioning after a step-down stay in a residential recovery-focused program

(K. A. Thomas et al., 2017). The service was a five-bed facility with 24-hour staffing that offered individual support. Key workers were allocated to each patient, assisting them to develop and provide support to attainment of recovery goals. The services included illness management, relapse prevention strategies to the teaching of life skills, psychosocial educational groups, activities designed to support recovery, cooking, budgeting, shopping, washing, and personal hygiene. The study found improvements in symptoms and functioning, and service providers report improvements in the area of self-care and social skills (K. A. Thomas et al., 2017).

A study from the US examined patients who participated in a step-down program in a residential 16-bed unit for adults with mental health and substance-use disorders (Zarzar et al., 2017). The patients had their own rooms but used shared bathrooms and could go off the unit on passes with family or outpatient teams. Among the 38 patients included, 8 were admitted from the state psychiatric hospital, where they had been for a median of 55.5 days, and 30 patients were admitted from a community hospital where they had been for a median of 17.5 days. The median length of stay in the residential step-down unit was 33 days for those from the psychiatric hospital and 13 days for those from the community hospital. Of the 38 patients, 30 completed the step-down program and were discharged to the community: 17 patients to private residences and 13 to group home or shelter housing (Zarzar et al., 2017).

An RCT from the US investigated levels of severity of psychiatric illness after two years in a sample of 270 persons (Majer et al., 2016). Participants were randomly assigned to one of three conditions upon discharge from inpatient treatment for substance-use disorders: A self-run residential setting in the community (Oxford House), a staffed residential community service, and usual care with treatment-specific aftercare referral. The study found that participants randomly assigned to either of the residential community services reported significant reduction in psychiatric severity, whereas those assigned to the usual care condition reported significant deterioration. There were no significant differences in outcomes between the two residential community services (Majer et al., 2016).

Examining the services offered in these studies, they either provided a range of in-house activities organized by staff or like, in one case, the service was self-run by the patients (Oxford house) (Majer et al., 2016). No study covers the middle ground, where there is staff available 24/7, but the staff is only there to support the patients to use activities in the community. Thus, there is a lack of knowledge on the effect of and experience with 24/7 staffed residential aftercare services in the community that do not offer organized in-house activities.

#### 1.4.2 Community 24/7 services in sheltered housing

There are a number of sheltered or supported housing options for people with severe mental disorders (Brunt & Tibblin, 2011; Chilvers, Macdonald, & Hayes, 2006; Dorvil, Morin,

Beaulieu, & Robert, 2005; Kyle & Dunn, 2008; Wolf et al., 2001). Sheltered, supportive and supported housing are often used as equivalent terms and, in this thesis, we have chosen to use the term 'sheltered housing'.

There is also large variation in the characteristics of sheltered housing services. Box 1 below lists eight dimensions that can be used to standardise the description of sheltered housing (Parkinson, Nelson, & Horgan, 2009).

#### Eight housing dimensions:

- 1. Own or had a lease in their own name
- 2. Housing and services are legally separate
- 3. Housing integrated in the community
- 4. Housing is affordable
- 5. Services are voluntary
- 6. Individuals has choice of housing and services
- 7. Services are community based, no live-in staff
- 8. Crisis services are available 24/7

A review of studies on sheltered housing found that most studies in this area did not provide sufficient details to classify them according to eight housing dimensions (Rog, 2004). The main characteristics of sheltered housing is that residents have their own room within a building complex with shared facilities such as a laundry, dining and living rooms, and services provided by in-house staff (Parkinson et al., 2009). Sheltered housing represents a housing arrangement in an independent living area in the community or in a residential institution for people who prefer to live independently but want the security and availability of assistance and care when needed (Tanzman, 1993). Most persons living in sheltered housing had no opportunity to choose where to live. Thus, the questions of whether the housing options that are being offered to people with SMI are effective in terms of integration remains unclear. Studies on residents in a range of different housing settings report problems such as social exclusion, chronic course of mental disorders, and poor physical health conditions (Richter, 2010).

The main goal of sheltered housing is often to support the residents in a rehabilitation process to prevent unnecessary admissions to mental health inpatients (Anthony, Cohen, Farkas, & Gagne, 2002; Ellison et al., 2011). However, there are both advantages and disadvantages to living in a sheltered housing. A study from the Netherlands found that service users living independently in the community were more likely to feel socially included than residents in sheltered housing (De Heer-Wunderink, Visser, Sytema, & Wiersma, 2012).

A qualitative study on housing preferences among 103 US adults with dual disorders (addiction and mental health) living in either supervised (sheltered housing), independent apartment housing, or single rooms found that those preferring supervised housing wanted

on-site staff and peer support, while preference for apartment housing was associated with autonomy and privacy (Tsai, Bond, Salyers, Godfrey, & Davis, 2010). Furthermore, the study found that those who lived in their preferred housing type did not report significantly greater satisfaction than those who were living in other types of housing. Participants living in their preferred housing type also reported greater choice over type of housing and activities. Hence, those who lived where they wanted to, tended to report a greater sense of control and choice (Tsai et al., 2010).

There is a range of reviews on the effects of different forms of sheltered housing (Chilvers et al., 2006; Fitzpatrick-Lewis et al., 2011; C. Forchuk et al., 2008; Kyle & Dunn, 2008; Leff et al., 2009; Parkinson et al., 2009; Rog et al., 2014; Tabol, Drebing, & Rosenheck, 2010; Thornicroft, Bebbington, & Leff, 2005) from participants' hospital use before and after housing interventions (C. Forchuk et al., 2008; Thornicroft et al., 2005), residential stability (Kyle & Dunn, 2008; Rog, 2004; Thornicroft et al., 2005), preventing homelessness for individuals with mental and substance disorders (Rog et al., 2014) to how the residents made sense of their occupational transformations in the context of their everyday life and life history (Lindstrom, Sjostrom, & Lindberg, 2013).

However, there are few publications that have investigated the experience of people with SMI living in sheltered housing (Bengtsson-Tops, Ericsson, & Ehliasson, 2014; Dorvil et al., 2005; Tsai et al., 2010; Wolf et al., 2001). Only one study, a Swedish qualitative study of 29 users with SMI, has been conducted on sheltered housing, where the residents live in fully equipped apartments or single rooms (Bengtsson-Tops et al., 2014). Thus, there is a need for more studies that investigate the experience of people with SMI living in their own apartment in a sheltered housing service with in-house staff.

# 2 Aims

The overall aim of this study was to investigate the use of 24/7 residential community mental health services that emphasise a high degree of independence for persons with SMI.

The following are the specific research aims:

- 1. Investigate the use of primary and specialised mental health care services and costs in patients with SMI the first 12 months after discharge from a mental health hospital, comparing community residential aftercare and treatment as usual (Paper I).
- 2. Explore how patients with SMI in need of community support after a mental health hospital stay experienced the stay in the community residential aftercare established in the City of Trondheim in Central Norway (Paper II).
- 3. Explore how people with SMI experience living in sheltered housing consisting of only private fully equipped apartments, including a shared accommodation room (Paper III).

#### 3 Methods

In this thesis, both qualitative and quantitative methods were used, as we seek to answer questions about the 'what', 'how' or 'why' of a phenomenon and questions about 'how many' or 'how much'. A quantitative study, an RCT, was used to fulfil aim 1 (Paper I); two different qualitative studies were used to fulfil aim 2 (Paper II) and aim 3 (Paper III).

Quantitative research is about quantifying observations and relationships and are divided into two types: descriptive (observational) and experimental studies (Hopkins, 2008). Experimental studies can be used to study the effect of an intervention, preferably with a control group to investigate if the change in the experimental group is different for the change in the control group. If the subjects are assigned randomly to the experimental and control groups, the design is known as an RCT. Random assignment is used to ensure that the groups are comparable, and that unobserved variables are distributed randomly between the groups (Hopkins, 2008). RCTs are widely accepted as the most reliable method for determining the causal effect between the intervention and the outcome (Campbell et al., 2000). RCTs have also been recommended for investigating the effect of complex interventions (Craig et al., 2008). Complex interventions are widely used in the health service, in public health practice, and in areas of social policy that have important health consequences, such as education, transport, and housing. Complex interventions are usually described as interventions that contain several interacting components (Craig et al., 2008).

Qualitative research methods are used to improve our understanding of a phenomenon (Malterud, 2001). They include various strategies for systematic collection, organisation, and interpretation of textual material obtained through observations or discussions (K. Malterud, 2012). The data comprise language data (written or oral) to obtain the participants' perceptions, collected, for example, through face-to-face and semi-structured group interviews (Sofaer, 2002). The researcher encourages the participants to describe as precisely as possible what they experience and feel and how they act. The focus is on nuanced descriptions that depict the qualitative diversity and the many differences and varieties of a phenomenon, rather than on ending up with fixed categorizations (Kvale, 2008). Interviewing is an evolving process during which the researcher attempts to understand the world from the participants' viewpoint and unfold the meaning of their experiences. Moreover, the researcher has to be aware of his own position as the empirical data are co-constructed by complex interaction between researcher and participant, and a number of issues determine the quality of the communication from which the information power is established ((K. Malterud, Siersma, & Guassora, 2015). The analytical value of the empirical data depends on the skills of the interviewer, the articulateness of the participant, and the chemistry between the two; it is difficult to predict the quality of the dialogue in advance (K. Malterud et al., 2015). There is diversity in the disciplinary and theoretical orientation, methods, and types of findings generated by qualitative research (Yardley, 2000). One approach is systematic text condensation (STC), which is a descriptive and

explorative method for thematic cross-case analysis (K. Malterud, 2012). This method represents a pragmatic approach, and is inspired by Giorgi's psychological phenomenology approach (K. Malterud, 2012; K. Malterud et al., 2015) and by Husserl's phenomenology (Zahavi, 2003). Husserl claimed that the world as it appears will always be recognized through a person; he wanted to establish a basic philosophical science that considered the first-person perspective when attempting to fully understand the world (Zahavi, 2003).

#### 3.1 Setting

In Norway, the health and social care services are mainly financed by and provided in the public sector (Romøren, Torjesen, & Landmark, 2011). Primary health and long-term care is the responsibility of the municipalities, while acute somatic and psychiatric hospitals and specialist services are run by the government through regional health authorities. Primary health and social care includes GPs, public health nurses, nursing homes, home care, and mental health care (some places including residential care). Specialist health care organises acute and psychiatric specialist services in mental hospitals, community mental health centres, mental health outpatient treatment, and mental health ambulant treatment.

During the period between 1998 to 2008, the Norwegian Government decided to implement a national development plan in mental health with earmarked funding both to communities and hospitals (Brofoss, 2009). The aim was to enhance the services for people with severe mental health problems, for example, establish sheltered housing with staff 24/7, and day centres and staff to support patients in their residences or in daily activities. Partially due to this, there was an agreement between the municipality of Trondheim and the Mental Health Hospital (MHH) and Community Mental Health Centre (CMHC) located in the municipality, with regard to how to begin the discharge planning process for discharge-ready patients. Table 1 shows the most common places patients are discharged to after a stay at the mental health hospital.

Table 1. Main places to be discharged to from the mental health hospital

Discharge to	Financed by	Financed by
	specialist care	primary care
Community mental health centre	Х	
Community residential aftercare		X
Sheltered housing (can get the same support as those discharged to independent living)		X
Independent living (home)		
-with support from ACT	Х	Χ
-with support from outpatient treatment	Х	
-with support from community mental health services		X

Since the 90s, the municipality of Trondheim and the mental health hospital (MHH), which is part of a University hospital, had an agreement on how to manage patients ready for discharge, for example, document-ready discharge date and meeting in the hospital by the community staff within three days. It was mainly staff in MHH that assessed and recommended the level of municipal services needed after discharge from MHH. To keep track of the number of patients ready for discharge at the MHH, the staff in the MHH sent monthly lists with the number of discharge-ready patients to the municipality. The list included the number of delayed days for each patient and how many were waiting for sheltered housing. Patients had up to 365 delayed days before discharge. In the first decade of 2000, there were 30-50 patients ready for discharge at any time. A high number of these, particularly those with severe mental illnesses (SMI), were assessed to need sheltered housing with staff 24/7. To reduce the waiting list of discharge-ready patients, the municipality established several sheltered housing units, which had 7-14 apartments. The result was that in the period from 2002-2008, the municipality established 123 apartments in sheltered housing units with staff 24/7. Typically, when a new sheltered housing was established, the waiting list was reduced by the number of new residences. After three to six months, the number of discharge ready patients returned to the same level as before.

After 2009, the year of the establishment of the community residential aftercare (CRA), the municipality established one sheltered housing (2010) comprising 10 residences, with staff present only in the daytime. An appraisal by professionals of 100 residents living in sheltered housing in the municipality of Trondheim (autumn 2017) considered that the level of care was too high for 35 residents, while 13 had too little care and 11 residents were assessed to

have a functional level that allowed them to move from sheltered housing to independent living.

Partially due to the steady increase in the number of patients assessed to need sheltered housing, a discussion arose in the municipality regarding the feasibility of having the staff at the MHH assess the needs of the patients after discharge. It was believed that municipality staff, who saw the patients in their home situation, was at least equally able to assess the level of the services required after discharge. The hypothesis was that the municipality's staff has 'specialist' competences in primary care services and better knowledge in how to assess patient needs in the community.

One outcome of this discussion was that in the autumn of 2009, the municipality established the CRA for patients ready for discharge from the MHH. One aim of the CRA was to reduce the time the patients, who normally would need community services after discharge, spent in the MHH after they had been declared ready for discharge. Another aim was to prepare patients for independent supported living and not offer organized in-house activities to prevent patients from being inactive and institutionalized (Shen & Snowden, 2014). Instead, the patients are informed about activities in their neighbourhood and in the community. Thus, there are no organized activities at the CRA such as common meals, therapy options, or equipment for exercise. Consequently, there is a strong emphasis on and practical training for support self-care: how to structure daily routines including sleep patterns, strategies to cope with difficult symptoms, personal hygiene, appointments with other agencies, self-care and independent living such as use of public transport, shopping, meal planning and social and leisure activities outside the CRA. The patients also have overnight stays in their own home during the stay at the CRA. The CRA is central in facilitating the process of establishing community health and social services to support the transition from the hospital to independent supported living.

These activities coincided with a focus on providing more services in the home and resulted in the establishment of the Psychiatric Ambulatory Rehabilitation Team (PART) in 2006 and the Assertive Community Team (ACT) in 2009. Both these services were jointly operated and financed by the University hospital and the municipality. The number of discharge-ready patients has been reduced after 2009. In 2017, the number of delayed discharges varied from 1–5 patients.

# 3.2 Quantitative Study (Paper I)

#### 3.2.1 Study design

As the aim was to investigate the effect of the CRA, the 'gold standard' for such investigations, the RCT was chosen. When the trial began, the CRA had been in operation for almost five years, and the study was thus conducted to investigate the effect of an

established service in operation. Thus, a pragmatic approach had to be adopted (S. Eldridge, 2010). One consequence was that it was not possible to blind staff or patients. The randomization was performed using a web-based computer program provided by trial services at the Norwegian University of Science and Technology. The staff at the MHH conducted the randomization after receiving informed consent and they also informed the patients about the allocation.

#### 3.2.2 Participants and recruitment

The inclusion criteria were discharge-ready adult patients with SMI at the MHH who were assessed to need aftercare services from the municipality. There were no specific diagnostic criteria, but this group mainly included people with a diagnosis of schizophrenia, schizoaffective disorders, major depression, or personality disorders. The exclusion criteria were patients with a mental disability, impaired level of consciousness, or acute confusion.

Staff in the hospital had the task of identifying eligible patients. During the recruitment period, there was some opposition to the study which mainly concerned whether the CRA was a suitable place, as there was only a general practitioner (GP) present one day per week. The doctors in the hospital were responsible for assessing whether the patient could understand the consequences of participating in the study. The hospital nurses were the ones mainly responsible for orally informing the patients about the study and giving them written information and informed consent. The patients were given one day to decide whether to participate, and those who wanted to take part signed the consent and gave it to the staff that collected baseline data.

#### 3.2.3 Outcomes and data collection

The outcome was measured as utilization of mental health-related care services for 12 months, taken from registers, and the cost of using these services was calculated. All the data from registries and health records was provided by the staff in the primary care and specialist health care services. Use of private specialist (psychiatrist and psychologist), somatic in- and outpatient use, or contact with GPs were not included.

To document the implementation of the intervention, the following data was collected: days in the MHH before randomization and days from randomization to discharge, where they were discharged to immediately after the index stay in the MHH, and the length of stay at an inpatient unit or residential unit after the index stay.

The primary outcome was consumption and costs of community health services during the 12-month period. This was measured as the total number of hours with home help (cleaning, shopping etc.), home care nursing, and community mental health consultations. All primary outcomes were collected from registries in the community of Trondheim.

The secondary outcomes were total inpatient days in the MHH, CMHC, and CRA as well as the total number of admissions and readmissions from baseline to 12 months after inclusion. Readmission was defined as acute unplanned admissions to the MHH, CMHC, or the CRA within 30 days after last discharge, which is a common outcome when testing the effectiveness of transitional care (Leppin et al., 2014). Consumption and costs in total number of hours with outpatient and ambulant treatment. Overall costs from primary and secondary outcome.

The management of the MHH gave the cost from the specialist care services and the cost of the primary care services was provided by the management of the municipality of Trondheim. The details of the unit costs are provided in Paper I.

#### 3.2.4 Statistical methods

Both primary and secondary outcome data were non-normal distributed. This, in addition to a small sample (n = 41), led to the effect of the intervention being analysed with the non-parametric Mann-Whitney U-test (Hollander, Wolfe, & Chicken, 2013). The data is presented as both mean and median for all participants, and mean differences between groups.

The mean difference between the groups and 95% CI was estimated using parametric t-tests with bootstrapped analyses. Bootstrapping uses random sampling with replacement and improves the accuracy (defined in terms of bias, variance, and confidence intervals) to sample estimates.

Due to differences in patient characteristics at baseline, additional analysis was done using a logistic regression model with total cost as the dependent variable and various baseline variables as independent variables.

# 3.3 Qualitative Studies (Papers II and III)

#### 3.3.1 Study design

A qualitative design was used to explore patients' experiences with a short-stay community residential aftercare (Paper II) and the experience of residents with SMI living in sheltered housing (Paper III). Qualitative research was selected as it is well suited for understanding phenomena within context, uncovering links among concepts and behaviours, and generating and refining theory (Bradley, Curry, & Devers, 2007). There are different forms for data collection, which—in addition to observation—typically include focus groups (Krueger, 2014) and individual interviews (Kvale, 2008). In both cases, the purpose is to better understand how people feel or think about an issue, idea, product, or service. In focus

groups, participants are selected because they have certain characteristics in common that relate to the topic of the focus group and the group dynamics help in sharing their ideas and perceptions (Krueger, 2014). Individual semi-structured interviews attempt to understand themes of the lived daily word from the subjects' own perspective in greater detail (Kvale, 2008).

#### 3.3.2 Participants and recruitment

The aim for both qualitative studies was to recruit participants who had experiences from using the services. The aim was to achieve variation in age, gender, and the time they had used the services. There were no exclusion criteria, except that the participants had to be able to provide consent to the participation themselves. To recruit participants, the researcher had meetings with unit managers and team leaders to inform them about the study so they could ask patients or residents to participate. It was emphasized that participation was voluntary.

#### 3.3.3 Data collection

In the study with those having stayed at the community residential aftercare (Paper II), the main topic in the interview guide was the experience of staying at the CRA in terms of facilities, activities, support, relation to staff, and patients. The average time of the individual interviews was 27 minutes (ranging from 15–45 minutes), and the group interview lasted 1.45 hours.

In the study with those living in sheltered housing (Paper III), the main topics in the interview guide was how patients experienced their living arrangements, activities, safety, relation to staff and residents. A co-researcher with previous experiences as a user of mental health services, and experience in asking questions from a user's perspective participated in all interviews. The average duration of the group interviews was 45 min (ranging between 42–48 min), and the average duration of individual interviews was 36 min (ranging between 23–64 min). The researcher conducted and transcribed all the interviews.

#### 3.3.4 Data analysis

The data were analysed using systematic text condensation (STC), a thematic approach developed by Malterud (Malterud, 2012) and inspired by Giorgi's phenomenological approach (Giorgi, 2000). STC is both pragmatic and descriptive and presents the experiences of the participants in line with what they have expressed. The STC analyses model contents of a four-step process: 1) total impression—from chaos to themes; 2) identifying and sorting meaning units—from themes to codes; 3) condensation—from code to meaning; and 4) synthesizing—from condensation to descriptions and concepts. This is detailed in table 5 below.

Table 5. Example of an analytical process.

Total impression	Identifying and sorting meaning units	Condensation	Synthesising	Final themes
Paper II. Residen	tial aftercare			
Information about the CRA offers	'I got information from the inpatient staff [at the hospital] that the CRA offers a single room, serves dinner and there were staff 24/7'.	I was only informed about the practical aspects of the CRA.	Some participants said that they were not informed about what they could expect at the CRA before they arrived.	Not what I expected
Paper III. Shelter	ed housing			
Satisfied with having own residence and shared accommodation room	'I'm satisfied with having a fully equipped residence and I can lock the door'.  'In the accommodation room, I get contact with someone, having a meal together or walking'.	I am satisfied with having a private apartment, but I use the accommodation room to be in contact with other residents.	Participants were particularly satisfied to have their own private fully equipped apartment, while at the same time have the opportunity to use the shared living room where they could be with other residents or service providers.	Experiences with the living arrangement

Total impression. In the first step, the research group read the entire transcript to get an overview and a general impression of the data, while at the same time bracketing preconceptions. We were looking for preliminary themes associated with the research aim. At this stage, the researcher team discussed with an open mind, with a sharp awareness of the participants' voices, to obtain an understanding of what the data were like from a bird's-eye view.

Identifying and sorting meaning units. In the second step, the transcript was systematically reviewed line by line to identify meaning units, such as a text fragment containing some information about the research question. Meaning units were identified and marked with a code, a label that connects related meaning units into a code group. During coding, the names and features of the code groups were elaborated from the themes from the first step of the analysis. Then, the codes were cultivated to transcend previous preconceptions and an understanding was developed therein. In this stage, we reflected both upon commonalities and differences within and across the coding groups and our preconceptions. Within each code group, a number of sub-groups were formed. During this process, we eliminated both code groups and refine codes.

Condensation. The third step of analysis uses systematic abstraction of meaning units within each of the code groups established in the second step of analysis. The empirical data are reduced to a decontextualized selection of meaning units sorted as thematic code groups across individual participants. This implies that to reduce the content (the meaning units) of a code group into a condensate, which is an artificial quotation that maintains, as far as possible, the original terminology applied by the participants. The researcher wrote the condensate in the first-person format to represent the participant who provided information on each code group. A part of this process was identifying meaning units that did not fit into the condensate. The research group discussed which meaning units belonged to different subgroups or whether it was a relevant meaning unit after all. In this manner, we reviewed and abstracted the complete amount of empirical data in a systematic manner, while continuously asking what these text elements told us about the study questions.

Synthesizing. In the fourth and last step of the analysis, data are reconceptualised by putting the pieces together again. The researcher had to ensure that the synthesized results still reflected the validity and wholeness of the original context. This entails assuming the role of a re-narrator and rewriting the condensates from step three in a third-person format. Thus, the condensates were transformed into analytic text with separate paragraphs for each subgroup, each of them illustrated by relevant quotations. Therefore, the analytic texts constitute sections of the results paragraph. Moreover, in this process, the research team identified issues that led to changes. Thereafter, the text was validated to confirm if the synthesis and the illustrative quotation appropriately reflected the original context and statements from the informants. In the final process in this step, the research group discussed the category headings in order to provide brief and expressive statements of the

most significant interpretations to express a highlighted perception of what this study adds to existing literature.

#### 3.4 Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2001). All three studies had direct contact with participants, and sensitive and personal health information was collected. The study was approved by the Regional Committee for Medical Research Ethics (2011/1770) and the RCT (Paper I) was registered on clinicaltrials.gov (NCT01719354). The participants were informed about the study from staff at the services, and only contacted the researcher afterwards. Confidentiality of the data was assured by de-identifying data files and keeping them locked down.

# 4 Summary of Results

# 4.1 Characteristics of Participants

Table 6 presents the characteristics of the 68 participants in the three studies: 41 were included in the RCT (Paper I), while 13 (Paper II) and 14 (Paper III) participants were recruited to the two qualitative studies. The mean age in the three samples was similar, but there was variation in gender across the studies. In Paper II, 5 of the participants (2 females and 3 males) interviewed were also allocated to the intervention arm in the RCT.

Table 6. Characteristics of the participants in the three studies.

Variables	•			Sheltered housing
	Paper I		Paper II	Paper III
	Intervention	Control		
N	21	20	13	14
Female	9 (43%)	12 (60%)	3 (23%)	6 (43%)
Age, mean	42.2	43.8	42	48.8
Living situation				
-Living alone	17 (81%)	12 (60%)	10 (77%)	0 (0%)
-Homeless	12 (57%)	3 (15%)	3 (23%)	0 (0%)
-Sheltered housing	0 (0%)	0 (0%)	0 (0%)	14 (100%)
Coercion	3 (14%)	5 (25%)	-	-
Employment status				
Disability pension	10 (48%)	13 (65%)	4 (31%)	14 (100%)
Full-time employment	1 (5%)	1 (6%)	1 (8%)	0 (0%)
Part-time employment	2 (10%)	0 (0%)	0 (0%)	0 (0%)
Unemployment	8 (40%)	2 (13%)	8 (62%)	0 (0%)
Student	0 (0%)	1 (6%)	0 (0%)	0 (0%)
Education level				
Compulsory school	7 (37%)	4 (23%)	-	-

Middle-level education	9 (47%)	11 (65%)	-	-
Higher education	3 (16%)	2 (12%)	-	-
Main diagnosis (ICD-10)				
F1	2 (10%)	2 (10%)	2 (15%)	-
F2	5 (24%)	5 (24%)	2 (15%)	-
F3, F4	12 (57%)	5 (24%)	5(38%)	-
F6	1 (5%)	4 (20%)	3 (23%)	-
F07.8	0 (0%)	0 (0%)	1 (8%)	-
Z03.2	1 (5%)	4 (20%)	-	-

F1; mental and behavioural disorders, F2; schizophrenia, schizotypal, delusional disorders, F3; mood disorders, F4; anxiety, F6; behavioural and personality disorders, F07.8; other organic personality and behavioural disorders due to brain disease, damage, and dysfunction, Z03.2; observation for suspected mental and behavioural disorders.

The picture below shows the outside of the community residential aftercare unit (Picture 1). Picture 1. The community residential aftercare unit.



4.2 Paper I. Health Care Utilization and Cost After Discharge from a Mental Health Hospital: An RCT Comparing Community Residential Aftercare and Treatment as Usual.

# 4.2.1 Implementation of the intervention

The intervention was implemented according to protocol as planned. All patients in the intervention group were discharged to the CRA. The mean length of mental hospital

inpatient stay from randomisation to discharge was as expected shorter in the intervention group (3.8 days in the intervention group and 10.1 days in the control group, p = 0.023).

#### 4.2.2 Outcome

For the primary outcome, utilization of community mental health services, the intervention group used, on average, 29% fewer hours (mean differences -21.6 hours, 95% CI -93.1 to 44.9, p = 0.096) with a cost saving of 29% (mean differences -1845 EUR, 95% CI -8267 to 4171, p = 0.102), but the estimates were imprecise as evident from the width of the confidence intervals.

Both study groups had the same total number of inpatient days (66 days) during the 12 months, but the intervention group had, on average, 13.4 days fewer inpatient days in the mental health hospital (95% CI - 29.9 to 0.9, p = 0.008).

Total cost for mental health care services was 38.5% (mean differences -23071 EUR, 95% CI - 45450 to 3027, p = 0.057) lower in the intervention group, also with imprecision in the estimates. The difference was mainly due to a reduced number of inpatient days in the MHH.

As evident from Table 6, there were some differences between the groups at baseline. Doing a linear regression model group allocation and some of the baseline characteristics showed that the reduction in total cost varied between -26 509 EUR and -17 356 EUR.

4.3 Paper II. Like a Hotel, But Boring: Users' Experience with Short-term Community-based Residential Aftercare

One of the main findings was that the participants found staying at the CRA similar to being in a hotel, but also boring. This was due to the lack of organized in-house activities, which was part of the philosophy. Some also said that they missed the opportunity to get in-house treatment options.

You feel that you are in a nice hotel, but nothing else.

The patients generally stated that they had not been informed about the philosophy of the CRA before their stay. Some stated that they had only been informed that they would be discharged to a residential institution in primary care settings and expected something like an MHH. Others said that they had received information about the CRA, but mostly about practical aspects, and that they would have a single room and a safe place to stay.

I got information from the staff in the mental hospital about the stay at CRA and was told they offer a single room, serve dinner, and there were staff 24/7. Otherwise, there was no detailed information given.

The participants had to look for activities outside the CRA themselves and said they got active help from the staff to do so; some experienced this as positive, whereas others wanted more organized in-house activities, like they were used to having at MHH stays.

I thought there would be more in-house activities, but there were none. So, you felt in a way that you were just sitting there waiting with nothing to do or that someone would try to take you out or get you to participate in normal life. You were on your own. The staff asked me how I was going to spend the day and I had to find out what to do.

Participants described the staff to be helpful and forthcoming, but they did not find the staff being active in organizing aftercare. Some participants said that they talked to staff about preparing themselves before meetings with other community agencies.

Yes, an employee from the Health and Welfare office [case handler] came and talked to me, and then I was offered a follow-up service that I still use, as well as help from the Child and Family agencies.

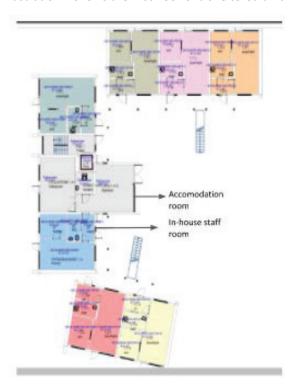
The six participants who were interviewed after discharge from the CRA talked about similar experiences regarding preparation for their home situation. They all expressed satisfaction with the services after discharge from the CRA and said that meetings with different agencies during the stay in CRA were essential in setting this up.

When I was at the residential care, they arranged a new system for me together with other agencies of the municipality.

4.4 Paper III. A Qualitative Study on How People with Severe Mental Illness Experience Living in Sheltered Housing with a Private Fully Equipped Apartment.

The illustration below shows the first floor of a sheltered housing unit with six private fully equipped apartments (41 square metres), one accommodation room (60 square metres), and an in-house staff room (41 square metres) (Illustration 1). The outside of the unit is presented in picture 2 (picture 2).

Illustration 1 shows the first floor of a sheltered unit.



Picture 1. The outside of one of the sheltered units.



The residents' access to the service providers in the sheltered housing was critical for their feeling of security. Some also said that the combination of ambulatory services and the security provided by the staff reduced the number of hospitalizations after moving into sheltered housing.

I have not had any hospital admissions after I moved here, so I feel safe in the residence.

However, as the residents have a three-year tenancy agreement, some were worried about whether or not their tenancy would be extended.

If we behave well and pay the rent on time, I think we should get to stay here as long as we want.

The staff were said to treat the residents with respect. Words like 'being treated with dignity', as 'ordinary people', and 'not as a diagnosis' were used. They also emphasised that the staff were skilled in observing their problems and offering counselling and practical help at an early stage.

I am treated with respect and dignity. The staff said they do not care about diagnoses—they care about people.

Residents highlighted the advantages of living in a private apartment and having access to a shared accommodation room to connect with other residents. It was repeatedly emphasized that having their own apartment with their own equipment helped reduce conflicts; they could go and be alone in their own apartment and avoid quarrels over who should use shared equipment such as the television or washing machine.

It's very good because we have our own apartments and a shared accommodation where we can go if we want to see people.

Most of the residents said that they had become friends with one or two of the other residents. This resulted in both increased social and physical activity. Some also reported that they participated in more activities now than in the place where they had previously lived.

I've become better acquainted with some residents that I can go hiking with, go to town or seek low-threshold services.

Most residents said that they had a limited social network outside the sheltered housing. One informant reported that he had only one friend apart from the fellow residents. Some stated that they have contact with family members who visit and help them pay bills, and others had support persons that they consider as friends.

I have a support person with me to visit the cinema, bowling, go-kart and café visits.

# 5 Discussion of Methods

Each of the papers in this thesis includes a discussion of the methods specific for each study. In this chapter, some general methodological issues are discussed across all three studies, focusing on reflexivity and external and internal validity.

# 5.1 Reflexivity

There is no doubt that the researcher influences the research process (Malterud, 2001). Thus, it is important that the researcher is honest and vigilant about own-perspectives, pre-existing thoughts, and beliefs (Starks & Brown Trinidad, 2007). According to Malterud (2001), reflexivity is associated with an attitude of attending systematically to the context of knowledge construction, particularly so to the effect of the researcher, at every step of the research process. This includes recognising that knowledge can be partial and situated (Haraway, 2003). Consequently, it is necessary to account for the researchers' role in order to judge the findings (Malterud, 2001).

My professional background is one of being a registered nurse. I began in the municipality of Trondheim in 1997 as an adviser for the chief municipal executive. I played a central role in developing a local development plan in accordance with the national development plan in mental health (2001–2009) (Brofoss, 2009). Among numerous other aspects, the local plan focused on collaboration with mental health specialist care for discharge-ready patients. At that time, this entailed establishment and operations of sheltered housing, which I took active part in from my advisory position.

As described, during the years from 2002–2008, the municipality of Trondheim established 123 residences in sheltered housing with in-house staff 24/7. This happened without a substantial reduction in the number of persons waiting to be discharged. Consequently, it raised the discussion on whether the assessment by staff in the hospital on the level of community services needed was correct.

In 2009, the municipality established the CRA unit (Papers I and II), where I had a key role in the process. The opinion held by me and my colleagues in the municipality was that the community staff had skills to assess the level of services needed in the community. And we had to find a solution to facilitate this. This implied that the patients with delayed discharge from the hospital because of waiting for community services like sheltered housing should be discharged to the CRA. This had to be balanced against the safety of the patient, including the quality of the care at the CRA. The others and I were concerned about finding the right balance between the type of patients admitted to the CRA, the level of service and competency among the staff, and the risk for the patients of not getting the right level of

care. I was involved in setting up the procedures in discussion with the MHH and, thus, I had a substantial influence on the principles for the set-up of the CRA as described in this thesis.

As it turned out, after the first three years of operation, most patients admitted to the CRA were discharged to independent living with various forms of follow-up services. I was inspired by the results and this was one of my main motivations to begin this PhD project. It is evident that I have had a professional involvement and interest in the services investigated in this thesis. This has been known to all those involved in the conduct of research projects. Thus, although my perspectives may have been influential, I have, to the best of my ability and with the help of those involved, attempted to identify my preconceptions and ensure that they have been challenged. This includes including a user as a co-researcher (Paper III), not being involved in the direct recruitment of informants (Papers I, II, and III), contrasting the findings of my studies with the published literature, and having discussions with my fellow researchers.

# 5.2 External Validity

External validity is a common term in quantitative research and concerns the generalisability of the results of a study to a larger population. One threat to generalisability is the selection bias regarding the enrolled patients (Higgins et al., 2011). In qualitative studies, the term 'Transferability' is also used for external validity, and it is also closely related to adequate and sufficiently varied samples and whom and what the findings concern (Malterud, 2001).

Those participating in the RCT (Paper I) and the qualitative study (Paper II) at the CRA also turned out to be similar to those staying at the CRA in 2016 (N = 69, statistics from the municipality), who had a mean age of 43.5 years (43 years in the sample in Paper I and 42 years in Paper II). The proportion of females was 48% (51% in Paper I and 23 % in Paper II), and the proportion of the homeless was 20% (37% in Paper I and 23 % in Paper II). The mean length of stay at the CRA in 2016 was 5.2 weeks, which was similar to the RCT (Paper I, 6.6 weeks) but shorter than those interviewed in the qualitative study (Paper II, 8.9 weeks). Taken together, although with some variation, the samples are considered to have been representative in terms of characteristics for those using the CRA. Further, the sample in the sheltered housing study (Paper III) is likely to be similar to those living in sheltered housing in the municipalities. Using data from a sample of 100 persons living in sheltered housing in 2017, it was found that 38% were females (43% in Paper III).

It is also of importance if the participants in qualitative studies represent or have experiences of the research topics, as this is fundamental for ensuring effective saturation of categories and providing optimal data quality (Morse, Barrett, Mayan, Olson, & Spiers, 2002). As all participants in Papers II and III had experienced the services, and it was ensured that participants had varied experiences, it is considered that the samples covered the experiences representative of the population of users of the services.

The RCT did not recruit as many patients as planned (Paper I). Before and during the first year of the enrolment period, the researcher organized meetings with contact nurses from all hospital wards almost weekly, to provide information regarding the recruitment procedure and discussed how to inform the hospital staff and doctors about the study. In addition, the researcher separately organized meetings with the staff in each hospital ward. Despite repeated instructions to inpatient staff, it became obvious that the staff did not introduce the study to the patients as expected. Thus, this raises the question of whether there was a selected group of patients that was asked, as, according to talks with management, many more patients were ready for discharge and met the inclusion criteria. The fact that there was a selection of patients that were asked was confirmed in the weekly meetings between the researcher and contact nurses. The nurses reported that almost all participants that were introduced in the study agreed to participate in the study. Further exploration into why patients were not asked to participate in this study revealed scepticism towards whether the CRA was sufficiently competent. This indicates that the doctors in the MHH was likely to enrol patients with less severe mental problems, as it is likely that they would not recruit those patients who they believed needed more specialists follow up than was offered at the CRA.

# 5.3 Internal Validity

The internal validity of a study is the extent to which it is free from bias (Higgins et al., 2011) and the applicability and precision of its results (Godwin et al., 2003).

# 5.3.1 Precision in outcome estimates (Paper I)

Precision depends on the number of participants and events in a study and can be independent of internal validity (Higgins et al., 2011). A small trial (few participants) with low risk of bias (high internal validity) can provide imprecise results, with a wide confidence interval. Conversely, the results of a large trial may be precise (narrow confidence interval) but have a high risk of bias if internal validity is poor. In the randomised controlled trial reported in Paper I, the sample was small and the results, with wide confidence intervals, were imprecise. One example is the primary outcome, where the intervention group used 29% fewer hours of community mental health services but where the confidence intervals were very wide (mean differences –21.6 hours, 95% CI –93.1 to 44.9, p = 0.096).

Using the conventional p-value of 0.05 as a cut off for deciding whether this was a valuable finding or not, would lead to the conclusion that the findings was not statistical significant at a 0.05 level. However, even though the p-value was above 0.05, the findings may still be of clinical importance and practical value (Fethney, 2010; Ranstam, 2012). This is judged on whether the ranges in the confidence intervals for the estimated difference may indicate an improvement that have practical value and consequently of interest for further

investigations. However, this must be balanced against whether the intervention is likely to inflict any harm.

Examining the main outcome, a 29% reduction in utilisation with a corresponding cost saving of 29% is substantial. Thus, the point estimate gives clear indications that being discharged to the CRA was beneficial. The next question then becomes whether the confidence interval (CI) gives an indication that there is a potential of harm. Although the lower confidence interval is well below zero, thereby implying that there is a chance that the use of the CRA can lead to increase in utilisation and cost, it is still more likely that the opposite is the case, as evident from the upper confidence limit.

In summary, it was not possible to draw a definite conclusion about the effect, due to the small sample and imprecision of the estimates in the RCT (Paper I). Although the outcome estimates in the RCT (Paper I) were imprecise, examining the size of the point estimates and the uniform direction of the other outcomes in favour of the intervention group and findings in other studies on community residential care, it appears fair to suggest that there are clear indications that discharge to the CRA can lead to outcomes that are of clinical importance and practical value. Nevertheless, more and larger studies are needed to reach a firm conclusion.

# 5.3.2 Lack of blinding (Paper I)

Another central issue regarding internal validity is the risk of bias in pragmatic trials due to the lack of blinding (Sandra Eldridge & Kerry, 2012). It has been argued that in some trials in routine practice, knowledge of the intervention by clinicians delivering the intervention and/or by patients receiving the intervention is a valid part of the intervention and, therefore, blinding is undesirable (Roland & Torgerson, 1998). In our intervention, it was impossible to blind groups of individuals involved in the trial, as all participants knew which group they were allocated to. Staff in the CRA was informed about the study and participants. This could introduce a bias if the staff at the CRA changed their behaviour from their ordinary practice to ensure that those participating in the trial got a level of services that made their outcome look better.

One example could be if they introduced specific measures to reduce length of stay at the CRA to reduce utilisation and cost. However, this was not the case, as the length of stay in the trial (45.9 days) was longer compared to all patients staying in the CRA in 2016 (37 days). Another example could be to offer the participants in the trial a lesser number of follow-up services, which would also reduce utilisation and cost. The results showed that the intervention group indeed used a lesser number of services. However, a lack of follow-up services could have led to more admissions, which was not the case.

Furthermore, the persons extracting the data from the registers were not aware of the allocation (assessor blinding). This is important as a review of trials with both blinded and

non-blinded outcome assessors found that no blinded observers tended to favour the experimental intervention, and exaggerated the hazard ratio by approximately 27% (Hróbjartsson et al., 2014). Taken together, there are no indications that the results on the main outcomes were unduly influenced by lack of blinding.

# 5.3.3 Quality of data sources (Papers I, II, and III)

The data sources used in this thesis were registers (Paper I) and interviews with services users (Papers II and III). In addition, it was planned to obtain data from self-reported outcomes measures after one, four, and twelve months in the randomised controlled trial (Paper I). However, it proved very difficult to get the participants to complete the questionnaires. It was decided that there was little use in spending large resources on attempting to get more responses, as it was not likely that this would result in usable data on self-reported outcomes.

The use of health service registers covering both specialist and community mental health care in Paper I ensured complete data on all participants, as none of the participants moved out of the region during the one-year follow up. All data on patients' contact with specialist and primary care are required to be documented by legislation. However, it is known that incorrect data can be entered (Jansen et al., 2005). In Paper I, only direct contact with the services was used, that is, the date of the beginning and end of the contact or the number of hours of services provided in a specific period. To control that this was done correctly, dates and places for admission and discharge were controlled. One example was comparing the dates of discharge registered at the MHH (taken from one register) to the date of admission at the CRA (taken from another register). Dates that could be classified as incorrect were not identified.

The interview between the researcher and the participant can led to misconceptions if they do not understand each other. The ordinary precautions to avoid this were taken, like asking questions such as 'Have I understood what you meant, when you said that...?' (Kvale, 2008). However, persons with SMI can have problems making themselves understood or may be difficult to understand, particularly in poor mental illness phases characterised by lack of insight and lack of verbal ability (Solbjør, Rise, Westerlund, & Steinsbekk, 2013), thereby posing additional challenges to the quality of the interview data. The interviews were conducted in a calm and harmonic atmosphere. Participants who were interviewed reflected individually on questions before they answered. It was also evident in the recordings and transcripts that they spoke with clarity and were comprehensible. However, there were ample examples of informants with short answers who did not elaborate or explain themselves in depth even when prompted.

# 6 Discussion of Main Findings

# 6.1 Summary of Findings

Patients with SMI randomised to be discharged to CRA had, on average, a total cost saving of almost 40% on specialised and primary health care use compared to usual care during 12 months. They had the same number of inpatient days, but fewer days in the mental health hospital. However, it was not possible to draw a conclusion about the effect, due to the small sample and imprecision of the estimates. The direction of the results indicates that transferring patients ready for discharge from MHH to CRA has the potential to reduce total consumption of health services and costs.

Even if patients experienced a hotel-like stay at the CRA, they found it boring due to the lack of organized in-house activities, the results from the RCT support that being discharged to the CRA leads to more independent living in the community. The likely mechanism is that the patients had to independently come up with activities outside the CRAs and obtained active help from the staff to do so. Nevertheless, there is room for improvement. Those staying there generally said they were not informed about the philosophy of the CRA before the stay. Persons living in a private fully equipped apartment in sheltered housing said that this could be experienced as giving room for independent living. This was mainly due to having a private fully equipped apartment that the residents could retire to at leisure and do the things they wanted. Another factor was the access to the in-house staff 24/7, which promoted a feeling of safety. However, this independence had certain limitations, as the residents told about contact with the other residents, but little about contact with people outside the sheltered housing.

# 6.2 Independence

This thesis concerns two 24/7 residential community services that aim to promote independence for its users. In the CRA, the independence was evident in, for example, leaving it to the patients to find ways to activate themselves in the community (Paper II). In the sheltered housing, the fully equipped apartment and access to the staff 24/7 were the main factors promoting independence (Paper III). To be almost self-reliant and be in command of one's own life are basic rights that most human beings take for granted, and it appears obvious that the services should focus on this. However, persons with SMI can periodically be less self-reliant and self-determined due to their illness. This raises the topic of when and to what extent services for this group of patients can leave a large amount of responsibility to the patients themselves, while simultaneously ensuring their safety and dignity.

One way of looking at independence is by examining motivation and behaviour, as the services attempt to motivate the patients to adopt a more independent behaviour. The self-

determination theory (SDT) sheds some light on this, as it claims to provide a universal framework for understanding the individual and environmental factors that shape motivation and subsequent behaviour (Deci & Ryan, 2000). SDT is particularly focused on the processes through which a person acquires the motivation for initiating new health-related behaviours and maintaining this behaviour over time. According to SDT, motivation depends on the (lack of) support for three basic psychological needs: autonomy, competence, and relatedness. SDT argues that developing a sense of autonomy and competence are critical to the process of internalization and integration, through which a person comes to self-regulate and sustain behaviours conductive to health and well-being. Relatedness provides a motivational basis for internalization, thereby ensuring a more effective transmission of group knowledge to the individual and the need to feel close to and understood by others.

There is some evidence for this claim also for patients with SMI in an outpatient setting. A study on the SDT process model found that it could explain clinical outcomes such as treatment engagement, psychosocial functioning, and quality of life to a substantial degree (Jochems, Duivenvoorden, van Dam, van der Feltz-Cornelis, & Mulder, 2017).

A closer examination of the elements of the SDT theory—autonomy, competence, and relatedness—in relation to the two settings in this thesis, add some further understanding of the process that can lead to the direction of the results seen in the RCT with less dependency on health care services. The hypothesis in the CRA of not offering in-house activities can be considered to be related to development of autonomy. The staff at the CRA emphasise supporting patients in self-care activities such as preparing their own meals and structuring their daily routines (Paper II). Moreover, the findings from the RCT (Paper I) of indications for reduced health service use, supports this strategy. It can thus be suggested that working according to the philosophy of the CRA can enable patients to begin activities in the community that they can continue after discharge. This is supported by a Danish study that found that community residential facilities were better able to promote residents' activities both within the facility and in the community as compared to hospitalbased psychiatric rehabilitation units (van Wel, Felling, & Persoon, 2003). The focus on autonomy was also evident in the sheltered housing setting (Paper III). The patients had experienced a shift in how the services were offered, from group activities such as frequent mini-bus tours and meals, to individual services that stimulated the residents to become independent in daily living arrangements, such as shopping, preparing food, and socialization.

Although the studies in this thesis did not focus directly on the competency of the patients, there is some evidence of its importance in mental health. A recent systematic review of fifteen studies on the effect of self-management interventions, which includes competency building, found that most interventions demonstrated feasibility, acceptability, and preliminary effectiveness for persons with both general medical and psychiatric illnesses (Whiteman, Naslund, DiNapoli, Bruce, & Bartels, 2016). Another means to improve

competency is helping patients to set incremental goals that can be achieved. It has been stated that it is essential that patients understand the importance of self-care and are able to formulate goals for the stay (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). A two-year Swedish follow-up study among 49 persons with SMI reported that self-formulated rehabilitation goals were important in daily activities and improved psychosocial functioning (Svedberg et al., 2014). Although not directly mentioned in Papers II and III, obtaining support to be active in the community is similar to goal-setting. The residents were expected to have as a goal the activities that they found valuable for themselves.

When it comes to relatedness, this was an evident topic in both the qualitative studies (Paper II and III). Patients discussed how they interacted with other residents and enjoyed their company. One example from the sheltered housing (Paper III) was how the patients said that they had become close to one or two other residents. This was said to result in both increased social and physical activity. However, it was also evident that there were constraints in who the patients formed relationship with. They seemed to be most related to another person with mental health problems, for example, by using day centres open only for persons with mental health illness. Furthermore, patients felt close to and were said to be understood by the staff, as they treated the residents with respect and saw them as human beings and not as a diagnosis.

Although there were ample examples of support for independency—including autonomy, competency, and relatedness—from the services, there are clear limitations to this independence. There is still a lack of options for persons with SMI when it comes to choosing where and how to live and which services they get access to. Many patients with severe mental illness prefer to live independently in ordinary residences in a neighborhood with other inhabitants (Richter & Hoffmann, 2017). To meet this desire, they ought to have access to a range of housing options and be supported to make choices based on their preferences. Users' choice and preferences are important factors in recovery, as it engages users' willingness and motivation to make life changes (B. Tanzman, 1993).

# 6.3 Dependency on In-house Staff

Another issue regarding promoting independency for persons with SMI is the aspect of having access to staff 24/7. Several studies have demonstrated the importance of continuity in the staff-patient relationship to achieve satisfactory results in treatment and follow-up (Brown, Brown, Howlett, & Howlett, 2017; Crawford, Jonge, Freeman, & Weaver, 2004; Hautala-Jylha, Nikkonen, & Jylha, 2006; Hesselink et al., 2012). This must be balanced against the problem arising if the patient develops a dependent relationship with the contact person (Griswold et al., 2008).

Having access to staff 24/7 was said to be a cornerstone for patients feeling safe (Paper III). The residents described the proximity and duration of relationships with the staff as

important factors for feeling confident to seek help from them and having a trusting relationship that gave them an experience of security and stability. This resonates with guidance on building trust in mental health services, which emphasizes confidentiality and continuity (Gaebel et al., 2014).

However, it can cause strong bonds and counteract independency because it could be a hindrance to normalization, participation in society, and recovery (Chesters, Fletcher, & Jones, 2005). Thus, it is important to be aware of the relationship between proximity and distance when assistance is to be provided to persons with SMI. It has been speculated that sheltered housing might increase dependency on service providers for people with SMI (Chilvers et al., 2006). However, we found that some of the residents felt more independent to manage on their own and less dependent on services from the staff after a few years in the sheltered housing (Paper III). Some residents also experienced that the staff played a major role in their disease management, as the staff observed changes in their mental symptoms and initiated therapy before problems were further aggravated. This was said to be the sole positive aspect of living in sheltered housing, which is also found in other studies (C. Forchuk et al., 2008). This indicates that having a focus on individual skills and resources and living rather independently in their own fully equipped apartment (for example, making dinner for themselves almost every day) could counteract some of the danger of becoming institutionalized and dependent on the staff.

The same can be said for the CRA (Paper II). Although having a designated contact person, it was evident that this contact person was not experienced as someone who took charge of his or her life. Rather, the focus on using community resources was likely to reduce the dependency on the staff.

# 6.4 Assessment of Level of Community Services Needed

A central issue underlying this thesis is the level of community services needed for persons with SMI after discharge from an MHH and how this level should be assessed. The traditional method for deciding on the needs for community services for patients ready for discharge from the MHH is discussion in meetings between hospital and municipality staff. The hospital staff has typically provided the current knowledge of the patients' situation and made their suggestions based on their observation of the patient in the hospital setting. As the staff from the municipality has no direct knowledge of the current situation, they are likely to agree with the hospital staff's recommendation. Thus, traditionally the staff at the hospital has a deciding role in assessing the level of community services required.

Doing the assessment within the setting of a CRA is another approach in assessing the level of community services required (Paper II). As indicated in the study on the effect of discharge to the CRA (Paper I), this can lead to a considerable lower level of utilization of mental health care services during the next year, even without any increased risk for

admissions to an MHH. Thus, the question becomes whether it should be recommended to introduce CRA as a common service to do the assessment of the level of services needed for persons with SMI who need community services after discharge?

Given the findings in this thesis and the literature, as outlined in the discussion in Paper I, it appears fair to suggest that the answer is yes. It then becomes necessary to identify the parts or principle aspects that must be present for successful operation of a CRA service. The following few aspects can be indicated as being central:

- That the CRA is staffed with persons who have experience from community services and who know the situation of persons with SMI in the community as well as the types of services that can be offered (Fairweather, Sanders, Cressler, & Maynard, 2017; Horvitz-Lennon, Kilbourne, & Pincus, 2006)
- Making the setting of the CRA more similar to a home-like situation than the hospital.
   This helps the staff get a chance to observe patients' resources, behaviour, sleep-patterns, symptoms and functioning in daily activities in a setting that resembles the community setting (K. A. Thomas et al., 2017).
- Not offering in-house activities, treatment therapy or group activities at the CRA to give
  a strong signal that the patients need to orient themselves toward activities and services
  in the community that can meet their needs (Shen & Snowden, 2014; van Wel et al.,
  2003).
- Having a focus on self-care support to strengthen the patients trust in their ability to manage independent living (Svedberg et al., 2014; Whiteman et al., 2016).
- Using a systematic approach to facilitate and involve all relevant parties in the process of
  establishing community health and social services to support the transition from the
  hospital to independent supported living in the future (Goncalves-Bradley, Lannin,
  Clemson, Cameron, & Shepperd, 2016).

# 6.5 Should the Local Government Take Over More Services?

In Norway, as in other countries, there has been a move towards providing more services in primary care, and to improve the collaboration between primary and secondary care (Romøren et al., 2011). One example is that the municipalities in Norway are required to offer acute 24/7 residential services for persons with somatic or mental illness or substance abuse. Moreover, from 2019 onwards, the municipalities have to pay a fine to the MHHs for patients with delayed discharge, a practice that has been in place for somatic hospitals since 2012. Thus, there is an ongoing discussion and process regarding the services that are to be operated by primary and secondary care.

As described in this thesis, Norway has what is called a community mental health center (CMHC) that is a part of the specialist care, and which has as one of its roles the reduction of the gap between mental hospitals and primary care (community). CMHC is responsible to serve the population in a certain geographical area (from 15,000 to 150,000 inhabitants) covering emergency mental health care and offering inpatient and outpatient treatment based on referrals from GPs and MHHs. A CMHC typically has 20 to 40 inpatient beds (step-up /step down), outpatient treatment, and operates an ambulant treatment team, such as an assertive community team (ACT). Some CMHCs also include self-referral beds. The main staff consists of nurses, psychiatrists, and psychologists.

As is evident, both the CMHC and the CRA have similarities when it comes to inpatient services and they both operate between the hospital and the home-based community services. Occasionally, these similarities can become problematic, both for the system, staff, and patients, as it is difficult to distinguish which patients are best served at the CMHC or the CRA in a discharge process. Furthermore, the system is not likely to be cost-effective if they operate with almost parallel services. Then, the question that arises is if the municipalities could and should take over the responsibility for the CMHC, either the entire service or part of it. The argument being that studies have found that community alternatives to acute in-patient care (step-up) are cost-effective (Byford et al., 2010), and step-down residential services provided services that improved self-care, symptoms, and social skills (K. A. Thomas et al., 2017). Moreover, the findings in Paper I lend support.

One argument is that the cost per day in the CRA amounts to 43% of the cost per day in the CMHC (Paper 1). These considerable differences in costs between these service levels are largely explained by differences in the number of employees and their level of education, as there are psychiatrists and psychologists in the CMHC. For the group of patients discharged to the CRA (Paper I), the results indicate that they managed well without having such specialists on site. Nevertheless, there are other groups of patients that need a specialist present during an inpatient stay even if they are deemed ready for discharge from the hospital.

If the municipality took over the responsible for these patients, they would have to build up services similar to the CMHC, but with community approaches. Such approaches include ensuring access to a broad range of community-oriented services (including housing, education, employment, peer support, recovery education, crisis support, support in everyday living, drug treatments, talking therapies, and advocacy), and promoting social inclusion and human rights (Coalition, 2008). It is reasonable to assume that a meaningful life is not lived within the boundaries of mental health services, and increased contact with non-mental health agencies and informal forms of support are often considered more valuable by service users than contact with formal services (Mike Slade et al., 2014).

Whether or not the municipalities should take over the responsibility for the CMHC is, thus, largely dependent on the type of services that should be offered in primary or secondary

care. If the service is aimed at preparing patients for independent living in the community, it appears sensible to let it be the responsibility of the municipality. The reason being that when the municipality is responsible for the service, the focus on the community services becomes stronger, at least as long as the service is integrated properly with the other community services.

However, such a change should be followed by research to test if moving the responsibility for the CMHC to the municipalities while simultaneously ensuring a strong community orientation can give the same quality with reduced use of resources.

# 7 Conclusion

Transferring patients ready for discharge from hospital to community residential aftercare has the potential to reduce total consumption of health care services and costs. The likely mechanism is that the level of services was determined in a more home-like setting, as the setting led the patients to be more independent. Despite the emphasis on independence in both the aftercare and sheltered homes, the presence of the staff 24/7 was very central to make the patients feel secure and, thus, able to act more independently.

# 8 Implications for Practise

Even if there is need for more research, it seems safe to suggest that community residential aftercare services have a place in the transition of persons with severe mental illness from hospital to supported independent living in the community. As such services have to be adapted to local context, it is important that an establishment closely monitored. A number of central aspects of such a service are suggested above, and it is not possible to identify which is the most central. However, it can be suggested that a strong community orientation among the staff is needed. This could mean that the majority of the staff should have experiences from working in community services. Furthermore, the strong emphasis on promoting independency by not offering organised in-house activities is likely to be another issue that should be copied.

For those establishing such services, the findings that some of those admitted was not aware of the philosophy, should be noted. As such services might be different from other types of residential mental health services, care should be taken to get this information across. This might not be easily done given the type of patients and their current situation. Thus, it is likely that the information should be repeated, preferably starting in the hospital before discharge and then both when admitted and during the next days, as this might help the patients to get a better understanding and hopefully also buy in.

Given the move towards delivering more healthcares in the community, trying out new forms of organising the responsibility of services should be encouraged. It has been discussed above whether municipalities in Norway should take over the responsibility of community mental health centres, which currently are part of specialist health care. In this thesis the question is merely raised, but in light of the ongoing debate, it seems worthwhile to try it out to gain experience. This should however be followed by research to ensure that sufficient knowledge is produced to guide future decisions.

The CRA investigated in this thesis offered self-referral inpatient stays for former users. This was said by the informants in Paper II to be helpful. Having access to such beds, can give a sense of security to the patients, as they know that if things becomes worse, they can admit themselves. This thesis have not investigated or discussed this any further, and no clear recommendation can be offered regarding the benefit itself. But the impression is that having self-referral beds is a signal to the patients that the CRA is a place where they can get low level help, and this might raise the trust among present and future patients.

According to the participants in Paper III, there were clear advantages of having a fully equipped apartment when living in a sheltered housing unit. Whether or not this arrangement is to be recommended is an issue for further research. What seems reasonable to suggest is that measures that promote independency also in sheltered housing should be sought for.

# 9 Suggestions for Future Research

The findings in this thesis make some areas for future research apparent. Even if the direction of the results in the RCT (Paper I) and similar findings in other studies indicates and effect of community residential aftercare, larger studies in other settings are needed to confirm this. Although frequently problematic due to low response rate, such a study would be strengthened by including patient reported outcome measures. Furthermore, the use of other types of services could be included to investigate if there e.g. is a shift from more traditional mental health services to other types of services. This could be the use of day care activities, self-help groups, but also use of GPs and other medical and health care services.

As we have found no other studies on services like the community residential aftercare investigated in this thesis, further investigation into the experience of those involved is warranted. This includes investigating the experiences of the staff in the CRA, those cooperating with the CRA in the mental health hospitals and community services and next-of-kind.

There are different forms of sheltered housing arrangements, from sharing rooms to fully equipped self-contained apartments. The findings in this thesis with indication that having one's own apartment within a sheltered housing unit promotes a feeling independence, also raises interesting questions. Is it in the longer run more or less costly from a societal perspective to invest in units with separate apartments, compared to alternatives that are less costly to build? Could sheltered hosing unit with fully equipped apartments with access to staff who are on call but not present 24/7 be an alternative?

#### 10 References

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# 11 Appendix

# Interview guide - main topics

# Paper II: Community residential aftercare (CRA) study

Could you please tell me how and from whom you get information about the CRA?

What kind of information was given in the hospital?

What kind of information was given after admission in the CRA

Could you please tell me about how you experience the facility at the CRA?

Could you please tell about how you experience the atmosphere in the CRA?

Relationship to the staff at the CRA

Relationship to other agencies during the stay at the CRA?

Could you please tell me about yours experiences with the stay at the CRA?

Could you please tell about the most important you get support within the CRA?

Could you please tell about why it is important?

Could you please tell if there was anything you missed in the CRA?

Could you please tell about the main differences between a stay in a mental hospital versus a community residential aftercare?

# In addition, for participants interviewed after discharge

Could you please tell about if the stay at the CRA was importance regarding to manage everyday life the first month at home?

Experience with use of self-referral stay at the CRA?

What are you most satisfied with regarding to:

- Housing
- Job leisure activities social network services from primary care services from the specialist

What are you not satisfied with regarding to:

- Housing
- Job leisure activities social network services from primary care services from the specialist.

Could you please tell if there are other themes, other than what we have talked about?

# Paper III: Sheltered housing study

Experiences with their living arrangement (housing)

- compared with previous housing

What are you most satisfied with regarding these sheltered housing facilities?

What are you not satisfied with regarding these sheltered housing facilities?

Could you tell about the services the municipality offers?

Could you tell about how you experience safety?

When you notice symptom change/increase -how do you get access to help?

Do you have a contact person among the municipality staff that is easy to get in touch with?

Are there other types of assistance that you miss or would have preferred to what get now?



 Region:
 Saksbehandler:
 Telefon:
 Vår dato:
 Vår referanse:

 REK midt
 Siv Tone Natland
 73598916
 03.02.2012
 2011/1770/REK midt

Deres dato: 17.01.2012

Vår referanse må oppgis ved alle henvendelser

Prosjektleder Eirik Roos

2011/1770 Etterbehandling i kommunalt helsehus - en arena for kartlegging og koordinering av kommunale tjenester som sikrer rask tilbakeføring til eget hjem.

Vi viser til e-post innsendt 3. februar 2012 med svar på komiteens spørsmål i vedtaksbrev datert 6. oktober 2011. Komiteen finner at spørsmålene er tilfredsstillende besvart.

#### Vedtak

Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge godkjenner prosjektet med hjemmel i helseforskningsloven § 10. Det knytter seg imidlertid vilkår til godkjenningen som må oppfylles før prosjektet kan igangsettes.

#### Vilkår

For å sikre et frivillig samtykke, er det viktig at de aktuelle pasientene ikke står i et avhengighetsforhold til den som informerer og spør om samtykke. Komiteen setter derfor som vilkår at forespørsel om studiedeltakelse gis av velinformert helsepersonell som ikke selv er med på forskningsprosjektet og som er fullstending uavhengig av forholdet mellom deltakeren og helsepersonell som er involvert i prosjektet.

#### Merknader:

- Godkjenningen gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.
- Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helseog omsorgssektoren».
- Alle prosjektmedarbeidere har taushetsplikt i henhold til helseforskningsloven § 7.
- Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Prosjektet skal sende sluttmelding til REK Midt-Norge på fastsatt skjema når prosjektet avsluttes.

#### Klagerett

Du kan klage på vedtaket, jfr. helseforskningsloven § 10, tredje ledd og forvaltningsloven § 28. En eventuell klage sendes til REK Midt-Norge. Klagefristen er tre uker fra mottak av dette brevet, jfr. forvaltningsloven § 29

Med vennlig hilsen, Siri Forsmo Førsteamanuensis, dr. med. Nestleder REK midt

> Siv Tone Natland Rådgiver

# Forskningsprosjekt om erfaringer med Kommunale tjenester Kontaktperson Stipendiat Eirik Roos

Til deg som er bruker av kommunale tjenester

Trondheim, februar 2014.

# Forespørsel om deltakelse i forskningsprosjekt

Erfaring med kommunale tjenester.

Dette er spørsmål til deg om å delta i en forskningsstudie for å undersøke erfaring med kommunale tjenester. Du får denne henvendelsen fordi du har kommunale tjenester som botiltak og ambulante tjenester. Studien er godkjent av Regional komitè for medisinsk og helsefaglig forskningsetikk, Midt-Norge.

#### Bakgrunn og hensikt

Det er igangsatt et forskningsprosjekt i regi av NTNU ved Institutt for samfunnsmedisin om nytten av ulike kommunale tiltak. Studien skal intervjue brukere om deres erfaringer for å få en bedre forståelse av brukernes opplevelse.

# Hva innebærer studien for deg?

Vi ber om et møte med deg sammen med 3 andre brukere, slik at dere sammen kan fortelle om erfaringer med den hjelpen som dere har nå. Hva er du fornøyd med / ikke fornøyd med av den hjelpen som du har og om det er andre typer hjelp som du kunne tenke deg.

Hvis du ikke vil intervjues sammen med andre brukere, kan du bli intervjuet alene.

# Om intervjuet

Intervjuet vil foregå på et kontor i nærheten av der du bor. Dersom du samtykker i å delta i intervjuet vil vi kontakte deg for å avtale dato og klokkeslett for intervjuet. Intervjuet vil vare fra ca 30 minutter til 1 time.

# Hva skjer med informasjonen du gir?

Alle opplysninger som du gir under intervjuet vil bli behandlet strengt konfidensielt. Opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun forskere med taushetsplikt knyttet til prosjektet som har adgang til

Forskningsprosjekt om erfaringer med Kommunale tjenester

Kontaktperson Stipendiat Eirik Roos

navnelisten. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Studien starter i mars 2013 og avsluttes i 2016. Etter dette vil det avidentifiserte datamaterialet bli lagret i fem år etter prosjektslutt for en mulig oppfølgingsstudie. Dersom det blir aktuelt å gjennomføre en oppfølgingsstudie, vil du få ny informasjon og ny forespørsel om å delta.

Taushetsplikt

Ansatte som deltar i forskningsprosjektet har en uavhengig rolle. Det betyr at ansatte i prosjektet ikke er representant for ledelsen, personalet eller pasientorganisasjoner. Alle ansatte i prosjektet har underskrevet taushetsplikt.

Rett til innsyn og sletting av opplysninger om deg

Dersom du trekker deg fra studien, kan du kreve å få slettet opplysninger vi har samlet inn under intervjuet, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Frivillig deltakelse

Det er helt frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, ber vi deg om å underskrive samtykkeerklæringen.

Du blir kontaktet for å spørre om du vil delta

Du vil om kort tid bli kontaktet av forsker Eirik Roos som vil gi deg mer informasjon og spørre om du vil delta i studien. Hvis du sier ja til å delta vil du bli bedt om å skrive under på vedlagte samtykke.

Hvis du ikke vil at forskere skal ta kontakt med deg, kan du si i fra til din primærkontakt eller en annen ansatt. Du vil da ikke bli kontaktet av forskeren.

Ta gjerne kontakt med prosjektleder selv dersom du har kommentarer eller noe du vil spørre om:

Prosjektleder Eirik Roos

Telefon: 952 632 22

E-post: eirik.roos@ntnu.no

Postadresse: NTNU, Det medisinske fakultet, Institutt for samfunnsmedisin, Postboks 8905

MTFS, 7491 Trondheim

# Forskningsprosjekt om erfaringer med Kommunale tjenester Kontaktperson Stipendiat Eirik Roos

# Samtykke til deltakelse i studien:

Dato:

Jeg har fått informasjon om studien, jeg har hatt muligheter til å stille spørsmål og er villig til å delta i intervju.

Navn:(BLOKKBOKSTAVER)
Signatur:
Underskrift av forsker
Dato:
Navn:(BLOKKBOKSTAVER)
Signatur:

Til deg som er pasien	nt ved St. Olavs Hospital, Divisjon	psykisk helsevern:
Østmarka sykehus,	Avdeling:	
		Trondheim, januar 2012.

# Forespørsel om deltakelse i forskningsprosjekt

Etterbehandling i kommunalt helsehus – effekt og erfaring fra døgninnlagte utskrivingsklare pasienter i Psykisk Helsevern.

Dette er spørsmål til deg om å delta i en forskningsstudie for å undersøke effekt og erfaring med etterbehandling i Østbyen helsehus, avdeling Leistad.

# Bakgrunn og hensikt

Mange døgninnlagte pasienter ved Østmarka sykehus, Nidaros og Tiller DPS kan bli værende i sykehus / DPS i lang tid etter at behandlingen er avsluttet. Pasientene kan oftest ikke utskrives, da de mangler enten bolig og / eller kommunale tjenester.

I 2009 opprettet Trondheim kommune 10 etterbehandlingsplasser (enerom) ved Østbyen helsehus, avdeling Leistad for å teste ut om pasientene kan utskrives raskere, når kommunen foretar kartlegging av kommunale hjelpebehov. Etterbehandling betyr at pasienter kan overføres fra Østmarka sykehus til Østbyen helsehus, avdeling Leistad, når den psykiske tilstanden er utredet, diagnostisert og den videre behandlingsplanen er avklart.

Etterbehandling av inneliggende pasienter i psykisk helsevern er et helt nytt tiltak som ikke er prøvd ut tidligere i Norge. Det er derfor igangsatt et forskningsprosjekt i regi av NTNU ved Institutt for nevromedisin/samfunnsmedisin på om et slikt tiltak gir færre oppholdsdøgn og i hvilken grad du er fornøyd med hjelpen du mottar etter utskriving.

# Hva innebærer studien for deg?

Basert på en tilfeldig utvelgelse blir du med i en gruppe som blir værende i psykisk helsevern inntil behandlingen er fullført eller i en gruppe som får tilbud om etterbehandling ved Østbyen helsehus, avdeling Leistad.

Forskningsprosjektet ber om en bekreftelse fra deg om å hente ut sykehusets journalopplysninger som omhandler; alder, kjønn, diagnose og årsak til innleggelser i Psykisk helsevern i løpet av første året etter siste innleggelse. Likeledes vil det bli innhentet opplysninger fra Trondheim kommunes journalsystem om hvilke kommunale tjenester og omfanget av tjenester som du mottar etter utskriving.

Likelede bes du om å svare på spørsmål om hvor fornøyd du er med ulike områder i livet ditt og om dine praktiske og sosiale ferdigheter tre måneder etter deltakelsen i prosjektet og etter 1 år.

#### Hva skjer med informasjonen du gir?

Alle opplysninger vil bli behandlet strengt konfidensielt og oppbevart i godkjent låsbart arkiv. Opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun forskere med taushetsplikt knyttet til prosjektet som har adgang til navnelisten. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Studien starter i januar 2012 og avsluttes i 2015. Etter dette vil datamaterialet bli lagret i fem år etter prosjektslutt for en mulig oppfølgingsstudie. Dersom det blir aktuelt å gjennomføre en oppfølgingsstudie, vil du få ny informasjon og ny forespørsel om å delta.

# **Taushetsplikt**

Ansatte som deltar i forskningsprosjektet har en uavhengig rolle. Det betyr at ansatte i prosjektet ikke er representant for ledelsen, personalet eller pasientorganisasjoner. Alle ansatte i prosjektet har underskrevet taushetsplikt ved sykehuset og i Trondheim kommune. Studien er godkjent av Regional komitè for medisinsk og helsefaglig forskningsetikk, Midt-Norge.

# Rett til innsyn og sletting av opplysninger om deg

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har også rett til å korrigere eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet opplysninger vi har samlet inn, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Frivil		

Det er selvsagt helt frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, ber vi deg om å underskrive samtykkeerklæringen nederst på siden.

Ta gjerne kontakt med prosjektleder, dersom du har kommentarer eller noe du vil spørre om:

Prosjektleder Eirik Roos, telefon 952 632 22
Samtykke til deltakelse i studien:
Etterbehandling i kommunalt helsehus – effekt og erfaring fra døgninnlagte utskrivingsklare pasienter i Psykisk Helsevern.
eg har fått informasjon om studien, jeg har hatt muligheter til å stille spørsmål og er villig ti å delta i studien.
Dato:
Navn:

# Paper I

# TITLE

Health care utilization and cost after discharge from a mental health hospital; an RCT comparing community residential aftercare and treatment as usual.

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Study design:	An open parallel group randomized controlled trial
Running title:	Health care utilization and cost after discharge from a mental health
	hospital; an RCT comparing community residential aftercare and treatment
	as usual.
Abstract/text:	350 words / 4490 words
Tables/figures:	6 tables / 2 figures
Keywords:	Community residential aftercare, step-down, discharge-ready mental
	health patients, severe mental illness

### **Abstract**

# **Background**

Community residential aftercare (step-down) services can ease the transition after a mental health hospital stay for patients with severe mental illness (SMI).

### **Aims**

To investigate use of community and specialised mental health care services and costs in patients with SMI the first 12 months after discharge from a mental health hospital (MHH), comparing community residential aftercare (CRA) and treatment as usual.

### Methods

An open parallel group randomised controlled trial with 41 participants. Data on use of specialist services (hospital, ambulant treatment and out-patient treatment) and community services (residential stays, home help, home care nursing, mental health consultation) were collected from specialist and community registers and health records.

#### **Results**

For the primary outcome, utilisation of community mental health services, the intervention group used, on average, 29% fewer hours (mean differences -21.6 hours, 95% CI -93.1 to 44.9, p = .096) with a cost saving of 29% (mean differences -1 845 EUR, 95% CI -8 267 to 4 171, p= .102), but the estimates were imprecise. For the secondary outcome, the study groups had the same total number of inpatient days (66 days), but the intervention group had on average of 13.4 fewer inpatient days in the MHH (95% CI -29.9 to 0.9. p = .008). The intervention group had on average a total cost saving of 38.5% (mean differences -23 071 EUR, 95% CI -45 450 to 3 027. p = .057). An exploratory post hoc multivariable regression analysis controlling for baseline characteristics gave results that changed estimated mean difference for total cost from -26 509 EUR (95%CI -52 107 to -910. p = .043) to -17 356 EUR (95% CI -41 726 to 7012, p = .158).

# Conclusion

In this study, it was not possible to draw a definite conclusion about the effect, due to the small sample and imprecision of the estimates. The direction of the results and size of the point estimate, including findings in other studies, indicates that transferring patients ready for discharge from mental hospital to community residential aftercare has the potential to reduce total consumption of health services and costs without increased hospital admissions.

**Keywords:** Community residential aftercare, step-down, discharge-ready mental health patients, severe mental illness

# Background

Most psychiatric inpatients can be discharged without comprehensive follow-up, yet patient with severe mental illness (SMI) often need long-term aftercare [1]. This is a particularly vulnerable group, as patients with SMI have a 10-25 year shorter life expectancy than the general population [2]. Furthermore, a Danish population-based cohort study found increased risk of hospitalizations and rehospitalizations within 30 days for patients with SMI compared with the general population [3].

The duration of hospital stays` is a major driver for health costs [4] and most Western countries have shifted more mental health care towards community-based settings [5]. However, it is a challenge to provide timely community services for patients who are ready for discharge from mental health hospitals. A study in the UK in 2005 found that the proportion of discharges classified as "delayed" varied from 4% to 16% of all hospital beds [6]. A study from Norway in 2013 found that 7% of all patients in mental health hospitals were ready for discharge, but were still waiting for municipal services to take over, mainly to provide sheltered housing [7]. A review of 35 studies, mostly from general hospitals, on delayed discharge [8] found that the average cost of one extra day per patient was between £200 and £565.

Early psychiatric readmission serves as a negative quality of care indicator in the mental health services [9, 10]. Some studies report that short inpatient treatment stays (< 28 days) increase readmission rates [11-13]. In contrast, a Cochrane review from six randomised studies did not find evidence suggesting that short-stay hospitalisation (<28 days), compared to long stay (>28 days), encouraged a 'revolving door' pattern of admission to hospital [14].

Community based residential mental health services can serve as an alternative to both inpatient admissions (step-up) and aftercare (step-down). A review from 2013 [15] evaluated such services for acute [16-18] and sub-acute admissions (step-up) [19] and concluded that these step-up residential community services offered a cost-effective alternative to hospital based inpatient services. Similarly, a few studies have evaluated community-based services in the form of residential aftercare after hospital stays (step-down) [20-23]. An RCT study on inpatient treatment for substance use disorders compared the effects of two types of community-based, residential treatment programs among justice involved persons with dual diagnosis and reported significant reductions in psychiatric severity for those assigned to residential conditions [23]. An observational study found that a staffed residential step-down facility with a comprehensive program improved symptoms and functioning for persons with psychosis or mood disorder [21].

Taken together, this indicates that patients ready for discharge could be discharged as early as possible to a community residential service, without the shorter stay leading to increased risk of readmission [14], and the costs would be reduced [8]. To make this happen for inpatients with SMI, there is a need for improved collaboration and communication between service levels [24, 25] as well as services that can receive patients who need community services after their hospital stay [20].

There is, however, still a need for studies on the effect and costs of residential aftercare services in the community, especially on residential aftercare services that do not offer organised in-house activities as such studies could potentially help patients use community services more actively.

The aim of this RCT study was to investigate use of community and specialist mental health care services and costs in patients with severe mental illness (SMI) the first 12 months after discharge from a mental health hospital (MHH), comparing community residential aftercare (CRA) and treatment as usual.

### Methods

This was an open parallel group randomised controlled trial including patients from January 2013 to April 2015. It was approved by the Committee for Medical and Health Research Ethics in Central Norway (2011/1770) and was registered in clinicaltrials.gov (NCT01719354).

# Change to protocol

Fewer patients than aimed for were included due to problems with recruitment (59% of calculated sample size). It was planned to collect self-reported outcome at 1, 4 and 12 months, but it proved very difficult to get the participants to complete the questionnaires even after 1 month despite several attempts. The collection of these data was therefore stopped, meaning that only outcomes on the consumption of health care services and costs as outcomes in used.

# Settings

In Norway, the health and social care services are mainly financed by and provided for in the public sector [26]. Community health and long-term care is the responsibility of the municipalities, while acute somatic and psychiatric hospitals and specialist services are run by the government. Community health and social care includes GPs, public health nurses, nursing homes, home care and mental health care (some places including residential care). Specialist health care organises acute and psychiatric specialist services into mental health hospital (MHH), community mental health centre (CMHC), mental health out-patient treatment and mental health ambulant treatment.

In central Norway, community residential aftercare units (CRA) have been established in order to improve the discharge process from hospital to independent supported living [27]. They facilitate the process of establishing community health and social services, support self-care and engagement, but do not offer organised in-house activities, to ensure community orientation and the fostering of initiatives among the patients. Both the community residential aftercare (CRA) unit and the university mental health hospital (MHH), the setting for this study, are in the City of Trondheim (190,000 inhabitants), in central Norway. The municipality of Trondheim offers a multitude of mental health services to people with mental disorders: community mental health consultation, home care nursing, home help,

day centre, short-stay residential aftercare, self-referral and housing arrangement. The MHH has 81 beds, half for acute admissions and half for long-stay patients.

# Eligibility criteria

All in-patients with severe mental illness (SMI) at the MHH who were assessed as discharge ready and in need of aftercare services from the municipality after discharge were eligible for this study. However, they had to have a treatment aftercare plan initiated by the time of inclusion. Furthermore, there were no requirements regarding specific diagnostic criteria, and this group mainly concerns people with a diagnosis of schizophrenia, schizoaffective disorders, bipolar disorder, major depression or personality disorders. Furthermore, the patients had to be older than 18 years and they had to sign the informed consent. The exclusion criteria were patients with impaired level of consciousness or acute confusion, those who were under coercion (those admitted under coercion were included if the coercion had been lifted) and patients assessed by the hospital to be without need of community services after discharge.

### Recruitment

All patients were recruited at the MHH in both acute and long stay departments after they were declared by the hospital to be ready for discharge. Staff in the departments identified eligible patients. The doctors in the hospital were responsible for assessing whether the patients were able to understand the consequences of participating in the study. The hospital nurses were the ones mainly responsible for informing the patients orally about the study and giving them written information and the informed consent. The patients were given one day to decide on their participation and those who wanted to take part signed the consent and gave it to the staff who collected baseline data.

### Randomisation and allocation

The randomisation was done using a web based computer program provided by a trial service at the Norwegian University of Science and Technology. The staff at the MHH conducted the randomisation after receiving the informed consents and the baseline data, and they informed the patients about the allocation.

### Intervention - the CRA

A more detailed description of the community residential aftercare unit has been published previously [27]. Briefly, the CRA was established in 2009 and has 14 rooms in total. A stay at the CRA is voluntary and the tentative length of a stay is up to four weeks, but for homeless patients the stay is longer due to the practicalities of making housing arrangements (14 homeless patients in 2016 had an average stay of 64 days) [27].

The CRA operates 24/7 and is staffed by psychiatric nurses, general nurses and nursing assistants. A general practitioner (GP) is present in the CRA one day a week and offers a consultation to all patients who have recently been admitted, and those in need of medical follow-up at the CRA.

The philosophy of the CRA involves the conscious decision not to offer any in-house activities. Instead, the patients are informed about activities in their neighbourhood and in the community. Therefore, there are no organised activities at the CRA such as meals in common, therapy options or use of exercise equipment.

The CRA staff facilitates the process of establishing community health and social services to support the transition from the hospital to independent supported living. The process is started as early as possible to establish a relationship between the patient, the responsible case handler in the municipality and the service providers offering follow-up services after discharge. During the stay, the result of the individual assessment is discussed with the patient, the case handler and it is communicated to the community Health and Welfare agency to help it to decide on the level of services provided by the municipality after discharge. Before discharge from the CRA, patients receive information about the possibility of later self-referral to a short (maximum of three days) inpatient stay at the CRA.

# Control – treatment as usual (TAU)

The TAU discharge process in the MHH for discharge ready patients in need of community follow-up typically includes one of the following: (1) The staff in the hospital contact the Health and Welfare agency in the municipality to clarify which type of follow-up services are needed from the municipality, including housing. This is settled before discharge to the home. (2) The staff in the hospital refers the patient to a community mental health centre (CMHC), which is part of the specialist services, where they continue the treatment plan initiated by the MHH before the CMHC contacts the municipality to make plans before discharge to home.

### Measures

To document the implementation of the intervention, the following data were collected: (1) days in the MHH before randomisation (expected to be equal between the groups), (2) days from randomisation to discharge (expected to be shorter in the intervention group), (3) where they were discharged immediately after the index stay in the MHH (only the intervention group should be discharged to the CRA), and (4) the length of stay at an inpatient unit or residential unit immediately after the index stay (expected to be longer in the intervention group).

# Primary outcome

The primary outcome was total hours of community health services and costs for these services during a 12-month. This included total number of hours with home help (cleaning, shopping etc.), home care nursing and community mental health consultation. The reason for having this as the primary outcome was that it was expected based on experience that patients discharged to the CRA was assessed to need less community services compared to the assessment made based on observation in a hospital setting.

# Secondary outcome

The secondary outcomes were number of and cost for the total inpatient days in the MHH, CMHC and CRA, total hours with outpatient treatment including ambulant treatment and the total number of admissions and readmissions from baseline to 12 months after inclusion. Readmission was defined as acute, unplanned admissions to the MHH, CMHC or the CRA within 30 days after last discharge. As a summary measure for the secondary outcomes, total cost of all services was used.

### Data collection

All data were provided by the staff in the community health and social care and specialist health care services, who collected the data from registries with data on contacts with the services ("consultations") which are registered with a very high grade of accuracy as it is both demanded by law to be registered and in the interest of the services to do so as it is connected to the use of resources and thus financing. In addition, data on patient characteristics was collected at baseline.

# Calculation of cost

The cost of the different services was provided by employees in the administration of the municipality of Trondheim and the university hospital, using the cost from 2015 (table 1). These figures included the total staff costs, rent and operating expenditures.

Table 1. Cost in 2015 per inpatient day and per hour for various mental health services, with the sector responsible for financing. Cost is in EUR.

Place	Cost	Financed by university hospital	Financed by municipality
Cost per inpatient day (24 hours):			
-Mental health hospital	1065 EUR	Х	
-Community mental health centre	619 EUR	Х	
-Community residential aftercare *	270 EUR		Х
Cost per hour:			
-Outpatient treatment at hospital	292 EUR	X	
-Ambulant treatment**	181 EUR	x	Х
-Home help	84 EUR		Х
-Home care nursing	84 EUR		Х
-Community mental health consultation	90 EUR		x

<sup>\*</sup> The cost of all operating cost (staff cost, and all expenditures) for the community residential aftercare in 2015 was 805 738 EUR excluding capital cost. The operating cost was divided by 14 beds and 365 days and gave a cost of 184 EUR per inpatient day. The capital costs used was the mean of all nursing homes and residential aftercare units in the municipality (86 EUR).

# Sample size

As there were no publications on which to base the power calculation, it was based on historical data (one month in 2012) from the municipal health registers for 14 patients who had stayed at the CRA and 13 who had been discharged directly from MHH. The mean number of hours of community care services per week was 3.7 (SD 3.5) for CRA patients and 20.91 (SD 40.4) for MHH patients. Mean daily function (ADL) score for CRA patients on a 1–5 scale was 1.58 (SD 0.37) and it was 1.94 (SD 0.65) for MHH patients.

Including 35 patients in each group, using a two-tailed t-test with a 5% statistical significance level and power of 80% would detect these differences. The aim was to include a total sample of 140 to allow for an expected high dropout and withdrawal rate.

# Blinding

There was no blinding of the patients or staff due to the nature of the intervention. The persons extracting the data from the registers were not aware of the allocation. The

<sup>\*\*</sup> For the ambulant treatment, the cost was recalculated as the provided cost (1168.16 EUR per hour) seemed too high given e.g. the inpatient cost, and those providing the cost figures could not specify this figure. The recalculation was based on the yearly budget in 2015 of 1062309 EUR. It was assumed that the 10-full time equivalent employees treated 100 patients and had face-to-face time contact in 50% of their total work-time.

outcome data only included data registered as part of the patients' regular care and, therefore, could not be influenced by the study staff.

# Statistical methods

The comparison between the groups was based on the intention to treat principle, where the participants were analysed according to the group they were randomised to. No per protocol test was planned or done. There were complete data on the use of all the outcomes for all participants, meaning that no measures had to be taken regarding missing. Due to the outcome data having a strong non-normal distribution and outliers, and the small sample size (n = 41), the comparison of the continuous variables was analysed with the non-parametric Mann-Whitney U-test [28]. The categorical data were calculated using Pearson chi square or Fisher exact test.

The outcomes in the groups is presented with both median and mean values and mean difference with 95% confidence interval (95% CI) which were calculated using t-tests with bootstrapping for the continuous data. Thus, the 95% CI (from the parametric test) does not correspond to the p-values reported (from non-parametric test). For the categorical data, the difference is presented in percentage points.

There were some differences between the characteristics of the groups at baseline. Therefore, a post hoc exploratory analysis was done using linear regression analysis with total cost as dependent variable and baseline variables as independent variables. Due to the small sample, and the rule of thumb of having at least 10 observation for every variable included in a regression analysis [29], first the forward selection procedure was used with all baseline characteristics as possible independent variables. Thereafter, different baseline variables were included in the model one at the time and in groups, to find those that changed the estimate for the mean difference in total cost between the groups the most.

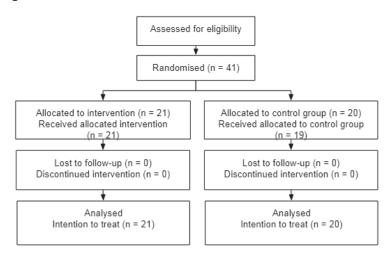
All analyses were done with SPSS 24 for Windows (IBM Corp. Armonk, NY).

# Results

Participants flow

The total number of participants assessed for eligibility was not registered. However, in the weekly meetings between the researcher and the contact nurses (one nurse from each department in the MHH), the nurses reported that almost all participants who were introduced to the study, said that they would participate. Forty-one participants met the inclusion criteria and were randomised.

Figure 1. Flow chart



# **Baseline data**

There were some differences between the groups on some variables at baseline (Table 2). There were more patients living alone, being homeless and unemployed in the intervention group, with one patient with a F6 diagnosis (personality disorder). In the control group, more patients were admitted under coercion and had a F6 diagnosis.

Table 2. Demographic variables and diagnosis for patients at baseline. Numbers are N (%) except for age which is mean (SD).

	All (n= 41)	Intervention (N= 21)	Control (N= 20)	Difference in % points
Age, mean (SD)	42.9 (14.7)	42.2 (14.9)	43.8 (14.8)	0
Female	21 (51 %)	9 (43 %)	12 (60 %)	-17
Living alone	29 (71 %)	17 (81 %)	12 (60 %)	21
Homeless	15 (37 %)	12 (57 %)	3 (15 %)	42
Sheltered housing	0	0	0	0
Admitted under coercion	8 (20 %)	3 (14 %)	5 (25 %)	-11
Employment status				
-full-time employment	2 (5 %)	1 (5 %)	1 (6 %)	-1
-part-time employment	2 (5 %)	2 (10 %)	0 (0 %)	10
-unemployment	10 (24 %)	8 (40 %)	2 (13 %)	27
-disability pension	23 (56 %)	10 (48 %)	13 (65 %)	-17
-student	1 (2 %)	0 (0 %)	1 (6 %)	-6
Highest level of education				
-compulsory school	11(31 %)	7 (37 %)	4 (23 %)	-14
-middle level education	20 (55 %)	9 (47 %)	11 (65 %)	-18
-higher education	5 (14 %)	3 (16 %)	2 (12 %)	4
Main Diagnosis (ICD- 10 code)				
-mental and behavioral disorders (F1)	4 (10 %)	2 (10 %)	2 (10 %)	0
- schizophrenia, schizotypal, delusional disorders (F2)	10 (24 %)	5 (24 %)	5 (24 %)	0
-mood (affective) disorders (F3) and anxiety disorders (F4)	17 (41 %)	12 (57 %)	5 (24 %)	33
-behavioral and personality disorders (F6)	5 (12 %)	1 (5 %)	4 (20 %)	-15
-observation for suspected mental and behaviour disorders (Z03.2)	5 (12 %)	1 (5 %)	4 (20 %)	-15

N varies due to missing: Employment (control = 3 missing). Education (intervention = 2 missing. Control = 3 missing).

# Implementation of the intervention

The intervention was implemented as planned, with changes in the observed variables in the direction expected (Table 3). All patients in the intervention group were discharged to the CRA. The difference in mean length of mental hospital inpatient stay (LOS) from randomisation to discharge was 6.3 days (3.8 days in the intervention group and 10.1 days in the control group, p = .023).

Table 3. Implementation of the intervention.

Variable	All (n= 41)	Intervention (N= 21)	Control (N= 20)	<i>P</i> - value
Discharged to	N (%)	N (%)	N (%)	
-Home	11(27 %)	0 (0%)	11 (55 %)	
-CMHC	9 (22 %)	0 (0%)	9 (45 %)	
-CRA	21(51 %)	21 (100 %)	0 (0%)	
Number of hospital inpatient days from index admission to discharge from MHH				
Mean (SD)	18.3 (26.9)	20.4 (30.9)	16.1 (22.5)	
Median (IQR), range	11 (5-16), 113	9 (4.3-17.5), 112.5	12.5 (6.5-16), 107	.531
Number of hospital inpatient days from index admission to date of randomisation (baseline)				
- Mean (SD)	11.4 (19.9)	16,6 (26.9)	6.0 (4.1)	
- Median (IQR), range	6 (3-10.5), 90	6 (2.5-13), 90	6 (3-8.5), 14	.495
Number of hospital inpatient days from date of randomisation (baseline) to discharge date				
-Mean (SD)	6.9 (15.4)	3.8 (5.8)	10.1 (21.1)	
-Median (IQR), range	3 (1-7), 97.5	1 (1-4), 23.5	4.5 (1.3-10), 97.0	.023
Length of stay at an institution immediately after discharge from the mental health hospital				
СМНС				
-Mean (SD)	5.9 (12.8)	0 (0)	12 (16.4)	
-Median (IQR), range	0 (0-0), 55	0(0-0), 0	0 (0-23), 55	
CRA				
-Mean (SD)	24.1 (35.6)	45.9 (37.6)	0 (0-0), 0	
-Median (IQR), range	1.5 (0-44), 176	44 (28-58), 175	0 (0-0), 0	

MHH, mental health hospital, CMHC, community mental health centre, CRA, community residential aftercare.

# **Outcomes**

There were large variation and some outliers for most of the outcomes (Figure 2).

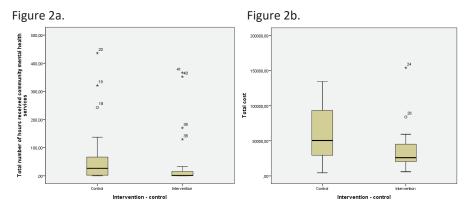


Figure 2a. Primary outcome presenting box-plot of total number of hours received community mental health services in the 12-months follow-up period.

Figure 2b. Secondary outcome presenting box-plot of total cost of specialist and community health services in euro from baseline to twelve months.

# Primary outcome

Those randomised to the CRA had on average 29% fewer hours of community mental health services for 12 months but the precision of the estimate was low, i.e. wide confidence intervals (mean differences -21.6 hours, 95% CI -93.1 to 44.9, p = .096) (Table 4). This difference was mainly due less use of home care nursing. The cost for the community mental health services was 29% lower with a mean difference of -1 845 EUR (95% CI -8 267 to 4 171, p = .102) with similar imprecision in the estimates.

Table 4. Primary outcomes: Number of hours, number of patients and costs of community mental health services in the 12 month follow-up period.

Table 4. Primary outcomes: Number of hours, number of patients and costs of community mental health services in the 12 month follow-up period.

Variable	A	All (n= 41)	Intervention (N= 21)	Control (N= 20)	Between groups	P- value
Number of hours	Mean (SD)	Median (IQR), range	Mean (SD)	Mean (SD)	Mean diff (95% CI)	
Total number of hours	62.9 (115.1)	6.0 (0.0-54.0), 436.0	52.4 (111.4)	74 (120.8)	-21.6 (-93.1 to 44.9)	960'
received community mental health services						
- Home help (cleaning,	1.8 (6.6)	0 (0-0), 39.3	1.4 (3.7)	2.3 (8.8)	-0.9 (-5.5 to 2.4)	089.
shopping etc.)						
- Home care nursing	55.3 (106.3)	0 (0-49.4), 396.7	47.4 (111.0)	63.5 (103.4)	-16 (-85.5 to 51.2)	.023
- Community mental	5.9 (20.7)	0(0-3.3), 128.6	3.6 (8.2)	8.2 (28.6)	-4.5 (-20.9 to 4.5)	.758
nealth consultation						
Number of patients	(%) N		(%) u	(%) u	Difference in %- points	
Total number of	29 (71 %)		13 (62 %)	16 (80 %)	-18	.209
patients with the listed services*						
- Home help (cleaning,	5 (12 %)		3 (14 %)	2 (10 %)	4	629.
shopping etc.)						
- Home care nursing	20 (49 %)		6 (29 %)	14 (70 %)	-41	600:
- Community mental	14 (34 %)		(% 8£) 8	(% 0£) 9	8	.589
nealth consultation						
Costs	Mean (SD)	Median (IQR), range	Mean (SD)	Mean (SD)	Mean diff (95% CI)	

Total cost of Community mental health services	5345 (9752.6)	5345 (9752.6) 546 (0-4587), 36773	4444.7 (9399)	6290.5 (10266.7)	-1845 (-8267 to 4171)	.102
- Home help (cleaning, shopping etc.)	153 (558)	0 (0-0), 3313	116 (310)	191 (743)	-74 (-476 to 200)	089.
- Home care nursing	4661 (8966)	0 (0-4165), 33460	3999 (9359)	5357 (8721)	-1357 (-7124 to 4683)	.023
- Community mental health consultation	530 (1864)	0 (0-300), 11605	328 (742)	741 (2577)	-413 (-1784 to 457)	.758

Each patient could receive more than one service

The exchange rates were €100 = 948.50 NOK, rate at the Norges Bank on 05.07. 2017 using the mid-price (the midpoint between the buying and selling price).

Cost per hour: Cleaning 800 NOK = €84.34; home care nursing 800 NOK = €84.34; mental health consultation 856 NOK= €90.24

P-value, between group differences has been calculated using Mann-Whitney U-test.

# Secondary outcomes

The total number of inpatients days after discharge from the initial stay to 12 months was 66 days for both groups (Table 5), but patients randomised to the CRA had 54% fewer inpatient days in the MHH (mean differences -13.4 days, 95% CI -29.9 to 0.9, p = .008). The number of inpatients days in the MHH after discharge was on average 7.1 days higher in the control group (13.4 days – 6.3 days before discharge).

The number of and proportion of persons with admissions and readmissions was slightly lower in the intervention group (Table 5).

The total cost for all mental health services for 12 months was 38.5% lower for patients randomised to the CRA (mean differences -23 071 EUR, 95% CI -45 450 to 3 027, p = .057) (Table 6). This was mainly due to lower inpatients costs which had a mean difference of -17 741 EUR (95% CI -36 824 to 4 503, p = .042) in favour of the intervention.

Table 5. Secondary outcomes. Number of mental health inpatient days, number of admissions and number of readmission < 30 days from baseline (date of randomisation) to twelve months.

lays	Mean (SD)					
inpatient days H IC self-referral		<u>Median (IQR),</u> <u>range</u>	Mean (SD)	Mean (SD)	Mean diff (95% CI)	
IC self-referral	66.5 (61.4)	50 (34.5-77.5), 306	(6.27 (55.9)	66.4 (68.1)	0.3 (-35.8 to 40.3)	.629
IC self-referral	17.8 (25.0)	8 (3-18), 97.5	11.2 (19.8)	24.7 (28.5)	-13.4 (-29.8 to 0.9)	.008
self-referral	17.9 (31.5)	0 (0-27.5), 120	7.9 (22.3)	28.4 (36.7)	-20.4 (-38.8 to -2.8)	.004
-CRA self-referral	29.7 (50.3)	2 (0-47.5), 255	45.9 (37.6)	12.8 (57.0)*	33.2 (-0.1 to 60)	000.
	1.2 (2.8)	0 (0-0), 12	1.7 (2.8)	0.6 (2.7)**	1.1 (-0.6 to 2.7)	.035
l otal number of admission after initial stay.	4.4 (4.0)	3 (1-5), 15	3.9 (3.9)	4.9 (4.1)	-0.9 (-3.5 to 1.5)	.224
-МНН	2.8 (2.9)	2 (1-3.5), 12	2.6 (2.8)	3.1 (3.0)	-0.5 (-2.3 to 1.2)	.358
-CMHC	1.2 (2.5)	0 (0-2), 14	0.7 (1.7)	1.8 (3.1)	-1.0 (-2.8 to 0.3)	.016
-CRA	0.5 (0.5)	1 (0-1),1	1.0 (0.0)	0.05 (0.22)*	0.9 (0.8 to 0.9)	0.00
-CRA self-referral	0.4 (0.83)	0 (0-0), 3	0.7 (1.1)	0.05(0.22)**	0.6 (0.2 to 1.1)	.019
Total number of readmissions after initial stay	1.5 (2.8)	0 (0-2.5), 11	1.2 (2.4)	1.9 (3.2)	-0.8 (-2.5 to 0.9)	.440
-МНН	1 (1.9)	0 (0-1), 8	0.81 (1.7)	1.2 (2.2)	-0.4 (-1.7 to 0.8)	.820
-СМНС	0.5 (1.9)	0 (0-0), 11	0.38 (1.2)	0.7 (2.5)	-0.3 (-1.7 to 0.7)	.396

-CRA		•	•	1	•
	(%) N	(%) u	(%) u	Difference %- points	
Number of patients admitted after initial stay	38 (93 %)	21 (100 %)	17 (85 %)	15	690.
-МНН	21 (51 %)	9 (43 %)	12 (60 %)	-17	
-СМНС	17 (41 %)	4 (19 %)	13 (65 %)	-46	
-CRA aftercare	22 (54 %)	21 (100 %)	1 (5 %)	95	
CRA self-referral	8 (20 %)	7 (33 %)	1 (5 %)	28	
Number of patient with readmission	15 (37 %)	6 (29 %)	9 (45 %)	-16	.281
-МНН	12 (29 %)	(% 62) 9	(% 0£) 9	-1	
-СМНС	6 (15 %)	2 (10 %)	4 (20 %)	-10	
-CRA	0	0	0	0	

MHH, mental Health hospital; CMHC, community mental health centre; CRA, community residential aftercare.

\*One patient in the control group who was homeless was discharged to the CRA from the MHH as the CMHC declined the referral from the MHH, and a solution had to be found. This patient stayed at the CRA for 255 days. \*\* One patient in the control group was admitted to a self-referral bed at the CRA from the patient's residence by a community mental health team as an emergency measure due to lack of similar services. The patient stayed at the CRA for 12 days.

Table 6. Cost for all inpatient and outpatient services from baseline to twelve months. Values are in euro (EUR).

Variable		All (n= 41)	Intervention	Control	Between groups	P- value
	Mean (SD)	Median (IQR), range	(Nean (SD)	(Nean (SD)	Mean diff (95% CI)	
Total cost	48131 (39726)	31232 (20813-57209), 149638	36877 (32647)	59948 (43745)	-23071 (-45450 to 3027)	.057
Sum inpatient service cost	38321 (34137)	25825 (14808-46641), 142643	29667 (31543)	47408 (35161)	-17741 (-36824 to 4503)	.042
- MHH	18920 (26663)	8518 (3194-19167), 103821	11941 (21085)	26248 (30304)	-14306 (-31754 to 912)	.008
- CMHC	11073 (19526)	8518 (3194-19167), 74237	4896 (13812)	17559 (22703)	-12663 (-23568 to -2632)	.004
- CRA	8018 (13573)	539 (0-12810), 68770	12380 (10142)	3428 (15377)	8941 (-608 to 16194)	000.
- CRA – self-referral	309 (749)	0 (0-0), 3236	449 (764)	161 (723)	287 (-199 to 714)	.035
Sum outpatient services cost	9809 (12934)	4916 (875-15192), 49443	7210 (9578)	12539 (15501)	-5329 (-13216 to 2546)	.215
<ul> <li>Mental health outpatient treatment</li> </ul>	2678 (7128)	486 (0-2178), 43757	2145 (3603)	3239 (9625)	-1094 (-6125 to 2240)	.843
- Mental health ambulant treatment	1786 (4050)	0 (0-180), 15619	620 (1920)	3010 (5250)	-2389.7 (-4681 to 90.6)	.160
<ul> <li>Home help (cleaning, shopping etc.)</li> </ul>	153 (558)	0 (0-0), 3313	116 (310)	191 (743)	-74.5 (-412.6 to 214.5)	.680
- Home care nursing	4661 (8966)	0 (0-4165), 33460	3999 (9359)	5357 (8721)	-1357.7 (-6520 to 4051)	.023

.758 -413.6 (-1773 to 411) 741 (2577) 328 (742) 0 (0-300), 11605 530 (1864) mental health - Community consultation

The exchange rates were £100 = 948.50 NOK, rate taken from the Norges Bank on the 05.07. 2017 using the mid-price (the midpoint between the buying and selling price).

Cost per 24 hours for inpatient services: MHH, mental health hospital 10,100 NOK = £1064.84; CMHC, community mental health centre 5,875 NOK =  $\pounds619.40$ ; CRA, community residential aftercare 2,558 NOK =  $\pounds269.68$  Cost per hour for outpatient services: out-patient treatment 2,770 NOK = £292.04; ambulant treatment 1,716 NOK = £180.91; cleaning 800 NOK = £84.34; home care nursing 800 NOK = £84.34; mental health consultation 856 NOK = £90.24

# Post hoc analysis

The exploratory post hoc analysis was done due to the observed differences in patient characteristics at baseline, using a multivariable linear regression model with total cost as the independent variable and baseline characteristics as dependent variables.

The regression with forward selection of baseline variables, resulted in a model with only the group allocation as the included variable (p= .041). Having the variables "living alone" and "admitted under coercion" as independent variables also increased the total cost saving increased in favour the intervention group (estimated difference -26 509 EUR (95%CI -52 107 to -910. p = .043). Having diagnosis as independent variables reduced the total cost saving between the groups (estimated mean difference -17 356 EUR (95% CI -41 726 to 7012, p = .158).

### Discussion

This is the first RCT study on the effect of discharge for patients with SMI to a community residential aftercare facility (CRA) with no organised in-house activities or on-site treatment. The differences in utilisation and cost during 12 months were in favour of the intervention group, but mostly with p-values above the conventional cut-off p<0.05. The confidence intervals were wide, meaning that there was imprecision in the estimates. Thus, no final conclusion on the effect of the CRA can be made based on this study.

However, the study gives strong indication of a potential effect of discharging patient in need of community aftercare to the CRA. The best estimates for this potential based on the present study is that it can reduce the use of hourly based community mental health services with 29% (22 hours), with a cost saving of 29% (1845 EUR) for each patient compared to usual care. The total number of inpatient days for one year was the same (66 days), but the number of inpatient days in the mental health hospital was 54% (13 days) lower. The most conservative estimate for the total costs for mental health care utilisation was a reduction of 29% (14600 EUR) per patient, mainly due to lower inpatient costs. Importantly, although using less services, the point estimate for the number of inpatient admissions and readmissions was respectively 18% (-0.9 admissions) and 42 % (-0.8 readmissions) lower in the intervention group indicating at least no major worsening in the intervention group.

Considering possible mechanisms and explanations for the direction of the observed effect, it seems that the CRA is successful in facilitating independent living which, in turn, leads to less mental health service use. Even if a stay at the CRA does not reduce the total number of inpatient days during the first year, spending more time in residential after care service can leave room for better assessment of and subsequent alignment between the patients' actual care needs in the community and the services offered. Another explanation can be that when the hospital staff communicate the care needs of the patient to the community services, they do so based on what they have seen during the hospital stay (observer bias) [30]. This can differ from the patients' behaviour in a CRA setting where there are no inhouse organised activities, and where, consequently, the staff can observe how the patient manages in a more home like setting. In addition, a stay in the CRA allows for more time in

assessing and setting up the required level of services to support independent living. This is in line with the finding in an observational cohort study among six community residential alternatives compared to six standard acute wards [18], which found that patients having used the community alternative had more contact with community mental health teams, early intervention services and crisis teams.

The chosen primary outcome, use of hourly based community health and social services, was chosen based on an assumption that discharge to the CRA would help identify the best level of service for each patient, which was expected to be lower than usual care. This does not imply that less use of community health and social services was a desired outcome by itself. The aim must be to balance the level of services to the patient's needs. However, with the aim to promote independency among service users, the level of services should not be so high as to jeopardise this. To be almost self-reliant and be in command of one's own life are basic rights that most humans takes for granted. Given the direction of the results in this study, pointing towards both less use of services and fewer re-/admissions for those randomised to the CRA, there are indications that having a strong community orientation in the discharge process can result in a service level promoting independency.

Even if both step-up [15-19] and step down [20-23] community residential services exist, none of the studies investigating the effects and costs are directly comparable to this study, as they offer in-house activities or treatment. However, according to these studies, there seems to be a clear indication that community residential services can reduce costs [17, 18, 20], similar to the point estimates found in this study of around 1/3 reduction: Byford et al. [17] found 22% lower total 12-month costs (£14,952 vs. £19,288), a UK based study by Slade et al. [18] reported 61% lower 12-month inpatient costs (£3,832 vs. £9,850) and Thomas et al. in Australia [20] found that the cost per day per client in the step-up step-down program was 32% lower (\$517 vs. \$758). The explanation for reduced costs in these studies and in our study, is chiefly due to reduced inpatient stays and use of specialist services.

We did not measure change in patients' level of symptoms and functioning, but two other studies on community residential aftercare have done this [21][23]. An observational study from Australia [21] found improvement in patients' symptoms and functioning three months after discharge from the residential inpatient step-down unit. An RCT among justice involved persons [23] found a significant reduction in psychiatric symptom severity after two years in those who had been admitted to self-run community residential aftercare (Oxford House).

# Strength and limitations

To the best of our knowledge, this is the first RCT-study to investigate a step-down model of a staffed residential aftercare not offering in-house activities or treatment therapy. The strength of this study is the use of data from health service registers covering both specialist and community mental health care utilisation, which provided complete data on all participants.

The major limitations were that the sample size was smaller than what was pre-planned, which in addition to giving imprecise estimates, also is the most likely explanation for the differences in patient characteristics at baseline. An alternative explanation of baseline

difference is flaws in the randomisation and allocation process. However, the randomisation was internet based and it was not possible for anyone involved in the study processes to influence the allocation.

The recruitment was both slow and low despite a range of study activities from information meetings to encouragement from management. The main reason expressed by some of the inpatient staff in the MHH was scepticism about the level of competence at the CRA, particularly the lack of psychologists. This scepticism was surprising as the CRA had been in operation before the study and should thus be known to the hospital staff with treatment responsibility. However, it cannot be ruled out that the persons with treatment responsibility recruiting patients to the CRA previously and maybe to the study represent a sub-set, as it was not collected data on who recruited patients. Nevertheless, the patients recruited are still representative of the group of patients with SMI that were considered suitable for the CRA by personnel with treatment responsibility in the hospital who are willing to refer patients to the CRA. This assumption is strengthened by the contact nurses for the study who reported that almost all participants that were introduced to the study agreed to participate.

Another reason for the recruitment problem can be that the staff at the hospital did not include patients for this study to avoid them being randomised to the control group, which meant that they would get a delayed discharge compared to being discharged to the CRA. This suspicion is strengthening by the fact that some patients were discharged directly to the CRA instead being recruited to the study.

# Conclusion

In this study, it was not possible to draw a definite conclusion about the effect, due to the small sample and imprecision of the estimates. The direction of the results and size of the point estimate, including findings in other studies, indicates that transferring patients ready for discharge from mental hospital to community residential aftercare has the potential to reduce total consumption of health services and costs without increased hospital admissions.

# List of abbreviations

SMI: Severe mental illness, typically persons with a diagnosis of schizophrenia, schizoaffective disorders, major depression, or personality disorders.

MHH: Mental health hospital

CMHC: Community mental health center

CRA: Community residential aftercare

**RCT: Randomized Controlled Trial** 

# **Declaration of interest**

Ethics approval and consent to participate

This was an open parallel group randomised controlled trial including patients from January 2013 to April 2015. It was approved by the Committee for Medical and Health Research Ethics in Central Norway (2011/1770) and was registered in clinicaltrials.gov (NCT01719354).

Consent for publication

Not applicable

Availability of data and materials

The data sets analyzed during the current study are not publicly available due to the restriction set by Norwegian Act concerning the Ethical Review of Research Involving Humans but are available from the corresponding author on reasonable request.

# Competing interests

The first author (ER) worked with the establishment of the CRA as an advisor to the chief officer in the municipality, but has not been involved in the day to day operation of the service. The other authors declare that they have no competing interests.

# Funding

Part of ER salary was covered by a grant from the Norwegian directorate for health.

# Authors` contributions

ER conceived of the study, participated in the design of the study, collected and led the analysis of the data and drafted the manuscript. OB participated in analyzing the data and contributed to the manuscript drafts. AS participated in the design, analyzing the data and contributed to the manuscript drafts. All authors read and approved the final manuscript.

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# Paper II

# RESEARCH ARTICLE

Open Access

# Like a hotel, but boring: users' experience with short-time community-based residential aftercare



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# **Abstract**

**Background:** The discharge process from hospital to home for patients with severe mental illness (SMI) is often complex, and most are in need of tailored and coordinated community services at home. One solution is to discharge patients to inpatient short-stay community residential aftercare (CRA). The aim of this study was to explore how patients with SMI experience a stay in CRA established in a City in Central Norway.

**Methods:** A descriptive qualitative study with individual interviews and a group interview with 13 persons. The CRA aims to improve the discharge process from hospital to independent supported living by facilitating the establishment of health and social services and preparing the patients. The philosophy is to help patients use community resources by e.g. not offering any organized in-house activities. The main question in the interviews was "How have you experienced the stay at the CRA?" The interviews were analyzed with a thematic approach using systematic text condensation.

**Results:** The participants experienced the stay at the CRA "Like a hotel" but also boring, due to the lack of organized inhouse activities. The patients generally said they were not informed about the philosophy of the CRA before the stay. The participants had to come up with activities outside the CRA and said they got active help from the staff to do so; some experienced this as positive, whereas others wanted more organized in-house activities like they were used to from mental health hospital stays. Participants described the staff in the CRA to be helpful and forthcoming, but they did not notice the staff being active in organizing the aftercare.

**Conclusions:** The stay at the CRA was experienced as different from other services, with more freedom and focus on self-care, and lack of in-house activities. This led to increased self-activity among the patients, but some wanted more in-house activities. To prepare the patients better for the stay at the CRA, more information about the philosophy is needed in the pre-admission process.

**Keywords:** Community residential aftercare, Discharge-ready mental health patients, Severe mental illness, Qualitative study

# Background

Collaboration between psychiatric hospitals and primary care services is essential to reduce length of stay and improve follow-up for hospitalized patients [1]. Recent study have found that 86% for individuals with severe mental illness (SMI) were reinstitutionalized over a 7-years follow-up period and 73% were readmitted in the first year after discharge [2]. This indicates that patients with SMI are in

need of aftercare [3]. They are also susceptible to ineffective coordination between systems [4, 5]. Therefore, a number of collaborative models between hospitals and primary care have been described in recent years [6].

A review of 21 randomized trials found that a structured discharge plan tailored to the individual patient probably brings about a small reduction in hospital length of stay [7]. Another review found a reduction in readmission between 14% and 37% due to pre- and post-discharge patient psychoeducation, structured needs assessments, and inpatient/outpatient provider communication [8]. There are also a number of interventions

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used in primary care such as brief motivational interviews [9], peer support and a good therapeutic relationship [10, 11], self-referral inpatient treatment [12], Crisis homes [13] and care management [14–17].

A study from Germany found that the most protective factors for rehospitalization were employment, partnership, and a sheltered living situation [18], whereas the risk factors for increased rehospitalization were urban living and concurrent substance use disorder. Patients with SMI have reported that they see social malaise as an explanation for being readmitted [19], and a qualitative study from the US suggested a history of frequent psychiatric hospitalizations, non-adherence to aftercare treatment, and substance misuse as possible risk factors for readmission [20]. Further, a review of qualitative studies on users' experience of progress and recovery from critical psychiatric illness during the first month after discharge suggests that patients and their families have a desire for more autonomous control over their own recovery [21].

A collaborative process between patients with SMI, hospitals, and primary care is thus needed to ensure that the most important services are in place immediately after discharge [4]. The patients' needs for aftercare services provided by primary care can be assessed by the hospital staff prior to discharge [7, 8, 22]. However, personnel in hospitals and community services will likely have different views on what types of services a person with SMI needs in the community. Personnel in the community mental health services often have long clinical experience following patients outside hospital settings, and are likely to be well suited to identify the type of community service needed, even though they do not have specialist-level competency.

One solution to these challenges is to discharge patients with SMI, who need community services, to inpatient short-stay in the community in a step-down model with focus on preparing for independent support living. There are examples of residential community units targeting the discharge process [23, 24]. These mirrors some of the features suggested for alternative hospital care with small units, normalizing facilities, more flexibility and open door and partnering with the community [25]. However, we have not found any studies on community residential aftercare (CRA) units that do not offer organized in-house activities. Such a CRA unit was established in the city of Trondheim in central Norway in 2009. The aim of this CRA unit is to improve the discharge process from hospital to independent supported living by facilitating the process of establishing community health and social services and supporting self-care, community engagement and not offering organized inhouse activities to ensure community orientation among the patients.

Therefore, the aim of this study was to explore how patients with SMI in need of community support after a mental health hospital stay experienced the stay in the CRA unit established in the City of Trondheim in Central Norway.

#### Methods

This was a descriptive qualitative study using nine semistructured face-to-face individual interviews followed by one group interview to validate and expand on the findings from the individual interviews. Qualitative methods are well suited for research relating to individual experiences and perceptions [26]. The individual interviews were conducted between May 2013 and May 2015, and the group interview was held in June 2016.

#### **Ethical considerations**

The study was conducted in accordance with the Declaration of Helsinki and was approved by the regional Committee for Medical Research Ethics in Central Norway (2011/1770). The participants received written and oral information about the study, and they were informed that they could withdraw at any time. Written consent was obtained before the interviews were conducted, and confidentiality was assured.

# The CRA service

The study took place in a community residential aftercare (CRA) service in Trondheim, a city in Central Norway with 190,000 inhabitants. In September 2009, the municipality established the short-stay CRA for patients with SMI discharged from the mental health department at the local university hospital. One aim of the CRA was to reduce the time the patients, who normally would be in need of public community services after discharge, spent in the mental health hospital after they are been declared ready for discharge. This is done by supporting self-care and facilitating community health and social services, as described below.

For the patients to be eligible for discharge to the CRA, the hospital must have assessed and document that the patients are ready for discharge, such as deciding on the main diagnosis and starting a treatment plan. The patients are usually transferred on the same or following day after the hospital have contacted the CRA. The stay at the CRA is voluntary, meaning that the patients can leave any time they want to. The tentative length of stay in the CRA is up to 4 weeks, based on experiences with the time it takes to organize public community services that the patients' needs once, when living at home. The length of stay is usually longer for homeless patients' due to the practicalities of making housing arrangement. In 2016, the average of length of stay at the CRA was 37 days (69 patients), 64 days for

homeless (14 patients) and 29 days for those with a residence (55 patients).

The CRA has 14 single rooms with their own TV and bathroom, 10 reserved for discharge-ready hospitalized patients (step-down), and for patients living in the community who are homeless or need another residence (step-up), two rooms reserved for self-referral patients who have previously been at the CRA, and two rooms reserved for sub-acute admission directly from patients' residence (step-up). There are also three single rooms not in use. Patients using beds as part of step-up were not part of this study. There are common rooms and kitchen where the patients can make their own food, whenever they want.

The CRA operates 24/7 and is staffed with psychiatric nurses, general nurses and nursing assistants. All except one have experiences from community services to ensure their understanding of the need a patient can have in the community. Four employees are present during the day, two at the evening shift and one nurse during night shift. In addition, a team leader is present at daytime on weekdays. The nurse on the night shift can alarm for assistance from nearby services. The staff has training in recoveryoriented strategies, such as self-management and selfresponsibility to manage daily activities. A general practitioner (GP) is present in the CRA 1 day a week and offers a consultation to all patients who have recently been admitted, and those in need of medical follow-up at the CRA. The GP cooperates with the patients' regular GP and requests the patients to make regular appointment with these.

To prepare patients for independent supported living the patients are directed to activities in the community. The philosophy of the CRA is to purposively not offering any in-house activities. Instead, the patients are informed about activities in their neighborhood and in the community. Thus, there are no organized activities at the CRA like common meals, therapy options or equipment for exercise. Consequently, there is a strong emphasis on and practical training to support self-care; how to structure daily routines including sleep patterns, strategies to cope with difficult symptoms, personal hygiene, appointments with other agencies, self-care and independent living like use of public transport, shopping, meal planning and social and leisure activities outside the CRA. The patients also have overnight stays in their own home during the stay at the CRA.

The CRA also is central in facilitating the process of establishing community health and social services to support the transition from the hospital to independent supported living. When patients arrive, they get a dedicated contact person whose main responsibility is to support the patient during the whole stay. The contact person also observes and assesses the patient following a checklist presented in Table 1, always with a focus on preparation for the discharge process from the CRA. During the stay, the result of the individual assessment is discussed with the patient and communicated to the community Health and Welfare agency services to help them agreeing on the level of services to be provided after discharge, e.g. housing for homeless, relocation (move away from a substance abuse neighborhood), home nursing services and home care services. This is

**Table 1** Checklist for observation and assessment of patients used by the staff during the CRA stay in preparation for the discharge planning process and to help decide on the type of services to be offered afterwards

Area	Cues
Self-care	Hygiene, food preparation, diet, cleaning, washing, shopping, exercise/activities, and mastering substance abuse problems
Medicating	Self-medicating, misuse of medicines, need of support with medicating
Economy	Assess needs of any support to manage finances, e.g. pay bills
Social network	Assess the social network, relationships, and participation in any social activities
Housing	Visit the residence together with the patients – assessment of the facilities in the residence, such as cooking and cleaning
Primary care services	Assess present follow-up services and other tailored services
Leisure time	Assess patients' hobbies and interests
Facility	Assess patients' technical aid needs
Mobility	Assess the need for assistance to take the bus, visit public offices, cultural and leisure activities
Job/education	Assess present education and job – arrange job/education or activities together with the patients
Before discharge	The contact person organizes a meeting with the patient and community agencies for assessment and approval of tailored services.  The follow-up services must be up and running at home at the expected date of discharge. The general practitioner has received discharge summary from the CRA.

done in meetings, coordinated by the CRA, between the patient and the agencies that offer the different types of services that are judged to be appropriate. The process is started as early as possible to establish relationship between the patient and the service providers offering the follow-up services after discharge.

Before discharge from the CRA, patients receive information about the possibility of later self-referral to a short (maximum of 3 days) inpatient stay at the CRA.

### Sample and recruitment

The aim was to recruit patients with SMI currently staying at the CRA or who had been discharged from the CRA within the last 4 months. Participants were selected to ensure variation in age, gender, and time from admission to the CRA or time since discharge from the CRA.

To recruit participants for the individual interviews, the team leader in the CRA introduced the study to eligible participants at the CRA both orally and by handing out invitation letters. Eligible participants who had been discharge were contacted by phone. The CRA staff passed on contact information for those who wanted to participate to the first author (ER). Then, the first author contacted the participants by phone and repeated and gave more information about the study. Patients were given the choice to be interviewed in their own apartment, in a public office, or in the CRA.

To recruit patients for the group interview, the team leader in the CRA handed out invitation letters to eligible participants at the CRA and scheduled the interview. The group interview was conducted in a common room at the CRA.

### Data collection

The individual interviews were conducted by the first author, and the group interview by the first (ER) and the fourth author (AS). The staff in the CRA did not take part in any of the interviews, but a contact person was present at one individual interview at the patient's request. The interviews were audiotaped and transcribed verbatim. The average time of the individual interviews was 27 min (range approx. 15–45 min), and the group interview lasted 1 h and 47 min.

An interview guide (Additional file 1) was used in all interviews to ensure that all participants were given the opportunity to comment on the same topics. The main question was "Can you tell me/us about your experience with your stay at the CRA?" The follow-up questions addressed what the participants were most and least satisfied with, their daily activities during the stay, and how they perceived the organization of services they would need after discharge. Those who had used the self-referral inpatient care were asked about their experience with this particular service.

#### **Analysis**

The data were analyzed following systematic text condensation, which is a method suited for thematic cross-case analysis inspired by Giorgi's psychological phenomenology approach [27, 28]. The analysis started after the first four interviews were done and continued simultaneously with the recruitment and interview process. The recruitment continued until no new themes emerged from the analysis and the material was considered saturated.

The analysis itself was also iterative, meaning that the four distinct steps of systematic text condensation were repeated during the process. The first step was to read the transcribed interviews with an open mind to obtain a general impression and to identify preliminary themes. The first author read all interviews and selected, based on richness, two individual interviews that all authors read. In the second step, the transcripts were systematically reviewed line by line to identify meaning units, which were classified and sorted into the preliminary themes. Particularly at this step, the authors had several meetings to discuss and refine the subthemes and themes. In the third step, the meaning units within each subtheme, established in the second step of analysis, were reduced into a condensate, an artificial quotation maintaining, as far as possible, the original terminology applied by the participants. This facilitated further sorting between the subthemes. In the fourth and last step, the condensates of each subtheme were rewritten in general descriptions, and the final sorting of subthemes into the main themes was finalized.

The main part of the analysis was performed by the first author and discussed with the co-authors. The analysis was further validated by a thorough review of the original transcript of each interview to ensure all points of significance were reflected in the results. The quotations that best illustrated the themes were chosen to support the results. The description of the chapter "The CRA service" was validated by the manager and the team leader of the CRA to ensure that the authors had understood the purpose and the philosophy behind the CRA.

# Results

A total of 15 patients with SMI were approached, and of these 13 participants were interviewed (Table 2), nine in individual interviews (seven men and two women) and four participants in a group interview (three men and one woman). Four participants were interviewed in their own apartment, seven in the CRA, and two in a public office.

The findings were categorized into five themes: 1) Not what I expected; 2) Like a hotel, but boring, 3) Treatment, a place to rest, or preparation for independent

**Table 2** Characteristics of the participants (n = 13)

Characteristics	N (%) or Mean (SD, range)
Gender	
-female	3 (23%)
-male	10 (77%)
Age	
-Mean age in yrs. (SD, range)	42 (13.0, 20 to 63)
Living situation	
-homeless	3 (23%)
-living alone	11 (85%)
-with wife/husband/live-in partner	1 (8%)
-with children	2 (15%)
Employment status	
-full-time employment	1 (8%)
-unemployed	8 (62%)
-disability pension	4 (31%)
Main diagnosis - ICD-10 code	
-mental and behavioral disorders (F10)	2 (15%)
-schizophrenia, schizotypal, delusional disorders (F20)	2 (15%)
-mood (affective) disorders (F30)	5 (38%)
-behavioral and personality disorders (F60)	3 (23%)
-Other organic personality and behavioral disorders due to brain disease, damage, and dysfunction (F07.8)	1 (8%)
Length of stay at the CRA	
-median (range) and mean (SD) duration in weeks	5 (3 to 24), 8.9 (7.4) <sup>a</sup>
Time of interview	
-during the stay	7 (54%)
-after discharge	6 (46%)

<sup>&</sup>lt;sup>a</sup>The reason for the high mean were three homeless patients staying respectively 19, 21 and 24 weeks waiting for residence. The range in length of stay without these participants was 3 to 8 weeks and the mean 5.2 weeks

living? 4) Coordination with other agencies; and 5) Use of self-referral stay.

# Not what I expected

Whether the participants appeared to have understood the philosophy behind the CRA seemed to influence their attitude and experience. Some clearly expressed that they did not expect anything from the staff and were happy with that, whereas others wanted a different type of service than the one the CRA offered. Some participants said they were not informed about what they could expect at the CRA before they arrived. They said that they had only been informed that they would be discharged to a residential institution in primary care settings and expected something like a mental health hospital. Others said they had received information about the CRA, but mostly

about practical aspects, like that they would have a single room and a safe place to stay.

"I got information from the staff in the mental hospital about the stay at CRA and was told they offer a single room, serve dinner, and there were staff 24/7. Otherwise, there was no detailed information given."

None of the participants clearly stated that they had received information that the CRA did not offer treatment or in-house activities, nor were they informed that they were expected to be active in finding their own recreation in the community. Typically, the participants received this information when they arrived at the CRA from the staff who welcomed them and gave them information about the stay. Nevertheless, some participants that had stayed for a while in the CRA still spoke about it in a way indicating that they expected the services they were used to from the mental hospital.

"I felt the stay was just as a place to rest."

#### Like a hotel, but boring

All the participants expressed great satisfaction with the freedom and privacy they had at the CRA, especially that they could leave the residential care whenever they wanted without asking for permission, since the staff trusted them.

"[You] can go in the fridge and prepare food for yourself whenever you want. It's just to let the staff know when you go for a walk — no begging."

All the participants agreed that their stay at the CRA was different from other mental health institutions they had experienced. One participant compared the stay at the CRA with a hotel stay. This was supported by others, such as with descriptions of freedom and having their own private room, where they could do what they wanted without interruption. Several spoke about the advantage of having a private TV in their room, which gave them the possibility of choosing their own TV programs. This was compared with institutions that had only one TV in a common room, with frequent discussions regarding which program to watch. Other characteristics of the CRA being like a hotel were the quiet and relaxed atmosphere without disturbance from other patients and deciding when to be alone, relax, and do activities.

"You feel that you are in a nice hotel, but nothing else."

However, as the previous quote illustrates, some participants experienced the stay as boring. It was clear from the

interviews that the freedom and lack of in-house activities came at a price for several of the participants. They talked about their previous experience where they were encouraged to interact with other patients and to participate in organized in-house activities like common meals, group therapy, walking tours, bowling, or the cinema. Several participants said that they missed these types of organized group activities, and some said that they did not understand why this was not offered at least to some extent at the CRA. Even when asked in detail in the interview about their understanding of the CRA not offering in-house activities in order to encourage them to be active themselves, some maintained that there should be at least some activities. They argued that they either did not feel they had other activities in the community to take part in or that there were some days they did not feel like going out due to how they felt.

"I thought there would be more in-house activities, but there were none. So, you felt in a way that you were just sitting there waiting with nothing to do or that someone would try to take you out or get you to participate in normal life. You were on your own. The staff asked me how I was going to spend the day and I had to find out what to do."

# Treatment, a place to rest, or preparation for independent living?

Participants' expectations concerning treatment at the CRA varied. Some said they were used to conversational therapy from their previous inpatient stay and that they felt a continuing need for this in the CRA. One participant said that despite recommendations from the hospital, he was not offered conversational therapy as part of the stay at the CRA. This participant expressed that the staff had failed in taking the responsibility to help him get appropriate treatment at both the CRA and outside.

"I was not offered conversational therapy, and there was no treatment."

In contrast, some participants said that the staff observed them without being intrusive, and they were confident that the staff would act if someone needed further treatment.

"It was only when I came to the residential care and got relaxed that I realized how tired I was. To have the opportunity only to withdraw, with no requirement to participate in activities, made me see my situation more clearly."

All participants reported some positive experiences with the staff at the CRA. They especially appreciated

getting a designated contact person. They compared this to their prior experiences from hospitals, where they sometimes had various "contact persons," who all had the same level of responsibility. This was reported to result in a lack of coordination between the different contact persons, misunderstandings, and sometimes inadequate help. Some stated that the staff in the CRA was more "hands-on" and solution-oriented in helping with practical and concrete tasks than the hospital staff. Some participants said that the contact person really wanted to help them, as they felt that the staff took personal responsibility for them during the stay.

There was variation to what degree the participants said that the staff activated them. Most said that they received information from the CRA staff about various activities in their own neighborhood, such as fitness centers, low-threshold services, and cultural and leisure activities, or were encouraged to take up their previous activities.

"They also teach me how to structure my life by finding housing and facilitate daily activities like cleaning and preparing meals."

However, some felt that the staff went too far in wanting the participants to become active themselves. One participant told about how he had asked the staff to accompany him to an activity center but they only encouraged him to go by himself.

"An employee from the mental health services [ambulant team, not part of the CRA] followed me to the activity center the first and second time I was there. Later, because of that support, I could go there by myself. So, it was very important for me that someone escorted me the first time and showed me the place so I felt safe."

# Coordination with other agencies

Most participants said they had been in meetings with community services where they discussed what type of services they needed after discharge from the CRA. Some participants said that the contact person had initiated such meetings, but in general the informants did not talk about the CRA as having an active role in planning their aftercare.

When asked about the meetings they had with the community services, the participants mostly remembered being asked which practical services they needed in order to manage everyday life at home. Some described their need for continuing conversational therapy and complained that there was no information on how to get help to cope with their mental health problems. Other participants said that

they talked to CRA staff about preparing themselves before meetings with other community agencies.

"Yes, an employee from the Health and Welfare office came and talked to me, and then I was offered a follow-up service that I still use, as well as help from the Child and Family agencies."

Some of the participants did not know whether the services they received prior to hospitalization were still available to them after their inpatient stay. It was said that they missed this contact and experienced a kind of discontinuity between the staff in the primary care and the specialist from the hospital. They said it would have been an advantage if the primary care staff they were used to at home also could visit them during the stay at the CRA.

"I have a good relationship with an employee in a community ambulant team, and I would have liked to keep contact with him while I was hospitalized. I would like to have a meeting with him once a week, as well as cooperation with the staff in the mental hospital."

The six participants who were interviewed after discharge from the CRA talked about similar experiences regarding preparation for their home situation. They all expressed satisfaction with the services they were offered after CRA discharge and said that meetings with different agencies during the stay in CRA were essential in setting this up. They told that they had been asked about their own needs, and some had ended up with different types of services than they had before their admission at the mental hospital. Examples of changes were from having had only Community mental health consultation, in addition they were offered services from the Agency of Children and Family Affairs, Day center, Assertive Ambulant Team (ACT-team) and self-referral at the CRA.

Three of the participants interviewed after discharge reported that they continued with activities they were introduced to during their stay in CRA, such as work experience at a private firm, volunteering in a church organization, and visiting a low-threshold day center. They found that planning the discharge process was different in the CRA compared to their prior experience with planning the discharge process from a mental hospital. In the CRA, they were asked which services they needed in order to manage their everyday life at home, such as follow-up visits from community agencies, and the Norwegian Labor and Welfare Administration (NAV) arranged work practice for them.

"When I was at the residential care, they arranged a new system for me together with other agencies of the municipality."

#### Use of self-referral stay

Nearly all patients said they were pleased with the possibility to self-refer from home for a short stay at the CRA. A typical comment from those who had been discharged from the CRA and who had used the self-referral was that it made them feel safe to know that they had the CRA to contact. One participant who had used the self-referral once talked about how the staff had encouraged him to try to stay at home a bit longer when he called and asked to be admitted. This made him aware of the importance of trying to postpone using the service

"When I'm home I push myself further and further and wait with requesting self-referral stay, so it will not be so often."

Those who had used the service said that they used it to get "back on track" again (e.g. re-establish daily routines like sleep pattern). They experienced the short self-referral stays in the CRA as a good way to stabilize their situation and relax. Some said that without the offer in the CRA they would have had more mental health hospital admissions, which they wanted to avoid.

"Self-referral stay at the CRA is much better than an 'emergency' admission at the hospital. In and out of the emergency department and then home again does not help."

Another participant felt that it was good to use self-referral stay for one or 2 days to relax and regain energy but would not want to stay there longer, because there were no organized activities offered.

# Discussion

The main findings of this study were that the participants experienced the stay at the CRA like a hotel, but that it was boring. There were participants who did not agree with the philosophy of the CRA of not offering inhouse activities, and they felt that it would have been better to have some activities. All participants said they appreciated the freedom to structure their daily routines without regulations. The participants reported that they had discussions with the CRA staff about how their services should be organized after discharge, but in general they did not acknowledge that the CRA had an active role in facilitating this.

#### What to do at the CRA?

We found that not all participants understood or agreed with the approach taken at the CRA of not offering organized in-house activities in order to encourage selfdirected activities. The CRA's philosophy to not offer organized in-house activities is to prevent patients from being inactive and institutionalized [29]. A review concluded that it is essential that patients understand to the importance of self-care and to formulate goals for the stay [30]. Also, a Swedish 2-year follow-up study among 49 persons with SMI reported that self-formulated rehabilitation goals are important in daily activities [15]. However, the participants in this study lacked information about the CRA and didn't feel prepared for the stay. In the future, this information should be given well ahead of discharge from the mental hospital. This is especially important, as it is likely that participants' expectations of the offered services were influenced differently, also depending on their diagnosis, ranging from personality disorders to organic brain diseases. Thus, as patients with SMI constitutes a heterogeneous group, the degree of self-directed activities and information to clarify the expectations of the services the CRA offers, should be individualized.

Some participants in our study said they took part in activities outside the CRA after some weeks, as a direct consequence of a boring stay, due to lack of in-house activities at the CRA. This indicates that the philosophy of the CRA can help patients to start activities in the community that they can continue after discharge. This is supported by a Danish study that found that community residential facilities were better able to promote residents' activities both within the facility and in the community than hospital-based psychiatric rehabilitation units [31].

The participants were satisfied with the freedom they experienced at the CRA. However, too much freedom could be problematic for some, as a previous study on patients with schizophrenia found that they spent a large amount of time engaging in passive activities like watching television or sleeping [32]. Therefore, the staff should be aware of the dilemma of supporting patients to rest or supporting them in a recovery orientation to engage in activities [33].

The CRA offered only single rooms where the patient could withdraw when he or she wanted, and this was mentioned by the participants as an important aspect of freedom. Our results are in line with a Danish study on Crisis houses also offering single room [13] where patients' experienced that they lived a normal life and were seen as humans — not patients. Previous studies have found that overcrowding in psychiatric wards may be associated with increased risk of anxiety and aggression in patients with SMI [34] and that a single room and fewer

patients in common rooms in wards lead to reduced levels of stress, pain, and anxiety [35, 36]. Further, our results are keeping with a narrative review [37] that found that well-designed interior settings play an important role in the healing process of patients in health care facilities. A review on the quality of institutional mental health care concluded that an ideal institution should be small and community-based and maximize flexibility, privacy, engagement, and positive therapeutic relationships [38].

## Coordination of services before discharge

The participants said they appreciated having a dedicated contact person in the CRA. Several studies have demonstrated the importance of continuity in the staffpatient relationship to achieve good results in treatment and follow-up [39-42]. However, this must be balanced against the problem arising if the patient develops a dependency relationship with the contact person [14]. Having a dedicated contact person at the CRA could create such dependency, but findings from this study did not indicate that this contact was a barrier to development of a relationship with community staff. However, as participants talked about not maintaining contact with the service providers they had before their hospitalization, more emphasis should perhaps be placed on facilitating regular contact with community service providers during the stay at the CRA. This could contribute to a stable relationship with the career in the community services [43].

In line with our findings, a qualitative study in a psychiatric emergency department in the US also found that it was beneficial to have a care manager to assist patients with primary care connections [14]. Previous studies have also pointed out the importance of involving and listening to patients' voices in the admission or discharge process [43, 44]. Thus, the approach of the CRA has support both among the participants and in the literature. Nevertheless, given the focus at the CRA of facilitating aftercare, it is surprising that the participants in our study generally did not acknowledge that the CRA had an active role in this, although some said that the contact person had initiated meetings.

# Strengths and limitations

To the best of our knowledge, this is the first study to explore the experience of a stay at a CRA not providing organized in-house activities for patients with SMI. It is also a strength that the participants interviewed during the stay reflected on the services they were just offered, and the participants interviewed after discharge at home could reflect on how their stay had an impact after discharge. We also achieved good variation among the informants, but there might have been patients at the

CRA who did not want to be included in the study but could have had other experiences. Further, the psychiatric diagnosis differed across the sample. Therefore, it could be difficult to recommend if there are patients with specific diagnoses that benefit from a stay in the CRA.

#### Conclusion

The stay at the CRA was clearly experienced as different from other services, with more freedom and focus on self-care, and lack of in-house activities. This led to increased self-activity among the patients, yet some wanted more in-house activities at the CRA. To prepare the patients better for the stay at the CRA, more information about the philosophy is needed in the preadmission process.

#### **Additional file**

Additional file 1: Interview guide. (DOC 31 kb)

#### Abbreviation

CRA: Community residential aftercare; SMI: Severe mental illness, typically people with a diagnosis of schizophrenia, schizoaffective disorders, major depression, or personality disorders

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#### Availability of data and materials

The transcripts from the interviews are confidential and will not be shared.

# Authors' contributions

ER conceived of the study, participated in the design of the study, conducted all the interviews, led the analysis, and drafted the manuscript. OB participated in analyzing the data and contributed to the manuscript drafts. MHS participated in analyzing the data and contributed to the manuscript drafts. AS participated in the design, the group interview, and analyzing the data and contributed to the manuscript drafts. All authors read and approved the final manuscript.

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#### Ethics approval and consent to participate

The study was approved by the regional Committee for Medical Research Ethics in Central Norway (2011/1770). Written consent was obtained before the interviews were conducted, and confidentiality was assured.

#### Consent for publication

Written informed consent was obtained from participants before the interviews were conducted, and confidentiality was assured.

#### Competing interests

The authors declare that they have no competing interests.

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# Paper III

# RESEARCH ARTICLE

Open Access



# A qualitative study of how people with severe mental illness experience living in sheltered housing with a private fully equipped apartment

Eirik Roos<sup>1,2\*</sup>, Ottar Bjerkeset<sup>3</sup>, Erik Søndenaa<sup>4</sup>, Dag Øyvind Antonsen<sup>5</sup> and Aslak Steinsbekk<sup>1</sup>

#### **Abstract**

**Background:** There are a number of supported housing options for people with severe mental illness (SMI), but limited knowledge about residents' experiences. The aim of this study was to explore how people with SMI experienced sheltered housing consisting of both a private fully equipped apartment and a shared accommodation room for socializing

**Methods:** Fourteen people with SMI living in sheltered housing apartments participated in a qualitative study with semi-structured face to face individual or group interviews.

**Results:** Residents' access to the service providers in the sheltered housing, who were seen as both "ordinary people" and skilled to observe symptom changes at an early stage, were major factors for the perception of security. In addition, residents highlighted the possibility of living in a fully equipped apartment, and having access to a shared accommodation room to connect with other residents. Having a fully equipped apartment including their own equipment such as a washing machine was said to help reduce conflicts. Short tenancy agreements made some informants feel insecure. It was also essential to have meaningful daily activities outside the residence to avoid re-hospitalization.

**Conclusions:** The positive experience was connected to having a fully private equipped apartment including shared accommodation room. The service providers should be aware of the dilemma with in-house support, to make residents feel secure versus increased dependency on service providers.

Keywords: Community mental health care, Serious mental illness, Sheltered housing, Qualitative study

#### **Background**

In the past decades many countries have initiated extensive mental health care system reforms, and the main goal of these reforms has been to transfer treatment and follow up for individuals with severe mental illness (SMI) from psychiatric hospitals to the community [1]. Deinstitutionalization policies represent a shift in practice for the treatment and support of individuals with SMI [2].

A consequence of this shift is that there is an increased need for services in the community. Beside therapeutic communities, supported independent tenancies, residential care or living with family, there are a number of sheltered or supported housing options for people with severe mental disorders [3–7]. Sheltered, supportive and supported housing are often used as equivalent terms and in this article we have chosen to use "sheltered housing."

The main goal of sheltered housing is often to support the residents in a rehabilitation process to prevent unnecessary admissions to mental health institutions [8, 9]. However, a review of studies on sheltered housing found that most studies in this area did not give enough details

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to classify them according to eight housing dimensions for people with SMI; 1) the individual owns the housing or has a lease in his/her own name, 2) housing and service agencies are legally and functionally separate, 3) housing is integrated into the community, 4) housing is affordable (i.e., no more than 40 % of adjusted gross income), 5) services (including medication) offered are voluntary, 6) the individual has choice of the housing and services, 7) services are community-based (there are no live-in staff) and 8) crisis services are available 24 h a day, 7 days a week [10]. Another review of the literature on housing approaches for psychiatric consumers found that the main characteristics of sheltered housing were that residents have their own room within a building complex with shared facilities such as a laundry, dining and living rooms and services provided by in-house staff [11]. Sheltered housing thus represents a housing arrangement in between independent living in the community and a residential institution [12] for people who prefer to live independently, but want the security and availability of assistance and care when needed [13, 14].

It is important to know how sheltered housing can be improved as studies from the Netherlands have found that service users living independently were more likely to feel socially included than residents in sheltered housing [15]. Another qualitative study among 40 US adults with dual disorders living in either supervised or independent housing arrangements [16], found that most of the clients living in independent housing arrangements either interacted only with other clients who were also living there or they kept to themselves. In contrast, nearly all clients in supervised housing reported a sense of community among the other tenants and receiving peer support [16].

There is a range of reviews on the effects of different forms of sheltered housing [3, 5, 11, 17-22]. Some of these have focused on participants' hospital use before and after housing interventions [21, 22], residential stability [5, 10, 22], preventing homelessness for individuals with mental and substance disorders [19] and among individuals discharged from hospitals [21], and how the residents made sense of their occupational transformations in the context of their everyday life and life history [23]. However, relatively few publications have investigated how people with SMI experience living in sheltered housing [4, 7, 16, 24]. We have only identified one study on how people experience living in private, fully equipped apartments with shared facilities [24], a Swedish qualitative study of 29 users with SMI living in fully equipped apartments or single rooms. Previous studies have shown inconsistency regarding social inclusion among those living in independent housing arrangement versus sheltered housing.

The aim of this study was to explore how people with SMI experience living in sheltered housing consisting of only private fully equipped apartments including shared accommodation room.

#### Methods

This was a qualitative study with semi-structured individual or group interviews. The data collection was conducted from September to November 2014 and started with the first group interviews, then five individual interviews, then the second group interviews and one individual interview.

#### Settino

This study took place in Trondheim, a city in Central Norway with 185,000 inhabitants. The municipality offers different types of services to people with severe mental illness (SMI) such as psychosocial support, training services, aftercare, supported housing with traditional case management and sheltered housing. A total of 140 persons with SMI currently live in sheltered housing owned by the municipality. The sheltered houses are organized as units consisting of one building complex with 7 to 30 one person fully equipped apartments with all amenities such as their own bathroom, kitchen and living room. They also have access to a shared accommodation room where the staff also attended. The residents are offered a 3 year tenancy agreement which has to be renewed at the end of the term. The sheltered housing looks like any other private homes in the area and is placed in different residential neighbourhoods. There are facilities like shops and walking areas nearby, and the distance to city centre is 10-20 min by bus.

Live-in staff (employed by the municipality) attended each unit 24 h a day, 7 days a week (24/7). The main purpose of these facilities is to maximize the personal autonomy of residents and encourage them to do as much as possible for themselves including personal care, shopping, cooking, domestic chores and leisure time activities with the support of the staff as needed. Most residents have daily or weekly meetings with a mental health nurse or a service provider to discuss topics such as how to cope with the psychiatric disease, somatic health, household tasks, and financial issues. All services offered are voluntary, meaning that users can decide whether they want to accept help or not.

#### Participant:

The aim was to include people living in different sheltered housing units who had a diagnosis of SMI (for example: schizophrenia, schizoaffective disorders or major depression, personality disorders) and who had a level of competency to consent themselves. It was aimed to obtain variation in age, gender and number of years of residence in sheltered housing.

To recruit informants, the first author had meetings with unit managers and team leaders of the sheltered housing to inform them about the study so that they

could ask residents with a level of competency to consent themselves to participate. The staff was informed about the need for variation among the informants and were asked to take this into account when recruiting. It was emphasized that participation was voluntary. The team leaders were asked to give this information both verbally and as an information sheet to residents who they thought may be interested in taking part in the study. The team leader at each unit organized meetings between the first author and residents who wanted to be interviewed. The first author gave the residents more information about the study and asked if they would like to participate. Then the residents were asked to sign the consent and they could choose whether they wanted to be interviewed individually or in a group. There were no exclusion criteria.

#### Data collection

The individual and group interviews took place in the sheltered housing where the informants lived. The first author took part in all the interviews; the fourth author (co-researcher) took part in seven interviews and the third author in one group interview. The co-researcher has previous experiences as a user of mental health services, and experience in asking questions from a user perspective. The group interviews took place in the shared accommodation room in the unit and the individual interviews were conducted in the informants' own apartments. The staff was not present at any of the interviews. To increase the sense of security, residents from the same sheltered housing were interviewed together in groups. The interviews were audio taped and transcribed verbatim. The average group interview duration was 45 min (range 42-48 min), and the average individual interview duration was 36 min (range 23-64 min).

An interview guide was used (Additional file 1). The main question was to ask about their experiences with their living arrangement, including follow-up questions about what they were most satisfied or not satisfied with, what kind of services influenced their feeling of security, how they experienced living closely with other residents and about their activities during the day.

#### Analysis

The data were analyzed, starting after the first interview, using systematic text condensation in an iterative process [25]. This is an iterative four-step process. All authors started by reading and rereading the transcribed interviews separately with an open mind to obtain a general impression, and identify preliminary overarching themes. In the second step, the transcripts were systematically reviewed line by line by the first author and the units of meaning identified, classified and sorted into themes. During all the phases of analysis, the authors had several

meetings to discuss meaning-bearing units, core meanings, subthemes and themes according to the purpose of the study. The findings were first categorized into three main themes; experiences with living arrangements, permanent or short tenancy agreement and relations with the staff, but this was later changed to focus on the overall experience and relationships. The third step was to sort the units of meaning into subgroups and reduce the content to a condensate of artificial quotations, maintaining as far as possible the original terminology used by the participants. In the last step, the contents of each code group were summarized into generalized descriptions and concepts.

The recruitment of participants continued until no new themes emerged. At that point, the material was considered saturated. The analysis was performed by the first author and discussed and negotiated with the coauthors. The analysis was validated with a thorough review of the original transcripts of each interview to make sure they were reflected in the results.

#### Result

A total of 14 participants (8 men and 6 women) with SMI were recruited from three different sheltered housing units (Table 1). They had lived in the current unit from 2 months to 12 years and none were employed. The most characteristics of the study entrants are frequent hospitalizations and lengthy hospital stay, poor independent living skills and limited social network before they moved to sheltered housing. The informants were interviewed in two group interviews with four participants in each group and six individual interviews.

### Experiences with the living arrangements

Participants were especially satisfied to have their own private fully equipped apartment, while at the same time having the opportunity to use the shared living room where they could be with other residents or service providers. It was repeatedly emphasized that the main advantage of sheltered housing is the combination of private and shared accommodation and all residents expressed that they felt safe in the sheltered housing.

**Table 1** Characteristics of the informants (n = 14)

Variable	N/Mean(SD)
Male	8
Female	6
Age	48.8 years (10.4)
Duration of housing	6.1 years (2.9)
In paid work	0
Disability benefit <sup>a</sup>	14

<sup>a</sup>Disability benefit provides secure incomes to those who have a permanently reduced earning capacity due to illness or injury.

"It's very good because we have our own apartments and a shared accommodation where we can go if we want to see people."

They carried out practical chores in their apartment, such as washing floors, cooking or washing clothes. As expected, they said that they could retire to their own flat if they wish to be alone. This was especially valued when they experienced other residents as having antisocial behaviour or being "in their own world." Some contrasted this with the situation of being an inpatient at a mental health hospital where they did not have the same opportunity to withdraw.

"I have a key to the apartment, it is 100 percent private."

They used the shared accommodation room to meet other residents for social contact. Examples of activities were participating in common meals once a week, playing games and attending organized activities like cookery courses once a month. However, one resident who had lived in the sheltered housing for 6 years said that although it was good to have shared activities, it was important that not everyone has to participate in all the activities as it would be like being in an institution.

"Initially there were two shared meals and day care three times a week, and a lot of trips with our own minibus. Now there is much less compared with earlier times. For me this is better because I used to feel guilty if I did not take part."

When asked about negative experiences with sheltered housing, the most common comment was about whether or not they could stay there as long as they wanted. The reason was that they have a 3 year tenancy agreement which has to be renewed. Some worried whether their tenancy would be extended.

"If we behave well and pay the rent on time, I think we should get to stay here as long as we want."

# Relations between the residents

Several residents talked about the difficulty of keeping friends when they had longer hospital stays. This was given by some as the reason for having a limited social network. Most of the residents said that they had become friends with one or two other residents. This was said to result in both increased social and physical activity. Some also reported that they take part in more activities now than where they previously lived.

"I've become better acquainted with some residents that I can go hiking with, go to town or seek low-threshold services." The residents said that it was easier to have social relations with the other residents when they were invited by staff to participate in shared activities or when the staff was present in the shared accommodation room because the staff encouraged people to talk or started activities. Typical topics for small talk were everyday activities such as where to go shopping and if anyone wanted to have a walk or topics from the newspaper. They said that they were encouraged by the staff to not talk about disease, but they still did as this was a topic they all could talk about.

"I have some friends, but most of them are sick too. I met them during my hospital stay. The staff say we should not talk about disease. But it is disease that is the connection between me and my friends, so we talk about it."

The residents also gave examples of situations with bickering or conflicts. Some said that quarrels between residents could make them feel unsafe. Examples of situations that could lead to conflicts were when they were together in the shared accommodation room without any kind of activity, especially on weekends as there were fewer staff and fewer activities. Throughout the interviews, it was talked about how they missed having a mini bus at their disposal to go for trips (they previously had a dedicated mini bus).

"We residents have no problem with being together, but due to a facility [the mini bus] having been taken from us, we are together a lot without activities – so there can be some frictions between us."

One resident said that she did not always experience a sense of community with other residents, because of different needs and interests. She instead preferred to go to cafés or a concert with friends with whom she had common interests.

# Relationship with the staff

When asked about how they experienced the staff, it was commonly commented that the staff treated the residents with respect and saw them as human beings and not patients. Words like being treated with dignity, as ordinary people and not as a "diagnosis" were used.

"I am treated with respect and dignity. The staff said they do not care about diagnoses – they care about people."

There were variations in how the residents saw the staff. One resident found it difficult to ask for help sometimes because she felt that she complained too much. Another resident disliked it when the service providers sometimes decided which activities she could attend, which made her withdraw from common activities. Yet another talked about how he saw one of the staff as his friend.

"I got great support from the nurse in the sheltered housing – I've got very good help and support. I see him as a best friend. He is so nice to talk to. He understands me so well. I feel that he builds me up in a way."

Another resident had experienced that when the staff contacted different services, then the problem was taken more seriously than if the resident was making the call. Some of the residents had started to get ambulatory services at the sheltered house, e.g. a psychologist who comes to have conversational therapy. This was highly valued as it was experienced to be easier to follow up.

"The psychologist can visit me and so there are fewer cancellations. So I am able to have conversational therapy even when I feel a little unwell. When I had a psychologist at the psychiatric hospital, I often cancelled because I could not make myself go there when I was depressed. Now they come to me and so there are many fewer cancellations."

Looking back on the time prior to acquiring sheltered housing, many residents described having experienced lack of follow-up services and a life with frequent hospitalizations. It was said that the staff were skilled in observing the residents' problems and offering counselling and practical help at an early stage. They also said that the staff offered methods so they could cope with symptom changes by themselves.

"I get good help from the service providers and I do not need help from specialist health services. When I feel depressed, it helps to read a book, watch TV – do something to get your mind on something else."

Some also said that the combination of ambulatory services and the security provided by the staff had led to fewer hospitalizations after moving into sheltered housing.

"I have not had any hospital admissions after I moved here, so I feel safe in the residence."

# Contact with family and friends

Most residents said that they had a limited social network outside the sheltered housing. One informant reported that he has only one friend in addition to some of the residents. "I have few visits. There is only one person I know in addition to some residents. He calls me once a week to take me for a drive or other activities."

Some said that they have contact with family members who, for example, visited and helped to pay bills. Others had support persons that they consider as friends.

"I have a support person with me to visit the cinema, bowling, go-kart and café visits."

Mostly the residents meet their friends outside the residence, for example going for a walk, visiting a café or experiencing cultural or entertainment activities. The advantage expressed was to spend time with others beside the residents.

Most residents said they often visited a low-threshold service to meet other users with mental disorders. However, they did not develop close friendships where they for example visited each other. Low-threshold service in this context means services provides by the municipality where neither scheduled appointments nor referral from specialist is needed.

#### Discussion

The main finding was that the residents in this study experience a high degree of security and satisfaction living in sheltered housing, on the one hand due to access to service providers and having the opportunity to seek the shared accommodation room for socializing, and on the other hand due to the possibility of withdrawing into their private fully equipped apartment. Having short tenancy agreements made some informants feel insecure. Nearly all the residents said that they could associate with most residents and often consider one or two residents as friends. They experienced little contact with people outside the sheltered housing and thus focused on activities with the other residents.

# Experiences with living arrangements

There seems to be few studies on the experience of living in sheltered housing where some of the residents had their own fully equipped apartment. In the Swedish qualitative study [24], it is obvious that having a private space gives residents a place with no demands from surroundings or other residents [26], having a fully equipped apartment adds other advantages as well. For example, having the possibility to cook or wash clothes without being dependent on the availability of a shared kitchen or washing machine. Furthermore, it can be experienced as recognition that the residents are "normal" since they have their own fully equipped apartment similar to other citizens. The perspective from a Dutch study [15] confirmed these findings, but

their study focused on social inclusion and not the housing arrangements.

Although, such a fully equipped apartment costs between 220 000 and 330 000 euro to build. The Norwegian State Housing Bank (NSHB) offer development programs to municipalities such as finance housing through loans and until 40 % grants of the total cost for building sheltered housing. The residents are paying approximately 36 % of their net income toward rent and utilities and this percentage is slightly larger than the recommendations for permanent supportive housing of 30 % [19]. The cost for a fully equipped apartment is obviously more expensive than a single room with shared accommodation room, but it is considered cost-effective in a Norwegian context if the residents can stay there for long periods without frequent hospitalizations.

One challenge of living in sheltered housing is the close proximity to other residents. Typically, as in this study and described by others [27], residents were allocated sheltered housing without having been involved in the choice of residence. However, nearly all the residents said they could associate with most residents and often considered one or two residents as friends. This confirms findings that sharing a common room and facilities give an experience of being part of a community [16, 24], even if it has also been found that some experience that being brought together was a sign of not being like "ordinary people" [24]. Taken together with the resident's experience of having few friends, even if residents cannot choose whom they live with, the sheltered housing in this study nevertheless functions as an arena for creating friendship and social contact. The most prominent reason for the sense of belonging given by the residents was the common activities organized by the staff which indicates that some conscious efforts on the part of the staff are needed.

In this study, the residents were unanimous that having the shared accommodation room was very important for them. Although some residents talked about not wanting to take part in all activities and sometimes withdrawing to their own apartment, no one expressed any major problems and conflicts. This is contrary to the Swedish study which found that shared facilities such as a laundry, dining and living room were positive, it was also an arena for conflicts [24]. Examples of situations that led to conflicts were having private property in shared rooms, starting to sing, talk, or quarrel at times that demanded relaxation and silence [24]. We have looked closely at our data, but could not confirm this part of the findings from the Swedish study. One reason might be that the residents in our study did not share this type of information with us, for example due to not wanting to say things that would create further conflicts in the future. This is a very likely explanation for not sharing this type of information in group interviews.

However, we also conducted individual interviews in part to overcome this problem, but neither those interviewed individually did not share any stories of conflicts connected to the shared accommodation room. Thus, it is likely that conflicts can arise when sharing common facilities, we think that having a fully equipped apartment including their own equipment such as a washing machine, helps reduce the conflicts. Another important factor is that residents are able to choose whether they wish to make use of the shared accommodation room for socializing or take part in activities organized by staff.

## Permanent or short tenancy agreement

Informants reported feeling insecure due to having a tenancy agreement of only 3 years. A previous study [27] found that it is important to offer an unlimited length of tenancy agreement because SMI is a chronic and fluctuating condition that requires stable surroundings throughout one's lifetime to maintain health. A recent review [19] also found that consumers consistently rated permanent supportive housing models highest and preferred them over time limited forms of care. Furthermore, stable housing circumstances may be a cornerstone of successful treatment, enabling persons with SMI to transfer their focus from merely surviving to seeking growth opportunities such as life skills programs or addictions treatment [28]. Thus, this literature indicates that it would be wise to give the residents permanent tenancies.

However, if the goal of the sheltered housing is to help some residents to become capable of living on their own in a self-contained apartment, giving this group a permanent tenancy might be counterproductive. It has, for example, been found that many clients indicated that their housing preferences have changed over time and some clients related housing preferences to recovery [29], indicating that a permanent agreement should not be an obstacle to further housing moves [29]. Thus there might be a conflict between having a permanent tenancy and aiming for recovery and independent living.

One possible solution is to design a "housing continua" where the residents move from one housing model to another as they progress in their rehabilitation and recovery [10]. Still, it is important to be aware that such changes would remove the resident from the very environment that enabled him or her to recover, cope and thrive.

#### Relations with the staff

The residents described the proximity and duration of relationships with the staff as important factors for feeling confident to seek help from them and having a trusting relationship that gave an experience of security and stability. This resonates with guidance on building trust in mental health services which emphasizes confidentiality and continuity [30]. However others have found that

residents in sheltered housing can experience relationships with staff as having a lack of recognition, broken agreements, being checked up on, or that the staff tried to influence daily activities [24]. One reason for this difference could be that the sheltered housing in our study seemed to have a very strong focus on individual skills and resources instead of viewing all residents as a homogeneous group [29, 31]. This is substantiated by some of the residents who had lived in the sheltered housing for a long time who talked about a shift from the staff organizing many common activities to today's situation with only a few organized activities during the week.

Access to staff 24/7 can cause strong bonds and counteract independency because it could be a hindrance to normalization, participation in society, and recovery [29]. It is important to be aware of the relationship between proximity and distance when assistance is to be provided. Furthermore, it has been speculated that sheltered housing might increase dependency on service providers for people with SMI [3]. However, we found that some of the residents felt more independent to manage on their own and less dependent on services from the staff after a few years. This also indicates that having a focus on individual skills and resources and living rather independently in their own fully equipped apartment (for example making dinner for themselves almost every day) could counteract some of the danger of becoming institutionalized and dependent on the staff.

But we also found that some residents experienced that the staff played a major role in their health care needs as they observed changes in the residents' mental symptoms and initiated therapy before problems were further aggravated. This was said to be a solely positive aspect of living in sheltered housing as they reported, in line with results from previous studies [5, 21, 32], that they had fewer hospitalizations after they moved into sheltered housing. This raises the question of whether they are still heavily dependent on the staff even if there are clear indications of independent living. One explanation is that the staff managed to allow the residents to live their own life while at the same time observing them. One challenge of this approach could be that the residents become overconfident in their ability to live independently. However, some residents also told how the staff had helped them to find methods to cope with symptom changes by themselves and thus becoming less dependent on the staff.

#### Strengths and limitations

The study has several strengths. First, one researcher had the main responsibility of all parts of the study and discussed all issues with the other researchers. Second, a co-researcher participated in 7 of 8 interviews and this helped to establish a relaxed atmosphere and an open

dialogue. Finally, participants represent variations in age, gender and time in sheltered housing. It was also important that the researchers had different backgrounds and could interpret the findings from different perspectives.

However, some limitations must be kept in mind. As we did not find other studies from sheltered housing with only private fully equipped apartments, these types of sheltered housing might not be a common one. This also implies that the findings might not be representative for other types of sheltered housing in other countries. It could be that the residents did not talk about conflicts and negative experiences due to a fear that others might get to know what they had said to the researchers. Finally, although it was experienced that the interviews went reasonable well, having interviews with people with SMI is challenging for example due to short and repetitive answers. It could have strengthened this study if the data collection also included long-term observation in the sheltered housing and interviewing the staff. However, this was not done, as the aim of the study was to explore the experience of the residents.

#### **Conclusions**

All residents in the study highlighted the importance of access to the service providers and their skills in observing symptoms at an early stage. They also emphasized the shared accommodation room as important to establish a relationship with other residents. The cost for a fully equipped apartment is more expensive than a single room, but the findings in this study indicate that it has many advantages for the residents. Having a short tenancy agreement made some informants feel insecure, but if the goal of the sheltered housing is to help some residents become capable of living in their own self-contained apartment, giving this group a permanent tenancy might be counterproductive. However, further research is required, preferably looking at possible differences in long-term outcomes in sheltered housing with single room compared to fully equipped apartments. The service providers should be aware of the dilemma with in-house support, to make residents feel secure versus increased dependency on service providers.

# Additional file

**Additional file 1:** Interview guide. Questions related to following main themes; Housing, Municipality services and Open Question about other experiences with other types of community services. (DOC 31 kb)

#### Abbreviations

NSHB, Norwegian State Housing Bank; SMI, Severe mental illness, typically people with a diagnosis of schizophrenia, schizoaffective disorders, major depression, or personality disorders

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#### Availability of data and materials

The transcripts from the interviews are confidential and will not be shared.

#### Authors' contributions

ER conceived of the study, participated in the design of the study, conducted all the interviews. Led the analyses and drafted the manuscript. OB participated in analyzing the data and contributed to the manuscript drafts. ES participated in one group interview, analyzing the data and contributed to the manuscript drafts. DØA participated in seven interviews and contributed in analyzing the data. AS participated in the design, analyzing the data and contributed to the manuscript drafts. All authors read and approved the final manuscript.

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#### Competing interests

The authors declare that they have no competing interests.

#### Consent for publication

Not applicable.

# Ethics approval and consent to participate

The study was approved by the regional Committee for Medical Research Ethics in Central Norway (2011/1770). To recruit informants, the first author had meetings with unit managers and team leaders of the sheltered housing to inform them about the study so that they could ask residents with a level of competency to consent themselves to participate. It was emphasized that participation was voluntary. The team leaders were asked to give this information both verbally and as an information sheet to residents who they thought may be interested in taking part in the study. In addition, the first author gave the residents more information about the study in a meeting at each unit. The residents volunteering were asked to sign the consent and they could choose whether they wanted to be interviewed individually or in a group.

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