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Routine outcome monitoring to improve mental healthcare practice for patients with severe mental illness

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Chapter 1

General introduction

INTRODUCTION TO SEVERE MENTAL ILLNESS

Case studies

The three fictive case studies described in Box 1 include different people with distinct problems who experience severe dysfunction in several areas. In addition, they have different care needs, and, as a result, several organizations and different forms of funding are involved. For example, in the Netherlands, sheltered living is funded by the Social Support Act, whereas psychological help is funded through the Health Insurance Act. This makes mental healthcare utilization a policy-related matter. Careful considerations must be given to what type of care is provided, by whom, and how to organize the mental healthcare system. Although the described cases differ from each other in their need for care and involved organizations, all three persons are classified as suffering from severe mental illness (SMI). This term is commonly used to refer to various mental disorders with severe mental and societal dysfunction as the common denominator.

Severe mental illness: background

The term SMI is used to describe a long-lasting psychiatric disorder with a severe impact on a person's daily life. Figure 1 contains the SMI criteria, as defined by Delespaul and colleagues (2013).

○ There is a psychiatric disorder that requires treatment
○ There are serious deficits in social and/or societal functioning
○ The disability is the cause and effect of a psychiatric disorder
○ It is long-term lasting (at least several years)
○ Coordinated care by professional care providers in care networks is necessary in order to realize the treatment plan

Figure 1. SMI criteria (Delespaul et al., 2013).

Those who meet these criteria often have several psychiatric disorders, a psychotic disorder being the most common (60%). They receive treatment within mental healthcare institutions, but as Case C (Box 1) shows, they are also represented in addiction and forensic care, social shelters, and prisons. Patients with SMI experience problems in several areas of life, for example, in mental and physical illness, employment, housing, and social relations (Drake et al., 2014; Viertiö et al., 2004). Research also shows that people with a psychotic disorder

Box 1. Fictive case studies of severe mental illness.

Case A

Daphne is a 42-year-old married woman who is a journalist and has two teenage daughters. Since her sister, who was her best friend, suddenly passed away two years ago, she became severely depressed, experienced anxiety, and was unable to leave the house. Because of her problems, she was no longer able to hold a job. She also started abusing alcohol in order to cope with her feelings. Her psychiatric problems caused relationship problems between her and her husband. As a consequence, she attempted suicide and was admitted to hospital. Thereafter, she followed a daycare treatment for several weeks. She gradually improved, but some depression and anxiety symptoms remained. Daphne currently works a few hours a week as a volunteer on a children's farm but wants to work as a journalist again.

Case B

Yassin is a 21-year-old single man who grew up in Morocco and came to the Netherlands seven years ago with his parents and three older sisters. School was not easy, partly due to language barriers; he hardly dared to talk to his classmates. He dropped out when he was fifteen and did not obtain a diploma. It was hard to find a job, but when he finally found one, he had the feeling that he was never good enough and therefore resigned quickly. A while ago, he lost his job as a dishwasher at a pizza restaurant and was so ashamed that he kept it a secret. Yassin gradually lost contact with his family and became isolated. His parents decided to move back to Morocco, and his sisters got married and moved away. The debts and shame piled up. He did not dare to show himself in public or even talk to the cashier at the supermarket. He also started neglecting his apartment. This was noticed by a friendly neighbor, who spoke to him and motivated him to seek help. Initially, when outpatient treatment started, he experienced a lot of stress because he did not want to be a burden to others. As a result, he did not attend his appointments. However, outreach mental healthcare workers who came to his house were able to gradually build up a relationship. A psychiatric nurse came by for his medication, and a social worker helped him with his finances. Furthermore, they walked with him four days a week to a daycare program, where he is creating a daily routine and meets other people in a safe environment.

Case C

Adam, a 56-year-old single man, start using cannabis when he was 13 years old. Thereafter, he started using several other drugs. Because of this drug use, he was remanded into custody and admitted to rehabilitation units several times. However, as soon as he went home, he started using again. He had no job, and in order to get drugs, he stole money from his parents and sold some of their furniture. This resulted in him being kicked out of the house by his parents. He lived on the streets for months and kept taking drugs. He experienced hallucinations and paranoid delusions and became violent. Because of this, he was admitted to a psychiatric hospital and treated for paranoid schizophrenia. After spending time in hospital, he got a room in sheltered housing. He used medication under supervision and received outpatient residential counseling. However, his aggressive behavior, drug use, and suspicion toward other people caused problems with other residents. Currently, he is homeless but has regular contact with the outreach mental healthcare team. The team is trying to win his trust and motivate him to get treatment.

have a shorter lifespan (Laursen, 2011; Ösby et al., 2000) and a lower quality of life (Sidlova et al., 2011). Moreover, patients with a psychotic disorder are often intensive healthcare users (Carr et al., 2003). Treatment for psychotic disorders is mostly on a pharmacotherapeutic basis. However, there is a lot of nonadherence to medication use due to severe side effects (Velligan et al., 2017). For example, mentioned side-effects are weight gain, emotional numbing, cognitive dysfunction, sedation, akathisia, effects on relationships, and suicidality (Read & Sacia, 2020). For recovery to occur, treatment should concurrently focus on other areas of treatment as well.

Patients with SMI experience problems in several areas and therefore require intensive and multidisciplinary treatment. Thus, It is important to keep investigating how we can arrange the care for this population and improve their quality of life. For this group of patients, mental healthcare is still developing. In the Netherlands, the organization of the mental healthcare for patients with SMI is changing from a more institutionalized focus towards a societal approach (Jeurissen et al., 2016; Project Group Action Plan for Serious Psychological Disorders, 2014).

An example of specialized care for patients with SMI is Flexible Assertive Community Treatment (F-ACT), which was introduced in the Netherlands in 2004. F-ACT is a Dutch intervention based on assertive community treatment but serves a broader range of individuals with SMI and contains more flexible support. Individuals are offered support in stable and crisis situations whereby the continuity of the care is also ensured with maintenance for the continuity of the care (Van Veldhuizen, 2007). Individual treatment plans are based on needs and wishes, which are formulated by Routine Outcome Monitoring (Van Veldhuizen et al., 2015).

Another example of an attempt to better arrange the care for the SMI population is the development of mental healthcare vignettes. In 2012, mental healthcare vignettes were developed in the Netherlands to create more transparency between insurance companies, municipalities, and mental healthcare facilities. Earlier, in 2010, an attempt was made to develop a decision tree based on care intensity and clinical judgment. However, this model did not fit in well with care needs, psychosocial functioning, and the actual required treatment time (Kwakernaak e.a. 2014). This illustrates how difficult it is to develop a model that estimates the required need for care accurately and takes individual needs into account. Therefore, it will be interesting to find out more about the individual and mental healthcare

variables that have a significant impact on the treatment process and the organization of the care for patients with SMI.

ROUTINE OUTCOME MONITORING (ROM) FROM A MICRO, MESO, AND MACRO PERSPECTIVE

ROM, a systematic evaluation of patient progress during treatment, is widely used in clinical practice (Buwalda et al., 2012). It serves different goals at several levels, ranging from the individual patient, organizational level, and the mental healthcare system as a whole.

ROM in clinical practice for SMI (micro)

One important function of ROM is supporting the treatment process of the individual patient. ROM-data provides feedback about progress, which can then be evaluated and give direction to the continuation of treatment. In addition, treatment plans and goals can be tailored to better meet the patients' needs. As is shown in Case A (Box 1), the demand for help changes over time and therefore needs to be properly monitored. However, Tasma and colleagues (2016) found ROM and clinical practice to be two separate processes, as ROM outcomes were barely visible in treatment plans and treatment goals were not found in the ROM-data. This argues for a good match between ROM-measurement tools and a specific population under treatment. Mulder and colleagues (2010) analyzed several types of measuring instruments and how they could be used to support the SMI population. They state that proper use will, among other things, lead to an improvement in mental healthcare.

ROM has proven effective in several psychotherapeutic treatments (Shimokawa et al., 2010). Moreover, its effectiveness has also been proven in specialized treatment settings (Knaup et al., 2009), among others, for treatment evaluating the SMI population. Fornells-Ambrojo and colleagues (2017) investigated experiences of ROM use in an SMI population and found that most of the patients (64-72%) rated the use of ROM as helpful. Repeated evaluation of treatment helped patients feel better understood, value opportunities to reflect, express feelings, and track progress towards goals. Benefits for clinicians are also found. In a review of Carlier and colleagues (2012), ROM was found to have positive effects on reaching diagnoses and more effective communication between the clinician and patient, especially for patients who struggle in therapy.

In brief, with appropriate measuring instruments, ROM can be used in clinical practice for setting treatment goals, treatment evaluation and to adjust treatment goals to meet the patient's specific needs. Furthermore, by using ROM, patients feel better understood and resources can be used more efficiently.

Despite the benefits, ROM is not yet sufficiently embedded within the field of SMI. Several challenges are found. For example, patients could be too ill, have no insight into the severity of their illness, have cognitive deficits, or not be motivated to get treatment. In addition, imbedding ROM in an institution and training personnel is costly, clinicians do not always see the benefits to their practice, and it is seen as an administrative burden (Gold et al., 2019).

ROM for organizational purposes (meso)

Another goal of ROM is to support policymakers at an organizational level. If an institution has collected data from a substantial number of its patients, it becomes interesting to analyze outcomes at a larger level. It is desirable to know how treatment processes will run and how the care should be best organized to offer the best treatment with the best results. In other words, when properly used, ROM can be used to determine the quality, effectiveness, and, thus, the policy of mental healthcare institutions.

There is an increasing demand for care and a limited set of resources. This challenge emphasizes the need to develop more efficiency within mental healthcare. One method expected to be effective in improving the mental healthcare system is to provide more insight into the patient's future use of mental healthcare resources. Once this can be well predicted, actors from the care system can anticipate by distributing resources well, thereby possibly lowering the costs. Also, predicting mental healthcare resource use at the group level can help institutions allocate resources accordingly. Adequate staff distribution is a challenge for a healthcare organization, given the tight labor market conditions and the changing demand from the population. However, Case B (Box 1) shows, for example, that intensive treatment by multiple disciplines is desired. When future mental healthcare use can be predicted within a given healthcare program, this can contribute to a more proactive response towards shifts within the population's mental healthcare demand.

To predict the resources needed, effectiveness, and quality of care, one needs to collect outcome data during the treatment process. However, it has been quite a challenge to measure mental healthcare outcomes, as most of the measures include subjective outcome

variables. Furthermore, because several aspects are important for an outcome, it is difficult to predict the course of events and to set up processes. A wide range of psychological, sociodemographic, and mental healthcare variables that influence mental health recovery must be taken into account as well. The more data are collected, the more research can be done.

In order to analyze this large amount of data, machine learning techniques can be used. These techniques inform diagnostic, prognostic, and treatment decisions. A machine learning technique is a computational strategy for working towards an optimal solution by automatically determining methods and parameters (Dwyer et al., 2018). In contrast to conventional approaches, which mainly focus on relations between variables, machine learning is aimed at making predictions. Machine learning techniques optimize predictions between predictor variables and outcomes and are assumed to add value beyond conventional statistical modeling due to the higher accuracy and better generalizability of the results. In addition, machine learning techniques offer a valuable extension of therapeutic strategies, such as prognostication (Koutsouleris et al., 2018).

The use of machine learning is quite well implemented in physical healthcare, but it is still upcoming within the context of mental healthcare (Tiffin & Paton, 2018). Even though several attempts have been made, an accurate model with good applicability for patients with SMI is still lacking. It is a challenge to make predictions in specialized mental healthcare settings, as it is difficult to predict patients' needs at an individual level. From a statistical point of view, mental healthcare costs are highly skewed (Baca-Garcia et al., 2008; de Oliveira et al., 2016). From a clinical point of view, we do not know exactly beforehand which treatment will work for which patient at what moment. Mental healthcare processes resemble a form of trial and error. This raises the question to what extent is it possible to accurately predict mental healthcare service use and what type of data contributes to these predictions? ROM, combined with adequate analysis, might help institutions identify high-risk groups and allocate resources more effectively.

ROM as part of the Dutch mental healthcare system (macro)

In the Netherlands, ROM was introduced at the end of the 1980s by different mental healthcare providers in order to improve clinical practice, based on clinical needs (Delespaul, 2015). In 2006, the Health Insurance Act was implemented in the Dutch mental healthcare

system, whereby every citizen is required to have healthcare insurance that covers necessary (mental) healthcare. In 2008, the registration of Diagnosis Related Groups (DRGs) became required for healthcare services. A DRG shows the relationship between the demand for care and the care provider's activities and operations. This provides transparency regarding the type of care, and for whom the care is delivered (Janssen & Soeters, 2010). As a result, adequate diagnosis and monitoring of treatment progress became increasingly important. Therefore, the decision was made to make ROM a requirement for the mental healthcare system.

A benefit of collecting ROM-data on a large scale is the ability to research the course of disorders, their (societal) impact, and appropriate treatment. Nevertheless, a greatly discussed purpose of ROM at the macro level is its use for benchmarking mental healthcare departments and institutions, whereby quality and results of different mental healthcare institutions are compared. This may lead to recommendations for quality improvement within the field of mental healthcare by creating more transparency and the possibility to compare departments and institutions so that they can learn from each other (Nugter & Buwalda, 2012). ROM allows for the quality improvement of practitioners and insurers to make statements about the quality of mental healthcare at an aggregated level (Laane & Luijk, 2012). However, it is difficult to compare departments or institutions, for example, due to a variety of case-mix variables, methodological biases, and different types of measurement instruments (Blankers et al., 2016; De Beurs et al., 2019; Hoenders et al., 2014; Mosterman, 2020).

Another discussion is the influence of healthcare insurers on the mental healthcare system. Insurance companies in the Netherlands have the task of contracting healthcare institutions to deliver necessary care, whereby DRGs are the basis for the negotiations. At the system level, they play an important role in guaranteeing that the system leads to affordable, accessible, and effective care. For that reason, health insurance companies can selectively contract healthcare institutions and are, therefore, able to influence the capacity and type of care offered by a healthcare institution. Healthcare insurers want an instrument to assess the effectiveness of the delivered care. They were strong advocates for implementing ROM as an instrument for improving the comparability of mental healthcare suppliers' quality and effectiveness. However, this is not always achievable in practice. For example, in Case C (Box 1), the patient is not seen regularly by a practitioner. This makes it virtually impossible to take a state measurement at a time determined by healthcare insurers.

The influence of healthcare insurers puts mental healthcare institutions in an uncertain position, as uncontracted institutions run more financial risk than those contracted (Janssen, 2017). Imagine what would happen if health insurers used ROM-data to make purchases based on healthcare treatment outcomes for the patient in Case B (Box 1). Also, insurance companies can give penalties if the previously agreed target regarding ROM response is not reached (Sytema & Van der Krieke, 2013). Nevertheless, several parties worry about the major influence of health insurers at the expense of quality care. This resulted in a serious discussion that led to the abolition of ROM as it was used at the time. Opinions are divided on the question as to whether outcome funding leads to better care (Eijkenaar & Schut, 2015; Van Os et al., 2017). In a recent report on Dutch mental healthcare in 2025, health insurers advocate that outcome information in the mental health sector will be structurally monitored and primarily used to learn from, but also to avoid paying for ineffective care (Kraaijeveld & Lomans, 2020). In addition, the current funding system often does not match the care a person actually receives. In this way, simple care can be too expensive, while reimbursement for complex care is sometimes too low.

Furthermore, there is increasing focus on value-based mental healthcare, whereby patients' needs and wishes are at the center of the care. Care focuses on achieving outcomes they value divided by costs of delivering these outcomes so that limited resources are focused on high-value interventions (Gentry & Badrinath, 2017; Porter & Lee, 2013). In order to achieve value-based care, it is important to have a good understanding of the patient's care needs and demands.

AIM AND OUTLINE OF THIS THESIS

As mentioned above, despite the advantages of ROM, there are several considerations for its use at the micro, meso, and macro level within mental healthcare for SMI. The overall aim of the present thesis is to explore how systematically collecting ROM-data supports the treatment of patients with SMI in terms of symptoms, functioning, care needs, and quality of life, so that patients receive the specific care that meets their needs, organizations can make policy and improve quality, and ROM becomes more transparent to care providers and useful in arranging the mental healthcare system.

We mainly focus on mental healthcare for patients with psychotic disorders as they represent a large part of the SMI population. Data was provided by the Genetic Risk and Outcome of Psychosis (GROUP) study (Korver et al., 2012) and Altrecht Mental Healthcare, a large specialized mental healthcare organization in the Netherlands.

In order to understand which factors at the micro and meso level are important for improvement, in *Chapter 2,* is explored which individual and mental healthcare factors are associated with symptomatic and functional remission and to what extent symptomatic and functional remission coexist. This was investigated in young adults with a psychotic disorder in a rehabilitation-focused team using ROM-data and data on met needs and unmet care needs.

As SMI is associated with dysfunction in various social areas, *Chapter 3* focuses on the relationship between psychotic symptoms and social functioning, specifically if social functioning can improve despite increasing symptoms. With this chapter, we wanted to obtain more insight into this relationship and thus give direction to treatment and treatment offerings.

From a macro-level perspective, we know that several attempts have been made to sufficiently arrange care for patients with SMI. However, this has proven to be very complex as many factors are involved. In *Chapter 4* is explored whether the mental healthcare vignettes for patients with SMI, developed in 2012 in the Netherlands based on care intensity, are functional and valid in relation to a patient's needs for care and psychosocial functioning.

As the cases in Box 1 illustrate, patients with SMI can have very different requests for help and therefore, also have different care consumption. As a result, healthcare costs vary and are difficult to predict. In order to facilitate negotiations between mental healthcare services and insurance companies, it is desirable to have an accurate picture of future healthcare consumption. In *Chapter 5*, the use of different machine learning techniques was explored to predict future mental healthcare consumption, thereby enhancing the design of an efficient, demand-oriented mental healthcare system. Several factors that affect the mental healthcare consumption of service users with non-affective psychosis were identified and subsequently used in a prognostic model.

Among the reasons why it is difficult to predict future mental healthcare use is that a small group of patients with SMI requires far more intensive treatment than others, thereby accounting for a large part of the mental healthcare costs. Therefore, it is useful to recognize this group of patients. *Chapter 6* focuses on mental healthcare use data as well as ROM-data

in order to recognize these high-cost patients beforehand. Identifying these patients ensures that policy may be pursued, and contracts between healthcare services and insurance companies can be facilitated.

The final chapter, *Chapter 7*, reflects on the findings of the studies conducted for this thesis. Methodological considerations and implications for the use of ROM within mental healthcare practice and policymaking in the field of SMI are discussed.

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Chapter 2

Symptomatic and functional remission in young adults with a psychotic disorder in a rehabilitation focused team

ABSTRACT

Objective

The aim of this study is to assess symptomatic remission (SR) and functional remission (FR) in a rehabilitation focused program for young adults with a psychotic disorder in the Netherlands, and to investigate which individual and mental healthcare (MHC) factors are associated with SR and/or FR, by using Routine Outcome Monitoring data and data on met needs and unmet needs for care.

Method

Individual characteristics over time were compared with McNemar's tests, independent sample t-tests and one-way ANOVAs with Bonferroni corrections for multiple testing. Remission transition was also tested with McNemar's tests. For a subgroup of the participants, we also studied remission over time and compared remission outcomes from the last two measurements, with 6-18 months between measurements. To study the relationships between the individual factors and SR and FR, estimated longitudinal correlations and generalized estimating equations (GEE) were analyzed.

Results

Data of 287 young adults were collected. Almost 40% achieved or maintained SR, 34% FR, and 26% achieved or maintained both. In addition to sociodemographic factors, living independently, paid employment, higher levels of compliance with treatment, and better fulfillment of unmet needs for care in relation to psychological distress, company and daytime activities were associated with better outcomes on SR and/or FR.

Conclusions

Our findings underscore that to successfully improve and sustain remission in young adults with a psychotic disorder, it is needed to conduct specific research into the relationship between SR and FR.

INTRODUCTION

While there are numerous longitudinal studies about the development of the mental and functional condition of individuals with severe mental illness (SMI; Drake et al. 2004; Harding et al. 1987; Mueser et al. 2003; Swanson et al. 2006), comparatively little is known about how fulfillment of specific needs for care contributes to recovery in terms of symptomatic remission (SR) and functional remission (FR). Mental healthcare (MHC) services often strive to monitor their treatment processes by measuring general outcome indicators such as mental health symptom level, psychosocial functioning, and quality of life. Harrison et al. (2001) and Lasser et al. (2007) point out that it could be helpful to have more specific insight into care factors and treatment characteristics that determine these outcome targets.

Remission is seen as the condition whereby people with SMI have experienced an improvement in core signs and symptoms in such way that any remaining symptoms are no longer of significant influence on behavior (Andreasen et al. 2005). Remission is seen by Andreasen et al. (2005) and Van Os et al. (2006) as a necessary but not sufficient step toward recovery, which these authors describe as a more permanent state. However, Davidson et al. (2005) stress in their review that the notion of being 'in' recovery has been developed in the last decades and captures the value that persons with SMI place on retaining their autonomy in the present rather than waiting indefinitely for later, when they will be cured.

Recovery processes are frequently divided into three overlapping dimensions: personal (Leamy et al. 2011), symptomatic and functional (Dröes and Plooy 2010). Lloyd et al. (2008) mention a fourth dimension: social recovery. Symptomatic remission (SR) and functional remission (FR) are the focus of our study here. SR is defined as a decrease in symptoms with a low to mild symptom threshold over a period of at least six months (Andreasen et al. 2005). Most researchers also incorporate a six-month period of improvement in daily living activities, employment and social relationships into the definition of FR (Andreasen et al. 2005; Harvey and Bellack 2009; Wiersma et al. 2015; Swildens et al, 2018).

Despite SR and FR being distinct concepts, there is a strong association between them. Wunderink et al. (2009) found that most individuals with SMI who were in FR were in SR as well. Similarly, in a review comprising studies conducted between January 1970 and July 2013 of SR (61 studies) and functional recovery (32 studies) of individuals with

schizophrenia, SR was achieved in 20 to 97% of the participants. Functional recovery was achieved in 10 to 68% for different groups of individuals with SMI (Valencia et al. 2014). The divergent percentages found in this review might result from the use of different definitions, such as whether or not the six-month criterion was included. Further, it should be noted that remission transitions take place over time. Individuals go through periods of improved functioning and relapse, and this must be seen as part of their recovery (Yarborough et al. 2016). Simon and Umbricht (2010) also underscore the transitory aspect of psychotic symptoms in identifying individuals at high risk for psychosis.

In order to better encourage remission, it is necessary to determine what demographic and care variables are associated with it. Although there are inconsistencies, multiple predictors are found in the research literature. Salokangas et al. (2013) found that, after a mean period of 14 months, remission at a psychosocial level was predicted by a good working/study situation in young adults at risk of psychosis. Low educational level and non-white ethnicity were associated here with poor outcomes. In a study of individuals with schizophrenia, Ciudad et al. (2009) found that individuals in SR were (among other things) younger, less frequently single, more often engaged in paid employment, and had a higher level of global functioning compared to unremitted individuals. Other studies also mention the following predictors for a better SR outcome: being female, being older, being married, higher educational level, shorter duration of untreated psychosis, medication adherence, higher level of functioning, and quality of life (Albert et al. 2011; Chang et al. 2012; Karadayi et al. 2011; Malla et al. 2002). Substantially the same predictors were found for FR (Helldin et al. 2007). As was found in the foregoing studies, Tse et al. (2015) also found that the chance of recovery increases with age, but these authors did not distinguish between SR and FR.

The divergent research results on predictors of SR and FR will probably coincide in part with characteristics of sub-selections of care recipients. But most interesting are the common factors in service delivery that favor remission. In this context, having more specific knowledge of fulfillment of particular needs for care can also contribute to insight into how to achieve SR and FR. The first aim of the current study is to determine how many care recipients in a rehabilitation focused young adult community treatment team for individuals with psychosis in a regional MHC in the Netherlands have achieved SR and/or FR, and whether it involves remission transition. In addition, the second goal of the current study is

to investigate which individual and mental healthcare (MHC) factors are associated with SR and/or FR.

METHODS

Participants and procedure

This study involves individuals from a rehabilitation focused center of a MHC organization in the Utrecht region in the Netherlands specialized in treating young adults with a psychotic disorder. The team is organized as a flexible assertive community treatment team (FACT; Nugter et al. 2016; Van Veldhuizen 2007), with day treatment activities and an inpatient facility (varying from 16 to 24 beds during the study). F-ACT teams are multidisciplinary and include individual treatment as well as shared caseload, if intensification of the care is needed. The teams deliver process-based care, whereby care recipients have multiple contacts over the years. The center provides rehabilitation, treatment, and lifestyle coaching for personal and societal recovery from the consequences of a psychotic disorder, in close collaboration with participants and their families. Mental healthcare workers are educated in the Boston Rehabilitation Approach by the Dutch Foundation for individual rehabilitation, with a strong focus on setting, achieving, and retaining personal goals of care recipients in the areas of education, work, social contacts and independent living (Anthony et al. 2002; Swildens et al. 2011).

Each year between 2008 and 2016, for measuring treatment outcome, care recipients and their clinicians were asked to participate in Routine Outcome Monitoring (ROM). Only individuals with at least one follow-up assessment were included in this study: 287 individuals (Figure 1). 37 individuals had no follow-up after a successful first measurement and were excluded because: (1) the clinician could not complete the ROM because there was low-frequency or no contact with the care recipient, or (2) the clinician was not able to perform an exit interview for other reasons such as being on sick leave, or the participant was lost sight of before follow-up. Data were analyzed anonymously. Under Dutch law for data collected in ROM procedures that are used anonymously, no informed consent is needed. Participants have the opportunity to refuse to take part via an opt-out system. The research was approved by the institutional review board. All authors certify responsibility for this present study and have no known conflicts of interest.
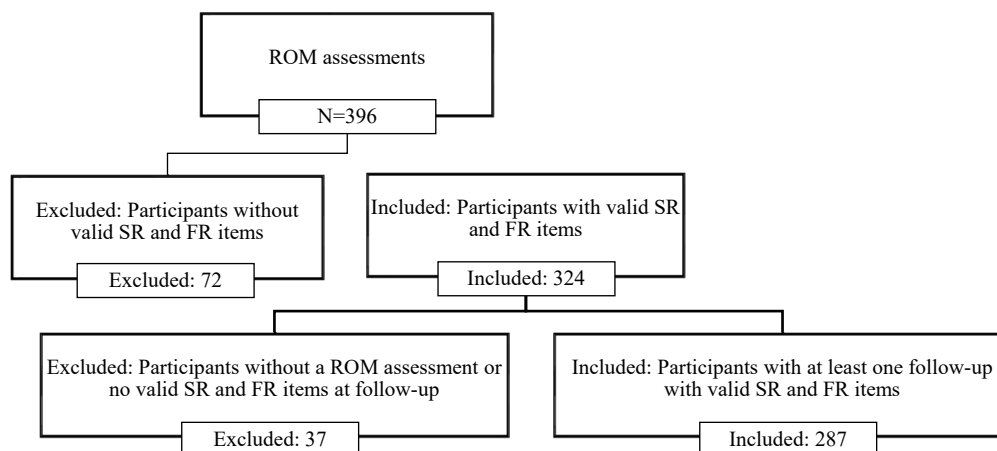
Figure 1. Selection of participants.

Measures

Data was collected on a yearly basis. It included information on sociodemographic and mental health services characteristics, met needs and unmet needs for care and the central outcome measures, SR and FR.

Primary outcome measures; symptomatic and functional remission

Items of the Dutch version of the Health of the Nation Outcome Scales (HoNOS; Mulder et al. 2004; Wing et al. 1998) were used to measure SR and FR. A distinction was made between partial (SR or FR) and full (both SR and FR) remission.

The HoNOS is a clinician-rated scale measuring psychosocial functioning in the past two weeks, consisting of 12 items and (in the Dutch version) 3 addendum items. For each item a severity score is given: 0 (no severity), 1 (minor severity, requiring no formal action), 2 (mild severity, requiring clinical intervention), 3 (moderate severity), 4 (severe to very severe problem). The HoNOS consists of the following items: 1 overactive, aggressive, disruptive or agitated behavior, 2 non-accidental self-injury, 3 problem drinking or drug-taking, 4 cognitive problems, 5 physical illness or disability problems, 6 problems associated with hallucinations and delusions, 7 problems with depressed mood, 8 other mental and

behavioral problems, 9 relationships, 10 activities of everyday living, 11 living conditions, and 12 occupation and activities. The reliability of the HoNOS in this study was found to be reasonable to good (α=.75).

Following Kortrijk et al. (2012), three HoNOS items were used to measure FR: (1) problems with relationships, (2) problems with activities of daily living, and (3) problems with living conditions. They did not use the item occupation and activities, probably because of its questionable interrater reliability and high correlation with other items (Mulder et al. 2004; Trauer et al. 1999). SR was measured using the items of the symptomatic subscale of the HoNOS: (1) problems associated with hallucinations and delusions, (2) problems with depressed mood, and (3) other mental and behavioral problems. Remission is achieved when all mentioned items are rated as subclinical (score $\leq$ 1, no or minor problems). This is a stricter definition of remission than that used by Kortrijk et al., who defined remission as involving only no or mild problems (score $\leq$ 2).

Change in fulfillment of met and unmet needs for care

A 25-item version of the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS; Slade et al. 1999), including three addendum items (Delespaul et al. 2008), was used to determine participants' needs. It included the following items: accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, childcare, basic education, telephone, transport, money, benefits, and three additional items: paid employment, medication side effects, and rehabilitation goals.

The instrument was clinician-rated, based on the individual's situation in the last month, and was used to determine the total number of needs, met needs and unmet needs for care, and needs at the item level. Each item was scored 0 (no need), 1 (met need) or 2 (unmet need).

Individual factors

A number of yearly collected individual characteristics have been tested as predictors for both FR and SR: age, age of onset of first psychotic episode, sex, ethnicity (first- and second-generation Western origin or other), permanent life partner (yes/no), educational level (lower yes/no), employment status (paid employment yes/no, regardless of the number of hours),

and problems with addiction (yes/no) and problems in the living situation (independent yes/no). Furthermore, we used a HoNOS addendum item, 'motivation for treatment' (item 14; Mulder et al. 2004), as an individual-related factor.

Mental healthcare use

Data on admission days and the number of outpatient contacts were collected from the MHC administration database.

Data analysis

All analyses were carried out using SPSS version 22. Statistical tests were two-sided and performed at a significance level of $\leq .05$. Baseline characteristics of the young adults in the study and data on mental healthcare use were summarized using descriptive statistics. The HoNOS addendum item motivation for treatment was also used on a descriptive level in the analysis.

We compared individual characteristics over time with McNemar's tests, independent sample t-tests and one-way ANOVAs with Bonferroni corrections for multiple testing. Remission transition was also tested with McNemar's tests. For a subgroup of the participants, we also studied remission over time and compared remission outcomes from the last two measurements, with 6-18 months between measurements. These data were not available for the whole group. To study the relationships between the individual factors and SR and FR, estimated longitudinal correlations between generalized estimating equations (GEE) were used, so that each measurement of each individual was included. GEE models account for correlations between outcomes across time within the same individual and allow for specification of both time-varying and individual difference variables (Zeger and Liang 1986).

A factor analysis yielded no factor structure in the CANSAS, and thus no subscores for specific domains were used. Following the advice of Wennström et al. (2004) for analyses with the CANSAS, we used single items which give more interesting insight into the relationship between unmet needs and outcome. The changes between first (T0) and last measurement (T1) in single items were added as process predictors of SR and FR and following the method of Kortrijk et al. (2014), a classification of change on individual outcomes was made per CANSAS domain: (1) very poor: T0 unmet need & T1 unmet need on a particular CANSAS domain, (2) poor: T0 no unmet need & T1 unmet need, (3) good:

T0 unmet need & T1 no unmet need, (4) very good: T0 no unmet need & T1 no unmet need. To investigate the predictive value of the CANSAS items for SR and FR, bivariate Spearman correlation coefficients were used, and logistic regression analyses were performed. For the logistic regression, only care domains with a significant correlation with SR and/or FR and r_s >.30 were included.

RESULTS

Data were collected in a naturalistic cohort study, based on 910 measurements from 287 individuals. On average the participants in this study were monitored 3.2 (SD=1.37) times, with a mean of 27.3 months (SD=18.08) between the first and last measurement. Excluded participants (N=37) differed slightly from the response group. Included participants were slightly younger (mean age 22.1 vs. 23.7 years, t(322)= 2.55, p=.002), had fewer problems with motivation for treatment (0.9 vs 1.4, t(311)= 2.32, p=.021), and were rated higher by their clinicians in their total number of needs for care (8.9 vs, 6.6, t(313)= -3.09, p=.002) and specifically in the number of met needs for care (5.7 vs, 3.8, t(313)= -3.46, p=.001).

Sociodemographic and clinical characteristics of the individuals are summarized in Table 1. Multiple differences over time were found. First, the number of participants living with their parents or relatives declined from 52% to 40% whereas the number of participants living independently increased. Fewer participants were admitted to a psychiatric hospital. The mean scores on problems with motivation for treatment increased slightly over time. Differences in educational level were also found. A significant number of participants whose educational level was middle to high obtained higher education degrees during treatment. Lastly, the total number of needs for care and the number of met needs for care of the participants decreased during treatment, while the number of unmet needs did not change significantly.

MHC use and remission

The participants had an average number of 165.7 contacts (SD=155.18) with their healthcare professionals from the health program; six contacts (3.6 hours) per month with a mean of 36.1 minutes (SD=29.79) per contact. The percentage of the participants admitted to the inpatient facility fell from 11 to 6% between first and last measurement.

The mean number of contacts per month between first and last measurement was distributed unevenly over the service users. Participants in the lowest quartile of care utilization (up to 3.2 contacts per month per person) accounted for 8% of the total mean number of contacts per month, participants in the second quartile (3.2 to 5.3 contacts) 17%, participants in the third quartile (5.3 to 8.1 contacts) 27%, and in the highest quartile (over 8.1 contacts) 48%.

We used descriptive analysis to summarize the relationship between the number of outpatient contacts with their healthcare professional and remission outcome. 35% of the participants within the group with the fewest outpatient contacts were in remission during the last measurement (18% sustained their remission status from the first measurement and 17% achieved remission). Within the second and third quartiles, percentages of participants in remission were respectively 35% (13 sustained and 22% achieved) and 18% (6 sustained and 13% achieved). In the quartile with the highest care utilization, 16% reached remission, 10% of whom sustained remission, while 6% of the participants went from no remission at the first measurement to full remission at the last measurement.

Table 1. Sociodemographic and clinical characteristics at first (T0) and last measurement (T1; N=287).

Characteristics	T0		T1		
	N	%	N	%	p
Sex, male	221	77.0	-	-	-
Ethnicity, Western origin (N=281)	184	65.5	-	-	-
Educational level completed (N=276)					
- Low	41	14.9	41	14.9	1.00
- Middle	179	64.9	163	59.1	.002
- High	56	20.3	72	26.1	>.001
Mild to severe problems with addiction[1] (N=284)	53	18.7	62	22.6	.233
Main psychiatric diagnosis, non-affective psychotic disorder	254	88.5	-	-	-
Main psychiatric diagnosis, bipolar disorder	17	5.9	-	-	-
Main psychiatric diagnosis, other or postponed diagnoses	16	5.6		-	-
Employment status					
- Paid employment (including sheltered work, N=234)	36	15.3	42	17.9	.381
- Volunteering (N=232)	20	8.6	32	13.8	.090
- Student (N=242)	54	22.3	51	21.1	.791
- Not employed and not studying (N=247)	149	60.3	138	55.9	.229
Living conditions (N=268)					
- With parents or other relatives	139	51.9	106	39.6	>.001
- Independent (alone, with partner and/or children, with others)	62	23.1	83	31.0	.001
- Sheltered living	26	9.7	37	13.8	.027
- Supervised independent living	5	1.9	15	1.5	.002
- Admitted to psychiatric ward or hospital	29	10.8	17	6.3	.012
	M	SD	M	SD	p
Age in years	22.1	2.94	24.4	3.14	-
Treatment duration (in months)	10.1	12.48	38.0	19.83	-
Age of onset of psychotic symptoms (N=244)	19.6	3.26	-	-	-
Age of first contact with a healthcare provider (N=258)	18.9	4.05	-	-	-
Treatment motivation[2]	0.9	1.17	1.2	1.33	>.001
Psychosocial functioning total mean[3]	8.8	5.94	8.9	7.19	.705
Total number of needs for care (N=273)[4]	8.9	3.95	8.1	4.84	.003
Total number of met needs for care[4]	5.6	2.86	5.0	3.30	.009
Total number of unmet needs for care[4]	3.2	3.21	3.0	3.75	.322

[1]Measured with HoNOS (score >1).

[2]Measured with HoNOS (0 = no problems to 4 = severe to very severe problems).

[3]Measured with HoNOS (0 = no problems to 48 = maximum number of problems).

[4]Measured with CANSAS (0 = no needs to 25 = maximum number of needs).

Chapter 2

Remission transition between first and last measurement

The first measurement took place on average ten months after the start of the treatment (*SD*=12.48). Over one-fourth (27.5%) of the individuals were in partial remission (only in SR or only in FR) at the first measurement, 31.7% were in SR, 36.9% were in FR, 20.6% were in full remission, and 51.9% had no remission status (Figure 2). A significant transition for SR occurred between T0 and T1: 49% of the 114 individuals with SR during the last measurement had no SR at the first measurement (χ^2=.019). No other significant transitions were found. The baseline levels of SR and FR predict 24% (Nagelkerke's R square) of the variance in the level of full remission during T1 (SR 19%, *b*=1.40, Wald $\chi^2(1)$=20.32, *p*<.001; FR 6%, *b*=1.20, Wald $\chi^2(1)$=12.48, *p*<.001).

For 162 participants it was possible to investigate the maintenance of the remission status. For this, we compared remission outcome from the last two annual measurements. Over 70% maintained the same type of remission, which was 72% for SR and 75% for FR.
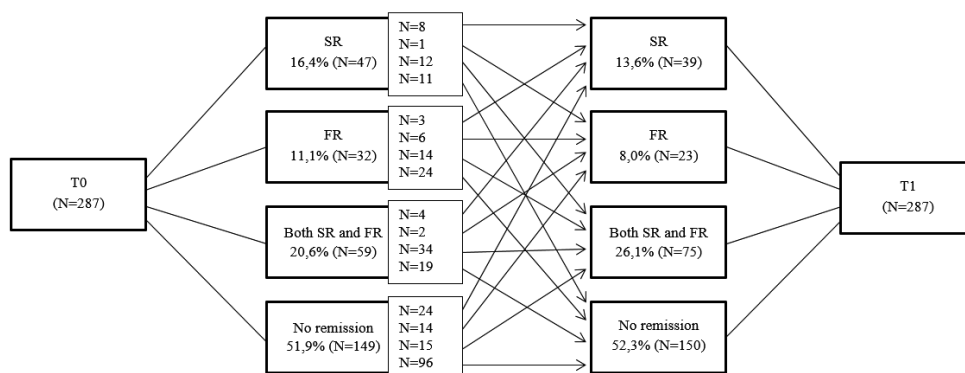
Figure 2. Remission transition between first measurement and follow-up.

Associations between individual characteristics and remission outcome

GEE analyses were performed on the sociodemographic data of all measurements between T0 and T1; the statistics are shown in Table 2. Participants living independently are over two times more likely to be in SR and/or FR (SR *OR*=5.73, *95% CI*=1.14 – 3.67, *p*=.017, FR *OR*=2.13, *95% CI*=1.25 – 3.61, *p*=.005). Having paid employment during treatment is also positively associated with both SR and FR and increases the chance of achievement by at

least more than two times (SR *OR*=6.90, *95% CI*=1.20 – 3.55, *p*=.009, FR *OR*=2.11, *95% CI*=1.02 – 4.36, *p*=.044). When problems with treatment motivation decrease, the chance of achieving both SR and FR increases by approximately .7 times (SR *OR*=.65, *95% CI*=.54 – .78, *p*<.001, FR *OR*=.66, *95% CI*=.55 – 79, *p*<.001).

More significant associations were found for FR. Participants who are male and of Western origin are also more likely to be in FR (male *OR*=2.17, *95%* CI=1.25 – 3.77, *p*=.006, Western origin *OR*=2.50, *95% CI*=1.12 – 5.60, *p*=.006). Furthermore, age is negatively associated with FR. As age increases, the chance of achieving FR declines approximately .9 times (*OR*=.89, *95%* CI=.81 – .99, *p*=.026).

Table 2. Generalized estimating equation (GEE) statistics for symptomatic and functional remission.

Variables	SR				FR			
	Coefficient	95% CI		OR	Coefficient	95% CI		OR
Sex, male	.29	.75	2.29	1.31	.77**	1.25	3.77	2.17
Age	-.06	.84	1.04	.94	-.11*	.81	.99	.89
Age of first psychotic episode	.06	.97	1.16	1.06	.04	.96	1.13	1.05
Western origin	.15	.64	2.12	1.16	.92*	1.12	5.60	2.50
Educational level, low	-.71	.20	1.20	.49	-.52	.31	1.13	.59
Life partner	.57	.93	3.37	1.77	-.44	.32	1.32	.65
Living independently	.72*	1.14	3.67	5.73	.75**	1.25	3.61	2.13
Paid employment	.73**	1.20	3.55	6.90	.75*	1.02	4.36	2.11
Problems with treatment motivation	-.43**	.54	.78	.65	-.42**	.55	.79	.66
Problems with addiction	-.48	.35	1.08	.62	-.30	.40	1.39	.75

* *p*<.05. ** *p*<.01.

Needs for care as predictors of remission

Using regression analysis, the relation between remission and the total number of met and unmet needs for care at the first measurement, and changes in needs for care (groups ranging from 1 very poor to 4 very good) at item level were tested (N=280). The total number of unmet needs for care significantly predicted 11% of the variation in SR (*b*= -.21, Wald $\chi^2(1)$= 20.29, *p*<.001) and 12% in FR (*b*=-.24, Wald $\chi^2(1)$=20.50, *p*<.001). The total number of met needs was not significantly related to remission outcome.

At specific item level, a positive change in unmet needs on the items company (b=.47, Wald $\chi^2(1)$=8.06, p<.005) and psychological distress (b=1.11, Wald $\chi^2(1)$=26.13, p<.001) were related to the achievement of SR (N=264), and together had a predictive variance of 35%. Changes in specific needs were also found to be of predictive value for FR (N=273). Fulfillment of needs for care in relation to psychological distress (b=1.12, Wald $\chi^2(1)$=21.82, p<.001) and daytime activities (b=.62, Wald $\chi^2(3)$=13.95, p<.001), are both positively associated with achieving FR. These two variables together predict 36% of the variance in FR.

DISCUSSION

This study yielded insights on SR and FR over time in a young adult population with a psychotic disorder in a specialized FACT team with a strong focus on psychiatric rehabilitation. The study shows that after a mean treatment duration of 27.3 months (SD=18.08), according to our predefined definition of remission, 26% of the participants achieved or remained in both SR and FR, 40% in SR and 34% in FR. A significant transition for SR occurred: 49% with no SR at the first measurement achieved SR. The population appeared also vulnerable to relapse; 36% relapsed from SR to no SR (p=.019).

Motivation for treatment, paid employment, independent living, and psychological distress are all associated with the achievement of SR as well as FR. Although there is much overlap between these contributing factors, small differences in the impact of participants' characteristics and fulfillment of the domains for care needs were found that specifically were associated with symptomatic outcome (fulfillment of needs for care in relation to psychological wellbeing and social goals) or functional outcome (sex, age, Western origin, fulfillment of needs for care in relation to psychological wellbeing and daytime activities).

The found remission rates differ from those in the study of Chang et al. (2012), in which only 17% of the individuals with a psychotic disorder were in both SR and FR during the last 12 months of a 3-year follow-up study. However, our results are in agreement with the study of Lee et al. (2014), which found a rate of 40% of full remission within individuals at clinical high risk for psychosis. Lim et al. (2016) even found 44% of a group of individuals with schizophrenia to be in SR after six months. In a study of Verma et al. (2012), higher remission rates were found; 54.1% of the individuals with first-episode psychosis were in SR

and 58.4% in FR after two years of treatment. Because of the different definitions of remission, comparisons should be interpreted cautiously. However, taken this together, different studies show a positive outcome on remission. Nevertheless, there is still much to be gained. This stresses the importance of finding factors which seem to be important to achieve remission.

The main question in this study was to find care factors that can be influenced by MHC workers in order to achieve SR and/or FR. The predictive value found for the change in unmet care needs in psychological distress and daytime activities for FR and psychological distress and company for SR is in line with several studies (Meesters et al. 2013; Ochoa et al. 2003; Van Wel and Landsheer 2012; Wiersma et al. 2009). Other studies (Chang et al. 2013) have also found that social-environmental factors have an important influence on recovery. Velthorst et al. (2010) state in this respect that disabilities in social domains might substantially contribute to the prediction of psychosis in individuals who are clinically at high risk. They found that individuals who made the transition to psychosis had greater difficulties at baseline in developing and maintaining friendships. In addition, Davis et al. (2013) found psychiatric distress to be significantly related to community activities and nonclinical recovery. Mental healthcare workers should pay attention to individual needs for care, specifically if there are unmet needs regarding psychological distress, daytime activities and social network. Because of the diversity of variables that correlate with achieving remission, it is recommended to view treatment from a multidisciplinary perspective that is focused on patient's rehabilitation goals concerning work, living, and social network.

Strengths and limitations

One of the strengths of this study is the longitudinal cohort design in which multiple measurements per individual were made for a robust number of participants (N=287) over a period of 18-36 months. The focus was on the CANSAS item scores rather than summary scores because this more properly reflects the change in needs (Wennström and Wiesel 2006), and therefore provides more specific information on treatment outcome.

Another strong point of our study is our strict definition of remission in functioning. FR was determined following Kortrijk et al. (2012), who studied individuals in ACT; in our study, using a cut-off score < 2 (no clinically relevant problems) versus ≤ 2 in the study of Kortrijk (slight clinically relevant problems): despite this stricter definition, remission rates were found to be slightly higher.

A limitation of the study is that SR was determined by three HoNOS items. This can be considered a lean definition compared to remission according to a larger number of BPRS or PANSS items, for instance (Andreasen et al. 2005; Caton et al. 2006; Kortrijk et al. 2012; Lasser et al. 2005). The use of the three items to measure FR is also debatable. There is no generally accepted definition of FR, and therefore there is still no official instrument for FR assessment. However, in the Netherlands, recently an instrument was developed for measuring FR that is easy to implement in regular ROM procedures (Wiersma et al. 2015; Swildens et al. 2018).

Another limitation regarding the remission criteria is the required time threshold of a period of six months of stable symptom severity. On average, measurements took place once a year as part of the ROM. Keeping in mind the remission transitions, in the most favorable condition we would need at least two yearly follow-up measurements per participant after the first measurement. However, with our available ROM-data, this would result in a large drop-out of individuals and a selection bias of those who stayed in care for a longer period. Nevertheless, it was found that over 70% of the participants who did participate in three or more measurements attained remission following the six-month time criterion. This remission criterion is relevant because participants tend to move in and out of remission over time (Eberhard et al. 2009; Emsley et al. 2011).

CONCLUSION

In conclusion, the founded associations confirm the importance of further research towards the influence of social functioning on symptomatic recovery. In order to facilitate rehabilitation, we recommend MHC services to regularly evaluate individuals' transitions in functional and symptomatic recovery and additionally assess their need for care to adjust the treatment to their specific needs that influence SR and FR.

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Chapter 2

Chapter 3

Is change over time in psychotic symptoms
related to social functioning?
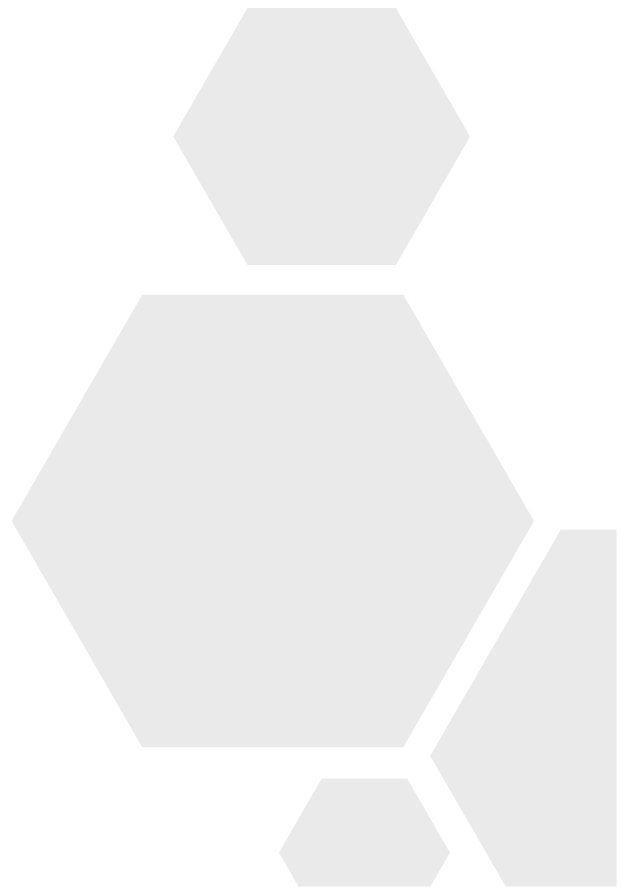
ABSTRACT

Objective

In psychosis, treatment often focuses on symptom reduction whereas social functioning is also essential. In this study, we investigate positive psychotic symptoms and medication use in relation to social functioning over a three-year time-period in patients diagnosed with psychosis. Furthermore, relations of positive symptoms with needs for care and quality of life were also investigated.

Method

Data from T1 and T2 from the GROUP project was used. Using repeated measures analysis, changes in psychotic symptom severity, social functioning, needs for care, and quality of life were measured over time in 531 patients. Hereafter, mixed model analyses were performed to determine the associations of social functioning, needs for care, and quality of life with psychotic symptoms and patient characteristics. Finally, we assessed differences in symptoms and medication dose between those with an increase and those with a decrease in social functioning.

Results

Patients significantly improved in social functioning, while psychotic symptoms increased. Although significant, the effect size of the association of positive symptoms with social functioning, needs for care, and quality of life, was relatively small compared to the control variables; sex, employment, use of antipsychotics (yes/no). Improvement in social functioning was associated with younger age, higher IQ, and lower social functioning at T1, but not with positive symptoms. Also, improvement in social functioning was found to be related to a decrease in the dose of clozapine.

Conclusions

Improvement in social functioning occurs despite worsening of positive symptoms. These findings suggest the need to further explore the relation between symptomatology, social functioning and medication use, as it is possible that the current focus to reduce clinical symptoms in psychiatry needs to shift much more towards improving functional outcome.

INTRODUCTION

Multiple studies suggest that the severity of psychotic symptoms is negatively related to overall functioning (Lee et al., 2019; Nevarres-Florez et al., 2019; Watson et al., 2018; Grau et al., 2016). In addition, both remission of negative symptoms and of positive symptoms were found to be contributors for better functioning in patients with a first-episode psychotic disorder (Jordan et al., 2014). This suggests that the course of the psychotic disorder and the patient's functional outcome is improved by decreasing clinical symptoms.

Social functioning in particular was found to be affected by negative symptoms (Gerritsen et al., 2020; Hasan, 2019; Stouten et al., 2017; Strassnig et al., 2018), but positive symptoms are also known to affect social functioning (Heering & Van Haren, 2016). Moreover, the use of antipsychotics can hamper social functioning because of its (long-term) side-effects on e.g. physical health and social inclusion (McGorry et al., 2013; Murray et al., 2016; Tenbac et al., 2012).

Besides symptom severity and medication use, several other factors are related to social functioning of patients with a psychotic disorder. It has widely been reported that an overall better social functioning is related to a decrease in number of hospital admissions, less outpatient visits, and more social engagement (Bellido-Zanin et al., 2015). Also, studies in early onset psychosis show that social functioning and patient's quality of life both improve despite the presence of psychotic symptoms (Albert et al., 2011, Garety et al., 2006). Interestingly, in 177 patients with chronic psychosis no relation between symptomatic remission and functional recovery was found by Oorschot et al. (2012), who therefore suggested that the main focus on symptomatic remission should be re-considered.

Thus, previous studies do not show a consistent relation between psychotic symptoms and social functioning. The aim of this research is to contribute to the enhancement of treatment in clinical practice. Treatment of psychotic disorders mainly focuses on positive symptoms. Therefore, the aim of the present study is to further investigate the relation between positive symptoms (i.e. hallucinations, delusions, thought disorder), antipsychotic medication and social functioning in a Dutch cohort of patients with a psychotic disorder, over a three-year period. Medication is prescribed mainly for positive symptoms. It is hypothesized that social improvement occurs despite the presence of persistently high positive symptoms. Also, a negative relation between social functioning and the use of antipsychotics is expected. Additionally, in order to be able to make statements about a

broader definition of functioning as well, associations of psychotic symptoms with quality of life and needs for care were investigated. Furthermore, clinical characteristics of patients who improved were compared to those of whom deteriorated in social functioning.

METHODS

Patient and data selection

This study uses a subsample of data from the Genetic Risk and Outcome of Psychosis (GROUP) study. GROUP is a naturalistic follow-up study in 1119 patients diagnosed within the psychotic spectrum, 1059 siblings, 920 parents and 586 unrelated control subjects. Measurements of the GROUP study were collected at baseline and at 3- and 6-year follow-up (T1 and T2). A detailed description of the study is available elsewhere (Korver et al., 2012).

For the current study, data from the 3- and 6-year follow-up were used, given that social functioning was not measured at T0. Patients were included if they were diagnosed with a psychotic disorder and if data regarding the severity of psychotic symptoms were available at both time points (N=531).

Measures

Severity of psychotic symptoms was measured by the Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987), which assesses the core symptoms of schizophrenia. The PANSS is a semi-structured interview whereby items are rated on a seven-point scale (1= absent to 7= extremely severe) over the past week. For this study, items that represent positive symptoms were included. Positive symptom items were grouped according to the 5-factor model as developed by Van der Gaag and colleagues (2006; delusions, hallucinations, unusual thought content, suspiciousness, grandiosity, somatic concern, lack of judgement and insight, active social avoidance, difficulty in abstraction; total score ranges from 9-63).

The level of social functioning was assessed by the Social Functioning Scale (Birchwood et al., 1990). The SFS consists of 76 items, assigned to the following seven subscales: social engagement/withdrawal, relationships, social activities, recreational activities, independence-competent, independence-performance, and employment/occupation. Four items are dichotomous questions, one item records the time of

getting up, one item is rated on a three-point Likert scale, two items are rated on a five-point Likert scale, and 68 items are rated on a four-point Likert scale (total score ranges from 55-135). A higher score indicates better social functioning.

Quality of life was measured with the WHOQOL-BREF (World Health Organization Quality of Life-Bref; Whoqol Group, 1998). This self-report scale assesses quality of life on four major domains (physical health, psychological health, social relationships, and environmental conditions). The total mean score was used (range 1-5). Higher scores indicate a higher perceived quality of life.

The Dutch 24-item version of the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS; Delespaul et al., 2008, Phelan et al., 1995) was used to assess individual needs for care. Each item was scored 0 (no need), 1 (met need) or 2 (unmet need). Higher scores indicate a higher need for care.

Furthermore, a number of demographic and clinical data were used: age, sex, ethnicity, educational level, employment status, IQ, global assessment of functioning (GAF; American Psychiatric Association, 2000), age of onset of first psychotic episode, duration of psychotic illness, number of psychotic episodes, diagnoses, and antipsychotic medication use.

Statistical analyses

Release 6.0 of the GROUP database was used for the analyses, and all data were analyzed with IBM SPSS Statistics 22. Data from two measuring points were used, 3 (T1) and 6 (T2) years after entering the GROUP study. First, using repeated measures ANOVA, scores over time were compared for positive symptoms, social functioning, needs for care, and quality of life, while controlling for T1. Hereafter, the relation of psychotic symptoms with social functioning, needs for care and quality of life and was analyzed by mixed model analyses with the positive symptom score as predictor variable and subject identifier as random and patient characteristics as fixed effects (sex male/female, employment yes/no, using antipsychotics yes/no), as previous studies suggest these factors are related to functioning (Jaracz et al., 2007; Schennach et al., 2012; Valencia et al., 2015).

Finally, based on the change in total scores over time, subjects were divided into two groups, those with an increase and those with a decrease in social functioning. One patient was excluded, since equal scores for social functioning for T1 and T2 were reported. Patient characteristics were compared to investigate if these differed between groups. In

addition, change in social functioning (decrease or increase) was investigated in relation to the dose of antipsychotics. For analyses regarding the specific type and dose of antipsychotics, only the top four most prescribed antipsychotics for patients in this study were used (risperidone, olanzapine, quetiapine, clozapine). Independent T-Tests were performed for comparing continuous variables, chi-square tests were performed for dichotomous variables.

RESULTS

Patient characteristics

Five hundred and thirty-one patients of T1 were included in the study, of which 77% were male with a mean age of 30.7 (SD=7.3) years old, and an IQ of 99.8 (SD=16.3). Mean illness duration was 8.3 (SD=4.2) years, with the onset of the first psychosis at the age of 22.6 (SD=6.7). The results are shown in Table 1.

Table 1. Demographics and clinical characteristics and functional outcome after three (T1) and six years (T2) of the GROUP study (N=531).

	N	%	Mean T1	SD	Mean T2	SD	p[b]
Age			30.7	7.25			
Sex, male	407	76.6					
Ethnicity (N=524)							
– Caucasian	453	85.3					
– Mixed	39	7.3					
– Other	32	6.0					
Number of patients with psychiatric hospitalizations in the past three years (N=465)	147	27.7					
IQ (N=511)			99.8	16.25			
Main diagnosis							
– Schizophrenia	300	56.5					
– Schizo-affective disorder	75	14.1					
– Other psychotic disorder	62	11.7					
– Other / unknown	94	17.7					
Age of onset first psychosis			22.55	6.73			

	N	%					
Mental illness duration in years (N=398)			8.34	4.22			
Paid employment							
– None	119	22.4					
– Voluntary	106	20.0					
– Paid	179	33.7					
– Mixed	62	11.7					
– Unknown	65	12.2					
Highest education degree							
– No school / primary	32	6.0					
– Secondary	140	26.4					
– Highschool	38	26.0					
– Vocational	181	34.1					
– University	40	7.5					
– Unknown	100	18.8					
Total PANSS score (N=521)			45.8	13.14	47.0	15.90	.038
– Positive symptoms (N=531)			14.6	5.74	15.6	7.06	<.001
– Negative symptoms (N=523)			11.4	4.82	11.5	5.50	.616
– Disorganization (N=523)			14.0	4.81	14.6	5.86	<.001
– Excitement (N=526)			10.5	2.92	10.8	3.50	.033
– Emotional distress (N=526)			13.3	4.92	13.4	5.16	.716
Social functioning (N=476)			113.0	9.46	114.0	9.05	<.001
Quality of life (N=474)			3.7	.92	3.8	.92	.253
Need for care (N=515)			5.5	3.72	5.2	3.62	.021
Medication top four, mean dose (oral, N=289)[a]							
- Risperidone	41	8.4	2.9	2.20	2.8	2.25	.937
- Olanzapine	72	14.7	12.5	7.85	12.8	12.20	.804
- Quetiapine	27	5.5	368.7	214.28	405.0	265.12	.284
- Clozapine	46	9.2	338.1	175.05	306.6	173.53	.073

[a]Participants included with the same type of medication at T1 and T2

[b]Repeated measure comparisons

Clinical and functional differences between T1 and T2

Psychotic symptoms, social functioning, needs for care, and quality of life were compared for T1 and T2. As shown in Table 1, patients experience significant more overall psychotic symptoms, positive symptoms, disorganization, and excitement at T2 compared to T1.

In contrary to the worsening of psychotic symptoms, a small but significant improvement was found in social functioning. In particular, better functioning was found for the subscales employment/occupation (mean difference=2.6, *SD*=11.9, *p*<.001), social engagement/withdrawal (mean difference=1.1, *SD*=10.4, *p*=.026), recreation (mean difference=1.89, SD=13.0, *p*=.002), and independence-performance (mean difference=1.9, SD=9.64, *p*<.001).

The total number of needs for care decreased (mean difference=.3, *SD*=3.8, *p*=.021). However, unmet needs increased. At T2, more unmet needs were reported for psychotic symptoms (χ^2=53.1, *p*<.001), medication side effects (χ^2=21.4, *p*=.042), and personal hygiene (χ^2=28.4, *p*<.001).

Use of antipsychotics

A large group of the patients (93%) used antipsychotics prior to inclusion; 7% of the patients did not use antipsychotic medication or medication use was unknown. Most patients used risperidone (32.7%), olanzapine (30.4%), clozapine (11.8%), or quetiapine (10.5%), primarily in oral form (N=392). Depot medication was used by 45 (9.1%) patients. Of all patients, 446 used medication at T1 and T2, of which 289 used the same medication at both time-points. Although no significant differences were found regarding the medication dose between T1 and T2 (T1: *M*=125.6, *SD*=196.2, T2: *M*=123.3, *SD*=202.8, N=213, *p*=.685), or medication type, a trend was found for a decrease in clozapine dose. Results of the top four medication used are shown in Table 1.

Relation between positive symptoms functional outcome

In the mixed model analyses, while controlling for sex, employment, and use of antipsychotics, positive symptoms (based on the PANSS) were significantly associated with social functioning, needs for care and quality of life. Nevertheless, the control variables were also significantly associated with the social outcome measures (see Table 2 for all results).

Compared to the control variables, the association between positive symptoms and social functioning is relatively small. For example, having employment at T1, is associated

with a higher social functioning score of approximately two points (a change of 2.5% on the SFS-scale). In our sample, 241 (50.6%) patients had voluntarily or paid employment during both time points, and another 98 patients obtained employment (information on social functioning was missing for 81 patients). However, a higher social functioning score of two points is associated with a decrease in positive symptoms of about six points, which equals a change of 10.7% of the positive symptom scale of the PANSS. In our sample, this change was seen only in 7.8% of the patients. Furthermore, a change of 25 points (44.6%) in the positive symptom scale is associated with improving quality of life by one point. In our sample, this was only the case for one patient. Thus, considering the small association, a large improvement in psychotic symptoms is needed for a change in functional outcome.

Table 2. Association of positive symptoms and patient characteristics with functional outcome.

Independent variables	Estimate	SE	t	p	95% CI	
Social functioning (N=476)					*Lower*	*Upper*
Positive symptoms	-.359	.042	-8.505	<.001	-.44	-.28
Sex, male	-2.493	.808	-3.093	.002	-4.08	-.91
Employment, yes	2.034	.463	4.390	<.001	1.12	2.94
Antipsychotics, yes	-2.463	.772	-3.188	.001	-3.98	-.95
Needs for care (N=515)					*Lower*	*Upper*
Positive symptoms	.215	.017	12.730	<.001	.18	.25
Sex, male	.349	.261	1.336	.182	-.16	.86
Employment, yes	-.628	.213	-2.949	.003	-.105	-.21
Antipsychotics, yes	1.419	.236	6.000	<.001	.95	1.88
Quality of life (N=474)					*Lower*	*Upper*
Positive symptoms	-.042	.005	-8.742	<.001	-.05	-.03
Sex, male	-.087	.075	-1.161	.246	-.23	.06
Employment, yes	.124	.059	2.101	.036	.01	.24
Antipsychotics, yes	-.088	.096	-.918	.359	-.28	.10

Social functioning, improvement versus deterioration

Based on change in social functioning between T1 and T2, patients were divided into two groups: those who improved (N=205) and those who deteriorated (N=207). Comparisons were made for the following variables at T1: age, sex, ethnicity, IQ, illness duration, GAF, positive symptoms, and use of antipsychotics, all factors known to influence social

functioning. Improvement in social functioning was observed in 57% of the patients. Those who improved showed a lower mean score (M=110.8, *SD*=9.7) in social functioning at inclusion compared to those who deteriorated (M=115.9, *SD*=8.4; *t*(473)=-5.974), *p*<.001). Also, they were younger and had a higher IQ compared to those who did not improve.

Change in social functioning was not related to the use of antipsychotic medication, the cumulative dose of medication at T1, or an increase or reduction in medication over time (see Table 3 for all outcomes). However, patients who improved in social functioning had a lower prescribed dose of clozapine over time (N=24; T1 M=368.8, *SD*=178.50; T2 M=320.8, *SD*=190.35, *p*=.040). No differences over time were found for change in social functioning in relation to the other types of antipsychotics.

Table 3. Demographic variables at T1 and change in social functioning (deteriorated vs. improved).

Deteriorated group				Improved group				
	N	Mean	SD	N	Mean	SD	χ^2	p
Age	207	31.6	7.23	205	30.1	7.37		.032
Sex, male (N=356)	152			204			.123	.726
Ethnicity (N=469)								
- Caucasian	180			229			.342	.559
- Mixed	16			19			.076	.783
- Other	8			17			1.420	.233
IQ (N=459)	258	97.8	15.30	201	101.1	16.69		.028
Mental illness duration in years (N=458)	257	8.5	4.68	201	8.2	3.62		.483
GAF (N=399)	234	63.1	14.92	165	62.4	14.65		.600
Positive symptoms	270	14.6	5.72	205	14.5	5.82		.867
Medication, mean dose[a]	119	103.5	199.74	156	121.6	193.84		.449
Medication increase, mean dose[a]	54	43.2	98.16	58	70.6	153.99		.268
Medication reduction, mean dose[a]	35	160.5	252.06	49	184.5	219.64		.644
Medication, mean dose (top 4)[a]								
- Risperidone	16	3.7	2.85	23	2.4	1.47		.080
- Olanzapine	28	10.8	6.68	35	13.3	1.30		1.85
- Quetiapine	11	332.3	252.95	14	392.9	185.90		.496
- Clozapine	16	298.0	166.26	24	368.8	178.50		.215

[a] Participants included with oral medication at T1 and T2

DISCUSSION

This present study shows that the contribution of positive symptoms is limited in relation to social functioning, needs for care and quality of life. Patients experienced more positive symptoms over time, whereas social functioning slightly improved, and quality of life and needs for care did not significantly change. Moreover, patients whose social functioning improved were taking a lower dose of clozapine over time. These findings suggest the need to further explore the relation between symptomatology, social functioning and medication use, as it is possible that the current focus to reduce clinical symptoms in psychiatry needs to shift much more towards improving functional outcome.

Our findings are consistent with studies in which no clear association between positive symptoms and social functioning was found (Albert et al., 2011; Cacciotti-Saija et al., 2018; Carrión et al., 2013; Oorschot et al., 2012). In addition, a likewise association was also found in a previous study with the GROUP data (Simons et al., 2016), which explored the relation between the positive symptom score at baseline and social functioning at T1 (B=-2.97, 95% CI=-3.86 - -2.080, *p*<.01). Furthermore, in the present study the found associations were relatively weak compared to employment (yes/no), sex, and use of antipsychotics (yes/no), which are also known to affect social functioning. The inconsistencies with studies that report a strong relation between social functioning and psychotic symptoms (Erol et al., 2009; Startup et al., 2010) could be explained by the use of different rating scales, research designs, duration of psychosis, and a shorter follow-up period (6-24 months).

The finding that positive symptoms increase over time is also found in a study of Górna and colleagues (2014). They found that psychotic symptoms decreased after 13 months but increased at follow-up eight years later. The increase of psychotic symptoms in chronic patients could be explained by patients being less well monitored and treated by mental healthcare providers over time as compared to an acute phase of the disease, but also by the progressive nature of the disease (Van Haren et al., 2016). Moreover, clinicians and patients might look for an optimum balance between effects and side-effects of medication in order to prevent medication discontinuation.

In our study, we found better social functioning with less clozapine over time, but with increasing psychotic symptoms. These findings need to be interpreted with care, but others have also suggested that functional outcome is better with less medication. Wunderink et al. (2013) were the first to report that after dose reduction/discontinuation of antipsychotics

in a 7-year follow-up study social functioning improved. Also, dosages of antipsychotic medication that are used for the maintenance treatment of psychotic disorders may be too high, as suggested by the findings of Read and Sacia (2020). They found that 57.5% of 650 users of antipsychotics had only negative experiences using medication. This was mainly caused by the side effects. To gain more insight into the effects of antipsychotics on personal and social functioning, psychotic symptom severity, and health-related quality of life, the HAMLETT study has been set up (Begemann et al., 2020). Hopefully, this study will shed more light on the relation between social functioning, symptomatology, and medication continuation and dose. An explanation for not finding relations with other antipsychotics in the current study may be caused by a lack of power. Also, medication side effects may be of interest here, since clozapine has more serious side effects that interfere with social functioning (De Berardis et al., 2018; McEvoy et al., 2006).

Furthermore, we examined if clinical characteristics differed between patients who improved compared to those who deteriorated in social functioning. Fifty-seven percent of the patients improved in social functioning. This was related to worse social functioning at inclusion, younger age, and higher IQ at baseline and in line with other studies that found younger age was associated with better outcome in social functioning in patients with schizophrenia (Martin et al., 2015), and higher IQ associated with better social functioning through time (Leeson et al., 2009). Also, no relation was found for improved/deteriorated social functioning and change in the positive symptoms scale.

In this present study, we did not find a relation of social functioning with illness duration, sex, ethnicity, GAF and medication dose. Although associations between GAF and SFS are found in previous research, the SFS measures different aspects of social functioning and is less influenced by clinical symptoms (Hellvin, et al., 2010). Contrary to other studies (Thorup et al., 2007; Vila-Rodriguez et al., 2011), we found no differences in sex. This may be caused by differences in populations. In our subjects, men are in the vast majority (77%). The same accounts for ethnicity, where 87% of the patients are Caucasian. Also, we found no differences in dose of antipsychotics, but this can again be explained by limited power.

Strengths and limitations

This study has several strengths and limitations. The main strength is the use of a large verified longitudinal dataset with extensive phenotyping. Data from a large number of patients were available over a three-year time period. By using the mixed model method,

within each patient, it was possible to account for the variation over time and missing data. Another strength is the use of the positive symptom category according to the 5-factor model (Van der Gaag et al., 2006). Five-factor models are thought to be more representative of the syndromes than the original subscales of the PANSS (Jerrell et al., 2013). Thus, by using the positive symptom scale following the 5-factormodel, we can assume that we measured what we intended to measure – i.e. psychotic symptoms.

There are also some limitations. First, not all measures were obtained at enrollment in the GROUP project and therefore this present study could not examine the relation between psychotic symptoms and functional outcome between T0 and T1. Measures obtained at the start of the GROUP project would have provided additional information on the change in social functioning and the associations with psychotic symptoms, in particular during the early course of the disease. Second, patients had a relatively high IQ, which could represent a selection bias with patients with a lower IQ dropping out during the follow-up of the GROUP project. However, previous research with data from the GROUP project found a relatively high estimated IQ of 94.9 at baseline (Meijer et al., 2012), indicating that the overall level of intelligence was relatively high from the start. Third, a relatively small number of data was available regarding the type and dose of antipsychotics. Although medication use (yes/no) at T1 and T2 was known for 84% of the patients type and dose of medication was only known in 55% of the cases. Nevertheless, to our knowledge, this is the first study that has examined the relation between clozapine dose reduction and social functioning.

CONCLUSIONS

Positive symptoms were associated with social functioning. However, this effect was relatively small and improvement in social functioning occurred despite a worsening of positive symptoms. This suggests that a reduction of positive symptoms is only partly related to social functioning, and that optimizing medication (effects versus side-effects) is needed to find the right balance between the two. In mental healthcare one should reconsider whether a strong focus on symptom reduction warrants the attention it gets in daily practice. Further research is needed to examine the use, type and dosage of antipsychotics and its relationship with symptomatology and social functioning.

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Chapter 3

Chapter 4

Regional healthcare vignettes: Differences in care needs and psychosocial functioning

ABSTRACT

Background

Severe mental illnesses (SMI) are associated with high mental healthcare and other healthcare costs. In 2012, mental healthcare vignettes were developed to create more transparency to improve the discussions between insurance companies, municipalities, and mental healthcare providers. The vignettes are based on care intensity and should provide a regional overview of the present groups of patients with SMI. The goal of this present study was to explore the functionality and validity of the used vignettes in relation to needs for care and psychosocial functioning.

Method

ROM-data (needs for care, functioning) from 706 patients were tested per vignette by Chi-square tests and ANOVA's. For the high complex vignettes (mental healthcare avoiders and persons with high risk of being a risk to themselves or others), repeated measures ANOVA's and McNemar tests were used for analyzing changes in functioning and needs over time.

Results

To a limited extent, the vignettes are able to distinguish between the different care needs and functioning of patient groups. The most restrictions in functioning and (unfulfilled) needs are present in the vignettes 'mental healthcare avoiders' and 'stabilization and averting danger'. These findings are stable over time.

Conclusions

Using ROM-data, this study shows that the healthcare vignettes are insufficiently distinctive, except for 'mental healthcare avoider' and 'stabilization and averting danger' vignettes. To enhance regional care planning, it is desirable to combine existing information about healthcare vignettes with care needs and functioning.

INTRODUCTION

The regional organization of the mental healthcare sector aimed at people with serious mental illness (SMI) has been developing strongly in recent years. The care offered to this group must be offered less in institutions and more in society from a differentiated field of ambulatory facilities (GGZ Nederland 2009, 2013; Project Group Action Plan for Serious Psychological Disorders 2014).

Various care models emerge from the literature in order to achieve a good allocation of resources, but their applicability to people with SMI is limited. This is because the course of the needed and given care is difficult to predict (Self et al. 2008). According to research, care pathways contribute to improving the quality of care and cost-effectiveness (Panella et al. 2003; Vanhaecht et al. 2009).

In the Netherlands, In Utrecht, a study was carried out in 2010 by organizational consultancy Plexus together with care providers from Altrecht Mental Healthcare to design care vignettes for the group of patients with SMI. The vignettes were based on a decision tree and treatment and rehabilitation needs estimated by the care providers. This turned out not to fit well with information from ROM-data, such as care needs (Camberwell Assessment of Need Short Appraisal Schedule; CANSAS), limitations in psychosocial functioning (Health of the Nation Outcome Scales; HoNOS), or the number of contact hours for treatment and rehabilitation (Kwakernaak et al. 2014).

In 2012, the project was continued with a partnership between Altrecht Mental Healthcare, mental healthcare residential assistance RIBW Kwintes and RIBW Lister, and addiction care Victas/Arkin, supported by KPMG Plexus and Achmea/Zilveren Kruis. A year later, the initiators of Altrecht and Kwintes presented a new model (de Jong & van Zuthem 2013). The classification was based on the nature of the care consumption (outpatient/inpatient setting) and care intensity (number of minutes) in the previous year (Altrecht et al. 2013; see Appendix 1 for the criteria). This categorized certain groups in order to distinguish the caseload of the institutions involved and, on that basis, to coordinate the allocation of staff and resources.

Commissioned by G4-User (academic workshop for Public Mental Healthcare, PMHC), earlier research was carried out into the question of how the vignettes could be distinguished on the basis of ROM results. A second question that raised was whether the demand for care and the supply of care by the PMHC vignettes could be distinguished

(Swildens & Theunissen 2014; Swildens et al. 2014). The conclusion was that the PMHC vignettes can be easily distinguished in terms of ROM outcomes such as care needs and limitations in functioning.

Following on from this study, this article focuses on the question whether the classification of patients with SMI in care vignettes can be related to patient characteristics, care needs and the level of psychosocial functioning (ROM-data). The vignettes 'mental healthcare avoider' and 'stabilization and averting danger' are specifically discussed. It is expected that in particular these groups will require a higher care intensity. Therefore, a different care planning and coordination is needed. It is then investigated whether the differences remain stable over time.

METHODS

Data collection and inclusion criteria

Data on the healthcare vignettes were obtained in 2012 via the Regional Working Group SMI-Utrecht. Mental healthcare institutions, RIBW and addiction care combined their data on healthcare use in the previous year via a trusted third party. Based on the intensity of care use, an individual care vignette for each patient was drawn up (Altrecht et al. 2013). The model contains the following vignettes: mental healthcare avoider, stable balance, promoting participation, recovery and consolidation, stabilization and recovery, stabilization and averting danger, SMI residential care, SMI severe residential care, and SMI clinic (see Figure 1). The vignettes 'mental healthcare avoider' and 'stabilization and averting danger' belong to the so-called PMHC vignettes.

No need for care	• No care
0. Mental healthcare avoiders	• Assertive outreaching care through untenable situations involving nuisance or social isolation, in many cases also involving comorbidity, addiction and/or homelessness.
1. Stable balance	• Medical care by outpatient general practitioner to maintain a stable balance. Often also welfare care. Maintaining the level of participation.
2. Participation promotion	• Medical care provided by an outpatient general practitioner and some outpatient guidance from mental healthcare. Emphasis on recovery and participation (especially work rehabilitation).
3. Recovery and consolidation	• Bringing medical care from specialized care to general treatment. Bring outpatient counselling from (F)ACT to mental health residential assistence and general practitioner. Emphasis on restoration and consolidation of stability.
4. Stabilization and recovery	• Specialized outpatient treatment (psychiatry/addiction), with supervision if there is reason to promote participation. Care aimed at further stabilization and recovery by means of treatment. Directed by a specialized outpatient care provider.
5. Stabilization and averting danger	• Specialized outpatient treatment (psychiatry/addiction) aimed at stabilization, because of the crisis situation and the seriousness and complexity of the problem. Directed by a specialized outpatient care provider.
6. SMI residential care	• Stay in a setting of protected residences, and outpatient treatment by a general practitioner.
7. SMI severe residential care	• Stay in a setting of protected residences, and specialist outpatient treatment (not from a general practitioner).
8. SMI clinic	• Integral clinical treatment is necessary to avert the omnipresent risk of danger, serious nuisance and/or neglect, to halt deterioration and to enable prospects for development.

Figure 1. Overview of care vignettes, based on the existing overview of vignettes (Altrecht et al. 2013).

ROM-data on patient characteristics, use of mental healthcare, care needs and psychosocial functioning were obtained with the Utrechtse Zorgmonitor. For patients with the vignettes 'stable balance', 'SMI residential care' and 'SMI clinic', ROM-data were collected by other parties than the Zorgmonitor, which were not available to us and therefore could not be included into this present study. Thus, only ROM-data from the Zorgmonitor and data from the Altrecht healthcare administration were used. Permission was obtained from the Altrecht Research Committee.

Data were available for 1,280 patients with an allocated care vignette. Measurements before and after the vignette allocation were selected in a time frame of 12 months (with an intermediate margin of at least 6 months). 706 patients with both a valid measurement of functioning and care needs remained (see Figure 2). All included patients received (F)ACT care.

Patients with a care vignette (N=1280)

HoNOS at baseline and follow-up (N=1259)

CANSAS at at baseline and follow-up (N=706)

Overview of the care vignettes
1) Mental healthcare avoiders (N=154)
2) Participation promotion (N=52)
3) Recovery and consolidation (N=94)
4) Stabilization and recovery (N=190)
5) Stabilization and averting danger (N=157)
6) SMI severe residential care (N=59)
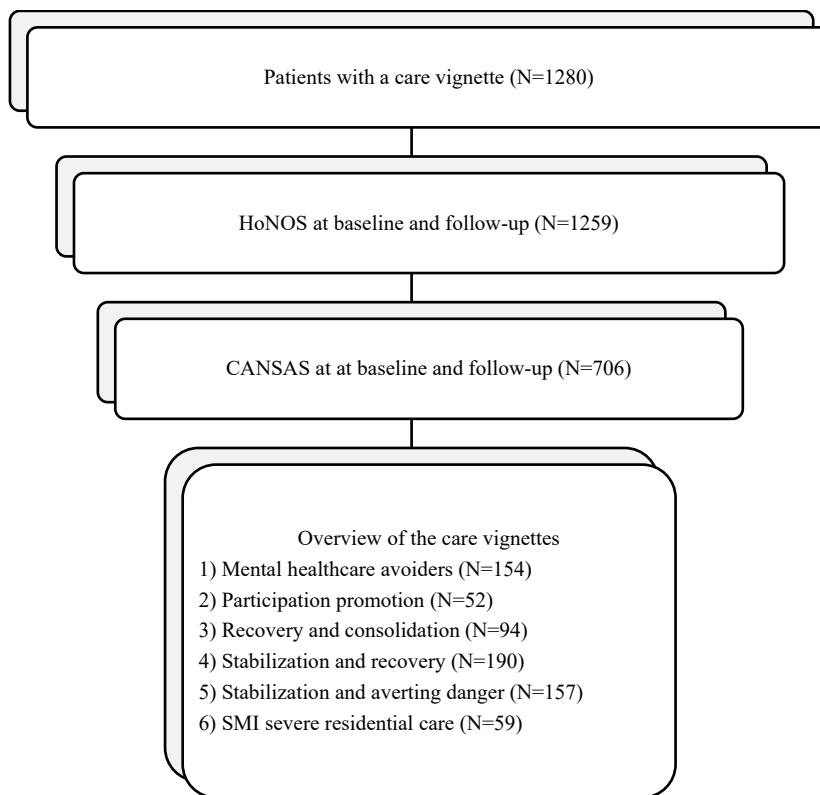
Figure 2. Inclusion per care vignette.

Patient characteristics

Examined patient characteristics are: sex, age, Western migration origin (yes/no), life partner (yes/no), educational level (low/high), voluntary or paid work (yes/no), housing situation, psychiatric main diagnosis (psychotic disorder/other diagnoses), legal status (voluntary yes/no), age of first contact with mental healthcare and age of first psychotic symptoms.

Psychosocial functioning

Psychosocial functioning was measured with the HoNOS (Wing et al. 1998; Mulder et al. 2004). For this study, separate serious to very serious problems (scores 3 and 4) in the item alcohol and drug use were also analyzed, as well as two items from the HoNOS addendum: motivation for the treatment and medication compliance.

The HoNOS items about psychiatric symptoms (hallucinations and delusions, depressive mood and other psychological and behavioral problems) were used to determine symptomatic remission (all item scores < 2). Functional remission has been determined with the items social contacts, ADL activities, and living conditions (all item scores < 2; based on Kortrijk et al. 2012).

Care needs

The CANSAS (Slade et al. 1999) with 25 items (Delespaul et al. 2008) is filled in from a social worker's perspective and is used to map out fulfilled and unfulfilled care needs in various areas of life. The items can be divided into various conceptual domains (Swildens et al. 2003): ADL (housekeeping, nutrition, self-care), mental health (physical health, psychotic symptoms, information, mental discomfort, safety for the person himself, safety for others, side effects of the medication, alcohol, drugs), rehabilitation (home, daytime activities, company, intimate relationships, perception of sexuality, care for children, paid work, recovery), and facilities (education, telephone, transport, money, benefits).

Data analysis

For baseline comparisons, characteristics of the patient groups within the six present vignettes were analyzed. The patient groups within the vignettes 'mental healthcare avoider' and 'stabilization and averting danger' were the main focus of the comparisons on the post measurement.

Differences in patient characteristics, numbers of contact within mental healthcare, functioning and care needs between the care vignettes were tested with Pearson's Chi square ($\chi 2$) and one-way ANOVA's, with Bonferroni corrections, both before and after the vignette allocation. Subsequently, for each vignette, averages of care needs and psychosocial functioning were compared with one-way repeated measures ANOVA's at both measurement points. For the dichotomous data, the same was done with McNemar's analyses. Two-tailed tests were performed ($p \leq .05$).

RESULTS

Included patients (N=706) differ from the excluded patient group (N=553) on age, diagnosis, ethnicity, education and number of hospitalizations. They are younger (on average 41 (SD=10.96) vs 43 years (SD=9.7), t=4.53, df=1257, $p<.01$), more often have a psychotic disorder (84% vs 67%, N=403, χ^2=45.062, $p<.01$), less often have a migration background (72% vs 79%, χ^2=8.465, $p<.01$)', and are relatively highly educated (primary education 24% vs 32%, N=296, χ^2=5.031, $p<.05$). Within the past year, they were also more often admitted to a psychiatric hospital (27% vs. 22%, χ^2=4.690, $p<.05$).

Baseline characteristics
Comparison of patient characteristics reveals significant differences (see Table 1). Within the care vignettes 'mental healthcare avoider' (column 1) and 'stabilization and averting danger' (column 5), 80% and 71%, respectively, are male. Within the other vignettes this varies between 59% and 62%. Patients in the vignette 'stabilization and averting danger' are relatively young at an average age of 37 years, compared to patients in the vignettes 'mental healthcare avoider' (M=42.1, $p<.05$), 'promoting participation' (M=43.5, $p<.01$), 'recovery and consolidation' (M=45.2, $p<.01$), and 'SMI severe residential care' (M=41.4, $p<.05$). They also have to deal with mental healthcare and the development of psychotic symptoms at a younger age, compared to patients within the vignette 'recovery and consolidation' ($p<.01$, $p<.05$). Within 'SMI severe residential care', patients also have to deal with psychotic symptoms at a younger age compared to 'recovery and consolidation' ($p<.05$). The main diagnosis of a psychotic disorder is the least common in patients within the vignettes ' mental healthcare avoider' and 'SMI severe residential care'. Of the patients with the vignette

'stabilization and averting danger', 32% had a legal measure in the past year (RM/IBS). For the other vignettes, this varies between 4% and 15%. It is also seen that within the vignettes, 'mental healthcare avoider' and 'stabilization and averting danger', the least number of patients are in symptomatic and functional remission, and they are more often confronted with severe to very severe problems with alcohol and drug use, motivation, and medication compliance.

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Table 1. Baseline characteristics prior to the vignette allocation (N=706).

Vignette[1]	1 (N=154)		2 (N=52)		3 (N=94)		4 (N=190)		5 (N=157)		6 (N=59)		Total (N=706)		Significance
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	
Sex, male	123	79.9	32	61.5	55	58.5	117	61.6	112	71.3	37	62.7	476	67.4	**χ^2=19.728
Western background(first and second generation)	102	66.2	38	73.1	65	69.1	136	71.6	115	73.2	50	84.7	506	71.7	n.s.
Main diagnosis psychotic disorder	118	76.6	47	90.4	88	93.6	162	85.3	128	82.8	45	76.3	590	83.6	**χ^2=16.834
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	
Age	42.1	10.03	43.5	10.07	45.2	8.19	39.1	11.35	36.5	11.19	41.4	11.43	40.7	10.96	**5<1,2,3; 4<3; *5<6; 4<1
Age of first MHC contact (N=631)	26.1	9.95	26.1	9.23	28.6	9.04	26.6	9.73	23.5	8.36	23.9	11.17	25.8	9.61	**5<3
Age of first psychotic complaints (N=554)	26.0	10.07	25.4	8.31	29.1	8.98	25.5	9.26	24.7	8.64	23.7	9.22	25.8	9.25	*5,7<3
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	
Life partner, yes (N=350)	8	16.3	7	24.1	18	36.0	28	25.9	15	21.5	7	15.9	83	23.7	n.s.
Education level (N=321)															n.s.
Low	15	35.7	7	26.9	6	13.3	24	24.2	13	19.7	13	30.2	78	24.3	
Middle	14	33.3	13	50.0	20	44.4	51	51.5	33	50.0	21	48.8	152	47.4	
High	7	16.7	6	23.1	14	31.1	18	18.2	16	24.2	7	16.3	68	21.2	
Employment															
Paid employment (N=371)	10	16.7	6	20.7	7	14.0	19	16.7	10	13.7	4	8.9	56	15.1	n.s.
Voluntary employment (N=365)	10	17.5	7	24.1	16	32.7	32	28.3	8	11.1	13	28.9	86	23.6	*χ^2=11.73
Living situation (N=300)															
With parents or other relatives	5	11.4	3	13.0	2	4.4	22	21.8	9	15.8	2	6.7	43	14.3	n.s.
Independent	26	59.1	19	82.6	38	84.4	77	76.2	20	35.1	-	-	180	60.0	**χ^2=86.95
Assisted	-	-	-	-	-	-	-	-	-	-	1	3.3	1	0.3	n.s.
Protected	6	13.6	-	-	3	6.7	-	-	10	17.5	27	90.0	46	15.3	**χ^2=154.21

	N	%	N	%	N	%	N	%	N	%	N	%	N	%	
Psychiatric admission in 2011 (N =705)	21	13.6	2	3.8	4	4.3	21	11.1	128	82.1	13	22.0	189	26.8	**X^2=19.31
Legal measure, voluntary (N n=676)	129	87.2	49	96.1	85	95.5	162	89.5	102	68.0	53	93.0	580	85.8	**X^2=54.98
Alcohol and/or drug use % severe problems	38	24.7	5	9.6	4	4.3	11	5.8	35	22.3	5	8.5	98	13.9	**X^2=44.25
Motivation % severe problemen	33	21.4	2	3.8	5	5.3	12	6.3	31	19.7	4	6.8	87	12.3	**X^2=35.57
Medication compliance % severe problemen	15	9.7	2	3.8	0	0.0	8	4.2	23	14.6	2	3.4	50	7.1	**X^2=26.91

[1]= Mental healthcare avoiders, 2= Participation promotion, 3= Recovery and consolidation, 4= Stabilization and recovery, 5= Stabilization and averting danger, 6= SMI severe residential care, *$p<.05$, **$p<.01$

Chapter 4

Functioning and care needs

Prior to the allocation of the vignettes, patients with the vignettes 'mental healthcare avoider' and 'stabilization and averting danger' had an average of respectively 12.6 (SD=6.79) and 11.7 (SD=7.01), more impediments in psychosocial functioning compared to the other vignettes (see Figure 3; 'promoting participation': M=6.3, SD=4.80, 'recovery and consolidation': M=6.6, SD=4.85, 'stabilization and recovery': M=8.1, SD=5.34, 'SMI severe residential care': M=8.5, SD=4.45). They also experience a need for care in more areas of life ('mental healthcare avoider': M=10.3, SD=3.92, 'stabilization and averting danger': M=10.6, SD=4.22) compared to the vignettes 'promoting participation' (M=6.7, SD=3.90), 'recovery and consolidation' (M=6.9, SD=3.29), and 'stabilization and recovery' (M=8.3, SD=3.73). In addition to the total number of care needs, this also applies to the four areas of care needs: ADL, mental health, rehabilitation, and facilities. An overview of the differences in terms of functioning and care needs can be found in Appendix 2.
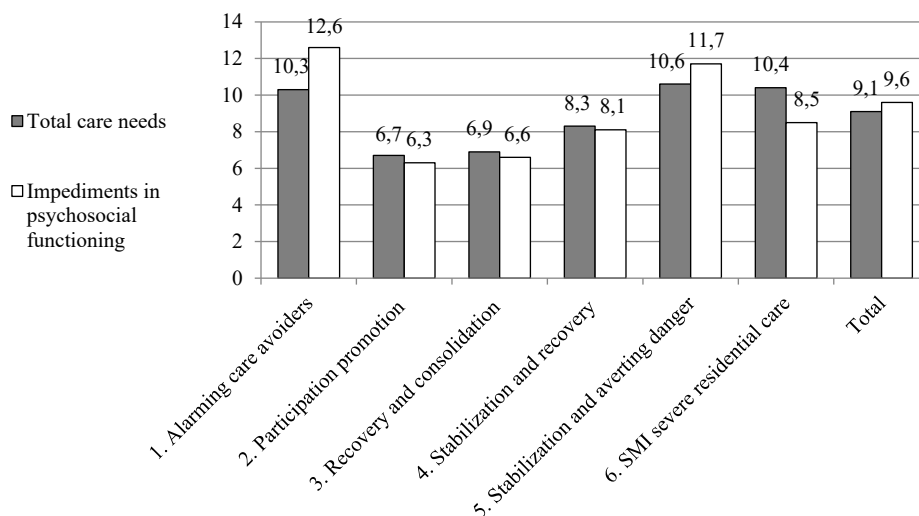

Figure 3. Healthcare needs (average total score, CANSAS) and impediments in psychosocial functioning (average total score, HoNOS) of (F)ACT patients classified by vignette in the year prior to the vignette allocation.

Differences after the vignette allocation

In the post-measurement, patients within the healthcare vignettes 'mental healthcare avoider' and 'stabilization and averting danger' once again have the largest number of limitations in their functioning (mental healthcare avoider: M=11.7, *SD*=6.43, stabilization and averting danger: M=10.4, *SD*=6.98). For the vignette 'mental healthcare avoider', this is higher compared to 'promoting participation' (M=5.9, *SD*=4.83, *p*<.01), 'recovery and consolidation' (M=6.4, *SD*=5.48, p<.01), 'stabilization and recovery' (M=8.0, *SD*=5.37, *p*<.01), and 'SMI severe residential care' (M=8.0, *SD*=4.71, *p*<.01). For 'stabilization and averting danger' this is significantly higher compared to 'promoting participation' (*p*<.01), 'recovery and consolidation' (*p*<.01) and 'stabilization and recovery' (*p*<.01).

Patients with the care vignettes 'mental healthcare avoider' and 'stabilization and averting danger' again have more care needs ('mental healthcare avoider': M=10.1, *SD*=4.15; 'stabilization and averting danger': M=10.2, *SD*=4.31). This is higher compared to the vignettes 'promoting participation' (M=6.8, *SD*=4.31, *p*<.01), 'recovery and consolidation' (M=6.6, *SD*=3.64, *p*<.01) and 'stabilization and recovery' (M=8.2, *SD*=3.72, *p*<.01). In addition, the percentage of symptomatic and functional remission in the care vignettes 'mental healthcare avoider' and 'stabilization and averting danger' is lower compared to patients in the other vignettes (symptomatic: mental healthcare avoider= 28%, stabilization and averting danger= 32%, χ^2=21.90, *p*<.01; functional: mental healthcare avoider= 26%, stabilization and averting danger= 34%, χ^2=39.67, *p*<.01).

Differences are also found within the vignettes over time. The number of restrictions in the functioning of the vignette 'stabilization and averting danger' has decreased by 1.24 (*p*<.05). The decrease within the vignette 'mental healthcare avoider' is not significant (*p*=.53).

Looking at care needs, for both 'stabilization and averting danger' (difference= -.81, *SD*=3.69, *p*<.01) and 'mental healthcare avoider' (difference= -.48, *SD*=2.82, *p*<.05), there is a decrease in the total number of unmet care needs. A detailed overview of the number of (unfulfilled) care needs and limitations in functioning at the time of the survey can be found in Appendix 3.

DISCUSSION

Using ROM-data, this study shows that the healthcare vignettes are insufficiently distinctive, except for 'mental healthcare avoider' and 'stabilization and averting danger'. Patients within these vignettes were more likely to be male and patients within the vignette 'stabilization and averting danger' were the youngest. They also had substantially more limitations in psychosocial functioning. At 12.6 and 11.7 respectively, this is above the threshold value (11) for intensifying the treatment (Nugter et al. 2012). These patients also have an (unfulfilled) need for care in more areas of life and experience more problems with motivation and medication compliance. This is in line with the fact that more problems in functioning go hand in hand with poorer motivation (Mulder et al. 2014).

One year after the vignette allocation, likewise differences were found. Even within the vignettes, hardly any differences were found over time. Patients within the vignettes 'mental healthcare avoider' and 'stabilization and averting danger' again have the most care needs and limitations in their functioning. The almost equal differences between the pre- and post-measurement show that there are no major changes in functioning and care needs. This is relevant for the planning, coordination and allocation of resources. In our opinion, the use of care vignettes in such a context can be improved by enriching them with ROM-data by characterizing groups more specifically, so that personnel and resources can be deployed more efficiently.

Finally, we would like to make a few comments. First of all, there is a lack of data on patients who mainly received psychological help via their general practitioner, those in sheltered housing and patients who stayed in the clinic. Patients in the latter group will probably distinguish themselves by more limitations in their functioning and more care needs than the patients in the vignettes studied here. With the use of six of the nine vignettes, we can state that on the basis of functioning and care needs, the vignettes are not very distinctive.

Secondly, only the mental healthcare providers opinion has been taken into account. Unfortunately, patients' opinion could not be taken into account as there were insufficient questionnaires filled in by patients. This is because patients refused or were unable to participate. It is possible that the results would have been different if the patient's opinion had also been taken into account. Previous research into care needs has shown that patients and care providers sometimes assess the patient's care needs differently (Lasalvia et al. 2000; Thornicroft & Slade 2002; Wiersma 2006; Kroon 2003).

CONCLUSION

This study shows that the vignettes based on care intensity do not coincide with the number of care needs and functional limitations. The differences found between the vignettes are not sufficiently distinctive. In order to achieve more personalized care, an adaptation of the model is desirable. Individual needs and an expected treatment result are the starting points for the provision of appropriate care in the integrated chain. Based on this study, the authors conclude that enriching the vignettes with individual characteristics can lead to more demand-driven planning and coordination at an aggregated level.

The authors are also of the opinion that a flexible care supply based on the individual demand for care, with optimized partnerships between mental healthcare institutions and social care institutions, is desirable. Integrated social and mental healthcare district teams could play a leading role. An active poverty policy and projects such as 'housing first' could contribute to personalized mental healthcare. A treatment plan based on the demand for care and the possibility of solving individual care needs should form the basis.

Chapter 4

Appendix 1. Criteria for vignette allocation.

Step 1. Residential vignettes

Vignette	Allocation
6	RIBW ZZP's* 2, 3, 4
	If DRG at Altrecht, ≤ 800 minutes
7	RIBW ZZP's 5 and 6
	RIBW ZZP's 2, 3, 4, and a DRG ≥ 801 minutes at Altrecht
8	Altrecht ZZP's in the B-category (mostly ZZP's 5, 6, 7)

* ZZP's = health care severity packages

Step 2. Ambulant vignettes

Vignette	Allocation
0	All patients with a care avoider DRG
1	Only medical care by a doctor
2	Outpatient care by RIBW type 2 + no DRG or DRG < 800 minutes at Altrecht
3	Outpatient care by RIBW type 2 + DRG > 800 minutes
	Outpatient care by RIBW type 3 + DRG < 1,799 minutes
	Outpatient care by RIBW type 3 + DRG ≥ 1800 minutes*
4	Outpatient care by RIBW type 4 or 5 + DRG ≥ 1,800 minutes
	Outpatient care by RIBW type 4 or 5 + DRG ≤ 1,799 minutes
5	Patients from Altrecht with ≥ 1 psychiatric admission

Note: patients < 5 hours of assistance by SBWU/Kwintes are transferred to vignette 2

Step 3. Outpatient vignettes, only residential care (RIBW)

Vignette	Allocation
2	RIBW type 2
3	RIBW type 3
4	RIBW type 4

Step 4. Outpatient vignettes, only WA

Vignette	Allocation
1	DRG < 800 minutes
3	DRG 800-1,800 minutes
4	DRG > 1,800 minutes

Step 5. All vignettes, only Victas
- Patients that receive care from Victas and who have been assigned to a vignette by (one of) the other institutions that have retained this allocation, have kept this allocation.
- Patients that receive care from Victas and do not receive care by (one of) the other institutions that have retained a vignette, are allocated to a vignette as follows:
    - Selection on empty fields
    - Exclude patients without a diagnosis on axis II or that are mentally disabled
    - Selection on outpatient care (FACT/SMT) with DRG < 1,800 minutes, go to vignette 3
    - Selection on outpatient care (FACT/SMT) with DRG > 1,800 minutes, go to vignette 4
    - Patients with one or more admissions, go to vignette 5
    - Vignette 7 was disregarded (no patients with AWBW living)

Appendix 2. Care needs and impediments in psychosocial functioning from (F)ACT patients divided per vignette, in the year prior to the vignette allocation. Means and standard deviations at premeasurement.

Vignette[1]	1 (N=154) M (SD)	2 (N=52) M (SD)	3 (N=94) M (SD)	4 (N=190) M (SD)	5 (N=157) M (SD)	6 (N=59) M (SD)	Total (N=706) M (SD)	Significance
Care needs Total	10.3 (3.92)	6.7 (3.90)	6.9 (3.29)	8.3 (3.73)	10.6 (4.22)	10.4 (3.51)	9.1 (4.09)	**1,5,6>2,3,4
Care needs UF[2]	4.0 (3.10)	2.1 (2.60)	2.0 (2.44)	2.7 (2.88)	4.3 (3.58)	2.5 (2.47)	3.2 (3.12)	*1>6; **1,5>2,3,4,5>6
ADL	1.3 (1.19)	.8 (1.01)	.8 (1.04)	.8 (1.00)	1.2 (1.10)	1.4 (.95)	1.0 (1.09)	*1>2; 5>3; **1,6>3,4; 5>4
ADL UF	.3 (.62)	.1 (.31)	.1 (.46)	.1 (.37)	.3 (.67)	.2 (.53)	.2 (.54)	*5>2,3; **5>4
Mental health	4.3 (1.69)	2.8 (1.36)	3.1 (1.17)	3.4 (1.59)	4.3 (1.81)	3.5 (1.51)	3.7 (1.68)	*1,5>6; **1,5>2,3,4
Mental health UF	1.5 (1.41)	.8 (1.23)	.7 (1.05)	.9 (1.28)	1.5 (1.54)	.9 (1.14)	1.1 (1.37)	*1,5>2; **1,5>3,4
Rehabilitation	3.3 (1.73)	2.2 (1.66)	2.2 (1.58)	3.2 (1.71)	3.7 (1.74)	4.0 (1.54)	3.2 (1.77)	*5,6>4; **1,4,5,6>2,3;
Rehabilitation UF	1.9 (1.64)	0.9 (1.30)	1.1 (1.32)	1.5 (1.54)	2.1 (1.83)	1.4 (1.39)	1.6 (1.62)	*5>6; **1,5>2,3; 5>4
Facilities	1.5 (1.18)	.9 (1.11)	.9 (1.24)	1.0 (1.15)	1.4 (1.20)	1.5 (1.29)	1.2 (1.21)	*1>2; 5,6>3; **1>3,4
Facilities UF	.3 (.66)	.3 (.60)	.1 (.42)	.2 (.52)	.4 (.72)	.1 (.25)	.3 (.59)	*1,5>6; 5>3
Impediments in functioning	12.6 (6.79)	6.3 (4.80)	6.6 (4.85)	8.1 (5.34)	11.7 (7.01)	8.5 (4.45)	9.6 (6.36)	**1,5>2,3,4,6

[1]1= Mental healthcare avoiders, 2= Participation promotion, 3= Recovery and consolidation, 4= Stabilization and recovery, 5= Stabilization and averting danger, 6= SMI severe residential care; [2]UF= Unfilled care need, *$p<.05$, **$p<.01$

Chapter 4

Appendix 3. Care needs and impediments in psychosocial functioning from (F)ACT patients divided per vignette in the year prior to the vignette allocation. Means and standard deviations at post-measurement.

Vignette[1]	1 (N=154) M (SD)	2 (N=52) M (SD)	3 (N=94) M (SD)	4 (N=190) M (SD)	5 (N=157) M (SD)	6 (N=59) M (SD)	Total (N=706) M (SD)	Significance
Care needs Total	10.1 (4.15)	6.8 (4.31)	6.6 (3.64)	8.2 (3.72)	10.2 (4.31)	9.4 (3.26)[3]	8.8 (4.17)[3]	*4>3; **1,5,6>2,3; 1,5>4
Care needs UF[2]	3.5 (2.75)[3]	1.6 (2.13)	1.8 (2.61)	2.7 (2.73)	3.5 (3.42)[4]	1.8 (1.87)[3]	2.8 (2.88)[4]	**1,5>2,3,6
ADL	1.3 (1.23)	.8 (.87)	.9 (1.06)	.9 (1.06)	1.2 (1.08)	1.3 (1.01)	1.1 (1.11)	*1>6; 5>4; **1>4
ADL UF	.3 (.69)	.1 (.31)	.1 (.46)	.1 (.38)	.2 (.52)[3]	.1 (.25)	.2 (.50)	*1>2,6; **1>4
Mental health	4.1 (1.79)	2.7 (1.57)	2.9 (1.45)	3.2 (1.59)	3.9 (1.79)[3]	3.3 (1.47)	3.5 (1.73)[4]	*1>6; **1,5>2,3,4
Mental health UF	1.3 (1.18)	.6 (.89)[3]	.6 (1.08)	1.0 (1.30)	1.2 (1.47)	.7 (1.04)	1.0 (1.27)[3]	*1>6; 5>2; **1,5>3; 1>2
Rehabilitation	3.1 (1.71)	2.2 (1.77)	1.9 (1.63)	3.0 (1.70)	3.5 (1.69)	3.5 (1.61)[3]	3.0 (1.77)[4]	*4>2; **1,5,6>2,3
Rehabilitation UF	1.6 (1.56)[3]	0.8 (1.23)	1.0 (1.46)	1.5 (1.64)	1.8 (1.73)	1.0 (1.04)	1.4 (1.58)[4]	*1>2,3; **5>2,3,6
Facilities	1.5 (1.24)	1.0 (1.23)	1.0 (1.43)	1.1 (1.22)	1.5 (1.21)	1.3 (1.16)	1.3 (1.26)	*1,5>3; 1>4
Facilities UF	.2 (.47)[3]	.2 (.41)	.1 (.46)	.2 (.46)	.3 (.58)[3]	.1 (.28)	.2 (.49)[4]	n.s.
Impediments in functioning	11.7 (6.43)	5.9 (4.83)	6.4 (5.48)	8.0 (5.37)	10.4 (6.98)[3]	8.0 (4.71)	9.0 (6.24)[4]	**1,5>2,3,4; 1>6

[1]= Mental healthcare avoiders, 2= Participation promotion, 3= Recovery and consolidation, 4= Stabilization and averting danger, 5= Stabilization and recovery, 6= SMI severe residential care; [2] UF= Unfilled care need; [3]Significant difference compared to pre-measurement, $p<.05$; [43]Significant difference compared to pre-measurement, $p<.05$, *$p<.05$, **$p<.01$

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Chapter 5

Using machine learning to predict mental healthcare consumption in non-affective psychosis

ABSTRACT

Background

The main goal of the study was to predict individual patients' future mental healthcare consumption, and thereby enhancing the design of an efficient demand-oriented mental healthcare system by focusing on a patient population associated with intensive mental healthcare consumption.

Method

Factors that affect the mental healthcare consumption of service users with non-affective psychosis were identified, and subsequently used in a prognostic model to predict future healthcare consumption. This study was a secondary analysis of an existing dataset from the GROUP study. Based on mental healthcare consumption, patients with non-affective psychosis were divided into two groups: low (N=579) and high (N=488) intensive mental healthcare consumers. Three different techniques from the field of machine learning were applied on cross-sectional data to identify risk factors: logistic regression, classification tree and a random forest. Subsequently, the same techniques were applied longitudinally in order to predict future healthcare consumption.

Results

Identified variables that affected healthcare consumption were the number of psychotic episodes, paid employment, engagement in social activities, previous healthcare consumption, and met needs. Analyses showed that the random forest method is best suited to model risk factors, and that these relations predict future healthcare consumption (AUC=0.71, PPV=0.65).

Conclusions

Machine learning techniques provide valuable information for identifying risk factors in psychosis. They may thus help clinicians optimize allocation of mental healthcare resources by predicting future healthcare consumption.

INTRODUCTION

In the last decades, there has been a focus shift within the Dutch mental healthcare system from delivery-oriented care towards a more demand-oriented care. Designing personalized treatment is a challenging task due to limited budgets and an increasing demand for mental healthcare. Insights into variables that influence healthcare consumption are needed to rightfully plan and allocate healthcare resources. Moreover, these insights could be used in a prognostic model to predict future healthcare consumption. Predictions from such a model could be used to identify the type of healthcare patients require, as well as prevent unnecessary healthcare consumption. Additionally, providing more insight into the factors influencing service use could result into new policies regarding healthcare organization and allocation of resources, by health insurance companies and municipalities.

One group of mental healthcare patients associated with intensive healthcare consumption are patients with a psychotic disorder (Carr et al., 2003; Raudino et al., 2014). Several predictive factors for healthcare consumption are known for this population. For example, early detection and intervention of psychotic vulnerability is very important to minimize long-term deficits (Hegelstad et al., 2012; Ising et al., 2016; Morrison et al., 2012). Moreover, several studies emphasize that longer duration of untreated psychosis is associated with reduced recovery (Boonstra et al., 2012; Marshall et al., 2005; Renwick et al., 2017). In addition, non-adherence to anti-psychotic medication results into higher rates of psychiatric and medical hospitalization (Andrews et al., 2017; Gilmer et al., 2004; Hui et al., 2016; Rittmannsberger et al., 2004). Likewise, misuse of drugs is related to hospitalization (Abdel-Baki et al., 2017; Crebbin et al., 2008), and hinders symptomatic remission (Lambert et al., 2005; Weibell et al., 2017).

Besides clinical related factors, several social demographic factors influence healthcare consumption of patients with a psychotic disorder. In numerous studies, women are found to use more healthcare compared to men (Bertakis et al., 2000; Bijl and Ravelli, 2000; Mackenzie et al., 2007). Other predictive factors included education level, employment, income, and living situation. Lastly, ethnic differences are also known to play a role in engagement in mental healthcare services (Diala et al., 1994; Garland et al., 2005).

This current study aims to predict individual patients' future mental healthcare use of patients with non-affective psychosis, by developing a prognostic model that supports planning, allocation, and possible prevention of the need for mental healthcare resources in

the treatment of psychosis. We aim to contribute to a first step towards an efficient service user-oriented healthcare system by focusing on a patient population associated with high mental healthcare consumption.

METHODS

Patients and data collection

Included patients were participants of the Genetic Risk and Outcome of Psychosis (GROUP) study. GROUP is a naturalistic follow-up study which involved the following groups of subjects: 1119 patients diagnosed within the psychotic spectrum, 1059 siblings and 920 parents related to the aforementioned patients, and 586 unrelated control subjects. Trained interviewers conducted extensive assessments. Measurements of the GROUP study were collected at baseline, three-year follow-up (wave two), and six-year follow up (wave three). A detailed description of the study is available elsewhere (Korver et al., 2012).

For the current study, data from a GROUP subsample was used. Patients diagnosed with a non-affective psychotic disorder were included if data about healthcare consumption was available. Wave one did not contain all the relevant data for this study, and therefore only patients from wave two and three were included. Finally, 58 records were excluded because of missing data in the top 20% of the most relevant predictive variables.

Healthcare consumption

For each wave, healthcare consumption was measured over a three-year period. The GROUP data contained the following binary (yes/no) variables about healthcare consumption: out-patient mental healthcare, protected housing, inpatient mental healthcare, and legal mandatory care. From these variables, two healthcare clusters were made, a low intensive and a high intensive cluster. Patients within the low intensive cluster receive no or only outpatient care. Patients within the high intensive cluster live by sheltered housing, or receive inpatient or legal mandatory care.

Measures

In addition to questions about sociodemographic factors and clinical related variables, further extensive data were collected on: the presence of core symptoms of schizophrenia (Positive

and Negative Syndrome Scale, PANSS; (Kay et al., 1987), social functioning (Social Functioning Scale, SFS; (Birchwood et al., 2014), need for care (Camberwell Assessment of Need, CAN; (Slade et al., 1999), global functioning (Global Assessment of Functioning, GAF; American Psychiatric Association (APA), 1994), and intellectual functioning (Wechsler Adult Intelligence Scale, WAIS; (Wechsler, 1997). For the PANSS and CAN, both individual items as well as sum scores were used. For intellectual and global functioning, the total score as well as the sum scores were used. For social functioning, only sum scores were used.

Statistical analyses

Models

In machine learning, more complex models are more flexible in modeling different types of (complex) relationships between variables. However, complex models have a black box character and are therefore less easy to interpret. With our models, we aim to predict future healthcare consumption and support clinicians in creating personalized treatment plans. Therefore, the model must predict future healthcare consumption as accurately as possible, and the clinician must be provided insight into the mechanisms because he or she will not blindly follow an algorithm. In order to deal with this dilemma, three models were compared, differing in complexity and interpretability: logistic regression, classification tree, and random forest.

Logistic regression estimates the relationship between the categorical patient outcomes and healthcare consumption with a logit function (Hastie et al., 2009). Predictions will be most accurate when healthcare consumption (the outcome) is built upon a linear combination of the factors. Coefficients of variables estimated by the regression model are easy to interpret, investigating these coefficients therefore provide a better insight into how a certain outcome prediction is made through a regressive model. A classification tree recursively partitions the data into smaller subsets until all patients in a subset have the same outcome class (e.g., low intensive cluster or high intensive cluster), or until further partitioning no longer adds value to the predictions. A new patient is classified by going down the decision rules in the tree until a leaf node is reached. The majority class of the leaf node is used as class label for prediction. A classification tree has the advantage of being able to model non-linear combinations, and it has an intuitive structure. Random forest is an algorithm that combines multiple decision trees to make predictions. Therefore, the algorithm

is often more powerful than a single tree. The downside of a random forest model is that it can create a black box, in which the relation between input factors (predictors) and healthcare consumption (outcome) is hard to explain.

GROUP release 6.00 was used for the current analyses (Korver et al., 2012). All three techniques, logistic regression, classification tree, and random forest, were used in step one and step two of the data analyses. These steps are explained below.

Step one

The data set was split, in which 70% of the data was used as training set (703 records) for model building and 30% of the data was used as test set (306 records) for the evaluation and validation. Within the training set, a subset of the 20% most important variables was identified by their information gain. The technical definition of information gain is given by the formula IG(T,a)=H(T)-H(T|a), in which the information gain (IG) is the change in entropy (H) on the outcome (T), given a certain variable (a). Entropy is defined as the negative logarithm of the expected probability mass function, H(T)=E[-ln(P(T))] (Quinlan, 1986). In other words, 'entropy' is a measure of uncertainty in the prediction of which patient will become a high intensive service user. The goal of machine learning models is to reduce uncertainty. Therefore, only variables that contribute to this goal should be used in the models. The 'information gain' of a variable describes how much uncertainty is reduced, measured with entropy, when a variable is included in a model. The 20 most predictive variables are chosen by their information gain. The subset of variables was used as input for each of the different algorithms. Incomplete records were ignored.

The classification tree and random forest algorithm contained hyper parameters, which were optimized on the training data to increase performance. Optimization was done by 10-fold cross-validation, by which the training set was split into a new training and test set, iteratively 10 times. Cross validation is aimed at finding generalizable models.

Next, the algorithms were evaluated by the Area Under the (Receiver Operating) Curve (AUC), the sensitivity (the number of high intensive healthcare consumers that were classified among the complete set of high intensive users), and positive predicted value (PPV; the proportion of correctly classified high intensive users), which relates to the specificity (proportion of low intensive healthcare consumers that were correctly classified). The algorithms predicted a probability that someone is a high intensive user. The threshold value to classify an individual as high care user was set to .5.

Step two

In the second step of the analysis, data from wave two were used to predict future healthcare consumption over the next three-year period (wave three). The set contained 350 longitudinal records and was split into a new training set of 70% of the data (N=205) and a test set of 30% of the data (N=145). The procedure from step one was applied to these sets. All analyses were done with R (R Development Core Team, 2008).

RESULTS

Sample characteristics

A total of 1067 data records were included in the first analysis. Of these records, 46% (N=488) was assigned to the intensive healthcare cluster, and 54% (N=579) to the low intensive cluster. The clusters differed in several ways (Table 1). Participants in the high intensive cluster were significantly younger, less often had (paid) employment, and had a lower estimated IQ, GAF scores and education degree. Furthermore, they had a higher number of psychotic episodes during the past three years, a worse outcome on all PANSS subscales and more needs for care. No significant differences were found for sex, ethnicity, and duration of psychotic illness.

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Table 1. Characteristics of the low and high intensive healthcare cluster (N=1067).

Characteristics	Low intensive cluster (N=579)		High intensive cluster (N=488)		
	Mean	SD	Mean	SD	p
Age	32.57	(7.53)	31.34	(7.16)	.007
Estimated intelligence quotient [a]	101.72	(17.54)	96.43	(16.25)	<.001
Psychotic episodes in the past three years	.29	(.60)	.81	(1.11)	<.001
Psychotic illness duration, years	10.00	(4.72)	9.79	(4.04)	.436
CAN[b] total unmet care needs	2.02	(2.31)	2.65	(2.32)	<.001
CAN total met care needs	2.76	(2.45)	4.05	(2.93)	<.001
PANSS[c] positive symptoms	11.42	(5.76)	12.78	(6.40)	<.001
PANSS negative symptoms	12.06	(5.44)	13.32	(6.13)	.001
PANSS general scale	1.48	(0.46)	1.57	(0.48)	.001
GAF[d]	62.35	(16.18)	54.88	(15.40)	<.001
	N	%	N	%	p
Sex, male N (%)	449	(77.5)	363	(74.4)	.257
Ethnicity, N (%)					.403
– Caucasian	476	(83.7)	406	(84.6)	
– Mixed	46	(8.1)	44	(9.2)	
– Other	47	(8.3)	30	(6.2)	
Employment, N (%)					<.001
– None	115	(19.9)	142	(29.3)	
– Paid	333	(57.6)	184	(38.0)	
– Voluntary	125	(21.6)	156	(32.2)	
– Unknown	5	(.9)	2	(.4)	
Highest education degree, N (%)					.004
– Primary	41	(7.1)	58	(11.9)	
– Secondary	146	(25.3)	136	(28.0)	
– Vocational	199	(34.5)	153	(31.5)	
– Highschool	134	(23.3)	114	(23.5)	
– University	56	(9.7)	25	(5.1)	

[a] Intelligence is estimated by the total score of the Wechsler Adult Intelligence Scale
[b] Camberwell Assessment of Need
[c] Positive and Negative Syndrome Scale
[d] Global Assessment of Functioning total score

Step one: Identifying risk factors

First, in step one, the 21 (top 20%) most predictive variables were selected from the cross-sectional data. The top five is shown in Table 2. The complete set of 21 variables is shown in Appendix 1. Records with incomplete information on these variables were excluded (N=58). The number of psychotic episodes contained the highest information gain of .06.

Table 2. Top 5 most predictive variables in cross-sectional data (N=1009).

Variable	Information gain
Psychotic episodes	.06
CAN[a] total met care needs	.04
GAF[b] disabilities	.03
Paid employment	.02
GAF[b] symptoms	.02

[a] Camberwell Assessment of Need

[b] Global Assessment of Functioning

As shown in Table 3, the random forest model has the best performance with the highest AUC (.74), compared to the logistic regression (.72) and classification tree (.65). An AUC of .74 indicates fair performance. The classification tree has the highest sensitivity, but the worst specificity and PPV. The classification results of each model were expressed in a confusion matrix, where after a McNemar test determined that there were no significant differences regarding the proportion of correct outcomes of the models (p>.01).

Table 3. Results of classification algorithms on the test set in step one with 95% bootstrapped confidence intervals (CI; N=306).

Method	AUC[a]	Sensitivity, CI	Specificity, CI	PPV[b], CI
Logistic regression	.72	.53 (.44 - .61)	.76 (.70 - .82)	.64 (.57 - .71)
Classification tree	.65	.59 (.51 - .67)	.72 (.65 - .78)	.63 (.56 - .69)
Random forest	.74	.58 (.50 - .66)	.76 (.69 - .82)	.66 (.60 - .73)

[a] Area Under the Curve

[b] Positive Predicted Value

Step two: Predicting future healthcare consumption

In step two, the model building process was repeated on 350 longitudinal records, which were split into test and training data. The top five identified most predictive variables are shown in Table 4 and the complete set of 21 variables in shown in Appendix 2. The care cluster in the previous three years contained the highest information gain of .08.

Table 4. Top five most predictive variables in longitudinal data (N=1009).

Variable	Information gain
Care cluster previous 3 years	.08
SFS[a] prosocial scale	.04
CAN[b] met care needs	.03
CAN money need	.03
GAF[c] symptoms	.03

[a] Social Functioning Scale

[b] Camberwell Assessment of Need

[c] Global Assessment of Functioning

The performance of the models on the AUC, sensitivity, specificity, and PPV are shown in Table 5. The random forest model performs the best with the highest AUC (.71). This indicates fair performance on longitudinal data. The sensitivity of the logistic regression model and classification tree are the highest (.37), whereas random forest model had the highest PPV (.65). The classification results of each model were expressed in a confusion matrix and a McNemar test determined that there were no significant differences between proportion of correct outcomes of the models (p>.01).

Table 5. Results of the classification algorithm on the test set in step two with their 95% confidence intervals (CI; N=105).

Method	AUC[a]	Sensitivity, CI	Specificity, CI	PPV[b], CI
Logistic regression	.67	.37 (.20 - .53)	.84 (.76 - .92)	.48 (.30 - .67)
Classification tree	.63	.37 (.20 - .53)	.80 (.71 - .88)	.42 (.27 - .59)
Random forest	.71	.31 (.17 - .47)	.93 (.87 - .99)	.65 (.40 - .88)

[a] Area Under the Curve

[b] Positive Predicted Value

DISCUSSION

The aim of current study was to assess whether patient's individual mental healthcare consumption can be predicted. The most important predictor in step one, based on information gain on the cross-sectional data, was the number of psychotic episodes (ranked seventh in step two). This result is consistent with findings suggesting that psychotic relapses lead to more utilization of healthcare consumption, and vocational and social disruptions (Bertsimas et al., 2008; Chi et al., 2016). This finding stresses the importance of relapse prevention. Moreover, factors such as paid employment and engagement in prosocial activities were present in the top five predictors of step one or step two. Apparently, individuals who do well in their job and/or social life are less likely to use mental healthcare sources intensively. This finding suggests that treatment should focus particularly on societal participation, which is consistent with earlier findings (Bellido-Zanin et al., 2015; Jäckel et al., 2017; Raudino et al., 2014). In addition, social deficits could already be present before the onset of psychotic symptoms, and are seen as a predictor for conversion to psychosis in clinical high risk patients (Addington et al., 2008; Andrews et al., 2017).

In step two, the most important variable predicting healthcare was previous mental healthcare consumption. When a patient has been an intensive mental healthcare user in the past, the more likely it will be that he will become an intensive healthcare consumer in the future. Past healthcare utilization was also among the strongest predictors in a Canadian study on the prediction of future high-cost patients (Chechulin et al., 2014). Early detection of patients being at high risk of becoming a high intensive healthcare consumer could change treatment strategies. Although various studies have shown demographic data being associated with mental healthcare consumption (Bertakis et al., 2000; Diala et al., 1994; Mackenzie et al., 2007), we did not find this. Furthermore, the level of psychotic symptoms was not incorporated in the models to predict healthcare consumption. This could suggest that if we want to prevent intensive healthcare use, treatments should not solely focus on symptoms (34). Moreover, this stresses, together with the findings in step one, the importance to increase societal participation to lower the risk of patients becoming a high intensive mental healthcare user. Social and economic inclusion of mental healthcare patients requires more than only the effort from psychiatric services. It also requires for example a change in societal attitude regarding mental illness, and access to employment for our patients (Chaturvedi, 2016).

After identifying the most relevant variables, it was tested whether factors associated with healthcare consumption could be used to predict future healthcare consumption. A comparison between the different machine learning techniques was made by two steps. One step with a larger cross-sectional dataset, a second step with a smaller longitudinal dataset. The more advanced technique, random forest, seemed to perform well in both step one and step two, with the highest positive predicted values and AUC. Compared to logistic regression, other studies comparing techniques on several (different) datasets also found random forest to be more accurate in making predictions (Chen et al., 2017; Couronné et al., 2018; Muchlinski et al., 2016). The downside of such a model is that less insight can be given into why a certain individual prediction is made. However, we have provided insight into the variables that are most important in making predictions in general. The top 22 predictive variables indicate which patient characteristics are used to classify low and high consumers. None of the predicted classifications results showed statistically significant differences. We are not sure whether this is caused by the small sample size or whether this is a true finding.

The random forest model showed promising results in predicting future mental healthcare consumption. Algorithmic prediction of future healthcare use holds implications for clinical practice in which machine learning algorithms could support clinicians in the identification of patients that need additional attention and a possible alternative intervention. When the model identifies a patient at high risk of becoming an intensive mental healthcare consumer, clinicians could adjust their treatment (Bird et al., 2010; Marwaha et al., 2016; Pfammatter et al., 2006). However, with a PPV of .65, roughly one third of the patients will be falsely identified as future high intensive mental healthcare users. Nevertheless, we propose that the cost of an alternative (initially) intensive treatment plan does not outweigh the possible savings by preventing relapse or an emergency situation for the other two third of patients.

Strengths

The main strength of the current study is the use of a large verified and longitudinal dataset, containing many different types of patient variables. This large set of variables, combined with a comparison of different machine learning techniques, gives insight into the underlying patterns of mental healthcare consumption. To our knowledge, the current study is the first

to examine different types of predictive algorithms to reveal predictors of mental healthcare consumption among patients with non-affective psychosis. In addition, an AUC of .71 was found, which means that the predictive value of the model is acceptable; there is a fair chance of correctly classifying an individual as a low or high intensive mental healthcare service user. Our results may be of importance for treatment interventions and policies concerning this patient population in the future. Furthermore, the method utilized in this study is straightforward and all analyses are undertaken with free R packages, which can easily be reproduced by other studies or implemented by healthcare organizations.

Limitations

This study has several limitations. First, in the first step, data from wave two and three of the GROUP study were used, which means that there was an overlap in subjects. Since wave three took place three years after wave two, it is possible that there are some alterations to someone's life which still make it interesting to look at both periods.

Second, the found information gain was minimal. However, this is not uncommon for machine learning in mental healthcare (Gillan and Whelan, 2017). In the short term, the application of machine learning in mental healthcare will not have such a big impact as is seen for the medical field, because for mental healthcare, diagnostic tests and technological measurements are less advanced (Fernandes et al., 2017). In other words, there are less 'good predictors' in mental healthcare. However, the machine learning models are still able to provide valuable information and show promising results. They are not 100% accurate, and therefore, we argue that the application of machine learning should not be seen as a substitution of a professional, but as a complementary step in the further identification and stratification of patients that are at risk of becoming high intensive healthcare users.

Third, in order to assess the robustness and generalizability of the results, it would be desirable to replicate the study in a different sample. However, because of the large number of variables entered into this study, it is difficult to find a comparable dataset. Additionally, when implementing the model in clinical practice, data collected in routine care necessary to predict patients' mental healthcare consumption might not be available. Therefore, we suggest that future research should focus on identifying the most relevant subset of measures, with the most predictive power, which can be used in a routine clinical care setting.

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Lastly, the healthcare consumption data was not detailed enough to make an accurate estimation of the individual healthcare consumption. Therefore, there was some degree of heterogeneity in healthcare use within each cluster.

CONCLUSIONS

Machine learning techniques provide valuable information for identifying risk factors in psychosis. They are suited to assist in the pursuit of personalized treatment plans, as well as the organization of demand-oriented care. The random forest model showed promising results in predicting future intensive mental healthcare consumers. Adapting alternative treatment strategies for this patient group could eventually result into a reduction of future mental healthcare consumption. The current results suggest that these alternative treatment plans should focus on early intervention, relapse prevention, and vocational and social support. Moreover, addressing social deficits should possibly be more effective than focusing on the reduction of clinical symptoms.

The findings of this study may contribute to personalized clinical practice, by helping clinicians to focus in an early stage on relevant risk factors, and therefore to optimize better allocation of the limited available resources to those who need it the most. Furthermore, the gained insights and types of predictive models could be used for developing clinical guidelines. We are convinced that the use of machine learning techniques, as we showed in this article, has the promise to contribute towards an efficient service user-oriented healthcare system.

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Chapter 5

Chapter 6

Predicting future service use in Dutch mental healthcare: a machine learning approach
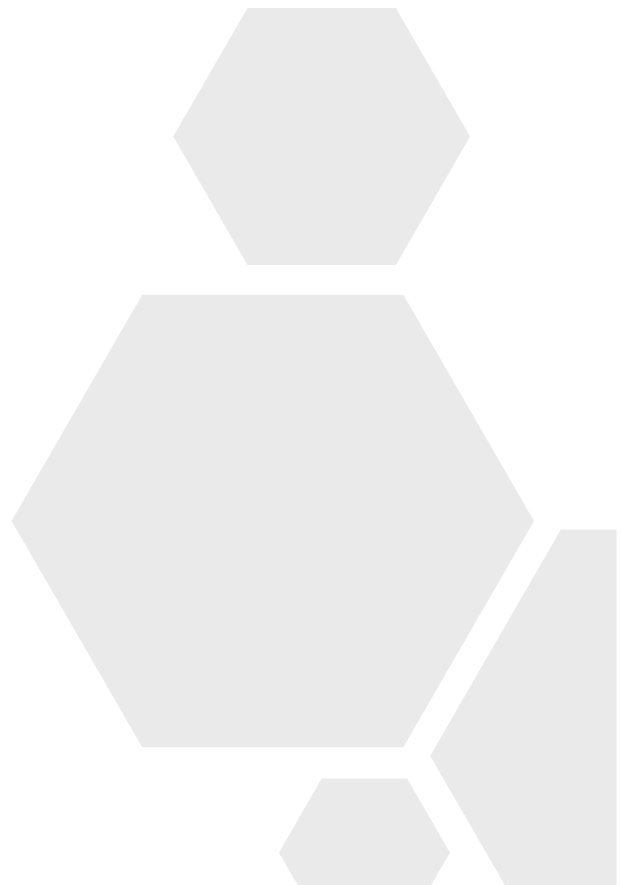
ABSTRACT

Background

A mental healthcare system in which the scarce resources are equitably and efficiently allocated, benefits from a predictive model about expected service use. The skewness in service use is a challenge for such models. In this study, we applied a machine learning approach to forecast expected service use, as a starting point for agreements between financiers and suppliers of mental healthcare.

Method

This study used administrative data from a large mental healthcare organization in the Netherlands. A training set was selected using records from 2017 (N=10,911), and a test set was selected using records from 2018 (N=10,201). A baseline model and three random forest models were created from different types of input data to predict (numeric) individual treatment hours. A visual analysis was performed on the individual predictions.

Results

Patients consumed 62 hours of mental healthcare on average in 2018. The model that best predicted service use had a mean error of 21 minutes at the insurance group level and an average absolute error of 28 hours at the patient level. There was a systematic under prediction of service use for high service use patients.

Conclusion

The application of machine learning techniques on mental healthcare data is useful for predicting expected service on group level. The results indicate that these models could support financiers and suppliers of healthcare in the planning and allocation of resources. Nevertheless, uncertainty in the prediction of high-cost patients remains a challenge.

INTRODUCTION

In high income countries, there is an estimated gap of 35% to 50% between demand and supply of mental healthcare resources (World Health Organization, 2013). Managing this gap is a top priority and poses a challenge to equitably allocate mental healthcare resources. An efficient mental healthcare system requires a transparent playing field in which agreements can be made between financiers and suppliers about the appropriate quantity of care. There is a time lag between the agreed budgets, the services provided and the reimbursement, which causes financial uncertainty for both parties. Therefore, there is a need for a predictive model regarding expected service use in mental healthcare (Morid et al., 2017).

Since 2008, significant changes have been implemented into the organization and financing of the Dutch mental healthcare system (Janssen, 2017). A regulated market was introduced in which insurance companies contract suppliers about the quality and quantity of care to be delivered. One of the rationales of the reform was to create transparency in expected healthcare costs by creating homogenous groups of service use. Therefore, new treatment products were introduced, called Diagnostic Related Groups (DRGs). A DRG includes a combination of diagnosis and the activities and operations performed by the care provider (Janssen & Soeters, 2010). Although patients in the Netherlands are clustered in DRGs, there still exists a large variance in service use within the groups (Boonzaaijer et al., 2015).

This variance in the use of healthcare resources shows that it is difficult to create homogenous groups or predict mental healthcare service use in general (Malehi et al., 2015). The variance is the result of a skewed distribution, in which a small group of patients is associated with a large part of the total costs (Wammes et al., 2018). In mental healthcare, this group consists of patients with complex problems in multiple areas, which have multiple care needs and a chronic course of illness (Kwakernaak et al., 2020). Because of the skewed distribution, most scientific research on predictive models use categorical outcome variables, in which healthcare resources are clustered in two or more bins, with often a focus on the 'high-cost' group (Boscardin et al., 2015; Chechulin et al., 2014; Colling et al., 2020; Rosella et al., 2018; Wang et al., 2017). National initiatives on predictive models, such as in the United Kingdom, Australia and New Zeeland also used a categorical outcome in which patients are assigned to clusters of service use, which can be used to adjust expected costs (Twomey et al., 2017). In the Netherlands, a similar cluster tool was developed to overcome

the shortcomings of the DRG system (Working group mental healthcare severity indicator, 2015). Evaluation of the different tools concluded that the homogeneity of resources within each cluster was still suboptimal and not suited for fixed payment adjustments (Broekman & Schippers, 2017; Jacobs et al., 2019).

Creating a predictive model in which healthcare resources are defined as a categorical variable instead of a numeric outcome, is statistically convenient and better suited to deal with skewness in the data. However, there is a trade-off with the practical utility of the model. The used cut-offs in these models are often arbitrary. Moreover, the practical challenge in healthcare is methodologically simplified and information in the outcome variable is lost. For example, changes in service use within the range of a bin stay undetected, which can have serious implications in the planning and allocation of resources, especially in the high-cost categories.

In order to design a predictive model for mental healthcare resources with a numeric outcome, a possible solution lies in the large amounts of data in electronic health records that are continuously generated and stored within mental healthcare organizations (Gillan & Whelan, 2017; Shatte et al., 2019). The emerging field of machine learning allows the exploitation of large data sets and the modeling of complex underlying non-linear relationships and therefore holds potential to deal with the skewed distribution of healthcare resources (Iniesta et al., 2016).

The goal of this study is to create a machine learning prediction model for expected service use, as a starting point for agreements between financiers and mental healthcare suppliers. We aim to predict the number of treatment hours which will be reimbursed as a part of the Dutch DRG payment system. Associated with the foregoing, we aim to contribute to more equitable resource allocation and more transparency in the system.

METHODS

Setting

This study was carried out at Altrecht Mental Healthcare, a large specialized mental healthcare organization with multiple sites in and around the city of Utrecht, The Netherlands (www.altrecht.nl). The organization offers both inpatient and outpatient facilities, and both secondary (regional) as well as tertiary (national) health services. For this study, we focus on

the outpatient treatment of patients of which nearly 60% has a personality disorder, psychotic disorder or depressive disorder as main diagnosis. Treatment is financed within the National health Insurance Act (NIA). The organization provides outpatient treatment to around 13,000 patients each year with an annual budget of approximately 83 million Euros.

Specialized mental healthcare products

In specialized mental healthcare, treatments within the NIA are reimbursed via products called Diagnose Related Groups (DRGs). These contain, among other information, all activities performed within a treatment that need to be reimbursed. The price of a DRG product is always based on a treatment component containing the number of treatment hours. The duration of a DRG is up to 365 days. After 365 days, the DRG is closed and a new DRG will start if more treatment is needed. Each year, organizations in mental healthcare in the Netherlands negotiate contracts about the budgets for the next calendar year with several insurance companies, which finance care in the NIA. This study concerns an organization with six main contracts. All DRGs starting in one calendar year are part of the contract of that year.

Data collection

Data were collected from reimbursed DRGs starting in the years 2017 and 2018. Demographic and clinical variables were assembled and integrated with the data regarding service use (treatment hours) and organizational properties, such as duration of treatment at the organization. Data from the four most commonly used routine outcome measurement (ROM) instruments were collected as well; the brief symptom inventory and the Health of the Nation Outcome Scale for adults, elderly and children (Burns et al., 1999; Derogatis, 1983; Gowers et al., 1999; Wing et al., 1998). Only DRGs regarding regular treatment trajectories were included, which means that the so called 'exceptional' DRGs related to sole diagnostic examination or acute care were excluded.

Anonymization

All data was collected and integrated within the data warehouse of the healthcare organization with a pseudonymized identifier. After the data was integrated with a SQL-script, the data was further anonymized by first removing the pseudonymized identifier such that the identifiers could not be recovered later. Next, techniques from statistical disclosure

control, such as recoding and local suppression, were applied on the demographic and clinical variables to remove risk of indirect identification. Dutch law allows the use of electronic health records for research purposes under certain conditions. According to this legislation, neither obtaining informed consent from patients nor approval by a medical ethics committee is obligatory for this type of observational studies containing no directly identifiable data (Dutch Civil Law, Article 7: 458). This study has been approved according to the governance code of the Altrecht Science department.

Input features

The selection of variables was based on earlier attempts to develop cluster tools, literature and input from expert discussions (Kim & Park, 2019; Twomey et al., 2015). The organization treats different populations of patients within different care programs such as community-based treatments, specialized treatments or elderly mental healthcare. This results in different types of registration data available within these programs. The feature creation phase was aimed at creating comparable features applicable to all (sub) populations. Since different ROM-questionnaires were used depending on the patient's treatment program, we used a normalized T-score, converted from the raw total ROM scores, which makes the scoring of all questionnaires comparable (Beurs et al., 2018). A T-score has a mean of 50 and a standard deviation of 10 and a score of above 55 is considered as highly severe symptoms. The T-score could be used as one feature within all four programs. In all features created, definitions were used that could be translated to other mental healthcare organizations such that the research findings are applicable to a broader spectrum. A complete list of features with a description is given in Appendix 1.

       The features were divided into three categories: patient, supplier and service use (first two months). We started with a model based on the input data from the first category only. Subsequently, we created a model with both the first and second set. Lastly, we created a model with all three sets as input. The first category consisted of clinical and demographic variables. The second category was related to history of service use and characteristics of the type of treatment (measured at the start of the new DRG). The third category included features from the administrative data of appointments, meetings and other types of activities performed within the first two months of the DRG. The time spent on these activities are part of the service use we aim to predict, so we use a part of the puzzle (the first two months) to predict the remaining part of the puzzle (the next ten months). In current practice, the time

lag between agreed budgets and reimbursement is about 14 months. Because of the uncertainty in budgets, negotiations and monitoring of expected costs go on continuously. Mental healthcare contracts are even negotiated ex post because they involve risks of millions of Euros in case of just one supplier. Therefore, in the third scenario, even after two months, it is still very relevant to reduce the uncertainty about expected costs in the upcoming ten months.

After deciding which variables to include into the three sets, there were some variables with missing values; living condition (60%), education (39%), marital status (25%) and baseline ROM score (9%). We imputed the label 'unknown' for missing values in the first three categorical variables. The numerical ROM-score was imputed with a k-nearest neighbor algorithm. All numeric variables were scaled and centered.

Modeling

The DRG data starting in the year 2017 were used as training data. To evaluate the model, the DRGs starting in 2018 were used as test data. The training set was used to describe the population and create the models. The test set was used only once for evaluation. We built three models on the three different sets of input data. In all three models a random forest algorithm was used to predict the number of treatment hours. A random forest is an example of ensemble learning, which is an algorithm that combines multiple predictors to make a single prediction. It has the advantage of being able to model complex interactions and non-linear relationships. The package *randomForest* as implemented in the statistical software R was used (Breiman et al., 2015; R Development Core Team, 2008). The model was trained with 10-fold cross-validation with 10 repeats. The hyper parameter 'number of trees' was tuned on the mean absolute error with the default grid search in the *caret* package in R (Kuhn, 2008). All input variables were scaled and centralized. The prediction error is visualized by plotting the predicted number of treatment hours versus the actual number of treatment hours with the *ggplot2* package (Wickham, 2016). The importance of the variables was assessed with the *caret* package.

Evaluation

Performance of the model was evaluated on individual and a group level, which are in this case the populations within the agreed budgets with the financier. Individual predictions were evaluated with the mean absolute error (MAE), whereas aggregated predictions on the

population of each insurance company were evaluated with the mean error (ME). The 95% confidence intervals for both measures were estimated taking 1,000 bootstrap samples. For comparison with other studies, we calculated R^2 measures on the test data. We analyze the added value of the models by comparing the results to a baseline prediction model. In practice, there are six separate contracts with each of the six insurance companies within the catchment area of the organization. In the baseline model, we used the mean hours of service use within each contract per insurance company from the training data to predict the service use in each contract in the test data. The results and visual analysis on the training data are shown in Appendix 2.1 and 2.2.

RESULTS

Demographic and clinical features

Slightly more than half of the patients included in the training set were female (56%) and the patients had a mean age of 44 (range 18 to 97). In the 75% patients for whom their marital status was registered, 26% was married. In the 40% patients for whom their living condition was registered, 40% lived alone and one in fourteen patients was either homeless, in jail or institutionalized. The demographic characteristics are shown in Table 1.

As shown in Table 2, the three most common diagnoses in the sample were personality disorders (22%), schizophrenia and other psychotic disorders (22%), and depressive disorders (14%). At the start of the DRG, the mean Global Assessment of Functioning (GAF) score was 49 which indicates serious symptoms or any serious impairment in social, occupational or school functioning. Of all patients, 7% started with a legal measure and 6% started their DRG with a crisis intervention, which both indicate a high urgency for care. The average T-score on baseline was 48. The duration of the start of the treatment up to the start of the DRG included in the training data was on average five years.

Table 1. Demographic description of patient population in the training data (N=10,911).

Demographic variables	Mean	SD	%
Age	44.0	16.55	
Sex, female			55.7
Marital status			
- Married			19.5
- Living together, unmarried			4.8
- Unmarried, never been married			38.9
- Divorced			9.5
- Widowed			1.9
- Unknown			25.4
Education			
- High			15.6
- Secondary			43.7
- Primary			1.5
- Unknown			39.2
Living condition			
- Single			16.2
- Without partner, with children			2.4
- With partner, without children			7.2
- With partner, with children			7.0
- Child with single parent			1.4
- Child with multiple parent			3.4
- Jail, institutionalized, homeless			2.8
- Unknown			59.7

Table 2. Clinical description of the patient population in the training data (N=10,911).

Clinical features	Mean	SD	%
Main Diagnosis Group			
- Personality disorders			22.2
- Schizophrenia and other psychotic disorders			21.9
- Depressive disorders			13.9
- Bipolar disorders			11.1
- Anxiety disorders			10.4
- Somatic symptom Disorders			5.0
- Pervasive developmental disorders			4.8
- Delerium, dementia			3.6
- Eating disorders			2.7
- Substance related disorders			1.9
- Other diagnosis			2.6
Occupational problem (DSM-IV) at start of DRG			10.9
Legal measure at start of DRG			6.9
Acute care at start of DRG			6.1
Global Assessment of Functioning at start of DRG	48.5	10.65	
T-score Baseline at start of DRG	48.0	10.85	
Treatment duration from start DRG, years	4.6	6.06	

Chapter 6

Performance of the machine learning model on test data

The output of the baseline model and the three machine learning models on the test data are shown in Table 3. The six rows resemble the six contracts with each insurance company, with the number of patients within the contract (N) and the actual mean hours. For each model, the mean error (group level) and mean absolute error (patient level) were estimated. There was considerable improvement in model2 over model1 and model3 over model2. Compared to the baseline model, all three models improved performance at the individual level. Only model3 showed considerable improvement at the group level.

In the total population of 10,201 patients, the actual hours of mental healthcare averaged 62. Model3 resulted in an average error of 0.35 hour (21 minutes) at the group level, which is 0.5% of the mean, and an average absolute error of 28 hours at the patient level, which is 45% of the mean.

Table 3. Results on test data (2018[a], N=10,201).

	N	Mean Hours	Baseline model (R^2 = .00)		Model1 (R^2 = .18)		Model2 (R^2 = .28)		Model3 (R^2 = .54)	
			ME	MAE	ME	MAE	ME	MAE	ME	MAE
1	3860	60.27	-1.62 (-3.66 - 0.44)	45.86 (44.42 - 47.36)	0.51 (-1.38 - 2.42)	40.09 (38.80 - 41.47)	-0.01 (-1.72 - 1.78)	35.86 (34.58 - 37.21)	-0.18 (-1.55 - 1.14)	27.36 (26.31 - 28.44)
2	1355	63.38	-1.64 (-5.3 - 1.89)	49.70 (47.29 -52.25)	3.25 (0.02 - 6.55)	43.19 (40.89 - 45.50)	2.17 (-0.84 - 5.27)	39.08 (36.85 - 41.28)	0.86 (-1.56 - 3.35)	29.84 (28.07 - 31.69)
3	300	68.54	7.58 (-1.99 - 16.87)	57.18 (50.74 - 63.59)	9.95 (1.83 - 18.12)	51.32 (45.36 - 57.13)	6.19 (-1.05 - 13.18)	42.44 (37.30 - 47.60)	-0.48 (-6.46 - 5.62)	32.37 (27.58 - 37.18)
4	1472	62.77	-2.02 (-5.27 - 1.37)	47.08 (44.63 - 49.45)	3.89 (0.91 - 6.94)	41.14 (38.90 - 43.22)	2.03 (-0.88 - 4.75)	36.86 (34.76 - 39.05)	0.36 (-1.96 - 2.62)	28.54 (26.70 - 30.35)
5	1431	59.25	1.70 (-1.55 - 4.84)	44.50 (42.26 - 46.93)	6.84 (3.85 - 9.74)	40.51 (38.28 - 42.71)	4.66 (1.90 - 7.34)	35.23 (33.15 - 37.20)	1.26 (-0.92 - 3.37)	26.55 (24.88 - 28.28)
6	1783	63.68	0.99 (-2.08 - 4.13)	49.06 (46.92 - 51.21)	4.12 (1.23 - 7.07)	43.56 (41.60 - 45.62)	3.31 (0.60 - 6.00)	39.77 (37.82 - 41.77)	0.52 (-1.62 - 2.60)	30.12 (28.53 - 31.77)
Total	10201	61.74	-0.49 (-1.81 - 0.78)	47.25 (46.35 - 48.14)	3.16 (1.98 - 4.32)	41.64 (40.81 - 42.45)	1.99 (0.87 - 3.02)	37.21 (36.42 – 38.00)	0.35 (-0.52 - 1.26)	28.37 (27.72 - 29.05)

[a]Aggregated predictions on test data for each insurance company population. ME = Mean Error, MAE = Mean Absolute Error, with 95% bootstrapped confidence intervals.

Chapter 6

Individual predictions compared to actual hours

A visual analysis of the prediction on the test data are shown in the scatterplot in Figure1. We observe both under- and overestimation by the distance of dots to the dashed diagonal line. There is a clear case of skewness, a high-cost group of 5% of the DRG products (>200 hours on the y-axis), which contain 22% of the total hours. Furthermore, we observe a cloud of dots above the diagonal line within this group, which indicate substantial and systematic underestimation of the actual hours.
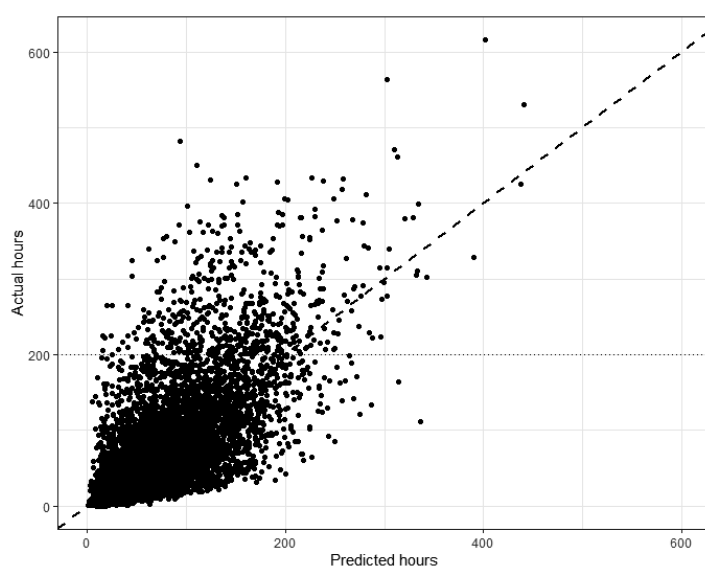

Figure 1. Scatterplot of predicted versus actual hours of model3 on test data 2018 (N=10,201).

Variable importance

The top five most predictive variables are shown in Table 4. The most important patient variables (model1) included functioning and the severity of clinical symptoms, expressed with a GAF-score or measured with a ROM-measurement. The most important organizational variables (model2) were related to previous healthcare use and duration of treatment. In model3, the most important variables relate to the total time as well as the duration of hours spent on appointments and activities in the first two months of treatment.

Table 4. Top five most predictive variables for each model

Rank	Model1	Model2	Model3
1	GAF	Hours previous year	Time spent in hours in month2
2	T-score baseline (ROM)	Duration of treatment at start of DRG	Time spent in hours in month1
3	Age	Crisis situation previous year	Duration of treatment at start of DRG
4	Raw score baseline (ROM)	T-score baseline (ROM)	Time spent on intake activities in month 1 and/or 2
5	Legal measures	Age	Time spent on treatment appointments in month 1 and/or 2

DISCUSSION

This is one of the few studies that use machine learning on a large database to predict a numeric outcome on mental healthcare service use. The goal of this study is to create a machine learning prediction model for expected service use, as a starting point for contracting processes between financiers and mental healthcare suppliers in the Netherlands. A random forest algorithm was used on a large electronic health record database to predict the number of hours in the DRGs of a large mental healthcare organization in the Netherlands.

Three models were created to predict the quantity of service use. The first model, using only patient-related data resulted in a group level error of 5% and an absolute (patient level) error of 67% of the mean. The second model, adding organizational data and data about past service use, reduced the error to 3% and the absolute error to 60% of the mean. The third model, adding data related to the first two months of the DRG, further reduced error to 1% and the absolute error to 46% of the mean.

We found that comparing the results to other studies is difficult because only a few studies used a numeric outcome with a train-test or other out of sample designs. With those studies, a direct comparison of the mean absolute error is not valid because the error depends on the distribution of the outcome in the dataset. Moreover, the type of input data available was not the same. As an indication, the study of Kuo et al. (2011) predicted costs and reported a R^2 of .48 and a mean average error of $507, which was 75% of the mean. In a study of Bertsimas et al. (2008), an absolute error of €1,977 was found, which was 79% of the mean. The absolute error in our three models ranges from 46% to 67% of the mean. Another comparison can be made within the Dutch context. The evaluation of the Dutch cluster tool reported an R^2 of .06, but no train-test design was used, which could result in an

overestimation of the performance of the model. In line with Yarkoni (2017), we argue that future studies and national initiatives about predicting service use should use fundamental concepts of machine learning and focus on making generalizable predictions. Nonetheless, compared to the cluster tool, which only used patient-related data, model1 already showed a R^2 of .18 on the test data, which implies that the model has higher predictive value.

We determine the practical implication of our model by translating the statistical performance to the case of our study, in which the healthcare organization had to establish six financial agreements in 2018. The models developed on the training data (2017) are used to predict the six budgets. The error of the best model is translated to a financial risk in Euros and is compared to risk of the baseline model. The financial risk is calculated by taking the absolute sum of the errors in each contract and multiply it with 110 Euros per hour, which is the hourly reimbursement value. The error in each contract is defined as the mean error times the number of patients. In our example, there would be a total error of 17,190 hours in the baseline model, valued at €1,970,100. When using model3 to predict the budgets, there would be a total error of 5,266 hours, valued at €579,228. The error is reduced by 71%, a reduction of financial risk for the organization of €1.4 million on a budget of €83 million.

The skewness in the healthcare data remains a challenge. From the visual analysis in Figure 1 we observed that there is a clear presence of a high-cost group and that we systematically under predict this group, which means that it is hard to distinguish this group from other patients in advance. In line with results from Yang et al. (2018), we expected that past year service use could be used within a machine learning model to predict this group. However, random forest is not immune to the challenge of skewness. Moreover, Johnson and colleagues (2015) found that high-care service use can be temporary and instable at the individual patient level. This proposes a challenge in practice, because small changes in the prevalence of this group can have a high impact on agreed budgets between financers and suppliers (Eijkenaar & van Vliet, 2017).

An important finding in the variable importance was that ROM-measurements appeared more important predictors than predictors capturing DSM-IV criteria. Therefore, we should look beyond the DSM-IV criteria when creating predictive models. The data in model2 substantially improved performance over model1, which means that predictive tools should also aim to incorporate features about past service use, such as volume or the presence of acute care in the near past. This is in line with another Dutch study in which past service use has been proven to improve predictive performance (van Veen et al., 2015). Data from

model3 improved performance, which means that using information from the first two months of treatment is valuable in predicting service use for the remaining duration of the DRG.

Limitations

The most important limitation is that data from only one organization was used. In order to further analyze the implication on national healthcare policies, a multisite research should be conducted. Second, our analyses are based on real-world registration data, which are limited in data quality. Furthermore, we did not have access to all data in the EHR and were dependent on the available data that could be automatically extracted from the data warehouse. Therefore, potentially predictive information such as medication use could not be used as input features.

Strengths

The major strength of this paper is that we used a machine learning approach on a large available dataset from a mental healthcare organization. We chose to predict the number of hours instead of the price in Euros to make the model more applicable to other types of financing systems based on treatment sessions or hours. As to our knowledge, this is one of the few articles using a machine learning approach, with a train-test design, to predict a skewed numeric outcome. Predictions could be further improved with data from other institutions, such as insurance claim data. Furthermore, implementing such machine learning models in mental healthcare contributes to transparency of service use and reduces uncertainty in financial risk for healthcare financiers and suppliers.

CONCLUSION

The application of machine learning techniques on mental healthcare data might be useful to forecast expected service use on the group level. The results indicate that these models support healthcare organizations and financiers to reach agreements on annual budgets. Broader multisite research is needed to develop a national model. Nevertheless, uncertainty in the prediction of high-cost patients remains a challenge in the allocation of resources.

Appendix 1. Feature list

| Feature	Model	Variable type	Description
Hours of treatment in DRG	outcome	numeric	Total hours reimbursed in DRG product
Number of legal measures	1	numeric	Number of legal measures during start of DRG
Legal measure (type = detention)	1	dichotomous	Yes/no legal measure at start is detention
Legal measure (type = Court authorization)	1	dichotomous	Yes/no legal measure at start is court authorization
Legal measure (type = other)	1	dichotomous	Yes/no legal measure at start is of type other
Crisis situation	1	dichotomous	Patient started regular treatment after having been in crisis situation
Age	1	continous	Age of patient at start of DRG
Sex	1	dichotomous	Sex of patient
Marital status	1	categorical	Marital status (without history)
Education	1	categorical	Level of education (without history)
Living condition	1	categorical	Living condition (without history)
Main diagnosis group	1	categorical	Main diagnosis group at start of DRG
Social economic status	1	numeric	Variable created from postal code with a table from Statistics Netherlands
Global Assessment of Functioning	1	numeric	GAF score at start of DRG
Comorbidity Substance abuse	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Anxiety disordser	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Bipolar disorder	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Dementia	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Depression	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Eating disorder	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Personality disorder	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Pervasive	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Somatoform disorders	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Schizofrenia	1	dichotomous	Yes/no comorbidity at start of DRG
Comorbidity Other diagnosis	1	dichotomous	Yes/no comorbidity at start of DRG
Social dysfunctioning	1	dichotomous	Yes/no at start of DRG axis IV DSM-IV
Occupational problems	1	dichotomous	Yes/no at start of DRG axis IV DSM-IV
Other additional problems	1	dichotomous	Yes/no at start of DRG axis IV DSM-IV
Financial problems	1	dichotomous	Yes/no at start of DRG axis IV DSM-IV
Raw score baseline (ROM)	1	numeric	Raw total score on ROM-measurement at start of DRG (BSI, HoNOS children, adult and senior)
T-score baseline (ROM	1	numeric	Converted T-score on ROM-measurement at start of DRG
Serial number of treatment	2	numeric	The number of which consecutive treatment the DRG belongs to
First year of treatment	2	dichotomous	Yes/no whether DRG relates to first year of treatment
Care program	2	categorical	To which care program was patient referred to at start DRG
Referral type	2	categorical	Type of referral (primary, secondary, police, other)
Duration of treatment at start of DRG	2	numeric	Number of years from start treatment at organization and start DRG
Past year hospitalization	2	dichotomous	Was the patient hospitalized at the organization in the past year
Past year total hours of treatment	2	numeric	Total number of hours spent on patient in last year
Past year use of emergency service	2	dichotomous	Did the patient receive care from emergency service in the organization in the last year
Time spent in hours in month2	3	numeric	Total hours spent in month 2 of the DRG
Time spent in hours in month1	3	numeric	Total hours spent in month 1 of the DRG

Time spent on meetings in month 1 and 2	3	numeric	Total hours spent in month 1 and 2 on activities of type 'meeting'
Time spent on administrative activities month 1 and 2	3	numeric	Total hours spent in month 1 and 2 on activities of type 'administrative'
Time spent on coordination of care in month 1 and 2	3	numeric	Total hours spent in month 1 and 2 on activities of type 'coordination of care'
Time spent on the intake activities in month 1 and 2	3	numeric	Total hours spent in month 1 and 2 on activities of type 'intake'
Time spent on treatment activities in month 1 and 2	3	numeric	Total hours spent in month 1 and 2 on activities of type 'meeting'
Time spent by a psychologist in month 1 and 2	3	numeric	Total hours spent in month 1 and 2 by a profession of type 'psychologist'
Time spent by a psychiatrist in month 1 and 2	3	numeric	Total hours spent in month 1 and 2 by a profession of type 'psychiatrist'
HoursOtherDirect	3	numeric	Total hours spent in month 1 and 2 on activities of type 'other'
Hospitalization in month 1	3	dichotomous	Yes/no was patient hospitalized during first month of DRG

Chapter 6

Appendix 2.1. Non-cross-validated performance of machine learning models on training data from 2017[a].

	N	Mean hours	Model1 ($R^2 = .81$)				Model2 ($R^2 = .86$)				Model3 ($R^2 = .92$)			
			ME	CI	MAE	CI	ME	CI	MAE	CI	ME	CI	MAE	CI
1	5371	58.65	.59	-.14 - 1.36	18.78	18.20 - 19.35	.52	-.12 - 1.19	14.82	14.33 - 15.33	.64	.17 - 1.11	10.73	10.33 - 11.10
2	1404	61.75	1.41	-.13 - 2.84	19.65	18.62 - 20.73	.77	-.54 - 2.10	16.49	15.48 - 17.49	.12	-.89 - 1.15	11.96	11.15 - 12.72
3	200	76.12	1.28	-3.64 - 6.47	26.14	22.24 - 29.94	-.37	-4.80 - 4.01	21.20	17.90 - 24.45	-.86	-4.00 - 2.27	13.6	11.04 - 16.24
4	1398	60.75	2.13	.70 - 3.57	18.99	17.94 - 20.04	1.37	.17 - 2.55	15.26	14.30 - 16.22	1.14	.26 - 2.02	10.71	10.01 - 11.42
5	709	60.94	2.06	.05 - 3.96	18.96	17.54 - 20.40	1.68	.06 - 3.38	15.61	14.37 - 16.90	1.13	-.12 - 2.42	11.73	10.70 - 12.74
6	1829	64.68	1.34	-.08 - 2.85	20.69	19.64 - 21.74	.39	-.86 - 1.69	17.05	16.00 - 18.03	.44	-.48 - 1.39	12.12	11.41 - 12.83
Total	10911	60.80	1.13	.58 - 1.67	19.38	19.00 - 19.79	.70	.24 - 1.17	15.63	15.28 - 16.00	.61	.26 - .95	11.23	10.96 - 11.51

[a] Aggregated predictions on training data for each insurance company population. ME = Mean Error, MAE = Mean Absolute Error, with 95% bootstrapped confidence intervals.

Appendix 2.2. Scatterplot of predicted versus actual hours of model3 on training data from 2017.
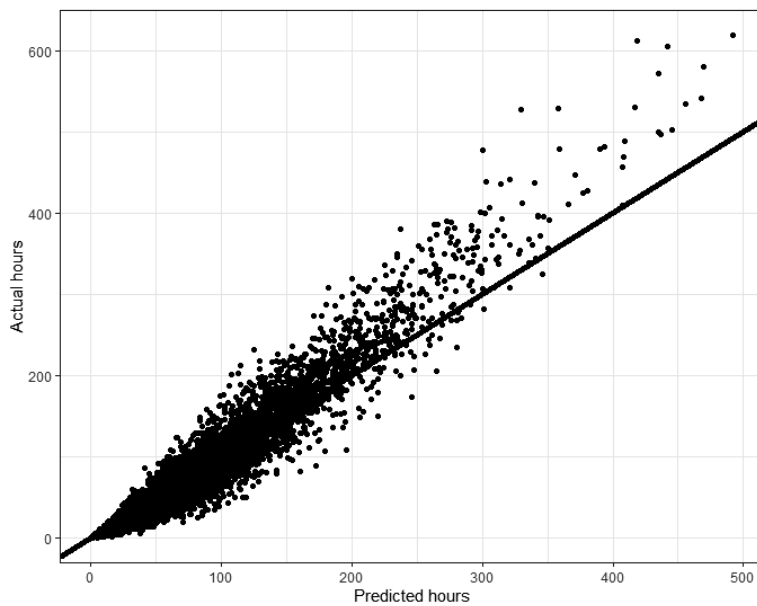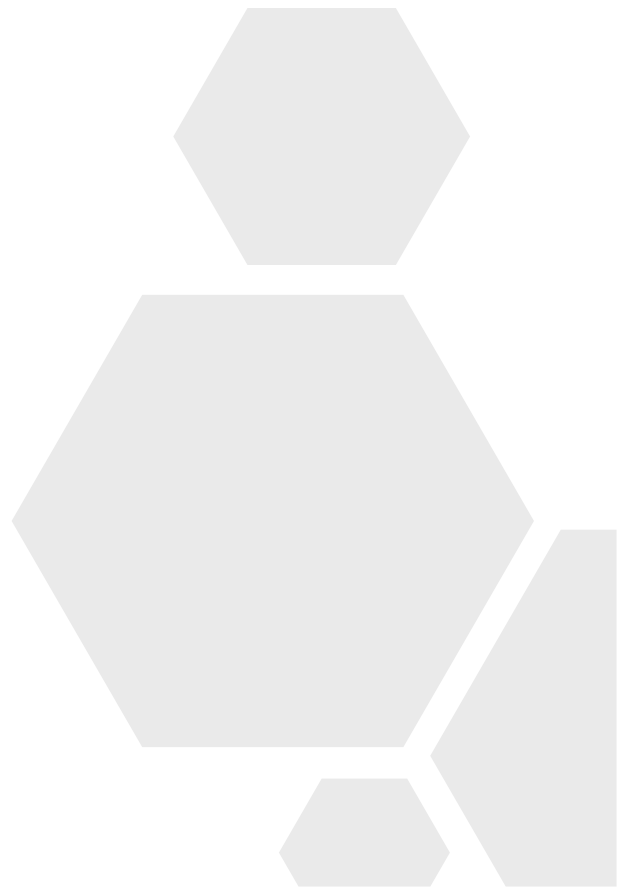
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Chapter 7

Summary and general discussion

BACKGROUND

The fundamental reforms within the Dutch mental healthcare that have been in place since 2006, are based on regulated competition. Care purchasers and care providers determine the price, quality and service on the basis of supply and demand, together and in competition with each other. One of the purposes of the reforms was to realize a shift from supply-driven to more demand-oriented delivery of care. In 2008, as a result of the implementation of the Health Insurance Act (HIA), the funding system for curative mental healthcare changed. Funding was no longer provided via the care act (AWBZ) but instead via the HIA, which focuses on cure-oriented healthcare. Hence, the focus shifted from 'care' to 'cure' (Janssen, 2017). Consequently, routine outcome monitoring (ROM) became a requirement for mental healthcare organizations in order to provide transparency regarding the type of care and for whom care is delivered. Health insurers, which became risk-bearing payers of mental healthcare, were particularly in favor of ROM-data to create a more transparent supply side. ROM is a process whereby systematic data collection and evaluation of treatment progress takes place. ROM-data can be used to evaluate individual progress and determine policy for mental healthcare institutions, health insurers, municipalities, and care users.

Insurance companies that have a large financial impact in the healthcare system use ROM-data for negotiations when establishing care contracts with healthcare organizations based on the volume, quality, and effectiveness of the care. In a recent document offered to the Dutch government, Van Os (2020) stated that there are differences in the quality parameters that insurers adhere to. In addition, the purchased amount of mental healthcare by insurers does not appear to be proportional to the population's need for care, especially when it concerns patients with complex problems. The method whereby insurers purchase mental healthcare should require, inter alia, more variables that provide information about the nature and effectiveness of care for people with complex problems.

Another large change in the mental healthcare system is the transformation towards providing more supported outpatient care. Assistance is increasingly being offered on an outpatient basis, for example, with F-ACT (Van Veldhuizen, 2007). Patients with SMI, of which psychotic disorders are highly represented, often need care in various domains. This requires collaboration from different agencies in order to meet the patient's needs, for example, mental healthcare facilities, protected housing, and municipalities in the context of debt restructuring and paid employment. In addition, interventions are becoming more

focused on rehabilitation and social participation, such as housing first (Nelson et al., 2020), supported employment (Frederick & VanderWeele, 2019), individual placement and support (Killackey et al., 2019). Although there are different requests for help, social participation in subgroups of patients with SMI can be distinguished based on their employment situation, daytime activities, and needs for care (Sanches et al., 2019). This is of importance, as it is assumed that change in SMI would lie more on the level of meaning or personal recovery than on symptomatic change (Macpherson et al., 2016). Also, greater emphasis is placed on shared decision making by involving the patient and significant others, as research has shown the positive impact of shared decision-making on health outcomes for patients with SMI (Huang et al., 2020).

Despite these changes within the field of mental healthcare, arranging the care system and allocation of resources for the SMI population is still a challenge. Moreover, although the quality is improving and the care provided is becoming more transparent, the average care does not yet sufficiently meet the individual needs of patients (Delespaul et al., 2017).

Goal of the thesis

Systematically collecting ROM-data has several advantages for the SMI population at the micro, meso, and macro level. Nevertheless, its use is widely debated. The aim of the present thesis was to explore how systematically collecting ROM-data contributes to the treatment of patients with SMI in terms of symptoms, functioning, care needs, and quality of life, so that patients receive the specific care that meets their needs, organizations can make policy and improve quality, and ROM becomes more transparent to care users and insurers, and useful in arranging the mental healthcare system.

MAIN FINDINGS

First, in *Chapter 2*, which individual mental healthcare factors play a role in achieving functional and symptomatic remission on micro and meso level was explored. This was investigated in young adults with a psychotic disorder. Of the 287 participants, almost 40% achieved or maintained symptomatic remission, 34% achieved or maintained functional

remission, and 26% achieved or maintained both forms of remission. Several important factors that play a role in achieving and maintaining remission. These include several sociodemographic factors and unmet care needs in the areas of psychological distress, company, and daytime activities. This implies that treatment requires attention towards symptom improvement as well as limitations in functioning. Also, in order to meet the patient's needs and provide the help necessary, it is important to repeatedly monitor care needs. Therefore, the systematic use of ROM on micro level is recommended.

In psychotic disorders, treatment strongly focuses on reducing psychotic symptoms, although it is known that other areas are important for general recovery as well. *Chapter 3* provides more insight into the relationship between positive psychotic symptoms (e.g., hallucinations, delusions) and social functioning, care needs, and quality of life. Over a three-year period, an improvement in social functioning was found, while positive psychotic symptoms increased. Also, improvement in social functioning was found to be related to a decrease in the dose of clozapine. These findings suggest that a reduction of positive symptoms is only partly related to social functioning. More research is needed to further explore the relation between symptomatology, social functioning and medication use.

Chapter 4 examines to what extent the healthcare vignettes, developed in 2012 for Dutch mental healthcare, are valid in relation to ROM variables (care needs and psychosocial functioning). They were developed in order to better arrange the mental healthcare for patients with SMI on a meso and macro level by creating more transparency regarding the allocation of resources. These vignettes were based on mental healthcare use in the previous year. It was found that the healthcare vignettes are insufficiently distinctive. Nevertheless, patients in the two complex care vignettes could be distinguished in terms of care needs and psychosocial functioning. This remained stable over time. In order to shape mental healthcare for the SMI population, it is important to take into account individual factors, such as care needs and the level of functioning, in addition to the required amount of care use.

Chapter 5 was explored whether individual future mental healthcare consumption can be predicted by ROM-data and three machine learning techniques. The Random Forest method proved to be the best predictive method (AUC= .71, PPV= .65). Mental healthcare use was influenced by the number of psychotic episodes, paid employment, involvement in social engagement, previous mental healthcare use, and the number of met care needs. The use of machine learning techniques, combined with ROM-data and information on care consumption, provides valuable information for identifying the risk factors of mental

healthcare consumption for the SMI population. Identification of these factors gives direction to the care to be provided. If immediate efforts are made to improve these variables, care consumption may decrease. Moreover, recognizing possible high healthcare consumers in advance helps to create more transparency in the treatment costs. This can be used in negotiations between mental health services and health insurers regarding the purchase of the care. However, these annual negotiations continue to be a challenge.

Chapter 6 built further on Chapter 5 to better understand the expected mental healthcare service use (hours) by developing a prediction model for individuals and groups using machine learning techniques. The model that best predicted service use had a mean error of 21 minutes at the insurance group level and an average absolute error of 28 hours at the patient level. This model contained clinical information as well as information regarding previous healthcare consumption. Of all patient characteristics, baseline ROM scores were the most predictive for healthcare consumption over time. Furthermore, systematic under prediction was observed for high service use patients. The results imply that the application of machine learning techniques to mental healthcare data might be useful to gain insight into the expected service. These models can support financiers and mental healthcare institutions in planning care and allocating resources. However, it remains a challenge, especially for the outliers who bear a large part of the costs. For this reason, more research towards predictive variables is needed as well as an economic perspective to express the prediction models in terms of costs and benefits.

In summary, at micro level this thesis found that ROM-data are able to support the determination of the treatment focus. Consistent use of ROM by clinicians gives more insight into the needs of the patient, allowing a more tailored care. In addition, symptom severity and level of functioning change over time, but for a great part they seem to be independent from each other. Treatment should therefore not only focus on reducing psychiatric symptoms but also on functional recovery. This requires collaboration and coordination between mental health organizations and social services.

At meso level is found that in addition to previous healthcare consumption and usual care consumer data, ROM-data are of importance in creating insight into future healthcare consumption. A small group of patients makes up a significant part of the costs, but the mental healthcare consumption of this group is difficult to predict. Together with the application of machine learning techniques, it is becoming more accurate to forecast expected service use. From an institutional point of view, a good policy on registration and collection

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of ROM-data are therefore essential. This, among other things, contributes to fair negotiations between healthcare suppliers and financiers. ROM-data also provides insights into the demand for care, allowing suppliers to use their resources more efficiently. This is relevant since there are long waiting lists and there is a shortage of healthcare professionals.

Finally, at macro level is found that categorizing patients with SMI into groups is a challenge. By categorizing patients into groups based on previous healthcare consumption, no clear distinctions for the groups can be made regarding patients' care needs and their impairments in functioning. As our research shows, ROM-data are important in predicting mental healthcare consumption. Therefore, by categorizing groups of patients in order to have a better overview of mental healthcare use and the allocation of resources, ROM-data should also be included. In addition, to enhance regional care planning and working towards a demand-driven transparent healthcare system, it is desirable to combine existing healthcare information with ROM-data.

CONSIDERATIONS

Methodological considerations

The main aim of this thesis was to investigate how ROM-data contributes to a better arrangement of mental healthcare for patients with SMI in terms of symptoms, functioning, care needs, and quality of life at the micro, meso, and macro level. The design includes secondary analyses on existing data. Annually collected (ROM) data from Altrecht mental healthcare was used as well as data collected by the GROUP study. A large part of the studies involved patients with a psychotic disorder. Psychotic disorders occur in a large number of SMI patients but may not be representative of the entire group. Also, a small note should be made about the use of the term ROM-data in the GROUP study. Technically, these data are not ROM-data because they were not collected in the context of outcome monitoring. Nevertheless, this study includes a large amount of data and repeated measurements over time, which gives us among other things a lot of information about the course of symptoms, functioning and care needs.

Reforming mental healthcare is a complex process and should be based on well-considered grounds from an empirical and practical perspective. In this thesis, insight into

several predictors of healthcare consumption is provided. However, not enough resources were available to replicate the findings. Also, the use of machine learning techniques is relatively new within the field of mental healthcare and SMI. As a consequence, some of the findings are not comparable with other studies. Therefore, we encourage others to follow the same methods so that this research approach can be replicated. We have described the methods used in detail. In order to replicate properly, it is important to take into account the use of the same type of data, as differences are found between the content and application of ROM-data (Gelkopf et al., 2020) as well as case-mix and mental healthcare variables.

Furthermore, data across several years was available, making it possible to track patients' symptoms and healthcare use over time. Although a lot of data was collected, due to changes regarding data collection and processing, questionnaires, and policy, missing ROM-data was unavoidable. Due to the ongoing transition within the mental healthcare system, we assume that changes will continue to occur. Therefore, it is important to create and maintain a steady policy on how to collect and process ROM-data. In the first place, ROM-data should be used for clinical practice. Its use at the meso and macro level has proven to be challenging and has unavoidable arbitrary aspects. For example, there are many collected case-mix variables and measurement instruments and several methodological biases (Hoenders et al., 2014). Another consideration is to what extent the proposed standardized questionnaires are useful for measuring the quality provided by the healthcare organization for benchmark purposes and to what degree patients' privacy is safeguarded (Van Os & Delespaul, 2018).

Clinical considerations

The chapters of this thesis have shown that ROM-data gives insights into patients' symptoms, functioning, needs, and quality of life. In this section, the clinical considerations of the findings are discussed. First of all, ROM is of significant value in evaluating and directing treatment, and essential in clinical practice. Although treatment is often focused on psychological symptoms, it should focus on social functioning as well, which is in line with previously mentioned studies. Additionally, attention should be given to individual needs, as they are related to functioning and might differ between patients and caregivers (Ganesh et al., 2019; Uygur & Esen Danaci, 2019). In order to provide tailored care, it is necessary to

know what other needs the patient has in addition to psychological symptoms. This provides useful information for developing treatment plans.

Another consideration is the consistent use of ROM-data. Our research has shown that predicting individual healthcare use is complex. Therefore, it is important to recognize the patients' needs from the start and evaluate treatment over time. Also, a well-implemented ROM process favors treatment outcomes (Brattland et al., 2018). Accordingly, which ROM-data will be collected and how it is collected must be well thought out, especially when comparisons are made between different institutions (Franchimont, 2013). ROM implementation has turned out to be a complicated process (Mackrill & Sørensen, 2019). In order to achieve better implementation, it is important to involve clinicians to improve the fit of the ROM process in clinical practice (Tasma et al., 2017), as well as patient experiences (Börjesson et al., 2019; Fornells-Ambrojo et al., 2017; Solstad et al., 2019).

A final consideration is, after using ROM for clinical purposes, to keep collecting ROM-data and analyzing it subsequently for policy purposes. This thesis has shown that it is not easy to arrange the appropriate care for patients with SMI, but by continuing to conduct research, one will gradually understand what patients need to recover. Therefore, even though good prediction models of arranging the care are not available yet, ROM-data should be gathered. With a large amount of data and thorough analysis this might be possible in the future. In the studies described in this thesis, we have taken a step into this direction by comparing several machine learning techniques that predict mental healthcare use. Because arranging care is an ongoing progress, close collaboration between mental healthcare institutions and other stakeholders will be required. Since the implementation of regulated competition and the allocation of certain responsibilities to municipalities, there are a lot more stakeholders. The clinical process is increasingly embedded in a society-oriented perspective, which again refers to healing aspects such as a social network, employment, or having meaningful activities.

Theoretical and policy considerations

As we have shown, ROM is useful in determining individual progress, but also supports policy making. Since SMI has a chronic course, often only small changes in symptoms and functioning are found over time as measured by ROM. For other syndromes with a less chronic course, such as anxiety or mood disorders, ROM seems more helpful in evaluating

individual treatment and will be used more frequent. As mentioned in the introduction, several factors make it challenging to use ROM in SMI patients. This is one of the reasons that clinicians discuss its value. Consideration should therefore be given to which measurement tool is appropriate (Mulder et al., 2010).

In order to provide efficient customized care and improve quality of life, it is necessary to consider the patient's needs and available resources to fulfill them, as is the case in value-based mental healthcare delivery. Hereby, the central goal of healthcare is to maximize value for patients, created from health outcomes which matter to patients relative to the cost of achieving those outcomes. This aims to contribute to solve the current challenge of unsustainable cost growth and variable quality in healthcare (Porter, 2008). Outcomes are considered at three layers: achieved health status, the nature of care and recovery (including readmissions and duration of return to normal daily activities), and sustainability of health (Porter & Lee, 2013). When transforming to value-based healthcare, several aspects should be taken into account, such as grouping patients by similar needs (not by diseases) and measure value for each group, implementing a payment scheme suitable for value, and focus on the whole cycle of care by integrating primary and specialist care (Porter et al., 2013).

Porter and Teisberg (2006) state that value will improve through competition among healthcare providers. In order to drive competition, transparent data on treatment outcome is needed. As a result, care can be selected that best meets the desired needs by the patient. To improve quality, healthcare systems will need a valid way to measure quality and address potential barriers among subpopulations and identify groups in most need (Kilbourne et al., 2018). This raises the importance of more routinely assessing mental health outcomes.

A point of criticism on value-based healthcare delivery, is its USA and acute-medicine centric origin. There are several challenges for implementing value-based healthcare towards other healthcare systems, amongst others: defining and developing outcome measurement, poor understanding of cost, most services cannot compete regionally or nationally (Baggaley, 2020). This is especially challenging for patients with long-term- and multi-setting-care needs that require support from various healthcare services (Elf et al., 2017), as is the case for SMI patients. It requires healthcare services to collaborate beyond the organizational boundaries to create clear patient trajectories.

Chapter 7

CONCLUDING REMARKS

Patients with SMI experience problems in several areas and, therefore, require intensive and integrated treatment. It has proved challenging to properly organize the mental healthcare system for this group of patients. In addition, it is also difficult to predict how much care someone will need, especially high-cost patients. This complicates negotiations between mental healthcare organizations and health insurers. Although it is difficult to pinpoint where mental healthcare can best be focused, ROM contributes to better insight into the progress of treatment and offers tools to improve mental healthcare at the micro, meso, and macro level. We have provided insights into several aspects of a patient's wellbeing, including psychological symptoms, psychosocial functioning, care needs, and quality of life. Treatment should not mainly focus on psychiatric and psychological symptoms, but also on the social aspect of mental health and the patient's personal needs. This also aligns with the report from Dutch health insurers describing their vision for mental healthcare in 2025, shifting the focus from treating and curing to working on social recovery (Kraaijeveld & Lomans, 2020). In addition, more research is needed into which individual and which mental healthcare factors are important actors in the treatment process, so that more personalized care can be offered, and institutions, municipalities, and insurances can align their policies accordingly. Therefore, replication of the results is desirable. If the same instruments are used, and research is carried out at several institutions, we can improve healthcare even further. Also, In order to better arrange the Dutch mental healthcare for the SMI population, the field should focus on collecting ROM-data and analyzing it with promising and up-coming machine learning techniques. To predict mental healthcare consumption more accurately, it is desirable to further develop a prediction model and investigate its economic impact.

To conclude, we especially get meaningful information from ROM-data at the micro level. It can also contribute to fairer resource allocation decisions at the meso and macro levels. However, this is accompanied by arbitrary elements and is a challenging path for further research. ROM increases quality and transparency for individual treatment, policymakers, and negotiations with insurers, among other things. However, ROM is just one piece of the mental healthcare puzzle. It is important that all parties agree on how and for what use these data are collected. Above all, let us respond to the patient's needs and learn from the value-based healthcare delivery approach. Insurers are key stakeholders in making

this a reality. Their vision of the near future in which they take as their basic premise that we as a society invest in increasing the solving and resilience capabilities of society as a whole and focus our attention more on social recovery (Kraaijeveld & Lomans, 2020) is one step towards this.

The introduction of this thesis started with several cases to give an idea of the complexity of the problems and needs for care that people with SMI may experience. Despite the complexity of treatment for patients with SMI, improvements can be achieved by multidisciplinary collaboration once the demand for help has been properly assessed and resources are available. Box 2 illustrates two successful cases as we would like to see it; different parties collaborate, and patients receive treatment with attention for both symptom improvement and personal recovery.

Box 2. Case studies.

Case A

Martin, a 59-year-old man, father of two children, and a former restaurant owner, got divorced after his company went bankrupt. As a consequence, he became depressed and started drinking. He moved to a campsite and only left to go to the supermarket to buy food and alcohol. Because of his debts, he became very suspicious of others. His children got worried and brought Martin to his general practitioner, who referred him to a mental healthcare institution. After he gained confidence, he got help with his finances from a social worker, who also helped him gain meaningful daily activities and find a new home. Meanwhile, a psychologist helped him to cope better with his depressive feelings, after which his craving for alcohol disappeared. His family stayed involved during the whole process. Even though Martin is currently still in the process of paying off his debts, he now has his own rental apartment, a new job, and has even met a new life partner.

Case B

Laila is a 27-year-old woman with psychotic episodes. These caused her to quit studying. She had a busy college life with a lot of parties and substance abuse. After her last psychotic episode, she got professional help, and after a year of intensive treatment, she is now able to recognize psychotic symptoms beforehand. She has them under control with medication and has changed her lifestyle. As a result, she has started studying again. To get her to this stage, a social worker, psychiatric nurse, and a psychiatrist worked together.

Chapter 7

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Chapter 7

Appendices

SUMMARY IN DUTCH
(NEDERLANDSE SAMENVATTING)

ACKNOWLEDGEMENTS
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ABOUT THE AUTHOR
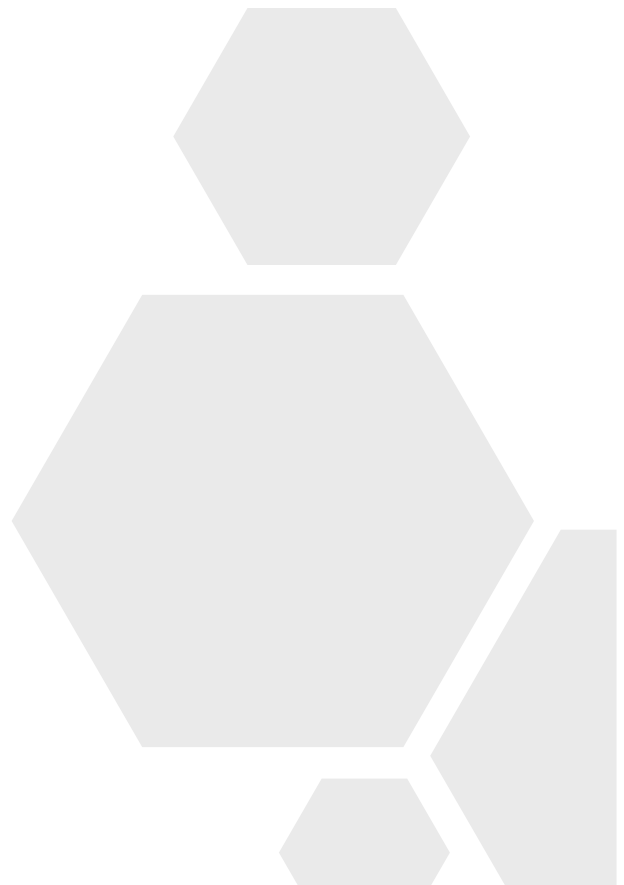
SUMMARY IN DUTCH

NEDERLANDSE SAMENVATTING

ACHTERGROND

Patiënten met ernstige psychiatrische aandoeningen (EPA) hebben te maken met langdurige complexe problematiek. Een groot deel van hen is gediagnosticeerd met een psychotische stoornis. Ze ondervinden problemen op verschillende levensgebieden. Denk hierbij aan geestelijke en lichamelijke ziekten, werkgelegenheid, huisvesting en sociale relaties (Drake et al., 2014; Viertiö et al. 2004). De problemen en zorgvragen die patiënten kunnen hebben op deze gebieden vragen om samenwerking tussen verschillende instanties, zoals GGZ-instellingen, beschermde woonvormen en gemeenten. Bijvoorbeeld in het kader van schuldsanering en betaalde arbeid. EPA-patiënten hebben vaak een intensieve behandeling nodig. Daarom is het belangrijk om te blijven onderzoeken hoe we de zorg voor deze groep kunnen vormgeven en daarmee de kwaliteit van leven verbeteren.

De organisatie van de geestelijke gezondheidszorg voor patiënten met EPA in Nederland is aan het veranderen van een meer geïnstitutionaliseerde focus naar een maatschappelijke benadering (Projectgroep Actieplan Ernstige Psychische Stoornissen, 2014). Sinds 2006 zijn er meerdere belangrijke hervormingen doorgevoerd in de Nederlandse GGZ. Een belangrijk doel hiervan was het realiseren van een verschuiving van aanbodgestuurde naar meer vraaggerichte zorg. De hervormingen zijn gebaseerd op gereguleerde concurrentie: zorginkopers en -aanbieders bepalen samen én in concurrentie met elkaar de prijs, kwaliteit en dienstverlening op basis van vraag en aanbod.

In 2008 veranderde het financieringssysteem van de geestelijke gezondheidszorg met de invoering van de Zorgverzekeringswet (ZVW). Hierdoor verschoof de focus binnen de GGZ van 'care' naar 'cure' (Janssen, 2017). Routine Outcome Monitoring (ROM) werd vanaf dat moment een vereiste voor GGZ-instellingen om transparant te zijn over het type zorg dat geleverd wordt en voor wie. Vooral zorgverzekeraars waren voorstanders van de inzet van ROM, omdat zij sinds de invoering van ZVW zelf het risico dragen voor kostenoverschrijdingen binnen de GGZ.

ROM is een proces waarbij systematisch gegevens zoals psychisch toestandsbeeld, patiëntkenmerken en zorggebruik worden verzameld. Behandelaars gebruiken ROM-data

voor het evalueren van de individuele voortgang van een patiënt. Een belangrijke andere toepassing van ROM ligt in het maken van beleid door o.a. GGZ-instellingen, zorgverzekeraars en gemeenten. Verzekeraars gebruiken ROM-data bij de onderhandelingen voor zorgcontracten met de zorgorganisaties. Zij kijken daarbij naar de omvang, kwaliteit en effectiviteit van de zorg. In een recent document dat aan de Nederlandse overheid is aangeboden stelt Van Os (2020) dat er verschillen zijn in de kwaliteitsparameters die verzekeraars gebruiken. Daarnaast lijkt de door verzekeraars ingekochte hoeveelheid zorg niet in de juiste verhouding te staan tot de zorgbehoefte van de bevolking. Dit geldt vooral voor patiënten met complexe problemen die zoals gezegd op meerdere gebieden zorgbehoeftes hebben. Van Os laat zien dat de wijze waarop verzekeraars de GGZ inkopen moet worden aangepast door meer variabelen op te nemen die informatie kunnen geven over de aard en de effectiviteit van de zorg voor mensen met complexe problemen.

Een andere grote verandering binnen de geestelijke gezondheidszorg is de transformatie van intramurale naar meer ambulante zorg. Steeds vaker bieden GGZ-instellingen ambulante hulp, bijvoorbeeld met Flexible Assertive Community Treatment (Van Veldhuizen, 2007). Dit maakt het mogelijk dat begeleiding op een door de patiënt gewenste locatie plaats kan vinden. Een andere verandering is dat interventies meer gericht zijn op revalidatie, herstel en maatschappelijke participatie, zoals housing first (Nelson et al., 2020), begeleid werken (Frederick & VanderWeele, 2019), individuele plaatsing en begeleiding (Killackey et al., 2019). In de ambulante zorg leggen GGZ-instellingen ook meer nadruk op gedeelde besluitvorming door patiënten en hun naasten actief bij de behandeling te betrekken. Hiervan is aangetoond dat het een positief effect heeft op de gezondheidsuitkomsten van patiënten met EPA (Huang e.a., 2020).

Ondanks deze veranderingen binnen het speelveld van de geestelijke gezondheidszorg is de inrichting van de GGZ en daarbij de toewijzing van middelen voor de EPA-populatie nog steeds een uitdaging. De kwaliteit en transparantie van de zorg wordt beter, maar komt nog onvoldoende tegemoet aan de behoeften van patiënten (Delespaul et al., 2017).

DOEL VAN HET PROEFSCHRIFT

Het systematisch verzamelen van ROM-gegevens heeft verschillende voordelen op micro-, meso- en macroniveau voor de EPA-populatie. Toch staat het gebruik ervan regelmatig ter discussie. Dit proefschrift onderzoekt hoe het systematisch verzamelen van ROM-data bijdraagt aan de zorg voor patiënten met EPA. Het uiteindelijke streven is bijdragen aan verbetering van de zorg, zodat patiënten de specifieke zorg krijgen die aan hun behoeften voldoet, organisaties beleid kunnen maken om de kwaliteit van zorg te verbeteren en ROM transparanter wordt voor zowel zorggebruikers als -financiers.

BELANGRIJKSTE BEVINDINGEN

In *hoofdstuk 2* is geanalyseerd welke patiënteigenschappen en kenmerken van de behandeling een rol spelen bij het bereiken van functionele en symptomatische remissie op micro- en mesoniveau. Dit is onderzocht bij jongvolwassenen met een psychotische aandoening. Van de 287 deelnemers bereikte of behield bijna 40% een symptomatische remissie, 34% functionele remissie en 26% beide vormen van remissie. Belangrijke factoren die een rol spelen bij het bereiken en behouden van remissie zijn verschillende sociaal-demografische factoren, maar ook onvervulde zorgbehoeften op het gebied van psychische gezondheid, gezelschap en dagactiviteiten. De resultaten maken duidelijk dat de behandeling zowel aandacht vraagt voor verbetering van psychiatrische symptomen als voor het sociaal-maatschappelijk functioneren en dat het belangrijk is om de behoeften van de patiënt consequent in de gaten te houden.

Bij psychotische aandoeningen is de behandeling sterk gericht op het verminderen van symptomen, hoewel bekend is dat ook andere gebieden belangrijk zijn voor het herstel. *Hoofdstuk 3* geeft inzicht in de relatie tussen positieve psychotische symptomen (bijv. hallucinaties, waanbeelden) en sociaal functioneren, zorgbehoeften en kwaliteit van leven. Over een periode van drie jaar werd een verbetering in het sociaal functioneren gevonden, terwijl de positieve psychotische symptomen toenamen. Ook blijkt er een relatie te zijn tussen verbetering van het sociaal functioneren en de afname van de dosis clozapine. Deze bevindingen suggereren dat een afname van positieve symptomen slechts gedeeltelijk

samenhangt met sociaal functioneren. Ze duiden op de noodzaak om de relatie tussen symptomatologie, sociaal functioneren en medicijngebruik verder te onderzoeken.

In *hoofdstuk 4* is onderzocht in hoeverre de in 2012 voor de Nederlandse GGZ ontwikkelde zorgvignetten inhoudelijk overeenkomen met ROM-variabelen (zorgbehoefte en psychosociaal functioneren). De zorgvignetten zijn ontwikkeld om de GGZ voor patiënten met EPA beter te organiseren op meso- en macroniveau. Dit gebeurt door meer transparantie te bieden over de toewijzing van middelen. De vignetten zijn gebaseerd op het GGZ-zorggebruik van het voorgaande jaar. Uit de resultaten blijkt dat de vignetten zich in beperkte mate onderscheiden. Wel onderscheiden patiënten in de twee complexe vignetten zich, gekeken naar zorgbehoefte en psychosociaal functioneren. Om de GGZ voor de EPA-populatie optimaal in te richten, is het van belang om naast de benodigde hoeveelheid zorggebruik ook rekening te houden met individuele factoren, zoals de zorgbehoefte en het niveau van functioneren. Op macroniveau is het daarom belangrijk om systematisch ROM-data te verzamelen, zodat deze factoren geïdentificeerd en meegenomen kunnen worden bij de besluitvorming over de inrichting van de zorg.

In *hoofdstuk 5* is onderzocht in hoeverre het toekomstig zorggebruik in de GGZ kan worden voorspeld met behulp van ROM-data en drie machinale leertechnieken. De Random Forest-methode blijkt hier de beste voorspeller te zijn (AUC= 0,71, PPV= 0,65). Zorggebruik in de GGZ wordt beïnvloed door het aantal psychotische episodes, betaald werk, maatschappelijke betrokkenheid, eerder zorggebruik en het aantal zorgbehoeften dat werd vervuld. Het gebruik van machine learning technieken, gecombineerd met ROM-data en informatie over zorggebruik, levert waardevolle informatie op voor het identificeren van risicofactoren van hoog zorggebruik. Identificatie van deze factoren geeft richting aan de te verlenen zorg. Bovendien helpt het vooraf herkennen van mogelijke grote zorggebruikers bij het creëren van meer transparantie in de behandelkosten. Dit kan vervolgens gebruikt worden bij onderhandelingen tussen GGZ-instellingen en zorgverzekeraars over de inkoop van zorg.

Hoofdstuk 6 bouwt verder op het vorige hoofdstuk, om beter inzicht te krijgen in het toekomstig zorggebruik in de GGZ. Met behulp van machine learning technieken is een model ontwikkeld voor individuele en groepsvoorspellingen. Hiervoor zijn zowel een training- als testset gebruikt. Het model met de beste individuele en groepsprestaties toonde aan dat voorspellingen op groepsniveau nauwkeuriger waren dan op individueel niveau op de testset en bevatte zowel klinische informatie als informatie over eerder zorggebruik. Er werd systematische te weinig uren zorggebruik voorspeld. Van alle patiëntkenmerken was

de basislijn ROM-score het meest voorspellend voor het zorggebruik. Uit de resultaten blijkt dat de toepassing van machine learning technieken op GGZ-data nuttig is om inzicht te krijgen in de verwachte dienstverlening. De modellen kunnen financiers en GGZ-instellingen ondersteunen bij het plannen van zorg en toewijzen van middelen.

CONCLUSIES EN AANBEVELINGEN

Patiënten met EPA ondervinden problemen op verschillende gebieden en hebben daarom een intensieve en geïntegreerde behandeling nodig. Dit proefschrift toont aan dat ROM bij kan dragen aan het verkrijgen van meer inzicht in de voortgang van de behandeling en handvatten biedt om de GGZ op micro-, meso- en macroniveau te verbeteren. Het blijft echter een uitdaging om de GGZ voor deze groep patiënten goed te organiseren. Zo is het moeilijk te voorspellen hoeveel zorg iemand nodig heeft. Dit geldt vooral voor intensieve zorggebruikers en bemoeilijkt de onderhandelingen tussen GGZ-organisaties en zorgverzekeraars.

We hebben inzicht geboden in verschillende aspecten van het welzijn van de patiënt, waaronder psychische klachten, psychosociaal functioneren, zorgbehoeften en kwaliteit van leven. De behandeling zou naast psychische symptomen ook gericht moeten zijn op het sociaal-maatschappelijk functioneren en de persoonlijke behoeften van de patiënt. Om zorg op maat te kunnen leveren is meer onderzoek nodig naar de invloed van individuele en GGZ-factoren in het behandelproces, zodat instellingen, gemeenten en verzekeraars daar hun beleid op af kunnen stemmen.

Om de GGZ voor de EPA doelgroep beter in te richten moeten we ons in de toekomst richten op het verzamelen van ROM-data en deze analyseren met machine learning technieken. Binnen de GGZ zijn er veelbelovende technieken hiervoor in opkomst. Om het zorggebruik in de GGZ beter te kunnen voorspellen is het wenselijk om het predictiemodel verder te ontwikkelen en de economische impact ervan te onderzoeken.

Er is veel zinvolle informatie te halen uit ROM-data op micro-, meso- en macroniveau. Het geeft inzicht en richting aan het grotere geheel, maar is ook een nuttig hulpmiddel om te werken aan kleinere doelen. ROM verhoogt de kwaliteit en transparantie voor onder andere individuele behandeling, beleidsmakers en onderhandelingen met verzekeraars. Toch is ROM slechts een stukje van de GGZ-puzzel. Het is belangrijk dat alle

partijen het eens zijn over hoe en waarvoor deze gegevens worden verzameld. Laten we vooral inspelen op de behoeften van de patiënt.

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- Voltaire -

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Sascha Kwakernaak was born on August 24, 1987 in Nieuwegein, the Netherlands and grew up in Houten with her parents and younger sister. She received her high school degree in 2004 (College de Heemlanden, Houten) and obtained a certificate in Social Work at Hogeschool van Utrecht in 2005, after which she continued her education with a study Psychology at the Utrecht University (2005-2008), where she also obtained her master's degree in Clinical and Health Psychology (2009). During this period, she followed an internship at BAVO-Europoort in Rotterdam as a psychologist in an outreaching mental healthcare team for patients with severe mental illness. After she graduated, she started in August 2009, as a junior researcher at Altrecht Mental Healthcare, in Utrecht. The major task here was collecting and analyzing ROM-data collected in the FACT-teams and a collaborating protected housing instance. She started with her PhD in 2015, as a scientist practitioner at Tilburg University for one day a week, next to her other research work at Altrecht. Two years later, she started working as a psychologist in the clinical practice in a FACT- team, also at Altrecht Mental Healthcare, combined with her PhD function. At the end of 2018 she started with a new job, as a psychologist, at PsyMens in Utrecht, which she combined with her dissertation. She treats patients with diverse psychological disorders and helped setting up psycho-education gatherings and self-study manuals for patients that are on the waiting list for psychological treatment.