Valorisation
Relevance

Patients with severe mental illness (SMI) are often ill for decades. They have a lower quality of life and much higher morbidity and mortality, both in comparison to the general population and other patients with mental disorders (1). It is estimated that there are around 281,000 patients with SMI in the Netherlands (2). The socioeconomic cost has not been calculated, but it is expected to be high, as patients with SMI often need ongoing psychiatric care and rarely have paid employment (3).

This thesis focuses on patients with SMI and specifically the long-term course, recognition, and treatment of movement disorders. Thus enabling us to i) identify which factors influence movement disorders over the course of a multidecade illness, ii) develop easier and more cost-effective ways of recognizing movement disorders, and iii) test if current treatment guidelines are effective in SMI patients. The Curacao Extrapyramidal Syndromes Study is well suited for this kind of research as it is the longest running study on movement disorders and it includes all patients with SMI on the island of Curacao thus limiting bias.

Studies have shown that over 80% (4,5) of SMI patients have at least one movement disorder and movement disorders are associated with lower quality of life (6), poor treatment adherence (7), and increased mortality (8–10). However, there is a paucity of research into movement disorders in psychiatric patients in general and movement disorders in SMI patients specifically. Currently, most treatment guidelines mentioning movement disorders do not differentiate between SMI and non-SMI. This differentiation is important because guidelines are often based on randomized controlled trials (RCTs) performed in populations that are less severely ill, younger, respond better to treatment and have fewer co-morbidities than SMI patients. Severity and duration of illness, co-morbidity, age, and duration of illness, are all factors known to influence the risk of developing movement disorders and their reaction to treatment. That is why multiple research groups have advocated to test RCT-based treatment recommendations in psychiatry with naturalistic studies (11,12).

Target groups

First and foremost this thesis is intended to improve the lives of patients with SMI and to inform the professionals who treat them on the prevalence and treatment options of movement disorders. This thesis is part of the movement for increased attention for SMI patients that started with the 2014 “Over de brug” report by the Kenniscentrum Phrenos. SMI patients have been receiving increased attention over the years as it has become clear that they are frequently at a disadvantage compared to other members of the population (Kenniscentrum Phrenos, ‘Over de brug’ report) both in the socio-economic realm as in
the medical realm. For instance, Dutch SMI patients have been shown to face stigmatization from health care professionals such as general practitioners and even doctors in training (13). Also the recent PHAMOUS study showed that patients with SMI have persistent low rates of treatment for various metabolic disorders (14).

This research has already been presented on multiple occasions both nationally and internationally and received the 2nd Prize for the best poster presentation from the Nederlandse Vereniging voor Psychiatrie (NNVP). It will also be presented to the Dutch organization for psychiatric patients and the organization for parents of psychiatric patients.

This thesis is of specific interest for the developers of treatment guidelines that cover SMI patients and policy makers connected to SMI patients, both in mental health organizations themselves and in the health insurance companies. To this purpose the members of committee that published the Dutch Schizophrenia treatment guideline have already been informed of the results of the article that show that the effect of switching antipsychotics and dose reduction on movement disorders is different in SMI patients compared to other psychiatric patients using antipsychotics.

Activities/Products

Wearables and other electronic monitoring devices are becoming more and more common in clinical and psychiatric practice. They have several important advantages over clinical rating scales and self report scales, firstly they offer an objective measurement thus reducing bias, secondly they can record patients symptoms in their daily life where they are most relevant and finally because they involve patients in their own treatment. As wearables are becoming cheaper and easier to use it is expected that they will become common place in psychiatric treatment.

Originally we investigated blink rate because it would be easy to integrate into an app for a mobile phone. However, blink rate alone cannot sufficiently differentiate between patients with and without parkinsonism. Combining the blink rate with the tasks developed in chapter six (walking, foot stamping, wrist rotation, and bending and extending the elbow) could drastically improve the sensitivity and specificity of such an app. This app could be developed by a researcher within the MHeNS or by an external company.

On a broader scale the knowledge generated by this thesis has also been used to improve national training programs on movement for residents in psychiatry and nurse practitioners. Thus improving treatment for patients all over the Netherlands.
Innovation

This thesis is the first to focus on the very long term course of movement disorders in psychiatric patients. Whereas previous studies lasted, at most, three to five years this thesis has an 18 year follow-up making it unique. This offers new insight into how movement orders develop and fluctuate over the decades. Over the course of 10 to 20 years movement disorders relapse and remit multiple times within a single patient, even when no changes in medication are made.

This thesis, along with other research(15,15–22), challenges the theory that movement disorders in SMI patients are entirely based on medication or, more specifically for tardive dyskinesia and parkinsonism, antipsychotic use. This is important because it has an enormous impact on how to treat these movement disorders and well as how to prevent them. When the assumption is that movement disorders are solely caused by antipsychotic medication research and treatment guidelines will focus on stopping medication and dose reduction. When movement disorders are considered part of the psychiatric disorder their treatment could be either focused on managing the movement disorders themselves or on optimally treating the psychiatric disorder. Either way they are much more likely to be effective if the base assumption is correct. This is reflected in our findings in chapter two in which recommendations in treatment guidelines did not affect movement disorders in patients with SMI as predicted but had no effect or in some cases made the movement disorder worse.

Another way in which this thesis is innovative is the use of instrumental measures to diagnose and track movement disorders. As has been mentioned previously instrumental measures have important advantages over the clinical rating scales that are currently used in both research and clinical practice. They are objective and can be used with minimal training in many different settings. They use a continuous as opposed to an ordinal scale which means they are easier to interpret and better suited for tracking a movement disorder over time. And finally they are more sensitive and can be used to identify subtle movement disorders which current rating scales cannot do.

Schedule & Implementation

As a continuation of this thesis a new thesis will be started at the end of this year, with the aim to develop an integrated set of measures for movement disorders. This set will be implemented in the yearly screening and medication review of the SMI patient ward of GGz Centraal in Amersfoort.

Also the new thesis aims to create a longitudinal naturalistic database with data of movement disorders, quality of life, psychiatric symptoms, and medication use. This data will be made publically available thus enabling both researchers from GGz Centraal as well as researchers from other Dutch institutions to replicate guidelines recommendations in a naturalistic real world clinical setting. The results from these repli-
cations for patients with SMI can be integrated into current diagnosis based treatment guidelines. Thus enabling treatment guidelines to have recommendations and information specific to SMI patients.

In the long-term treatment guidelines specifically for SMI patients could be developed, thus making more tailored treatment possible for this patient group.
### References


