On the road to recovery
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CHAPTER 1
Introduction
SEVERE MENTAL ILLNESS

Many of us experience psychological problems at some point in our lives. Most of the time people can overcome these struggles on their own, with their loved ones, or with help from mental health care professionals. For some people, their problems become so severe that they need more intensive psychiatric care for longer periods of time. When their problems seriously affect their social lives, their professional careers and their ability to function in the community for a prolonged period of time, we speak of a severe mental illness (SMI)\(^1,2\).

In the Netherlands, an estimated 1.6% of the people aged between 18 and 65, who receive mental health care in the Netherlands, suffers from a SMI\(^2\). Approximately two thirds of these patients are diagnosed with schizophrenia or a related psychotic disorder\(^2\) which is characterized by a variable and fluctuating presentation of positive symptoms (such as hallucinations and delusions), negative symptoms (such as amotivation, social withdrawal and blunted affect) and cognitive deficits (such as planning, memory and attention issues)\(^3\). The remaining group with SMI consists of patients with severe depression, bipolar disorder, personality disorder, developmental disorder or addiction\(^2\). Moreover, it is common for SMI patients to have co-morbid psychiatric and somatic disorders\(^4,5\). The majority of SMI patients receives mental health care within the community, but a small proportion of the SMI patients are dependent on care in a residential psychiatric facility due to the consequences of their illness.

HISTORY AND DEVELOPMENT OF RESIDENTIAL CARE

Psychiatric institutions have historically been located in relative isolation from society. They were the last resort of psychiatry and once admitted, a large number of these patients would remain in the institution for the rest of their lives. The general opinion was that the admitted patients were ‘incurable’ and they were thus ‘given up’\(^6\). However, in the last half of the previous century there was a shift from institutional care towards community care in most Western countries. This was due to the recognition of the poor condition of the old mental hospitals\(^7\), the introduction of the neuroleptics and an increased awareness that living in the community would promote social inclusion and role functioning\(^8-10\). The United States and many European countries have since then downsized and closed many psychiatric hospitals in the 1960s and 70s (e.g. in Italy and the United Kingdom). Community based mental health care services were developed to support patients with gaining and maintaining skills that are necessary for successful community living\(^9\). In the United Kingdom, it turned out that many previously hospitalized patients were able to live in the community; nevertheless a small group of patients remains in need of inpatient care\(^11\).
Residential care in the Netherlands

In the Netherlands, the process of deinstitutionalization was not quite as rigorous. Although community services for mentally ill patients were evolving, there was no large movement of patients from mental hospitals to the community, at least not to the degree of other western countries. In the 1980s, sheltered facilities were built to offer hospitalized patients a place within the community. These smaller-scale facilities would function as a bridge between psychiatric hospitals and society (De Nieuwe Nota, 1984). In sheltered facilities, patients usually have their own bedroom in a house within the community that they share with other patients. The form and intensity of the support provided by health care workers depends upon the needs of the patient, and usually encompasses support with everyday tasks such as household activities, or by providing everyday life structure. In the long-stay clinical care facilities patients generally share a house with others or have their own room in larger buildings at the site of a mental health organization. In these facilities, the nursing staff is available around the clock offering support with basic daily activities for the majority of patients.

From the 1990s to the early 2000s, there was indeed a decrease in patients staying in the long stay clinical care institutions. However, the total number of people living residentially increased due to the growth of sheltered facilities. The interpretation of the reduction of hospital beds in favor of the sheltered facilities can be ambiguous; it can be regarded as a positive change since sheltered facilities are considered a step towards independent living, but it can also be a new form of institutionalization.

Currently, approximately 26,000 people in the Netherlands live in long-term residential facilities, including sheltered living facilities (70%) and clinical care facilities (30%). Compared to other countries, the number of beds in the Netherlands is still large but the amount of patients staying in clinical facilities generally decreases or shows a smaller increase, and the growth of sheltered facilities now has come to a stop. In the next few years, due to changes in laws and legislation, more patients will move from clinical facilities to sheltered facilities and from sheltered facilities into the community. The ambition is to reduce the number of hospital beds in the Netherlands by 30% by 2020 as compared to 2008.

Residential SMI patients

Patients who are admitted to residential facilities have often insufficiently recovered after previous hospitalizations. They usually find it difficult to take initiative, to make use of their strengths and to ask help from others. Especially people who have been in residential care for a longer period of time have lost contact with the people they knew before their admission, and have thereby lost sight of their life outside of the residential facility. It must also be noted that patients are usually confronted with their illness in their late teens or early twenties, which is a time where people normally build
their social networks, finish school, and get a job. Instead, they have often lost friends, family ties were loosened, and they have left school without graduating or have been unable to get or keep a job. Thus, their psychiatric condition hampered participating in society and building a social network, which causes problems with functioning in the community\textsuperscript{2,18,19}. In addition to these societal or environmental factors, social and everyday functioning is largely impacted by negative symptoms and cognitive deficits\textsuperscript{9,20–22}. These aspects of illness are considered to be most profound in the residential patient group and are difficult to treat\textsuperscript{9,23,24}.

**NEGATIVE SYMPTOMS**

Negative symptoms refer to the loss or reduction of functions and behaviors that are present in the general population. They encompass impairments in affect and emotion, social interaction, purpose and motivation\textsuperscript{25}. The negative symptom construct includes blunted affect (reduced range of emotional perception, experience and expression), alogia (poverty of speech), anhedonia (reduced ability to experience pleasure), asociality (reduced social drive and interaction) and avolition/apathy (reduced desire, motivation, and initiative)\textsuperscript{26}. They are most common in schizophrenia patients, but can also be present in other illnesses, such as bipolar disorder\textsuperscript{27}. Negative symptoms are often present as early as the prodromal phase\textsuperscript{28–30}. Although they are more prominent in chronic patients compared to first episode patients, they are generally assumed to be relatively stable and enduring\textsuperscript{31–33}. Fluctuations in negative symptoms may occur during acute psychosis, when negative symptoms can be masked (or aggravated) by the clinical presentation of positive symptoms, or when they worsen after a psychotic relapse\textsuperscript{30}.

**COGNITIVE DEFICITS**

Cognition is an umbrella term for mental processes that we use to perform goal-directed behavior. Cognitive functions include working memory (the ability to keep information active and to process this information), attention/vigilance (the ability to focus and maintain focused on a task, or the ability to direct attention to relevant stimuli), verbal learning and memory (the ability to store and retrieve verbal information), visual learning and memory (the ability to store and retrieve visual information), reasoning and problem solving (the ability to use information to draw conclusions, make decisions, conceptualize problems and generate solutions), speed of processing (the amount of time it takes to perceive and process information and/or to respond) and executive functions (the ability to plan, monitor and adjust goal-directed behavior)\textsuperscript{22,34}. Cognitive deficits are common in psychiatric disorders\textsuperscript{24}. For example, patients with schizophrenia generally show impairments in multiple cognitive domains\textsuperscript{35} and patients with bipolar disorder show a similar pattern but are usually less severely impacted\textsuperscript{36}. In schizophrenia, cognitive problems are not merely a consequence of the disease
or the psychotic episodes, as they are often present before the onset of psychosis. Cognition can deteriorate further after psychotic episodes, but is usually fairly stable within persons.

**THE IMPACT OF NEGATIVE SYMPTOMS AND COGNITIVE DEFICITS**

The presence of negative symptoms often severely interferes with everyday functioning, for example by impaired psychosocial functioning, reduced participation in leisure activities, fewer meaningful relationships, and impaired occupational functioning. Cognitive impairments are also severely disabling, because we need our cognitive functions to plan, perform and succeed in all kinds of everyday tasks. Problems with cognition, and with executive functioning in particular, can impair vocational functioning and social functioning as well as basic activities of daily living. Cognitive functioning is not only a predictor for psychosocial functioning and community functioning, but also for the degree of care dependency and quality of life. Further, it influences the ability to benefit from psychosocial rehabilitation and hampers functional recovery. In addition, both cognitive deficits and negative symptoms have an impact on somatic health, as they provide additional barriers with maintaining or even starting a regular exercise routine and adopting a healthy diet. Thus, they also affect the lifestyle behaviors, which have been related to the elevated prevalence of metabolic syndrome and the shortened life expectancy of SMI patients due to large to cardiovascular diseases. The profound impact of negative symptoms and cognitive deficits on various aspects of functioning and well-being stresses the need for research contributing to the knowledge of these disabling characteristics, and for the evaluation of methods to reduce their impact on patients’ everyday lives.

**DISENTANGLING NEGATIVE SYMPTOMS**

The lack of successful treatments for negative symptoms is a serious unmet need in the treatment of patients with SMI. The development of treatment for negative symptoms is complicated by their heterogeneity, which is not yet fully understood. When symptoms or groups of symptoms respond differently to treatment, evaluating change in global negative symptoms could average out individual differences in responsiveness to treatment in clinical trials, which may lead to false negative findings. Therefore, efforts have been made to define more homogenous subgroups within negative symptoms. A first distinction was proposed in the 1980s, between primary and secondary negative symptoms. Although similar in clinical presentation, primary symptoms refer to those negative symptoms that are core features of schizophrenia. Secondary negative symptoms are a consequence of factors other than the pathology of schizophrenia per se, such as depressive symptoms, anxiety, antipsychotic medication, perceived stigma, cognitive deficits and environmental deprivation. Secondary negative symptoms are...
thought to disappear or diminish when their underlying cause is addressed\textsuperscript{51}. However, not all secondary negative symptoms respond to treatment and they can be enduring as well\textsuperscript{52}. So far, treatments targeting enduring negative symptoms have failed to achieve a reduction of these symptoms.

**SOCIAL AMOTIVATION AND EXPRESSIVE DEFICITS**

The latest efforts in disentangling the negative symptom construct have taken a dimensional rather than a categorical approach. For a decade now, researchers have investigated a division into separate clusters of negative symptoms. Although the use of different negative symptom instruments and differences in terminology complicate a clear definition, there is consensus on the division into a motivational subdomain and an expressive subdomain\textsuperscript{23,53}. The literature on this subdivision is dominated by studies using the Scale for the Assessment for Negative Symptoms (SANS)\textsuperscript{54}, in which the motivational subdomain consists of the subscales anhedonia, asociality and avolition, and the expressive domain includes the blunted affect and alogia subscales. Thus, both subdomains are associated with reduced self-initiated behavior, with the motivational subdomain reflecting a reduced drive (interest, motivation) to engage in social interactions, and the expressive domain reflects a reduced emotional perception and a reduced verbal output. Although the evidence for these subdomains is quite established, there are a number of questions that warrant further research.

First, it is not clear whether the subdomains can be distinguished in patients with a severe course of illness, since most studies have investigated relatively young patients in the early stage of their illness\textsuperscript{55,56}. Further, although the Positive and Negative Syndrome Scale (PANSS)\textsuperscript{57} is widely used in both research and clinical practice, only two studies have investigated the subdomains using the PANSS\textsuperscript{56,58}. Though one study included a group of patients with a chronic psychotic disorder, these patients participated in a medication trial in which selection bias and generalizability to patients stable on medication may be an issue\textsuperscript{58}. Both studies using the PANSS have indeed found a motivational and expressive domain. To investigate whether the division in subdomains can be replicated in an unbiased severely ill population (i.e. not selected based on participation in a treatment trial), we performed a factor analysis on PANSS items in outpatients and residential patients with a duration of illness of 5 years or more. The results are presented in chapter 2.

Second, the functional and clinical correlates of each subdomain seem to be different. The literature is not consistent on these relationships, although the motivational subdomain is most often seen as the major cause of functional problems, while the expressive subdomain is usually reported to be less important for functional outcomes\textsuperscript{23,53}. If the domains relate differentially to outcomes, one may not only be able to predict (to some extent) outcomes based on the profile of negative symptoms,
but also direct treatment accordingly. In chapter 2, we therefore also cross-sectionally investigated the relationship between the subdomains and functioning.

Third, the course of these subdomains over time remains unclear. The course of each subdomain may differ from the course of global negative symptoms which could also be masked when investigated together. It is possible for example, that changes in expressive deficits are more easily detected because they can change even during an interview. The motivational domain is evaluated based on engagement in the social environment, which takes more time to change. On the other hand the expressive domain may be more stable as it has been related to cognitive deficits\textsuperscript{38,39}, which are constant over time\textsuperscript{38,39}. We investigated the course of SA and ED over a period of six years and investigated whether SA and ED could predict functioning and quality of life six years later in chapter 3. Furthermore, we examined whether subgroups with a different course of SA and ED could be identified and whether these subgroups could predict the level and course of outcome over a time period of six years.

**Moving forward in the treatment for residential patients**

A better understanding of negative symptoms may ultimately lead to treatments that are able to reduce the level of negative symptoms. However, symptomatic relief is not always enough to improve functioning or well-being. At the same time, people can develop a new meaning and purpose in life despite enduring symptoms\textsuperscript{60} or in other words: learning to live better in the face of mental illness\textsuperscript{61}. The personal and unique process of adapting to the limitations that are caused by aspects of the illness is called recovery\textsuperscript{60}. The task of the mental health care professional is to support patients with their recovery, by supporting and encouraging them in their needs, wishes and goals. The care for SMI patients therefore no longer merely constitutes the relief of symptoms, but also involves support with developing a new meaning and purpose in order to live a fulfilling and satisfying life\textsuperscript{60}. The wishes and goals that SMI patients have in this process are not different from those of people without a mental illness. They include social and intimate relationships, having a place of their own, having a job, physical health, financial independence and being accepted as a person\textsuperscript{19,62,63}.

Despite the movement towards recovery-oriented care, research on recovery-oriented interventions and methods for residential patients is scarce and there is a lack of evidence-based interventions for this population\textsuperscript{64}. Several factors influence recovery processes, including negative symptoms and cognitive deficits, but also other aspects such as (internalized) stigma and demoralization. Furthermore, the residential environment can evoke passivity, dependence and an unhealthy lifestyle as a result of the hospital routine. In the hospital environment, many tasks are taken over by the staff and there are often limited opportunities for adopting healthy lifestyle behaviors. One way of supporting patients with their recovery process is through adaptation of
the environment, so that the person is able to “make the best use of their residual capacities” and can function on the highest level possible. We have adopted this environmental approach with two interventions evaluated in this dissertation. The first aimed to reduce the impact of cognitive deficits on everyday functioning and is described in chapters 4 and 5. The second is an intervention aimed at reducing the impact of environmental factors of residential facilities on lifestyle behaviors, described in chapter 6.

REDUCING THE IMPACT OF COGNITIVE DEFICITS

Pharmacological agents, mainly the newer antipsychotics, have been shown to have a positive but small effect on cognitive functioning in some studies. Although there are trials investigating add-on medication to enhance cognitive functions, at present there is no pharmacological treatment that improves cognitive functioning with a large effect size. Younger patients are thought to be more responsive to medication or other forms of treatment that aim to enhance cognitive capacity, because of their greater neuroplasticity than older patients. Cognition has also been the target of psychosocial interventions. Roughly two types of strategies can be defined: restorative and compensational approaches.

RESTORATIVE VERSUS COMPENSATORY APPROACHES

Restorative interventions aim to achieve durable improvement in functioning by improving the performance on one or more cognitive domains, for example through repeatedly practicing computer tasks or games. Drill-and-practice techniques have shown to improve a variety of cognitive functions, such as attention, speed of processing and memory. Cognitive training may be limited to rote learning of skills, as in drill-and-practice training, but several studies have also used training of cognitive strategies to improve memory, attention and executive functioning. For restored or enhanced cognitive functions to improve functional or psychosocial outcomes, transfer to other tasks at home or at work is essential. It has been recognized that this generalization to other activities does not usually take place spontaneously. Additional rehabilitation programs in which the patient can practice their cognitive skills in real-world settings do increase the impact on (psychosocial) functioning. With additional programs, patients are provided the opportunity to put their enhanced cognitive capacities into practice, which has a higher chance of generalization. Combining restorative approaches and supported education or vocational programs shows promise in improving durable functional outcomes. However, some studies have reported that restorative techniques do not have an additional effect to that of rehabilitation programs alone.

Compensatory treatments do not aim to restore cognitive functions themselves but they target the performance of everyday tasks in a more direct way, through bypassing
cognitive functions. Cognitive Adaptation Training (CAT) is a compensatory training with an individually tailored approach.\textsuperscript{79–82} That is, compensatory strategies used with CAT are based on the individuals’ specific problems in daily life, and are adapted to the level of cognitive impairment and the characteristic behavior of the person. By using environmental supports, such as checklists, alarms or pill containers, the extent to which patients need to rely on their cognitive functions is reduced. The supports are set up in the patient’s own living environment, or in the working area, where activities actually take place. Several studies on the effects of CAT in schizophrenia outpatients have shown that CAT improves everyday functioning, quality of life, medication adherence and reduces relapse rates in outpatients with schizophrenia.\textsuperscript{80,81,83} Compensatory treatments may be especially suited for residential patients whose cognitive and functional deficits can be considered to be most severe.\textsuperscript{84} Moreover, CAT focusses on simple daily living activities which fits the level of support that these patients need.

**Reducing the impact of the obesogenic environment**

Negative symptoms, cognitive deficits and other factors such as side-effects of medication (including increased appetite and sedation) pose difficulties for patients to adopt a healthy lifestyle.\textsuperscript{85} On top of that, residential facilities usually offer unhealthy meals (e.g. salty meals from a central kitchen, high-calorie snacks and food low in fibers), and few opportunities for exercise.\textsuperscript{86} This is referred to as an obesogenic environment.\textsuperscript{87} There is a growing awareness that mental health professionals have underestimated the effect of lifestyle factors and that mental health services should play an important role in promoting a healthy lifestyle.\textsuperscript{88,89} Lifestyle is obviously related to physical health, and has a great impact on cardiometabolic risk factors such as waist circumference, triglycerides, fasting glucose.\textsuperscript{80} Considering the dramatically elevated prevalence of metabolic syndrome and the shortened life expectancy of SMI patients due to cardiovascular diseases,\textsuperscript{49,50} efforts to improve the lifestyle of SMI patients are necessary to reduce these cardiometabolic risk factors.

**Lifestyle and mental well-being**

Besides having an effect on physical health, lifestyle is an important factor for mental well-being. A healthy lifestyle, such as regular physical exercise and a healthy diet, has a positive effect on psychopathology and can also be seen as a form of daytime activities.\textsuperscript{89} Furthermore, a healthy lifestyle is important for preserving and optimizing cognitive capacities.\textsuperscript{89} Research has shown that exercise programs or nutritional interventions can have a positive effect on several aspects of well-being, such as psychotic symptoms, anxiety, stress, depression and quality of life.\textsuperscript{91–94} Generalizability to residential patients is difficult however, because most studies evaluating psychosocial effects of lifestyle interventions have only included outpatients. Only one study so far evaluated a
lifestyle intervention in long-term hospitalized patients who were overweight or obese, showing improvements in quality of life after three months but no changes in psychotic symptoms. Because of the role of the residential environment in health behaviors and because small lifestyle changes can have a large impact on health status, a small change approach was adapted in an effort to change the obesogenic environment of residential SMI patients in the Effectiveness of Lifestyle Interventions in Psychiatry (ELIPS) study. The primary aim was to reduce the cardiometabolic risk factors that contribute to the increased morbidity of cardiovascular disease in these patients compared to the general population. The secondary aim was to investigate the effect of the lifestyle intervention on psychosocial outcomes. The results of the intervention on psychosocial outcomes are presented in chapter 6.

**Outline of this dissertation**

In this dissertation we address factors that influence the recovery process of residential patients with a SMI, with a focus on negative symptoms, cognitive deficits and lifestyle. In chapters 2 and 3, we aim to contribute to the understanding of negative symptoms by investigating their subdomain structure, longitudinal course and the impact on functioning and quality of life. In chapter 4, we describe the results of a pilot study on Cognitive Adaptation Training (CAT), a psychosocial intervention aimed at the reduction of the impact of cognitive deficits on everyday functioning. The rationale and study design of the multicenter RCT on CAT are described in chapter 5. In chapter 6 we describe the results of the Effectiveness of Lifestyle Interventions in Psychiatry (ELIPS) study, aimed at the reduction of the impact of the obesogenic environment on psychosocial functioning. Finally, in chapter 7, the clinical and scientific implications of the work united in this dissertation is discussed and suggestions for further research are proposed.
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