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PLANTING A TREE

On Recovery, Empowerment and Experiential Expertise

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In memory of George Witte

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Chapter 1

INTRODUCTION

This book is about recovery, empowerment and experiential expertise, three concepts that are gaining popularity in psychiatry and mental health services. It integrates different kinds of knowledge: reflections on my experiences as a psychiatric patient and as a client in mental health care[1], experiential knowledge or 'collective' knowledge, built within the psychiatric user movement, and, finally, scientific knowledge. This integration is intended. I am convinced that while the user movement is built on experience, it will only become influential and change how psychiatry is practiced in the future, when its knowledge leads to documented effective change. Therefore, quantitative and qualitative outcome and implementation research is necessary.

There is an interaction between the three sources of knowledge: my lived experiences are influenced by, and reciprocally influence experiential knowledge from a growing group of peers. Collective knowledge within the psychiatric user movement is knowledge that is based on years and years of exchanging experiences with severe mental suffering and with the psychiatric system. This collective knowledge is not just 'anti' or some sort of political activism. It is autonomous, critical and very rich in innovative ideas on how to help persons with severe mental distress to deal with life. It just needs to be explicated and disseminated as useful and enriching knowledge.

Insights and experiential knowledge derived from the lived experiences of users of mental health care systems have increasingly influenced the research agenda of academic psychiatry. Recovery has become a mainstream concept. For some researchers with lived experience, it became the basis of their scientific work. The challenge remains to what degree the user movement can present the case that tools developed by and for peers are effective, using the criteria and rigor of evidence-based practice in the scientific community. And of course, as is the case for all social scientists, who we are, colors our scientific work and its directions. I want my work to be based on the integration of these different kinds of knowledge, because I believe in a productive and impactful interaction.

For a long time, I was split between worlds. My first contacts with mental health care were more than 35 years ago. My role as a psychiatric patient made me active in the psychiatric user movement and made me sensitive for the implicit knowledge that users and survivors of psychiatric services share. And ever since I started to work

1 I use 'patient', 'client' and 'user' (of psychiatric services) by each other. Which of the three I use is depending on the context.

as a researcher in the field of mental health care, I saw a huge gap between worlds. Professionals in psychiatry, academics and policy makers were (and remain, to a degree) ignorant of the perspectives, experiences and knowledge of and within the user movement. More so, they were unaware of the potentials of 'their' patients. And the user movement did not have effective strategies to link their experiential knowledge with the practice of professional psychiatry.

With this book, I aim to contribute to bridging this gap between the experience-based perspective and the scientific perspective.

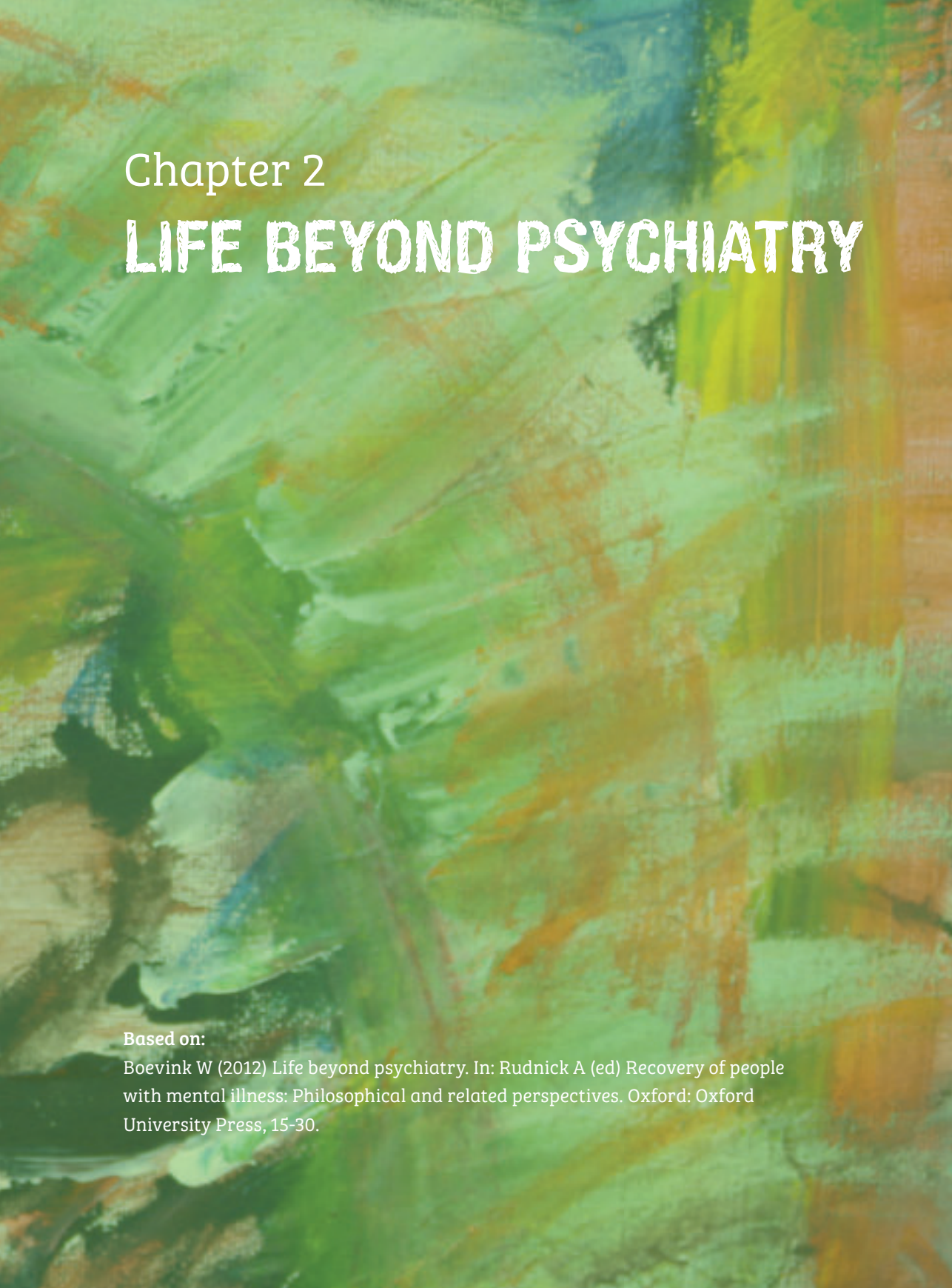
Part one of this dissertation consists of three experience-based qualitative accounts on the concept of recovery. *Chapter two* illustrates the concept of recovery, drawing on my personal experiences during a long period as a psychiatric inpatient, numerous short admissions on closed wards and as a user of outpatient care. I found that recovery is a subjective, natural process, which can (also) develop independently of the professional support offered. The best that professionals in psychiatry can do in this process is to acknowledge, follow and support it. It is paramount they should not frustrate, but facilitate recovery. *Chapter three* serves to analyze my discovery journey in more detail. In particular, it is helpful to discover the association between life history and severe mental distress. I describe how in my case – as well as in the case of many others – there appeared to be an association between childhood trauma and psychoses later in life. *Chapter four* is an illustration of the (inter) relations between trauma, dissociation and psychosis. Psychotic experiences, which can easily be seen as symptoms of a latent construct called schizophrenia – when isolated as mere symptoms, become real and meaningful once put back in the context where they occurred for the first time. Apparently abnormal behavior can be logical once the link is made to the original context.

Part two focuses on empowerment. In *chapter five* the content of this concept is explored from the perspective of persons with severe and long term mental suffering. Empowerment denotes the process for persons with severe mental suffering who regain control of their lives. It is a rich concept in which helpful components are: survival techniques, life art, connectedness and good help and support. Based exclusively on user input, we developed the Netherlands Empowerment List (NEL) for adults with

psychiatric disabilities. The instrument has good psychometric properties. The NEL is a suitable instrument to capture the dimension of empowerment and the dimension of empowerment in recovery in European mental health settings. This is described in detail in *chapter six*.

Part three is about experiential expertise, about its development and its effectiveness in practice. In *chapter seven*, I describe my work in the TREE program (toward Recovery, Empowerment and Experiential expertise). The TREE program was a user movement initiative facilitated by Trimbos Institute and was in place from the late nineties to 2015. TREE was developed and led by service users with mental vulnerabilities. It set out to provide effective methods and strategies to help people help themselves in their process towards recovery. The TREE program facilitated user self-management through group meetings. The group meetings were supervised by trainers, themselves service users, who used their own knowledge and experience to help others with mental health difficulties. The long term aim was to facilitate empowerment in as many ways as possible. *Chapter eight* reports a randomized controlled trial on TREE. It shows that user-developed and user-run recovery programs may bring about small but reliable changes in recovery and community outcomes after two years.

In the **final part**, the relevance and valorization of this dissertation is discussed. Is it possible to bridge the gap between the experiential expertise of users of psychiatric services and scientific knowledge? The chapters of this thesis aim to contribute to bridge this gap. Did I succeed? Can we better understand how the knowledge contained within the user movement contributes to and facilitates what people with severe, sometimes disruptive, long term mental distress can do to help themselves? Is it possible to dialectically combine this perspective with the language and conceptual approach of evidence-based practice and the culture of psychiatry as embedded in mental health services? Can we develop novel, multi-expert practices derived from this perspective?



Chapter 2

LIFE BEYOND PSYCHIATRY

Based on:

Boevink W (2012) Life beyond psychiatry. In: Rudnick A (ed) Recovery of people with mental illness: Philosophical and related perspectives. Oxford: Oxford University Press, 15-30.

Introduction: overwhelming experiences

During one of my psychotic episodes I did not go outside the house. There was too much movement and there were too many sounds in the world outside. My brain could not put them in an order of importance. It could not set priorities anymore. I just had to deal with everything at the same time. So I stayed at home. There I started seeing strange things. I saw structures in the world which linked all kinds of different events together into one logical scheme. I thought the music on the radio was about me. I saw bad signs everywhere. For instance, there were a lot of birds in my garden. I thought they had come to get my soul. I was guilty. For all their baby birds that had not made it, they came to get my soul. And I saw my best friend, who committed suicide a few years before, sitting on a cloud, waving at me and laughing, waiting for a chance to take me with her.

I also experienced that the movement in the world, including myself, had slowed down. My body could only move very slowly. When in my head I had the will to lift my arm, it would take ages before that message was received by my arm. It felt as if I was in thick water and could only move in slow motion. Everything around me had this same slow motion. These were very frightening experiences and they could last for days, although back then I did not have a sense of time. Time did not exist. Even time was in thick water. It was a kind of vacuity, a no man's land. Not in real life, but also not dead.

Words confine

Inevitably, a story of recovery is also a story about suffering. There is no getting away from that, if only because you have to explain what it is you need to recover from. When generating a recovery story you try to capture this immense suffering in words. Psychosis is hard to describe. It is far-reaching and overwhelming. Many mental health challenges are farreaching and overwhelming. They involve a severe distortion of meaning.

They render the world unfamiliar, unrecognizable, and threatening. Mental suffering can turn life into a living hell. Just 'being' can no longer be taken for granted. In fact, nothing can be taken for granted. Once you know that life will become unbearable beyond a certain boundary, once you know that you have such

a boundary, very little can be taken for granted again. A psychiatric disorder is also accompanied by a sense of estrangement. What you have is often closely allied with who you are. The manifestations of the disorder sometimes dominate your entire personality. The distinction between the individual and the disorder is soon lost, and it is very difficult to regain (Geekie et al, 2011).

Being able to find words that describe your overwhelming experiences increases the likelihood that you will learn to stand up to these experiences instead of getting lost in them. Recovery means finding the right words for yourself in order to regain and maintain some sense of self. You are not your disorder. You are a person, a human being who for some reason has to deal with immense suffering (Boevink and Corstens, 2011).

I am a person and this is my life

I was not yet twenty when my first psychotic episode occurred. More than 20 years have since elapsed. That first psychosis was not the last. I am still not rid of it. Am I expected to wait another 20 years until cure descends upon me? Well, to be honest, I am not willing to do so. I have decided that I will not wait for the doctor to give me a pill that will cure me. I have decided that my condition and I are two separate entities. I am not my disorder (Boevink, 2006).

My life – and that of many other people with a psychiatric disability – is all about learning to cope with that which cannot be cured. We have not yet experienced the miracle of cure. For many of us, waiting for it to come along is a complete waste of time. The psychiatric system is not able to cure nearly as often as some would like to believe. Waiting for this to happen keeps us submissive and passive. It is better to ask 'What are the obstacles in my life, and how should I deal with them?' The question to be answered is 'What do you want to do with your life and what care and support do you need to make that possible?' We are not psychiatric disorders with care needs – we are people with lives to be led, some aspects of which may require professional care or assistance. It is relatively unimportant who provides such assistance or where we obtain it. The primary aim of psychiatric care should be to enable us to lead our lives in the manner that we wish. Care is a means to an end, not an end in itself.

To maintain an existence with a psychiatric disability is difficult enough. To build a life around that condition demands courage, perseverance, and creativity. People with a psychiatric disability are true 'life artists'. We tell each other about this art of living in our stories, and in doing so we face the things that overwhelm us. Through our stories, we are able to see the difference between who we are and the problems that we have. We learn to formulate for ourselves what care we need. We develop stories in which we recognize ourselves. We search for the right words to do justice to our experiences, and in doing so we regain our own identity. Through our stories we say 'This is my life, this is who I really am, and this is how other people can help me' (Stastny and Lehmann, 2007).

'Negative symptoms': the necessity not to move

Overwhelming experiences can trigger psychosis. On the other hand, psychosis itself is an overwhelming experience. For me, psychosis means that I lose every attachment to the common, shared life. I become a wanderer in an infinite space. There is no longer any hold, any shared understanding, or any anchor. Psychosis is horrifying. And when I think that the worst is over, I may find myself in a psychiatric institution, on an admission ward, crowded with crazy people. Some of them may be so confused that I feel threatened by their falling apart. Others may be suffering so much that I feel sick just looking at them. There are a few staff members who spend a lot of time in their office, observing and controlling their patients through a glass wall. I am in fact on my own.

A closed ward is a place to lie low, a place where you should not want too much. Those who have the keys in their pocket decide whether you can have a will or not. Psychosis and psychiatry do not feed my courage. Usually they frighten me off, scared of my will and scared of the unknown.

And then I find myself in a day care center with many others just like me. There are a few staff members who spend a lot of time in front of their computer and talking on their mobile phone. I can call them if I need them. But others can call them, too, if they need them. They are being called all the time when I need them. I am in fact on my own.

And so I take stock of my situation. I know what I have achieved. I survived psychosis and I survived psychiatry. What more would I want? To want more could lead to the loss of everything that I have achieved. To have a will can lead to the next psychotic episode, and the next psychiatric admission, and that's what I don't want anymore. That's for sure.

I come to a standstill. I live my life in the same way day after day and I do not deviate from my routine. Hang on. Hang on! No spreading my wings or self-development for me, thank you. Nice words for people who can permit themselves that luxury. In a rigid way I follow my routine, day after day, because of all that I have been through. I get out of bed, fight my way through the side-effects of my medication, smoke, drink coffee, smoke, drink coffee, smoke, drink coffee. I go to the shop, take a nap, walk to the day activity center, go home for a meal, watch television, and then I take my medication and face the next fight against its side-effects. I follow the safe path and never ever deviate from it.

I survive. I don't have the courage for anything more than that. I cannot permit anything new in my life. I am grateful for what I have, and I never knowwhere something new might take me. I cannot permit myself more than survival. People around me don't understand. They call me unmotivated or say I have negative symptoms (Strauss et al, 1985; Strauss, 1994). However, the only thing I am trying to do is to survive. Because somewhere, deep inside, I have this little bit of hope for better times. If I could just hang on for long enough.

When psychiatry takes over

One of the consequences of serious psychiatric suffering is that you will find yourself as a patient in a psychiatric hospital. This is an overwhelming experience for many of us, especially the first time. It is difficult to cope with being a patient in a psychiatric hospital. It is a place where traumas are likely to be experienced, and where even abuse may be undergone or witnessed (Deegan, 1993).

My stay in the institution damaged me in several ways, however unintentional that might have been. When I look back at how undignified it was to be a psychiatric

patient, the self-respect for which I fought through the years feels shaky. When I remember the humiliation inherent in being a psychiatric patient, I feel so angry that I am liable to forget my resolution that it will never happen again.

No matter how you look at it, psychiatric institutions are reservoirs of human suffering. Other people's misery that you witness there is added to your own. This, to me, is one of the contradictions of psychiatry – we herd together people who are suffering and then expect them to feel better –. Even someone who is feeling relatively well will be affected by the hectic and ever changing tensions of an admission ward. So how can a person suffering from psychosis, in such a place with all these tensions, ever recover from their psychosis (Mosher et al, 1975)?

The first experiences of psychiatry among people who will probably have to deal with it for a long time are usually more negative than positive. The literature stresses the importance of compliance – it is essential for the success of the treatment that the patient does what the doctor says. But how can compliance be expected from people whose memories of their first psychosis are dominated by the constraint and violence of the admission? Compliance usually refers to the prescribed medication, but how can people who are injected with prophylactic drugs during admission be expected not to have a negative view of psychiatric medication?

As a researcher I visited a psychiatric hospital where there was no form of authoritative supervision of the practising psychiatrists. Over the years they had developed the habit of working weekend shifts from home, from their back garden. Any person who was admitted at the weekend would automatically be sedated without being seen by a doctor. It often took days before the heavy sedation and all of its side-effects wore off and specifically prescribed medication was administered. Try to imagine the consequences of this kind of introduction to psychiatry. I believe that many people have had to pay a high price for the indifference of the responsible psychiatrists.

Recovery is not only about mental problems but also about the consequences. You also have to adjust to the typical life of an institution, to which you become accustomed more quickly than you realize. Then there is the stigma attached to being a psychiatric patient, which is very real if you yourself start to believe in it,

or the marginal position that society assigns to former psychiatric patients, or their meager financial position, or job discrimination (Van Weeghel, 1995). Psychiatric institutionalization deeply affects a person's life, and its consequences will, in some form or other, persist for so long that it will never really belong only to the past. It is important to acknowledge this.

Holy science

Psychiatry is not accustomed to see its users as we really are – as people with a past, a present, and hope for the future. Psychiatry, at least in its traditional and mainstream versions to date, aspires to be a medical science – it wants to deal with the pathology of the individual. It is not really concerned with the contexts in which mental health problems develop. Consequently, on entering the psychiatric institution we are reduced to the status of carriers of a mental illness, or we are even seen as the illness itself. In order to classify the disorder, our behaviour as well as our stories are analyzed for symptoms. Only what is significant to the diagnostic examination is seen and heard. We are examined but not really seen, and we are listened to but not heard. Psychiatry does not regard us as serious discussion partners: after all, if you have a disorder you cannot speak (Antonovsky, 1987; Thomas, 1997).

Chronification

The longer you are a psychiatric patient – so becoming a 'chronic' patient in the extant psychiatric jargon – the more likely you are to forget how to lead a normal life. Admission to a hospital means that you exchange your familiar, trusted surroundings for hospital life and routine. You can no longer call upon the person you were. Your main role in life now becomes that of a patient. This role should not be underestimated – it demands certain skills, such as the ability to adapt. As a patient, you have to fall into the rhythm and routine of the large hospital organization. You have to comply with the rules. Unfortunately, the dividing line between adaptability and submission is not always clear, and it can easily become less so over time. Once a sense of resignation has taken hold, you have absolutely no means of help to regain your former life. A situation develops which could well endure until the end of your days.

The longer you remain a psychiatric patient, the more likely you are to forget the rules of normal life. You forget that life itself has its ups and downs, and you forget

that you used to be a person with both good and bad traits. As a patient, you learn to blame all the negative aspects of your life on your disorder. During my career as a patient, I learned to attribute every setback and every minor disappointment to my disorder. I now know that everyone has the occasional bad day when nothing seems to go right and the entire world seems to be conspiring against them. But for a long time, that sort of day would set alarm bells ringing for me because I thought that it was the precursor of a relapse. I had forgotten about life's everyday irritations. For a long time I did not dare to take matters into my own hands, to lead my own life. I relied on the professionals, as they were the experts. Other people knew how I should lead my life, whereas I did not. When you are a psychiatric patient, it is extremely difficult to retain your self-esteem and your own values and opinions. And it is almost impossible to explore or develop them.

Regaining normality

I need to regain, maintain, and cherish my strength. After a psychotic episode or a psychiatric admission, I do not feel strong enough to rely on myself. It takes time to regain strength once you have experienced how unlivable life can be beyond certain limits. Once you know these limits, little can ever be taken for granted again. You are confronted with an overpowering vulnerability which must be surmounted. You have to test yourself again. The world and all it contains must be rediscovered. Yet you have been drained of self-confidence, which makes it a hazardous journey. The right balance must now be found between when to act and when to leave well alone, and between when to protect yourself from the dynamics of life and when to participate in life.

The recuperation phase is precarious. It is no coincidence that most readmissions take place during the period shortly after discharge. Inadequate resilience is partly, but by no means entirely, responsible.

There is also a transition to be made from being a psychiatric patient to full-time citizenship. You must resume daily life. Psychiatric treatment does not usually teach you how to do these things. It does not show you how to manage your finances, find accommodation or turn it into a home. Of course we now have psychiatric rehabilitation (PSR), which aims to achieve these aims and is often successful. However, PSR

is commonly not well integrated with mainstream psychiatry, in practice if not in theory. Forms have to be filled out, visits have to be made to the social services or housing corporations and job medical assessments are needed. These are daunting tasks for anyone, and they all require plenty of resilience. Rules and procedures are complex, waiting is endless, and people can be unfriendly. Even if you have not been recently discharged from an institution, this is all very challenging.

You must learn to take things for granted again. You must regain the 'normalcy' of everyday life. That, too, is a matter of time, of adding every day without calamities to the previous one. And when things have gone well for a while, you may tentatively relax and think that perhaps the worst is over.

Cling to the patient role

For a very long time I was afraid of a repetition of what had preceded my first psychiatric admission. This should not be confused with fear of my own madness. My madness was simply the culmination of years of gradual deterioration, and in some ways constituted a relief in the form of a refuge. I watched myself slowly but surely lag behind my peers. I felt life slipping through my fingers. This is still one of my nightmares, that I am gradually being sidetracked away from everyone. I dream that first my own track runs parallel to the main road where all the others are, so things still appear OK. Only I know that there is already no going back, and that what happens is irreversible. Then suddenly everyone else veers off in another direction and I am left all alone.

For a long time, my reaction to a lack of strength and self-confidence was to cling without questioning to the course adopted by those who had treated me. It was as if they were looking over my shoulder and commenting on everything I did in terms of their model of treatment: 'Take care not to be too reclusive or on your own', 'Remain concrete and concentrate on the here and now', and 'Keep awake during the day, you can sleep at night'. I saw myself through their eyes and applied their methods. I was unyielding for fear of a relapse if I deviated from the prescribed path. Perhaps you see no harm in this, but it kept me in my role of psychiatric patient. I attributed much of what is part of life to my illness.

Now I know better. For example, I discovered that insomnia need not automatically mean a point of no return. I now know that everyone has bad days on which nothing seems to go right and the whole world seems to be against them. That is all right – tomorrow is another day. But back then those days alarmed me, because I thought they heralded a relapse. I learned to distinguish between life's normal irritations and issues that warrant real concern. Recovery means that you have to 'de-psychiatrize'. You have to learn to attribute some if not most setbacks to life itself rather than to that so-called disorder inside you. You must accept life and take responsibility for it.

It takes a long time before you dare to lead your own life again, and before you trust your own judgement again. I am now 10 years further on, and I have discovered that regaining strength and self-confidence requires endless patience.

Making stories

An important part of my recovery is my set of attempts to grasp what is going on in my life. For a long time I did not want to know, and settled for the role of psychiatric patient. A turning point for me was the moment when I dared to look back on my life. Until then, there had been only one official version of my life story. According to this version, I have a psychiatric disorder which every so often lands me in a psychiatric hospital. There I receive 'treatment', and although I will never be entirely 'cured', I am able to live with the remnants.

This is not my story. I do not believe in it anymore, and it is of no use to me. My own version is different. In my own version I am not the carrier of a psychiatric disorder, but a very damaged person. In my story my admission to hospital was the result of a complex interaction of factors. My story tells you that I am also the victim of abuse. My madness is undoubtedly a reaction to these unhealthy circumstances. Why was I never asked about my circumstances? Why did no one ever ask 'What was it that drove you mad?' Such obvious questions are not usually asked in mainstream psychiatry. In psychiatry it is all-important to establish a diagnosis. And once this diagnosis has been made, it is assumed to automatically provide answers to all pertinent questions. From that moment on, everything you say and do is regarded as a logical manifestation of the diagnosed disorder.

Victims of abuse who are struggling with psychotic experiences will not therefore receive recognition as such from psychiatry – unless they are formally diagnosed with post-traumatic stress disorder, in which case their experience may be pathologized (if that is indeed what they seek). The victim with psychotic experience is not recognized, but is highly likely to be labeled as schizophrenic and thus to receive the opposite of what they need. Many victims of abuse have feelings of enormous guilt and are convinced that they are to blame for the crime of which they are in fact the victim. They search in numerous ways for confirmation of their guilt and wickedness. They punish themselves in a multitude of ways. In becoming a psychiatric patient, victims of abuse are supported in their belief that they are 'bad'. As a psychiatric patient they in fact keep alive the patterns with which they are so familiar, so they succeed in prolonging their victim role. Being a psychiatric patient could therefore be described as a form of self-harm.

An essential part of recovery is to look back at what has happened to you and to create your own story about it. In fact you rewrite your history in a way that suits you. You claim right of ownership of your own experiences. What is important is that you, and no one else, give meaning to what has happened.

Ups and downs

It is no easy task to look back at what has happened to you. However, it is important to determine for yourself what led to your admission to a psychiatric institution. This is the only way to come to terms with your life. This process of understanding your life history takes time and will have its ups and downs. It is not a story of success with an ending like 'and she lived happily ever after'. It is essential to realize that the process of recovery is not one upward line on a graph. There are numerous lines along which recovery develops. The only thing they have in common is that not a single line leads straight upward. It is important to learn why this is so.

For some time during my life I experienced periods of apathy. I stayed in bed all day. I did nothing and wanted nothing. I felt as if I was trapped by something over which I had no control, and I felt powerless and desperate. I now know that those periods served a purpose. They were the only way in which I was able to recuperate and to regain strength when things got on top of me, and when life went too fast for me.

I gradually learned that apathy can serve as a survival mechanism and that I would get moving again when I was ready to do so. I was later to learn how to avoid such circumstances. I learned to intervene earlier, thus limiting the damage. And I am now learning how to determine for myself the rate at which I live, instead of feeling as if I am 'being lived'. But I expect I am not very different from others in this respect.

There are times when I feel completely trapped inside myself. The world and all the people in it only seem to threaten me. This makes me very suspicious. Voices inside my head and a dazed vision complete my isolation. I withdraw from the world and will not speak to anyone for days. This isolation seems to develop suddenly and seems endless. Now I learn to listen to my body (Boevink and Corstens, 2011). I learn that I can choose to be alone when I seem to be losing myself. It is difficult to be sociable when one loses track.

Every so often I also feel that everything becomes too much. One could see this as a return of the symptoms, as a relapse. However, seeing it this way does not help me very much. Yet I try to see those dark periods not as a relapse, but as a breakthrough. Apparently changes are taking place and I must conquer old fears and tread new paths (Deegan, 1993). I have resigned myself to the fact that in my life these developments will always be accompanied by a great struggle. This does not alter the fact that a crisis is a crisis, but it helps if I understand what its meaning is, and what purpose it serves.

The principle of increasing recovery

Recovery does not mean that everything will turn out all right. Some things never will, and it is best to learn to live with that. In the literature, these are called impairments, but I prefer to call them vulnerabilities. If you can identify them, you can then make allowances for yourself. This spares you a lot of misery. And it saves your energy for what you can do, which will build your self-confidence. This is what could be called the *principle of increasing recovery* (Henkelman, 1995).

I have accepted that occasionally crises occur in life. I have accepted that occasionally they occur in my life. This does not mean that I allow them to get the upper hand. I try to limit the damage as far as I can. For example, I try to take things easy for the

duration of the crisis. As long as I feel vulnerable, I must be careful not to undertake too much. I may also arrange a kind of action protocol (such as an advance directive) with my psychiatrist for when I cannot decide for myself whether I will take more medication or not, and for whether I should be admitted, and if not, what should be done instead. I also try to limit the consequences of psychosis. There are still times when such consequences seem unavoidable. There are times when there is no other way to survive. By acknowledging this I am able to anticipate the situation, however difficult this may be. In this way I ensure that I do not spend all my time picking up the pieces after each crisis. It leaves time for living as well.

No happy ending

Recovery does not mean that everything will get better. It is vital to acknowledge and accept this. I must look back on times in my life when my behaviour was odd – to put it mildly. Although I would like it to be different, that was me and no one else. The worry that these behaviors will recur may never go away.

There is also the stigma that goes hand in hand with having been a psychiatric patient, and the anger about the injustice of this stigma. My anger about my stigma, while others get off scot-free – and even have the right to point out my stigma to me – still sometimes clouds my view of my own life.

No, some things never get better. Many people have to cope with permanent physical and mental damage as a result of abuse. Although recovery means licking your wounds, some scars will remain visible forever. And this is a painful conclusion, particularly once you dare to compare your life with that of other people. In doing so, you realize how different yours might have been. From this comparison you are able to deduce what you have missed. And this is accompanied by inevitable anger about all those things which it is too late to correct. You may even hate all those seemingly happy people who are leading their apparently easy lives. This view is deceptive, because things are never as they seem. Losing yourself in these emotions is a dead-end street. It is important to be proud of what you have achieved so far. You can make comparisons using different criteria. You can switch from one frame of reference to another.

There were times when I was fixated on all those 'normal' people who had a good education, a job, a relationship, a house, and even children. When I compared my situation with 'where I had wanted to be', I always came off worse – I felt a failure, a fool, and that life was not worth living. Fortunately, however, there were also moments when I looked back at 'where I had come from', and I would feel proud knowing that at least I had managed to leave the mental institution. I had come through this far. It is very important whether you compare your actual situation with 'where you had wanted to be' or with 'where you come from'.

In the end you may even get as far as realizing what positive outcomes you have gained from the course of your life, and that your experiences may provide you with something from which others can benefit.

Stigma

The psychiatric hospital where I lived for years is situated in the middle of a city –not hidden in the woods or isolated in the country, but precisely where busy societal life takes place. At first sight, one would say that it is integrated. Patients buy what they need in the shopping area just around the corner. We would go there to buy our daily bread, just like 'normal' people living there – except that we would buy twelve loaves of bread each day, whereas the 'normal' people would take home one loaf or less. Because we were such good customers the manager of our ward obtained a discount at the bakery and with the milkman.

I hated it when it was my turn to do the shopping, and I had to go into this normal world with that conspicuous shopping trolley, because when we entered the shop the other customers would always fall silent. They could all see that we were psychiatric patients. That shopping trolley would betray us, but also the way we looked – overweight and trembling because of the medication, often not really neat or clean, with nicotine stained fingers, and very shy and humble too. We would be served politely, but the shop staff would never give us more than the minimal politeness of tradespeople who know when they can make a profit. Their cordiality was reserved for the normal customers.

After my discharge from the hospital I still received the discount for a while, until they realized that I no longer bought twelve loaves of bread. When they stopped giving me the discount, I also stopped going there.

Recently I visited the bakery again. I found a social gathering of customers who were exchanging small talk and the latest gossip, until the door opened and two new customers entered. I recognized the shopping trolley at once. Silence fell and the people stepped aside a little. They were all staring at the two newcomers, and giving each other a meaningful look or smile. And I saw from the way they were staring at the floor, and fidgeting nervously, that these two psychiatric patients felt it too, just as I had always done.

Auntie Annie

During my first and longest psychiatric admission I was permitted to visit my parents for the weekend. I traveled to the small village where I grew up, and then remained inside my parents' house all the time. I did not dare to go outside, as I was afraid to meet other people. I used to meet with other people, but I could not find the courage to do so this time. I was ashamed of myself. Because of my hospitalization I had become the subject of community gossip. Nobody knew exactly what was wrong with me and what shape I was in. They knew that I was staying in a psychiatric institution, so things must have gone really wrong. Was there a problem with alcohol, drugs, or sex? And I had lost my mind, but no one could imagine what that was like. So they combined all the loose ends and made up their own stories – terrible stories. According to their fantasies I had become some kind of dangerous monster, and people were rather scared of me. And to be honest, they made me a little scared of myself as well.

My mother said that I should not stay in bed during the day and that I should meet other people. She sent me to the neighbors, to visit Auntie Annie. This was an enormously stressful undertaking for me. I was afraid that my Auntie Annie would ask questions, and I was also afraid that she would not ask anything. I was worried that I might do or say something stupid. And I was worried that she would do or say something stupid, or that another member of her family would, because of course they all came to have a look at me. However, the visit went quite well. I was given a cup of coffee, managed to exchange some small talk, and then I wanted to go home again. Relieved that all had gone well, I wanted to leave as quickly as possible. I was already standing by the door and then Auntie Annie asked me whether I had plans for the summer that year. I said that I intended to go camping for a week with a friend. And while I was walking away, my Auntie Annie shouted from her front door 'How nice that there is someone who wants to go with you.'

Things never worked out well again between me and Auntie Annie, or between me and the village where I grew up. I never went back. After my stay in the institution I started another life somewhere else. I had that opportunity and used it. However, it took a very long time before I grew beyond the effects of psychiatry, not least because of all those distorted reactions of others when they learned that I was a psychiatric patient.

It's all in your head

The literature distinguishes between two kinds of stigma – enacted and perceived. In other words, it distinguishes between what really takes place (socially) and what takes place in our imagination (individually); note that these two kinds of stigma interact with and influence each other. Perceived means that Auntie Annie didn't mean it like that, but I interpreted her words very negatively, or that the people in the bakery were not afraid of me, but I was a little paranoid. Perceived means that we experience our stigma not because it is there, but because we suffer from self-stigmatization. We have a lot of negative self-images in our heads, and little self-esteem, no self-confidence, and a lot of doubts about ourselves, because a long career as a psychiatric patient leads to suffering from self-stigmatization. We think we are unable, unworthy, have no rights, and have no reason to be proud, or we present ourselves to others in a wrong, clumsy way, which only confirms to those others their opinion about us.

Self-stigmatization exists. I do not deny that. However, I do worry a little about the extreme attention that this self-stigmatization mechanism has received recently, about the emphasis on this perceived discrimination, and moreover about the fact that this concept expresses doubts about the self-perception ability of psychiatric patients. Publications about the stigmatization of psychiatric patients often start with a critical sociological analysis of the negative forces of stigma and discrimination in societies. They also promise to describe whether the practice under study is tackling these forces effectively, to proceed with an extensive discussion of the perception of psychiatric patients and their self-stigmatizing impulses, and to end with a proposal for training psychiatric patients to improve their self-worth or assertiveness. I think that this is sheer reductionism – the individualization of a societal problem. Does everybody feel so powerless in relation to this complex and stubborn society that they

all prefer to turn away from it and accept its intolerance, and develop a 'how to manage stigma' module? This is because all of those individual psychiatric patients are easier to reach and easier to handle. The prevalent approach may be that it is better to train ten crazy attendants managing self-stigma than to prepare a community to establish in its midst a psychiatric center or a sheltered home (or the more progressive residential approach of supported housing). I strongly feel that there is a need to redirect this emphasis on yet another ability that psychiatric patients supposedly need to acquire. We have tried to fit in for long enough, and we have adapted more than enough. It is about time to denounce societal intolerance and call those who discriminate against us to order. Perhaps it is now their turn to follow a few modules on 'How to manage and control my discriminating impulses'.

A ban on exclusion

The ending of stigmatization does not mean the end of our suffering. Of course not, but with our impairments it would make it easier for us to build an existence among other people in society. I have succeeded in the past 15 years. I became a mother and I have a partner, a home, a job, and an income. And in my life I choose my identity and what I disclose about my psychiatric history. I have to confess that in my private life I am very reluctant to disclose my experiences. Although I am an activist in the psychiatric service user movement, I often choose to be anonymous in my personal life. I guess one has to be very courageous to face and fight discrimination on one's own.

I have a choice as to whether I disclose my patient identity. Many of us do not. When you live in an institution or a sheltered home you become known as a psychiatric patient, whether you want this or not. The neighborhood will learn about 'those living in that house at Number 7'. And sometimes this leads to a hostile atmosphere, just because the neighbors are afraid of you. In their eyes you are crazy, and therefore dangerous and unwanted. To end such simplistic thinking it is not enough simply to organize an assertiveness module for the victims. To end such discrimination we have to find the courage to disclose our experiences and tell our stories. I think that society has demanded for too long the right not to be disturbed. I think it is about time we remove this right and exchange it for something else – a ban on exclusion and the obligation to let us join in.

Supporting recovery

Recovery is what we ourselves must do. No one can do that for us. Stories of recovery are our stories, and only we can make them. It is important that mental healthcare professionals leave it this way. Yet they, as our care providers, must have a detailed knowledge of what recovery means. They can do a great deal to facilitate and improve our processes of recovery (Anthony et al, 2002).

In order to help us to identify and use opportunities for recovery, it is vital that professionals in psychiatry and other mental healthcare disciplines are familiar not only with our past and our hopes for the future, but also with our ordinary personal circumstances. Our lives do not consist only of the times when we are 'seen' in the consultation room. Recovery takes place outside it.

It is important that our professional helpers do not take away our hope of recovery. After all, no one can predict the course that our lives will take. What is called schizophrenia is no longer thought to be a chronic condition characterized by inevitable invalidity. It is even described by some as a scientific delusion (Bentall, 2009). We constitute a heterogenous group with very diverse histories. It is important that the professionals who surround us keep this in mind when dealing with us and our problems, so that they see us for who we are, and so that they can truly hear our stories.

We cannot survive without hope for better times. Of course we also need realistic feedback, but that does not mean that we have to be forced into total invalidity. We deserve a more nuanced approach. Realism is not the same as preaching doom and gloom.

Our stories of recovery are not automatically stories of success. Although the recovery concept seems to be increasingly claimed by people who talk of progress, development, and even cure, our recovery attempts do not automatically lead to visible progress and improvement. Crises and periods of apparent apathy may still occur. During these periods it is important that there is someone to help us to find the meaning of it all. Especially when we ourselves no longer believe in our recovery, it is important that others help us to regain hope.

Improvement in one area does not automatically mean that things will go well in other areas as well. Processes of recovery cannot be represented as one steady upward line on a graph, but rather are subject to temporary setbacks or what may seem to be a standstill. Allow us these lesser periods. We need to use such occasions to take stock and consolidate what we have achieved. We cannot continually chase progress. No one has the stamina to do this.

We do not need a so-called 'treatment relationship', but rather a relationship of collaboration. A shared understanding is very important. It is vital that there is a shared understanding of what is going on. And 'shared' does not mean that patients should share in the understanding of the professional, thus becoming compliant and blessed with this so called insight into the illness. For professionals in psychiatry the process of 'helping to find the meaning of what is happening' can easily change into 'knowing things better', particularly when they have little time available and their case load is too large. 'Sharing' actually implies that there is mutual give and take.

Fundamentally, recovery is about daily life – something that all of us have in common. Here, for me, lies the strength of the concept of recovery. It provides users of psychiatric facilities with an instrument with which to 'de-psychiatrize' themselves. It allows us to view what happens to us as something that is part of life as well. I see recovery as being inextricably bound up with users' emancipation and empowerment. Professionals in psychiatry can make a valuable contribution by working with us as equal and valuable discussion partners. We are not alien, just human.

Conclusion: recovery, empowerment, and experiential expertise

Stories of recovery are of great importance to users of psychiatric services, as it is we who must carry out the recovery work. Those of us who are aware of this have started their own recovery. I think it is very important that we exchange our experiences and our stories. It may be mostly thanks to this that I am now able to tell my own story of recovery.

To me, recovery is inextricably bound up with emancipation and empowerment, areas in which a great deal has yet to be improved. I believe that we can help and support each other in our recovery to a far greater extent than is currently the case.

Much can be learned from knowledge based on experience that we have gained over the years. I think we expect too much of the psychiatric system and underestimate its iatrogenic side-effects. Others cannot do our recovery work for us, and the psychiatric system does not often offer an environment that is supportive of healing and recovery.

We help ourselves with our stories. We do that and much more to help ourselves. We have a wealth of experience in doing so. We learn to see the true value of our experiences and to see them in a meaningful way. We try to learn from them what we all have in common and what the differences are. We attempt to identify what will help us and what will stand in our way. We develop knowledge – experiential knowledge. We pass that knowledge on to others, to the next generation of care service users, to give them strength and hope, to professionals in mental healthcare, so that they learn to hear our voices, and to people outside the mental healthcare system, so that our human face can be seen.

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Chapter 3

FROM BEING A DISORDER TO DEALING WITH LIFE: AN EXPERIENTIAL EXPLORATION OF THE ASSOCIATION BETWEEN TRAUMA AND PSYCHOSIS

Based on:
Boevink W (2006) From being a disorder to dealing with life: an experiential exploration of the association between trauma and psychosis. Schizophrenia Bulletin, 32, 17-19.

What You Have Is Who You Are

I was not yet 20 when my first psychosis emerged. I was convinced that we were on the verge of a world war. The public defense sirens were tested every first Monday of the month. To me, those sirens meant that the cruise missiles had already been launched. We had just minutes to do what had to be done: find each other and wait to die. Sometimes I could actually feel the radiation taking effect. I felt nauseous and believed that my hair was falling out. The rest of the world pretended to carry on as normal, but I could see that everyone was afraid. They knew that we were all about to suffer a slow, painful death, but nobody knew how to prepare for it. And so we all continued our daily lives with stolid determination. I experienced at the time that the world, including myself, began to move in slow motion. Although I could hear extremely well – I heard everything – my body moved very slowly. When I had the will to lift my arm, it took ages before that message reached my arm. It was as if I was in thick water and could only move in slow motion. It was the same for the movement around me: everything moved slower. The strange thing is that time did not exist for me in that situation. Time was also in thick water. It is a kind of vacuum, no-man's-land. Not in real life, but also not dead.

A psychosis is far-reaching and overwhelming. A psychosis involves a severe distortion of meaning. It renders the world unfamiliar, unrecognizable, a threat. Psychosis can turn life into a living hell. Just 'being' can no longer be taken for granted. Nothing can be taken for granted. A psychosis is also accompanied by a sense of estrangement. What you have is often closely allied to who you are. The manifestations sometimes dominate your entire personality. The distinction between the individual and the condition is soon lost, and it is very difficult to regain. I have been my disorder for a very long time.

I was not yet 20 when I developed severe psychotic complaints. They were accompanied by a lot of powerful noises inside my head and by an unlimited fear. To control both I became addicted to alcohol, drugs, and self-harm. In fact, I was trying not to hear and not to feel. The numbing effect was – although it sounds paradoxical – at the same time both a survival strategy and destruction. It was the intoxication that drew me out of reality. But it also allowed me to withdraw more and more into my own crazy world and to isolate myself from the world around me. One of the few things I

can remember from this time is my fear and the smell of destruction that surrounded me. When I finally also stopped eating and moving, I had literally become a living dead. Now I know that traumatic experiences from my past haunted me. But then I was convinced that the inevitable was happening: I was the problem, and the problem had to be solved.

The Illusion of Cure

The problem was solved by an admission to a psychiatric hospital. I lived there for 3 years and became a chronic nonclinical patient afterward. I was treated for my disorder, but I did not find any cure. Twenty years have passed since then. That first psychosis was not the last. I didn't get rid of them. I didn't witness the miracle of cure. To wait for cure in psychiatry is, as far as I am concerned, a waste of time. Because psychiatry doesn't cure as much as she wants us to believe. Psychiatry wants to be a medical science. In psychiatry practitioners want to deal with individual psychopathology. Of course, we know the bio-psycho-social model, but interventions are mostly aimed at the biological factors, and the psychosocial context is often ignored. If you enter the psychiatric business as a patient, then you have a high chance of being reduced to a disturbed object or to the disorder itself. Only that which is significant to the diagnostic examination is seen and heard. We are examined but not really seen; we are listened to but not really heard. Psychiatry does not regard us as serious discussion partners: after all, with a disorder you cannot speak.

Psychiatric Alienation

In psychiatry my family and I were given an explanation for what was wrong with me. For a long time there has only been this one official story about my life. According to this version I am disturbed; I have a psychotic disorder. I was severely mentally ill and had been treated for my disorder. I, too, saw myself for a long time as disturbed, as having a disorder that I did not control. In fact, I had become very alienated from myself. I saw myself from a distance, as an alien, for whom a special treatment was needed. When my symptoms got worse, I would need the doctor, the hospital, and medication. And I had to live by the rules: Concentrate on the here and now, don't be ambitious, and be awake during the day and sleep at night. I distrusted myself because at any moment my disorder could get worse. I had a dark side inside myself, a side I didn't know and didn't dare to explore. I didn't think about what preceded my

admission, and I didn't think about its meaning. The only thing I tried was to stay away from my dark side as far as possible. This was encouraged by the professionals I met in the course of my life. The general idea still is that talking about psychosis increases the risk of a next one and that is why you shouldn't talk about it. So I covered it up, this disorder inside myself. I didn't want to look at it, I wasn't allowed to look at it, and we all hoped the best of it.

In the years after my psychiatric admission, I succeeded in obtaining stability in my life. I have been free from psychoses for years. I have been able to build an existence, to obtain a relationship, and to hold a job. My disorder disappeared to the background. To be honest, I thought I had conquered it. I thought I had outsmarted it. In fact, I was convinced that I would never experience something like a psychosis again. I had a husband, a job, a house. Everything was different. But then I experienced a few shocking events in a short period of time. Then I got psychotic again.

No Psychotherapy for Psychotics

In the years afterward I had to choose: Would I see this again as a revival of a deteriorating disorder, or would I really try to see what was going on in my life? I didn't like the first option. It made me powerless. To accept my psychotic experiences as a disorder felt like surrendering, not in the least because of the nasty side effects of the antipsychotics. I couldn't see how to combine this with all that I had achieved so far. So I wanted to learn to talk about my psychotic experiences, to communicate about them, and to learn to see their meaning. I learned that this wish is not accepted as a legitimate need for care. A psychiatric history with psychosis is considered a contraindication for any kind of serious communication. It is my experience that professionals are reluctant to work with people like me, to go back into a dark history with persons with psychotic responses. There are no guidelines to do that. I think it takes a large amount of courage to do that – from the patient as well as the therapist.

From Child Abuse to Distortion of Reality

Now I no longer see my psychoses as isolated psychopathology. It's even hard for me to remember that I once viewed them as such. My psychoses are my way of reacting to my life history. They are my response to the unpredictable abuse I had to face as a child. I hit my father back when I finally was angry enough, after years of submission.

My father left the house after threatening to kill himself, after which the whole family turned against me. That was the last time for a very long period that I got angry. I just didn't feel anger anymore. In the years to follow I lost all my strength and exchanged it for guilt, fear, and incomprehensible psychotic experiences. I became the problem that had to be solved.

I don't think that abuse itself is a strong cause for psychosis. It hurts, but it is rather simple. I think that the threat and the betrayal that come with it feed psychosis. The betrayal of the family that says, 'you must have asked for it,' instead of standing up for you. That excuses the offender and accuses the victim. And forces the child to accept the reality of the adults. That forces the child to say that the air is green, while she sees clearly it is not green but blue. That is a distortion of reality that is very hard to deal with when you're a child. You are forced to betray yourself. That is what causes the twilight zone. What makes you vulnerable for psychosis.

Repetition of Trauma

In psychiatry my twilight zone was extended. There a distortion of reality was forced on me once more. Nobody ever asked me what had happened to me. Nobody ever asked me: what was it that drove you mad? I was observed, diagnosed, and treated as a disturbed person, but nobody ever looked at the association with my life history. Victims of abuse who react with psychosis will not receive recognition as such from psychiatry – if that's what they seek at all. Many of us entertain huge guilt complexes, and we are convinced we are to blame for the crime of which we, in fact, are the victim. We search in numerous ways for confirmation of our guilt and wickedness. We punish ourselves in a multitude of ways. In becoming a psychiatric patient, we are supported in our belief that we are bad. As psychiatric patients we in fact keep alive the patterns with which we are so familiar. Thus, we succeed in prolonging our victim role. Becoming a psychiatric patient could essentially be called a repetition of trauma.

Stages Toward a Psychosis

Rewriting my life story is a hard and sometimes risky process. I have to fight for every chapter in my version, not in the least with myself. Something that has been forbidden for so long does not become legal easily. Next to that is the fact that

psychotic experiences are risky subjects. They can distort your sense of reality once again if you're not alert. Yet, I am happy with what I have achieved so far. My psychotic experiences are no longer a mystery. I know what triggers them and what makes my memories turn into uncontrollable flashbacks and incomprehensible hallucinations. I learn to describe them. That makes them less threatening. I have discovered that certain hallucinations are not threatening in themselves. It is the fact that I see something which I know shouldn't be there that scares me most.

I have also discovered a sequence in the development of my psychoses. I have to work hard to avoid flashbacks and memories, so there is always stress and exhaustion. Next, there is chaos in movement. Then there is a distortion of meaning. The world is no longer recognizable for me; there is something fundamentally wrong in the world. That frightens me and leaves me without boundaries. Then I start seeing things that others don't see, and to make that right I build my own logical system of thought. Once I am this far, it is hard to go back, because every response of others is integrated in my delusion. In that stage every response of others only confirms the evil that already found a place inside my head.

The discovery of this sequence is extremely important to me. It enables me to keep in contact with the persons around me. In the stage of distortion of meaning and fear, I now try to communicate with others. I learn to recognize my early signs. Yet all this hard work does not guarantee the prevention of a psychosis. I have also learned that recognition of early signs is not the miracle cure we would so much want it to be. Self-management is only possible to a certain extent. A psychosis remains treacherous.

For me it is effective to discover the association between psychosis and life history. It diminishes my self-distrust because it makes my psychotic experiences understandable. And what is more important: my anger is back. If it is felt in the right dose and is well used, my anger doesn't have to be destructive but could be a source of enormous strength.

Help Discovering the Association With Life

Why read a story like mine? What should you do with such a story about the association between psychosis and life history? When I was overwhelmed by both, I wasn't

aware of this association. I only saw isolated parts. Perhaps that is the most important remark that can be made about this association between trauma and psychosis: when you're overwhelmed by both, you don't see the association or any logical sequence of events. If you would see the association, that could prevent a psychosis because then you could start getting control on your life. That is why someone else, a professional caregiver perhaps, should make the association visible. The question is when, at what moment. I think that I, during the years that I was overwhelmed, could not have coped with the causes and with confronting my family. I would rather have gone to hell myself. And that is where I went. On the other hand, however, I think now that I went to hell because there was nobody to point out the association for me.

Toward Recognition and Adequate Help?

I come to the end of my story. I didn't mean to say that abuse always leads to psychoses for the victim, or that all persons with psychotic experiences must be victims of abuse. I don't want to go back to the 'blame the mother' era. I did want to illustrate that psychosis could be an understandable response to trauma, a more likely response than is acknowledged now. I present you my story. It is a story of one person. It doesn't matter if you forget about my story. But my story isn't the only one of its kind. There is evidence 1,2 that traumatic experiences like child abuse are associated with psychotic experiences. So, that is not just the case in my story. Yet, this association is hardly recognized. There is no routine inventory concerning traumatic experiences when you enter the world of psychiatry with a psychosis. Persons who respond psychotically to child abuse can hardly count on recognition or adequate help. I think it is about time that we do something about that.

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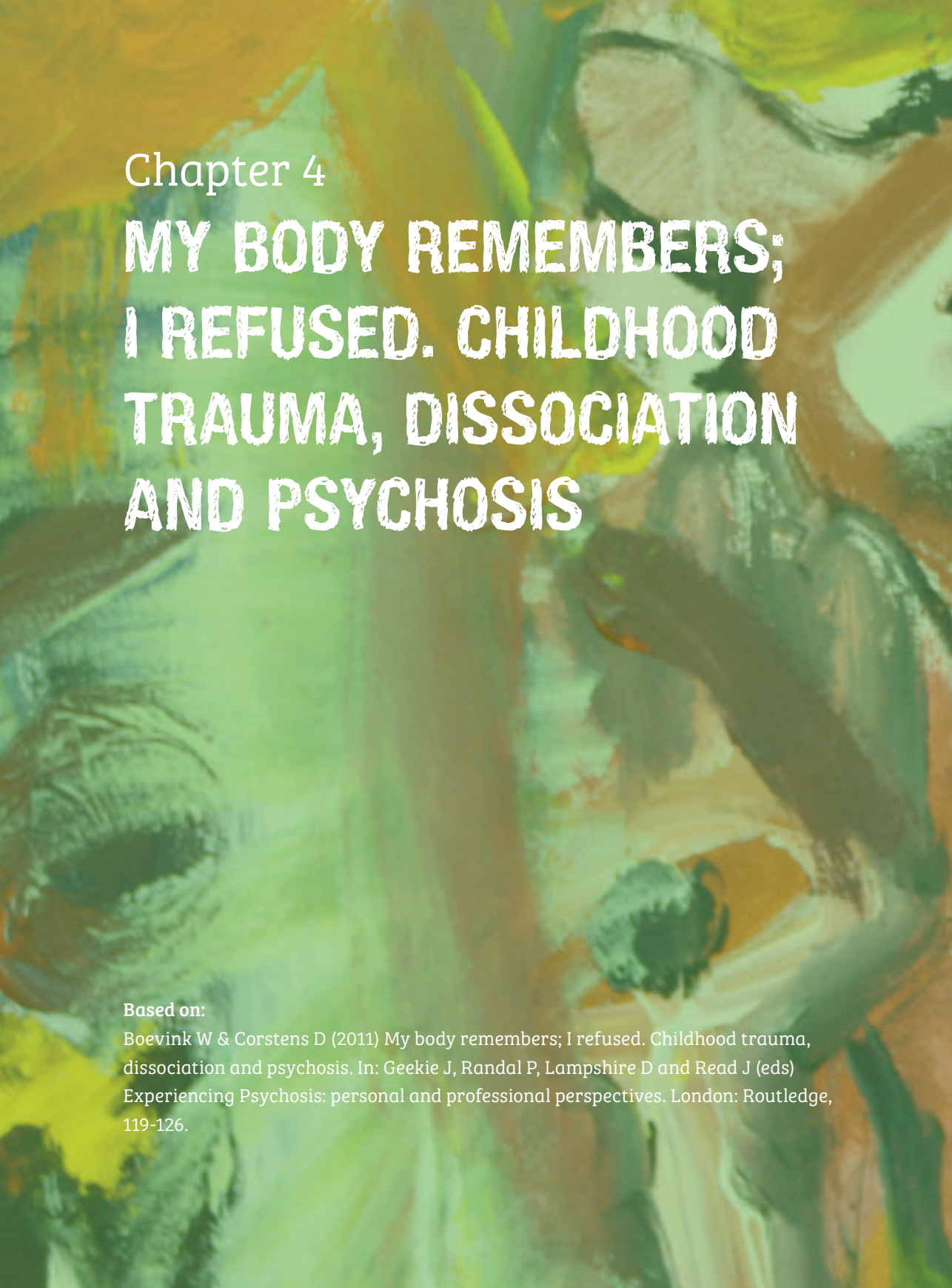

Chapter 4

MY BODY REMEMBERS; I REFUSED. CHILDHOOD TRAUMA, DISSOCIATION AND PSYCHOSIS

Based on:

Boevink W & Corstens D (2011) My body remembers; I refused. Childhood trauma, dissociation and psychosis. In: Geekie J, Randal P, Lampshire D and Read J (eds) Experiencing Psychosis: personal and professional perspectives. London: Routledge, 119-126.

Preferring psychosis

I cannot remember any violent struggles connected to forced sexual contact, to abuse. At least I cannot remember a fight. At most some pushing and pulling on an unwilling child. That child, that's me. Inside, that child continues to brace. By bracing I try to defend my inner self enormously. The worst moment is when my body surrenders. The moment at which my body becomes unresisting. 'OK, go ahead, do what you want.' That is the worst moment: to surrender. From then, my body is doing something other than what I want inside. I turn my head and die a little. Inside I scream 'no, no' and I weep for the bad thing being done to me. Inside, I am overwhelmed by despair. But that should not come out, that may never be expressed, may not be seen.

Fear.
From that moment on
there is a shell,
that thing,
that body
and an 'I'.
I do not want to be that body.
Take it away from me.
Get me out.
I'd rather be psychotic.

Making it exist

A story about abuse is an intimate story of suffering. Yet I want to tell my story. I just have to find the right words because after 40 years it is not easy to just tell what happened, to present the facts instead of prolonging the fiction of normality as some sort of 'survival strategy'. It took me 40 years to be able to really go back to how it all started. All these years I did not know what kept me caught by fear, what made me become a chronic psychiatric patient. It is only recently that I started to search for the right words to tell my story. And now I have found a few and used them. Now my story exists and it can be told. Now I can start working on the integration of the words in my head, the sensations of my body and all those long forbidden emotions.

Many stories of one reality

There are many stories about me: a story about a mental health activist, about a social scientist, about a recovery coach. There is also the story of a chronic mental health care patient which is partly written in psychiatric files, reduced to a list of symptoms, psychiatric diagnoses and medications. During my psychiatric career I got reduced to different diagnoses and became detached from my original experiences. My symptoms and the context in which they developed lost their meaningful connection. For a long time I have considered myself as mentally ill, disturbed, psychotic. I had experiences I did not understand, which made me feel powerless. I considered these experiences to be a consequence of brain disease. I felt myself a failure of nature: 'I am a mentally ill person, a patient in psychiatry.' For years and years I believed psychiatry could cure me, that doctors could intervene in the course of 'my illness', taking away the symptoms. I felt powerless and passive. I was not able to see how I had already taught myself to survive. I was blind to my own ways of coping with my psychotic experiences and the ways I maintained some kind of sense of self, despite being admitted to a psychiatric institution for many years. Now, looking back, I can see those strategies. I also see why they didn't work in the long run: they were built on quicksand.

The courage to discover

Survival is not the same as healing. It is merely an attempt to hang on, to keep on breathing. Healing means more than that. Healing for me means finding the courage to start on the road of discovery. It means creating space for the damage, for the madness felt inside. And exploring the many sides of being a victim of abuse. Healing for me now means being able to hear my voices, to listen to the damaged child inside, to make room for my outrage, grief, shame and fear, to accept the battle that is going on inside. It is my battle which I know I have to fight to banish monsters from my past. It is a battle that cannot be fought in solitude. I learned that I need allies, that only in contact with others is healing possible. Now that I have found them, I know how important they are: reliable persons, not afraid to see and accept me and my madness and who have the courage to accompany me on my road of discovery and give me support and hope every time I lose hope myself.

The eye

When my children were still small I had a terrifying experience. It was just one of many psychotic experiences I had at the beginning of my motherhood. These always originated from fear of an emerging war, and the necessity to flee. And in an endless row of fugitives my children would die from famine and I would have to leave them behind.

The most striking experience was when I was alone one day. I was cleaning the house and saw a big eye in my children's toy castle. I saw this eye watching me through the little windows and doors. A tremendous fear took hold and paralyzed me. When my family returned home I tried not to look at the eye any more. Nothing seen, no harm done. Keep up normality. A few days later my husband put the castle in a box. But I still felt the presence of the eye. I avoided the room. In time the walls of the room became alive, pulsating as if a big heart pounded in that room.

Later I was asked: 'What does the eye do?' Then, I dared to look at it. To my astonishment it wasn't an angry or threatening eye. It was a big friendly eye that blinked now and then. It looked like a cow's eye that winked at me encouragingly. What had made me so anxious? I was paralyzed from fear because I knew I saw something that wasn't there. I was frightened by my madness and not by the eye.

The eye was familiar to me. It was a maternal eye, comforting, giving a sense of safety. It was not my biological mother's eye, but it reflected the soul of Diana, my favorite cow on the farm where I grew up. I learned to milk by hand; in the mornings and evenings I sat leaning against her fat, warm belly and heard the gurgling and ruminating noises she was making inside. But she fell ill and it was uncertain if she would get better. My parents told me that they would have to sell her at the market. She would be sure to find a good new home, my mother said. When I heard that, I rushed to the field where Diana was lying. I crawled up against her, weeping, snuggled up against her warm, soft belly. She turned her head and looked at me, blinking with her friendly eyes, comforting me, as if it was I and not her being sent away.

The suggestion that she was going to find a good home by being sold of course was a lie, because the treatment animals received at the cattle market was often

rough and abhorrent. It turned out to be a double lie. The next day I returned home to find my mother and grandmother busily cutting up meat. I heard my grandmother ask my mother whether I had been told Diana had been slaughtered. To my face they denied it completely. But I knew it was her who was lying there in pieces. That scene is closely related to the content of my psychoses. The great lumps of bloody meat, the big jug full of blood, the sausage machine. For me, that is so close to life, my life. It's as if it is not my 'mom' but me lying there in bloody pieces. For me, it is total surrender.

Wet dogs

There are periods in my life, lasting days or weeks, when I find myself surrounded by a certain smell. A stench that penetrates everything, even my body. It smells like moldy humidity, clothes that have not been dried properly or rotting wood. During these periods I get very restless, constantly trying to find the source of the stench. I ask people around me whether they smell it too, but apparently it is for my nose alone. Sometimes the wet smell develops as a cloud of destruction and I am afraid it stems from my body. The penetrating smell convinces me that I produce death, not life.

What smells wet like my olfactory hallucinations I finally identified as wet dogs. Dogs having been in the water and not dried off yet. Just like the dogs of a man I visited every once in a while when I was a child. I was a little afraid of his dogs. I remember that they smelled wet, just like their owner, who liked me a lot.

He always loved seeing me. He was a hunter. He shot animals for fun. He liked me, giving me candy, pulling me onto his lap, touching my little body, especially when he was drunk. For fun. And he liked taking me to the woods in his car, showing me the deer. I do not remember seeing any. I remember that the man was nervous, driving back and forth in his car in a brusque manner. I felt threatened by him, hunted. I tried to avoid him, but as a child you can't direct the course of your life. The man with the wet dogs was the first one who in his way used this body I am in for his sexual needs. He would not be the last.

Werewolves

Recently I had to travel to Freiburg, Germany, to give a lecture on recovery. This town sits in the shadow of the Black Forest. I think I was already heading towards psycho-

sis, or too tired to make the long trip and be on my own in a strange country and city. Or was it the other way around? Did something during the trip trigger my psychosis? I don't know. But I started becoming psychotic. My hotel room was in a noisy street with a lot of traffic, so I slept poorly. There was no host to welcome me. Of course, as a professional, well-paid lecturer, you should be independent. But, I am also an expert by experience, and these experiences are not always in the past – something most people don't realize or want to see. Like me. I feel very vulnerable sometimes and need some support. At that time I was unable to admit this and arrange some supportive contacts during my stay.

I felt very isolated. My fears and confusion came out during my excursion into town the second day. There was a very strange atmosphere: a mist was hanging low over the town. It felt like there was something fundamentally wrong with this world, but I couldn't specify what this was. I saw in the mist the contours of something black hanging over the city. I walked through the streets with a map, trying not only to behave like a tourist, but to feel like one as well. All to allay my fears and hang on to normality. I didn't succeed. I felt more and more, because of the mist and the dark decor, as if I was in a film studio. It didn't seem real, this world. No one else seemed to notice. Perhaps I was the only 'outsider' there? Perhaps I was a spy! Then I saw a war memorial which startled me: a war memorial in Germany? Did they honor the dead soldiers that fought for Hitler in his dirty war? Perhaps I had a spying mission in this neo-fascist town? I noticed that all the city buses had this war memorial as an end station, which felt like a message, a warning to me. Next it occurred to me that I never saw any dogs. How come? I found the explanation in the mutants I met. Several men already had the first signs of their transition to werewolves. Their ears grew, their beards became like wolves' fur. They showed their teeth and their fingers and nails grew longer and thinner. Freiburg was inhabited by werewolves, proving it was a fascist bastion. Werewolves fought with and ate dogs. That's why I didn't see any dogs.

Being hunted in a hostile world is a recurring theme in my psychoses. Do I have the genes of a paranoid schizophrenic? In fact, every time, my psychotic adventures are a repetition of what I experienced when I was young. Then too I felt haunted in a hostile world. When I get afraid, when my old fears are triggered, the world becomes threatening and populated with werewolves. This is a sharp representation of how

grown-ups, especially men, behaved during my childhood. My father was a community man, very active in our village, popular and respected. But for me, he was angry and aggressive, unreliable, unpredictable and short tempered. Other men during my youth mutated in the same way: they started off being nice and friendly, but at some point showed their true evil faces. What they really wanted was my body, to get sexual fulfillment. I learned to see their 'wolf side', despite the fact that to the outside world they were just good men.

Voices

My head is full of sounds, echoes, animals, music, screaming, crying and voices. For a long time it was just a bunch of noises, being the voice of Evil. It was my punishment. No one knew how bad I was, only the Evil which the noise inside my head represented. It got worse, more threatening, when I had done something wrong. I communicated with that noise. Evil had me in its power. I felt I was at the mercy of something that wanted bad things of me.

Over the years I started to distinguish specific sounds – some nice, others scary. A tree full of birds twittering, a football field of little boys shouting and sometimes cheering, angry voices, heavy breathing, screaming of little children and animals, cows or pigs screaming in pain and panic.

I have a family of heavy breathers inside my head: on the right side there is the always-present father and on the left side sometimes his son appears. The son is unreliable, more impulsive and aggressive, while his father is stable, always hissing: 'I watch you, you cannot escape, I am always watching you.' The son is always sexually aroused; dad is sometimes. It is difficult to have them both at the same time, because they don't breathe simultaneously. If they are both there, I always get dizzy and confused: whom should I serve? Whom should I listen to? Their breathing is destructive and threatening for me, because it makes me feel very dirty, ugly and used, as if they constantly want to remind me that abuse is the only thing I deserve.

I hear another voice as well. At first I thought the breathers were the only inhabitants in my head, but now I am not sure. Father and son are bad guys, but they don't seem evil enough to give me all these messages: 'Whore, kill yourself, you're not worth

living, be there for me, I want you, you are nothing, ugly one, you're mine, listen to us or we will get the ones you love'. These messages are so negative that it is very hard to reject and resist them. Sometimes I don't succeed and have to give in and harm myself to make him satisfied and silent for a while. It is very hard and exhausting to deal with these negative and destructive inhabitants and not get upset, desperate or confused. I suppose these negative voices represent people who subjected me to abuse; the abuse made me hate my body. The voices hate me.

There is someone or something else inside me. I often have a heavy stone in my stomach which is the source of my nausea and extreme uneasiness. Sometimes I can hear someone crying inside my body. It is heartbreaking to hear that. I think it is a very little girl. She doesn't have words, but she definitely is very upset.

Quicksand

Hanging on to normality to cover up reality helped me through my childhood. Perhaps that is why I used this splitting between apparent normality and reality in life again. After I broke down at around the age of 20 I was in a psychiatric hospital for three years. During these years I prolonged the splitting: the violence I had been a victim of was never mentioned. My breakdown was said to be the consequence of my psychiatric disorder. I survived by getting away as far as possible from my 'undertow'. Once I restored normality I was discharged and faced with the task of building a new life. I developed a grim determination. I went to university, got a job as a researcher and later developed my career as an experiential expert. Together with others I developed the Towards Recovery, Empowerment and Experiential Expertise (TREE) (Boevink et al. in progress) program for users of long-term mental health care to support them in their recovery and their career as experts by experience. We create jobs in psychiatry to work together towards healing-based help for people with severe human distress. And we are developing a research program in this area.

I worked and worked. I learned what love is and became a mother as well. My normality became a wonderful reality. But every now and then I stumble, because of exhaustion, ugly memories, flashbacks, nightmares and psychotic experiences – as if my dissociation from the dark side of my life isn't strong enough. Every now and then my dragon taps me on my shoulder reminding me he is still there and that there

will come a moment when I will have to look him in the eye. I don't want to and try to postpone this moment as long as possible. For this I pay a price of drifting every now and then into this endless world of psychosis. I built myself a life, but it is based on quicksand, because I deleted the dark side and tried to live just in the light.

Listening to my body

For as long as I can remember I have considered myself mainly as brains for which unfortunately I need the rest of this body I am in. I never was friends with this shell. I ignored it and refused to listen to it. To suppress whatever difficult sensations or emotions I must have had during the course of my life, I worked very hard, got psychotic, then used psychopharmacological medication, alcohol, drugs and self-harm. Thus I could keep up some kind of normality.

In the past year my body gave up. I got contaminated with the mononucleosis virus and had to stop working and being active in the outside world because of an invalidating exhaustion. My dragon tapped me on my shoulder again and this time I had to look him in the eye. Fortunately, I have met a few courageous fellow dragon fighters who support me along with the few good friends I have. Slowly but surely, it became less vital to hang on to the fiction of normality and I made room for the damaged parts inside me. I learned to share my inner world, to relate it to the outside world. I was taught how to listen to my body. Nausea is a message, hyper-arousal a response and exhaustion means I have to rest. I learned to register when my senses become over alert and how my body pumps up to 'go to war'. I explored what makes me feel safe. I learned about trusting others even though I cannot hide my vulnerability. I learned to tolerate the voices inside my head. When they get angry, I try to slow down and ask for extra help and a helpful place to stay for a while. Instead of listening to the voices I try to enjoy music. I am discovering what kind of music I like. Instead of harming myself I should comfort myself, but this is still very difficult for me to do. Comforting myself triggers more pain and grief than self-harm. It is as if it cracks the stone in my stomach, which hurts a lot.

The stone in my stomach seems to be the source of the little girl's voice. Although I am afraid of her outrage, grief, shame and fear I am also curious about this little girl inside me. What is she like? I look at other girls and try out their colors, perfumes,

dresses and make-up. I got myself a bear and a little pink doll. I sometimes like to sing, I like picture books about animals and watch everything grow in my garden. Through the damage and all the scars a little person becomes visible who I think I could like. It is a start, but I guess I still have a long way to go before I will be able to embrace her and the body she is in.

Me and my body: implications for understanding

In this chapter I have tried to illustrate the relations between trauma, dissociation and psychosis from the perspective of experience. In psychiatric practice, psychosis and dissociation seem to be viewed as being mutually exclusive. In my experience they are different but not separate. Trauma can connect them. Both dissociation and psychosis can be personal ways of reacting to overwhelming life circumstances. Dissociation, once, early in life, a necessary survival strategy, later becomes the prelude or perhaps even the cause of psychosis. To illustrate this I started by describing psychotic experiences, which can easily be seen as symptoms of what is called schizophrenia when you isolate them as mere symptoms. My next step was to put these experiences back in the context in which they could become real, thus making them meaningful. This step reveals how apparently abnormal behavior can be very logical once seen in its original context.

Healing and help: implications for practice

I have illustrated part of my personal journey of discovery. Healing becomes possible when the content of what is generally considered as psychotic phenomena is taken seriously and is related to painful truths in the past. Dissociation is an important mechanism to survive and isolate unbearable and overwhelming emotions. It is an important coping mechanism for traumatic experiences during childhood. However, it can also be the cause or the basis of the development of psychotic symptoms. These symptoms conceal meaningful relational aspects experienced in harsh circumstances. They can be translated into what really happened in the past. Yet so far, this has not been common practice in psychiatry. Depending on co-morbidity, those labeled dissociative have a chance to get some kind of therapy. Those people identified as psychotic, however, are denied the opportunity to explore the significance of having had a painful past that can be addressed. I am convinced that this practice should and can be changed.

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Chapter 5

REGAINING CONTROL OVER YOUR OWN LIFE. A CONCEPTUAL EXPLORATION OF THE CONCEPT OF 'EMPOWERMENT' FOR PEOPLE WITH PSYCHIATRIC DISABILITIES)

Based on:
Boevink W, Kroon H, Griesen F, (2008) Controle herwinnen over het eigen leven. Een conceptuele verkenning van het begrip 'empowerment' van mensen met psychische handicaps. Tijdschrift voor Rehabilitatie, 4, 16-26.

This article reports on an exploratory study on the concept of 'empowerment' in relation to people with long-term and severe mental illness. The Concept Mapping method was used to explore what these people understand by the term 'empowerment'. The concept of empowerment was analysed on the basis of 96 statements, grouped into eight domains and four dimensions. The domains were arranged in order of importance. The results showed that empowerment is related to the dimensions survival, life art, connectedness and adequate help. The emphasis placed on the empowering sources in 'normal life' is striking.

Introduction

Deinstitutionalisation in psychiatry and empowerment are inextricably linked. They both refer to processes designed to contribute to full participation in society by people with severe mental illness (SMI) (Taskforce Vermaatschappelijking, 2001; Ministerie van VWS, 2001). Empowerment is about 'the way in which people with a chronic disease or disability are able to play a full part in society in their own way' (Dekkers, 1997). It is about regaining control of one's own body and life, reinforcing feelings of self-esteem and self-respect and strengthening the position of mental health care users as a group (De Jonge, 2001).

Empowerment is not a new concept. It has its origins in the 1960s in the United States, where it was a central theme in areas such as the civil rights movement and the women's movement (Jacobs, 2001). Community initiatives were developed under the banner of 'empowerment' aimed at eliminating the powerlessness of disadvantaged groups. These initiatives were characterised by a politicising approach to people's problems and complaints and attention for power processes and power differentials. Two decades later, the term is also becoming more and more embedded in the literature in related domains, such as social work (Solomon, 1987), mental health care (Rose & Black, 1985), organisational science (Clutterbuck, 1994) and work with specific target groups such as immigrants (Zeegers et al., 1998) and the chronically sick and disabled (Van Gennep, 2000). A common feature of empowerment in all these domains is that it is based on people's own capacity to bring about desirable changes in their lives and living conditions (Jacobs, 2001).

The term 'empowerment' first emerged in mental health care in the wake of the – mainly American – deinstitutionalisation movement which began several decades

ago (see e.g. Rose & Black, 1985). Strategies and interventions were developed as part of the development of 'community-based' programmes which were intended to support existing and former users of psychiatric services in growing out of their role as patients and taking their place as citizens in society. More recently, the concept has acquired a prominent place in the literature on rehabilitation and recovery, where it is linked to the view that people with severe and persistent mental health issues, such as psychotic disorders, are not meek, passive victims of their condition but look for ways of dealing with their disorder, tackling their symptoms and giving their mental health problems a place in their lives (Anthony, 1993; Deegan, 1993; Van Weeghel, 1995). 'Recovery' is often interpreted as a psychological construct which is related to self-awareness, hope and the development of coping strategies (see e.g. Rogers et al., 1997; Spaniol et al., 1994; Yanos et al., 2001). Research into the relationship between recovery and empowerment – and what separates them – is in its infancy (Boevink et al, 2008; Corrigan et al., 1999; Wowra & McCarter, 1999).

Empowerment in the user movement

For users of psychiatry, 'empowerment' today provides a framework within which they can exchange experiences and build on their own self-awareness. Their initiatives have in common that they give participants the opportunity to share experiences, to increase their knowledge about themes that are important for them, to work on building a positive self-image and building experiential knowledge, and learning to apply these to their own lives and in mental health care practice.

Characteristic of the way in which users interpret the concept of empowerment is that they largely work in a way which is not diagnosis-specific. The central focus is on the common problems people with psychiatric disabilities are confronted with, not on the differences between specific disorders. In addition, they mainly join in individual processes of increasing self-determination and growing out of the patient role. Empowerment is interpreted above all as the development of survival strategies and self-development. The underlying idea is that, once the individual basis has been laid, empowerment follows naturally at the level of patients as a group. At that group level, empowerment is associated with user participation and advocacy of user interests in mental health care.

Users of mental health care services are a quiet voice in society. They themselves demand virtually no attention for the position occupied in society by people with a chronic illness or disability. This is in contrast with the disability movement in the somatic health care system, which appears to portray itself much more as a social movement.

Although the term 'empowerment' is now widely used by various actors, especially in long-term mental health care, up to now there is little consensus on its content. Users in psychiatry interpret it in various ways, but do not make their underlying views explicit. They generally lack the opportunity and means to bring together and turn their views and experiential knowledge to advantage, regarding their individual commitment to growing self-determination and full citizenship and their collective emancipation. So far, in Europe no systematic study has been made of the aspects that people with severe and persistent mental health issues attach to the concept of 'empowerment' and there is no consensus on its meaning. As a result, (long-term) users of the mental health care services lack a relevant framework against which to test the quality of care from their own perspective.

Method

In 2003, Trimbos Institute started a research project on the content and meaning of the concept of empowerment in mental health care. At the heart of the research was an exploration of the content of the concept from the perspective of people with SMI, using the Concept Mapping method. The research question on which this exploration was based was 'Which aspects do people with SMI assign to the concept of 'empowerment'?'

Concept Mapping is a structured method which can be used to break down a complex concept. It is suitable for working with a minimum of 8-10 and a maximum of 98 respondents. The method gives respondents an opportunity to explain their views and ideas on the topic verbally. Concrete statements are used as a starting point in working towards more comprehensive, abstract concepts which together provide a picture of all relevant aspects of the concept in question. An essential part of the method is that respondents first form associations regarding the topic and then assess the relevance

and content of their associations (Trochim, 1991; De Ridder, 1991; Ketelaars et al., 1993).

The method requires a simple and unambiguous focus sentence to which respondents can react. For this reason, the term 'empowerment' was avoided in the focus sentence, and instead respondents were presented with the following sentence: 'In order to gain control over my life it is important for me that', with the request that they complete the sentence. This sentence does tend to push the interpretation of the concept 'empowerment' in a certain direction, but this is inherent in the formulation of a focus sentence and therefore in the method. 249 statements were collected in this way. The researchers assessed the statements on the basis of four criteria: unambiguity, singularity (a statement relates to one topic rather than two or more), degree of concreteness and any overlap with other statements. This enabled the number of statements to be reduced to 96, a suitable number for the next stage of the study. We then asked the respondents to rank these statements by content and importance. Following analysis, the Concept Mapping program produced a graph of the results.

In the final phase of this study the results were interpreted through submission of our findings for discussion by a group of experiential experts[1]. This was followed by a presentation and discussion of the results in a plenary meeting for all respondents.

The respondents

The respondents in the survey were people who find they have to live with persistent mental vulnerabilities and who make long-term use of mental health care services. They were contacted with the help of several user organisations[2]. These organisations recruited respondents from their members in the north, east, centre and south of the Netherlands. There were 12 respondents in Utrecht (central region), 11 in Zwolle (east), 15 in Groningen (north) and 18 in Maastricht (south). We sought to achieve a broad cross-section in terms of the nature of their mental health problems.
Of the total of 56 individuals who participated, 30 were men. The average age of the respondents was 45 years. Seven of the respondents lived in some form of sheltered housing and there were two long-term residents of a psychiatric hospital. On average, the respondents had a high education level: six of the 56 respondents (11%) had a low

1 With thanks to the following members: Conny Bellemakers (Kantel Consult), Liesbeth Reitsma (†, former chairman of LPR), Hans van der Zee (†, former chairman of Cliëntenbond), Gaby Jacobs (former employee at Universiteit voor Humanistiek) and Steven Makkink (formerly of RegioConsult, VOICE).

2 Platform GGZ Utrecht, Patiënten Consumenten Platform Zwolle, Huis voor de Zorg in Maastricht, Samenwerkende Patiënten-/Consumentenorganisaties Groningen.

education level (no formal education, special education, primary education) and 15 (27%) had a higher or university education. By way of comparison, a literature survey by Michon et al. (2003) showed that between 23% and 54% of people with severe and lasting mental health issues had a low education level and 5-17% a higher or university education background.

In forming the respondent group, we sought to achieve a mix of individuals who:

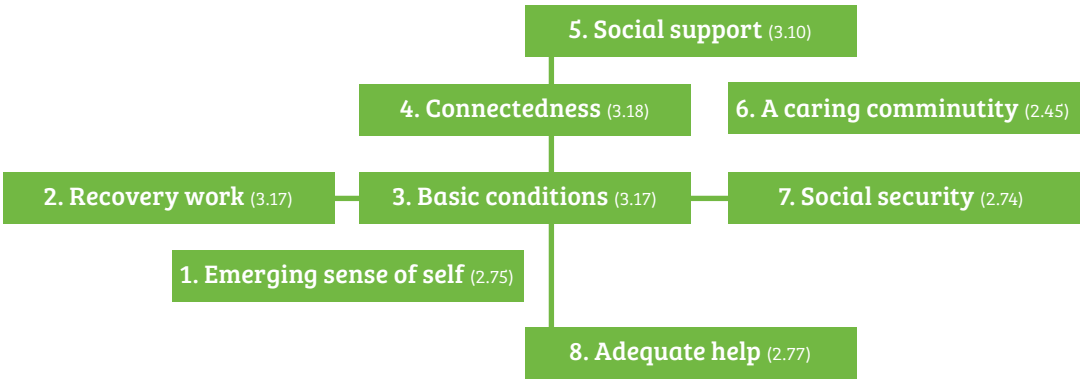
1. Use psychiatric care services and are also dependent on those for their daily survival;
2. Are also active in the user movement (user councils, user-run initiatives);
3. Have succeeded alongside or after their experiences as a psychiatric patient in building a place for themselves in society.

A large majority of the respondents reported that they were active in the user movement; there were only six respondents for whom this did not apply. Activities cover membership of user councils at mental health care institutions, administrative functions, buddy projects and complaint committees in the mental health care sector. 14 respondents felt they had been successful after or alongside their role as a psychiatric patient in building a place for themselves in society.

Eighteen per cent (ten individuals) had a paid job and 38 people (68%) were engaged in voluntary work. The number of people engaged in some form of work-related activity was high in comparison with other users of mental health care services. In a study by Michon et al. (2003) of 2,070 clients of case management and regional sheltered housing (RIBW), only 9% of the respondents were engaged in voluntary work and 10% had a regular paid job. A total of 25 respondents in our study received a disability benefit. On average, respondents had been psychiatric patients for 11 years. Forty four individuals (79%) had been admitted at some time, ten of them in the year preceding the study. Twelve respondents had at some time been admitted to a psychiatric institution once; 15 respondents had been admitted twice or three times; four had been admitted five times and 14 respondents had been admitted more than six times. Thirty four respondents (62%) were taking medication; 21 of them were taking antipsychotic drugs. We asked the respondents to describe their mental health complaints. Thirteen reported that they suffered from psychotic disorders; 12 reported personality dis-

orders and 13 said they had mood disorders; the remaining 18 respondents suffered from anxiety, autism-related disorders, trauma-related disorders or did not describe their complaints.

Figure 1. A 'picture' of empowerment



A 'picture' of empowerment[3]

The Concept Mapping program represents the statements as points (nodes) on a plot. In figure 1 the 96 statements that people consider important in regaining control over their own lives are combined to create domains of the empowerment concept. These domains are briefly discussed below. The number of statements mapped to each domain is shown in brackets.

Domain 1: Emerging sense of self (4)

This domain contains statements about people's realisation that the 'self' is separate from the disorder and that the 'self' has to take action in relation to the suffering or disorder. In order to regain control of your life and move beyond the disorder it is important not to remain stuck in the role of patient. Taking medication for years also means it is necessary to work on your physical condition. Finally, it is important to accept what is going on and to recognise the signs of a potential relapse.

Domain 2: Recovery work (34)

This domain contains the most statements. They all relate to the individuals them-

3 The statements in each domain can be obtained on request from the first author.

selves and their survival strategies and life art. On the one hand these are statements about learning to deal with one's own vulnerabilities and limitations, developing one's own meaning of what is happening in one's life and developing a healthy lifestyle. These are more at the bottom to the right. The statements more towards the centre of the plot concern basic elements such as safety, but also having a purpose in life, peace and relaxation and having the courage to be curious. At the top to the left in this domain are the statements with the highest scores, such as self-confidence and self-esteem, but also self-help strategies such as turning negative thoughts into positive thoughts, deriving satisfaction from things that go well and humour.

Domain 3: Basic conditions (10)
This domain is in the central area of the plot and impinges on all other domains. The process of empowerment requires a number of basic conditions to be met which enable people to free themselves from their problematic lives. They include peace and safety in the home, spending the day usefully, having enough money to live and be able to do nice things, and having a structured day. Other statements relate to appropriate (paid or voluntary) work, activities outside psychiatry and working for the user movement.

Domain 4: Connectedness (6)
Respondents not only expect a good deal of themselves when it comes to empowerment; those around them are also important, especially in providing a sense of connectedness. A sense of belonging and meaning something to someone else are statements which belong in this domain. This sense of wanting to be connected also emerges in the statement that it is important not just to talk to other people about your problems. Arrangements outside the home are important, but so is being able to set boundaries in important relationships: daring to say 'no' and not being dependent on other people's approval.

Domain 5: Social support (15)
Gaining control over your own life requires support from family and friends who are not put off by problems or the negative image of mental health care users. Those in the immediate social setting can support the process of empowerment by an understanding attitude, listening and maintaining a good relationship. Further to the right

in this domain are statements which apply more broadly than the immediate family and friends; more generally, there must be respect for people with psychiatric disabilities, even when things are going badly for them. The provision of information and coming into contact with mental health care users can contribute to this.

Domain 6: A Caring community (5)
Where domain 5 is concerned with the respondent's immediate social setting (family, friends and acquaintances), the social setting in this domain is wider and more abstract. A caring community is in the first place populated with people with whom experiences can be shared, but also 'others' who are involved with people who have mental health issues. Society more generally respects chronic diseases, does not allow itself to be misled by negative images, does not take responsibilities and freedoms away from people with mental health problems, but is concerned enough to observe and accommodate mental illness in fellow citizens.

Domain 7: Social security (3)
It helps in gaining control over one's life if society provides social security for people with a psychiatric disability, but also support at work or when returning to work and information on legislation and regulations.

Domain 8: Adequate help (19)
Demand-driven professional help is important in gaining control over one's life. On the one hand this means that adequate help must be available, and this is the topic of the statements at the bottom right in this domain. On the other hand, a demand-driven approach requires that users are able to make good use of the right help. The statements on the left-hand side of this domain relate to this aspect. Adequate help means that social workers take the possibilities of their clients (what they can do) as the starting point rather than their limitations (what they cannot do), work with them and are there for them when needed, including in the longer term. They do not take more (responsibility) from their clients than is necessary and keep a finger on the pulse. They allow their work to be led by the choices made by their clients and fit in with the life narrative of their clients. The medication prescribed by professionals should reduce symptoms and not have toomany side-effects. Finally, social workers must recognise that they can learn from their clients and allow users into their

working domain as experiential experts. Adequate help requires an 'adequate user'. An adequate user indicates him/her self when an admission is needed – and is listened to, so he/she is not afraid to ask for help, takes medication when necessary and does not expect that health professionals can resolve all problems.

Priorities

Now that it is clear how the respondents in the survey interpret the 'empowerment' concept, the question arises of how they weight the constituent parts. What relative importance do they attach to the different domains of empowerment?

The highest priority is assigned to the domain 'connectedness', closely followed by 'recovery work' and 'basic conditions' (see chart 1). The domain 'social support' is only fractionally lower. The other domains are considered much less relevant for the process of empowerment. In this group, 'adequate help' scores highest, followed closely by 'emerging sense of self' and 'social security'. Bottom of the rankings is 'a caring community'.

The following five factors are the most important in enabling people with a psychiatric disabilities to gain control over their own lives:

1. Having a purpose in life
2. Having self-confidence
3. Valuing yourself for who you are
4. Finding a peaceful and safe environment in your home
5. Friends

The process of empowerment requires both individual recovery activities (self-confidence, self-esteem) and basic conditions (safety) as well as social connectedness. It is striking is that the list of the five most important statements does not contain a single statement about professional help. The five factors that are seen as relatively least important in gaining control over one's own life – though still important enough to be included in the Concept Map – are:

1. Not getting angry about things you cannot change
2. Being aware of legislation and regulations
3. Knowing what you can no longer do

4. Anger as a source of strength
5. Acceptance of the illness

Table 1. Prioritising of the empowerment domains (scale from 1 to 5; the higher the score, the more important the domain).

Connectedness	3.18
Recovery work	3.17
Basic conditions	3.17
Social support	3.10
Adequate help	2.77
Emerging sense of self	2.75
Social security	2.74
Caring community	2.45

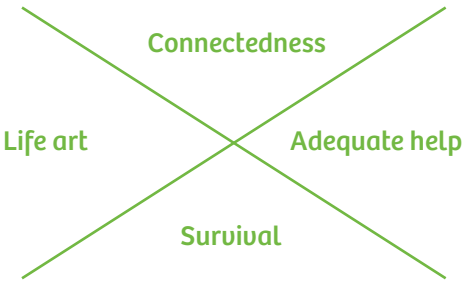
Perspectives

So far, in interpreting the data, no distinction between the three groups of respondents has been made. Yet it is plausible that there are differences of perspective or at the very least differences of emphasis between mental health care patients (6), those who are active in the user movement (36) and 'successful former patients' (14). In principle, the different perspectives of empowerment can apply to each phase of the Concept Mapping process. Here we look only at the comparison of the priorities assigned on the basis of the group averages in each domain. Due to the wide difference in the numbers of respondents in each subgroup and the small differences in the averages, the results should be interpreted with some caution.

Respondents who reported that they are dependent on the mental health care services for their daily survival and are not active in the user movement assigned the highest priority to 'social security' and 'adequate help'. They expect considerably less of themselves with regard to their empowerment process. They give relatively low priority to their 'recovery work' and 'connectedness', which are in the top three for the other two groups. Those who are active in the user movement or who regard themselves as successful former patients have corresponding lists of priorities, though former patients not unexpectedly attach less value to 'adequate help'. Those active in

the user movement consider 'social security' to be less important in gaining control over their own lives.

Figure 2. Four dimensions of empowerment



Survival, life art, connectedness and adequate help

Summarising, the concept of empowerment can be divided into several components. For people with psychiatric disabilities seeking to gain control over their lives, it is important that they are able to grow beyond their disorder, have access to adequate help and social security and that the community cares about the chronically sick. The interpretation of the concept, however, is not only based on the presence of mental health problems. More important is feeling socially connected and finding support from the immediate social setting, in addition to meaningful mutual relationships. Certain basic conditions are also important, such as having a peaceful and safe place to live. All kinds of recovery activities that people with psychiatric disabilities have to perform themselves also help in regaining control of their own lives. Empowerment can thus be broken down into four dimensions: survival, life art, connectedness and 'adequate help'.

The emphasis that is placed on 'normal life' is striking. For people with psychiatric disabilities, a process of increasing control over their own lives is not so much a matter of learning to deal with their disorder, of psychiatric support, psycho-education or other forms of mental health care or adaptations focusing on the psychiatric problems and limitations. Much more, this process is driven by (re-)learning to lead an ordinary, normal life. For them it is a matter of developing and strengthening their mental health and knowing that they are valued in a normal social context, in normal human relationships; it is about connectedness and mutuality.

In conclusion

This conceptual exploration[4] of the concept 'empowerment' marks the first phase of a larger research project. A questionnaire was developed on the basis of the study described here and subjected to psychometric testing. This questionnaire is described elsewhere (Boevink et al, in progress). At present, it is not usual for long-term mental health care services to be judged on the degree to which they contribute to the empowerment of their users. Both the questionnaire and the Concept Map can be used in the daily practice of mental health care as part of the quality assessment system.

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Chapter 6

EMPOWERMENT ACCORDING TO PERSONS WITH SEVERE MENTAL ILLNESS: DEVELOPMENT OF THE NETHERLANDS EMPOWERMENT LIST AND ITS PSYCHOMETRIC PROPERTIES

Based on:
Boevink W, Kroon H, Delespaul P & Van Os J (2017) Empowerment according to Persons with Severe Mental Illness: Development of the Netherlands Empowerment List and its Psychometric Properties. Open Journal of Psychiatry: vol.7, no.1.

Objectives. It is unclear whether and to what extent purportedly empowering practices in mental health care, like rehabilitation programs, recovery-supporting mental health care environments and peer-run services, contribute to the process of empowerment. Several American empowerment questionnaires have been developed in recent years, facilitating the measurement of empowerment outcomes. Given likely major transatlantic cultural differences in a value-sensitive concept such as empowerment, this article describes the development of the Netherlands Empowerment List (NEL) and its psychometric properties. *Methods.* Patients in Dutch mental health services provided meaning to the empowerment concept from which the NEL was derived. Based on 531 completed questionnaires, analyses in agreement with COSMIN criteria examined aspects of internal consistency, content validity, structural validity, convergent validity, discriminant validity, reproducibility and responsiveness of the NEL. *Results.* The NEL is a 40-item self-report questionnaire with six subscales: Social support, Professional help, Connectedness, Confidence and purpose, Self-management and Caring community. Internal consistency (Cronbach's alpha = 0.94), aspects of validity, reproducibility (intra-class correlation – 0.79) and responsiveness were good. Correlation with existing scales was the highest for the Mental Health Confidence Scale (r = 0.78) and the lowest for the Boston Empowerment Scale (r = 0.61). *Conclusion.* The NEL appears to be a suitable instrument to capture the dimension of empowerment in European mental health settings.

1. Introduction

Empowerment is a concept that is used in many sectors, including mental health care [1] [2]. Partly because of this, the concept is defined and interpreted in different ways. Rappaport describes empowerment as a process in which people, organisations or communities are able to influence events and situations that are important for them [3]. Zimmerman and colleagues describe the required ingredients to acquire such influence: access to information, knowledge and skills, the ability to take decisions, individual strength, participation in society and real control [4]. Corrigan notes the importance of hope, shared decision making, community approaches and stigma [5]. Leamey and colleagues defined empowerment as a core component of the CHIME recovery framework, together with connectedness, hope and optimism about the future, identity and meaning in life [6]. A distinction can be made between empowerment at the individual and the collective level. At the individual level, empowerment

is about processes in which the person rediscovers his identity and self-esteem and 'takes his life in his own hands'. At the collective level, it is about the contribution by people with lived experience to the organisation and practice of mental health care and society. The concept of empowerment and the activities it embraces have been receiving growing attention in mental health care in several European countries in recent years, including the Netherlands. The focus is on the development of so-called best practice, particularly those that are co-set up and/or co-controlled by people with lived experience [7].

A large number of instruments to measure empowerment exist, among which a number is specifically in the area of mental health [8] (Table 1). Different instruments assess different aspects of empowerment; in fact empowerment appears to be defined so broadly that it is not possible to show convergent validity across different instruments [9]. Nevertheless, the overarching structure underlying all empowerment questionnaires appears to include domains of: patient states, experiences and capacities; patient actions and behaviors; patient self-determination within the healthcare relationship and patient skills development [8]. In mental health settings, the most frequently used instrument is the Boston Empowerment Scale, which was developed in the USA [10] [11]. As cultural factors are likely to play a role in how the concept of empowerment is framed and experienced in different parts of the world, psychometric properties of assessment scales may vary across countries and cultures.

Table 1. Existing empowerment-related scales demonstrating wide range of conceptual approaches

Scale	Subscales	N	Scale items	Original language
Personal Empowerment Scale (Segal, Silverman, & Temkon, 1995)	Two subscales: Discretion and Reduction in Chance	20	5-point Likert Scale	English
Mental Health Confidence Scale	Three subscales: Optimism, Coping, Advocacy	16	6-point Scale	English
(Carpinello et al., 2000) Boston Empowerment Scale-Version 2 (corrigan et al., 1999)	Two super-ordinate factors: (i) Self-orientation:Three sub-scales Self-esteem, Self-efficacy Optimism (ii) Community orientation: three subscales: Community action, Powerlessness, Effecting change	25	4-point Likert Scale	English
Health Promotion Intervention Uestionnaira-Original (Svedberg, Svensson, Arvidsson & Hansson, 2007)	Four subscales: Alliance, Empowerment, Educational support, Practical support	19	5-point Likert Scale	Swedish
Empowerment Questionnaire for Inpatients (EQuIP)-Original (Lopex, Orrell, Morgan & Warner, 2010)	No subscales reported (Expected sub-scales were information, choice, and communication, but CFA did not confirm this and EFA was not conducted)	16	4-point Likert Scale	English
Consumer Evaluation Of Mental Health Services (CEO-MHS)- Original (Oades, Law & Marshall, 2011	Two subscales: Empowerment consumers' sense of control over their illness, treatment and stigma), Dehumanization	26	5-point Likert Scale	English
Inpatient Consumer Survey-original (ortiz & Schacht, 2012)	Six subscales: Outcome, Dignity, Rights, Participation, Environment, Empowerment (patient choice & communication)	28	5-point Likert Scale	English

For example, research in European samples suggests relatively poor psychometric properties for the Boston Empowerment Scale and relatively good properties for the Mental Health Confidence Scale [12], which is designed to measure self-efficacy and therefore has a focus on intrapersonal aspects of empowerment [9]. Another issue is that the Boston Empowerment Scale does not tap into the domain of interactions between professionals and patients within the mental health system, and the extent of opportunities for (guided) self- management. This is important because many users, in their commitment to more self- determination, are also actively trying to get a better grip on their own mental health problems. In a pilot study, we examined which aspects people with severe mental illness related to the concept of empowerment [13]. Based on the findings of this exploratory study, a Dutch empowerment questionnaire was developed. In this article, the development of the Netherlands Empowerment List (NEL) and the results of the reliability and validity analyses are described. To conform with COSMIN criteria [14], we describe internal consistency, reproducibility, responsiveness, construct validity (convergent and discriminant validity), content validity and structural validity.

2. Methods

2.1. Sample 1: Development of NEL and Content Validity

The items in the NEL were based on the results of a conceptual study of empowerment, using Concept Mapping, in which 56 people with psychiatric diagnoses of severe mental illness according to DSM-IV criteria mapped out the concept of empowerment [13]. Eight domains were identified based on a total of 96 statements. The domains were: 1) Emerging sense of self, 2) Recovery work, 3) Connectedness, 4) Basic conditions, 5) Social support, 6) A caring community, 7) Social security, 8) Adequate help.

Forty-five of the 96 statements were converted into questionnaire items. The selection was based on high indicated priority and low standard deviation: for each quadrant of the Concept Map we selected the items with the highest priority and a standard deviation of <2. We also screened for overlap. Finally, we assessed whether the items covered the tenor of the quadrant of origin. The items were cast in the form of concrete and unambiguous statements.

Respondents indicate on a five-point scale the extent to which they agree or disagree with the statements (‘strongly disagree’ [1], ‘disagree’ [2], ‘neither agree nor disagree’

[3], 'agree' [4], 'strongly agree' [5]). Four items relate to mental health care services; these items have a sixth response category: 'not applicable'.

Six peers from the Dutch psychiatric user movement evaluated the first version of the questionnaire. In addition, a supervisory committee of peers with lived experience assessed the questionnaire in particular in relation to its face validity. Finally, 33 current and former users of mental health services completed the draft questionnaire. Based on the outcome of this first test, we reformulated several items and reduced the total number of items to 42.

After completion of the test, the NEL was sent to 823 current and former users of Dutch mental health care services aged 18 - 65 years, distributed throughout the Netherlands (Table 2). We attempted to reach a representative group of current and former users, from people receiving long-term intensive care, to people who currently make little or no use of mental health care services, to people (self) employed as peer workers. The questionnaires were distributed by professionals working at mental health institutions (n = 364), staff of user-run projects (n = 224) and rehabilitation programmes (n = 235). In addition to these, a few respondents received a questionnaire directly from the researchers (n = 9). A total of 368 completed questionnaires were completed and returned by reply-paid envelope, representing a response rate of 44%.

2.2. Sample 2: RCT Sample

In addition to sample 1, data from a recently published randomised controlled trial with data collected at baseline and two follow-up points (one year and two years), were used to examine the NEL [15]. The sample was divided in a group of 'early starters' (sample 2a) and a group of 'late starters' (sample 2b). The NEL had been collected at year 1 and year 2, allowing an analysis of the effect of TREE on NEL outcomes in those who started with TREE after year 1 [15]. The RCT examined, over a two-year period, the impact of a user-developed and user-run recovery program (Toward Recovery, Empowerment and Experiential Expertise - TREE) on outcomes in individuals with severe mental illness, as add-on to care as usual. A randomised wait-list controlled design of TREE (n = 80), added to care as usual (CAU; consisting of professional case management), versus CAU only (n = 83), was implemented in patients with severe mental illness. Follow-up was at 12 and at 24 months after inclusion [15]. The data

pertaining to the RCT sample were used to examine NEL reproducibility (comparing repeated measures of NEL after the start of the intervention in the RCT) and responsiveness (change in NEL after treatment). In addition, convergent validity with both the Boston Empowerment Scale [10] [11] and the Mental Health Confidence Scale [12]

Table 2: Sample characteristics

	Sample 1	Sample 2a	Sample 2b
Age: mean (n; SD)	43.9 (361; 12.0)	44.1 (79; 10.8)	43.7 (83; 12.0)
Male n (n total; %)	182 (362; 50.3)	46 (80; 57.5)	39 (83; 47.0)
Born in the Netherlands n (%; n total)	329 (364; 90.4)	71 (77; 92.2)	75 (83; 90.4)
Living in institution* n (n total; %)	106 (362; 29.3)	24 (80; 30.0)	32 (83; 38.6)
Paid employment n (n total; %)	37 (353; 10.5)	16 (80; 20.0)	6 (83; 7.2)
Education$			
Low n (n total; %)	117 (355; 32.9)	39 (80; 48.8)	36 (83; 43.3)
Middle n (n total; %)	142 (355; 40.0)	29 (80; 36.3)	25 (83; 30.1)
High n (n total; %)	96 (355; 27.0)	9 (80; 11.3)	22 (83; 26.5)
Psychosis n (n total; %)	198# (358; 55.3)	32 (80; 40.0)	34 (83; 41.0)
Never admitted (n total; %)	69 (361; 19.1)	12 (64; 18.8)	10 (63; 15.9)

Sample 2a – RCT sample group of 'early starters'
Sample 2b – RCT sample group of 'late starters'
#Higher educational level: higher professional/university; Lower educational level: no formal education, special or primary education, junior secondary vocational education.

was analysed, hypothesizing greater convergent validity compared to the Boston Empowerment Scale, given previous research suggesting relatively poor psychometric properties for the Boston Empowerment Scale and relatively good properties for the Mental Health Confidence Scale [9]). Finally, discriminant validity was assessed against the number of met and unmet needs as assessed by the Camberwell Assessment of Need (CAN) [16] and the Community Assessment of Psychic Experiences (CAPE) total score [17] [18]. The CAN is designed to discuss and rate 22 different needs covering all aspects of an individual's life and mental wellbeing including accommodation, daytime activities, psychotic symptoms, childcare, money, psychological distress, physical health and relationships. Each of the 22 needs can be rated as 'met'

or 'unmet' depending on whether the person is receiving help in that area, yielding scores of the number of met and unmet needs. The CAPE is a 42-item self-report instrument that trans-diagnostically captures psychotic (20 items), depressive (8 items) and negative symptoms (14 items) [19]. Items are scored on a scale from 1 to 4, and can be added to form a total score.

2.3 Instruments

In addition to the NEL, data were collected on several other outcomes. The Boston Empowerment Scale [10] was translated to the Dutch 'Making Decisions Scale' [9]. The 28-item scale consists of five factors: self-efficacy and self-esteem, power and powerlessness, community activism, righteous anger, and optimism toward and control over the future. Items are true or false statements. Possible scores range from 1 to 4, with higher scores indicating more empowerment [10]. Quality of life was assessed with the Maastricht Brief Quality of Life Scale [20]. Information about mental health was provided by the Mental Health Index (MHI-5), comprising five items from the SF-36 [21] and items on care use and use of medication. Finally, we collected socio-demo- graphic information and asked the respondents to classify their mental health problems, giving them the options of 'psychotic disorder/schizophrenia', 'personality disorder', 'anxiety disorder' and 'mood disorder'.

2.4. Ethics

The standing medical ethical committee approved the study. The study was conducted according to the principles expressed in the Declaration of Helsinki. All participants provided written informed consent. No incentives were offered for participation.

2.5. Analysis

Analyses were carried out in SPSS [22] and STATA, version 14 [23]. In order to examine the structural validity, a principal component analysis was carried out with listwise deletion. Principal components were selected based on the screeplot as well as on interpretability and face validity in relation to the concept mapping exercise of the pilot study [13]. Given the fact that the items on mental health services and care were missing for the sizeable proportion of participants who did not receive care, analyses were repeated without these items, in order to examine stability of the principal component structure without these items. On the basis of the principal component

structure of the principal component analysis, scale scores were calculated as the weighted average of the items with high loadings (>0.4) on that particular scale. The missing data rule for the scale score analysis was that if more than 20% of the items on a particular scale were missing, the scale score was not computed.

Internal consistency of the total questionnaire as well as the subscales was determined by calculating Cronbach's alpha. Two items were dropped due to ambiguity and low item-rest correlations (<0.40), leaving 40 items in the final instrument. Convergent validity was evaluated by calculating the Pearson correlations between the scores on the NEL on the one hand, and the scores on the Boston Empowerment Scale (both sample1 and sample 2) and the Mental Health Confidence Scale (sample 2) on the other, hypothesizing that the correlation between the NEL and the Mental health Confidence Scale would be high, and significantly higher than the correlation with the Boston Empowerment Scale. This latter hypothesis was examined in sample 2, using the MVREG (multivariate regression) procedure in STATA. Discriminant validity was examined using the Quality of Life questionnaire, the Mental Health Index, the CAPE total score and the CAN total number of met and unmet needs, hypothesizing that Pearson correlations between NEL and these scales would be low to moderate. Reproducibility and responsiveness were analysed in sample 2 as described in detail in an earlier report [15]. A multilevel random regression analysis, adjusted for location, was conducted using the XTREG routine in STATA, in order to take into account clustering of observations (level 1) within persons (level 2). In the XTREG multilevel random intercept regression model, the dependent variable was the continuous outcome measure and the independent variable was condition (TREE or CAU). Effect sizes were expressed as the regression coefficient ß.

3. Results

3.1. Sample 1: Respondent Characteristics

The average age of the 368 respondents was 44 years (in a range from 18 to 82 years). Half was male, 90% was born in The Netherlands, 46% lived alone; 29% resided in a mental health institution or some form of sheltered housing. 10 percent had a regular paid job (full or part-time); 37% were engaged in voluntary work, were homemaker, studying or going to school. Twenty-seven percent of respondents had a higher educational level (higher professional/university); 33% had a lower educational level (no

formal education, special or primary education, junior secondary vocational education). More than half reported they had suffered from psychosis and 19% was never admitted to a psychiatric hospital.

3.2. Sample 2: Respondent Characteristics

Sample characteristics of the 163 participants have been described in detail elsewhere [15]. The mean age was 43.9 (years, SD = 11.4), 52% was male, 91% was born in the Netherlands. Fourteen percent were in (part/full time) paid employment, 50% were engaged in voluntary work/housemaker/study. The proportions with low, medium and high educational level were, respectively, 47%, 34% and 19%. Eighteen percent was living with parents or with children (with or without a partner); 42% lived alone, 34% were living in an institution. Forty percent suffered from a psychosis and 17% was never admitted to a psychiatric hospital (Table 2).

3.3. Structural Validity (Sample 1)

The principal component analysis of the 40 items produced six components explaining 54% of the variance (N = 235). These components corresponded well with the domains identified in the Concept Map and were labelled Self-management; Social support; Caring community; Connectedness; Confidence and purpose and Professional help. The principal component analysis was repeated without the four items with the highest loadings on the factor Professional help. Sixty participants who did not receive care could now be included in the analysis (N = 295). Results of both analyses were highly comparable. Only two items had a higher loading on another component. Therefore, calculation of the six scale scores was based on the results of the second principal component analysis (Table 3). Correlations between subscales were low to moderate; only a single correlation – between Confidence and purpose and Self-management – had a value ≥0.8 (Table 4).

A short version with 25 items can be composed of three subscales: confidence and purpose, social support and connectedness. Together these three subscales explained 95% (sample 1) and 96% (sample 2) of the variance in the total score.

3.4. Construct Validity

3.4.1. Convergent validity (Table 5)

The correlation between the NEL and the Boston Empowerment Scale was moderate at 0.663 and 0.614 in sample 1 and sample 2, respectively. The correlation with the Mental Health Confidence Scale was high at 0.778, significantly higher than the correlation with the Boston Empowerment Scale ($p < 0.001$). Entering, in sample 2, the Boston Empowerment Scale and the Mental Health Confidence Scale in the same regression model of the NEL revealed that the association with the Boston Empowerment Scale ($b = 0.010$, $p = 0.176$) was entirely reducible to the association with the Mental Health Confidence Scale ($b = 0.478$, $p < 0.001$).

3.4.2. Discriminant validity (Table 6)

Pearson correlations were low to moderate for the CAPE total score, CAN unmet needs, CAN met needs, Mental Health Index and Quality of life (Table 6).

3.5. Internal Consistency (Sample 1 and Sample 2)

Cronbach's alpha was 0.94 (sample 1) and 0.95 (sample 2) for the total scale. The outcomes for the subscales are reported in Table 4 (sample 1), showing good internal consistency.

3.6. Reproducibility (Sample 2)

In the RCT sample, repeated measures of NEL in the treatment group were available for 57 individuals. The NEL intraclass correlation coefficient in this group was 0.79.

3.7. Responsiveness (Sample 2)

In the RCT sample, the responsiveness of NEL to the TREE intervention was examined in 131 individuals who had been exposed to one or more elements of the TREE intervention in the trial (see [15] for details). Of these, 63 had NEL administered at baseline before the TREE intervention, 127 after one year of TREE treatment, and 57 after two years of TREE treatment. From year 1 to year 2, there was a small but significant effect of TREE treatment over time, similar to the effects on other outcomes reported previously [15] (Table 7).

Table 3. Results of factor analysis of scale items

Scale items	Factor loadings*	
	F1	f2
	Confidence and purpose	Social support
33. I think of myself as a person worth something	0.79	
34. I turn negative thoughts into positive ones	0.75	
43. I am not afraid to rely on myself	0.67	
19. I am determined to go on	0.64	
13. I derive satisfaction from the things that go well	0.58	
4. I have a purpose in my life	0.57	
41. I can deal with my vulnerabilities	0.54	
22. The role of patient is no longer central in my life	0.54	
14. I am able to deal with the problems that come my way	0,46	
3. I have the feeling that I can mean something for someone else	0.46	
16. I decide how I control my life	0.45	
36. I can see how my life has made me who I am today	0.43	
10. The people around me take me as I am		0.75
42. I can fall back on the people around me		0.73
17. The people I love support me		
28. I have a good relationship with the people around me		0.71
6. The people around me accept me		0.71
9. Those around me offer me a listening ear		0.67
18. I can obtain adequate support when I need it		0.64
39. This society does not discriminate against people with a mental disability		

f3 Caring community	f4 Connecte-ness	f5 Self management	f6 Professional help
0.78			

Scale items	Factor loadings*	
	F1	f2
	Confidence and purpose	Social support
12. In our society, people with a mental disability are considered full citizens		
24. This society offers social security to people with a mental disability		
29. This society creates opportunities that fit my level of participation		
2. This society makes allowance for people with a psychiatric disability		
20. Society respects my rights as a citizen		
25. I regularly meet people outside my home		
40. I do the things that I think are important		
26. I can share my experiences with others with similar experiences		
38. I have enough to do each day		
32. I have a sense of belonging		
37. I find peace and safety in my home		
8. I am able to set my boundaries		
11. I know what is good and what is not good for me		
27. I know what I am good at		
21. I have structure in my life		
23. I am not afraid to ask for help		
15. My caregiver is there for me when I need him/her		
1. My caregiver and I have a good collaborative relationship		
7. My caregiver takes my abilities as a starting point, not my limitations		
30. The care I receive fits in well with my life		
Cronbach's alpha in first sample	0.89	0.87
Cronbach's alpha in second sample	0.92	0.89

* factors 1-5 calculated in sample of n=295; factor 6 calculated in sample of n=235

f3	f4	f5	f6
Caring community	Connecte-ness	Self management	Professional help
0.73			
0.73			
0.72			
0.64			
0.55			
	0.66		
	0.60		
	0.59		
	0.58		
	0.52		
	0.38		
		0.70	
		0.68	
		0.50	
		0.50	
		0.42	
			0.79
			0.77
			0.70
			0.61
0.81	0.74	0.78	0.81
0.84	0.78	0.80	0.84

Table 4. Pearson correlations (r*) between subscales of the Netherlands Empowerment List

		Self-management	Social-support	Caring-community
Self-management	r	1	0.521	0.380
	N	356	351	335
Social-support	r	0.521	1	0.423
	N	351	357	334
Caring-community	r	0.380	0.423	1
	N	335	334	338
Connectedness	r	0.706	0.592	0.640
	N	328	326	317
Confidence an purpose	r	0.803	0.469	0.296
	N	355	355	336
Professional help	r	0.351	0.500	0.272
	N	311	308	298
Total score	r	0.873	0.777	0.612
	N	352	349	336

* All correlations in table p-value <0.001

Table 5. Convergent validity: Pearson correlations between Netherlands Empowerment List and other empowerment-related scales

		Empowerment scale †	Empowerment scale ‡	Mental Health Confidence scale ‡
NEl Total score	r#	0.663	0.614	0.778
	p-value	0.000	0.000	0.000
	N	345	102	111

r = Pearson correlation coefficient

† Sample 1

‡ Sample 2

Connectedness	Confidence an purpose	Professional help	Total score
0.706	0.803	0.351	0.873
328	355	311	352
0.592	0.469	0.500	0.777
326	355	308	349
0.640	0.296	0.272	0.612
317	336	298	336
1	0.541	0.555	0.860
331	329	305	329
0.541	1	0.251	0.762
329	360	310	353
0.555	0.251	1	0.600
305	310	311	309
0.860	0.762	0.600	1
329	353	309	353

Table 6. Discriminant validity: Pearson correlations between Netherlands Empowerment List and other scales

		Quality of life†	Mental Health Index†	CAPE total score	CAN unmet needs ‡	CAn met needs ‡
NEl Total score	r#	0.663	0.442	-0.583	-0.585	-0.009
	p-value	0.000	0.000	0.000	0.000	0.927
	N	345	346	112	112	112

r = Pearson correlation coefficient

† Sample 1

‡ Sample 2

Table 7. Effect if TREE* intervention on NEL empowerment in RCT sample (adjusted for site)

	Level of need for care					
Time	CAU		Tree 1-year follow-up		Tree 2-year follow-up	
	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N
Baseline	--#					
Year 1	3.41 (0.64)	63	3.52 (0.60)	63		
Year 2			3.49 (0.64)	64	3.60 (0.55)	57
Stratified effect size¶	0*		0.083 (-0.040, 0.21), p=0.189		0.172 (0.002, -0.34), p=0.047	

CAU = care as usual

= the NEL was not administered at baseline

* = reference category

¶ = regression coefficient B of TREE at year 1 and year 2. Between brackets: 95% confidence interval

4. Summary and Discussion

The NEL questionnaire was created exclusively on the basis of contributions by people with mental disabilities from all over the Netherlands suggesting good content validity. It contains 40 statements with which respondents can agree or disagree. Principal component analysis produced six interpretable subscales: social support, professional help, connectedness, confidence and purpose, self-management and caring community. Internal consistency was good, with the items forming a coherent whole. Discriminant validity was also good. Although there was a degree of association among NEL and constructs of quality of life, mental well-being, needs and psychopathology, these correlations were not so high that they could be described as the same constructs. Convergent validity was, as expected, better for the Mental Health Confidence Scale than for the Boston Empowerment Scale, suggesting the need for a culturally sensitive scale. The NEL showed good reproducibility and was responsive to a user-led intervention.

The NEL was devised before the publication of the CHIME framework [6], with which it clearly shows a degree of conceptual overlap. The dimensions of the NEL, similar to the CHIME framework, point to the importance of kindling strength and support for

self-narrative development, promoting the role of mental health services in building inclusive communities enabling access to peer support as well as providing sanctuaries, and clinical skills that promote self-management.

Conceptually, the scale describes feelings, competencies and actions reflective of personal empowerment (confidence and purpose, self-management, connectedness), and the resources in support of this process (social support, professional help, caring community). The first factor 'Confidence and purpose' describes core aspects of personal empowerment: identity, self-esteem, control, willpower and purpose. A short version of 25 items can be composed of this subscale combined with social support and connectedness.

The Netherlands Empowerment List was developed with and for adults with psychiatric disabilities and was psychometrically tested in institutionalized and non-institutionalized settings, and in consumer-run initiatives. To date, the scale has been used in a wide range of settings in and outside mental health care in the Netherlands and Belgium, including services for homeless people, youth care, social work, visual impairments, intellectual disabilities, and physical revalidation [24]-[32].

Study Limitations

The findings should be interpreted in the context of a number of strengths and weaknesses. An advantage is the user-led development of the NEL, thus ensuring content validity. A further strength was adherence to the full set of COSMIN criteria [14], making NEL the exception in this regard [8]. Weaknesses are the lack of psychopathology interview data and the use of two different samples for the analyses, although the samples are quite comparable clinically and demographically. Future work should include psychopathology interview data and attempt further alignment with the CHIME framework [6].

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Conflict of Interests

The authors have no conflict of interests.

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Chapter 7

TREE: TOWARDS RECOVERY, EMPOWERMENT AND EXPERIENTIAL EXPERTISE OF USERS OF PSYCHIATRIC SERVICES

Gebaseerd op:

Boevink W (2012) HEE: Towards Recovery, Empowerment and Experiential Expertise of Users of Psychiatric Services. In: Rian P, Ramon S, Greacen T (eds) Empowerment, lifelong learning and recovery in mental health: towards a new paradigm. New York: Palgrave MacMillan, 36-50.

The burgeoning user moment in the Netherlands

The user movement in psychiatry has a lot to offer, more than we have been aware of so far. In the Netherlands, we take initiatives to strengthen our position and offer a different perspective on living with severe human distress with long-term mental illness or psychiatric disorders. We develop training courses for professionals in psychiatry. We start self-help groups and educate and train fellow users of psychiatry who want to integrate their experiences in professional roles. User-initiated projects are gaining in popularity and in substance. In countless areas, we have created activities on our own initiative. The underlying motivation is the conviction that our personal and collective experiences will lead to new insights regarding severe mental suffering and care (Boevink and Escher 2001, Boevink 2007, Boevink and Corstens 2011, Coleman 1999, Lehmann 2004). We are confident that we can contribute to building psychiatric services that are more supportive and human than the existing ones. Self-help and user initiatives in psychiatry are a response to the fact that our individuality, our experience and our knowledge are not yet adequately represented within mainstream psychiatry. For us, the emphasis is increasingly being placed on self-determination, our own responsibility and personal efforts, rather than devoting our strength to railing against the power of other stakeholders and their agendas. Until now, there has been no general overview of European user and survivor initiatives unlike in the USA with the Consumer-Operated Services Program Multisite Research Initiative (COSP 2004). There is no account of the strategies we use, the experiences gained have yet to be collated and no solid scientific basis for our methods has been established. To contribute to the development of knowledge in the area of initiatives of users of psychiatry, long- term mental healthcare users in the Netherlands developed TREE –'Towards Recovery, Empowerment and experiential Expertise'– by, for and with persons with long-term and severe mental health problems.

Recovery

Persons labeled 'chronically mentally ill' can and do recover, whatever the general, negative, idea about them might be (Anthony 1993, Boevink, Plooy and van Rooijen 2006a, Deegan 1993). Recovery refers to the personal process of persons living with mental vulnerabilities in which they try to give new sense and meaning to their lives beyond the devastating effects of mental suffering. The recovery concept puts an end to the idea that you have to be 'cured' and without psychiatric symptoms to (be

allowed to) participate in society. Whether prostheses ('mental wheelchairs') are needed or not, it is perfectly possible for people with psychiatric disabilities to occupy significant and valued roles in society. Recovery is about giving meaning to whatever it is you are overwhelmed with and about no longer letting the symptoms control your entire life. To recover means, on the one hand, not accepting the label of being 'untreatable' or 'therapy resistant' and, on the other hand, not or no longer fooling yourself that everything is all right in your life. Recovery means having the courage to face what is going on in your life and to accept there is extra and hard work to do. And of course it means actually starting working. To get to know your talents and possibilities, but also your vulnerabilities and less positive sides. To dare to have hope again and to (also) look towards the future. To dare to rely on your own strength and in your own way.

Empowerment

Recovery and empowerment are closely related. Recovery is not possible without empowerment and it is at the same time an empowering process. Empowerment is the development of the ability of people to wrestle their way out of hopeless situations and find new ways in life. In doing so, they learn by themselves how to choose ways of coping with new challenges and the kind of support they want.

Experiential expertise

To gain confidence with your own strengths and then develop and expand them, one needs experiential knowledge: knowledge about what helps and hinders in one's own recovery process. In our opinion, recovery and empowerment lean on experiential knowledge and expertise. People with the experience of severe and long-term human distress all have their own unique story. This story includes the meaning they give to their problems and the strategies developed to handle these problems. This is the so-called personal experiential knowledge. All these individual stories together form collective experiential knowledge: knowledge about how it is to live with mental vulnerability and its consequences. If one is capable of passing on this knowledge to others in any form, then we use the word experiential expertise. Experiential expertise is essential for the recovery of persons labeled mentally ill. On an individual level, it helps empower fellow sufferers in their quest for their own strength(s). On a higher level, it paves the way for user influence in improving mental healthcare services.

TREE is a company developed and run by experiential experts. Participants in TREE activities have the opportunity to develop their own skills as experiential experts.

The TREE program

TREE brings together the strategies and methods users and survivors of psychiatry have developed and which are thought to account for their success. It aims at enabling people with psychiatric disabilities to support each other towards recovery, empowerment and experiential expertise, thus enhancing their ability to manage their own lives and to counter their marginalization in society (Boevink et al. 2002, Boevink 2006b). To this end, the program enables its participants to exchange experiences and offer mutual support. It also encourages them to develop knowledge and to use such knowledge by making it available to others. The program promotes user/survivor-led change within mental healthcare organizations towards recovery-based services. Finally, TREE has an important destigmatising influence: research shows that the most effective way of combating stigma is to bring the general public in direct contact with the stigmatized group ('to know one is to tolerate one') (Corrigan et al. 2001). TREE participants are trained to make and tell their stories to a range of target groups, among them subgroups from the general public. In the TREE program, participants develop, transform and disseminate experiential knowledge. They perform these tasks themselves, as volunteers or in paid jobs in the mental healthcare organizations where the program is implemented. If necessary, they hire others, for example, mental healthcare professionals, as protheses to enable them to perform their tasks.

TREE may sound self-evident, but it becomes very special if one takes into account the fact that the program is for, by and with persons with long-term mental health problems, such as psychiatric disabilities. They often struggle with multiple and complex problems in several domains of life and most of them have impressive patient careers in psychiatry. As a consequence, they face dependency, lack of self-confidence and self-esteem, loss of control over their lives, loss of meaningful identity and greater social vulnerability.

There are no other criteria to enter the program than to have (the courage to have) some interest in what the program is about. We do not know which factors predict

success. Perhaps it is better not to know. The program is developed in order to create opportunities for recovery and empowerment and to facilitate whoever wants to make use of these opportunities. Inherent to this goal is that everybody can participate. Practice will show for whom it is a successful opportunity and for whom it is not. The program is open to all users and survivors of long-term mental healthcare. There are no inclusion criteria, no demands, no examination and it can be used as often and as long (or as short) as one likes.

Stories in TREE

A person with a psychiatric disability can take part as a member of a self help group, as a student of one of the courses, a volunteer or as a paid experiential expert.
The program offers the opportunity to:

- communicate with others about experiences that are overwhelming;
- create some distance from these experiences and reflect upon tem (develop one's own narrative);
- make a we-story out of several I-stories (experiential story);
- make the experiential narrative useful for disseminating knowledge to fellow users and survivors of psychiatry, mental healthcare professionals and others; and participate as a (paid) trainer or lecturer in training programs.

The underlying principle is that an important element in recovering from long-term mental illness is to develop and pass on narratives (Baart 2002, Boevink 2006c, Chamberlin 1979). To make and to tell a narrative enables us to overcome whatever it is we are overwhelmed with, for instance a psychosis, because it empowers us to recover our sense of self (Herman 1992). Through telling our story, we grow from being a disorder to becoming a person trying to deal with life (Boevink 2006d, Ridgeway 2002). And it enables us to learn to formulate what it is we need to recover (from).
To develop your own narrative and compare it with the narratives of other users and survivors of psychiatry is the beginning of building experiential knowledge.
A collective story develops out of several individual narratives. To this end, we look for underlying principles, for what we have in common and for what distinguishes us from one another. Finally, the experiential story is transformed and used for knowledge dissemination in training programs and courses.

Basically the program consists of:

- self-help groups and working groups;
- training, courses and workshops for fellow users and survivors of psychiatry;
- training programs for professional caregivers;
- training for professionals and users together; and
- consulting and coaching of TREE innovations in organizations in mental healthcare.

The TREE team

The TREE team consists of 60 persons from all over the country in different phases of their recovery process and in different phases of their development as experiential experts. An important condition for joining the team is to have had a psychiatric (serious, long- term and disrupting daily life) past and present. TREE has experienced members, veterans and trainees. Responsibility for the implementation of an entire TREE program in a mental healthcare setting lies with the veterans in cooperation with the TREE coordinator.

Participants play different roles: there are people who support a recovery group, participants who present their recovery story and, for example, team members who take overall responsibility for providing a training course or seminar. Of course, combinations of tasks are possible. One can still be a trainee concerned with one competency, but at the same time be working relatively autonomously on another task. For instance: a member can have shared responsibility with a co-facilitator of a self-help group (there are always two facilitators for each group), but still be under tight supervision as a lecturer about recovery. The TREE team has a system of coaching in inter/supervision. Veterans support juniors, and mutual support among all is stimulated strongly. Not just in the recovery self-help groups, but also within the TREE team, mutual support and self-help is a powerful source of resilience.

TREE is unusual in that there is no traditional distinction between 'professionals' who do the work and 'patients' who are helped or 'served'. It is the psychiatric services users themselves who are the actors and who, if they want to, develop into the ones who carry out work in paid jobs. Most TREE members started by working on their own recovery in a recovery self-help group and then, at one point, chose to further

develop their knowledge and skills as TREE members. Several members are now working in paid jobs in psychiatric institutions or other organizations as experiential experts. We always strive to do these jobs while still staying a member of TREE, thus guaranteeing ongoing learning and exchange of experiences and support. This ongoing contact (and contract) has the advantage that the members are dispatched for temporary jobs to other organizations than their own or even other countries. This keeps them alert and inspired and also prevents n arrow mindedness and a feeling of powerlessness when pioneering within one's own organization.

Informing fellow users

Usually, the first phase of TREE interventions in psychiatric institutions consists of visiting its patients and telling them our own stories, thus allowing them to familiarize themselves with the hopeful perspective of recovery. We visit people in places with which they are familiar and where they feel comfortable. We try to fit the information sessions into their daily routine and we adapt our ways of communicating to each different audience. We try to ensure that the people providing the information share experiences with their audience. Providing information to people living in a sheltered housing facility, for example, is ideally carried out by people who also live or have lived in such a facility. The information meetings are, of course, not obligatory. All that the facilitators can do is to create the opportunity for the audience to become curious or to be tempted (to open up) by something new. That in itself is often a big task for people who have ground to a hopeless halt after years of loss and suffering.

Kick-off meeting

After contacting the people living in the psychiatric institution, a kick off meeting is organized. These meetings are chaired by a TREE team consisting of a senior trainer, a trainee who presents the experiential story and two participants in TREE projects elsewhere. We invite a maximum of 25 users, family members, care givers, managers and policymakers to the meeting. Users must always make up at least half plus one of those present at the meeting to ensure that they are properly represented and that their voice is heard. In order to make it possible for people to attend, it is made clear that one can leave the meeting for a break and come back whenever one wants. It is pointed out that people's limitations in terms of energy or concentration, for example, should be taken seriously, that the TREE team is familiar with them and knows how

important it is to respect them. The purpose of the meeting is to present a clear explanation of TREE so as to lay the basis for local TREE projects and activities. The meeting often takes up a whole morning (or an afternoon or an evening) and is divided into three parts.

In the first part, the meaning of the three concepts (recovery, empowerment and experiential expertise) is explained in a brief information session using experiential stories. After the experiential stories, the senior trainer asks those present to think of an overwhelming experience in their own lives from which they have had to recover. He or she then asks each person which strategies they used to bring about that recovery and, above all, which strategies helped and which did not. The responses are then collected and written on a flip chart; the aim is to show that there is (virtually) no difference between the strategies used by people with and without psychiatric disabilities.

The second part is devoted to TREE activities elsewhere in the country. These are described briefly and specifically, so that those present are able to form a picture of them. A number of participants from other locations are also interviewed about their participation in the TREE activities in their own region.

In the third part, a basis is laid for TREE within the host institution. Those present are then invited to make known their own preferences and wishes in smaller groups. Based on the outcome, the TREE team then writes a project proposal.

The kick-off meeting is often also the place where people register for the proposed activity. Contacts are also established at these meetings with enthusiastic professionals who can play the role of ambassadors later on in the project.

The recovery self-help group: developing strengths

This group forms the basis for the program. It consists of a maximum of eight participants plus two experiential experts to act as facilitators. They meet for two hours every two weeks. The workshop activities are based on recovery and empowerment. The emphasis in the discussion of personal experiences is not on problems and illness, but on strengths and possibilities. This is not to say that mental suffering is denied or

ignored; the group develops ways of increasing each member's strengths and possibilities so they are better able to deal with their suffering. It is not a therapy group, but a self-help group.

During the meetings, which have a set structure, participants are given the opportunity to talk about their daily lives. This enables them to learn to talk about their experiences using self-chosen words and to learn to listen to each other. Both are skills that seem rarely to be used and often forgotten when living as a chronic patient in a psychiatric institution. The participants share experiences and give each other support and advice. In this way, they experience the positive value of their own experiences and learn to see them as a source of knowledge. The different contributions and discussions are recorded in the minutes of the meeting. This is an important part of the meetings: discussing the meetings helps people to look at their own experiences from a distance and to place them in a broader context. In this way, themes can be identified on the basis of everyday personal experiences. These themes are then discussed in more depth at subsequent meetings.

The next step is to make individual experiential stories based on the answers to questions such as, 'Who am I? What is it that I have to learn to live with? How can I help myself? How can others help me?' For this purpose, the participants prepare a presentation for fellow users outside the group. The idea is that they tell the audience about their own recovery experiences and explain what recovery from mental illness can mean. The fact that there is now an audience of relative outsiders means their experiences have to be molded into a coherent and accessible story, with a beginning and an end.

The reports of the discussions in the group can also be used to enable people to mix their own experiences with those of others. This integration of personal stories into one collective story is not the same thing as aiming for consensus. On the contrary, the whole point of experiential knowledge is that it describes different standpoints, overlaps and differences. Experiential knowledge should not reduce these complexities, but make them understandable. Finally, participants are offered training in constructing stories and presentation techniques to help them convey recovery stories to other people. The recovery self-help groups are the basis for the implementation

of recovery-oriented programs in psychiatric institutions. They form a potential source for new experiential experts who, later in the process, can become the new leaders of the innovative changes in their own institution.

The recovery seminar

One of the ways of transferring experiential knowledge is by organizing seminars on recovery. The seminar program targets patients receiving long- term care and their professional mental healthcare workers. They can only take part if they come as a pair (patient and professional). The aim is to familiarize participants with the meaning of recovery and to teach them to apply that meaning in their own lives. All the trainers are experiential experts based on their career as users of long-term care. During the introductory session, participants are interviewed about their lives, their experiences, their dreams and their frustrations. The trainers focus on what patients and professionals have in common, with a view to blurring the traditional dividing line between the two groups. During the morning, there is also information transfer about recovery, including through the use of experiential stories. In the ensuing discussion, the aim is to generate a conversation between the patients. This is usually the first time in their lives that they hear about hopeful recovery experiences from fellow patients, and they often are very eager to talk about them. The professional workers are (respectfully and implicitly) placed in the position of audience. They are given the chance to witness the sometimes enormously positive changes that patients undergo when they first come into contact with recovery and with experiential experts.

In the afternoon, based on an experiential story, the focus is on the relationship between patient and professional and the development of the recovery concept. The participants can then practice more personal interaction with their pairs; based on the idea that recovery support is a two-way process, the members of each pair are invited to talk to each other. Both write down a positive and a less positive experience they have had with the other person and then read it out loud. It is difficult for patients to mention a less positive experience concerning the professional, because they are generally not accustomed to this or do not have the courage to give feedback about such an experience to their professional care-giver. For professional workers in psychiatry, it is often extremely difficult to produce a non-therapeutic comment, one

with a more personal input; they are not used to it as they have learnt to maintain a professional distance in their contact with clients.

'Making a start on recovery' course

'Making a start on recovery' is a familiarization course on the meaning of the concept of 'recovery' for patients using long-term psychiatric care. Recovery is to do with learning to live with persistent (vulnerability to) mental health problems. The course is intended to serve as an initial familiarization with the concepts of recovery and rehabilitation, to help people gain experience in discussing these concepts and to prompt people into an awareness of their own recovery process. The course does not involve any homework or reading work: the entire course consists of a structured discussion with other participants and with the experiential experts who are the course leaders. The course consists of five meetings: each lasting two hours, spread over a maximum of ten weeks. Each meeting has the same structure: introduction; presentation by guest lecturer; questions; exercises; close. The five meetings are based around the themes of the meaning of recovery; support with recovery; traps; the role of professionals in recovery; and how to continue your own recovery process. These themes are also the themes of the first series of meetings of the recovery self-help group. This means that a participant can easily become a guest lecturer on the 'Making a start on recovery' course. This enables them to practice in different roles and to experience how life as a psychiatric patient can also mean having rich sources of knowledge to use. The guest lecturers are interviewed and supported in preparing for their task. They receive payment for their visit in the course so as to not interfere with whatever income they have. Participation in the course is free of charge. There is place for five to seven participants.

The 'Recovery-Supportive Care' training program

A basic course, 'Recovery and Recovery- Supportive Care', was developed jointly by experiential experts and rehabilitation trainers. It was developed for professionals for whom the terms 'recovery' and 'recovery supportive care' are relatively new. The course lasts for two days.

On Day 1, the TREE concepts are presented, with the aim of helping participants to learn about the concepts of recovery, empowerment and experiential expertise; gain an insight into the meaning of these concepts in their own lives so that they can ima-

gine how those concepts might take form in the lives of their patients. The program on Day 1 consists of teaching the TREE concepts, both theoretically and through an experiential story. The day is also focused on familiarization with the meaning of recovery in the lives of course participants. A number of exercises and assignments are carried out in small groups.

On Day 2, the meaning of recovery-supportive care is added to the personal meaning of recovery, with the aim of giving participants knowledge of what recovery-supportive care is and developing a number of ideas about what it can mean in their day-to-day work; knowledge of the relationship between recovery-supportive care, treatment and rehabilitation, and exchanging first ideas about how treatment and support can be changed through the use of recovery supportive care. The program on Day 2 begins with the homework assignment from Day 1. The concept of recovery-supportive care is explained and discussed. Recovery-supportive care, rehabilitation and treatment and their mutual relationships are then explored through knowledge transfer, experiential stories and exercises. Day 1 is led entirely by experiential experts from the TREE team. On Day 2, the training team consists of an experiential expert and a rehabilitation trainer. The course can be given to a maximum of 14 people. This might be an existing team from a mental healthcare organization, or a mixed group with professionals from different parts of the organization. Each day goes from 10 am to 5 pm.

Towards evidence for our wisdom

In the Netherlands, the TREE program, or parts of it, has become increasingly popular among people with psychiatric disabilities themselves as well as among care providers. Most mental healthcare organizations have started to support their users to implement the program. A nation-wide operating team of experiential experts is now frequently hired to provide kick-off meetings, support users and survivors in their recovery and in building recovery narratives, coach persons with psychiatric disabilities to become experiential experts, train fellow users and survivors of psychiatry and professionals, give lectures and design new program modules. From 2004 to 2007, a randomized, controlled trial of TREE (n=80) versus care (struggling) as usual (n=83) in patients with severe mental illness was conducted at four Dutch sites. Follow-up measures were collected at 24 months. Primary patient outcome measures were empowerment, mental health confidence, loneliness and quality of life. Secondary

patient outcomes were s elf- reported symptoms and care needs. The primary process outcome was successful implementation and sustainability (continued engagement more than 50 per cent of the program over the two-year period).The program was implemented successfully and sustained over the course of 24 months in the majority of participants. Despite the limited number of participants, the experimental condition was associated with small positive impacts on mental health confidence and self-reported symptoms and no negative impacts. User-developed/run recovery programs can be implemented in a sustainable fashion alongside traditional mental healthcare services; they are furthermore open to evaluation by traditional trial methodologies. Results suggest that they may aid recovery processes.

TREE for the future

The development of new training and courses continues. The themes for training are numerous and there is great need for TREE in psychiatry, both for users and for professionals. A number of courses have been developed since the early years with regard to making and telling stories, coping with voices and growing beyond self-harm. TREE also experiments with new formats, like theatre, photography and voice exercises. At the same time, training experiential experts has developed further. The training consists of on-the-job competency education and training under supervision of senior TREE members. Finally, TREE grows in its knowledge and use of the possibilities of vocational rehabilitation, especially when it comes to creating spaces for slower rehabilitation processes and being paid for first attempts without losing the safety of one's social pension. In TREE, we develop experiential knowledge. We pass that knowledge on to others: to the next generation of care service users, to give them strength and hope; to professionals in mental healthcare, to learn to hear our voices; to people outside mental healthcare altogether, so that our human face be seen.

The TREE program is facilitated by Trimbos Institute (www. trimbos.org) and the Rehabilitation '92 Foundation, an organization aiming to introduce and implement the psychiatric rehabilitation approach of the Centre for Psychiatric Rehabilitation of Boston University in the Dutch Mental Health Care System. Research on recovery and empowerment received financial support from the Foundation for Mental Health in Utrecht. The TREE effectiveness study was made possible by the Netherlands Organization for Health Research and Development (www.ZONMw.nl/en) and by the Foundation for Sheltered Housing Accommodation in Utrecht (SBWU).

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Chapter 8

A USER-DEVELOPED, USER RUN RECOVERY PROGRAM FOR PEOPLE WITH SEVERE MENTAL ILLNESS: A RANDOMIZED CONTROL TRIAL

Gebaseerd op:
Boevink W, Kroon H, Van Vugt M, Delespaul P & Van Os J (2016) A user-developed, user run recovery programme for people with severe mental illness: A randomised controlled trial. Psychosis, 8, 287-301.

We examined, over a two-year period, the impact of a user-developed and user run recovery program (Toward Recovery, Empowerment and Experiential Expertise – TREE) on outcomes in individuals with severe mental illness, as add-on to care as usual. A randomized wait-list controlled design of TREE added to care as usual (CAU) (n = 80), versus CAU only (n = 83), was implemented in patients with severe mental illness. Follow-up was at 12 and at 24 months after inclusion. Primary outcome measures were empowerment, mental health confidence and loneliness. Secondary outcomes were quality of life, self-reported symptoms, care needs, service use and community outcomes (likelihood institutional residence and paid employment). TREE was associated with more mental health confidence (effect size for each year in TREE: 0.058, p = 0.043), less care needs (effect size for each year in TREE: −0.088, p = 0.002), less self-reported symptoms (effect size for each year in TREE: −0.054, p = 0.040) and less likelihood of institutional residence (risk ratio with each year in TREE: 0.79, p = 0.027). User-developed and user-run recovery programs may bring about small but reliable changes in recovery and community outcome after two years. More research is required to examine how such programs can become more successful within the context of disability-focused mental health services.

Introduction

Peer-delivered mental illness self-management training may reduce symptoms, enhance participants' hopefulness, and improve their quality of life over time (Cook et al., 2012). Recent meta-analyses and reviews of randomized trials of peer support for patients with severe mental illness yield some evidence that peer support is associated with positive effects on measures of hope, recovery and empowerment (Lloyd-Evans et al., 2014). It has been noted, however, that while the evidence base is promising, the field could benefit from more rigorous, pragmatic trials of sufficiently long duration to establish a solid evidence base (Castelein, Bruggeman, Davidson, & van der Gaag, 2015). In a recent meta-analysis, only three studies reported on interventions that lasted more than one year (Lloyd-Evans et al., 2014). Here, we report on a pragmatic trial of peer support in The Netherlands, describing the specific ingredients and their impact on recovery outcomes at 12 and 24 months follow-up. Patients in Dutch chronic mental health service settings developed the TREE program (Toward Recovery, Empowerment and Experiential Expertise), which supports persons with severe mental illness to manage their own lives and to counteract their marginali-

zation in society (Boevink, 2006, 2012). The program enables its participants to exchange experiences and offer mutual support. It also encourages them to develop knowledge and to use such knowledge by making it available to others. In addition, the program promotes user-led change within mental health care organizations in the direction of a more recovery-based orientation (Ashcraft & Anthony, 2009). Each person in TREE can take part either as a member of a self-help group, a student on one of the courses, a volunteer peer support worker or a recovery coach. Participants can grow into and take different roles. A randomized controlled trial (RCT) of TREE was conducted to test whether the program impacted on a-priori specified outcomes. The aim of the study was to determine the effectiveness of TREE as add-on to care as usual (CAU; consisting of professional case management) in persons with severe mental illness (SMI). It was hypothesized that TREE participants, in comparison with CAU only, would show more progress in a-priori defined recovery-related outcomes.

Method - Design

The study was a randomized wait-list controlled trial. It was performed in collaboration with four mental health care organizations serving individuals with SMI: two community treatment teams and two sheltered housing organizations in four different cities. They were selected on the basis of expressed willingness to implement TREE. Patients from the community treatment teams were individually allocated to either direct exposure to TREE (starting after baseline = Early Starters group) or late exposure to TREE (starting after 12 months = Late Starters group) using a procedure of computer-generated groups of eight. Patients from the sheltered housing locations were similarly randomized, in groups of eight, to either the Early Starters or the Late Starters group. Participants were followed for 24 months, with interviews at baseline, and after 12 and 24 months. There were two conditions (CAU, coded '0' and TREE, coded '1'). The Early Starters group was exposed to CAU up to baseline (condition = 0), and to TREE after baseline at 12 up to 24 months (condition = 1). The Late Starters group was exposed to CAU at baseline up to 12 months (condition = 0), and to TREE after the 12 months assessment up to 24 months (condition = 1) (Table 1). The outcome parameters were collected using self-administered questionnaires, mostly during group sessions.

The standing medical ethical committee approved the study. Participants provided written informed consent. Data are reported according to the CONSORT statement. No incentives were offered for participation. Recruitment took place between 2004 and 2009.

Hypothesizing an effect size of 0.5 SD, an alpha of 5% and 10% attrition, the required number of participants was 80 for each group to yield a power of 84% for continuous outcomes; the equivalent power for binary outcomes assuming a 40% outcome base rate and a 25% difference between groups was 85%.

Table 1. Course of TREE (1) versus CAU (0) in the groups of Early and Late Starters over the follow-up period.

Time	Early Startes	Late Starters
At baseline	0	0
Baseline-Year 1	1	0
Year 1- Year 2	1	1

The Early Starters group was exposed to CAU up to baseline (condition = 0), and to TREE after baseline up to 12 and 24 months (condition = 1). The Late Starters group was exposed to CAU from baseline up to 12 months (condition = 0), and to TREE from 12 months up to 24 months (condition = 1).

Recruitment

Five senior recovery peer workers organized a large number of small-scale meetings with users at different mental health service delivery settings ranging from a living room in a sheltered home to a meeting room in a psychiatric hospital. It was explained that users who were interested in participating in the program could leave their name and address and would be contacted for more information. In the second telephone contact, one of the researchers explained the subject about the research on TREE and asked whether he/she still wanted to participate in the program.

Intervention

At each site, TREE was provided by two or more senior peer workers. The TREE model under study consisted of (i) recovery self-help working groups, (ii) a one-day 'Reco-

very' training course and (iii) a training course Starting with Recovery. TREE has been reported in detail elsewhere (Boevink, 2006, 2012).

Training course 'Starting with Recovery'

'Making a start with recovery' was a familiarization course on the meaning of the concept of 'recovery' for patients using long-term psychiatric care. Recovery includes learning to live with a vulnerability of persistent mental health problems. The course served as an initial familiarization with the concepts of recovery and rehabilitation, to help people gain experience in discussing these concepts, and to prompt people into an awareness of their own recovery process.

Developing strength: recovery self-help working groups

These groups formed the core of the program. Each group consisted of a maximum of eight participants plus two peer workers who acted as facilitators. Most groups continued in the years after the research period. Consequently, the Early Starters met for two hours every two weeks during 104 weeks and the Late Starters for 52 weeks. The workshop activities were based on recovery and empowerment and organized as a self-help rather than a therapeutic group activity. The emphasis in the discussion on personal experiences was not on problems and illness, but on strengths and possibilities. This did not mean that mental suffering could not be discussed or was ignored; the aim was to develop ways of increasing each member's strength and possibilities so as to enable them to better cope with their suffering.

A one-day 'Recovery' training course

One of the ways of transferring experiential knowledge was by organizing seminars on recovery. The seminar program targeted patients receiving long-term care and their professional mental health care workers. They could only take part if they came as a pair (patient and professional). Mental health care managers facilitated the professionals to attend the seminar during working hours as part of the internal education program. The aim of the seminar was to familiarize participants with the meaning of recovery and to teach them to apply these values to their own lives (users), as well as to the mental health system (professionals). All trainers were peer workers based on their career as users of long-term care.

Outcome measures

A-priori selected primary outcomes were recovery-related: empowerment, mental health confidence and loneliness.The Boston Empowerment Scale (Rogers, Chamberlin, Ellison, & Crean, 1997) was translated to the Dutch 'Making Decisions Scale' (Castelein, van der Gaag, Bruggeman, van Busschbach, & Wiersma, 2008). Possible scores range from 1 to 4, with higher scores indicating more empowerment (Rogers et al., 1997). For the assessment of resilience, the Dutch version of the Mental Health Confidence Scale was used (Carpinello, Knight, Markowitz, & Pease, 2000). This 16-item scale was designed to assess the health-related self-efficacy beliefs of persons suffering from mental disorders. Items are rated on 6-point Likert scales with scores ranging from 1 ('absolutely no confidence') to 6 ('full confidence'). The De Jong-Gierveld Loneliness Scale (11 items) was used to assess feelings of loneliness, with higher scores (range 0–11) indicating more severe loneliness (De Jong Gierveld & Van Tilburg, 1991). Secondary outcomes were quality of life, self-reported symptoms, care needs, service use and community outcomes (likelihood institutional residence and paid employment). We used a shortened Dutch version of the Lancashire Quality of Life Profile (van Os et al., 2006) to measure quality of life, higher scores indicating better quality of life.

The Dutch version of the Community Assessment of Psychic Experiences (CAPE) was used to capture self-reported symptoms including depressive symptoms, positive psychotic symptoms and negative symptoms (Konings, Bak, Hanssen, van Os, & Krabbendam, 2006). The mean total CAPE frequency score was used as the symptom outcome. We used the Dutch version of the Camberwell Assessment of Need Short Assessment Schedule (CANSAS) to assess (un)met care needs (Phelan et al., 1995). The mean self-rated problem score of the 22 needs was used as the need for care outcome.To assess care use (use of out-patient services) and community outcomes (paid employment and hospital/sheltered housing residence) of the participants we used the Trimbos/iMTA questionnaire (Hakkaart-Van Roijen, 2010).Professional caregivers provided information about DSM-IV diagnosis and the Global Assessment of Functioning-Symptoms, Dutch version (GAF-S) (World Health Organisation, 1992) and Functioning, Dutch version (GAF-F) scores (World Health Organisation, 1992) were collected.

Statistical analysis

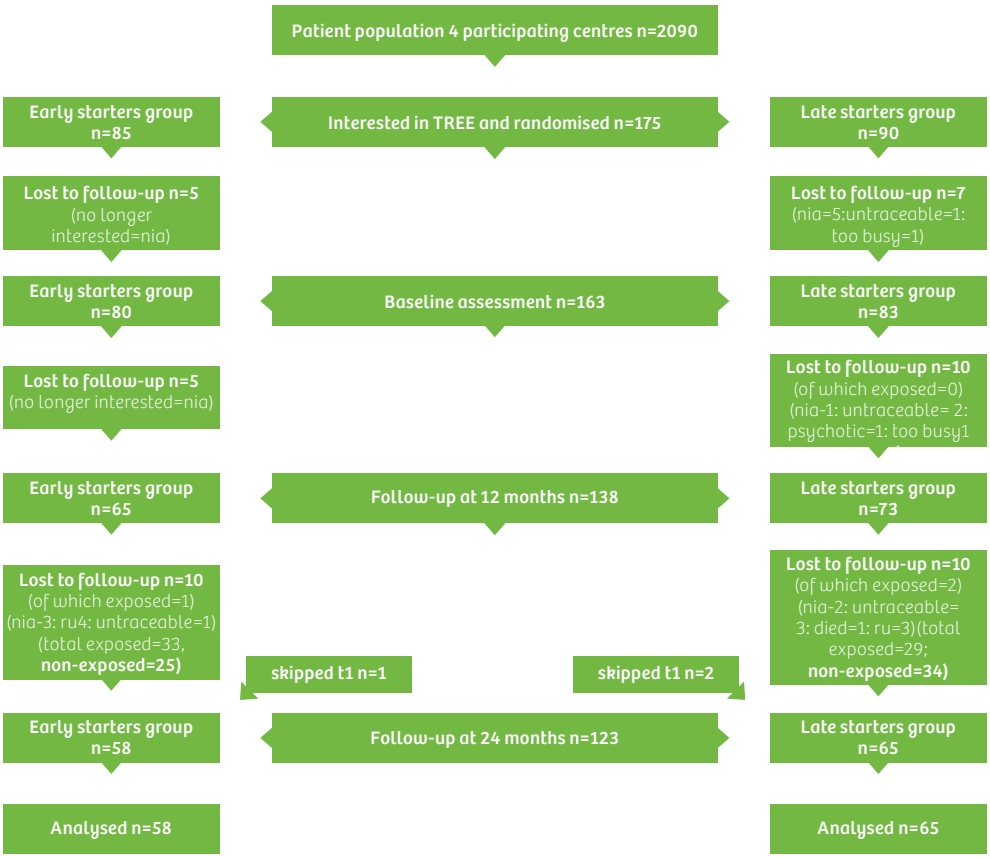
Analyses were done using Stata 13 (StataCorp, 2013). Analyses were carried out according to 'intention to treat'. As each individual contributed three observations to the analysis (baseline, 12 and 24 months), a multilevel random regression analysis was conducted using the XTREG routine in STATA, in order to take into account clustering of observations (level 1) within persons (level 2). The dependent variable was the continuous outcome measure and the independent variable was condition (TREE or CAU). Effect sizes are the regression coefficient B. In the analyses, treatment (TREE or CAU) was dummy coded as '0' (CAU) for baseline in both the Early Starter and Late Starter groups and for year 1 in the Late Starter group (Table 1); '1' (indicating exposure to TREE after 1 year) for year 1 in the Early Starter group and year 2 in the Late Starter group and '2' (exposure to TREE after 2 years) for year 2 of the Early starters group (Table 1). Site was included as covariate in all the analyses using three (n - 1) dummies reflecting the four (n) sites. Standardized beta coefficients (ß) were derived from the multilevel model with the ESTADD/ESTOUT commands. Binary outcomes were analyzed using the Stata BINREG risk regression routine with cluster-robust standard errors, yielding risk ratio's (RR), taking into account intra-person clustering of observations. Given relatively low participation rates with the intervention (see below), the intention-to-treat analysis was complemented with a sensitivity analysis in the subgroup who had participated per-protocol with at least one element of TREE. The sensitivity analysis was carried out by modelling an interaction term with actual TREE exposure (0 = no exposure, 1 = any exposure) in models of outcomes, excluding those who had dropped out before they had been scheduled to commence with TREE (see below). Stratified effect sizes were calculated from the model with the interaction term, using the Stata MARGINS routine.

Results

A total of 163 individuals were assessed at baseline (Figure 1); 80 in the Early Starters group and 83 in the Late Starters group. At 12 months, 25 participants (15 Early Starter and 10 Late Starter) were lost to follow-up, of whom three did have an assessment at 24 months. At 24 months, 18 were lost to follow-up (8 Early Starter and 10 Late Starter). The total attrition rate thus was 40 participants out of 163 (24.5%). At baseline, there were no large or significant associations between attrition and group

(p = 0.39), sex (p = 0.13), age (p = 0.65), level of need for care (p = 0.65), mental health confidence (p = 0.64), loneliness (p = 0.66), quality of life (p = 0.76), CAPE self-reported

Figure 1. Consort diagram randomized controlled trial



psychopathology (p = 0.08), use of out-patient mental health services (p = 0.063), paid employment (p = 0.36) and residence in hospital/sheltered housing (p = 0.11).
The demographic and baseline characteristics are shown in Table 2.The mean age was 43.9 years, range 22–73 years. The majority was not married, lived alone or in a sheltered home. A minority had a paid job. The educational level was moderately high but the number of individuals with a low educational level was twice as high as in the

general population. The most common diagnostic group was non-affective psychotic disorder; most had been admitted to hospital. Most used psychotropic medications in the month before baseline.

Table 2. Baseline characteristics of Early Starter and Late Starter groups.

	Early Starters (n=80)	Late Starters (n=83)
Age: mean (n; SD)	44.1 (79; 10.8)	43.7 (83; 12.0)
Male n (%)	46 (57.5)	39 (47.0)
(Living as) married n (%)	9 (11.3)	9 (10.8)
Living situation n (%) Independent/alone	32 (40.0)	37 (44.6)
Independent/with others	15 (18.8	9 (10.8)
In institution (incl. sheltered housing)	24 (30.0)	32 (38.6)
Single parent	3 (3.8)	3 (3.6)
Other (living rough/pension)	6 (7.5)	2 (2.4)
Paid employment (%) (Part-/full-time) paid employment	16 (20.0)	6 (7.2)
Voluntary work/ housemaker/study	20 (25.0)	30 (36.1)
Other	44 (55.0)	45 (54.2)
Missing	0 (0.0)	2 (2.4)
Education n (%) Low	39 (48.8)	36 (43.4)
Middle	29 (36.3)	25 (30.1)
High	9 (11.3)	22 (26.5)
Missing	3 (3.8)	0 (0.0)
	Early Starters (n=80)	Late Starters (n=83)
Clinical diagnosis n (%) Non-affective psychotic disorder	32 (40.0)	34 (41.0)
Affective disorder	15 (18.9)	4 (4.8)
Personality Disorder	10 (12.5)	14 (16.9)
Other	23 (28.9)	31 (37.4)

GAF (n; SD) Symptoms	58.9 (64; 13.9)	60.2 (64; 11.8)
Functioning	55.7 (62; 14.2)	59.2 (63; 14.4)
Never admitted	12 (15%)	10 (12.1)
Admitted in last month n (%)	11 (13.8)	8 (9.6)
Out-patient care past 4 weeks n (%)	41 (51.3)	58 (69.9)
Used meds in past 4 weeks n (%)	67 (83.8)	65 (78.3)

GAF, Global Assessment of Functioning.

The success of randomization was confirmed by the absence of large or statistically significant differences between the Early Starter and Late Starter groups on most characteristics with the exception of a significantly different diagnostic distribution ($p = 0.042$). Similarly, there were no large or significant differences between the two groups in any of the baseline values of the primary or secondary outcomes, with the exception of a greater proportion of the Early Starter group having paid employment at baseline ($p = 0.020$), and a greater proportion of the Late Starter group making use of out-patient mental health services ($p = 0.015$) (Table 2).

Treatment exposure

Of the 163 individuals in the trial, 21 dropped out before they were scheduled to commence with TREE, and 11 had exposure to TREE but dropped out before follow-up assessment. Of the remaining 131, 75 (57%) took part in at least one of the three elements of TREE. There were no large or significant differences on any of the baseline values of the continuous and dichotomous trial outcomes between those who were exposed to TREE and those who were not, with the exception ofloneliness: those that took part in TREE had significantly lower values on the loneliness scale (mean = 5.3, SD = 3.7) than those that did not (mean = 6.6, SD = 3.4; $p = 0.04$).

Table 3. Primary outcomes (adjusted for site)

Loneliness						
Time	CAU		Tree 1-year		Tree 2-year	
	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N
Baseline	5.60 (3.65)	163				
Year 1	5.62 (3.40)	73	6.00 (3.56)	65		
Year 2			6.00 (3.56)	65	5.69 (3.93)	58
Stratified effect size¶	0*		-0.12 (-0.58, 0.33), p=0.59		0.084 (-0.58, 0.75), p=0.80	
Effect size linear trend			-0.005 (-0.31, 0.30), p=0.98			
Standardised effect size linear trend			-0.001			
Empowerment						
Baseline	2.74 (0.30)	163				
Year 1	2.79 (0.32	73	2.73 (0.26)	65		
Year 2			2.79 (0.34)	65	2.78 (0.26)	58
Stratified effect size¶	0*		0.016 (-0.023, 0.055), p=0.43		0.049 (-0.01, 0.11), p=0.094	
Effect size linear trend			0.022 (-0.004-0.048), p=0.10			
Standardised effect size linear trend			0.053			
Level of mental health confidence						
Baseline	4.13 (0.90)	163				
Year 1	4.14 (0.99)	72	4.26 (0.80)	65		
Year 2			4.18 (1.05)	65	2.78 (0.26)	58
Stratified effect size¶	0*		0.10 (-0.008, 0.20), p=0.069		0.13 (-0.028, 0.28), p=0.109	
Effect size linear trend			0.073 (0.002, 0.14), p=0.043			
Standardised effect size linear trend			0.058			

* Reference category.

Between brackets: 95% confidence interval.

Differences between TREE and CAU after 1 and 2 years

Results are graphically depicted in Figure 2, showing outcome values in CAU only, after one year of add-on TREE and, after two years of add-on TREE. The continuous outcomes generally showed a degree of improvement after one year of TREE, with additional gains over the second year of exposure to TREE (Figure 2a–f). The dichotomous outcomes showed gains in the first year of TREE with little additional change over the second year of TREE exposure (Figure 2g–i).Analyses indicated that improvements were attributable to TREE for the primary outcome of Mental health Confidence, with a small effect size (standardised effect size 0.058 for each year of exposure to TREE), and for the secondary outcomes of Level of Need for Care (standardised effect size – 0.088 for each year of exposure to TREE); CAPE psychopathology (standardised effect size – 0.054 for each year of exposure to TREE); and residence in hospital/sheltered housing (RR = 0.79 – i.e. a 21% reduction in risk) (Tables 3–5).

Sensitivity analyses

In the 131 individuals who had commenced with TREE as scheduled, sensitivity analyses modelling the interaction between the linear TREE exposure and dichotomous actual TREE exposure revealed that the interaction term reach statistical significance for two outcomes: mental health confidence ($p = 0.005$) and quality of life ($p = 0.032$), indicating a large effect size in those actually exposed to TREE (mental health confidence: effect size linear trend: $B = 0.15$, $p = 0.001$; quality of life: $B = 0.17$, $p = 0.039$) and no effect in those not actually exposed to any of the elements of TREE (mental health confidence: effect size linear trend: $B = -0.07$, $p = 0.25$; quality of life: $B = -0.12$, $p = 0.22$).

Discussion

Main findings of the studyTREE was associated with increased mental health confidence, less self-reported symptoms, lower level of need for care and reduced risk of institutional residence. Although effect sizes were small (in the order of 0.1/0.15 over 2 years), the results in combination are nevertheless consistent, as higher levels of mental health confidence may result in better coping with needs and symptoms, resulting in reduced institutional dependence.The results have important implications; although there is much debate as to what the ingredients of recovery-oriented services are, their cost-effectiveness and how they should be implemented, user-developed

Table 4. Secondary continuous outcomes (adjusted for site)

Level of need for care						
Time	CAU		Tree 1-year		Tree 2-year	
	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N
Baseline	1.59 (0.43)	163				
Year 1	1.55 (0.48)	73	1.56 (0.43)	65		
Year 2			1.56 (0.45)	65	1.47 (0.35)	58
Stratified effect size¶	0*		-0.041 (-0.089, 0.008), p=0.098		-0.11 (-0.19, -0.044), p=0.002	
Effect size linear trend			-0.053 (-0.085, -0.020), p=0.002			
Standardised effect size linear trend			-0.088			
Self-reported psychopathology (CAPE total score)						
Baseline	1.82 (0.44)	163				
Year 1	1.78 (0.46)	73	1.80 (0.38)	65		
Year 2			1.77 (0.47)	65	2.78 (0.26)	58
Stratified effect size¶	0*		-0.048 (-0.093, -0.002), p=0.041		-0.052 (-0.12, 0.015), p=0.126	
Effect size linear trend			-0.032 (-0.063, -0.001), p=0.040			
Standardised effect size linear trend			-0.054			
Quality of life						
Baseline	4.39 (1.23)	163				
Year 1	4.49 (1.18)	72	4.63 (1.28)	64		
Year 2			4.48 (1.27)	65	4.73 (1.20)	58
Stratified effect size¶	0*		0.066 (-0.11, 0.25), p=0.47		0.15 (-0.12, 0.41), p=0.27	
Effect size linear trend			0.072 (-0.050, 0.19), p=0.25			
Standardised effect size linear trend			0.042			

* Reference category.

Between brackets: 95% confidence interval.

Table 5. Secondary binary outcomes (adjusted for site)

Level of need for care						
Time	CAU		Tree 1-year		Tree 2-year	
	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N
Baseline	13.7	161				
Year 1	8.3	72	15.4	65		
Year 2			12.7	63	13.8	58
Stratified effect size¶	1*	1.17 (0.82, 1.67),	1.17 (0.82, 1.67), p=0.40		1.14 (0.60, 2.16), p=0.69	
Effect size linear trend		1.09 (0.81, 1.46), p=0.58				
Self-reported psychopathology (CAPE total score)						
Baseline	34.4	163				
Year 1	31.5	73	26.2	65		
Year 2			21.5	65	22.4	58
Stratified effect size¶	0*		0.72 (0.56, 0.92), p=0.008		0.69 (0.44, 1.08) p=0.10	
Effect size linear trend		0.79 (0.64, 0.97), p=0.027				
Quality of life						
Baseline	60.7	163				
Year 1	74.0	73	76.9	65		
Year 2			69.2	65	72.4	58
Stratified effect size¶	0*		1.03 (0.90, 1.17),, p=0.68		1.00 (0.82, 1.22), p=0.99	
Effect size linear trend		0.92, 1.10), p=0.92				

* Reference category effect size expressed as risk ratio

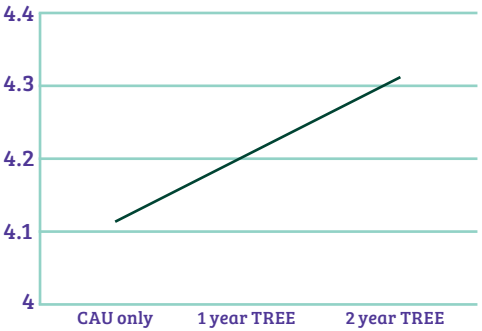
Risk ratio linear trend.

Between brackets: 95% confidence interval.

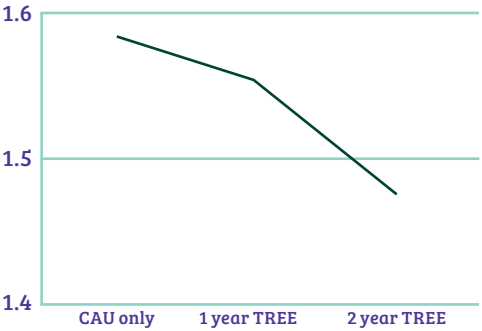
and user-led recovery-based interventions care considered a core element (Castelein et al., 2015). The current study showed small effects on both recovery (mental health confidence) and more traditional clinical outcomes (symptoms and needs). Although the pattern of results suggests a degree of outcome specificity, the direction of effects was uniform across all outcomes, indicating a global effect across outcomes rather than specific effect for some outcomes.Small effect sizes may be attributed to several factors. First, the findings are in line with meta-analyses of the peer-support literature suggesting small and uncertain effects (Davidson, Bellamy, Guy, & Miller, 2012; Davidson et al., 1999; Lloyd-Evans et al., 2014). An important emerging factor that may explain the lack of strong impact is that peer support interventions invariably are organised within the context of mainstream mental health services.

Figure 2. Graphical display of results, showing outcome values in CAU only, after one year of add-on TREE, and after two years of add-on TREE.

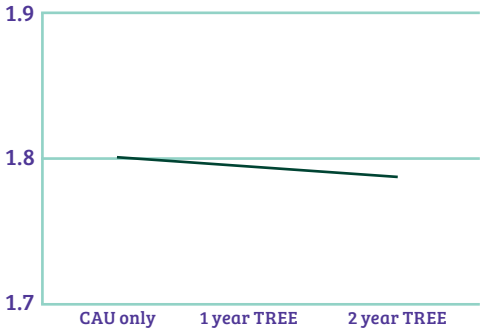
c. Mental health Confidence



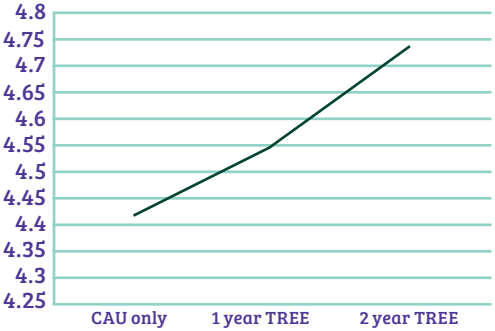
d. Need for care



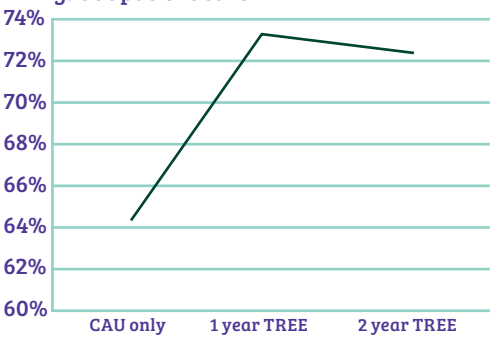
e. Psychopathology



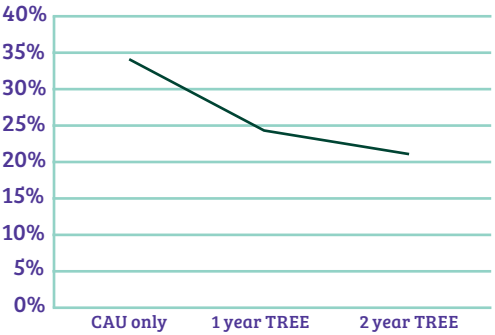
f. Qol

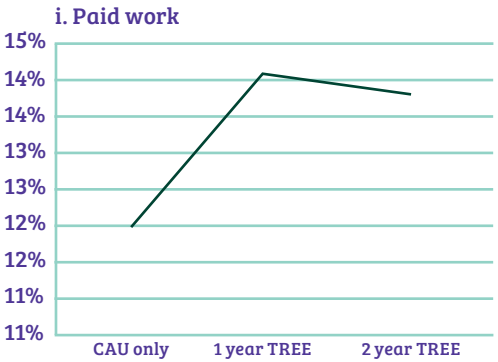


g. Out patient care



h. Non-institutionalised





It has been shown that recovery-promoting interventions can fail because uptake or engagement in existing mental health structures may be suboptimal (Henderson et al., 2015; Thornicroft et al., 2013). Mainstream mental health services are often organised around a discourse focusing on the limitations associated with disability arising from mental disorder, rather than the possibilities for living well with mental health problems (Slade & Longden, 2015). It has therefore been suggested that recovery-oriented practice may only succeed in the context of carefully planned pilots of disruptive change of both the discourse and the operationalisation underlying mental health services (Delespaul et al., 2016). Second, actual per-protocol participation in TREE was relatively low and the sensitivity analysis suggests that true effect sizes may be considerably larger than suggested in the intention-to-treat analyses. Third, it may be difficult to capture 'existential' recovery outcomes with traditional methodologies such as scales. Further research is required to investigate this issue; a combination of quantitative and qualitative methodologies may be required to capture changes in recovery outcomes over time (Lloyd, King, & Moore, 2010). Fourth, TREE is an ongoing development and it may be that some components are suboptimal in relation to the desired outcome of recovery. Fifth, recovery likely reflects a non-linear process that for many may take more time than the 1–2 years of the duration of the trial. Sixth, although persistence of TREE in many parts in the Netherlands (see below) suggests a degree of organisational readiness, this was not formally tested and may have been more variable in the initial phases of the trial in some sites.

Study limitations

A strength of the study is the focus on a user-developed and user-led paradigm. Although there is no strong evidence that mental health outcomes improve if consumers are employed to do the same role within a mental health service as professionals (Pitt et al., 2013), lack of clinician competence can be a crucial weakness if the focus is on recovery rather than traditional outcome measurers (McGuire et al., 2012). In addition, there is growing support for consumer-led research and intervention in alignment with recovery principles and policy directives.

Some of the limitations were already discussed above. No information was available on 'model fidelity' over time at the different locations. Subtle deviations may have occurred, although there was central supervision and regular quality assurance site visits were conducted throughout the period of the trial. Not all participants were individually randomised. Patients from the sheltered housing locations were clustered by location and these clusters were randomly allocated to either the Early Starters or the Late Starters group. This was assumed necessary to reduce reactivity due to patients living together being assigned to different conditions. A further limitation is that comparison with CAU only rather than CAU plus another structured add-on comparison intervention can create non-specific effects due to increased attention. This requires further investigation.

Although CAPE self-reports in patient groups correspond with clinician-rated measures, regardless of insight (Liraud, Droulout, Parrot, & Verdoux, 2004), the study did not take into account the fact that some patients with poorer metacognition would have needed specialised treatment in order to make them improve their capacity to understand their psychological needs and life goals before being able to make sense of TREE (Lysaker et al., 2011). The relatively high drop-out rate may be related to this. Finally, TREE has not been extensively manualised, providing clear anchors allowing detailed assessment of fidelity. It is therefore difficult to replicate. However, the current trial was a first pilot in a longer-term effort to develop a fully manualised programme for mental health reform in the Netherlands, as recently published (Delespaul et al., 2016).

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Chapter 9

DISCUSSION AND VALORISATION

This thesis is about recovery, empowerment and experiential expertise in psychiatry. It integrates my personal experiences as a psychiatric patient with the experiential knowledge accumulated in the user movement, as well as scientific knowledge in psychiatry. It aims to create a dialectical debate and bridge the gap between these different perspectives. The perspective of recovery made psychiatric patients more aware of themselves as active and acting individuals, although with severe and long term psychological suffering. 'Therapy-resistant' patients became aware of the 'cure trap'.

As the practice of psychiatry does not cure nearly as much as is assumed in general (Delespaul et al., 2016) – mental vulnerabilities typically expressing themselves periodically over the person's life, the long term course of which is not impacted to a large extent by treatments – people lost valuable years of their lives waiting for a 'miracle cure' to happen (Labruyère, 2012: 'Verloren Jaren', filmproductie). In the user movement, the focus shifted to resilience as the ability to cope with persisting vulnerability and its consequences. To document this process from the user perspective, an assessment tool was required (the Netherland Empowerment List). This instrument enables the user movement to find out whether psychiatry can assist in strengthening the resilience of its patients and if the practice of psychiatry can be helped to not obstruct the process of building resilience and the perspective of living a meaningful live despite persisting mental vulnerabilities. There is little doubt that people with severe and disruptive suffering are helped tremendously by peer support and self-help. However, until recently there was no or only little evidence that peer support and self-help in psychiatry were effective. The trial on TREE adds to the development of evidence based practice in the field of experiential expertise. While evidence-based practice certainly is not the only or necessarily the most important dimension underlying recovery, it is important to link the largely qualitative perspective of recovery from the user perspective with the quantitative language of evidence-based practice that feeds the professional perspective and professional identity. Only a dialectical process of finding truth between two relatively opposite perspectives can bring solutions to patients. Working in isolation from each other may serve the interests and influence of organisations, but does not serve the interest of individual users in their quest for recovery. A critical and dialectical interaction between the qualitative recovery and the largely quantitative evidence-based perspectives is required.

This dissertation reflects a personal quest in my struggle with a mental vulnerability that repeatedly threw me out of charge of my life. It spans a period of 3 decades and covers three crucial themes that bare relevance for the parallel process of becoming a scientist and builder of bridges: my personal history and experiences with mental vulnerability and the struggle to find the right words to describe the process of escaping the seemingly un-escapable alienation that the illness imposed upon me, an alienation that professionals were unable to alter (in fact only confirmed); the shared experiences of fellow travellers on this pathway to recovery. The user movement has integrated personal recovery narratives into a comprehensive change-related framework and developed protocols that facilitate the process of recovery for peer sufferers; attempts to bring this body of experiential knowledge to mainstream mental health practice. In a practice that is increasingly evidence-driven, the professional practice of the mental health field can be helped to accept experience-driven consumer interventions when these are assessed using the same quantitative scientific methods that are used in 'state of the art' psychiatric services.

A personal history is not science - yet. But starting from my own experience and integrating the narratives of others I explored how personal factors are shared and become a pattern. This is essentially a scientific track: exploring the underlying patterns of individual life stories and formulate the ingredients that help disseminate knowledge and facilitate the process of change. In Boevink et al (2002) 'Woring together on recovery: from exchanging experience to disseminating knowledge' this specific 'scientific' track was described in detail (Boevink et al., 2002). Scientific knowledge should be valorised, and if no attempt is made to translate knowledge to practice, science risks losing purpose – a very topical theme in traditional biomedical neuroscience (Lumbreras et al., 2009, Paulus, 2015). User involvement refocuses the relevance of care on the person's daily life – there where people want to succeed (a proposition that was framed by NorthHolland-North Mental Health Trust). Purposeful activities, meaningful relations, being able to participate and enjoy are the primary objectives of most individuals. Traditional psychiatry has an exclusive focus on what goes wrong, disregarding personal strengths. What does relevance mean, when what really counts is disregarded in care? User involvement revalorizes what matters for users of mental health care. And a science that is inspired by this input brings a new focus on mental health and improves the content of care (Delespaul et al., 2016).

Most clinicians will ascertain that the path to become a scientist-practitioner is not easy. The track of a patient to become 'scientist-user' is even worse and cannot be taken for granted. One has to grow beyond one's lived experience and reflect on it. One has to conceptualize and develop new perspectives without losing the connection with the mother source. A 'scientist-user' is never a scientist only. Experiential expertise is always the main resource and a compass to focus the process of 'doing science'. Moreover, mainstream scientific language is not always applicable to the work of a scientist-user, because the traditional scientific perspective in psychiatry is overwhelmingly preoccupied with quantitative and neuroscientific paradigms that do not fit the 'science of experiential expertise'. Scientist-users are faced with the additional challenge of developing new language between the language of 'evidence-based practice' and the language of hermeneutics – the science of meaning; in practice, the science of the user movement perhaps comes closest to the tradition of story-telling, which recently has seen a revival in areas as sociology (Brinkgreve, 2014).

Language is important in the user/recovery movement. Developing a personal narrative (adopting self-chosen words) to describe to others how it is to live with severe and long term psychological suffering, is part of the process of 'depsychiatrizing' and (re-) discovering a meaningful identity as a person. In the early days of the recovery movement, users created niches or sanctuaries within psychiatric hospitals to meet and share experiences. User initiatives, like 'Cliënten Belangen Bureau', were empowering breeding places where psychiatric patients developed resilience, organized joint decision making and initiated all kinds of activities. They were the recovery working places/academies or colleges avant la lettre. These early initiatives now inspire users and professionals/providers to develop recovery-based care within the mental health care sector.

Zelfregiecentra (self-help centres) have the same aims, outside psychiatry, within the community. This agenda redesigns psychiatry. It not only covers the development of recovery-stimulating environments run by users, or of recovery support offered by mental health care professionals, but also builds networks of all kinds of support in small scale communities where persons with severe mental disorders can lead meaningful lives and bring newfound resilience into practice in newfound meaningful goals. This reflects real integration and opens a world where stigma and discrimination do not exist anymore.

The recovery movement in The Netherlands exists for more than twenty years. What has been the contribution of TREE for this movement?

The TREE trial demonstrated how recovery processes germinate in self-help and mutual support environments. That does not mean that recovery can never evolve (or be facilitated) within mental health care. But the mental health care sector, despite all good intentions, implicates that people are handicapped and in need of care, in the context of which a persistent focus on evidence-based symptom reduction drives an important part of the legitimacy of the sector. This blurs the idea that people can and should also help themselves (and each other). In a sector where peers and not professionals are present, or where peers and professionals practice true co-creation of services, this insight is more self-evident. And therefore, a user-driven sector is needed to facilitate recovery oriented care.

This user-driven sector exploits the knowledge acquired over years by people with lived experience and exchanged and synthesized personal stories that are embedded in local culture, into emerging patterns. This is a shared process that continually reinvents itself and rejuvenates in mutual exploration of each other's narratives. It strongly contrasts with the conservative practice of professionals in mental health who focus on traditional solutions and the classical organization of psychiatric care as if the continuation of this status quo is an end in itself. These strategies are inflexible and irresponsive to the real needs of 'consumers'. From their perspective, psychiatric care should be supportive to what they want for their lives and care should facilitate this and help to deal with the obstacles. Often, the focus of professional care in mental health does not match this need. We are not there yet. Much work remains to be done. Work that includes changes in the thoughts and expectations of patients, family members and professionals, but also supporting research that creates the evidence for integrated care strategies. The academic User Research Centre (Robotham et al., 2016) is the primary instrument to accumulate the evidence that will help develop and implement altered recovery-oriented care into mainstream in psychiatry. It requires a network of motivated user-researchers, embedded in an open academic environment of high-quality, creative and open-minded dialectical research practice that provides on-site scientific supervision and opens financing channels. It will also provide the PhD students of the User Research Centre a job opportunity that will be instrumental to their own recovery process.

Is it possible to create a mental health care network that is truly person-centred and that efficiently harvests knowledge from the lives of its customers, relatives and professionals and results in recovery practices that restore the autonomy of patients?

It has been proposed that acquired knowledge is implemented in the grass-root movement of the New Mental Health Care (DNG='De Nieuwe GGZ') in The Netherlands (Delespaul et al., 2016). DNG intends to change mental health practice and is rooted in some of the most important topics within the user movement as well as (a novel and critical interpretation of) state of the art evidence-based practice. DNG has three pillars: an altered vision on what matters for mental health, refocusing from symptom reduction to daily life functioning and sense of purpose (needs, goals and intervention strategies); an altered vision on resources, that can significantly contribute to population mental health and bridge the gap between self-help, mutual help and professional/non-professional care to realize an effective true multi-expert triadic care; an altered vision on communities: original integrated care strategies were based on F2F care and could be overly optimistic while suffocating patients. Now, virtual communities can be activated to supplement the F2F care and allow real help through sense of community and relationships while remaining anonymous.

The application of experiential expertise has never been a goal in itself, but is a means to an end. The aim is to bring in user experiences and user experience-based knowledge to bridge the gap between what users need/want/ask and daily practice in psychiatry. As a consequence of the recovery movement – persons with serious mental suffering developed a language to describe their suffering and their lives with this suffering and to share it with others - people became aware of what they do to help themselves and of what frustrates their recovery attempts, finding ways to influence daily psychiatric practices. Mutual influence developed between their perspectives and knowledge and the perspectives of professionals in mental health care, and, although much less, scientific knowledge. This mutual influence, a fruitful exchange of how care for and support to persons with serious mental suffering can connect to these people and their lives, is the aim of using experiential expertise.

DNG may be considered in part as an extension of the work presented in this thesis; a tool to set up novel practices inspired by much-needed multi-expert dialectical

co-creation. DNG is emphatically not about creating a systematic, country-wide 'prescription' change, but about setting up a number of small area pilot projects (in areas of approximately 15.000 inhabitants) across the country, in which users, relatives and professionals co-create novel practice along the principles described above, with a focus on community, the importance of relationships, close collaboration with GP practices, a consumer-run social economy, open dialogue crisis interventions, the importance of resource strengthening and, in general, resilience-strengthening practices, a focus away from guideline-driven symptomatic treatment escalations towards phasic, context-driven care. A re-evaluation of evidencebased practice, allowing for a proper scientific appreciation of the effects of relationship and community that drive much of the improvement in randomised trials of specific pharmacological and pharmaceutical interventions, together with a sizeable investment in User Research Centres to help co-create novel practices with academic input from users, complementing the rich array of narrative recovery traditions and practices, will help change the landscape of mental health practice in Western Europe that currently is characterised by incremental loss of quality (Van Sambeek et al., 2011) and is even considered a 'dysfunctional system' (Schizophrenia Commission, 2012). Within these changing dynamics of perspectives on tools and identities, a series of Socratic dialogues on the issue of multi-expert co-creation in the area of mental health is now required to bring forward the next phase of meeting the challenge occasioned by severe mental distress in society.

Chapter 10

SUMMARY

This thesis is about recovery, empowerment and experiential expertise, three concepts that become more and more popular in (long term) mental health practice in The Netherlands. The aim was to better understand how the experiential knowledge that was developed within the psychiatric user movement, contributes to and facilitates how persons with severe and long term mental distress can help themselves, and how this knowledge can be incorporated in the language of evidence-based practice, setting up a dialogue between user-based and professional-based perspectives.

Part one of this thesis explores the concept of recovery. Recovery refers to the personal process of regaining control over one's life after a mental breakdown and the user-developed vision on how to overcome severe psychological distress. Recovery offers a hopeful perspective for persons who suffer from severe, long term and sometimes disruptive mental distress and have lost all perspectives on a meaningful life. It is not the same as cure. Persons in recovery can still have symptoms, but with adaptations and personalized support, they are able to build a new and meaningful life around these symptoms. The recovery concept is powerful. Psychiatric patients involved in the process of recovery shift the focus from resignation from dreams and goals due to the overwhelming symptoms of the psychiatric disorder, to new possibilities, focus and control over one's own life. Users of psychiatry develop their stories of recovery based on individual experiences and the knowledge derived from these experiences. They exchange their personal stories about how they manage to build a meaningful live despite severe mental distress. Through these stories they can testify: 'this is who I am, this is my vulnerability and by doing this or avoiding that, others can help me'. The most important aspects of recovery seem to be: growing beyond the diagnostic label and develop a sense of self as a person. Fundamentally, recovery is about daily life: it provides long term psychiatric patients with a strategy with which they can abandon their psychiatric identity ('de-psychiatrize' themselves) and become human again, with a sense of purpose. The perspective of recovery allows a developmental process from being a disorder to dealing with life, without outcome demands of 'normality' and 'societal success'. *Chapter two* is an experience-based illustration of what recovery processes can look like. Recovery means struggling beyond overwhelming suffering and building a life around persistent complaints and vulnerabilities. The work of recovery also aims at overcoming iatrogenic effects of psychiatry. Growing beyond the psychiatric diagnosis and regaining humanity,

finding new hope and develop new personal meaning of what is happening adds to healing from the essentially violent psychiatric system. Although recovery is not only a psychological construct, in the first years of the recovery movement the focus was on psychological processes of change within the person. *Chapter three* presents an experience-based paper on the association of early childhood trauma and psychosis later in life. This association was made visible through user stories of recovery and discovery of the context in which problems could develop (Read et al., 2005) and through the voice hearing movement (Corstens et al., 2014). There is now strong scientific evidence for this association (Varese et al., 2012), but the dissemination of this knowledge to innovative care is lagging. Although for first-onset patients a routine screening of traumatic experiences is deploying, there are many victims of childhood abuse in long term mental health care with undetected trauma histories and neglect of adequate help, which some mental health institutions are attempting to take seriously (Kees Lemke, personal communication, 2015). Current psychiatric practice still considers psychosis and dissociation as mutually exclusive, the first assumed to be a genetic organic disorder and the latter contextual, trauma-related. We now know that both dissociation and psychosis are personal ways of reacting to overwhelming life circumstances, potentially triggered by underlying vulnerabilities as a result of genes and life histories. Dissociation, with onset early in life as a necessary survival strategy, can evolve into or perhaps even cause psychosis.(Longden et al., 2016, McCarthy-Jones & Longden, 2015) In *chapter four*, this process is illustrated by describing psychotic experiences, which can easily be seen as symptoms of what the psychiatric tradition calls 'schizophrenia'. Only in the context in which these experiences became real, can they be understood. Apparently abnormal behaviour can be very logical if considered in the context in which they originated. Recovery is facilitated when the content of what is generally considered as psychotic phenomenon is taken seriously and is related to painful truths of the past. Dissociation is an important mechanism to survive and isolate unbearable and overwhelming emotions. It is an important coping mechanism for traumatic experiences during childhood. However, it can also be the cause of, or a fertile ground for, the development of psychotic symptoms. These symptoms conceal meaningful relational aspects experienced in harsh circumstan-ces. They can be translated into what really happened in the past. Yet, to date, this has not been common practice in psychiatric services around the world. Depending on co-morbidity, those labelled 'dissociative' have a

chance to get some kind of therapy. Those people identified as psychotic, however, are still often denied the opportunity to explore the significance of having had a painful past that can be addressed. Recovery from major psychiatric suffering is inextricably related to empowerment and emancipation (Slade & Longden, 2015).

Part two of this thesis presents the concept of empowerment which refers to an individual process of change in which individual strengths, talents and possibilities are (re)discovered, developed and ascertained. In *chapter five*, a study is presented on the content and meaning of empowerment in the experience of 56 persons with severe mental illness. Using a method called Concept Mapping, we explored the aspects as they relate to 'empowerment'. A total of 96 statements were formulated that were aggregated into eight domains: (1) Emerging sense of self, (2) Recovery work, (3) Basic conditions, (4) Connectedness, (5) Social support, (6) A caring community, (7) Social security, (8) Adequate help. Empowerment emerged as a concept with four dimensions: survival techniques, life art, connectedness and adequate help. The emphasis that the subjects placed on 'normal life' is striking. For people with psychiatric disabilities, empowerment is not facilitated by interventions from traditional psychiatry that focus on symptoms and illness experiences, for example 'learning to deal with the disorder', 'psychiatric support' or 'psycho-education'. In contrast, the process of empowerment is driven by (re-)learning to lead an ordinary, normal life with a sense of purpose. It is a matter of developing and strengthening mental health and knowing that one is valued in a normal social context, in normal human relationships; it is about connectedness and reciprocity. *Chapter six* presents the psychometric properties of the Netherlands Empowerment List (NEL). The NEL questionnaire was created by people with mental disabilities from all over the Netherlands, in order to ensure adequate content validity. The NEL has 40 statements with which respondents can agree or disagree. Principal component analysis produced six interpretable subscales: Social support, Professional help, Connectedness, Confidence and purpose, Self-management and a Caring community. Internal consistency was good, with the items forming a coherent whole. Discriminant validity was also good. Although there was a degree of association between NEL and constructs of quality of life, mental well-being, needs and psychopathology, these correlations were not so high that they can be considered as largely overlapping constructs. Convergent validity was, as expected, better for the Mental Health Confidence Scale than for the Boston Empowerment Scale, suggesting the need for a culturally sensitive scale. The NEL showed

good reproducibility and was responsive to a user-led intervention. The NEL was devised before the publication of the CHIME framework (Leamy et al., 2011), with which it clearly shows conceptual overlap. The dimensions of the NEL, similar to the CHIME framework, point to the importance of kindling strength and support for self-narrative development. This promotes the role of mental health services in building inclusive communities enabling access to peer support as well as providing sanctuaries, and clinical skills that promote self-management. Conceptually, the scale describes feelings, competencies and actions reflective of personal empowerment (confidence and purpose, self-management, connectedness), and the resources in support of this process (social support, professional help, caring community). The first factor 'Confidence and purpose' describes core aspects of personal empowerment: identity, self-esteem, control, willpower and purpose. A shorter 25-item version of the NEL can be composed using this subscale in combination with social support and connectedness. The Netherlands Empowerment List was developed with and for adults with psychiatric disabilities and was psychometrically tested in institutionalized and non-institutionalized settings, as well as in consumer-run initiatives. To date, the scale has been used in a wide range of settings in and outside mental health care in the Netherlands and Belgium, including services for homeless people, youth care, social work, visual impairments, intellectual disabilities, and physical revalidation.

Part three is about the development and evaluation of the TREE user-initiated recovery strategy. *Chapter seven* describes TREE (toward Recovery, Empowerment and Experiential expertise) or HEE in Dutch (Herstel, Ervaringsdeskundigheid en Empowerment). This comprehensive recovery strategy was developed and led by service users. It was intended to provide effective methods to help them to take the lead of their own recovery process. The TREE program facilitated user self-management groups and was staffed by trainers who were themselves service users and passed on their knowledge and experiences with respect to mental health difficulties to others. The long term aim was to facilitate empowerment in as many ways as they could. *Chapter eight* presents a randomized controlled trial on TREE. In the Netherlands, the TREE programme, or parts of it, became increasingly popular among people with psychiatric disabilities, as well as among care providers who intended to facilitate recovery in their services. Mental health care organisations therefore supported their users to implement the program. A national team of

experiential experts was frequently hired to provide kick- off meetings, support users and survivors in their recovery and in building recovery narratives, coach persons with psychiatric disabilities to become experiential experts, train fellow users and survivors of psychiatry and professionals, give lectures and design new programme modules. From 2004 to 2007, 163 participants with severe mental illness at four Dutch sites were randomly assigned to TREE and care (struggling) as usual. Follow- up measures were collected at 24 months. Primary patient outcome measures were empowerment, mental health confidence, loneliness and quality of life. Secondary patient outcomes were self-reported symptoms and care needs. The primary process outcome was successful implementation and sustainability (continued engagement in more than 50 per cent of the programme over the two-year period). The program was implemented successfully and sustained over the course of 24 months in the majority of participants. TREE had a small positive impact on mental health confidence and self-reported symptoms and no apparent negative effects. User-developed/run recovery programmes can be implemented in a sustainable way in traditional mental healthcare services. Also, they are open to evaluation by traditional trial methodologies. Results suggest that they may facilitate recovery processes. TREE was associated with increased mental health confidence, less self-reported symptoms, lower level of need for care and reduced risk of institutional residence. Although effect sizes were small (in the order of 0.1/0.15 over 2 years), the combination of results is consistent as higher levels of mental health confidence may result in better coping with needs and symptoms, resulting in reduced institutional dependence.

These findings have important implications. Of course there is still much debate about the ingredients of recoveryoriented services, their cost-effectiveness and how they should be implemented. But user-developed and user-led recovery-based interventions should be considered core elements of care (Castelein et al., 2015). The current study showed small effects on both recovery (mental health confidence) and traditional clinical outcomes (symptoms and needs). Small effect sizes may be attributed to several factors. First, the findings are in line with meta-analyses of the peer-support literature suggesting small and uncertain effects (Davidson, 2015, Davidson et al., 2012, Lloyd-Evans et al., 2014). An important emerging factor that may explain the lack of strong impact is that peer support interventions invariably are organised within the context of mainstream mental health services. It has been shown that recovery-promoting interventions can fail because uptake or engagement in existing

mental health structures may be suboptimal (Henderson et al., 2015, Thornicroft et al., 2013). Mainstream mental health services often focus on limitations associated with disability, rather than the possibilities for life with mental health problems (Slade & Longden, 2015). It has therefore been suggested that recovery-oriented practice best succeeds in the context of carefully planned pilots of disruptive change, both in the rationale and operationalisation of mental health services (Delespaul et al., 2016). Second, actual per-protocol participation in TREE was relatively low and the sensitivity analysis suggests that true effect sizes may be considerably larger than suggested in the intention-to-treat analyses. Third, it may be difficult to capture 'existential' recovery outcomes with traditional methodologies such as scales. Further research is required to study this issue; a combination of quantitative and qualitative methodologies may be required to capture changes in recovery outcomes over time (Lloyd et al., 2010). Fourth, TREE is an ongoing development, possibly some components are still suboptimal to reach the desired outcome of recovery. Fifth, recovery likely reflects a non-linear process that for many may take more time than the 1–2 years of the duration of the trial. Sixth, although persistence of TREE in many parts in the Netherlands (see below) suggests a degree of organisational readiness, this was not formally tested and may have been more variable in the initial phases of the trial in some sites. The strength of the study was the focus on a user-developed and user-led paradigm. There is no strong evidence that mental health outcomes improve if consumers are employed to act as professionals of mental health services (Pitt et al., 2013). Anyway, there is growing support for consumer-led research and intervention in alignment with recovery principles and policy directives. Some of the limitations were already discussed above. No quantified information was available on 'model fidelity' at the different locations. Subtle deviations are possible. We did, however, monitor the implementation with central supervision and regular site visits. Also, due to logistic reasons not all participants were individually randomised. Patients from the sheltered housing locations were clustered by location and these clusters were randomly allocated. This was assumed necessary to reduce reactivity because patients living together could contaminate conditions. Also, we used a self-report instrument (CAPE) regardless of insight (Liraud et al., 2004) to assess measures that are traditionally clinician-rated. Finally, TREE has not been extensively manualised, providing clear anchors allowing detailed assessment of fidelity. It is therefore difficult to replicate. However, the current trial was a first pilot in a longer-term effort to develop a fully manualised programme for mental health reform in the Netherlands, as recently published (Delespaul et al., 2016).

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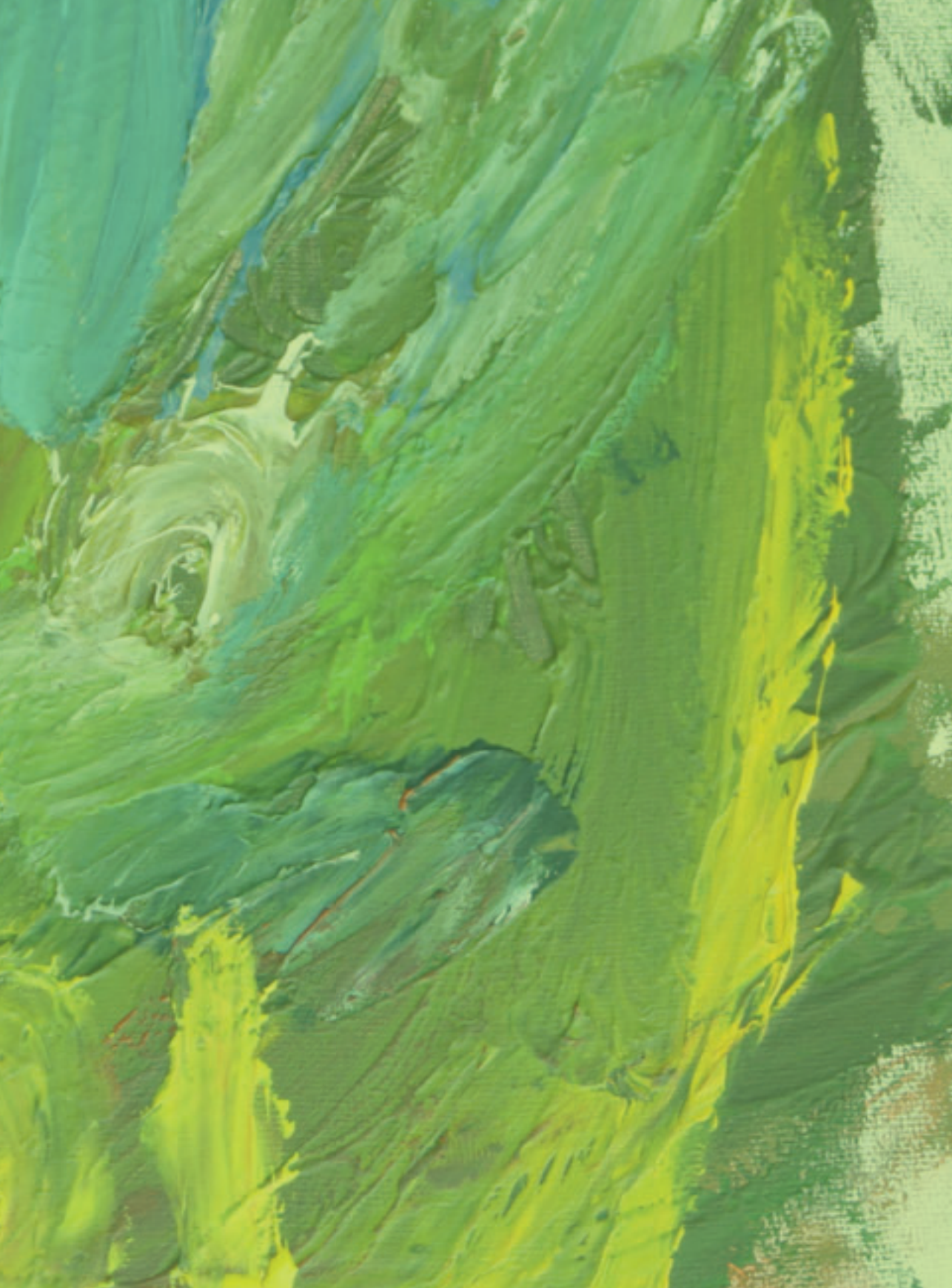
After having received the 'Parelprijs' from ZONMw and the Douglas Bennett Award for her work, she was honoured with an oeuvre award from Fonds Psychische Gezondheid. She received this prestigious price because of the remarkable way in which she – based on experiential knowledge and expertise – inspires persons with severe mental health distress to develop their strengths and talents fort the sake of their recovery.



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