FACULTY OF PSYCHOLOGY
AND EDUCATIONAL SCIENCES

# Unraveling recovery:
## A qualitative study rooted in the lived experiences of persons with complex mental health needs

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*“Strikt genomen ben je de fysieke uiting van een kans van één op de miljard. Wanneer je uit de baarmoeder wordt getild, ben je al een soort van winnaar. Oprah Winfrey weet dat. Dat is het gemakkelijkste deel. Dan begint het zware werk. De kleur van je huid, je toegewezen geslacht, je sociale klasse en de religieuze, economische en geopolitieke omstandigheden op je willekeurige plaats van aankomst worden verenigd tot één blok, als een bondgenootschap dat samenspant om je kansen in het leven te verknallen dan wel te vergroten. Hoewel we ons geleidelijk bewust worden van die verschillende stromen zijn we, in het begin althans, volkomen stuurloos. Het leven overkomt ons, en soms, als we geluk hebben, als we macht hebben, kunnen wij het leven overkomen.”*

(Marianne Thamm, *De Ondraaglijke Blankheid van het Bestaan*, p. 33)

# PREFACE

Flashback to 30 January 2013, a gloriously bright winter day in Villa Voortman, a community-based meeting place for persons with complex mental health needs in Ghent (Belgium) where I was doing my final internship as orthopedagogue-to-be. The meeting place, at that time still housed in a grandiose, stately and old villa, was surrounded by an enormous and magnificent garden that we looked out on from our balcony. For some weeks, it had been a running joke that, one day, we should go for a winter swim ('*bibberduik*') in the central pond of the garden. And so it happened – as it is in the spirit of Villa Voortman that no plan is ever too absurd to try. Encouraged by the enthusiasm of the other visitors and incited by the prospect of the ice-cold water, three of us took a plunge in the muddy and smelly pond. Although various reasons had caused our paths to cross and bring us together as visitors of Villa Voortman (be it our life histories, living circumstances, curiosity, professional backgrounds), in that very moment, these differences did not matter. We were just three foolish daredevils, conquering the freezing sting of the water hand-in-hand and sharing the thrill of the experience.

The welcoming, creative and warm culture of Villa Voortman set the scene of my first encounters with persons with complex mental health needs and initiated me in an alternative practice of engaging with this group that is often looked at as hard-to-reach, due to the complex interplay of the mental health problems, substance use problems and social challenges (e.g. homelessness, poverty, social isolation) they face. One of the most important things that Villa Voortman has taught me, both as a pedagogue and as a person, is the art of the encounter: to always be open to engage in dialogue, to see the other in all his/her complexity, to continuously search for a common language, to immerse yourself in the other's lifeworld and to let yourself be affected by the other's stories. In that sense, the afternoon of the winter swim is engraved in my memory, not only because the water was really cold, but also in a metaphorical way, as a constant reminder of what can happen when you dare to fully take the plunge in the encounter.

It is precisely in the many conversations and experiences that I shared with the visitors of Villa Voortman that the first ideas and my personal conviction of the necessity of this research project have sprouted. To both make visible and do justice to the everyday realities of persons with complex mental health needs, this research project is rooted in their lived experiences and aims to unravel what it means for them to be in recovery and how their recovery trajectories can best be supported in today's mental health care.

# ACKNOWLEDGMENTS

*Little darlin', come with me*
*Won't you help me share my load*
*From the dark end of the street*
*To the bright side of the road…*

*(Van Morrison)*

Writing this PhD has been an adventurous journey. Luckily, I had many travel companions who showed me the way, brightened up the road when I risked getting lost, broadened my horizon, challenged me to go off the beaten track, and provided necessary pit stops…

First of all, I want to express a very important thank you to all the participants of this research project, for sharing your stories with me (both on and off the record), for being so open about them and for trusting me with them. Thank you for allowing me to come closer, challenging me, affecting me, and widening my lens on life. Without your stories, this work would be meaningless.

Where it all started… Villa Voortman. From the first moment I set foot in the villa as an intern in January 2013, it has a very special place in my heart. To all the visitors, staff and volunteers, thank you for all the beautiful moments we have shared together in the past years: the sunny days on the balcony in the 'old' villa, the countless moments in the living room of coffee and small talk, the *bibberduik*, the cosy lunches at the big table, the Indian Summers, the amazing Utopia and Avanti theatre adventures, dancing together on the Kouter, the philosophy ateliers, the music moments, the at times intense encounters,… The list is long. All these experiences, no matter how small or big, have had such a profound impact on me, both as an orthopedagogue and a person. To the visitors that are no longer with us, this work is for you... I will never forget your stories. Dirk, I am forever grateful that you gave me the opportunity to do an internship in Villa Voortman. It proved to be the start of a beautiful journey and it opened more doors than I ever could have wished for. I hope to keep learning from your bottomless commitment, expertise, charisma and creativity for many years to come. Being a part of the colorful Villa Voortman collective is something I will never take for granted.

To the patients and staff of the rehabilitation ward at PC Sleidinge, thank you for welcoming me without hesitation, for your openness, and for engaging me in so many different aspects of the ward's daily practice. The opportunity you gave me to experience the ward in all its diversity has helped me a lot in broadening my perspective on recovery and support.

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Thank you for sharing with me your life story, your passionate activism, the bricolage adventure, your thoroughness, the London endeavor, our love for Indian food,… It has been such a privilege to work with you, to become your friend. I hope our dialogue will never be finished…

Stijn Vandevelde and Stijn Vanheule, *de twee Stijnen*, I feel spoiled to have you both by my side as supervisors. Thank you so much for at the same time opening up doors to interesting fields of research and letting me wander and explore different paths. Stijn Vandevelde, your dedication and kindness are admirable. Thank you for paving the way to my first research years at HOGENT, for encouraging me to write the proposal that led to this research endeavor, but above all, for supporting me and believing in me every step of the way. Stijn Vanheule, your determination and eagerness to keep opening up new spaces of thought have inspired me a lot during the course of this PhD. I sincerely hope we will continue working as a team!

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Clara

Ghent, May 2019

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# Chapter 1
# General introduction

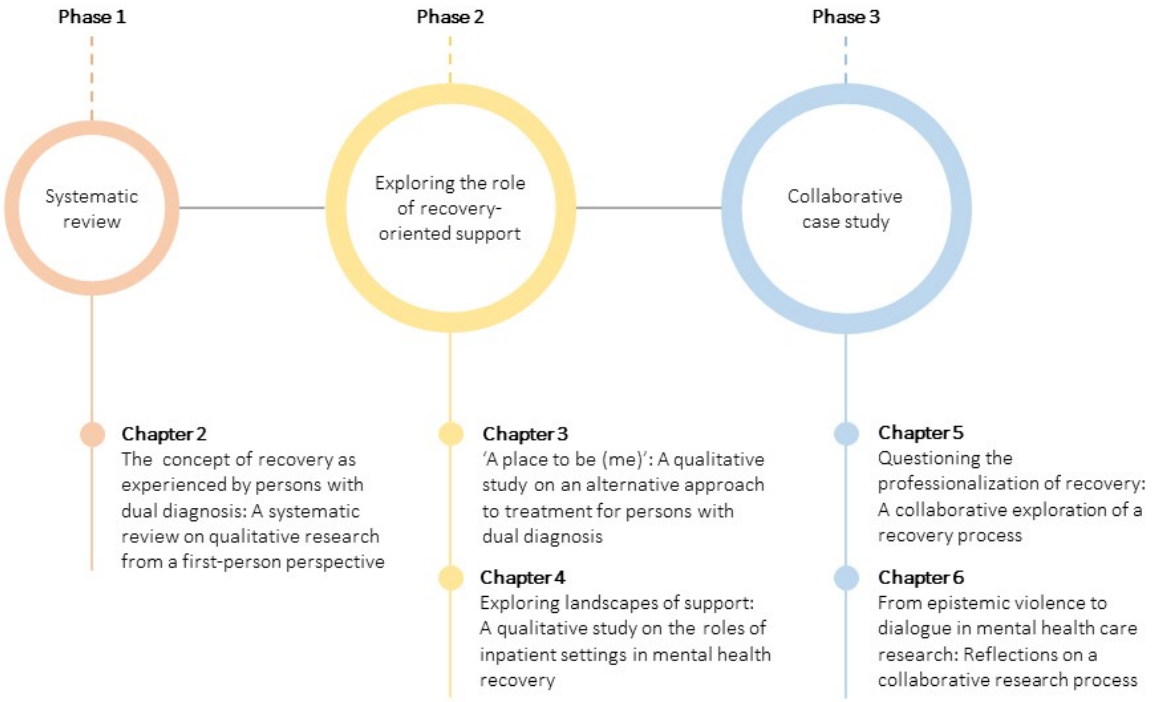
Based on

De Ruysscher, C., Bryssinck, D., Vanheule, S., & Vandevelde, S. (2017). Ondersteuning en behandeling van personen met een dubbele diagnose. In W. Vanderplasschen & F. Vander Laenen (Eds.), *Naar een herstelondersteunende verslavingszorg: Praktijk en beleid* (pp. 201-212). Leuven: Acco.

## 1.1 Outline

The aim of this general introduction is to give an overview of the most important concepts, frameworks and reflections that shaped this research project. More specifically, I will start by introducing the protagonists of this work: persons with complex mental health needs. Next, the historical roots and existing conceptualizations of recovery in today's mental health care will be discussed. Also, I will introduce the idea of *enactments* as an innovative way of thinking about recovery. After describing the overarching research aims and questions, I will shed light on the methodological and ethical choices and reflections I made during the course of this research project. Particular attention will be paid to the centrality of lived experiences in this work and the *bricolage* character of my research trajectory. I will conclude this introduction by giving a brief overview of the research process. Figure 1 provides a schematic outline of the three research phases of this PhD and how they relate to the different studies and chapters included in this thesis.

*Figure 1 - Overview of the research process*



## 1.2 From dual diagnosis to complex mental health needs

### *1.2.1 State of the art*

From the early 1980s onwards, a specific group came into the picture of international mental health care and addiction treatment services: persons with dual diagnosis, i.e. the comorbidity of substance use problems and mental health problems (e.g. psychosis, mood disorders) (Drake et al., 2001; Drake & Wallach, 2000). Over time, many different labels have been used in literature to describe this population, such as mentally ill chemically abusing (MICA) (Conner, Silverstein, Melnyk, & Maxey, 1995), substance abusing mentally ill patients (Warner et al., 1994), co-occurring addictive and mental disorders (COAMD) (Kessler et al., 1996) and chemically addicted mentally ill (CAMI) (Rassool, 2002). Today, despite the diversity of prevalence numbers, it is widely acknowledged that the comorbidity of mental health problems and substance use problems is the rule rather than the exception: up to 50% of persons with substance use problems also have mental health problems and vice versa (Carrà, Bartoli, Clerici, & El-Guebaly, 2015; Drake et al., 2001; Murthy & Chand, 2012). However, talking about the concept of 'dual diagnosis' as a sum of two disorders is misleading, as the everyday realities of persons with dual diagnosis are more complex than their twofold label suggests. Besides mental health problems and substance use problems, they are often also confronted with homelessness, a poor physical health, judicial problems, financial problems and social isolation, amongst other difficulties (Kavanagh & Mueser, 2007; Ness, Borg, & Davidson, 2014).

As mental health care and addiction treatment services have traditionally been two separate sectors, neither of these sectors initially considered themselves fully responsible for the treatment of this population (Donald, Dower, & Kavanagh, 2005). As a consequence, persons with dual diagnosis failed to find a connection to existing services, as their mental health problems were too severe to fit into addiction treatment services and vice versa. Additionally, several studies have shown that the separate treatment of both problems – in a sequential or parallel way – leads to a lack of continuity of care and places the responsibility to integrate both treatments in the hands of individual service users (Watkins, Lewellen, & Barrett, 2001). Based on these insights, it soon became obvious that an integrative and multidimensional approach to support, in which mental health care and addiction treatment are combined flexibly, is the most adequate to meet the needs of this heterogeneous group (Drake, Mercer-McFadden, Mueser, McHugo, & Bond, 1998; Murthy & Chand, 2012; Ziedonis, 2004; Ziedonis et al., 2005). Such an integrative approach also fits well with existing etiological models that assume a strong link between both disorders. For example, one group of etiological models states that the comorbidity can be explained by a common underlying biological, social or individual factor (e.g. trauma after abuse

as a child) (Mueser, Drake, & Wallach, 1998). Other etiological models assume that both problems are continuously and mutually influencing each other (e.g. through self-medication) (Carrà et al., 2015).

In recent years, both mental health care and addiction treatment services have adopted the concept of recovery (cf. infra) as the guiding principle of policy and practice which, according to Davidson and White (2007), provides a solid common ground from which integrative forms of support can be mapped out (Davidson & Roe, 2007). This led to the development of a wide diversity of support modalities, such as (closed) psychiatric wards, specialized Therapeutic Communities, case management, harm reduction and community-based and outreaching initiatives (Horsfall, Cleary, Hunt, & Walter, 2009). Despite these developments, however, persons with dual diagnosis still fall between the gaps of existing support. A recent literature review by Priester et al. (2016) shows that there remain several personal (e.g. lack of motivation, low ability to seek and access treatment) and structural (e.g. lack of specialized services, excessive waiting lists) barriers to treatment for persons with dual diagnosis.

### *1.2.2 A 'hard-to-reach' population*

As a consequence of these barriers and based on high drop-out rates and a pessimistic prognosis, persons with dual diagnosis are often considered 'hard-to-reach', 'at the end of their therapeutic trajectory' or 'worrisome care avoiders' (*'zorgwekkende zorgmijders'* in Dutch) (Bryssinck, 2013). However, labeling persons with dual diagnosis as 'hard-to-reach' would be an unjust simplification, as a number of important nuances are omitted in this description.

First, the low treatment adherence and seeming lack of motivation of persons with dual diagnosis are in many cases related to previous unsuccessful, even traumatizing, treatment experiences. Second, today both mental health care and drug treatment services are shifting towards a culture of evidence-based practice, in which standardized care, outcome evaluation, quality monitoring and effective short-term treatment are highly valued (Minkoff, 2001). Such a culture does not fit well with service users who at times show challenging behavior (e.g. substance use, psychosis, aggression, fickle treatment adherence), have to deal with difficult living circumstances (e.g. homelessness, lack of social network, traumatizing experiences, stigma) and whose recovery processes are characterized by intense ups and downs (Ness et al., 2014). In a different light, however, these characteristics can be seen as symptoms of exclusion from society, incited by experiences of stigma and marginalization. Paradoxically, precisely these symptoms of exclusion risk becoming the reasons for exclusion from treatment settings (Bryssinck, 2013). In that sense, it can be stated that persons with dual diagnosis face a double exclusion: not only are they excluded from taking part in community life as inclusive citizens, often they also lose connection to professional support modalities. However, labeling persons as 'hard-to-reach' ignores

these exclusion mechanisms and instead blames the individual service user (or in this case so-called 'service-avoider') for difficulties with treatment engagement (Bryssinck, 2013). In that respect, Kalathil (2015) argues that *"the problem with using a term like 'hard to reach' to define these groups is that it assumes homogeneity within disparate groups and places the problem within the group rather than the approaches used to enable engagement"* (p. 123).

Third, despite developments towards recovery-oriented support, available treatment programs often still primarily focus on symptom reduction and crisis management (Horsfall et al., 2009). Also, the available scientific evidence for the impact of these programs on the recovery processes of persons with dual diagnosis is very limited, as the focus of evaluation often solely lies on clinical outcome parameters (e.g. abstinence) (Chow, Wieman, Cichocki, Qvicklund, & Hiersteiner, 2013; Hunt, Siegfried, Morley, Sitharthan, & Cleary, 2013; Tiet & Mausbach, 2007). This shows how the support given to persons with dual diagnosis fits well with an exclusively medical discourse in which the focus lies on individual deficits, cure rather than support and long-term stability rather than recovery (Roberts, 2010). Through such a medical approach of persons with dual diagnosis, there is the risk that other – often social – factors that have a major impact on their lives are disregarded (Jaeger & Hoff, 2012). As a consequence, existing treatment modalities risk failing to offer the most adequate support due to a lack of understanding of the lifeworlds of service users with the most complex needs.

### *1.2.3 Towards complex mental health needs*

Throughout the course of this research project, it became clear how 'dual diagnosis' could be regarded as too much of a one-sided concept to describe this group, for different reasons. First, the concept of 'dual diagnosis' seems to suggest that the support needs of this group can be explained by the co-morbidity of substance use and mental health problems alone. In contrast, the above reflections show how the complexity of their everyday realities should rather be situated precisely at the intersection of multiple personal and social problems such as mental health and substance use problems, poverty, judicial problems, lack of social network, structural exclusion, marginalization and social isolation (Ness et al., 2014). As 'dual diagnosis' primarily functions as a diagnostic psychiatric label prompted by classification systems such as the DSM, it fails to address this entanglement and even risks medicalizing and individualizing the social realities of persons who face this complexity (Roberts, 2010; Staiger et al., 2011). In that respect, talking about the persons under study in my research in terms of 'dual diagnosis' would be at odds with the perspective from which I write this thesis, i.e. the Ghent Orthopedagogics, in which problematic situations in life are seen through a holistic and systemic lens (Vandevelde et al.,

2017). From that perspective, individuals are considered inextricably linked to their context and the wider social developments around them (Broekaert, Vandevelde, & Briggs, 2011).

Motivated by these reflections, and above all to do justice to the complex everyday realities of the persons under study in this research project, I decided during the course of my PhD trajectory to change the terminology I use to describe them, from persons with 'dual diagnosis' to persons with 'complex mental health needs'. This terminology is also used in recent literature on this population that acknowledges the heterogeneity of complex mental health needs and starts from a more social and holistic perspective (e.g. Bevington, Fuggle, Fonagy, Target, & Asen, 2013; Knightbridge, King, & Rolfe, 2006; Rosen, Killaspy, & Harvey, 2013). Rather than covering up this reflective process about terminology and presenting you a 'smooth' story about persons with complex mental health needs, I realize that the above reflections are perhaps some of the most important insights from my PhD trajectory. Although the concept of 'dual diagnosis' is used in a part of the presented studies (cf. Chapter 2 and 3), I invite the reader to interpret this work through a pedagogical lens and to search for the nuances that bear witness to my reflective process, as the chapters progress.

## 1.3 Conceptual framework of recovery

Recovery is the central concept of this dissertation. In what follows, I will give an overview of the historical context and dominant conceptualizations of recovery. I will conclude this section by introducing the idea of enactments as a way of thinking about recovery in today's mental health care policy, practice and research.

### *1.3.1 Historical context*

Today, recovery is the guiding vision of international mental health care policy and practice. The roots of the concept can be traced back to diverse intellectual and social movements that were active in the field of mental health care during the past half-century (Braslow, 2013). In the 1960s, the antipsychiatry movement gained momentum internationally under influence of thinkers such as Foucault (France), Basaglia (Italy), Laing (UK) and Szasz (USA) (Rissmiller & Rissmiller, 2006). This intellectual movement played a groundbreaking role in criticizing the power of totalitarian psychiatric institutions, the overly medicalized framing of mental health problems and the seeming endlessness and involuntary character of psychiatric admissions. In the same period, and especially from the 1970s, the American psychiatric survivor movement stood up against the inhumane circumstances of psychiatric hospitals, pointed to

social inequalities as a cause of mental health problems and started advocating the rights of persons with mental health problems (Morrison, 2013). These critiques, together with the optimism of the 1960s and 1970s, led to a wave of deinstitutionalization in which psychiatric hospitals were closed, inpatient beds were reduced drastically and psychiatric patients were released in the community (Sealy & Whitehead, 2004). These developments were based on the assumptions that community-based care would be more humane, more therapeutic and more cost-efficient than its institutional counterpart (Lamb & Bachrach, 2001). The 1970s American survivor movement further expanded into a heterogeneous group of consumers/survivors/ex-patients (c/s/x) in the post-deinstitutionalization era, demanding more choice and information for psychiatric service users, refusing to play the 'patient role' and addressing the power imbalances at play in treatment relationships (Morrison, 2013). It is in this c/s/x context that the concept of recovery first emerged, described by Deegan (1988) in the following way:

> *"[Recovery is] a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. […] The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution."* (p. 15)

According to its advocates, the recovery movement embodied a revolutionary new way of thinking about mental health problems that is rooted in the hopeful belief that the lives of persons with mental health problems are worth living to the fullest (Corrigan, Giffort, Rashid, Leary, & Okeke, 1999). From the early 1990s onwards, this recovery vision was adopted by mental health care professionals and policy makers in the United States and in a later phase also in Europe (Chow, Ajaz & Priebe, 2018; Kidd, McKenzie & Virdee, 2014). It appeared as a promising paradigm that turned away from the false belief that mental health problems are chronic and require life-long dependency on the mental health care system (Braslow, 2013; McCranie, 2010). In contrast to an overly biomedical approach that mainly focuses on clinical outcome parameters such as symptom reduction and treatment adherence, consensus grew that recovery is a unique, multidimensional and personal process that also entails empowerment, self-determination, finding meaning in life, dealing with stigma and overcoming the iatrogenic effects of treatment (Anthony, 1993).

Today, 30 years after its introduction, recovery has become a ubiquitous framework in international mental health care. In Flanders (the Dutch-speaking part of Belgium), the deinstitutionalization process has been formalized in Article 107 of the Hospital Law, that became operational from 28 September 2009 (Vlaamse Overheid, 2010). Article 107 allowed psychiatric hospitals to reduce beds, promoted the

prevention of mental health problems and aimed to provide continuity of care through developing support networks and circuits (Pattyn, 2014). The recovery framework played (and is still playing) a pivotal role in shaping this reform and is the underlying principle of many of the community-based and outreaching initiatives that were founded under impulse of Article 107.

### *1.3.2 Recovery conceptualizations*

The professional adoption of recovery led to the development of several theoretical frameworks that aim to conceptualize it. Although these frameworks are diverse and divergent, four broad types of recovery are generally distinguished: clinical, functional, personal and social recovery (Lloyd, Waghorn, & Williams, 2008). In what follows, this division will be used to give a brief overview of dominant conceptualizations in existing recovery literature.

*Clinical recovery*

This conceptualization of recovery is grounded in a medical approach and focuses on symptom reduction, clinical improvement over time and returning to a healthy state prior mental illness (Whitley & Drake, 2010). From a clinical perspective, recovery is the outcome of successful medical or psychological treatment (Pilgrim, 2008). Because clinical recovery is characterized by well-defined criteria such as levels of symptoms, a decrease in substance use, medication use and remission points, it is a very measurable type of recovery. Consequently, it is often used by policy makers and researchers as outcome measure to evaluate the effectiveness of mental health care treatment modalities (Davidson & Roe, 2007). Clinical recovery is described by Davidson & Roe (2007) and Pilgrim (2008) as recovery *from* mental illness and can be compared to recovery from physical illness.

*Functional recovery*

This type of recovery finds its roots in a number of longitudinal recovery studies that showed how a large percentage of persons with mental health problems (up to two-thirds, depending on the study) managed to resume personal, social and vocational (e.g. employment, education) activities despite the fact that they were not fully recovered in clinical terms (e.g. because they still experience mental illness symptoms) (Carpenter & Kirkpatrick, 1988; Davidson & McGlashan, 1997; Davidson & Roe, 2007; Davidson, Harding, & Spaniol, 2005). The notion of functional recovery is based on the idea that symptom relief alone is not sufficient to increase well-being and recognizes the impairments in everyday functioning that persons with mental health problems face (Harvey & Bellack, 2009). In this

conceptualization, recovery is characterized by a return to 'normal' functioning, in which living independently, employment and education are considered to be key features. Pilgrim (2008) situates functional recovery within social psychiatry and considers it the outcome of successful rehabilitation rather than treatment. Within a rehabilitative approach, support primarily focuses on community integration and successful participation in society by improving psychosocial functioning (e.g. through social skills training) (Lloyd et al., 2008; Whitley & Drake, 2010).

In essence, both clinical and functional recovery are based on the belief that persons with mental health problems have a (medical or functional) deficit that needs to be resolved in order for recovery to occur, preferably with the help of (expert) professionals.

*Personal recovery*

This conceptualization of recovery tallies best with Deegan's (1988) original definition (cf. supra). From a personal perspective, recovery is described as *"a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life, even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"* (Anthony, 1993, p. 527). The underlying assumption of this conceptualization is that persons with mental health problems are fundamentally similar to persons without mental health problems in their community in the ways they try to give meaning to their lives (Slade, 2012). Rather than an outcome measure, personal recovery is seen as a non-linear and idiosyncratic process that is characterized by self-determination, self-responsibility, a sense of hope, feelings of belonging, empowerment and the development of supportive relationships (Anthony, 1993; Schrank & Slade, 2007). An often-used model to conceptualize personal recovery is that of Leamy et al. (2011), who distinguish five interlinked recovery processes: Connectedness (peer support and support groups, relationships, support from others, being part of the community), Hope and optimism about the future (belief in the possibility of recovery, motivation to change, hope-inspiring relationships, positive thinking and valuing success, having dreams and aspirations), Identity (dimensions of identity, rebuilding/redefining positive sense of identity, overcoming stigma), Meaning in life (meaning of mental illness experiences, spirituality, quality of life, meaningful life and social roles/goals, rebuilding life) and Empowerment (personal responsibility, control over life, focusing upon strengths) (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Recently, this CHIME framework has been expanded into CHIME-D by Stuart, Tansey and Quayle (2017) to address the Difficulties (e.g. intrapsychic, interpersonal and social) that persons in recovery face. Personal recovery is described by Davidson & Roe (2007) as recovery *in* mental illness.

Thinking of recovery as a multidimensional, non-linear and unique process has implications for support. First, it is the persons with mental health problems themselves, rather than professionals, who hold the key to recovery (Anthony, 2000). Second, it is assumed that the resources for personal recovery can be found in diverse formal (e.g. treatment) and informal (e.g. social network) contexts (Vanderplasschen, Rapp, Pearce, Vandevelde, & Broekaert, 2013). Although professional support can take many forms (e.g. residential treatment, community-based support, medication, peer support), the following principles are generally put forward as essential conditions to support personal recovery: an individualized and person-centered approach, starting from a holistic rather than a medical perspective, promoting hopefulness and focusing on the strengths and capabilities of the person with mental health problems (Gagne, White, & Anthony, 2007; Slade, Amering, & Oades, 2008; Torrey & Wyzik, 2000). Additionally, Slade (2012) argues that recovery-oriented support should focus on *"everyday solutions for everyday problems rather than providing specialized treatments for mental illness-related problems"* (p. 702).

*Social recovery*

Although the concept of personal recovery provides a shift away from a mostly deficit-oriented approach to mental health problems, it has been criticized for focusing too exclusively on individual aspects of recovery, disregarding the social context (e.g. material deprivation) that persons with mental health problems find themselves in (Hopper, 2007; Khoury & del Barrio, 2015; Price-Robertson, Obradovic, & Morgan, 2017). To fill this gap, social recovery has been put forward as a conceptualization that recognizes the invalidating impact of stigma, discrimination and social exclusion in the lives of persons with mental health problems (Pilgrim, 2008). From a social perspective, inclusive citizenships, helpful social relationships, valued social roles and having access to enabling resources are considered key components of recovery (Schön, Denhov, & Topor, 2009). In this social conceptualization, recovery-oriented support is mainly rooted in social work practice and has an emancipatory agenda. In this respect, Tew et al. (2012) stress the necessity of two parallel and interlinked approaches: (1) supporting persons with mental health problems to increase their access to social capital and community activities, and (2) working with the community to enhance their levels of inclusiveness and social capital.

Whitley & Drake (2010) rightly point out that a division into the above-described recovery conceptualizations is somewhat artificial, as all these aspects overlap and are entangled in the recovery processes of persons with mental health problems. For example, having paid work might increase feelings of belonging and provide access to enabling resources; feeling hopeful about the future might be incited by fulfilling valuable social roles and symptom reduction. These interrelations bear witness to

the fact that recovery is a complex, multi-dimensional and layered process that takes place in idiosyncratic and non-linear ways.

### *1.3.3 Towards enactments of recovery*

Today, the recovery paradigm is widespread in mental health care policy, practice and research. It is used in different (professional, service user, advocacy, policy) contexts, at various (personal, organizational, societal) levels and to support diverse (research, practice, policy) agendas. Jacobson (2004), for example, distinguishes a number of different manifestations of recovery, such as recovery-as-experience, recovery-as-policy, recovery-as-evidence, recovery-as-ideology and recovery-as-politics. However, due to the multi-dimensionality of recovery and as a result of its professional adoption and ubiquity, several authors have warned that recovery has become a floating signifier that is widely used but in reality represents very divergent views (Duff, 2016; Hopper, 2007). Another important risk of this conceptual confusion is that, although the recovery movement has its origins in activist service user contexts, the real experiences of persons in recovery are moved to the margins and no longer form the core of the debate on recovery (Pilgrim, 2009).

McWade (2016) puts the polyvalence of the recovery concept in a different perspective by adopting the idea of *enactments*. Rather than problematizing the conceptual confusion regarding recovery as something that stands in the way of adequate recovery-oriented support (as often happens in existing literature), she argues that different practices give shape to different enactments of recovery, depending on the material, institutional and relational power dynamics at play. These enactments can be seen as discursive practices that embody different subjective positions and temporalities in the promotion of social change. McWade (2015) argues that within today's mental health care reform, different – even competing – practices and enactments of recovery are at play.

In this research project, the lived experiences of persons with mental health problems are the central focus from which recovery is studied. However, precisely because of the above-described inevitable conceptual and discursive confusion regarding recovery, different (e.g. professional, service user-based) enactments of recovery have found their way into this dissertation. Unraveling these enactments by holding them against the light of the lived realities of persons who experience recovery first-hand has become one of the key objectives of this research project. Therefore, rather than searching for a universal and straight-forward definition of recovery as the backbone of this work, I encourage the reader to keep the idea of recovery enactments in mind throughout the different chapters.

## 1.4 Research aims and questions

Internationally, mental health care policy and practice are undergoing a remarkable shift towards recovery-oriented systems of support, motivated by a growing awareness that support should be tailored to the unique recovery processes and needs of its users (Cruce, Öjehagen, & Nordström, 2012; Slade et al., 2008). However, despite these developments, persons with complex mental health needs are still considered a 'hard-to-reach' group that risks slipping through the net of current recovery-oriented mental health care (Ness et al., 2014).

Whilst there is consensus that support for persons with complex mental health needs should be characterized by an integrated and holistic approach (e.g. by addressing both substance use and mental health problems) (Minkoff, 2001), existing research mainly focuses on identifying barriers to treatment (e.g. lack of motivation, waiting lists, lack of specialized services) (Priester et al., 2016) and measuring clinical outcome parameters (e.g. symptom reduction, abstinence) (Chow et al., 2013; Hunt et al., 2013; Tiet & Mausbach, 2007). What is often ignored is the way persons with complex mental health needs experience treatment and how it affects their recovery process (Lietz, Lacasse, Hayes, & Cheung, 2014). Even more so, although there exist support modalities that do seem to engage successfully with this heterogeneous group (both in community-based and residential mental health care), the daily practices and the actual processes taking place in such places remain largely understudied (Chase et al., 2012; Farkas, Gagne, Anthony, & Chamberlin, 2005).

In other words, in order to tailor support to the recovery processes of persons with complex mental health needs, it is essential to understand how they experience their recovery (Pilgrim, 2009). Despite the fact that there is a substantial body of literature that focuses on dimensions, facilitators and barriers of recovery, these (largely professionalized) notions of recovery fall short in a number of ways. First, in the multitude of recovery enactments and reductionist frameworks, the idiosyncratic nature of recovery processes gets lost (Duff, 2016; Khoury & del Barrio, 2015; Price-Robertson et al., 2017). Moreover, existing literature that specifically focuses on recovery in persons with complex mental health needs is rather scant (Davidson & White, 2007; Kaite, Karanikola, Merkouris, & Papathanassoglou, 2015; Ness et al., 2014). Additionally, the social realities (e.g. homelessness, social exclusion, social isolation) that have a defining impact on the recovery processes of persons with complex mental health needs are heavily underexposed in existing recovery frameworks and conceptualizations (Hopper, 2007).

However, it is only by gaining understanding of the ebb and flow of recovery in the lives of persons with complex mental health needs that it becomes possible to organize more adequate and person-centered support for this group. Therefore, this research project aims to unravel, in all its complexity, how persons

with complex mental health needs experience their recovery, how and where they find helping recovery resources and what roles professional support modalities play in their recovery trajectories. These aims can be translated into the following main research questions:

1. *What does it mean for persons with complex mental health needs to be in recovery?*
2. *How can the recovery processes of persons with complex mental health needs be supported?*

In search of adequate answers to the above research questions and to do justice to the idiosyncratic nature of recovery, the lived experiences of persons with complex mental health needs are put at the heart of this research project by applying a phenomenological approach. More precisely, data are collected by means of (1) a systematic review of existing recovery literature based on first-person perspectives (Chapter 2), (2) two qualitative studies focusing on recovery-oriented support as perceived by different stakeholders involved (Chapters 3 and 4), and (3) a collaborative case study together with an expert by experience (Chapters 5 and 6).

In the next section, the methodological and ethical framework that shaped this research process will be discussed. This introductory chapter will be concluded by giving a brief overview of the research process and the linked subsequent chapters.

## 1.5 Methodological and ethical framework

### *1.5.1 Lived experiences as foundation*

The lived experiences of persons with complex mental health needs form the beating heart of this research project. The reason for this choice is threefold. First, the question of *how* persons with complex mental health needs experience their recovery is in essence a phenomenological question. Second, it has been argued that qualitative research methods that focus on lived experiences and micro-level processes are the most adequate to gain understanding of recovery in all its complexity (Stanhope & Solomon, 2008). Third, the central position of lived experiences in this work is grounded in the ethical responsibility to give voice to people whose voices have traditionally been marginalized, in their everyday lives, in mental health care practice, and in academia. In this section, I will elaborate on these lines of thought.

*A phenomenological approach*

Phenomenology is the study of first-person experiences and embodied meanings of phenomena, based on the assumption that the best way to understand a certain reality is through the eyes of those who

have experienced it first-hand (Matua, 2015). In general, two phenomenological approaches can be distinguished. Descriptive phenomenology, that is inspired by the work of Husserl, aims to describe the essence and general characteristics of a certain phenomenon in its purest form, i.e. untouched by contextual factors (e.g. culture, attitudes, opinions, prejudices) (Dowling, 2007). In interpretive phenomenology, on the other hand, the possibility of such an objective and pure understanding of experience is questioned (Dympna et al., 2013). Instead, interpretive phenomenology aims to understand people's lived experiences based on the assumption that individuals are 'beings-in-the-world' (Heidegger, 1962): their realities and experiences are inevitably influenced by the social, political and cultural context they find themselves in (Flood, 2010). Another characteristic of interpretive phenomenology is that it is underpinned by a double hermeneutic: the researcher aims to make sense of the way research subjects experience and give meaning to their personal and social world (Dympna et al., 2013; Smith, 2011). As a consequence, it is impossible to directly grasp a person's experiences and therefore, the researcher can only try to get 'experience close' (Smith, Flowers, & Larkin, 2009). In that respect, Gadamer (1976) argues that, because both the researcher and the research subject have a personal horizon that is colored by ever-changing experiences, meanings, assumptions and ideas, hermeneutical research should always happen through a 'fusion of horizons'. In other words, to get as 'experience close' as possible and to do justice to the lifeworlds of the research subjects, knowledge construction in phenomenology should always take place in co-creative and dialogical ways (Flood, 2010).

Based on the above characteristics, the way in which the lived experiences of persons with complex mental health needs are viewed in this research project can be situated along the lines of Heideggerian interpretive phenomenological thinking.

*Getting a grip on recovery*

Recovery is considered a unique and personal process that comes about in idiosyncratic and non-linear ways. At the same time, however, different enactments and theoretical frameworks of the concept circulate in current mental health care policy, practice and research. A worrying side-effect of these enactments is that, in today's focus on evidence-based practice, recovery is increasingly being used by professionals as an outcome parameter to measure the effectiveness of (alleged) recovery-oriented treatment programs and as a criterion to measure the service users' progress (Webb, 2001). What makes these enactments problematic is that they become increasingly removed from the fundamental ideas that recovery processes are non-linear (e.g. by assuming that recovery progress can be measured

(Andresen, Caputi, & Oades, 2006)) and deeply idiosyncratic (e.g. by developing standardized instruments to measure recovery (Burgess, Pirkis, Coombs, & Rosen, 2011)).

To counteract this, several authors have theorized that the only way to untangle the essential meaning of recovery in the multitude of enactments is by returning to the heart of the matter: the lived experiences of persons who find/found themselves in recovery (Anthony, 2003; Ness et al., 2014; Torrey, Rapp, Van Tosh, McNabb, & Ralph, 2005). To do so, dominant notions of what counts as evidence need to be expanded. In this respect, Stanhope and Solomon (2008) argue that qualitative research methods that focus on micro-level recovery processes are the most adequate for getting a grip on the recovery concept. In line with this, Pilgrim (2009) argues that research into recovery should be of ethnographic nature, stay context-close and aim to answer the following questions: *"What is the relationship between intent (rhetoric) about recovery (…) and its enactment? What does recovery actually mean to different actors in particular local contexts?"* (p. 484). Because such questions manage to provide contextualized understandings of recovery, they (1) do justice to the idiosyncrasy and complexity of recovery processes and (2) hold the potential to address larger structural and social developments that impede or facilitate recovery (Stanhope & Solomon, 2008). These reasons form the second motivation to focus on the lived experiences of persons with complex mental health needs in this research project.

*The ethical imperative to give voice*

The third line of thought is linked to the previous point and addresses the position of persons with mental health problems in mental health care practice, policy and research. As stated above, today's rhetoric on recovery is predominantly shaped by professional voices. However, this professional and academic discourse is no longer representative of the activist and social justice nature of the original recovery ethos that was rooted in the lived experiences of persons with mental health problems themselves (Beresford, 2005). Several c/s/x academics have pointed out how this rhetorical shift provides a striking illustration of the power dynamics at play in psychiatry, as Beresford and Boxall (2015) describe in the following way: *"Psychiatric knowledge has been based on the 'knowledge claims' of others about the experience of mad people and mental health service users. They have played the key role in interpreting service users' experience, while the latter's own interpretations have, as has been argued, been excluded or devalued."* (p. 71). In other words, in the bulk of existing recovery practice and research, the narratives of persons with mental health problems have been moved to the sidelines in favor of professional and academic 'expert' interpretations of recovery (Russo & Beresford, 2015). Liegghio (2013) goes as far as labeling these mechanisms as acts of epistemic violence, i.e.

professionalization processes through which the personal perspectives of persons with mental health problems are rendered 'disordered' and made invisible.

The only way academic research into recovery can address these power imbalances and avoid reproducing epistemic violence is by placing the lived experiences of persons who are or have been in recovery at the heart of research (Faulkner, 2017). Therefore, the central position of the participants' lived experiences in this research project is not only a methodological choice, but above all an ethical necessity. In that respect, it can be stated that this research project is embedded in an emancipatory research paradigm that is *"about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs"* (Oliver, 1992, p. 110).

### *1.5.2 A bricolage research trajectory*

In preparation of this research project, I had drafted a clear, straightforward and linear research plan to study recovery in persons with dual diagnosis (at that moment not yet adjusted to 'persons with complex mental health needs', cf. supra). However, the research process that is described in this dissertation has taken a different, much less linear, more adventurous route than the one that was initially mapped out. During the final work packages of this research project, I came across the concept of *bricolage* as a methodological and ethical approach to pedagogical research. Although this concept will be discussed extensively in Chapters 5 and 6, it has also proven to be a helpful approach when thinking about this research project in its entirety. In what follows, I will touch upon a number of characteristics of bricolage to reflect on the twists and turns this research project has taken. Also, I will briefly link these bricolage ideas to how this research project is embedded within the Ghent Orthopedagogics.

#### *Bricolage as a metaphor*

In Dutch language, being called a bricoleur can have somewhat negative, questionable connotations of being a bungler, of working without a clear plan of action and without the most suitable tools at hand. However, within the field of social inquiry, the concept of bricolage (borrowed from Levi-Strauss' *The Savage Mind*) is used to describe an eclectic and rigorous approach to meaning-making that is characterized by the flexible combination of different research methods and respect for the complexities and at times contradictoriness of the social realities under study (Rogers, 2012). In that sense, I consider it a suitable metaphor on which to share a number of personal reflections at the start of this dissertation.

From the onset of this research project, I was confronted with the fact that mental health care preeminently is a domain in which different interests and agendas are at stake, various discourses are used interchangeably and deeply rooted power imbalances are at play. Moreover, developments in mental health care are inextricably linked with wider social, political and structural developments in society. I became well aware of the fact that the everyday realities of the persons under study in my research are shaped by all these dynamics and can be looked at in many different lights. Soon I realized that glossing over these entanglements by trying to impose a well-prepared, structured and linear research plan onto this complex and layered reality would be too reductionist (Rogers, 2012). This is a first point at which a bricolage perspective is helpful in thinking about this research project. Rather than clinging to a predefined (and possibly alienating) research plan, Kincheloe (2001) argues that it is precisely by opening up to this multitude of perspectives, power dynamics and contexts, that researchers-as-bricoleurs can *" (…) move into a new, more complex domain of knowledge production where they are far more conscious of multiple layers of intersections between the knower and the known, perception and the lived world, and discourse and representation"* (p. 688). Such a radical openness is only possible when preconceived research ideas are approached as questionable, re-evaluable and negotiable.

In the case of this research project, my ideas of recovery were inevitably and continuously affected by the encounters I had in different (research, academic, personal) contexts, by reading literature from diverse (e.g. medical, psychological, political, social work and activist) backgrounds, and above all by the many stories I was privileged to listen to, both on and off the record. It was precisely these stories that made me aware of how the lived experiences of persons with complex mental health needs are often at odds with the way recovery is defined in literature. For example, one afternoon I was sitting in sun in the garden of one of my research settings, catching up with a few service users I had met. One of them confided to me that he had not slept at home for nearly seven weeks, because he no longer felt safe in his apartment. Instead, he spent the nights wandering through the city under influence of heroin and cocaine in order to stay awake. He told me this lack of a home and sleep felt like an endless cycle that made him feel exhausted, lonely and desperate, and made his life feel meaningless. Another service user sitting with us picked up on that story and told me he also felt like *"his life was going nowhere"*, as his persistent alcohol problems meant that he was no longer welcome in psychiatric services and that even the mobile outreach teams did not want to visit him in his home anymore as long as he kept drinking like that. Such stories made me feel increasingly uncomfortable with the way my research was framed. I started doubting whether the professionalized recovery discourse I was using did justice to the everyday realities of my participants. Am I unconsciously reproducing social inequality by putting the concept of recovery at the heart of my research project, rather than social inequality itself?

To deal with these doubts and changing insights, *"bricoleurs allow for dynamics and contexts to dictate which questions get asked, which methods to employ and which interpretive perspectives to use"* (Rogers, 2012, p. 6). In that sense, researchers-as-bricoleurs adopt a flexible approach to methodology in which research materials, tools and methods are creatively combined as they emerge. Instead of 'passively' using standardized and universally acceptable methods, bricoleurs thus engage in an active search for multi-perspective and reflexive insights by using relevant tools that help understand the research context in its complexity (Kincheloe, McLaren, & Steinberg, 2011).

In line with these ideas, I responded to the doubts and challenges I was faced with during my research (e.g. regarding recovery as a framework, my original research aims and questions, my relationship with the participants) by coming off the research path that I had planned and by allowing my research encounters to guide me in the direction of 'what matters' in the lives of persons with complex mental health needs. To do this, I experienced the necessity of immersing myself in the contexts I studied (i.e. a community-based meeting place and an inpatient psychiatric ward) through intensive participant observations and by engaging in long-term contact with the people I met in these places (rather than having one-off interviews). In that respect, a very valuable encounter I had was with Pete, a mental health service user and peer worker (and the protagonist in Chapters 5 and 6 of this dissertation). Although I considered our initial conversations as interesting exchanges in the margins of my research, they gradually grew more frequent and more intense, and I realized they touched upon topics too important to ignore. Through our mutual concerns and engagement with today's mental health care system, it 'clicked' between us and Pete became my sounding board, co-researcher and co-author. Although I could never have imagined such an intensive and dialogical collaboration at the start of this project, my encounters with Pete grew into one of the fundamental pillars of this PhD.

For me, traveling this bricolage trajectory was the only way to open up spaces of thought that made it possible to really listen to the stories of the participants and to gain understanding of the complexity of their everyday realities. In doing so, rather than trying to take the position of neutral observant or detached analyst of a certain social reality, I hope to contribute to what Denzin (2013) calls *"a discourse that troubles the world"* (p. 390) that aims to question and transform unequal living conditions and social injustice.

*Bricolage and Orthopedagogics*

This bricolage research project is embedded within the field of Orthopedagogics. As an action-oriented science that aims to improve the quality of life, living conditions and participation in society of persons who find themselves in vulnerable situations, Orthopedagogics has a clear emancipatory and

empowering agenda (Vanderplasschen, De Schauwer, & Vandevelde, 2015). It starts from a holistic and systemic approach that focuses on the connections, relations and interactions between individuals and the social context they find themselves in (Vandevelde et al., 2017). In line with this, in bricolage individuals are seen as 'things-in-the-world', inseparable from their context and larger ongoing social, cultural and historical dynamics in society (Rogers, 2012). In this respect, a bricolage approach fits well with Orthopedagogics, as researchers-as-bricoleurs aim to give voice to people whose perspectives have been marginalized or subjugated, in an attempt to transform unequal living conditions, disrupt dominating power dynamics and address social injustice (Kincheloe et al., 2011). Moreover, what is described in bricolage theory as the need for methodological and paradigmatic flexibility tallies well with the integrative approach of Orthopedagogics in the Ghent University tradition, in which *"various complementing (partial) approaches alternatively go together in their never-ending pursuit of unity and transformation of actual conditions"* (Broekaert, Autrique, Vanderplasschen, & Colpaert, 2010, p. 234). By combining and integrating empirical-analytical, existential-phenomenological and critical approaches, Orthopedagogics as a holistic science aims to provide a multi-perspective insight in the social realities of persons who find themselves in vulnerable living situations (Broekaert, Van Hove, D'Oosterlinck, & Bayliss, 2004). However, such a dynamic interaction between different complementary and contradictory approaches, between thesis and antithesis, is by definition never-ending as synthesis remains elusive and inaccessible. In that sense, Orthopedagogics can be seen as a science of uncertainty that recognizes that the meaning of *"improving one's living situation"* is always contextual and consequently, that knowledge is inevitably partial and incomplete (Broekaert et al., 2004).

Based on the above reflections, I view this research project as an on-going process of bricolaging; of tinkering, being challenged, returning to my steps; of moving between thesis, antithesis and synthesis; of trying to understand and address the lived realities of my participants; of seeking balance in my own position as researcher, orthopedagogue, activist, friend.

## 1.6 Overview of the research process

The above concepts, frameworks and reflections gradually dotted the path of my research trajectory. Looking back on the entire research process, three perspectives can be distinguished from which I studied recovery in persons with complex mental health needs: (1) from a bird's-eye view, (2) by visiting places that engage with this group, and (3) by going *en route* with a travel companion. In what follows, I will briefly explain each of these perspectives as introduction to the subsequent chapters.

### *1.6.1 A bird's-eye view: zooming out on lived experience*

In the first step of this research project, a systematic review was conducted that aimed to synthesize existing qualitative research on personal recovery that started from the lived experiences of persons with dual diagnosis. Based on the analysis of 16 selected empirical articles (published between 1993 and 2016), four major themes could be identified: social relationships (i.e. the role of family support, peer support and community belonging), treatment (i.e. the importance of a holistic and individualized approach, having good therapeutic relationships, the role of medication), personal beliefs (hope, identity, self-determination and spirituality), and meaningful activity. Although these themes tally well with the CHIME framework of recovery (Leamy et al., 2011), a number of research gaps came to the fore in this systematic review. For example, the results failed to give insight into the role of social and structural factors (e.g. having access to recovery resources) in the recovery processes of persons with dual diagnosis. Also, based on the results, it remained difficult to understand the actual lived experiences of persons with dual diagnosis in recovery, as the included studies primarily focused on facilitators and barriers to recovery instead of experiential components (*how* does recovery come about?). In that respect, this systematic review study provided me with a bird's-eye view, a zoomed-out perspective on the lived experiences of persons with dual diagnosis in recovery.

This study is described in detail in Chapter 2, *'The concept of recovery as experienced by persons with dual diagnosis: A systematic review of qualitative research from a first-person perspective'*.

### *1.6.2 Visiting places: exploring the role of recovery-oriented support*

It is known that persons with complex mental health needs risk slipping through the net of mental health care, due to the misalignment between the functions of existing support modalities and the complexity of the mental health, substance use and social problems they face. Therefore, in the second phase of this research project, the aim was to gain understanding of how the recovery processes of persons with complex mental health needs can best be supported. This was done by exploring the roles of places that seem to successfully engage with this so-called 'hard-to-reach' (cf. supra) population. More precisely, two ethnographic studies were conducted that aimed to unravel the daily practice of two diverse support modalities: (1) a community-oriented meeting place located in the heart of Ghent (Belgium) and (2) a residential ward located in a psychiatric hospital near Ghent.

In the first study, which took place in a community-based meeting place, data were collected by means of participatory observations and 12 in-depth interviews with visitors (as service users are called), staff members, volunteers and persons that are involved in the daily practice of the meeting place from

outside (e.g. a judicial actor, an artist). Data were analyzed by means of thematic analysis, inspired by Interpretative Phenomenological Analysis (IPA) principles (Smith et al., 2009). The results showed how on the one hand, the meeting place is experienced as *'a place to be'*, i.e. a safe place where visitors feel welcome and accepted, and gradually even start to feel 'at home'. On the other hand, the meeting-place also functions as *'a place to be me'*. Through creative activities that are rooted in personal interests and talents, visitors find a language to re-engage in dialogue with others. In doing so, they start rebuilding positive identities that move away from other stigmatizing identities and become visible citizens in society.

The second study took place in a residential psychiatric ward that engages with a similar group of persons with complex mental health needs. Again, data were collected by means of participatory observations (as I conducted an internship at the ward in preparation of data collection) and 17 in-depth interviews with patients and staff members. In accordance with the other study, data were analyzed by means of thematic analysis, based on IPA principles. In this study, three important functions of the ward were identified. First, the ward functions as an *asylum*, i.e. a safe haven in terms of both space and time that for some patients even functions as a 'second home'. Second, the ward is experienced as a *particularizing space* in which support is organized tailored to the patients' individual needs and is focused on finding anchor points outside the hospital walls. Related to this, the ward's third function is that of a *transitional space* towards a meaningful community life (e.g. through searching for adequate housing).

Despite the diversity of the places under study, the results of both studies showed a remarkable overlap regarding the functions they fulfill in the lives and recovery processes of persons with complex mental health needs. Based on these insights, it is argued that recovery-oriented systems of support should be thought of as differentiated landscapes, existing of a diversity of settings (e.g. community-based, residential) and approaches (e.g. therapeutic, social) between which persons with complex mental health needs can circulate to find the resources for their recovery.

The results of these location-based studies are described in Chapter 3, *'A place to be (me): A qualitative study on an alternative approach to treatment for persons with dual diagnosis'* and Chapter 4, *'Exploring landscapes of support: A qualitative study on the roles of inpatient settings in mental health recovery'*.

### *1.6.3 En route with a travel companion: a collaborative case study*

In the wake of the study I conducted in the community-based meeting place, my communication with one of the participants intensified: Pete, an experienced visitor and peer worker. During these

conversations, we discussed Pete's experiences regarding psychosis and recovery, my doubts and worries regarding my research and our thoughts regarding the recovery framework, amongst other things. Eventually, this continuous exchange of ideas formed the foundation of the third phase of this research project, as Pete and I jointly decided to start recording our conversations. In doing so, our exchange of ideas turned into a study of its own: a collaborative case study that aims to capture in all its complexity what it means for Pete to be in recovery.

Out of methodological and ethical considerations, we adopted a bricolage approach (cf. supra). This allowed us to let the context shape our research questions and to creatively combine different data sources (e.g. nine recorded conversations, emails, Pete's poetry, existing literature). Through this co-creative bricolage process, four important themes regarding Pete's recovery came to the fore: life rebuilding, identity, continuity of care and the role of substance use. By exploring these themes, however, a number of contradictions related to the way recovery is operationalized and professionalized in today's mental health care came to the fore. Although recovery is promoted as a hopeful and empowering process towards a meaningful community life, current mental health care still seems to be characterized by a medical gaze that considers mental health problems to be chronic and fails to address the social realities of persons in recovery. Consequently, recovery risks being reduced to a tokenistic model that is shaped by an expert-driven discourse and holds low expectations of recovery for persons with complex mental health needs.

In this third phase of the research project, my perspective on the role of lived experience shifted, as Pete was not only the research subject but also became my travel companion as co-researcher and co-writer. In other words, lived experience became an essential part of the entire research process and not a mere data source. Through our collaborative research project, Pete and I became aware of the power imbalances at play in both mental health care practice and research, and searched for more equal ways of relating to each other. The concept of bricolage helped us give shape to a more dialogical research approach that can be seen as an open-ended and relational meaning-making process, rather than an academic monologue in which the researcher claims the final word about the research subject's experiences.

The results and reflections related to this collaborative journey can be found in Chapter 5, *'Questioning the professionalization of recovery: A collaborative exploration of a recovery process'* and Chapter 6, *'From epistemic violence to dialogue in mental health care research: Reflections on a collaborative research process'*.

In Chapter 7, the *General discussion*, I will reflect on the most important insights from this research project and their implications for mental health care policy, practice and research.

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# Chapter 2

# The concept of recovery as experienced by persons with dual diagnosis: A systematic review on qualitative research from a first-person perspective

Based on

De Ruysscher, C., Vandevelde, S., Vanderplasschen, W., De Maeyer, J., & Vanheule, S. (2017). The concept of recovery as experienced by persons with dual diagnosis: A systematic review of qualitative research from a first-person perspective. *Journal of Dual Diagnosis, 13*(4), 264-249. doi 10.1080/15504263.2017.1349977

## Abstract

In recent years, the concept of recovery has gained ground in the treatment of persons with dual diagnosis (DD). Recovery refers to living a meaningful life despite limitations caused by mental illness and substance use disorders. It also implies that support for persons with DD should be organized according to the personal needs and wishes of its users. Therefore, it is important to gain insight into the aspects that persons with DD deem important for their recovery process. This systematic review aims to summarize existing qualitative research on the meaning of recovery from the perspective of persons with DD. A literature search was conducted following the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for systematic reviews in the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycInfo, Medline, Embase and Web of Science. Sixteen studies using a qualitative research design were retained in which four overarching themes could be identified. The first theme focused on feeling supported by family and peers and being able to participate in the community. The second theme focuses on the need for a holistic and individualized treatment approach, seeing the persons 'behind the symptoms'. The third theme that emerged was having personal beliefs, such as fostering feelings of hope, building a new sense of identity, gaining ownership over one's life and finding support in spirituality. The last theme identified was the importance of meaningful activities that structure one's life and give one motivation to carry on. In this review, the participants pleaded for 'flexibility' in mental health care, i.e. an approach that allows for both successes and failures. However, in order to come to a more comprehensive theoretical model of recovery in persons with DD, future research is necessary to gain insight into the underlying mechanisms of recovery processes.

## 2.1 Introduction

The concept of dual diagnosis, the co-occurrence of mental illness (e.g. psychosis, mood disorders, anxiety disorders, neurodevelopmental disorders etc.) and a substance use disorder, first emerged in mental health care in the late 1980s (Drake & Wallach, 2000). Today, despite the fact that the numbers vary across studies, it is widely accepted that the prevalence of this comorbidity is frequent: up to 50% of persons with severe mental illness have a substance use disorder and vice versa, often combined with social, financial, judicial and health problems (Drake, 2002; Drake et al., 2001; Murthy & Chand, 2012).

As a consequence, an overly narrow focus on drug addiction and psychiatric problems alone in treatment programs would not fully reflect the needs associated with having a dual diagnosis (Banerjee, Clancy, & Crome, 2002). For these reasons, consensus exists both amongst practitioners and in literature that integrated treatment programs, in which parallel treatments for both disorders are combined, are more aligned with the complex care needs of dually diagnosed persons and are more likely to be beneficial (Davidson et al., 2008; Drake & Wallach, 2000; Minkoff, 2001; Murthy & Chand, 2012). However, such integrated treatment programs too often remain characterized by a prognostic pessimism, a persistent focus on symptom reduction and crisis management, and a poor link between mental illness and the social context (Carrà, Bartoli, Clerici & el-Guebaly, 2015; Drake et al., 2001; Flynn & Brown, 2008; Horsfall, Cleary, Hunt & Walter, 2009; Slade, Amering, & Oades, 2008).

To address these shortfalls, the concept of personal recovery has been put forward as the bridging principle between mental health care and substance abuse treatment (Cruce, Ojehagen, & Nordstrom, 2012; Davidson & White, 2007; Drake et al., 2001). In contrast to clinical recovery, in which the focus is mainly on symptom improvement and long-term mental stability, the notion of personal recovery builds on accounts of individuals who have experienced mental illness and is described as a personal and unique journey towards living a valuable and satisfying life, despite challenges caused by mental illness (Anthony, 1993; Jaeger & Hoff, 2012; Tew et al., 2011; Whitley & Drake, 2010). It is characterized by a sense of hope, a sense of choice, being responsible for one's own actions, feelings of belonging and connectedness and a sense of empowerment (Davidson, Shahar, Lawless, Sells, & Tondora, 2006; Jacobson & Curtis, 2000; Jacobson & Greenley, 2001). Another important aspect of recovery is the development of adequate supportive relationships, coping skills and a secure sense of self, such that social inclusion can be realized (Tew et al., 2011). Slade (2012) states that it is most helpful to consider persons with mental illness as persons who strive to live the most fulfilling life possible in fundamentally similar ways to other members of their community who do not experience mental illness. This idea has major implications for everyday practice, i.e. that recovery-oriented care is about *"supporting everyday*

*solutions for everyday problems rather than providing specialist treatments for mental illness-related problems"* (Slade, 2012, p. 702).

Despite the fact that the recovery concept is increasingly incorporated in substance abuse and mental health care policy (e.g. the SAMSHA Principles of Recovery on a national policy level in the USA) and in the daily practice of organizations providing care for persons with dual diagnosis, its application and interpretation remains challenging (Sheedy & Whitter, 2013). For example, when organizations are obliged by policy decisions to put the emphasis on treatment outcomes and solely use the recovery concept as an outcome measure, there is a risk that the core of recovery is disregarded, i.e. that it is a *process* (Lal, 2010). Furthermore, an instrumental use of the recovery concept ignores the fact that a person with dual diagnosis, rather than professionals or policy makers, is the expert about his/her own recovery process (Khoury & del Barrio, 2015). Also, austerity measures within the (mental) health sector and a focus on efficiency within organizations might leave less room for flexibility and person-centeredness, which lies at the heart of a recovery-oriented approach (Hyde, Bowles, & Pawar, 2015).

In order to cope with these challenges and because recovery-oriented care should be strongly linked to the personal needs and wishes of its users, it is invaluable to take into account the personal perspectives of persons who (have) experience(d) recovery themselves (Cruce et al., 2012; Velpry, 2008). Currently, existing research on the lived experiences of persons with dual diagnosis with regard to recovery is rather scant (Davidson & White, 2007; Kaite, Karanikola, Merkouris, & Papathanassoglou, 2015; Ness, Borg, & Davidson, 2014). However, in order to support one's recovery process as well as possible, it is important to bundle these personal experiences, because they are crucial to gain insight into the needs of this heterogeneous and complex group (Edward & Robins, 2012; Stanhope & Solomon, 2008).

In 2014, Ness, Borg and Davidson conducted a literature review on facilitators and barriers towards personal recovery, as experienced by persons with dual diagnosis. However, this review applied rather narrow search criteria. Firstly, the search was limited to mostly medical databases (CINAHL, Medline, Embase, SweMed+ and NORART) and one database on behavioral sciences and mental health (PsycInfo). Secondly, despite the fact that the concept of personal recovery has been widespread in international mental health care policy since the 1990s, only articles published between 2000 and 2013 have been included in the study.

In order to put the personal perspectives of persons with dual diagnosis at the heart of the conceptualization of personal recovery, the focus of this systematic review is solely on qualitative studies starting from the perspective of persons with dual diagnosis themselves. The aim is to synthesize existing qualitative research on personal recovery, and to update and broaden the work of Ness, Borg and Davidson (2014), answering the following research questions: *'How do persons with dual diagnosis*

*think of personal recovery?'* and secondly, *'What do persons with dual diagnosis experience as facilitators and barriers on the path leading to personal recovery?'*

## 2.2 Methods

A review of the literature was conducted following the guidelines of the PRISMA statement (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) for systematic reviews (Moher, Liberati, Tetzlaff, & Altman, 2009). The databases used by Ness, Borg & Davidson (2014) formed the basis of this literature search. However, only the English-language international databases were included, i.e. CINAHL, PsycInfo, Medline and Embase. In addition, Web of Science was added to this list in order to include an interdisciplinary database (also including social sciences).

The following keywords were combined and searched for in each database: "dual diagnosis" OR "co-morbidity mental illness and substance use" OR "mentally ill chemically abusing" OR "mentally ill substance abuser" OR "mentally ill substance using" OR "chemical abusing mentally ill" OR "chemically addicted and mentally ill" OR "substance abuse and mental illness" OR "substance abusing mentally ill" OR "substance abuse and mental illness" OR "mentally ill chemically dependent" OR "individuals with co-occurring psychiatric and substance disorders" OR "co-occurring addictive and mental disorders" AND "recovery".

Figure 1 gives an overview of the selection process of the eligible studies. In the first phase, the titles and abstracts of the studies (N = 3564) were screened by the first author of this review, applying the following eligibility criteria: (1) articles published from 1993, i.e. when personal recovery was defined in literature for the first time by Anthony (1993), to present, (2) articles published in a peer-reviewed journal (in English), (3) articles that focus on the lived experiences of dually diagnosed individuals (co-morbidity of a psychiatric disorder with substance use disorder) with regard to recovery by means of a qualitative research design (interviews, focus groups and self-report if resulting in a qualitative analysis). Articles in which the concept of dual diagnosis was interpreted in a different way (e.g. co-morbidity of intellectual disability with substance use disorder) were excluded. At the end of this phase, a selection of 37 articles was obtained. For these articles, the full text was retrieved.

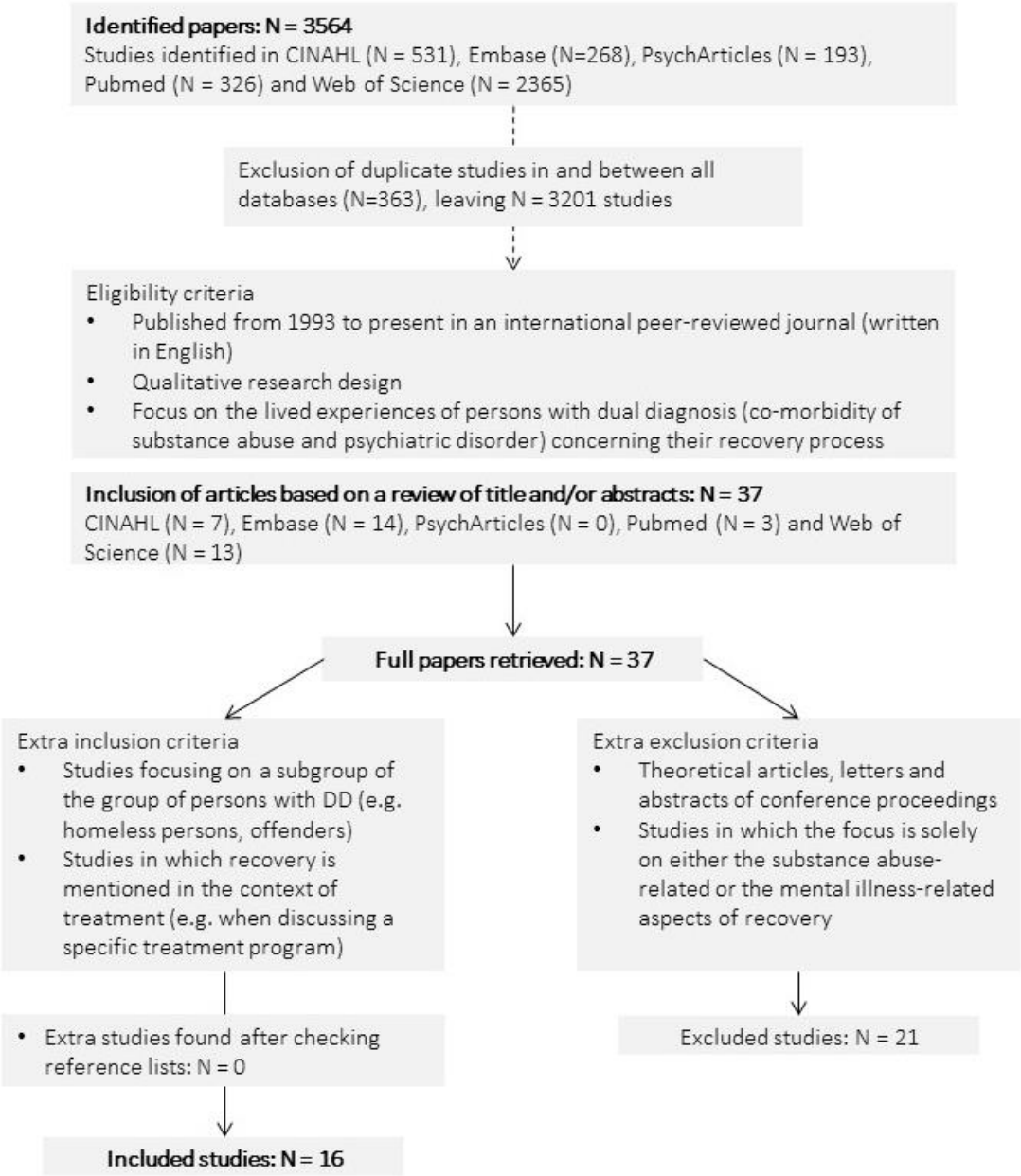
In the second phase, the first author and one of the co-authors independently scrutinized the full text of these articles, discussed them and concluded that it was necessary to broaden the eligibility criteria in order to obtain a rich data set (without adjusting the keywords). It was decided that the following articles would also be included: (1) articles in which the focus is on a subgroup of dually diagnosed persons (i.e. homeless persons, offenders) (O'Sullivan, Boulter, & Black, 2013; Padgett, Henwood,

Abrams, & Drake, 2008; Smith, Padgett, Choy-Brown, & Henwood, 2015) and (2) articles in which recovery is mentioned in the context of treatment (e.g. when discussing a specific treatment program) (Brooks, Malfait, Brooke, Gallagher, & Penn, 2007; Hagler et al., 2015; Matusow et al., 2013). In addition, the following exclusion criterion was added: studies that deviate from the personal interpretation of the recovery concept or solely focus on either the substance use-related or mental illness-related aspects of recovery. Based on these extra eligibility criteria, a total of 16 studies was retained. Additionally, the reference lists of both these 16 articles and the systematic review of Ness, Borg and Davidson (2014) were screened. However, this did not lead to the inclusion of additional articles.

Four out of seven studies that were included in the study of Ness, Borg and Davidson (2014) have not been selected for this review, as they did not meet the inclusion criteria. More precisely, these studies were excluded for the following reasons:

- *Behrman (2005)* and *Gail (2007):* These self-reports do not result in a qualitative analysis;
- *Davidson et al. (2008):* In the results section, the focus is on addiction recovery and recovery from mental illness separately, as experienced by persons who are either dealing with addiction problems or mental illness. As a consequence, it is not possible to use these empirical data to discuss how persons with dual diagnosis experience recovery;
- *Laudet et al. (2000):* This study applies a quantitative research design.

*Figure 1 - Overview of the selection process*




Note: CINAHL = Cumulative Index to Nursing and Allied Health Literature

Following a suggestion during the peer review process, a quality assessment of the articles was conducted by the first author and discussed at two stages with the second author, following the guidelines of Hawker et al. (2002). At the first stage, the way of scoring the different quality criteria in this specific set of articles was discussed, primarily in relation to the subtle differences between scoring categories. At the second stage, the results of the assessment were reviewed, during which the first author gave a detailed explanation of the scores. Using this assessment tool, all articles scored between 31-36 points on a total of 36 points and thus were considered to be of a high quality (category A, 30-36

points). A detailed overview of the quality screening of the studies is available as a supplement to this article.

## 2.3 Results

In the 16 selected studies, different qualitative research designs were applied: six studies using focus groups (Brooks et al., 2007; Hagler et al., 2015; Hipolito et al., 2011; Matusow et al., 2013; Roush, Monica, Carpenter-Song, & Drake, 2015; Whitley, 2012), eight studies using in-depth interviews (Cruce et al., 2012; Green et al., 2015; Kennedy & Horton, 2011; Maybery, Reupert, & Goodyear, 2015; O'Sullivan et al., 2013; Padgett et al., 2008; Staiger et al., 2011; Turton et al., 2011), one study using photo-elicitation interviews (Smith et al., 2015) and one study reviewing the Internet in order to find narratives (Edward & Robins, 2012). Three studies focused on the concept of recovery in relation to a specific treatment program (Hagler et al., 2015; Matusow et al., 2013; Roush et al., 2015). Of the 16 selected studies, eight were conducted in the USA, three in Australia, three in the UK, one in Canada and one in Sweden. Table 1 (cf. end of chapter) provides a summary of the aims, methods of data collection and analysis and participant characteristics of all included studies.

In order to answer the above-mentioned research question, overarching themes and subthemes were identified throughout all articles by means of thematic analysis, with special attention paid to ambivalences and contrasts within these themes (Clarke & Braun, 2014). In the initial analysis phase, the first author scrutinized all included articles and composed a list of the themes discussed in the results sections. In the second phase, the first author ordered these themes within overarching categories (‘treatment’, ‘structural factors’, ‘personal and psychological factors’, ‘recovery tools’, ‘social factors’, ‘activities’, ‘other’). Third, the first author reanalyzed the included studies and placed relevant citations from the results sections within these overarching categories. During this phase, this classification was discussed extensively by the first and second author in order to further order and synthesize the themes covered. Finally, the overarching categories were clustered around four main themes and ten subthemes: social relationships (family support, peer support, community belonging), treatment (holistic and individualized approach, therapeutic relationship, and medication), personal beliefs (hope, identity, self-responsibility and self-determination, spirituality) and meaningful activity. Table 2 (cf. end of chapter) gives a detailed overview of the thematic analysis.

### *2.3.1 Feeling supported: social relationships*

Fourteen out of 16 studies stressed the importance of building personal relationships, expanding social roles and gaining a sense of belonging as facilitators of the recovery process. More precisely, feeling supported by family and peers and belonging to the wider community are themes that were discussed. However, the lack or unavailability of social relationships can also be detrimental to the recovery process, as some participants reported experiencing feelings of loneliness and isolation after becoming abstinent (Smith et al., 2015). The switch to a substance-free lifestyle often implies giving up previous social networks and old friendships. In turn, these struggles to build up a substance-free social network form a risk for relapse and a possible barrier to recovery (O'Sullivan et al., 2013; Padgett et al., 2008; Staiger et al., 2011). Also, an increase in mental illness symptoms can make it more difficult for persons with dual diagnosis to engage in social interactions (Padgett et al., 2008).

*Family support*

Seven studies explicitly described the need for persons with dual diagnosis to be supported by family (Brooks et al., 2007; Kennedy & Horton, 2011; Maybery et al., 2015; Padgett et al., 2008; Turton et al., 2011). Kennedy and Horton (2011) describe these forms of emotional, moral, spiritual and structural support from family members as *intangible* support. They make a distinction between *active* (e.g. setting boundaries, being vigilant for potential setbacks) and *passive* ('just being there', family as a motivation for recovery) intangible support. At the same time, some ambiguity resides in this theme as participants report that family members could also be a burden to their recovery process. Padgett et al. (2008) characterize these family relationships as volatile, since family members' support is often dependent on 'good behavior' of the person with dual diagnosis. In addition, family members often face their own problems such as mental illness, poverty and substance abuse problems (Padgett et al., 2008). Other studies also mentioned that family support can be a source of stress and conflict (Kennedy & Horton, 2011; Smith et al., 2015).

*Peer support*

Eight studies mentioned the importance of meeting and receiving support from persons with similar backgrounds and experiences, especially in the context of self-help groups. Participants stressed the value of self-help groups as 'safe spaces' where they can identify with persons who have dealt with the same struggles and where they feel welcome, accepted and respected. In self-help groups such as Double Trouble in Recovery (DTR), Dual Diagnosis Anonymous (DDA), Alcoholics Anonymous (AA) or Narcotics Anonymous (NA), persons with dual diagnosis can experience an ongoing mutual support and

a shared sense of belonging (Edward & Robins, 2012; Green et al., 2015; Hagler et al., 2015; Matusow et al., 2013; Roush et al., 2015; Turton et al., 2011). On the other hand, a few studies mentioned that the program requirements of certain self-help groups such as AA or NA, e.g. becoming abstinent or not using medication, might collide with personal goals and therefore not contribute to an individual's personal recovery process (Green et al., 2015; Hagler et al., 2015).

*Community belonging*

Besides the need to experience a sense of belonging among peers, participants also talked about the need to expand social roles and to play a valuable role as a responsible citizen in the wider community (O'Sullivan et al., 2013; Smith et al., 2015). This sense of community participation and belonging forms a facilitator of recovery and takes shape by gaining employment or education, and by engaging in community activities (e.g. religion, leisure) (O'Sullivan et al., 2013; Turton et al., 2011).

### *2.3.2 Looking 'beyond the symptoms': treatment*

Ten studies discussed treatment (both psychosocial and medical) as a valuable contributor to personal recovery. Themes that recurred were the need for a holistic and individualized approach, the characteristics of a good therapeutic relationship and the role of medication in treatment.

*Holistic and individualized approach*

For most participants, treatment should be addressing both mental illness and substance abuse problems from a holistic and individualized approach (Cruce et al., 2012; Staiger et al., 2011; Turton et al., 2011). This implies that treatment should focus on all aspects of the patients' lives (e.g. medical, social, psychological, financial aspects) and should be negotiated and adjusted to personal needs rather than putting forward a standardized program (Brooks et al., 2007; Cruce et al., 2012). As a consequence, treatment should not be limited to or automatically be focused on total abstinence (Brooks et al., 2007). Furthermore, treatment should primarily be organized in outpatient (community) settings and promote autonomy, self-determination and citizenship of persons with dual diagnosis (O'Sullivan et al., 2013). Residential admissions can be helpful when psychiatric symptoms are so severe that a person is not capable of taking care of him/herself, but should be voluntary and as short as possible (Cruce et al., 2012; O'Sullivan et al., 2013). In several studies, the participants also stressed the need for continuity of care and a long-term outpatient treatment plan, since recovery is a slow and lifelong process with many ups and downs (Brooks et al., 2007; Cruce et al., 2012; Padgett et al., 2008; Turton et al., 2011).

*Therapeutic relationship*

Participants stressed the role of therapists and caregivers in the treatment process and stated that the therapeutic relationship should be characterized by mutual honesty, continuity of contact, acceptance and respect (Cruce et al., 2012; Staiger et al., 2011). Participants also stressed the need for caregivers to boost their self-worth by having interest in the person 'beyond the symptoms', fostering a sense of hope and not giving up on the person when a setback or relapse occurs (Brooks et al., 2007; Cruce et al., 2012; Hagler et al., 2015; O'Sullivan et al., 2013; Turton et al., 2011).

*Medication*

In the six studies that mentioned the use and role of medication in the recovery process, most participants agreed that medication (e.g. antipsychotics, mood stabilizers) could be helpful to control mental illness symptoms, provided that the dose was adjusted properly (Brooks et al., 2007; Cruce et al., 2012; Green et al., 2015; Matusow et al., 2013; Roush et al., 2015). On the other hand, some participants had a more critical attitude towards the use of medication. In the study of Turton et al. (2011), some argued that in treatment settings medication is likely to be used as a management tool rather than for its therapeutic purposes. Another pitfall that was mentioned is that the negative side effects of psychotropic medication could be detrimental for the recovery process (Brooks et al., 2007).

### *2.3.3 Building a positive future: personal beliefs*

Eleven studies shed light on aspects and beliefs that help rebuilding positive future perspectives. The following themes could be identified: having hope, regaining a sense of identity, building self-responsibility and self-determination, and spirituality.

*Hope*

Many participants referred to hope as the central drive in their recovery process (Brooks et al., 2007; Hipolito et al., 2011; Roush et al., 2015; Smith et al., 2015; Turton et al., 2011). This sense of hope was described as maintaining a positive outlook, being grateful, having a sense of humor, making plans for the future, yearning for personal growth and thinking about goals and expectations.

*Identity*

For many persons with dual diagnosis, mental illness and substance abuse problems make up a large part of their identity (Brooks et al., 2007; O'Sullivan et al., 2013; Smith et al., 2015; Turton et al., 2011). In this respect, some participants talked about having 'spoiled identities' that contribute to stigma and self-stigma (Brooks et al., 2007; Smith et al., 2015; Turton et al., 2011). Being in recovery implies regaining a positive view of the self, developing self-confidence and self-efficacy, and building a new sense of identity by taking on valuable social roles (Green et al., 2015; O'Sullivan et al., 2013; Turton et al., 2011). In this process, participants considered it helpful to gain insight into the influence of mental illness and substance abuse problems on all aspects of their lives (Hipolito et al., 2011). However, some ambivalence resides in this theme as some participants also reported that they find it difficult to give up certain aspects of their 'old' identity, such as a previous (drug-using) social network (cf. supra) (O'Sullivan et al., 2013; Padgett et al., 2008; Staiger et al., 2011).

*Self-responsibility and self-determination*

In nine studies, participants described that actively taking charge of your own problems and recognizing your own capacity for change are integral to the recovery process (Brooks et al., 2007; Cruce et al., 2012; Edward & Robins, 2012; Green et al., 2015; Hipolito et al., 2011; O'Sullivan et al., 2013; Roush et al., 2015; Smith et al., 2015; Turton et al., 2011). Other strengths such as honesty to self, self-respect, self-acceptance, having a sense of personal growth and ownership over one's life were put forward as preconditions for self-responsibility and self-determination.

*Spirituality*

In four studies, the role of spirituality in recovery was discussed (Cruce et al., 2012; Hipolito et al., 2011; Matusow et al., 2013; Whitley, 2012). More specifically, spirituality (e.g. religion, a belief in a higher power) can contribute to the recovery process by fostering feelings of hope, self-compassion, serenity and a determination not to give up in difficult periods. In the study of Whitley (2012), which specifically focused on religion, it was mentioned that interiorized religion (i.e. having a personal relationship with God) plays a more important role than exteriorized religion (e.g. church attendance, activities in a congregation) in relation to personal recovery. It is notable that this theme mainly emerged from studies in which there is a high percentage of African American participants (e.g. 90% in the study of Whitley (2012)). This indicates that the role of spirituality and religion in the recovery process might be subject to cultural differences.

### *2.3.4 Having somewhere 'to be': meaningful activity*

Six studies discussed meaningful activity as a catalyst for recovery (Cruce et al., 2012; Edward & Robins, 2012; Hipolito et al., 2011; O'Sullivan et al., 2013; Turton et al., 2011; Whitley, 2012). Examples of meaningful activity include physical exercise, creating art, reading and writing, education, employment and cultural and religious activities. Such activities contribute to the recovery process because they help to give structure to one's life, make one feel productive and expand one's social life by giving one somewhere 'to be' (Cruce et al., 2012; Edward & Robins, 2012; Hipolito et al., 2011). However, these activities can take place both in and outside the context of treatment. Participants in the study of O'Sullivan et al. (2013) pointed out that existing activities are too often organized segregated from the wider community. They stressed that taking part in meaningful activity *in* the community can be a powerful tool to fight stigmatization.

## 2.4 Discussion

This systematic review aimed to shed light on how persons with dual diagnosis think of personal recovery and on what they experience as facilitators and barriers on the path leading to personal recovery. In addition to the systematic review of Ness, Borg & Davison (2014), in which seven studies were retained, a total of 16 eligible studies was selected for this review. The larger number of retained studies relates to three reasons. First, an interdisciplinary database, i.e. Web of Science, was added in order to incorporate studies within the field of social sciences (expanding the medical databases), which resulted in four additional articles (Cruce et al., 2012; Hagler et al., 2015; Smith et al., 2015; Staiger et al., 2011). Second, this systematic review applied broader inclusion criteria. Studies focusing on a subgroup of persons with dual diagnosis only (e.g. within forensic mental health care) (O'Sullivan et al., 2013; Padgett et al., 2008; Smith et al., 2015), studies in which the focus is not only on persons with dual diagnosis (substance abuse and psychiatric disorder) but also on persons suffering from other (psychiatric) disorders (e.g. eating disorders) (Turton et al., 2011), studies focusing on recovery in relation to a specific treatment program (Hagler et al., 2015; Hipolito et al., 2011; Matusow et al., 2013) and studies focusing on a specific aspect of recovery (e.g. family, religion) (Kennedy & Horton, 2011; Whitley, 2012) were also included. Third, five qualitative studies on recovery from the perspective of persons with dual diagnosis were published since Ness, Borg & Davidson (2014) completed their selection process (1 September 2013) (Green et al., 2015; Hagler et al., 2015; Maybery et al., 2015; Roush et al., 2015; Smith et al., 2015). By adjusting the search criteria, themes that were not included in the systematic review of Ness, Borg & Davidson (2014), i.e. identity, peer support, medication, self-responsibility and spirituality, could be discussed in detail in this review.

Despite the good representation of minority groups (e.g. African American, Hispanic) within the 16 selected studies, the results of this systematic review are entirely based on research conducted in western, mostly English-speaking countries. This imbalance may partly be due to the fact that this review solely focused on publications in English language. At the same time, however, it is an accurate reflection of the general trend that the concept of recovery is mostly described in the English-speaking world (USA, UK, Australia, and Canada) (Slade et al., 2012). Cultural differences in the way recovery is conceptualized undoubtedly influence the results of this systematic review. For example, in American literature, there is a tendency to define recovery as an individual process and to minimize the emphasis on the fact that it is a social process as well (O'Hagan, 2004). Also, in British policy documents, being abstinent is considered to be an important aspect of recovery (Iveson-Brown & Raistrick, 2016). As a consequence, the results of this review should be generalized with care, taking into account these specific cultural contexts. Indeed, Slade et al. (2012) state that it is necessary to be more sensitive to cultural differences within recovery research and to conduct more research in non-western countries in order to get a more multicultural understanding of the concept. For example, it would be interesting to gain insight into the cultural differences when discussing spirituality as a contributor to the recovery process.

Within the 16 selected studies, four overarching themes were identified, i.e. treatment, psychological factors, social relationships and meaningful activity. With regard to *treatment*, participants stressed the need for a holistic and individualized approach, shedding light on 'the person behind the symptoms'. This should also be reflected in a long-lasting respectful therapeutic relationship with caregivers. Medication was considered as helpful in the recovery process, as long as the dose was adjusted to their personal needs and only used for therapeutic purposes. When talking about *personal beliefs*, participants mentioned the power of hope, having goals for the future, spirituality and the importance of gaining responsibility over your own recovery process. Participants also stated that recovery implies building a new identity, which inevitably collides with giving up aspects of their 'old' identity. With regard to *social relationships*, participants made a distinction between family support, peer support and community participation. Related to community participation, participants mentioned that *meaningful activity* contributes to recovery in the sense that it gives you somewhere 'to be' and adds structure to your life, as long as these activities are organized within the community. It is remarkable that the role of the wider society in participants' personal recovery processes is only scantly discussed in the included studies. Despite the fact that persons with dual diagnosis often find themselves in disadvantaged social contexts (e.g. poverty, homelessness) (Draine et al., 2002; Henwood et al., 2015), an important aspect that remains underexposed in the results is how persons with dual diagnosis experience the influence of having (a lack of) resources on their recovery process. In this respect, Cloud and Granfield (2008)

stress the importance of having access to physical (e.g. having an income), and social (e.g. belonging to a social group) capital as facilitators of recovery.

The results of this review thus give an overview of the themes persons with dual diagnosis deem invaluable for their recovery process. These themes show a large overlap with the themes identified by Slade et al. (2012) in the CHIME framework that describes the recovery process of persons with severe mental illness in five themes, i.e. Connectedness, Hope and optimism about the future, Identity, Meaning in life and Empowerment. This framework has proven to be applicable to the field of addiction recovery as well (Best & Lubman, 2012). However, since recovery remains a deeply unique and individual process, it is impossible to consider the above-mentioned themes as a rigid model of recovery (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Instead, they could serve as *sensitizing* themes that can help address gaps in current mental health care policy and practice. For example, this review shows that persons with dual diagnosis put forward a nuanced vision on recovery-oriented care by pointing out that treatment should not automatically prioritize total abstinence and should be organized as much as possible in outpatient community settings. First and foremost, however, participants state that treatment can only be successful when tailored to their personal needs and adjusted to the pace and unpredictable nature of their recovery process. As a consequence, different treatment approaches might be desirable at different moments of the recovery process. The experiences of the participants can thus be read as a plea for 'flexibility' in mental health care, i.e. a plea for an approach that allows for both successes and setbacks, and that recognizes that recovery is a non-linear process. This can be related to the concept of 'permissiveness', described by the social psychiatrist Maxwell Jones as the freedom for patients to openly show and talk about their emotions, and/or to relapse or to show 'difficult' behavior without being immediately followed by negative (and often far-reaching) consequences (e.g. punishment or exclusion from treatment) (Vandevelde et al., 2015).

Remarkably, however, the above-mentioned themes are mainly focused on the facilitators and barriers of recovery, rather than on the actual meaning of the recovery concept for persons with dual diagnosis. Based on the results of this review, it thus remains very difficult to fully understand which experiential components contribute to the interpretation of being recovered by individuals who suffer(ed) from dual diagnosis. Similarly, the underlying mechanisms that allow for recovery to occur and the way the aforementioned elements interact with each other could not be clarified. Indeed, most research thus far conducted in the field for dual diagnosis strongly maintained a descriptive focus, mapping diverse helpful recovery strategies and the subjective and psychosocial effects these produced. What largely remains neglected is the personal meaning and lived experience of recovery such as thought of by (former) dual diagnosis patients. This lack of insight exposes a gap in the field of recovery research in that it remains challenging to grasp the actual *processes* taking place. In this respect, it might be

important for qualitative research to shift focus from '*what* facilitates recovery?' to '*how* does recovery come about?' when thinking about ways to support persons with dual diagnosis in their unique recovery processes. In order to answer this question, Stanhope and Solomon (2012) state that it is crucial to focus on the phenomenological aspects of recovery and to study individual recovery journeys and experiences (Leamy et al., 2011; Stanhope & Solomon, 2008). Looking into such individual micro-processes of recovery could for example help us understand *how* hope is awakened, *how* a new identity is built, *how* spirituality could be integrated into treatment (and if that would be desirable), *how* supportive therapeutic relationships can be created and sustained, *how* structural and social factors (e.g. poverty) influence the recovery process, and *how* recovery unfolds over time. In other words, uncovering these mechanisms in individual recovery processes could give us a greater understanding of what it means to be 'in recovery' (Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008). In doing so, the relationships between the ingredients identified in this systematic review could be made more transparent and could form the basis of a more comprehensive – however not rigid – theoretical model of recovery in persons with dual diagnosis.

In summary, the voices of persons with dual diagnosis should form the beating heart of such a theoretical model. In this respect, Parker (2014) states that *"social justice is only possible when the expertise of those who are theorized about begin to have their own voices heard, in all their complexity and contradictoriness"* (p.32). Even more so, their experiences should form the core of any recovery-oriented policy, intervention or treatment program. By bundling the existing qualitative research on recovery from the perspective of persons with dual diagnosis, we aimed to help consolidate this foundation. However, more research into how the individual elements of recovery interact with each other is necessary in order to gain a better understanding of how recovery takes place.

*Table 1 - Overview of the included studies*

| | Country | Aims | Data collection methods | Data analysis methods | Number of participants | Participant characteristics |
|---|---|---|---|---|---|---|
| Brooks, Malfait, Brooke, Gallagher, & Penn (2007) | USA | To explore the experiences of persons with DD with regard to treatment and to identify factors facilitating and hindering the recovery process | Focus groups | Grounded theory | 35 | 66% male, 25 White |
| Green, Yarborough, Polen, Janoff, & Yarborough (2015) | USA | To gain insight into the personal perspectives of persons with DD with regard to their recovery process | In-depth interviews | Grounded theory | 177 (171 with DD) | 48% male, 94% White, age 16-84 |
| Hagler, Rice, Munos, Salvador, Forcehimes, & Bogenschutz (2015) | USA | To examine reasons for attending TSF-DD and DTR | Focus groups | Grounded theory | 15 | 53% male, 27% Hispanic, average age 47.86 years |
| Hipolito, Carpenter-Song & Whitley (2011) | USA | To gain insight into the meaning of recovery, based on the experiences of persons with DD who live in intentional recovery communities | Focus groups | Grounded theory | 8 focus groups | 25% male, 83% African American, average age 47.11 years |
| Kennedy & Horton (2011) | USA | To illustrate how family can influence recovery | In-depth interviews | Grounded theory | 325 | 39.5% male, 36% White, 38% Hispanic, 19% Native American, 5% Mixed Racial Heritage, 2% African American, age 16-70 |
| Matusow, Guarino, Rosenblum, Vogel, Uttaro, Khabir, Rini, Moor, & Magura (2013) | USA | To investigate the perceptions of people with DD who attend DTR meetings about the impact of DTR on their lives and to gain understanding of the specific self-help processes that underlie DTR group dynamics. | Focus groups | Grounded theory | 31 | No demographic data due to anonymity |
| Padgett, Henwood, Abrams, & Drake (2008) | USA | To investigate the role of positive social relationships in recovery among homeless individuals with DD | In-depth interviews | Multiple case study analysis | 41 | 71% male, 46% African American, 29% Hispanic, 17% White, 5% Asian American, 2% mixed race, age 21-60 |

| | Country | Aims | Data collection methods | Data analysis methods | Number of participants | Participant characteristics |
|---|---|---|---|---|---|---|
| Roush, Corbett, Carpenter-Song, & Drake (2015) | USA | To study first-person perspectives on DDA | Focus groups | Grounded theory | 13 focus groups | 6 focus groups in the community, 4 in a women's correctional facility, 1 in a men's correctional facility, 2 in the state hospital. 77.4% Hispanic, average age between 18-49 years |
| Smith, Padgett, Choy-Brown, & Henwood (2015) | USA | To explore the role of place in recovery among formerly homeless adults with DD | Photo-elicitation interviews | Content analysis + thematic analysis | 20 | 82.4% male, 70.6% African American average age 45 years |
| Whitley (2012) | USA | To analyze the relationship between religion and recovery from the perspective of persons with DD | Participant observa-tion + focus groups | Grounded theory | 50 | 20% male, 90% African American |
| Maybery, Reupert, & Goodyear (2015) | Australia | To explore the goals set by families where a parent has a mental illness and families where a parent has DD. | In-depth interviews | Goal setting | 10 families in which a member has DD | 20% male, 8 white Australian, 1 Aboriginal, 1 part-Aboriginal, average age 36.3 years |
| Staiger, Thomas, Ricciardelli, McCabe, Cross, & Young (2011) | Australia | To explore the barriers to treatment and suggestions for improvement as experienced by persons with DD | Mixed-methods: administration of CIDI and PS + in-depth interviews | Thematic analysis | 44 | 52% male, age 23-55 |
| Edward & Robins (2012) | / (Internet study) | To explore the personal experiences of persons with DD | Internet review | Content analysis | 108 quotes | Quotes collected from 9 online peer support groups (4 based in USA, 2 based in Australia, 1 based in UK, 1 based in Ireland, 1 based in Thailand) |
| O'Sullivan, Boulter, & Black (2013) | UK | To explore the experiences of offenders with DD who are treated in a Medium Secure Unit with regard to their recovery process | In-depth interviews | IPA | 5 | 100% male, 3 Afro-Caribbean, 1 British Caucasian, 1 mixed heritage, age 26-42 |
| Turton, Demetriou, Boland, Gillard, | UK | To investigate the meaning of recovery from the perspective of | In-depth interviews | Grounded theory | 18 (6 with DD) | 50% male (in the DD subcategory) |

| | Country | Aims | Data collection methods | Data analysis methods | Number of participants | Participant characteristics |
|---|---|---|---|---|---|---|
| Kavuma, Mezey, Mountford, Turner, White, Zadeh, & Wright (2011) | | users of 3 specialist mental health settings (eating disorders, forensic and DD) | | | | |
| Cruce, Öjehagen, & Nordström (2012) | Sweden | To explore the experiences of persons with DD concerning recovery-oriented care | In-depth interviews | Grounded theory | 8 | 75% male, age 27-54 |

*Table 2 - Thematic analysis*

| | Themes | | | |
|---|---|---|---|---|
| | **Belonging** | **Treatment** | **Personal beliefs** | **Meaningful activity** |
| **Brooks, Malfait, Brooke, Gallagher, & Penn (2007); USA** | Helpful to have a support system of non-agency sources<br><br>Need to be surrounded by others with similar backgrounds | Poor therapeutic environment: lack of acceptance of relapse, ineffective treatment strategies, lack of understanding of the client, antagonistic power structures<br><br>Medication is helpful, but can have negative side effects<br><br>Importance of supportive staff, having a good therapeutic relationship<br><br>Important to have input in your own treatment | Important strengths: maintaining a sense of humor, having a positive outlook and feelings of hope<br><br>Necessary to take responsibility for yourself (self-advocating, self-awareness)<br><br>Specific coping skills (setting goals, seeking support, anger management, cognitive strategies) are helpful | / |
| **Cruce, Öjehagen, & Nordström (2012); Sweden** | Belonging to a group, offering communication and solidarity are crucial | Preference for comprehensive, voluntary and holistic outpatient care<br><br>Relationship with staff: importance of honesty, reinforcing hopefulness, offering companionship and continuity of contact<br><br>Important to see the person behind the symptoms and 'really listen' | Self-determination supports the recovery process<br><br>Faith in God can contribute to feelings of hope<br><br>Endurance, self-tolerance and a capacity not to give up are necessary | Participation in meetings with staff and (sports) activities contributes to a structured day<br><br>Life routines are important<br><br>Rehabilitation programs offering stimulating group activities are fun and helpful<br><br>Cultural activities (art, reading, writing, music, etc) help to avoid drug use |

| | Themes | | | |
|---|---|---|---|---|
| | Belonging | Treatment | Personal beliefs | Meaningful activity |
| | | Medication can help control symptoms<br><br>Essential to offer individualized treatment | | |
| Edward & Robins (2012); Australia | Peer support is powerful | / | Being honest with self and others is important | Being productive and having 'somewhere to be' is helpful |
| Green, Yarborough, Polen, Janoff, & Yarborough (2015); USA | Self-help groups were crucial supports for some participants | Learning about how drugs interact with mental health conditions and medications is helpful<br><br>Treatment programs provide support, knowledge and skills | Overcoming substance abuse helps to gain self-confidence, self-efficacy and a sense of agency. These are important turning points in the recovery process | / |
| Hagler, Rice, Munos, Salvador, Forcehimes, & Bogenschutz (2015); USA | DTR creates a safe space in which participants feel comfortable and welcomed | Benefit from learning about their dual diagnosis<br><br>Importance of a caring environment and a valuable therapeutic relationship | / | / |
| Hipolito, Carpenter-Song, & Whitley (2011); UK | / | / | Acknowledging your reality and gaining self-knowledge is a difficult and gradual process<br><br>Important to take responsibility for mistakes in the past<br><br>A focus on the present but also the capacity for change are integral to recovery | / |

| | Themes | | | |
|---|---|---|---|---|
| | Belonging | Treatment | Personal beliefs | Meaningful activity |
| | | | Centrality of hope and being positive | |
| Kennedy & Horton (2011); USA | Family provides resources (funds, transportation, etc)<br><br>Family offers 'active' and 'passive' intangible support<br><br>Family members can have mistaken understandings of recovery<br><br>Restoring interpersonal trust is crucial | / | / | / |
| Matusow, Guarino, Rosenblum, Vogel, Uttaro, Khabir, Rini, Moor, & Magura (2013); USA | Experiencing acceptance among people with a similar background is powerful | DTR creates a 'safe space' and a sense of community<br><br>Gaining insight into relationship between substance use and mental illness<br><br>Importance of medication adherence<br><br>Important contributor to having a 'schedule'/ritual | Belief in God can contribute to feelings of hope | / |
| Maybery, Reupert, & Goodyear (2015); Australia | Importance of family connectedness, interpersonal skills, community and social connectedness, family health and well-being | / | / | / |

| | Themes | | | |
|---|---|---|---|---|
| | **Belonging** | **Treatment** | **Personal beliefs** | **Meaningful activity** |
| **O'Sullivan, Boulter, & Black (2013); UK** | Need to expand/change social roles<br><br>Important to feel like valuable, responsible citizens<br><br>Abstinence is experienced as related to social exclusion | Lack of choice and lack of hope in treatment are disempowering<br><br>Hospitalization is seen as a negative experience, but provides space to understand experiences, self-discovery and self-reflection<br><br>Treatment needs to respect participants' desire for autonomy and self-determination | Recovery process can be part of transition into adulthood<br><br>Importance of readiness for change, self-determinism, self-efficacy, self-awareness and authorship over own behavior | Lack of meaningful activity contributes to offending<br><br>Available activities often furthered segregation from the general public |
| **Padgett, Henwood, Abrams, & Drake (2008); USA** | Family can both be a source of warmth/nurturing and prone to rejection<br><br>Family relationships are often volatile<br><br>Children are a source of positive motivation<br><br>Making friends and catching up with family is more of priority than finding a romantic partner<br><br>Recovery often implies letting go of previous social circles | / | / | / |
| **Roush, Corbett, Carpenter-Song, & Drake (2015); USA** | Feeling connected to others | Importance of feeling safe without being judged | Importance of hope, self-responsibility, self-awareness | / |

| | Themes | | | |
|---|---|---|---|---|
| | Belonging | Treatment | Personal beliefs | Meaningful activity |
| | | Treatment addressing both the psychiatric disorder and substance abuse problems<br><br>Room for medication<br><br>Having a structure that allows (not) talking | | |
| Smith, Padgett, Choy-Brown, & Henwood (2015); USA | Community participation creates a sense of belonging, engagement and pride<br><br>Having housing creates control in managing relationships<br><br>Social relationships can provide support but also increases stress through nonsupport | / | Housing offers a sense of security, ownership and stability, and marks a new phase of life<br><br>Recovery implies moving beyond past 'spoiled identities'<br><br>A sense of hope and determination for a better future are crucial | / |
| Staiger, Thomas, Ricciardelli, McCabe, Cross, & Young (2011); Australia | Committing to recovery can imply isolation from previous friends<br><br>Need for mutual support from peers | Barriers to treatment: lack of knowledge about treatment options, breakdowns in referral process, inability to adapt to individual circumstances<br><br>Necessary for treatment to address issues beyond dual diagnosis (e.g. housing, social support, family roles)<br><br>Importance of therapeutic relationship<br><br>Support groups are helpful | / | / |

| | Themes | | | |
|---|---|---|---|---|
| | **Belonging** | **Treatment** | **Personal beliefs** | **Meaningful activity** |
| **Turton, Demetriou, Boland, Gillard, Kavuma, Mezey, Mountford, Turner, White, Zadeh, & Wright (2011); UK** | Rebuilding valuable personal relationships<br><br>Importance of peer support | The absence of collaborative and negotiated approaches is not beneficial<br><br>Medication is helpful when it is used therapeutically and not as a management tool<br><br>Importance of positive staff attitudes and a caring environment<br><br>Importance of aftercare | Positive personal attributes: positive view of the self, self-esteem, sense of identity, regaining a sense of purpose in life<br><br>Important to take responsibility for own recovery process | Engaging in community activities, gaining employment, taking part in leisure or religion are seen as important factors |
| **Whitley (2012); Canada** | / | / | God (rather than congregational participation) can be an important ingredient of recovery<br><br>Church attendance imparts intellectual, emotional and social benefits | / |

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# Chapter 3

# 'A place to be (me)': A qualitative study on an alternative approach to treatment for persons with dual diagnosis

Based on

De Ruysscher, C., Vanheule, S., & Vandevelde, S. (2017). 'A place to be (me)': A qualitative study on an alternative approach to treatment for persons with dual diagnosis. *Drugs: Education, Prevention and Policy, 26*(1), 50-59.

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## Abstract

This study aims at gaining insight into an alternative approach to treatment for persons with dual diagnosis by unraveling the daily practice of Villa Voortman, a community-based meeting place in Ghent (Belgium) offering support to this group. Twelve in-depth interviews were conducted with several actors: visitors, staff members, volunteers and persons involved from outside the meeting place. First, Villa Voortman is experienced as 'a place to be', providing visitors a possibility to feel safe and accepted, and belong to a peer group. Voluntary participation to activities is crucial to install such feeling. In time, the meeting place also becomes 'the place to be', as visitors start to feel at home. Secondly, it functions as 'a place to be me', helping participants to (re)build their identity and become visible citizens. The findings are highly consistent with recovery literature and Lacanian ideas on the treatment of psychosis. Some 'contours' that shape the daily practice of Villa Voortman could be identified: particularizing to personal needs, having a focus on personal, social and structural aspects of recovery and the coexistence of different discourses.

## 3.1 Introduction

Persons with dual diagnosis, i.e. the comorbidity of a substance use disorder and a psychiatric disorder (e.g. psychosis), are often characterized by a variety of complex needs. In addition to addiction and mental health problems, they frequently face judicial problems, housing problems, poverty, a poor physical health and social isolation, among other things (Drake et al., 2001; Ness, Borg, & Davidson, 2014). As a consequence, the treatment of persons with dual diagnosis is experienced as challenging by many professionals working in mental health care and addiction treatment settings. Today, an integrated and multidimensional treatment approach is increasingly considered to be more adequate than a parallel or sequential treatment approach, although scientific evidence remains weak (Drake & Wallach, 2000; Murthy & Chand, 2012). In such integrated programs, the focus is placed on both substance use problems and psychiatric problems, in order to meet the complex needs of persons with dual diagnosis (Horsfall, Cleary, Hunt, & Walter, 2009). Additionally, in line with recent trends in both mental health care and addiction policy, the emphasis of these integrated programs is increasingly shifting from symptom reduction and cure towards supporting personal recovery processes and stabilization of persons with dual diagnosis, moving away from deficit-oriented approaches (Anthony, 1993; Cruce, Öjehagen, & Nordström, 2012; Davidson & White, 2007; Drake et al., 2001; Gagne, White, & Anthony, 2007).

These recent developments towards integrated stabilization- and recovery-oriented treatment for persons with dual diagnosis led to a wide variety of treatment modalities, ranging from specialized therapeutic communities and pharmacological treatment over case management to harm reduction and self-help groups (Drake et al., 2001; Horsfall et al., 2009). However, recent literature shows that there remain several barriers to treatment for persons with dual diagnosis, related to both personal characteristics of the patients (e.g. low motivation for treatment, cultural beliefs, (self-)stigma) and structural factors (e.g. exclusion from specialized treatment services, excessive waiting lists, organizational and financial aspects of treatment) (Le Boutillier, Slade, et al., 2015; Priester et al., 2016). Such barriers contribute to high dropout rates, an overly narrow focus on symptom reduction and lack of attention for the social context in integrated treatment services for persons with dual diagnosis (Drake et al., 2001; Farkas, 2007; Le Boutillier, Chevalier, et al., 2015; Slade, Amering, & Oades, 2008).

In order to tackle these challenges, it could be helpful to look at innovative practices that manage to engage with this often 'hard-to-reach' group. An example of such a practice was developed in Ghent (Belgium): Villa Voortman. This community-based meeting place aims to offer 'a welcoming place' for persons with dual diagnosis (comorbidity of psychosis and substance use) who often lost connection to other more traditional psychiatric and social care settings (Vandevelde et al., 2015). The central aim of

Villa Voortman is to enable 'human encounters' as a starting point for empowering visitors (as they are called) to find a valued place in society. Therefore, a minimal structure is provided in which only two rules apply: physical/verbal violence and drug use (or being under influence) are not tolerated at the meeting place. Its daily practice is underpinned by a horizontal organizational structure, inspired by democratic drug-free therapeutic community principles and Rapoport's (1957) principles of permissiveness and communalism (Broekaert, Vandevelde, Soyez, Yates, & Slater, 2006; Rapoport & Rapoport, 1957; Vandevelde & Broekaert, 2009; Vandevelde et al., 2015). Visitors come on a voluntary basis and are free to take part in a wide range of activities, such as poetry writing, sculpting, painting, philosophy and cooking. The daily practice and artistic projects of Villa Voortman are funded by the psychiatric hospital from which it was founded, the city council and a not-for-profit association (called 'friends of Villa Voortman'). A more detailed description of Villa Voortman can be consulted in (Vandevelde et al., 2015).

The meeting place offers an alternative to spending time on the street or in residential psychiatric settings, thus countering social isolation and medicalization. The experience and tacit knowledge built in practices such as Villa Voortman could play a vital role in recognizing how support for persons with dual diagnosis can best take shape (Kirmayer, 2012; O'Sullivan, 2005). Indeed, Stanhope and Solomon (2008) argue that, in order to gain better understanding of the ways personal recovery processes can be supported through treatment, research should focus on micro-level practices and processes rather than aiming to measure generalizable outcomes (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). In particular, they refer to qualitative research methods that give a central position to the lived experiences of the persons involved in the practices under study (Stanhope & Solomon, 2008). Also Pilgrim (2009) argues for the use of practice-based, context-close and ethnographic research methods in order to get close to the personal meanings and experiences of the participants. Therefore, the aim of this study is to gain insight into an alternative community-based approach to treatment for persons with dual diagnosis, by unraveling the daily practice of Villa Voortman from an idiographic qualitative perspective.

## 3.2 Methods

*Methodological approach*

In order to focus on idiographic perspectives of treating dual diagnosis, an explorative qualitative study was conducted (Baxter & Jack, 2008). Data were collected using in-depth interviews and analyzed by means of thematic analysis (Clarke & Braun, 2014). In order to focus on micro processes, each case was analyzed in detail before searching for patterns and themes across cases (Flood, 2010; Smith et al., 2009).

*Research location and participants*

The study took place in Villa Voortman, a community-based meeting center in Ghent (Belgium). Characteristically, most of the visitors, as the service users are called, of Villa Voortman are excluded from society on several levels. Their persistent psychotic symptoms and substance use problems, together with financial, judicial, and housing problems often cause visitors to live on the street or spend a lot of their time alone, isolated from community life. Moreover, they often lost connection to regular treatment after a series of unsuccessful admissions and bad experiences: their substance use problems are believed to be too severe to fit into psychiatric treatment and vice versa. On a daily basis, an average of 25 to 35 clients visit Villa Voortman, staying for a few hours or a full day. Besides staff members (psychologist, psychiatrist, social workers), there are also volunteers and interns around supporting the daily practice.

In order to obtain rich information on the functioning of Villa Voortman, and to do justice to its complexity, triangulated participant perspectives were obtained by recruiting 12 participants from four groups of actors: three visitors (i.e. persons with dual diagnosis), three staff members (one psychologist, one psychiatrist, one creative therapist), three volunteers and three people who are involved from outside the meeting center. The visitors were purposefully selected based on the fact that they are senior regular visitors. In the selection process of the other participants, we aimed at obtaining a wide diversity of perspectives and backgrounds. The volunteers had different professional backgrounds. The group of persons involved from outside the meeting place consisted of one street corner worker, one artist with a studio in the building where Villa Voortman houses, and one judicial actor who helped establish a good working relationship between the prison of Ghent and Villa Voortman. All participants were considered to be good informants because of their extensive experience with Villa Voortman. Table 1 gives an overview of participant characteristics.

*Table 1 – Participant characteristics*

| *Name* | *Sex* | *Age* | *Role at Villa Voortman* | *Amount of years active at / connected to Villa Voortman* |
|---|---|---|---|---|
| Nick | M | [41-50] | Visitor | 5 years |
| James | M | [51-60] | Visitor | 5 years |
| Amanda | F | [51-60] | Visitor | 3 years |
| Chris | M | [51-60] | Psychologist | 5 years |
| Adam | M | [41-50] | Psychiatrist | 5 years |
| Rob | M | [41-50] | Creative therapist | ½ year |
| Katie | F | [51-60] | Volunteer | 4 years |
| Hannah | F | [51-60] | Volunteer | 2 years |
| Fay | F | [21-30] | Volunteer | 2 years |
| Jim | M | [31-40] | Artist | 5 years |
| Andy | M | [61-70] | Judicial actor | 4 years |
| Caroline | F | [31-40] | Street corner worker | 3 years |

*Procedure*

All participants were personally invited by the first author for an in-depth interview covering their personal viewpoints about the daily practice of Villa Voortman. More precisely, they were asked about what it is that makes activities work (or not) for the visitors; about the kind of social relating taking place; about key values and working principles; and about the role that the meeting place plays in their lives. The interviews took place in a quiet room at Villa Voortman, except for one that took place in a local café. Interviews lasted between 40 and 120 minutes, were audio-recorded and transcribed verbatim by the first author. Additionally, during the entire period of the research project (May – October 2016), the first author conducted a participant observation at Villa Voortman for approximately one day per week. The researcher recorded thoughts and reflections in a research diary.

*Data analysis*

First, an individual idiographic analysis was conducted for each interview. After transcribing the interview, the first author read it multiple times to get immersed into the data, whilst writing down

thematic descriptive comments. Based on these exploratory notes she drew up a schedule of emergent themes and links between the themes. In the second phase, the schedules of the individual interviews were gradually integrated in a scheme in order to identify superordinate themes and dynamics. During this phase, participant observation data became intertwined with the interview data.

In order to deal with subjectivity, and to increase the interrater reliability of the results, the first author and the co-authors met at several moments during the analysis process. The analysis of the first interview was carried out by all authors. In the second phase, we selected four interviews, based on their richness and the diversity of topics covered. These were discussed extensively and integrated into the scheme with superordinate themes and dynamics. After the first author completed the entire analysis, the co-authors independently scrutinized one additional randomly selected interview and verified to what extent their analysis related to the themes identified by the first author. They concluded that the overall results fit the information from the additional interviews.

*Ethical considerations*

Ethical approval was granted by the Ethics Committee of Ghent University Hospital (EC UZG 2016/0530). Written informed consents were obtained from all participants. In order to guarantee anonymity, names of participants are altered.

## 3.3 Results

Participants' experiences can be clustered around two main themes: on the one hand Villa Voortman functions as *a place to be*, and even starts functioning as *the place to be;* and on the other hand it functions as *a place to be me*.

Most visitors of Villa Voortman are confronted with exclusion from society on several levels; they are 'invisible' citizens, who lost 'their' place in society. Villa Voortman, by contrast, offers a safe hub where they feel welcomed and accepted. In that sense, the meeting place functions as *a place to be*. Gradually, visitors even start to feel 'at home' at the meeting place, as becomes apparent in daily routines: visitors gather in the living room to drink coffee and chat, and have lunch together. In that sense, the function of Villa Voortman makes a transition from being *a place to be*, i.e. a safe haven, to being *the place to be*, i.e. a homely place that the visitors have made their own.

At the same time, Villa Voortman is a vibrant place where artistic and creative activities and projects are continuously taking place. These activities are organized on a voluntary basis, and start from visitors'

personal interests, as well as from personal interests of volunteers and staff. By cultivating these interests, visitors find a (new) way to express themselves and gradually build up a new sense of identity. In doing so, senior visitors inspire new visitors, who might primarily come to Villa Voortman to find some peace of mind. In that way, the meeting place is experienced as *a place to be me*, i.e. a place where visitors are encouraged and even expected (in balance with their own capacities) to go through a processes of transition: by engaging in valued activities they start cultivating positive identities, thus taking a distance from (self-)stigmatizing labels. Importantly, these activities and projects provide an important link to the outside world.

Table 2 provides an overview of the themes and subthemes detected across the interviews. Also, it shows the number of participants talking about these themes, per participant group.

*Table 2 – Overview and occurrence of themes*

| | | *Occurrence of themes per participant group* | | | | |
|---|---|---|---|---|---|---|
| | | Visitors (3) | Staff members (3) | Volunteers (3) | Persons involved from outside (3) | Total (12) |
| *Themes* | *Villa Voortman as a/the place to be* | | | | | |
| | Feeling safe | 3 | 3 | 3 | 3 | 12 |
| | The predominance of the peer group | 2 | 2 | 3 | 2 | 9 |
| | Feeling accepted | 3 | 3 | 3 | 3 | 12 |
| | Feeling at home | 3 | 3 | 2 | 2 | 10 |
| | Voluntary basis | 2 | 2 | 2 | 3 | 9 |
| | *Villa Voortman as a place to be me* | | | | | |
| | (Re-)building one's identity | 2 | 3 | 2 | 2 | 9 |
| | Becoming a visible citizen | 2 | 2 | 3 | 3 | 10 |

Table 2 shows that all themes are well-represented in the accounts of the participants. However, some of the themes were discussed in more positive or negative ways depending on the participant group. In the description of the results, these ambiguities will be further explored and made explicit.

### *3.3.1 From 'a place to be' to 'the place to be'*

When asked about the important elements of Villa Voortman, most participants described the meeting place as welcoming. Different factors contribute to this welcoming climate: feeling safe, feeling accepted, feeling 'at home', organizing all activities on a voluntary basis and treating each other as equals. Chris, the psychologist, refers to the primary function of Villa Voortman as "*creating an asylum*", that is, a safe place where people feel protected and at ease. In what follows, the experiences of the participants regarding each aspect of the meeting place as *a/the place to be* are described in detail.

*Feeling safe*

All participants expressed the importance of feeling safe. This sense of safety is twofold: Villa Voortman provides a safe haven away from threatening aspects of the visitors' outside world (e.g. homelessness, judicial problems) and the restlessness of their inner world (e.g. psychosis, drug craving, loneliness). Nick, a visitor, describes this as follows:

> *"A lot of people, me too sometimes, find more rest here than at home. So at home they can't sleep, then they come here, they lie down on the sofa and fall asleep. Because it is calm, because it feels safe."*

The importance of having a safe haven also becomes apparent in the story of Amanda, a visitor who spends a lot of time in *"the crowdedness of the streets"*, as she calls it, where she is often confronted with bullying others. For her, knowing that the outside world cannot simply come in, e.g. because every visitor needs to have an intake conversation before being allowed to Villa Voortman, contributes to her sense of security. Indeed, Villa Voortman is her hideaway from the tumult of the streets:

> *"When I need to leave the Villa at the end of the day, back into that rotten world, it already starts on the tram… Crowded, full. Students. It is totally different. When I come from here and have to go back into the mass. Into that buzz. You can't imagine how much I suffer from that."*

Adam, the psychiatrist of Villa Voortman, added another dimension to this theme. Most visitors lost connection to treatment after a long and difficult trajectory within regular psychiatric services. In order to offer them a real break, Villa Voortman aims to be a safe haven, not only away from street life, but also away from the pressure of psychiatric and social services:

> *"You are safe in the sense that you won't be asked certain questions, that you can trust that they won't be asked. And safe for the chase of psychiatric services or judicial authorities who try to correct you. So that… That no unexpected things will happen when you are here. And that's when*

> *you feel at home. […] The outside world can come in, but the outside world has to obey to the rules of the house. A sort of code, almost like a code of conduct."*

Another aspect of safety is related to the inner world of the visitors, as most of them suffer from both psychosis and substance use problems. Villa Voortman counters these threatening aspects of their inner world, in different ways. For example, while keeping away from moral judgments about illicit drugs, there is a clear rule that all drug-use is forbidden within the meeting place. As a consequence, visitors experience a sense of safety: they know that being in the meeting place keeps them away from the compulsion to use drugs for a few hours. Frequently, psychotic experiences too trigger a severe sense of inner restlessness. On the one hand visitors are allowed to speak about psychotic experiences, on the other hand Villa Voortman aims at providing a protective buffer by actively setting boundaries. Fay, a volunteer, expresses this as follows:

> *"When there are people suffering from acute psychosis or schizophrenia, yeah then it isn't always useful to talk to them loads. Sometimes you need to take control, in order to avoid it getting out of hand for them."*

However, sometimes finding a good balance between, on the one hand, accepting psychotic idiosyncrasies and visitors' drug-related activities outside the meeting place, and, on the other hand, providing a buffer against excessive problems is difficult, as the sense of safety is also subject to interactions between the visitors. For example, when visitors encourage each other to use drugs, this might impose a threat to that sense of security. This becomes apparent as Andy, a judicial actor, expresses his concerns regarding Vicky, a former mentally ill offender who visits Villa Voortman on a regular basis:

> *"Sometimes Vicky has moments that she doesn't want to go to the Villa because she thinks there is too much drug use, or… Even if she doesn't use in the Villa herself… but because the visitors are still using it. And offer her stuff, or… I don't know. That is a problem too. How can you keep that under control without being repressive?"*

Andy's concern indicates that Villa Voortman as 'a place to be' is also fragile, since the sense of safety is constantly subject to detrimental group dynamics too.

*Feeling accepted*

Another aspect that contributes to the welcoming climate is for its visitors to feel accepted. All staff members and volunteers expressed the importance of accepting visitors as they are, rather than having

the reflex to 'cure' or improve them. For instance, Katie, a volunteer, clearly put this forward as the most important aspect of Villa Voortman:

> *"It is just the acceptance. That you come in and it is OK, you are OK. Not like "we will change this and that and we will make you better", no, there is no… There is no recovery policy here or a vision to strive for recovery. This is a meeting place and by accident recovery can occur. But it is not the aim. And that creates an enormous sense of security. As soon as you enter, you get a kiss and the question "welcome, how are you?" instead of "did you use drugs yesterday?" or "are you gonna use again tomorrow?" or "it would be better if you didn't use"."*

This is also expressed by Nick and James, who described that, in contrast to other psychiatric settings, in Villa Voortman you get the freedom to 'bluntly' be yourself without being judged for it:

> *"Visitors are often rebellious here, and that is tolerated by the staff. In most other settings you need to behave. […] I find that the most important thing here is tolerance. […] Also from staff towards patients. Visitors can be brutal towards staff members sometimes. And in psychiatry that is not allowed. Or way way way less." (Nick)*

> *"No matter how extreme it is, your thoughts or your way of thinking, you can say it here. And I couldn't do that at all in psychiatry. By doing that, I have violated many crusted established values there (in psychiatry)." (James)*

*The predominance of the peer group*

Several participants discussed how in Villa Voortman, everyone treats each other as equals. For many visitors, this contrasts with previous experiences in traditional hierarchically structured psychiatric settings. In society too, visitors often find themselves in unequal power relationships, and are addressed from a dominant position (e.g. by police, judicial actors). In Villa Voortman, however, the group is structured horizontally and everyone (visitors, staff and volunteers) is part of this group: the peer group predominates and power inequalities are minimized. For example, this is reflected in the way that everyone greets each other, i.e. in a cordial way with a kiss and a hug. Equality is also reflected in weekly 'visitors meeting', where the visitors themselves plan the activities of the next weeks. Adam, the psychiatrist of Villa Voortman, links this horizontal structure to recent trends in mental health care:

> *"It is a different movement, one in which patients can truly speak up, one in which caregivers can truly speak up. Both as caregivers and humans. And it shouldn't be the organizations or the financial means that determine the rules. […] Everyone has the right to speak up, both the users of the system and the ones organizing the system. And that's what also happens here."*

According to Hannah, a volunteer, one reason why such horizontal structure can be maintained is because Villa Voortman does not actively take up medical tasks. She explains that unavoidably, the prescription and distribution of medication (e.g. antipsychotics, methadone) installs a power imbalance between 'staff' and 'patients', and therefore better takes place in services outside Villa Voortman:

> *"I think, if you'd get your medication here, you'd feel more like a patient. I think we'd also have to be like "did you take your medication?" and thus play a different role. It is not just them (the visitors) who feel more like patients. We'd also play a different role and position ourselves above them and tell them what to do. So I wouldn't like that."*

However, despite the predominance of the peer group, several participants indicate that in practice, there are still hierarchical differences between visitors, staff members and volunteers. This is illustrated in the story of Katie, one of the volunteers, as she explains her own position:

> *"As a volunteer you have a position, imagine… Even if I wouldn't cook here, I feel like the cook [of a summer camp]. You get to hear different things. Because you are not… I think that we, even though in theory there is no ranking and power and order, are experienced as different. […] And volunteers don't have their own agenda, zero point zero, unlike the interns and staff members. But I don't know if they think about it a lot, but they do experience a difference."*

Also, Caroline, a street corner worker who regularly visits Villa Voortman, recalled feeling surprised and disappointed when some visitors told her that she could never fully be 'one of them':

> *"I was seen as a staff member, and the volunteers were too. Whilst… Yeah, of course, I'm not a visitor, of course I'm different and look differently at things. […] But no matter how open you are, you can't be one of them. And that doesn't mean they (the visitors) don't like you, but you are different. […] In the evening, you go home to your own house. You close the door whilst you know some visitors will have to sleep rough."*

Remarkably, the horizontal structure at Villa Voortman is not explicitly discussed by the visitors themselves. Moreover, they even appear to prefer a certain level of hierarchy. For example, Amanda mentioned that she would prefer the staff to install a drug test at the entrance, in order to make sure nobody enters under influence. Nick, in his turn, indicated that he prefers to have patient files in order to keep track of the visitor's treatment trajectory.

*Feeling 'at home'*

All participants talked about the 'warmth' that creates a feeling of being 'at home': Villa Voortman is not only *a place to be*, i.e. a safe shelter, but also *the place to be* for visitors. One aspect that contributes to this feeling of homeliness is the fact that Villa Voortman is located in an old and almost worn-down house with many rooms, decorations, a grand staircase and a big private garden. Fay explains that this sense of 'faded glory' creates a relaxed and chaotic atmosphere that gives visitors freedom to find their place within Villa Voortman:

> *"The house has little corners and things to do everywhere, which gives people the option to hide for a little while, and actually they are free to do what they want, and I think that's what appeals to people. Also with having psychosis and addiction problems, you can't ask for too much. And… There is always a bit of chaos that… sometimes causes problems but I think that is why most people like it here."*

This sense of homeliness is also clearly present in the experiences of Amanda. As she was giving a detailed description of the house, she attached a lot of importance to the status and grandeur of the building. A few months after the interview with her, Villa Voortman would move to a new location. This caused a lot of distress, as she was afraid that the new location would not have the same outlook:

> *"Why do you think people love to come here? When you enter you see these wooden stairs. When it is cleaned, it is so pretty. And all the marble around it. […] You really are in a villa. […] Now we move to those barracks. They are nothing compared to this. Such ghetto, such poverty. Are you still gonna call it Villa Voortman? […] Bungalow Voortman, that's what you can call it."*

Another important aspect that contributes to feeling at home is the fact that a hot lunch is prepared and served every day. Fay explains how this daily routine provides structure and predictability:

> *"It may sound really silly, but I find it important, the eating together, doing the dishes together. I find it important because it… Yeah, the homeliness, it provides a solid ground, the normal reference... How to say… Reference points, things to hold on to."*

*Voluntary basis*

In Villa Voortman everything is organized on a voluntary basis: there are no mandatory therapeutic sessions, visitors are free to come and go as they wish, and take part in the activities they want. However, voluntariness does not imply that nothing is demanded; visitors are expected to take responsibility for their own actions and choices. This became visible in the story of Nick, as he was

comparing residential psychiatric treatment to Villa Voortman. In a residential treatment program, he felt like he was not expected to do much since all control was taken out of his hands. In Villa Voortman this is different:

> *"You can be more yourself, yeah, that's true. But the trick at Villa Voortman is to make use of it, to really see it as an opportunity for yourself as a visitor. So 'what can I do with the Villa?' rather than 'what is the Villa going to do for me?'. Do you understand? Like drumming and taking part in the workshops."*

Thus, visitors themselves are made responsible for their own acts and activities. This requires a different attitude of the staff, as Rob, a staff member, explains:

> *"From the moment that something goes wrong in a hospital, they will intervene and try to correct it and… Whilst here, there is more of a 'wait and see' attitude… For example Bert (visitor), he is not well, everyone can see that he is not well, and everyone makes a careful attempt to get closer to Bert. But if Bert says "leave me alone", yeah, then we'll listen to that and the team will wait rather than saying "okay, we have to arrange an involuntary admission to the hospital"."*

However, at certain moments, voluntariness comes under pressure. For example, when visitors do not respect house rules (i.e. no drug use or violence inside the meeting place) or refuse to engage in any activities, staff members sometimes feel frustrated and are tempted to take more control and make certain activities obligatory (e.g. the weekly visitors meeting). Psychologist Chris claimed that it is important to resist this temptation:

> *"When you take over, then actually what you are saying is "they cannot do it, we have to take control". And then you are going away from the empowerment idea. […] I think, when you create more rules or become stricter, it is out of a kind of overpowering, a sort of fear that it will go wrong."*

At the same time, visitors indicate that sometimes it would be desirable for staff to take initiative and be more proactive with regard to the needs of the visitors. For example, according to Nick, the meeting place does not play an active enough role in 'caring' for its visitors:

> *"But the staff isn't really proactive here. It is not like they… It is not like they have a big plan to help people. Not enough, if you ask me. I would do a bit more. And have patient files and all that. But they don't want that. So they only work in a reactive way. Only… They mainly are reactive to situations. […] Actually, the question is 'who is taking care of me?' That is the question. They don't do that here. They don't take care of you here. And that is exactly what they do in psychiatry. A lot more than here."*

### *3.3.2 Villa Voortman as 'a place to be me'*

The fact that visitors feel welcome, safe and accepted forms the breeding ground for subsequent creative processes taking place at Villa Voortman. More specifically, visitors usually start engaging in activities such as making music, painting, cooking, bike repairing… These activities express and cultivate own interests and talents, thus giving visitors a medium and language to start dialoguing with others. In that respect, Villa Voortman helps establishing a personal identity, and is experienced as *a place to be me*, i.e. a place where social processes take place, and where a safe sense of self gets established. In particular, two processes stand out: (re-)building one's identity through self-expression and becoming a visible citizen.

*(Re-)building one's identity through self-expression*

At Villa Voortman, visitors are encouraged to express themselves by finding a medium through which they start conversations with others. The many creative activities organized at Villa Voortman are main facilitators of these identity-building processes. Rob, a staff member, explained that creative activities bring the interests and talents of visitors to the foreground:

> *"I think that most creative activities actually allow for visitors to regain status: 'I am the poet', 'I am the illustrator', 'I am the painter', 'I am the artist'. And I think that fits well within society."*

As a result, visitors stop seeing themselves, and are no longer seen by others as 'patients' or 'persons with dual diagnosis,' but as individuals with a unique identity. Jim, an artist with a studio in Villa Voortman, mentioned that these creative processes have a destigmatizing effect, even to the point that it is difficult for outsiders to distinguish staff members from visitors:

> *"The biggest question that people ask at the… at the like Indian Summer events… "is that a visitor or do they work here?" And in the end, does it matter? Because he's a musician now, so who cares if he's a visitor or if he works here. And… But the fact that people are asking that question already kind of takes away the stigma a little bit. […] But it takes time before people are still seen as equals."*

In this respect, Adam, the psychiatrist, explained that despite the voluntary basis of these artistic and creative activities, visitors are expected and encouraged to actively elaborate a sense of self. He explained that at the basis of this expectation lies the idea that every person nurtures the desire to 'be someone' and to give shape to this sense of identity by expressing oneself and engaging in dialogue with others. Thus, at Villa Voortman, visitors are encouraged to actively (re)build their identity, away from old 'spoiled identities' (Smith et al., 2015):

> *"Actually, we ask a lot from our visitors. We don't patronize them, it is not like we put nothing in the way. Actually, we put a lot in the way. We insist on being someone here. (…) We say "you have to show yourself", so you have to look yourself in the eyes. That is the consequence. You can only show yourself if you are willing to look at yourself. That is what we expect. So it's not like we don't ask for anything."*

Remarkably, however, all three interviewed visitors expressed their frustrations concerning other visitors' lack of engagement in these creative processes. For example, when James was asked why he thinks other visitors come to Villa Voortman, he answered the following:

> *"I think some come for the same reasons as I do, but unfortunately most visitors come here to just spend their day, drink coffee and smoke cigarettes and sit in the sofa all day."*

Also Nick, who organizes the philosophy activities, showed his disappointment when talking about other visitors' motivation:

> *"There are a few projects that involve some people, but at the moment many visitors come without doing anything, and I'd like to change that. It has decreased a bit compared to before. I tried to organize a writing workshop, but it didn't work out. They weren't interested."*

However, these frustrations are put into a different perspective by Chris, the psychologist, as he described how visitors go through transitions during their time at Villa Voortman. He stressed the importance of maintaining a good balance between the visitors' needs and strengths by fostering different expectations for each visitor, rather than applying a one-size-fits-all approach:

> *"I think we need to individualize more, particularize. And with people who are still very confused or psychotic, you just need to try to build a connection, until something comes, and only then you can expect more. […] It's the principle of 'the strongest links can bear the greatest burdens', I think. If you'd ask everyone to bear the same burden, it just wouldn't be a democracy."*

All three interviewed visitors are senior regular visitors. As a consequence, they are expected to play an active role in Villa Voortman. For them, this might seem in contrast to visitors who are not ready to be as active. Also, Hannah, a volunteer, gave a counterweight to their frustrations by pointing out that such individual differences and expectations are inherent to life outside Villa Voortman too:

> *"I don't think we necessarily need to be better than the world around us. You also have… I know quite a lot of people, especially amongst elderly, who don't do much more than have breakfast, watch some TV, read the newspaper, take a nap, have a chat with the neighbors. We aren't all*

> *as creative. But it needs to be stimulated and we need to be open to it. But on the other hand, we shouldn't judge too fast by saying things like "oh, he isn't doing anything"."*

*Becoming a visible citizen*

A second process coming to the fore when talking about Villa Voortman as *a place to be me* is becoming a 'visible' citizen in society. Certain participants explicitly talked about the visitors as a group of people who usually remain invisible in society. Chris stresses that they should help visitors in becoming visible citizens:

> *"It is very important that we don't just stay a ghetto here and an alternative psychiatric setting that works in a certain way, but that we also make a link to the outside world. […] The more interest, the more people talk about Villa Voortman, the more these vulnerable citizens get to be seen. Indeed, many of our visitors are that damaged that we cannot turn them into 'good' citizens. But inclusion should be more than just taking them out of psychiatric institutions and dropping them in a meeting place."*

In this respect, volunteer Fay explained how social relationships and feeling accepted can provide a boost for visitors to build new connections in the 'outside world':

> *"Because you welcome people here, and they feel included… Cause often it is about people who are excluded, who… From their own circles, and then from psychiatry… They get kicked out everywhere. And when they can find connection here, they start making links to the outside too. […] In a city, that is really important."*

For example, by taking part in the music activities, Amanda gradually discovered that singing provides her an outlet. She also learned that she loves to perform and started singing at the monthly 'Open Gate' events. This led to the invitation by a theatre company to perform during one of their show tours, which Amanda accepted. Consequently, she started sharing positive stories about her theatre experiences, and along this way served as an example for other visitors.

However, according to some participants such strong link to the outside world has disadvantages too. For example, volunteer Katie explained that she avoids coming to the monthly 'Open Door' afternoon, because it might undermine the feeling of safety:

> *"What I find problematic sometimes is the… The constant showing to the outside world. I think it happens too often and too much sometimes. […] The focus is on it too much. And what are the*

*disadvantages of that? The security is lost, the safety feeling, and the fact that the same people are in the spotlight and others fall by the wayside. And it brings along a lot of stress."*

## 3.4 Discussion

The aim of this study was to gain insight into an alternative community-based approach to treatment for persons with a dual diagnosis, by means of a qualitative interview study in the Belgian meeting place Villa Voortman. The results show that the meeting place is experienced as '*a place to be*' (i.e. a welcoming, safe place where visitors feel accepted), as *'the place to be'* (i.e. a second home), and as '*a place to be me*' (i.e. a place where visitors gain a new sense of identity and become visible citizens in society). These results tally quite well with a number of perspectives that have been articulated in relevant literature.

First, there are remarkable similarities between our results and the way in which the recovery paradigm has been conceptualized and operationalized in mental health care and addiction treatment. For example, in Villa Voortman major importance is attached to creating a safe and homely atmosphere. Together with the horizontal structure between all parties, this encourages open human encounters. Not only do these social relationships create a sense of belonging and connectedness, they also constitute a starting point for visitors to (re)build a positive sense of identity away from (self-)stigma. Such transitional interpersonal processes towards a new identity are seen as vital to recovery (Leamy et al., 2011; Price-Robertson, Obradovic, & Morgan, 2016). Slade (2012) argues that in order to support personal recovery processes, it is crucial to create opportunities for individuals to discover new ways to express themselves and engage in a dialogue with others: *"hope, without opportunity, dies"* (Slade, Williams, Bird, Leamy, & Le Boutillier, 2012, p.101). At Villa Voortman, this is done by offering a wide range of activities and by encouraging the visitors to use these opportunities as they wish. Interestingly, the recovery-promoting activities at Villa Voortman do not start from an explicit model as to what recovery implies for individual visitors. Through its internal dynamics the meeting place implicitly encourages personal recovery. Perhaps internal tensions in the functioning of the meeting place (e.g. disagreement about obligatory participation in activities or not; imposing more explicit rules of conduct or not), which are not always easy to bear, provide a space where individual participants are brought to the point of making a decision about, and taking responsibility for their own life.

Also, despite the fact that Villa Voortman is defined as a 'meeting place', i.e. a place where human encounters take place, its actual function is mostly defined by the visitors themselves. Visitors are given the freedom to set their own priorities and find support at the meeting place in a way that complies

with their own preferences, interests, and needs. This implies that visitors are approached as active agents who set the course for their own recovery process rather than as passive recipients of a predefined therapeutic program, which tallies with ideas in recovery literature (Davidson, Shahar, Lawless, Sells, & Tondora, 2006; Gagne et al., 2007). At the same time, different expectations are held for each visitor, according to their strengths, needs and motivation. For example, experienced visitors are expected to play a more active role and take greater responsibility within the daily practice, whilst new visitors are only expected to feel welcome, explore the meeting place and build social relationships. Such a case-by-case, particularizing approach fits well with the recovery paradigm, as recovery processes are deemed deeply personal and unique in nature (Anthony, 1993; Leamy et al., 2011). Therefore, applying a one-size-fits-all approach would not meet the needs of the visitors.

The particularizing not pre-programmed approach of Villa Voortman also tallies with Lacanian ideas on the stabilization of psychosis (Leader, 2011; Vanheule, 2011). In line with what psychologist Chris indicates, the Lacanian model suggests that to stabilize psychosis a safe haven is primordial or, as Zenoni suggests, an 'asylum' should be provided. Derived from the Greek, 'asylum' (ἄσυλον) literally means 'without the right of seizure' or 'safe from violence' (http://www.etymonline.com). In analogy with this meaning, the primary function of Villa Voortman thus is to be an inviolable place, i.e. a place of protection where visitors are allowed to 'simply be', without any further expectations (cf. *a place to be*). Another Lacanian idea permeating the practice of Villa Voortman is that clinical work is organized along the lines of an 'ethics of lack' (Zenoni, 2009). This means that a priori normative expectations formulated for help-seeking persons are kept minimal, while maximal space is created for individual expression and exploration. The focus is on the particular situation of each patient ('what do they want?') instead of focusing on a therapeutic ideal ('what do we want for them?') (Zenoni, 2009). In this context two characteristics are of key importance: (1) a distance is taken from normalizing goals that aim at 'improving', 'adapting to reality', or 'getting better', and (2) a wide range of possible activities is provided and encouraged (e.g. art, creativity, games, sports, music), such that help-seeking individuals engage in undertakings that support a stable self-experience and secure relations with others (Zenoni, 2009).

Next to supporting the individual stabilization- and recovery-oriented processes in its visitors, Villa Voortman also has a significant structural and social orientation, which adds another component to how they stimulate recovery (Harper & Speed, 2012). Indeed, several activities such as the monthly 'Open Gate' afternoons (where the local neighbors come over for coffee and cake) tally with a social approach to recovery, in which full participation and the reclaiming of valued social roles are crucial (Price-Robertson et al., 2016; Tew et al., 2011; Vandekinderen, Roets, Roose, & Van Hove, 2012). Moreover, these activities put Villa Voortman on the map as an established, visible and well-known meeting place with a positive reputation, known by many citizens of Ghent. By actively pursuing social inclusion and

full participation, the meeting place fights the 'invisibility' of its visitors in society, thus counteracting stigma and social inequality.

As already indicated, the results showed that different participants sometimes had diverging and conflicting opinions about aspects of how Villa Voortman functions. A recurrent point of tension lies in the fact that the feeling of safety is continuously subject to group dynamics and interactions. For example, the presence of certain visitors can be experienced as threatening or unfavorable by others, e.g. out of fear that they will encourage them to keep using drugs. Also, the balance between creating a safe haven and having a strong link to the outside world is often fragile. For example, not all visitors enjoy the public events organized by Villa Voortman because it might disrupt the safety of 'their home'. Also, the balance between the personal agency of the visitors and the sense of responsibility of the staff is fragile. Interestingly, these tensions are not problematized at Villa Voortman. The (apparent) contradictions between different aspects of the daily practice coexist and are not considered obstacles that need to be resolved, but issues that need to be discussed, and tensions that might guide visitors in making own choices.

Overall, the ever-changing group dynamics and particularizing approach to the individual needs of each visitor make it difficult to capture the practice of the meeting place in a set of 'active ingredients'. This is in line with conclusions in the recovery literature that state that providing standardized 'cookbook' guidelines for recovery-oriented treatment of persons with dual diagnosis is impossible: recovery processes are deeply personal in nature and take place in non-linear ways (Khoury & del Barrio, 2015; Vandekinderen et al., 2012). Instead, it is more meaningful to understand the above-mentioned key aspects (i.e. particularizing, having a focus on both the personal, social and structural aspects of recovery and allowing tensions to exist) as important outlines or 'contours' that shape the meeting place. At the same time, as Villa Voortman mainly engages with a subgroup of clients who have gone through a long treatment trajectory without lasting success, it remains vital to situate the meeting place within a broad policy context and continuum of treatment modalities. The daily practice of Villa Voortman bears witness to an active and ongoing process in which a variety of perspectives can be integrated and that is inherently characterized by dynamics, contradictions, simultaneity and complementarity (Broekaert, 2009; Broekaert, Van Hove, D'Oosterlinck, & Bayliss, 2004).

*Limitations and future directions*

A first limitation of this study lies in the fact that the three visitors that were part of the participant group can be seen as 'role models', i.e. experienced visitors who are in a further stage of their recovery process. Therefore, their experiences might not be an accurate reflection of the entire visitors

population of Villa Voortman. Second, the results of the study should be generalized with care: the research sample was small (12 actors involved in one setting), and the meeting place is embedded in specific local social, cultural and health-care related processes that we did not study. Future research is necessary to further elaborate the link between the concept of recovery and meeting places such as Villa Voortman, by means of qualitative research methods focusing on the personal meaning of recovery for persons with dual diagnosis.

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# Chapter 4

# Exploring landscapes of support: A qualitative study on the roles of inpatient settings in mental health recovery

Based on

De Ruysscher, C., Vandevelde, S., Tomlinson, P., & Vanheule, S. (Submitted). Exploring landscapes of support: A qualitative study on the roles of inpatient settings in mental health recovery.

## Abstract

Today, international mental health care increasingly focuses on creating recovery-oriented systems of support. This study aims to unravel the daily practice of an inpatient psychiatric ward that engages with persons with complex mental health needs. 17 in-depth interviews were conducted with patients and staff. Three important functions of the ward were identified in the participants' experiences. First, it functions as an *asylum*, a safe environment where patients can 'simply be'. Second, the ward is experienced as a *particularizing space*, as support is organized in an individualized way and patients are encouraged to reconnect with their own identity. Third, the ward functions as a *transitional space* towards a valuable community life, in which finding adequate housing is of central importance. The results show that inpatient forms of support tally with personal and social dimensions of recovery and fulfill important roles in recovery-oriented systems of support.

## 4.1 Introduction

Under impetus of the deinstitutionalization wave from the 1960s onwards, international mental health care has been undergoing a reform in an effort to offer more adequate and holistic support to persons with mental health needs (Kidd, McKenzie, & Virdee, 2014; Tsai & Salyers, 2010). In that reform, and especially over the last two decades, policy makers and practitioners have increasingly adopted the concept of recovery as a guiding principle, that is generally understood as a personal journey towards a meaningful community life, even with limitations caused by mental health problems (Anthony, 1993; Davidson & Roe, 2007; Farkas, 2007; Waldemar, Esbensen, Korsbek, Petersen, & Arnfred, 2018). Inclusive citizenship, feelings of connectedness and belonging, a positive social identity, meaningful activities (e.g. employment), self-determination and a sense of empowerment are considered key features of this process (Le Boutillier et al., 2015; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Tew et al., 2012). Influenced by these recovery ideas, the focus of international mental health care has shifted from a primarily medical approach to the creation of recovery-oriented systems of support that are anchored in the community and are characterized by person-centeredness and a flexible collaboration between different sectors (e.g. mental health care, addiction treatment, the forensic sector, community social work) (Farkas, 2007). In the Belgian context, for example, this shift towards recovery-oriented support has led to the reduction of beds in residential psychiatric care, a growing focus on short intervention-based treatment and the development of more support facilities in the community, such as mobile (crisis) teams and sheltered housing for persons with mental health problems (Cools, 2007).

Whilst residential treatment in psychiatric hospitals still makes up a large part of today's mental health care, the implementation and operationalization of the recovery concept has primarily and most explicitly taken place in outpatient and community settings (Waldemar, Arnfred, Petersen, & Korsbek, 2016). Many go further and believe that it is impossible to implement the principles of recovery-oriented practice in more traditional inpatient settings (Kidd et al., 2014). However, there remains a substantial group of persons with complex and long-term mental health needs for whom lengthier and more intensive admissions to psychiatric hospitals continue to be a necessary part of their recovery journey (Chen, Krupa, Lysaght, McCay, & Piat, 2013; Killaspy, 2014). Although this is a heterogeneous group, the complexity of their support needs can often be situated at the intersection of the mental health problems they face and multiple other problems such as homelessness, substance abuse, poor physical health, poverty and judicial problems, often leading to experiences of exclusion, long treatment trajectories and social isolation (Ness, Borg, & Davidson, 2014; Priester et al., 2016). As a result, the recovery processes of persons with complex mental health needs have a slow and unpredictable course

and are characterized by many ups and downs (De Ruysscher, Vandevelde, Vanderplasschen, De Maeyer, & Vanheule, 2017). Although admissions to psychiatric wards play a significant role in their recovery process, most of the scientific evidence on recovery-oriented practice has been developed in organizations that are located outside the hospital walls (e.g. community-based initiatives, outreaching support and case management) (Waldemar et al., 2018).

If we want to avoid having persons with complex mental health slipping through the net of recovery-oriented systems of support, it is crucial to understand *how* these inpatient spaces play a role in their recovery journeys. Considering the idiosyncrasy of recovery processes and the versatility of such settings, several authors have recommended the use of qualitative research approaches that are context-close, focus on micro-level recovery dynamics and are grounded in the lived experiences and perspectives of the persons who are directly involved in the practice under study (Leamy et al., 2011; Pilgrim, 2009; Stanhope & Solomon, 2008; Velpry, 2008). Therefore, the aim of this study is to gain insight into the different functions these inpatient settings have in the recovery processes of persons with complex mental health needs, by unraveling the daily practice of one ward (located in a psychiatric hospital in Belgium) that actively engages with this complex and long-term patient population.

## 4.2 Methods

*Methodological approach*

This study aims to gain insight into the daily practice of the ward by focusing on the patients' and staff members' personal experiences. Therefore, an ethnographic qualitative research approach was applied (Denzin & Lincoln, 2011). Data were collected by means of participant observations and in-depth interviews, and analyzed using thematic analysis (Clarke & Braun, 2014).

*Research location and participants*

The study was carried out in a residential ward of a large psychiatric hospital in Flanders (the Dutch-speaking part of Belgium), that offers support to a diverse group of patients with serious and more chronic mental health problems, who have often lost connection with other treatment settings. Besides mental health problems, many patients on the ward deal with substance use problems, a lack of social network, financial and judicial problems, and housing problems (more than 50% of patients on the ward are homeless). Rather than focusing on treatment, the ward aims to support patients in their recovery process towards a meaningful life in society. Considering the heterogeneity of the patient group, the

ward offers several support modalities that are used in an individualized way, depending on the personal needs and situation of each patient. The largest part of the ward consists of a residential unit with 27 beds. Additionally, the ward runs a housing project (attached to the hospital) in which six patients live together more independently (for a period of maximum one year) after a stay on the residential unit, in preparation of living alone. Besides residential support, the ward also offers aftercare for patients when they leave the ward and outreach case management for patients who find it difficult to engage with a residential treatment approach.

To obtain rich and triangulated perspectives on the daily practice of the ward, both patients (10) and staff members (10) were recruited as participants for in-depth interviews. Patients were deliberately selected based on their treatment history, length of stay on the ward and the way in which they make use of the ward (e.g. residential unit, housing project, case management). The patient participant group consisted of seven men and three women, aged between 23 and 59. At the time of the interviews, two patients were staying at the housing project, six patients were staying at the residential unit (two of which were interviewed together) and two patients visited the ward a few times per week for aftercare. In the recruitment of the staff members, we aimed at obtaining a wide diversity of professional backgrounds. The group of participating staff member consisted of a psychiatrist, two psychologists, a social worker, two psychiatric nurses, a caregiver and three occupational therapists (who were interviewed as a trio). All 20 participants were considered to be suitable informants, based on their lived or professional experience with the ward.

*Data collection and analysis*

To prepare for the interviewing phase, the first author did an internship on the ward from April to June 2018. During this internship, she enrolled in the staff shift system, took part in therapeutic group activities (such as the daily morning meeting), staff meetings and individual activities with patients, and engaged in many informal conversations with both staff and patients. In doing so, she gained a better understanding of the daily practice and became familiar with the staff and patients on the ward. Towards the end of the internship, the first author personally invited patients and staff members to take part in an in-depth interview focusing on their personal perspectives on the daily practice of the ward. A total of 17 interviews was conducted (some participants preferred to be interviewed as a duo or a trio). During the interviews, participants were asked about important values and activities on the ward; about the function(s) the ward fulfills in patients' lives and society; and about social dynamics on the ward. Interviews lasted between 28 and 68 minutes, were audio-recorded and transcribed verbatim by the first author.

In the analysis phase, the first author conducted an idiographic analysis of each interview by reading the transcript multiple times, writing down descriptive and interpretive comments, and drawing a mind map of emerging (dynamics between) themes. After this initial analysis of each interview, mind maps were gradually combined to gain insight into overarching themes and into the ways they interrelate, complement or are in tension with each other. In the first step of this integration phase, the first author selected five key interviews based on their thematic richness and the diversity of perspectives. These interviews were independently analyzed by all co-authors and integrated into one mind map, which was extensively discussed. Based on this discussion, the first author completed the entire analysis, which resulted in an overall thematic structure. In turn, this structure was discussed again in a meeting with all co-authors. Through this iterative process, the authors aimed to increase the inter-rater reliability and to deal with the subjective nature of the analysis.

Although this article is written from a social science (rather than a medical) perspective, we will continue to use the term 'patient' (rather than 'client' or 'service user'), as this terminology was used by the participants during the study.

*Ethical considerations*

This study was granted ethical approval by the Ethics Committee of Ghent University Hospital (EC UZG 2016/0530). Written informed consents were obtained from all participants.

## 4.3 Results

The aim of this study is to unravel the different roles the ward plays in the recovery processes of its patients. In that respect, three main functions come to the fore in the experiences of the participants. In the first place, the ward fulfills the function of an *asylum*, i.e. a safe environment where patients feel sheltered, allowing them to catch a breath and 'simply be'. Within this safe environment, the patients' psychiatric diagnosis does not determine their therapeutic trajectory. Instead, through offering an individualized and tailor-made approach, patients are actively encouraged to take (back) agency over their recovery process and to (re)connect with their personal identity. From this follows the second function of the ward: that of a *particularizing space*. Importantly, the focus of this individualized approach is always on finding and creating anchor points in the community, rather than on functioning within the safe shelter of the ward. This leads to the ward's third function: that of a *transitional space* towards a valuable life in the community. Providing as much continuity between life outside and inside the ward as possible, and searching for adequate housing are key elements of this function.

### *4.3.1 The ward as an asylum*

All interviewed patients talked about how they see the ward as a safe haven. In the experiences of the participants, three aspects of this asylum function were distinguished: feeling safe, feeling 'at home', and the ward as a safety net. In what follows, these will be discussed in detail.

*Feeling safe*

Most patients arrive at the ward after a turbulent period of being homeless, spending time in prison, facing difficulties living alone (e.g. social isolation, mental health problems, substance use) or after a long trajectory in other (more treatment-focused) psychiatric settings. For many of them, a primary function of the ward is that of a safe haven and a place to catch a breath. In the first place, the fact that a number of basic needs, such as having access to food, a bed, laundry facilities and a daily structure, are met during their stay is of fundamental importance, as these things are often not self-evident in the patients' lives. At the same time, patients are not pressured into taking part in a strict therapeutic program. As a result, they feel like they are given comfort, time and space to rest and recover from the turbulent period they went through. Because everything is voluntary, patients themselves are in control of the pace of their stay, which adds to their feeling of safety:

> *"It is important for me that when I feel down or sleepy, that I can take a rest here and that nobody is shaking my bed. Sometimes they check on me, but that I shouldn't feel embarrassed when I really have an off-day. That I can be myself in that too. And when I reconnect, there is always something to do here."* (patient)

In addition, for some patients, the constant presence and close proximity of the staff on the ward is another invaluable condition to be able to feel safe and at ease:

> *"At home I always sit inside, me, at home. But here I go for a walk every now and then. (…) Here I find more peace than at home, I must admit. There are nurses day and night, that reassures me. In sheltered housing, if I don't feel well after four pm, nobody's there. But here I can count on a nurse. That reassures me… Not to go to them, but that I just know in the back of my mind that there are nurses here, you get it?"* (patient)

In other words, the proximity of the staff and the presence of all basic services provides patients with a sense of security. At the same time, however, using the ward as a safe haven also brings the risk for patients getting so accustomed to these comfortable circumstances that they become less inclined to pick up their lives outside the ward, where the fulfillment of basic needs such as having food and shelter are less self-evident. This risk is also pointed out by one of the patients:

> *"You feel safe. You have food every day. In the beginning that is good, because you feel bad. But after a while you feel like 'oh, I'd like to cook for myself again'. Or 'how on earth am I going to do this again at home, making food again?'"* (aftercare patient)

*Feeling 'at home'*

Some patients on the ward have been living at the psychiatric hospital for more than ten years. These long-term admissions flow from an outdated institutional reasoning that for some patients, life outside the hospital is too challenging and that the hospital can function as their life-long safe haven. Having lost contact with their social network and social roles outside the hospital, these patients experience the ward as their home. However, this is an unintended function, as the ward primarily aims to help patients find a meaningful place outside the hospital. This shows how the ward's current shift from an institutional logic to a more recovery-oriented logic confronts these long-stay patients with a new set of expectations (i.e. focusing on a life outside the hospital rather than feeling 'at home' inside). In that respect, one of the psychologists explains how challenging it can be to create a perspective on a life outside with this group of long-stay patients:

> *"There are people who've lived here for more than ten years. We shouldn't really use the word 'live', but who are here for ten years. In such cases it is difficult to say that people don't feel at home here. People do. At the same time, in the same sentence, we need to add that we should also keep trying to also give those people some kind of perspective outside the walls of the psychiatric center. And it is possible. (…) But it has to be a perspective that is acceptable to them and in which they feel that they have some ownership, some choice."* (psychologist)

According to the ward's psychiatrist, however, it can be particularly difficult to bring out this agency and sense of ownership in patients who have been at the ward for years, as they have grown so accustomed to life inside the hospital that they can no longer imagine feeling at home anywhere else. She refers to this danger as the 'hospitalization syndrome':

> *"A lot has changed here over the past five to ten years. People were used to the idea that they could live here. They were even told by the staff that they could stay here for the rest of their lives. And often it is the people themselves who show a lot of resistance, who say 'I don't want it at all. You guys with your recovery, leave me be'. (…) But you just know they can't imagine how it is like to make yourself a cup of coffee when you wish, or to have your own room. They just don't remember what it is like to have privacy and to… So actually they need to experience it first hand before they… Before they can let go of a place like this and move on to a more uncertain… So sometimes, it doesn't work out."* (psychiatrist)

The ward aims to counteract the effects of this syndrome and to keep a perspective on the outside world alive, by actively encouraging patients to find activities in the community, help them (re)build a social network and support them in finding adequate housing. However, dispirited by long and often unsuccessful previous treatment trajectories, some patients consider these efforts pointless. One of the patients explained how he finds the asylum function of the ward the most important at this stage in his life:

> *"For some people it should be comfortable. I am not saying that for people who just start their career, to say it like that, who have their first admissions, it should be like that. But for people who have been through a lot, you shouldn't make too much effort. Leave people be, and give something, a place where people can feel good. That's all it should be."* (patient)

*The ward as a pit stop*

After discharge, most patients return to the ward on a regular basis for a few months, as aftercare. For most patients this means spending one or two days a week at the ward, taking part in activities and seeing the psychologist. Other (ex-)patients continue to use the ward more intensively by returning regularly for shorter admissions (e.g. one or two weeks). Talking about how she found balance in her life after having spent long periods in the psychiatric hospital over the past 24 years, one of the aftercare patients explains the importance of these short returns to the ward:

> *"I think I'm happy with the balance that I've found. The aftercare, I come here for a few hours and I go again. And actually, yes, even when I'm admitted for a few days, it calms me down, and yeah… If it would be up to me, I'd prefer to keep it like that. (…) The periods that I spend a little while here, I have to let go of everything. My volunteering job, my household. (…) It's a few days of not thinking of anything and just being here and doing things that I love doing, which I don't have time for at home."* (aftercare patient)

In this way, the asylum function of the ward carries on after discharge, as it remains a pit stop for ex-patients after they have left. Although the aftercare phase is an essential part of the therapeutic trajectory, its aim is to be as short as possible, as ex-patients increasingly find more meaningful activities in their community. However, this is in contrast with the way some external partners 'make use' of this aftercare program. For example, for sheltered housing organizations, having structural daytime activities (e.g. a paid job, volunteering, a hobby) is a prerequisite to get a place at a housing unit. When (ex-)patients have not found such activities yet, the aftercare program is often considered as a 'good enough' structural daytime activity by these organizations. Consequently, (ex-)patients are under pressure to keep coming to the ward instead of engaging in other more meaningful activities in the

community. In other words, the logic of these organizations sometimes contradicts the ward's recovery-oriented way of working, as one of the psychologists explains:

> *"Something that we often encounter nowadays, is that organizations of sheltered housing, but also judicial persons, put a lot of emphasis on having daily activities and structural daytime activities… People don't always have those sorted when they leave here, so then they [those organizations] almost use us to fulfill that role. (…) I don't know if you've noticed, but there aren't many people who enjoy coming here as aftercare. Actually, they just want to leave."* (psychologist)

To counteract these dynamics, the ward actively provides support and coaching to both professional (e.g. mobile teams, estate agents, judicial partners, social housing organizations) and informal (e.g. family, neighbors) partners that are part of the support networks of their patients. In that sense, the ward fulfills a function as a pit stop not only for its patients, but also for these organizations and partners. One of the staff members describes how providing such a safety net opens up new spaces for external partners to engage with (ex-)patients, as they have the insurance that the ward will stand beside them and guarantee adequate support in crisis situations:

> *"What I am often confronted with… When you try something with someone, that you almost guarantee that, if it would go wrong for the client, that you offer the service that partners aren't left alone with it. So that you become a safety net, of giving information in consultation with the client, or that that person can come back to us for a while. Also, that we fulfill a coaching function. Often, partners have many questions, but are also looking for reassurance: okay, we want to work with that patient, but what if it goes wrong? Instead of leaving that person to his fate, he can come back to you? (...) And I notice, if you can offer that guarantee, people dare to take more space to try something."* (caregiver)

### *4.3.2 The ward as a particularizing space*

The asylum function of the ward creates a safe climate, in which it becomes possible to offer support in a tailor-made and individualized way. In that respect, the patient's therapeutic trajectory is subject to a continuous process of negotiation between patient and staff. Through such a particularizing approach, space is created for patients to (re)connect with their personal identity and aspirations. In this section, these aspects will be elaborated.

*A tailor-made approach*

The patient population at the ward is characterized by a large diversity in terms of mental health problems, biography and the shape their recovery process takes. Consequently, all patients have different motives for spending time at the ward, as one psychiatric nurse describes:

> *"For example, Tom finds it really annoying to be here, it is like a love-hate relationship. He is polite and he knows he sometimes needs it, but he is… Yeah, at the same time he hates it, being here. He finds it awful. Then… Do you know Leanne? (…) A very compulsive neurotic woman who also has psychotic outbursts every now and then. She lives alone, but has spent a long time here, and sometimes asks for a (short) admission. She can clearly define that for herself, 'I will stay here this long and then I can carry on again'. (…) And I think we have a bit of everything in between [these extremes], a bit between Tom and Leanne."* (psychiatric nurse)

Given the great heterogeneity in the motives and support needs of the patients, it would be inadequate to provide a one-size-fits-all therapeutic group program. Instead, the ward aims to give shape to an approach that is tailored to the recovery process of each patient. Rather than starting from a predefined therapeutic program that comes with a set of expectations ('what do we want from the patient?'), patients are encouraged to formulate what they expect from their admission and how it can support their recovery process. In doing so, they are actively invited to give meaning to their stay on the ward themselves, thus take (back) agency over their lives:

> *"Here, everything is very open. A lot more like, yeah… You (the patient) tell us what to do. And that's what we work with. We are not going to tell you here how you should do it, but you have to do it for yourself."* (occupational therapist)

> *"Having a low threshold. Not setting too many conditions for someone to come to the ward. (…) Actually, you put forward that the aim is to travel a road that is very individual. (…) What does one expect? And that is very individual… Different expectations. What does one expect of one's future? How does one picture that? What does one need? And we try to anticipate that. (…) But we try to do it in a very individual way, because it should always fit like a key in a lock."* (psychologist)

This particularizing approach is also reflected in the ward's policy regarding substance use. Although using alcohol or drugs on the ward is not allowed, there is also no zero-tolerance policy. Instead, an individual approach is outlined for each patient, that corresponds to that patient's personal needs and wishes. In other words, in the ward's vision on recovery, abstinence is not put forward as a fundamental

precondition. One of the psychologists explains how such an individual approach can possibly take shape:

> *"If someone says 'I want to use cocaine weekly for the rest of my life, but I can do it in a limited way and I can do it once a week on Saturday night at a friend's house', then we won't… As long as his cocaine use doesn't stand in the way of his trajectory towards outside… If he has enough money to rent a house or something else, then we won't make a problem of it. (…) But imagine that the same man says 'I want to live in sheltered housing, anything else isn't possible for me', then we will make a problem of it, because no sheltered housing unit will allow [people who are not abstinent]."* (psychologist)

In other words, the ward's substance use policy is attuned to the recovery process of each patient, as it is the result of a negotiation between staff and the patient. Consequently, patients gain a sense of ownership over these rules. For example, one patient explains how he is not allowed to use drugs during his admission period, because of the legal conditions that were imposed on him after he left prison. Although he knows some other patients can get away with using drugs during their stay, he does not have a problem with the nuances in the reactions of the staff depending on the patient involved:

> *"They approach everybody individually here. And I think that they know of some people that they drink something every now and then, or smoke a joint, and that they turn a blind eye. Well, that's what I think. And they can't do that for me, because it is not allowed. If they know that I drink, they are legally obliged to pass it on. If they know that I smoke a joint, they are legally obliged to make me pee or so, you know. So for me, it is different."* (patient)

*Reconnecting with one's identity*

In their daily lives, patients are often confronted with stigmatizing experiences in which their identity is narrowed down to their psychiatric label or their status as a homeless person. Facilitated by the individualized approach of the ward, however, patients are not reduced to their psychiatric diagnosis but are rather seen as individuals with unique aspirations and vulnerabilities. One of the psychologists explains how the staff on the ward actively tries to oppose a narrow interpretation of the patients' identities:

> *"Definitely when you're homeless, you don't have many friends or acquaintances, you don't own things. And then you're put into a system where the only thing that is left of your identity is that you are a patient. And that can… work in a paralyzing way, depressing way, make you apathetic*

> *if you stay in it. So it is an art to listen… like what do you identify yourself with that might be snowed under by your patient identity?"* (psychologist)

By actively engaging in dialogue with patients about their personal interests and social roles, a new dynamic is created in which they are challenged to (re)connect with and show these aspects of their identity, thus shifting their 'illness identity' to the sideline. Consequently, patients are not approached as passive recipients of a certain treatment but rather as active agents of their own (personal and social) recovery process. In this respect, one of the patients points out how this activating approach caused a shift in his mindset regarding his own recovery process:

> *"There (at another ward) I had the impression that they had a prejudice or an image that something was wrong with me, that I had symptoms, those moments of illness or when it became acute… Something that had something to do with my mental problems. And that it is disabling. And here, indeed, it is more… I grow conscious of the fact that it is just… That it is about functioning… How can I function outside the admission?"* (patient)

This shows how, through widening the lens on their identity, patients are no longer seen (and see themselves) as fundamentally different, i.e. as mentally ill persons who need to recover clinically. Rather, they are approached as individuals who try to give meaning to their lives in fundamentally similar (personal and social) ways to most people. This is reflected, for example, in the experiences of one of the patients who stresses the importance of being able to fulfill valuable social roles in the community:

> *"First I need to find some day activities. Maybe a volunteering job, then that would also be fine. But I am going to work so that I can find my own apartment, my own job. I just want to get away, I want to get back into the system, work every day so I have money in my pocket. So that people look at me respectfully because I work. And that's all I want to have. I am just gonna go for it."* (patient who stays at the housing unit)

In its daily practice, the ward strives to support patients in establishing a personal and social identity. As this support is powered by the patients' own interests and aspirations, it can take on many forms, such as searching for meaningful activities in the community, restoring contact with family, finding a place to live, helping applying for volunteering/paid work, developing an interest or skill, and so on. Paradoxically, helping patients (re)connect with their personal identity is at times hindered by factors that are characteristic of the culture of the psychiatric hospital itself. For example, the psychiatric hospital has to comply with legislation in which a set of rules and regulations regarding the hygienic and safety standards of the provided care is specified. However, one of the psychologists gives a list of illustrations of how these imposed rules can stand in the way of a more tailor-made and identity-focused approach to support:

> *"Often it is about really practical things, such as… letting patients decide about certain things. It is about food, about TV, about… (…) You can't let family stay over, because of the fact they're all hospital beds. People who have a pet, who need to find shelter for it because it is a hospital. But also really small stuff… Having a piano on the ward, because of fire safety. Such things. Having your own key to your room. I could spend a whole day listing these things."* (psychologist)

Also at the level of the ward itself, different factors (e.g. the large patient population, the absence of a mandatory treatment program, the large amount of meetings, having an individualized rather than a group-oriented approach) can at times make the atmosphere on the ward hectic, even chaotic, leading to more superficial and fragmented conversations between staff and patients and leaving less room for quality interactions such as one-to-one trips outside the hospital.

*A continuous (re)negotiation*

An important implication of offering an individualized approach to support on the ward is that patients do not follow a pre-structured, one-size-fits-all therapeutic group program. As patients are encouraged to take agency over their own recovery process, support takes the shape of a continuous (re)negotiation, both between the staff and each patient and between the staff members themselves. Consequently, the therapeutic trajectories that patients travel during their stay often take a less straightforward, less predictable course. One of the psychiatric nurses explains how this requires a particular attitude from the staff, that is different from other more traditional inpatient settings:

> *"I have worked at a ward with more rules, and that is very comfortable but also quite blunting, because you… You are just a representative of rules that you can hide behind. And here, that is way less the case. It is a tiring reflex to continuously find the particular… In consultation with the patient or with each other, to get to a logical plan of action. It is more intensive, but I believe in it. (…) At the same time I hope it is that vision, that you can't simply summarize people or practices into something that is easy to capture. It is all very difficult to capture and that takes time and communication and re-inventing."* (psychiatric nurse)

In such a process of negotiation, staff members take the position of travel companion rather than guide in the recovery journey of the patients, as one caregiver explains:

> *"That's recovery. That you never say to someone… In the beginning, 'this is not going to work'. But that you stumble over the same things together and that you keep standing beside that person and that you try something different, something that person can identify him/herself with."* (caregiver)

In doing so, patients are given as much ownership as possible over their own trajectory, but this can also bring new difficulties. One staff member explains how she finds it difficult to take the position of travel companion when the direction the patient chooses is, in her opinion, not realistic:

> *"But what I personally find difficult sometimes, is when you have the feeling that what someone wants is very unrealistic. (…) But that is also part of the job of course. (…) From that perspective I can frame it and I know it is linked to recovery, with ups and downs, and that people have to learn to discover things for themselves. Or rather, that we need to let them discover."* (social worker)

In other words, offering particularizing support is time-intensive and requires space for trying different things, starting over and thinking outside the box of traditional options. However, in the daily practice of the ward, precisely this improvisational space is continuously under pressure from macro-level (e.g. government, hospital) policy decisions regarding personnel and finances. For example, to meet the patients' individual needs, the ward offers a wide range of support modalities (e.g. case management, outreaching support, a housing project), which is a very challenging task compared to the financial resources of the ward. Also, during weekends the ward is only staffed by one or two people. One of the psychiatric nurses expresses how he finds it frustrating to work at weekends, when the ward can only fulfill its asylum function because of staff shortage:

> *"When you are alone here, you are like a walking key who just keeps things going a bit. Then you can't really speak of rehabilitation. Then it is just a hospital here, with… with people who… The only people who are here then, are the ones who are bored, who don't have much outside, who aren't always feeling very well. Then I rarely go home happy."* (psychiatric nurse)

This example illustrates how the economic logic of the hospital (i.e. the financing and allocation of personnel) can sometimes be in conflict with the particularizing vision of the ward.

### *4.3.3 The ward as a transitional space*

The third function of the ward that can be distinguished in the experiences of the participants is that of a place of transition towards a meaningful community life. When discussing this function, two themes come to the fore: minimizing disruptions between life inside and outside the ward, and finding adequate housing.

*Continuity between inside and outside*

Many patients on the ward have experienced previous admissions as major disruptions to their everyday life. The ward aims to avoid such disruptions, by striving for a seamless continuity between life 'inside' (i.e. spending time on the ward) and 'outside' (i.e. having a valuable community life), both by bringing in the outside world (e.g. by talking about it) and by actively supporting patients in finding a meaningful place in the community (e.g. by searching for a place to live, restoring contact with family, searching for hobbies). Considering the heterogeneity of the patient population, the psychiatrist describes how challenging it can be to work towards a life outside with/for the patients on their ward:

> *"Here, we really need to work hard towards outside. (…) Because actually you still need to create the outside. You still have to register them on a waiting list for sheltered living or the social housing company. And sometimes the work will never be finished, because they will never make it outside. Or working outside means installing the idea of outside, that there is something else besides the ward."* (psychiatrist)

Although periods of admission are inevitable for many patients on the ward, one of the psychologists points out how the psychiatric institution in itself has an alienating effect on their everyday lives. More precisely, he warns for the risk of installing a false dichotomy of the ward as a safe shell versus the outside world as threatening. From that perspective, he argues that a continuous focus on the outside world in the ward's daily practice, no matter how challenging, offers an indispensable counterbalance for this alienating effect and a vital complement to the asylum function of the ward:

> *"It always surprises me when people are told "you're safe here, outside it is dangerous". (…) To say it in psychoanalytic terms, you're working in a very dual way, I find. (…) It has the consequence that something binds you to the other and the other to you, making it hard for him [the patient] to leave. So it comes down to saying "you are here and I am here and outside we might find some people who could be interesting and reliable, I don't know". (…) It is by talking about the other that you install a third point."* (psychologist)

Another essential facilitator of this continuity between life inside and outside the ward is to install a non-controlling climate, in which patients are not punished for their setbacks or mistakes but remain welcome on the ward and are encouraged time and time again to pick up the thread of their lives. Talking about this, one of the caregivers stresses the importance of applying a long-term vision to the recovery trajectories of the patients they work with, to prevent bridges being burnt (e.g. by excluding them from the ward):

> *"We work with long trajectories. To continuously try again. For example, someone who's having a hard time on the ward, to give him a break, such as asking for a time-out, but to then… always give him or her the chance to return if that person wants to. At the moment, I don't think that is the case on other wards. (…) And I notice that people find it easier to return to us too. That it is an interruption, but not a stepping out of the trajectory. I think there's a big difference."* (caregiver)

This climate also becomes visible in the fact that patients are given as much freedom as possible by not obliging them to take part in the available therapeutic activities (e.g. cooking therapy, creative therapy, music therapy, sports activities). As a result, they are more inclined to engage in meaningful activities outside the ward. For example, one of the patients explains how the fact that no obligated therapeutic program is imposed on him motivates him to work on his living conditions outside the ward:

> *"I like it here, that the activities are not mandatory. If they would be mandatory, yeah, then I'd… I'd take part in them, but there wouldn't be much benefit for me. (…) Actually, now I mainly need to do things outside the clinic, like cleaning up my apartment and stuff. Yeah, and if I can do sports here, or reading together or… Then that is nice, but I mean, in the first place I need to do some things outside if I want to feel better."* (patient)

The above experiences clearly show how the ward's mission to provide continuity between being admitted and living in the community also entails a shift in the job description of the staff working on the ward, from a traditional institutional approach towards a more community-oriented way of working. This shift is formalized in the job description of certain staff members. For example, three staff members practice the function of 'road builders' ('*spoorleggers*' in Dutch) and actively search and create spaces (e.g. libraries, sports centers, voluntary/paid jobs, cultural events) in the community that welcome people with mental health problems. In doing so, they actively pave the way (hence the name 'road builders') for the patients on the ward. In that sense, their primary function is that of 'quarter making' ('*kwartiermaken*' in Dutch), i.e. actively creating hospitable niches in society for people with mental health problems, who are often confronted with exclusion and stigma (Kal, 2012). Another group of staff members work as case managers for patients who have difficulty engaging in the ward's residential unit for a long period of time, and continuously move in and out of the ward. As a result, not only in the patients' experiences, but also for the staff, the boundaries between inside and outside become more blurred and porous:

> *"There is some sport, and music therapy and stuff, but most of the therapists are already looking towards the outside, or even the other way around. They are sitting outside and looking in and*

> *asking people 'do you wanna come? There is an event in the library, we are helping with that, do you want to help too?' That vibe. Yeah, that's something I believe in strongly."* (psychiatric nurse)

*Housing first*

Housing came to the fore as a prominent theme in all interviews. Since the majority of the patients on the ward are or become homeless during their admission, finding adequate housing forms an essential part of the patient's transition process towards a meaningful community life. For example, one patient expressed how, for him, finding a place to live in which he can feel safe and at ease is a primary need:

> *(interviewer) "When will you be ready to leave the ward, do you think?" (patient) "That is related to finding alternative ways of living that for me… So somehow I expect a search to find another place I believe in. (…) If I get discharged whilst I don't believe there is a connection, I will go back into crisis. Period. This is no emotional blackmailing, that's just how it goes. Then I go into destruction."* (patient)

Although searching for adequate housing is a key function of the ward, the rhythm of this search is largely determined by external organizations and factors. For example, social housing companies, organizations for sheltered living and psychiatric nursing homes often have long waiting lists. Also, in some cases, it is not the patient but a judicial actor who decides if and when one is capable of living independently. Another factor that often impedes the search for appropriate housing, especially on the regular housing market, is the stigma that many patients have to face on a daily basis. One of the psychiatric nurses gives a striking example of the impact of this stigma, as he talks about the frequent but unsuccessful attempts he has made together with a patient to find an apartment to rent:

> *"I think we do miss opportunities sometimes, but… I can also see why. Jimmy (one of the patients) is my referee. I find it difficult to keep it going with him. Sometimes we go look at a house, and then he makes a bit of a strange impression. Maybe this will stick to the estate agent, and then we are back at… I would like to spend an entire day convincing landlords that actually, Jimmy is the perfect tenant. (…) He's on benefits, that is pretty stable, I mean, that will keep going… And he is clean, he is very predictable. He is supported by us in case something goes wrong. So actually he is a catch, but I'd like to see that happen."* (psychiatric nurse)

As a result of these external factors, patients and staff do not have control over the search for adequate housing, which has implications for the daily practice of the ward. According to one of the psychologists, the rhythm of the (regular/social/care) housing market is predominant in such a way that it makes it impossible to see the ward as a space where patients 'are being prepared' for a more independent life

in the community. Instead, both staff and patients need to respond *ad hoc* to housing opportunities when they present themselves:

> *"Deciding whether someone is ready, is something we actually never do. It depends on what is available at that moment. Because there always is a long waiting time between the admission and finding a place where one can live, individually or sheltered. (…) Often, when a situation presents itself and the patient agrees, then we try to look which supportive framework we need to install, so that it might succeed. Does that mean that people are ready or not? Actually that is a question we never ask ourselves."* (psychologist)

As a consequence of the fickle rhythm of the housing market, patients are more often discharged from the ward based on the availability of a housing spot than based on their 'readiness' to go. Although the staff always attempts to build a supportive network to make the move to the new living situation as smooth as possible, it does not always end successfully. Some patients need to return to the ward several times and make repeated attempts at living independently before finally succeeding in finding a stable place in the community. For other patients, the ward has become more of a 'waiting room', as it can take a long time until a housing spot is available:

> *(patient) "Our problems are solved, so actually we could go, but yeah… We can't go because we don't have that one thing." (interviewer) Because you don't have a roof over your head? (patient) "Yeah."*

## 4.4 Discussion

This study aimed to gain insight into the different functions that inpatient psychiatric settings have in the recovery processes of persons with complex mental health needs. We investigated this by unraveling the daily practice of one ward that actively engages with this population. The results showed how the ward's daily practice takes shape in the continuous dialectic between the inside and the outside world, in the tension between different (e.g. economic, therapeutic) dynamics, and in the – at times dissonant – harmonies between the rhythms of different actors involved (e.g. patient, ward, hospital, society). Within this entanglement, three functions of the ward could be distinguished: the ward as an *asylum* (i.e. a safe haven where patients are given time and space to 'simply be'), the ward as a *particularizing space* (i.e. a place to reconnect with one's identity and aspirations), and the ward as a *transitional space* (i.e. a place to work towards a meaningful community life).

Several aspects of these functions tally well with the personal, social and relational ways in which recovery is conceptualized in the literature (Leamy et al., 2011; Tew et al., 2012). First, by applying a tailor-made approach to support in which patients are encouraged to explicate their expectations regarding their stay, the ward manages to connect with and provide an answer to the nonlinearity and idiosyncrasy of the patients' recovery journeys (Deegan, 1988). Importantly, in this particularizing approach, personal recovery is not considered a solely intrapersonal process of gaining a sense of self-direction, developing resilience and independence, feeling hopeful about the future and establishing a sense of identity. Instead, at the ward, support takes the shape of a continuous negotiation in which both staff and patients stand side by side in searching for the most adequate response to the patient's needs and wishes. This shows how recovery is above all a relational process that comes about in the interdependence between an individual, his/her social context and relationships (e.g. professional actors, personal and social network) (Price-Robertson, Obradovic, & Morgan, 2017; Tew et al., 2012). Additionally, the ward aims to keep this interdependence intact by minimizing disruptions between life inside and outside the hospital, and by developing a tolerant climate in which patients are not obliged to follow a set therapeutic program (allowing them to spend time outside the ward) and are not punished for setbacks (that can often be related to the fickle nature of their recovery). However, due to experiences of stigma and exclusion, these positive social contexts and relationships are often limited or even lacking in the lives of persons with complex mental health needs (Drake et al., 2001). To fill this void, the ward considers it one of its core tasks to actively create enabling environments in the community for its patients, operationalized through the work of the 'road builders'. Described by Kal (2012) as *quarter making* (translated from the Dutch '*kwartiermaken*'), their work does not take place within the ward, but explicitly aims to open up welcoming spaces in society in which patients can participate and belong as inclusive citizens. In other words, our findings show how, in the daily practice of the ward, interdependence and connectedness are the driving forces that power other processes of installing hope, establishing a sense of identity, finding meaning in life and empowerment (Leamy et al., 2011). Related to the above reflections, Quirk et al. (2006) refer to the concept of institutional *permeability* to describe the extent to which psychiatric (inpatient) settings are interacting with the outside world. The findings of our study show that the ward's high degree of permeability is an indispensable facilitator in the patients' recovery journeys.

Whilst the daily practice of the ward shows a lot of common ground with the recovery framework, it also remains interwoven with the more traditional institutional culture of the hospital in which it is located. In that respect, two critical side notes need to be made. First, under impulse of Goffman's *Asylums* (1961) and the subsequent deinstitutionalization wave, the image of psychiatry as totalitarian and hermetically sealed institutions was gradually rejected and replaced by a focus on community-

oriented support (Quirk, Lelliott, & Seale, 2006). However, the negative connotation of these outdated institutions as asylums should not be confused with the basic asylum function of psychiatry, i.e. *"the provision of safety and security for individual patients needing refuge"* (Bachrach, 1984, p. 976). In our study, the importance of this asylum function clearly came to the fore: patients experience the ward as an inviolable place, both in terms of space (cf. *feeling safe*) and time (cf. *the ward as a pit stop*), where they find rest and feel contained. However, in today's recovery-oriented and community-based mental health care policy, in which the focus lies on supporting people with mental health problems to live independently in the community, the provision of this asylum function risks being overlooked or even ignored (Chow, Ajaz, & Priebe, 2018).

Second, although the ward aims to help patients gain perspective on a meaningful life in the community, the results also showed that it can be particularly challenging to do so with patients who have lived at the ward for many years, as they experience the hospital as their home. One participant attributes this difficulty to the fact that these patients suffer from the *"hospitalization syndrome"*, i.e. the inability to imagine a life outside the hospital walls. Alternatively, however, this (apparent) lack of imagination could also be explained as a side-effect of the ward's former institutional vision that some patients should be given life-long protection from a threatening outside world. Today, the ward has shifted to a recovery-oriented vision in which patients are seen as active agents of their lives and are encouraged to (re)connect with social roles and aspirations outside the hospital. A potential danger of this activating and individualized approach is that difficulties in orienting patients towards a valuable community life are translated as a matter of reluctance or inability on the patients' side, e.g. by saying that they suffer from a *"hospitalization syndrome"*, rather than considered the shared responsibility of different parties (e.g. hospital, patients, actors in the community). In other words, when the psychiatric institute represses its own historical evolution, it risks slipping into a neoliberal mindset in which patients are exclusively seen as individuals, self-managing and self-responsible for the success or failure of their therapeutic trajectory (Vandekinderen, Roets, Roose, & Van Hove, 2012; Vandekinderen, Roets, & Van Hove, 2014).

*Future directions*

Up until today, research into recovery-oriented practice has largely focused on outpatient and community-based initiatives (Kidd et al., 2014). Although our study is atypical in this respect, as it focuses on a residential psychiatric ward, it illustrates how inpatient settings play valuable roles in the recovery processes of persons with complex mental health needs. Remarkably, our study shows striking similarities with the results of another study that focused on the daily practice of an alternative

community-based meeting place. Whilst this setting can be situated at the other end of the mental health care continuum to an inpatient ward, it engages with a similar group of persons with complex mental health needs (De Ruysscher, Vanheule, & Vandevelde, 2017; Vandevelde et al., 2015). Like the inpatient ward, the meeting place is experienced as a safe haven where visitors (as clients are called) feel welcome and accepted. This is done by having a horizontal structure and by organizing activities on a voluntary basis (e.g. visitors can come and go as they wish). In that respect, the meeting place functions as *a place to be*, or even as *the* place to be, as visitors experience the place as their 'second home'. These characteristics tally well with the asylum function of the ward in the current study, in which aspects such as feeling safe and feeling 'at home' also stand out. Besides a safe haven, the meeting place also functions a lively hub in which all kinds of (artistic, creative, sports) activities are organized, all rooted in the personal interests of the visitors. Through these activities, visitors are encouraged to find a medium to engage in dialogue with others and to establish a personal sense of identity (e.g. artist, musician, cook, yogi) that moves away from other stigmatizing identities. Because these activities often take place in the community (especially through the performing arts), they help visitors become 'visible' citizens in society. In that sense, the meeting place functions as *a place to be me*. In this function, several commonalities can be found with the ward as a *particularizing* and *transitional space*, such as the function of 'quarter making' (cf. supra), the focus on inclusive citizenship and the importance of creating space for patients to (re)connect with their identity (e.g. by not having an obligatory set of activities).

Despite their diverse contexts, the similarities between these studies show how recovery-oriented support is not the exclusive terrain of community-oriented initiatives. Moreover, the daily practice of the ward also shows that a recovery-oriented approach is not irreconcilable with an institutional approach to support. It is precisely in the entanglement of different approaches and in the complementarity and diversity of different support settings that persons with complex mental health needs find the resources for their recovery. Therefore, we propose to think about recovery-oriented systems of support in terms of differentiated landscapes in which persons with mental health needs can circulate between different enabling places, tailored to the ebb and flow of their recovery process (Duff, 2011, 2012). As these enabling places can take various shapes (e.g. residential/community-based, professional/informal), future research is necessary to further explore the diversity of such landscapes of support and to gain understanding of the ways in which persons with complex mental health needs navigate them.

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# Chapter 5

# Questioning the professionalization of recovery: A collaborative exploration of a recovery process

Based on

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## Abstract

While the recovery concept strongly resonates in clinical mental health care today, it arose first in service user-led contexts. A major risk of this professionalization shift is that recovery primarily becomes defined by treatment providers. This study aims to keep the debate on recovery alive through a collaborative exploration of Pete's recovery process by means of a bricolage approach. This resulted in an idiographic portrait of Pete's experiences of recovery and treatment, clustered around four themes: life rebuilding, identity, continuity of care and the role of drugs. His experiences illustrate a number of contradictions in the operationalization of the recovery ethos in today's mental health care: whilst it appears as a hopeful vision of empowerment, it also risks being reduced to a tokenistic model that fails to address the social realities of people in recovery and in which the assumption that mental illness is chronic is still latently present.

## 5.1 Introduction

Today, recovery is a central guiding principle in international mental health care (Braslow, 2013). Moving away from a biomedical approach to mental illness, recovery has been described by Deegan (1988) as *"a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. […] The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution"* (p. 15). The origin of the recovery concept traces back to the 1960s, when psychiatric institutions were increasingly criticized for their collectivist work regime that disregarded the embeddedness of mental illness in people's lives (Goffman, 1961). During the 1970s, the anti-psychiatry movement gained ground and stood up against seemingly endless psychiatric admissions and a medicalized view of mental illness and treatment. The American *survivor* movement advocated the acknowledgment of depriving living contexts as the primary cause of mental health problems (Morrison, 2013). These developments led to a wave of deinstitutionalization and a shift towards a more person-centered treatment approach (Rissmiller & Rissmiller, 2006). Gradually, recovery was presented as a fundamentally new way of thinking about mental illness, challenging the assumption of chronicity and the belief that mental health problems always lead to life-long dependency on the mental health system (Anthony, 1993; Braslow, 2013; Price-Robertson, Obradovic & Morgan, 2017).

During the 1990s, the recovery ethos gradually found its way into the American mental health care system, and in a later movement also into European mental health care. Especially during the last decade, the recovery concept has increasingly been adopted by professionals, policy makers and academics in the field. For example, in search of the clinical utility of the recovery philosophy, Leamy et al. (2011) composed a synthesizing framework of recovery based on a narrative synthesis of first-person accounts. According to this CHIME framework, recovery comes about through the interplay of five central processes: Connectedness, Hope and optimism about the future, Identity, Meaning and purpose, and Empowerment (Leamy, Bird, Le Boutillier, Williams & Slade, 2011). Later, Stuart, Tansey and Quayle (2017) added 'Difficulties' to this framework (CHIME-D), to include struggles and challenges that persons in recovery face. However, Duff (2016) argues that such a conceptual model, despite being based on first-person accounts, fails to grasp 'real' recovery experiences as they merely offer an abstracted idea of possible recovery experiences, thus resulting in a generic model that pays insufficient attention to idiosyncratic and contextual recovery dimensions (Price-Robertson, Obradovic & Morgan, 2017). Moreover, reducing the recovery framework to a model risks overlooking disabling structural factors and social realities (e.g. material deprivation, homelessness, judicial problems) that often play a

central role in the emergence and course of mental illness in people's lives (Hopper, 2007). Related to this, Stuart, Tansey and Quayle (2017) warn for unintended side-effects of the 'professionalization' of the recovery ethos, i.e. *"(…) the danger of imposing professional ideas of recovery onto what was originally a service-user-led concept"* (p. 302). Indeed, recent studies show that there often reside subtle gaps and contradictions between the recovery discourse and its implementation in everyday mental health care practice (Khoury & del Barrio, 2015; Lietz, Lacasse, Hayes & Cheung, 2014; Slade et al., 2014). A major risk of this professionalization trend is that recovery becomes predominantly defined by treatment providers and leaves little room for a person-centered approach (Hyde, Bowles & Pawar, 2015; Pilgrim, 2009). Consequently, it is far less seen as a personal journey that only makes sense in terms of the challenges and contexts one is confronted with in life. In light of this shift, several authors have warned for the 'mainstreaming' (Rose, 2014), 'theft-through-adoption' (Hunt & Resnick, 2015), 'colonization' (O'Hagan, 2009), 'popularization' (Stuart, Tansey & Quayle, 2017) and 'hijacking' (MHRSWG, 2009) of the recovery concept, all referring to the danger of recovery becoming a surrogate specialist discourse that is shaped by practitioners and policy makers and no longer reflects the original user-led concerns (Pilgrim, 2009). In other words, professionalizing recovery runs the risk of pushing people with mental health problems back into a more passive role: the role of the ones who need to accomplish targets that others have imposed.

As a result of these developments, recovery has become a floating signifier, an umbrella concept that can be interpreted in many different ways but fails to grasp the actual underlying mechanisms that ebb and flow in the lives of people in recovery (Duff, 2016; Hopper, 2007; Price-Robertson, Obradovic & Morgan, 2017). Experiential knowledge is essential to fill this knowledge gap and to critically discuss if and how professionally led recovery-oriented treatment and support programs actually support recovery processes or rather impose societally valued targets onto people (Pilgrim, 2009). First and foremost, to do justice to the ethical imperative inherent to the recovery discourse, i.e. that persons with mental health problems themselves hold the authority to talk about recovery, service users should be acknowledged as *experts by experience* (Beresford, 2005; Pilgrim, 2009). Moreover, Stanhope and Solomon (2008) argue that experiential knowledge, even when it is rooted in micro-level processes, has the potential to address larger social, structural and political developments. However, until today, the perspectives and involvement of service users have largely remained in the margins of academic discourse and disability research (Beresford, 2005; Faulkner, 2017; Jones & Brown, 2012; Roets, Kristiansen, Van Hove & Vanderplasschen, 2007), or have been used in a strategic way, "(…) *to represent and speak for an essentialized group of others whose interests are wide and varied"* (Voronka, 2016, p. 198). Such an approach reduces persons with lived experience to a homogeneous group, reinforcing epistemic inequalities between professional and experiential expertise (Voronka, 2016).

In contrast, the aim of this study is to capture, in all its complexity, what it means to be in recovery and how (recovery-oriented) treatment and support are experienced. Following the statement of Faulkner and Thomas (2002) that research into mental health services should always be a marriage between expertise by experience and expertise by profession, this article is the result of a co-production between an academic researcher and a person with lived experience. More precisely, this article is the result of a journey of 'bricolaging' that Pete (an expert by experience) and Clara (an academic researcher) have traveled together, aiming to draw a portrait of Pete's recovery process and treatment experiences. During this collaborative journey, they were confronted with a number of tension points and entrenched assumptions regarding the conceptualization and operationalization of recovery in today's mental health care system. Based on the premise of Roberts and Boardman (2013) that an emphasis on recovery in mental health care can only be of value as long as it remains open to debate, this article aims to provide an experience-based contribution to that debate by discussing Pete's experiences and challenging these assumptions.

This study is part of a larger research project that has been granted ethical approval by the Ethics Committee of Ghent University Hospital (EC UZG 2016/0530). As an expert by experience who openly talks and writes about his experiences in psychiatry as part of his profession, Pete has full understanding of the fact that this publication, in which he also shares these experiences, is publicly available and might have an impact on his life.

## 5.2 Methods

*Context*

This study took place in Flanders (Belgium), where the recovery concept has gained dominance in mental health care during the last ten years. Pete and Clara met for the first time at Villa Voortman, a community-based meeting place for persons with dual diagnosis in Ghent in January 2013 (De Ruysscher, Vanheule, and Vandevelde, 2017). Villa Voortman offers a welcoming shelter for persons with co-occurring psychosis and addiction problems who have lost connection to regular treatment. Besides a safe haven, Villa Voortman is also a creative hub where a wide range of activities (e.g. sports, cooking) and workshops (e.g. poetry, philosophy, music, art making) are organized, both by staff members and visitors (as service users are called). Clara got to know Pete as a daily and enthusiastic visitor of Villa Voortman who organized philosophy and poetry workshops for fellow visitors and started thinking about becoming a peer worker at the center where he was treated for depression and for alcohol and cannabis addiction. From November 2013 to September 2015 Pete suffered a paranoid

delusional psychosis, the first of his life, that led to a series of further (involuntary) admissions and the loss of contact with his social network – especially the (temporary) loss of contact with his teenage daughter. Since September 2015, Pete frequents Villa Voortman again, which is where Pete and Clara picked up again. From then on, and especially during the last year, Clara increasingly started sharing and discussing thoughts and questions regarding her research on recovery with Pete. In turn, Pete let her read the poetry and texts he was writing at that time about his recovery and treatment experiences. Writing poetry has always been a crucial aspect of Pete's recovery process:

*I wrote my way into this mess*
*Into this crisis of self and reality*
*The intentionality was mine all along*
*I resolve to write my way out again*

*To take control of the process*
*To assert my will that way*
*To get it all down*
*With the intention to publish*

*(20 September 2015)*

During the writing process of this paper, Pete and Clara have had lengthy discussions about the necessity to include details on Pete's diagnosis and treatment history. Initially, it seemed self-evident to include this information as background to understand the article. Additionally, adding details on Pete's treatment history would stress the individuality of his experiences and would anticipate the question: recovery from what? Most importantly, Pete considered it crucial to include details on his diagnosis and treatment history in the text, as they serve as proof that persons who experience(d) something as life-changing as psychosis are capable of (co)writing academic papers. Based on these arguments, the decision was made to include details on Pete's treatment history.

In this article, Pete draws on his whole experience of three years (from November 2013) staying in four different hospitals plus Villa Voortman.

*Research process*

To do justice to both the complexity of recovery processes and the versatility of experiential knowledge, we have adopted a collaborative case study design, starting from a bricolage approach (Kincheloe, 2001;

Baxter & Jack, 2008). Building on the work of Denzin and Lincoln (2011), Kincheloe (2001) describes bricolage as a hermeneutic process that allows the researcher to move towards more complex and layered ontological insights, as it starts from the assumption that *"any social, cultural, psychological or pedagogical object of inquiry is inseparable from its context, the language used to describe it, its historical situatedness in a larger ongoing process, and the socially and culturally constructed interpretations of its meaning(s) as an entity in the world"* (p. 682). In other words, bricoleurs allow for contextual contingencies to prompt the questions that should be asked and combine empirical methods and materials creatively in search of answers to these questions (Rogers, 2012; Van Hove, De Schauwer & Platel, 2017).

Gillard et al. (2012) emphasize the importance of applying methodological flexibility in such a process of knowledge co-construction, to create space to situate and challenge entrenched assumptions and existing professional practices. Therefore, during the entire bricolage process, which took place between May 2016 and January 2018, Pete and Clara worked closely together as they combined the following information sources:

- A series of nine in-depth conversations between Pete and Clara over a wide range of topics including the concept of recovery, Pete's experiences of psychiatric treatment, the role of substance use in psychosis, and the organization of the mental health care system. To keep track of the topics discussed, all conversations were audio-recorded and transcribed verbatim as they went along. The conversations took place in Dutch, and the excerpts used were translated into English by Pete himself, who is a native English-speaker;
- *'From the inside: My escape from paranoid delusional psychosis'*, a poetry bundle by Pete that he describes as a view of *"material parts of my psychosis and (…) a large part of the therapeutic work I have done to stay out of psychosis and deal with the wreckage of my life";*
- Email conversations between Pete and Clara;
- Pete's recovery story, which he wrote as part of a course he followed to become a peer worker;
- Conversations with the third and fourth author. Being Clara's supervisors, they were involved in the research process from a further distance. Their 'outsider' perspective gave Pete and Clara multiple opportunities to discuss their ideas on the professionalization of recovery, which helped facilitate the research and writing process;
- Existing recovery (research and policy) literature.

*Data analysis*

During the bricolage process, Pete and Clara engaged in an iterative process in which data collection and analysis alternated. After each conversation, Clara conducted an initial thematic analysis following the guidelines of Clarke and Braun (2014). Secondly, this analysis was extensively discussed and checked with Pete, generating new questions to discuss in the following conversations, which were in turn analyzed. This process was repeated until a saturation point was reached and no further questions came up. During this iterative process, the emerging themes were also linked to poetry extracts from Pete's bundle. In a later stage, a group meeting was organized with the third and fourth author to discuss interpretive perspectives and identify themes which remained untouched in the analysis (Gillard, Simons, Turner, Lucock & Edwards, 2012). This way of working resulted in an elaborate idiographic portrait of Pete's experiences regarding his recovery and treatment trajectory, which was clustered around four key themes (cf. infra).

## 5.3 Results

Pete describes his recovery in the following way: *"It is getting a life back after the destruction caused by the illness. Essential to my personal recovery is going back to not living in isolation. Recovery is also a therapeutic process, of getting to know yourself better, of becoming better informed and of overcoming symptoms by understanding and tackling them. Recovery after mental illness is especially the restoration of a sustainable and sufficiently positive emotional life after the prolonged suffering associated with illness and (forced) admissions to hospital. I think that deinstitutionalization ('vermaatschappelijking' in Dutch) should be seen in terms of so complete possible psycho-social reintegration of the mental hospital population into general society for patients who want that. Empowerment means being accepted as we really are by public opinion. People should not need a collective name for people who have been in mental hospital because outcomes are so diverse."*

During their conversations about recovery and Pete's treatment experiences, Clara and Pete were repeatedly confronted by dilemmas and tension points, which they clustered around four themes: life rebuilding, identity, continuity of care and the role of drugs. Each of these themes will be discussed in detail.

### *5.3.1 "Some people really believe I would recover by having a TV installed": Life rebuilding*

During their initial conversations, Pete and Clara gave a central position to the concept of recovery as

such. However, they soon noticed that they were constantly fluctuating between different interpretations of the concept, which prevented them from touching the core of Pete's experiences. In search of a new common language they started talking about 'life rebuilding', described by Pete in the following way:

> "*To have a life again. A better life than recently, you know. Definitely full working days – paid or voluntary. A relationship. More friends. Interesting things to do with others. Finally succeeding in getting my poetry published, which will probably never happen, but I still put it on the list, why not. Maybe a bit Utopian, but for me... My ideal world, my ideal existence is one in which I am constantly engaged in a fascinating conversation, with company whenever I want it."*

One aspect that Pete considers crucial in this process of life rebuilding is to lead a life with responsibilities in which leisure time alternates with meaningful activities (such as having a job, writing poetry), and to always have plans and be learning new things. He calls this 'self-realization', another concept he prefers to recovery:

> *"I prefer the discourse of self-realization to recovery. I know it's old-fashioned, but it appeals more to me because it is more social. (…) Recovery is getting better after something… which implies a norm, yes. But self-realization does not. You relate it to yourself. (…) A lot of people achieve their goals. They graduate from college, or they find a job they want and a relationship... Of course their lives will not be perfect, they will have their disasters, loved-ones who die, divorce, that kind of thing... That's life. And yet they still feel good about who they are in society. That's the feeling I'd like to have."*

What stands out in Pete's description of both life rebuilding and self-realization is the importance of rebuilding a social network and having a family life. In this respect, two aims are especially high on his agenda: to restore a positive contact with his daughter and to find a romantic partner. However, this is a very arduous process, because of how difficult it is to overcome the stigma caused by his psychotic episode *("I have been a very public lunatic"*) and his psychiatric admissions. To explain how he felt on returning home after a series of admissions, Pete used the metaphor of moving to a different country where you have to start all over to build a network:

> *"I have experience in moving around a lot. As an immigrant, I have been faced a number of times with situations where I had lost everything. My life is fragmented. (…) I have learned that it takes a very long time to make friends. Years. If you find one or two new friends in a year, to put it simply, you are doing well."*

However, the conversations about life rebuilding and self-realization were often in stark contrast to moments in which Pete's experiences in residential psychiatric treatment were discussed. In his perception, people become seriously mentally ill because of the problems in their lives and go into hospital when they cannot function any more. However, when Pete was admitted, he felt as if he was in limbo, in a sort of vacuum space where he was not actively working towards rebuilding his life and that the ideas and effort to recover came entirely from himself:

> *"When I'm in mental hospital, it feels like I am normally there, that hospital is my real life, the continuity in my life. Such thoughts do not make you happy. Sometimes you go into hospital highly motivated, but often, once you are there... Your motivation falls away. It is very difficult to explain. (…) You are not really recovering, you are not really improving, you are not really getting worse either. You're just there."*

He attributes this state of limbo to a lack of contact (*'non-contact'*, cf. infra) between the psychiatric context and the real world. He experienced residential psychiatry as a sort of 'waiting room', a place to stabilize one's life rather than to actively pursue a different life. Pete describes how psychiatric admissions can even become integrated into destructive and hard-to-break cycles:

> *"We come from mental hospital. We are depressed because we have no money. Because we have no life. Many of us have no friendships with people who have never been admitted to mental hospital. And... then they begin to use illegal drugs, often for the first time during an admission. In the beginning it's all right, I mean... it seems to help, but in the end these drugs always lead to new problems with money or mental instability or illness, and then they go to ground in mental hospital. You get ill enough to need residential treatment when your problems become unbearable, for example, with money. I ran up debts of 3000 euro in six months during my illness. Only the intervention of a friend prevented me from becoming homeless. Many of my fellow patients are not lucky enough to have such a friend. They lose their accommodation, because they didn't pay the rent when they were ill. Poverty makes you ill, then the illness makes you poorer. Such vicious circles are cruel. They can break a person."*

In Pete's experience, this lack of contact (*'non-contact'*) between residential psychiatry and the real world also extends to a lack of insight from staff into his personal life-world. For example, in his recovery story, Pete describes how social isolation remains a daily struggle for him:

> *"I spend 75% of my waking hours alone. This has been the situation since I came home from hospital in May 2016. I am a very social person and I do not like being alone, so this extended, deep solitude, forced on me by the fall-out from my illness (broken relationships), is something I*

*have learned to live with – a very difficult but extremely educational experience. Not being able to be alone is a psychological vulnerability which I have overcome. I will not consider myself recovered until my life changes dramatically."*

To counteract this social isolation, however, Pete has been advised by one psychiatric staff member to install a TV in his apartment. This advocacy of passivity is in sharp contrast to how Villa Voortman positively challenges him. In this meeting place, visitors are encouraged to elaborate a sense of identity and to engage in dialogue with others, expressing who they are by different means. In line with this personalized approach, Pete learned how to play the drums and organizes weekly philosophy and poetry workshops in the meeting place, because those roles in those activities suit him. He feels that these opportunities and activities help him rebuild his life, both because they fill his days with meaning and because they help him move away from his identity as psychiatric patient.

### *5.3.2 "Are we strong people with difficult lives, or weak people who can't handle life?": Identity*

Pete's identity has many facets: he is a father, he is a poet, he is a philosopher, he is a peer worker, he is an (ex-)psychiatric patient. In his poetry, Pete describes how these different facets are often intertwined and alternately play a central role in his life:

*For many years*
*If asked who or what I was*
*The answer came easily and immediately*
*I am a father*
*The rest of my existence*
*I built up and held together*
*In function of this primary responsibility*
*To make my fatherhood possible*
*Now that's had to change*
*She's still number 1*
*But no longer my centre*
*That is being a writer*

*(11 September 2015)*

However, the one aspect of Pete's identity that was discussed the most was that of (ex-)patient, as he felt that during treatment his identity was primarily defined by his illness *("first and foremost, we are people with an illness"*). In the current recovery discourse in the Flemish mental health care system, persons with mental health problems are no longer called 'patients' but 'persons with a psychological vulnerability' (*'psychische kwetsbaarheid'* in Dutch). However, this new wording can prompt one to make a number of flawed assumptions. Firstly, using 'persons with a psychological vulnerability' as a name suggests that there exists a category of people without a psychological vulnerability. Pete has reservations about this categorization, because it appears as if psychological vulnerability is something that coincides with and defines yourself as a person, thus implying that it is something entirely about the individual. However, Pete clearly attributes his psychosis to traumatizing experiences in his childhood and his social situation at the time. Also, since he clinically recovered from his psychotic episode, he sees his vulnerability especially becoming visible in interaction with others, rather than within himself:

> *"Then a psychological vulnerability is just a euphemism for an incurable sickness. But for me, my vulnerabilities are more social. It is how people react to me, how they see me since the madness. I was a very public lunatic, you know, a lot of people recognize me. And that is in fact more than one problem (…) I am a vulnerable person, yes, but not for psychosis. Am I more vulnerable than the average person? I don't think so. I think others have had better luck. (…) I am not so much a vulnerable person, I am a person with average vulnerability and a lot of problems. My daughter is gone, because of the illness. Am I ever going to get over that? I don't know. As a patient you are expected to simply accept those things."*

Secondly, psychological vulnerability is often assumed by staff to be something which is always permanent and incurable, thus chronic. As a consequence, labeling people with a 'psychological vulnerability' implies a constant expectation of relapse. Because of this expectation, psychiatric staff put patients under pressure to lower their expectations of recovery. Pete sees this being reflected in the daily practice of some residential psychiatric wards where he has stayed:

> *"There are no group talking therapy sessions, because the whole emphasis is on keeping people as calm as possible. We have pills to make us calm, we follow therapies which relax us. There is the routine, the structure. But I do not necessarily see recovery as a process of calming down. For me, you have to tackle the problems, don't you think? For example, you have to say why you refuse to talk to staff, if that is a problem."*

Although Pete himself is opposed to this assumption of chronicity, he does think there are persons with chronic mental health problems who need long-term treatment. What he finds problematic is how other

aspects of people's identity are overshadowed by their illness identity:

> *(Clara) "Do you think chronic patients exist?" – (Pete) "Well yes, I think so. But it is what that means, do you see? Because you can also say... 'OK. I am a chronic patient.' But what does that mean? It is the limits on my life that the staff think I have. It is always down, down, down, down."*

In the same vein, Pete told Clara that some staff members have asserted that after he recovered from his psychosis, he should only expect a life in which he mainly has contact with other (ex-)patients. Pete links these low expectations towards patients with his perception that residential psychiatry is a deeply entrenched system, in which thinking in terms of the deficits rather than the strengths of people to recover is still latently present:

> *"They are far too unambitious when it comes to the life-prospects of patients. You come under a lot of pressure to be passive, that's what it amounts to. It is the whole system and the medication which pushes you in that direction. (…) I have the feeling that people are deeply entrenched. That attitudes in psychiatry are dyed in the wool, you know. Certainly with respect to the whole chronicity thing, that in the last analysis, we have fallen out of society because we are inadequate in some way and there is not much you can do to help us."*

This attitude from staff members refers only to one aspect of Pete's identity, namely his 'psychiatric' identity, relegating other aspects of his identity to relics from the past. As a consequence, it is difficult to reconcile such an approach with the future that Pete pictures for himself:

> *"I have fifteen years to go to retirement. If I just take this time. I don't see why they can't be the fifteen happiest years of my life. Why not? I don't say that is going to happen. Why not? But the assumption is that it is not possible."*

Pete refers to these low expectations from staff members as 'diagnostic overshadowing', a concept originally used to describe the negative bias of clinicians towards symptoms and behavior of patients with mental illness (Jones, Howard, and Thornicroft, 2008). In Pete's sense, this negative bias also extends to patients' capabilities and plans for the future. According to him, diagnostic overshadowing is the way that, once someone knows you have a diagnosis (e.g. psychosis), all your behavior is interpreted as being related to the diagnosed disorder. Frequent diagnostic overshadowing is counterproductive in supporting patients' recovery processes, especially because patients are often prone to internalizing these low expectations (leading to self-diagnostic overshadowing).

### *5.3.3 "Sometimes it felt like I was sitting on a conveyor belt": Continuity of care*

During conversations about what constitutes good treatment, Pete unhesitatingly put continuity of care forward as an indispensable component. However, during a large part of his treatment trajectory, Pete has missed this continuity, in the sense of having long-term contact with one or a few staff members. In one of his poems, he describes his therapists as *"pass-the-patient-parcel therapists"* who fail to truly connect to his life story and long-term needs:

> *"As a patient in the mental health system, I feel like I'm sitting on a conveyor belt. I pass on from one psychology expert to the next. They all do their required interventions, then I pass on to the next. No one tries to stop the line. No-one tries for or expects a full recovery."*

In that sense, we came to the realization that the non-contact Pete experienced between psychiatry and the outside world (cf. life rebuilding) also extends to the contact between himself and the psychiatric staff, manifesting itself in a distant attitude from staff members and a lack of personal(ized) (talking) therapy. This non-contact became eminently visible during Pete's three involuntary admissions:

> *"You arrive, you've been sectioned, and nobody says anything to you, you are treated from a distance. You're completely crazy, of course, but nobody tries to bring you back to reality. No-one tries to… Nobody talks to you about your delusions and the like. You can talk to the psych's but if you don't talk about your illness, they don't. And that is not enough. Because if you… In my opinion, talking and thinking about delusions and discussing them does have value. Analyzing delusions helped me, why shouldn't it help some others?"*

He partially attributes the lack of talking therapy to the fact that in the psychiatric wards where he stayed, a group approach was applied to treatment. In Pete's case, this meant that most therapeutic activities – apart from a weekly thirty minutes of individual therapy with the psychologist – took place in the group and that the many hours of spare time were spent just hanging around in the ward. However, as our conversations progressed, we touched the core of Pete's frustration: patients are insufficiently approached as individuals with own life stories, problems and personalities. This has far-reaching consequences; looking back at this period in his life, Pete goes as far as identifying the distant attitude of some psychiatric staff and the lack of attention to his personal story as important causes of the stigma he experienced during and after his admissions.

> *"When you are there, you are merely a member of the group. You lose half your personality when you go into mental hospital. And then, when some staff are more personal, more direct, then you really appreciate it. Those are the positive memories I have. But between those moments...*

*Mental hospital is mostly hanging around. It is mostly waiting."*

Pete believes that continuity of care can only be realized when staff connect with patients over a longer period of time and across different settings, without losing the link to patients' personal life-worlds. In his view, continuity of care is interwoven with a made-to-measure treatment approach that is flexible in addressing the different needs that patients have at different times. This flexibility is something Pete experiences in Villa Voortman, which he visits almost daily:

> *"Homeless? Eat and sleep in the bed. Staying in mental hospital? Come to the Villa as a stepping stone to going home and to keep in contact with the outside world. Dying of boredom? Take the initiative and organize or do something for yourself or others. In crisis? Welcome. During my psychosis, I came back to the Villa repeatedly and was very well received, despite my behavior at that time."*

### *5.3.4 "I call it chemical company": The role of drugs*

The role of drugs in Pete's life and recovery is a topic that was only discussed during Clara and Pete's later conversations. The use of cannabis has been an integral part of Pete's daily life since before his psychotic episode and continues to be so today. The primary functions of his cannabis use are to fight boredom and to fill up the void caused by loneliness, as he describes in his recovery story:

> *"Both in company and alone, I pursue my three passions: philosophy, writing and drumming. These are how I fill most of my time. These and cannabis, which I smoke alone in the evenings. It is my way of dealing with the loneliness, I call it "chemical company" and it has helped me therapeutically, for example by freeing me to have animated conversations with myself. Because I smoke cannabis, I do not need heavy sedative medication such as second generation anti-psychotics or benzos. (…) I have never taken other drugs. I will not consider myself recovered until my cannabis problem is of a lower order."*

What stands out in this exert is that Pete finds it a necessary condition for his recovery to deal with his cannabis use. For quite some time, Pete did not consider his daily cannabis use to be a problem and found it very convenient that the staff on the ward where he stayed were oblivious to it, as this gave him the space to continue using. However, recently he started seeing his use as a problem and worrying about the damage it brings to his physical health and financial situation. Also, now he realizes that it would benefit his recovery process if he could find a suitable alternative to face the 'challenge of solitude':

> *"Drugs are very important to me and a very conscious aspect of my life. I rely on them. If I want to stop, I'll need an alternative, but they really don't have an alternative, except other medication. I could stop tomorrow by going over to heavy medication."*

As a consequence of his recent concerns regarding his drug use, Pete considers it his moral obligation to begin speaking about it to his therapists:

> *"But it's not good for my therapy. I'm in therapy at hospital X, and there I do not talk about drugs. This is not good. (…) I am still a bit worried about my mental health and there are a couple of symptoms I get, especially when I have smoked. And I want to discuss these things with someone. But I can't do that without talking about my drug use, do you understand?"*

However, part of him still feels reluctant to talk about it to his psychiatrist, for a number of reasons. First, he points out that drug use remains taboo in certain treatment settings. Second, he is scared of patronizing conversations from a lack of understanding of the function of Pete's cannabis use and, in a broader sense, his lifeworld. Third, Pete is scared that his drug-related worries will be misunderstood as drug use is often seen as a trigger for psychotic thoughts. In other words, he is concerned that the psychiatrist might suspect him of turning psychotic again:

> *"I used [cannabis] before my psychosis, during my psychosis and I still use and have no psychosis. So, in my case... but I can understand what they mean. It can provoke certain phenomena, voices and the like. But to become really psychotic, you have to start interpreting these phenomena. If you experience but don't interpret the experiences, you don't become full-blown psychotic."*

## 5.4 Discussion

While the concept of recovery arose first in activist, personal and social justice contexts, it currently strongly resonates in clinical mental health care settings (Hunt & Resnick, 2015; Roberts & Boardman, 2013). This mainstreaming shift might imply that the personal perspectives of persons with mental health problems get somewhat neglected. To counteract this, this study aimed to keep a critical debate about recovery alive by means of a collaborative exploration of Pete's recovery process. In so doing, a number of tension points and ambiguities were identified and clustered around four themes: life rebuilding, identity, continuity of care and the role of drugs. Discussing these themes exposed a number of gaps between the original recovery ethos and the professionalized translation of the concept and its operationalization in today's mental health care. In other words, it became clear how Pete's individual

meaning of recovery is in tension with a professional enactment of recovery as mental health care policy and practice (McWade, 2016). In what follows, we will elaborate on these gaps and situate them in the wider debate on recovery and recovery-oriented care.

### *5.4.1 Recovery: a never-ending journey?*

Recovery is generally described as a personal, unique and non-linear journey towards living a meaningful and contributing life, even with limitations caused by mental illness (Anthony, 1993; Deegan, 1988). Built on the idea that people with mental health problems strive to live a meaningful life in fundamentally similar ways to those without mental health problems, Slade (2012) argues that the role of recovery-oriented treatment is to *"support everyday solutions to everyday problems"* (p. 702). Contrary to this statement, however, Pete experienced residential psychiatry as a 'waiting room' in which his everyday life was put on hold and in which he was reduced to a member of a group, rather than an individual with unique needs and aspirations. Moreover, driven by a reflex of diagnostic overshadowing, he was often urged by psychiatric staff to lower his expectations for his further life (e.g. by suggesting that his social network would mainly consist of other (ex-)patients) (Jones, Howard & Thornicroft, 2008). These low expectations of staff members towards Pete's further aspirations carry a sense of chronicity in them, as they seem to assume that being in recovery implies being condemned to a never-ending journey (Gordon, 2013). In this respect, Khoury and Del Barrio (2015) suggest that it is precisely the unique nature of recovery processes, characterized by intense ups-and-downs, that is often misread by psychiatric staff as a sign of chronic illness. Pete's experiences show that, while the recovery movement openly rejected thinking in terms of deficits, the medical gaze still remains the norm in daily mental health care practice (Lietz et al., 2014). A consequence of this underlying belief in biomedical treatment is that it discourages people with mental health problems from finding their own creative and non-coercive ways of recovery (Howard & Voronka, 2012; McWade, 2015). Hopper (2007) offers a promising alternative to this hidden assumption of chronicity by putting forward a capabilities approach to recovery. Rather than (implicitly) focusing on a process of 'getting better' or 'healing', a capabilities approach is built on the principle of equality, as *"recovery asks not what such people should be content with but what they should be capable of, and how that might be best achieved and sustained"* (Hopper, 2007, p. 9).

### *5.4.2 Recovery: a personal process?*

A capabilities approach to recovery also acknowledges the embeddedness of a person in a social context and the contribution of structural and social factors to both mental health problems and recovery (Harper & Speed 2014; Hopper, 2007). During the bricolage process, Pete's social vulnerabilities and aspirations continuously permeated our conversations; we talked about his daily fight against social isolation (which is directly related to his drug use), the disabling effect of the stigma from psychiatry, his desire to have a family life and to fulfill a meaningful role in society. In contrast, Pete experienced that these vulnerabilities and aspirations were insufficiently understood and addressed during his psychiatric admissions. The distant attitude from psychiatric staff and the fact that he was primarily seen as a 'person with an illness' (rather than a father, artist, citizen) made him feel disconnected from his lifeworld and society. Pete's experiences provide a striking illustration of a growing body of critique on individual conceptualizations of recovery that give insufficient weight to the social and interactional nature of both mental illness and recovery (Price-Robertson, Obradovic & Morgan, 2017; Schön, Denhov & Topor, 2009; Topor, Borg, Di Girolamo & Davidson, 2011; Vandekinderen, Roets, Roose & Van Hove, 2012). For example, in the commonly used CHIME-D framework, Connectedness is listed as one of five central recovery processes (Leamy et al., 2011; Stuart, Tansey & Quayle, 2017). Considering the centrality of the social struggles in Pete's story, however, this framework falls short in two ways. Firstly, lining up Connectedness alongside four intrapersonal processes (Hope, Identity, Meaning and Empowerment) suggests that the latter processes take place in a vacuum space that is sealed from one's social context (Price-Robertson, Obradovic & Morgan, 2017). Secondly, picturing Connectedness as one of five processes gives the impression that the social context and social interactions are a mere contributing aspect, rather than a vital facilitator of recovery processes. Pete's experiences show how his social context is the very medium through which processes such as finding meaning in life, rebuilding a new sense of identity and feeling empowered come about. Moreover, when thinking in terms of the CHIME-D framework, nearly all of the Difficulties that Pete faces are of a social nature (e.g. overcoming stigma, fighting social isolation).

In other words, an individual recovery approach fails to fully address the complex social realities of people in recovery. Even more so, Vandekinderen et al. (2012) argue that such an individual approach promotes a neoliberal interpretation of care and citizenship, as it entails *"a socially constructed norm of the self-managing, self-sufficient, and independent consumer-citizen who is fully responsible for his/her own choices"* (p. 3). Instead, it proves more valuable to start from a relational recovery approach that is characterized by interdependence rather than individualism (Price-Robertson, Obradovic & Morgan, 2017). From a relational perspective, care takes the shape of a continuous dialogue between persons

with mental health problems and professionals, characterized by a shared responsibility and the constant renegotiation of rights (Hopper, 2007; Vandekinderen et al., 2012).

### *5.4.3 Recovery: a tokenistic model?*

The original recovery movement rejected thinking in terms of diagnoses and reducing people to a psychiatric label (Hunt & Resnick, 2015). This aversion to labeling people has found an echo in today's mental health care system in the sense that a deficit-oriented language (e.g. 'disorders', 'diagnosis', 'patients') is increasingly being replaced by person-first language that aims to minimize (self-)stigmatization. In the Flemish mental health care system, people with mental health problems are referred to as persons with a psychological vulnerability instead of as patients. However, Pete's experiences showed that, notwithstanding the good intentions of this new wording, it still risks becoming the next categorization of people with mental health problems (*'the psychologically vulnerable'*), with its own predefined characteristics and expectations. Although Pete describes his own vulnerabilities primarily as social and of a passing nature, these vulnerabilities were often perceived and treated by psychiatric staff as intrapersonal (rather than interactional), chronic and something that fundamentally differentiates him from people without mental health problems. The problem with such preset expectations is that they make psychiatric staff unable to understand the perceptions of people with mental health problems and the way psychiatric symptoms are embedded in their lives (Vanheule, 2015). Consequently, they stand in the way of a personalized treatment approach that is tailored to the lifeworld, personality, needs and wishes of each person. In his recovery story, Pete also expressed this need for personalization and differentiation by saying that the *"psycho-social reintegration of the mental hospital population into general society [is desirable] for patients <u>who want that</u>"*, thus pointing out the need for a particularizing approach that starts from each person with mental health problems' personal meaning of recovery (De Ruysscher, Vanheule & Vandevelde, 2017).

To prevent the recovery discourse from being reduced to a tokenistic or superficial model, it is necessary to rethink the roles and aims of mental health care treatment and therapy. Rather than a deficit-oriented approach to diagnosis that categorizes symptoms into disorders and results in a psychiatric label, it would be more valuable to focus on the way one's problems and symptoms are embedded in one's life and functioning. Such a functioning-oriented approach to diagnosis results in an organized narrative that offers personal starting points for support (Vanheule, 2015). As a consequence, professionals in the field no longer function as labeling experts but as *'compagnons de route'* who continuously search for the most appropriate support through engaging in a dialogical process together

with the person with mental health problems. Such a dialogical and equal partnership only becomes possible when continuity of therapeutic contact is guaranteed.

The initial, service user-led recovery movement pursued high ambitions with regard to fighting stigma, rejecting unnecessary labeling and redressing power imbalances in the mental health care system (Roberts & Boardman, 2013). However, our bricolage journey showed that the translation and operationalization of the original recovery ethos into today's mental health care system contains several contradictions (Khoury & del Barrio, 2015). It simultaneously appears as a hopeful vision of person-centeredness and empowerment, and an expert-driven discourse in which diagnoses still have a major impact and low expectations of recovery are still latently present. The findings from this collaborative case study are in line with insights from authors in the field of Mad Studies who warn for mechanisms of epistemic violence in psychiatry (Liegghio, 2013). Through these mechanisms, the personal meanings which service users have of their recoveries remain overshadowed and even marginalized by professional recovery discourses, based on the hidden assumption that persons with mental health problems' own perceptions are a symptom of mental illness and invalidated as necessarily flawed (Faulkner, 2017; Russo, 2016; Voronka, 2016). Instead, professionals need to (re)connect with the activist spirit of the original user-led recovery movement and adopt a more ambitious attitude regarding the lives of people with mental health problems.

*Limitations and future directions*

The bricolage journey that Pete and Clara traveled allowed them to make the professionalization trend of recovery tangible and visible through Pete's experiences. However, as these findings are situated within a specific (Belgian) mental health care context, they cannot simply be generalized to other (international) contexts. Also, the wards where Pete stayed during his admissions are currently in transition towards a more explicitly recovery-oriented approach (e.g. by abandoning the practice of daily staff meetings). The question arises whether and how these recent developments might affect the experiences of people who are currently staying there. Therefore, and also considering the idiosyncrasy and diversity of recovery processes and treatment experiences, it would strengthen our findings to combine Pete's experiences with other experiences of persons with mental health care problems.

In short, it is now time that people with mental health problems are given back ownership of a philosophy that was originally theirs (Pilgrim, 2009). Within an academic context, this means that more ethnographic and collaborative research into recovery and recovery-oriented treatment is much needed, as it is precisely the first-person perspectives of service users that raise the most relevant questions and hold the potential to address assumptions that otherwise remain unchallenged.

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# Chapter 6

# From epistemic violence to dialogue in mental health care research: Reflections on a collaborative research process

Based on

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## Abstract

In today's recovery-oriented mental health care practice and research, the perspectives of persons with mental health problems are considered of great importance. However, in reality, their experiences often remain overshadowed by professional and academic voices. To counteract this, several user/survivor researchers stress the importance of co-productive research between academics and persons with lived experience. The aim of this paper is to unravel the research process that we, an expert by experience and an academic researcher, have conducted. We reflect on the methodological consequences of applying a bricolage approach and the ethical implications of developing a more equal research relationship.

*"I am not the object of research because I am not an object of any kind, I am a full human subject. The stigma of mental illness is that it is a sign of a deficit in the person marked, that we are not complete subjects, a deficit which has a profound impact on our ability to reason for ourselves, distinguish reality, get anything in perspective, in short, to achieve any kind of maturity as a person."*

*Peter Tomlinson*

## 6.1 Introduction

Within the recovery discourse in international mental health care policy, practice and research, the personal perspectives and experiences of persons with mental health problems are taken to be of great importance (Velpry, 2008). Policy makers and professionals increasingly see persons with mental health problems as experts of their own recovery process (Davidson et al., 2005; Slade & Hayward, 2007; Stanhope & Solomon, 2007). Consequently, rather than focusing on professionally defined therapeutic goals, recovery-oriented support should be tailored to the personal perspectives, experiences and preferences of its service users (Slade & Hayward, 2007). As experiential knowledge becomes all the more necessary to understand what it means to be in recovery and how support should be organized, academic research on mental health increasingly focuses on the lived experiences of persons with mental health problems. These findings are collected in a still-growing evidence base that can be placed on a continuum ranging from research that merely collects service users' voices (e.g., through ethnographic and phenomenological methods) to research that is fully controlled by service users themselves (Beresford, 2005; Pilgrim, 2009; Stanhope & Solomon, 2007).

In sharp contrast to this consensus on the importance of experiential knowledge, several authors within the user/survivor movement have raised questions about how the personal experiences and perspectives of persons with mental health problems are still overshadowed, and even marginalized, by professional and academic voices in today's recovery era (Beresford, 2005; Costa et al., 2012; Crepaz-Keay, 2016; Faulkner, 2017; Grey, 2016; Jones & Brown, 2013; Russo, 2016; Swerdfager, 2016; Voronka, 2016). In this respect, Liegghio (2013) refers to the concept of epistemic violence, originally used in post-colonial studies to describe how institutional practices disqualify certain groups in society as legitimate knowers. In psychiatry, epistemic violence occurs when the personal experiences and perspectives of persons with mental health problems are reinterpreted and reduced to professional explanations and labels that represent the person (e.g., through the use of the DSM) (Liegghio, 2013; Pattadath, 2016). As a result, persons with mental health problems are *"(…) rendered out of existence by the assertion that their experiences are 'disordered,' or the symptoms of a 'mental illness'"* (Liegghio,

2013, p. 125) and become invisible within society. Several authors highlight how this epistemic violence is also maintained and reproduced in academic research, in various ways (Russo, 2016). For example, some authors warn for the risk of homogenizing experiential knowledge, referring to the whitewashing of any diversity in the way people with mental health problems make sense of their experiences and reducing them to their common 'psychiatric' identity, disregarding other aspects of their identities and the individuality of their experiences (Rose, 2017; Russo, 2016; Voronka, 2016). Moreover, such a homogenized representation of lived experience risks being used by policy makers and academics in a sanitized and strategic way, which fits comfortably into their own dominant paradigms (Costa et al., 2012; Leblanc & Kinsella, 2016). This is also described by Grey (2016) as 'benevolent othering', a process that *"(…) involves simplistic and self-serving representations that gloss over the complexity and diversity of people's lives, constructing a self-affirming image of 'benevolent subjects' as superior and masterful"* (p. 243). Another related question that comes to the fore is one of narrative ownership: who does the story belong to (Russo, 2016)? To what extent has the research agenda been co-produced (Grey, 2016)? Participants share their personal experiences with researchers, but as they are often not involved in the further stages after data collection, their own perspectives unavoidably become compromised by the researcher's interpretive gaze (Costa et al., 2012; Russo, 2016; Smythe & Murray, 2000).

These findings illustrate how the discursive dominance of mental health professionals and policy makers is reproduced through the power inequalities that remain inherent to researcher-subject relationships in academic research (Swerdfager, 2016). As a result, the voices of persons with mental health problems are once again silenced by dominant paradigms of illness and recovery (Faulkner, 2017). Even when focusing on lived experience, academic research into mental health still tends to produce a scientific monologue in which the researcher has the last word about the subject's experiences. Therefore, alternative research approaches and different, more equal ways of relating are much needed (Beresford & Menzies, 2014; Russo, 2016; Russo & Beresford, 2015). To disrupt processes of epistemic violence, several user/survivor researchers stress the importance of a shift towards survivor-controlled research and 'truly' co-productive research between academics and persons with lived experience in which a co-produced agenda aims to challenge dominant ideas and entrenched assumptions (Beresford, 2005; Faulkner, 2017; Pilgrim, 2009).

Until now, however, few concrete research accounts have described *how* such co-production comes about, what possible form it can take, and *how* the researcher-participant relationship can be rethought to a more equal partnership. The aim of this article is to share our experiences and reflections on a co-productive research project that we, Clara (an academic researcher) and Pete (an expert by experience), conducted between May 2016 and January 2018 (De Ruysscher, Tomlinson, Vanheule, & Vandevelde, 2019). Our collaborative case study started from a bricolage approach and focused on Pete's

experiences regarding recovery and psychiatry. In this article, we will reflect on how this research project was carried out, which methodological choices were made and how these choices shaped our research relationship.

## 6.2 Unraveling our research process

We first met at Villa Voortman in January 2013, a community-based meeting place in Ghent (Belgium) that aims to offer a welcoming shelter for persons with co-occurring psychosis and addiction problems (De Ruysscher, Vanheule, & Vandevelde, 2017). In Villa Voortman, visitors (as service users are called) are free to organize and take part in a wide range of activities and workshops (e.g. poetry, music, cooking, sports, philosophy). At that time, Pete was an enthusiastic and committed visitor of the meeting place, organizing writing and philosophy workshops for other visitors. Clara spent time there in the role of intern, as part of her education to obtain a MA degree in Special Needs Education. Although Pete did not suffer from psychosis at that time, he had already spent almost two years in mental hospitals, where he had been treated for depression and addiction. However, from July 2013, Pete developed his first full-blown psychosis, which caused a series of further (involuntary) admissions, major disruptions in his social life and the loss of contact with his teenage daughter. In September 2015, Pete recovered from this psychosis and started visiting Villa Voortman again which is where Clara and Pete picked up. In 2016, by that time working as a researcher in the field of Special Needs Education, Clara conducted a qualitative study in Villa Voortman in order to gain insight into how an alternative approach for persons with co-morbid psychosis and addiction problems can take shape (De Ruysscher, Vanheule, et al., 2017). As one of the visitors, she also interviewed Pete about his experiences in the meeting place.

In the wake of that study, the mutual communication intensified, leading to a continuous exchange of thoughts and ideas regarding psychiatry and recovery. Initially, we talked a lot about Pete's time in mental hospitals during his psychosis. Also, Pete let Clara read the texts and poetry he had been writing on his experiences regarding psychosis, psychiatry and recovery. Gradually, Clara also started sharing with him her doubts and worries about the centrality of the recovery framework in her own research (*To what extent is the recovery framework meaningful to the participants of my studies? Am I doing justice to their stories by focusing on recovery, rather than, for example, social inequality?*). This interaction led to the joint decision to turn this exchange of thoughts into a research project of its own and to start recording our conversations.

Although there was no clearly defined research agenda or purpose at that time, a total of nine conversations were recorded and transcribed between May 2016 and January 2018, all primarily

focusing on Pete's personal experiences with recovery and psychiatry. Besides a few exploratory questions at the start (*How did you experience your admissions and treatment? What do you think of recovery?*) no predefined interview guide was used, as each conversation prompted new themes to be discussed in the next conversation. In doing so, data collection and analysis continuously alternated; each conversation was analyzed and discussed in preparation for the next conversation, until no further questions and themes came up. Looking back on those conversations, the topics discussed were the aspects of psychiatry that most bothered Pete at that time: problems with drugs, continuity of care, identity issues and rebuilding your life after an illness. By focusing on Pete's experiences of recovery, both in the sense of his experience of recovering from psychosis and his ideas on today's recovery era in mental health care, it became clear how they are in tension with more professional enactments of recovery as mental health care policy and practice (McWade, 2016). For example, although recovery is conceptualized as a non-linear and unique journey towards living a meaningful life, Pete experienced that he was often urged by psychiatric staff to lower his aspirations for his future (e.g. having a job, having a social network outside psychiatry). These low expectations of staff show how a medical approach of mental illness is still present in mental health care, characterized by thinking in terms of deficits rather than strengths and the assumption that mental illness is chronic. Moreover, the challenges that Pete faced during his recovery process were all of a social nature, such as fighting stigma, coping with social isolation and rebuilding his family life. However, during his admissions, these vulnerabilities were often not perceived as of a social nature but as intrapersonal. Also, Pete experienced that he was reduced to a 'person with an illness' and that other aspects of his identity (being a father, poet, citizen) became invisible. In that sense, Pete's experiences illustrate how individualized conceptualizations of recovery (e.g., the CHIME framework) fall short in addressing the social and interactional nature of both mental illness and recovery (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). In other words, today's recovery ethos simultaneously appears as a hopeful vision of empowerment and an expert-driven discourse that fails to address the social realities of people in recovery and in which diagnoses still have a major impact.

Discussing these tension points resulted in a critical paper about the professionalization and operationalization of the recovery concept (De Ruysscher, Tomlinson, Vanheule, & Vandevelde, 2018). As with the data collection and analysis phase, the writing process was also completed in a co-creative way. This is well illustrated by the way we dealt with the conversation data. The original conversations took place in Dutch and were transcribed by Clara. However, based on the agreed themes, extracts were selected and translated into English by Pete (a native English speaker). This gave Pete the chance to revisit his ideas in detail, rephrase what he had said and add nuances. In addition, Clara gained insight into Pete's experiences by reading his poetry and through email conversations during the research

process. This way of working is in contrast to a more traditional interviewing process in which the participant is often not given much space to reflect upon the questions, since all processing and interpretation of ideas is done by the researcher alone. Clara also provided relevant academic papers on recovery that were read together, which gave Pete more confidence in using the philosophical vocabulary that he had developed passively over many years of reading but had never used in his writing.

## 6.3 *"I'll play it first and tell you what it is later"*: bricolage

In line with Miles Davis' famous jazz premise, it was only after we started recording our conversations that we sought inspiration from methodological concepts that could help describe the journey we were traveling. In doing so, we found several points of recognition in the field of critical pedagogy, more precisely in the concept of *bricolage*. The concept first appeared in *The Savage Mind* of anthropologist Lévi-Strauss (1968), who uses bricolage as a metaphor to advocate a multi-faceted approach to meaning-making in which fieldworkers assemble and combine all possible tools available (e.g., observations, hypotheses, social practices, dominant discourses, narrative techniques) to produce relevant knowledge (Earl, 2013; Lévi-Strauss, 1968; Rogers, 2012). At a later stage, the concept of bricolage was adopted by Denzin and Lincoln (2011) who define bricolage as a multi-methodological research approach that adds rigor to social inquiry, because it respects the complexities and contradictions of the social world. Building on Denzin and Lincoln's work, Kincheloe (2001) describes critical bricolage as a continuous hermeneutic search for more layered and rigorous ontological insights, starting from the assumption that *"any social, cultural, psychological or pedagogical object of inquiry is inseparable from its context, the language used to describe it, its historical situatedness in a larger ongoing process, and the socially and culturally constructed interpretations of its meaning(s) as an entity in the world"* (p. 682). Rooted in an *epistemology of complexity* (Kincheloe, McLaren, & Steinberg, 2011), researchers-as-bricoleurs thus recognize that knowledge is always temporary, questionable, ever-changing, specific to the cultural context and subject to power dynamics at play (Kincheloe, 2001). In search of richer and more complex forms of knowledge, bricoleurs apply an active attitude towards research methodology. Rather than predetermining and passively following standard research methods and procedures, they allow the context to prompt relevant questions and creatively combine empirical methods in a quest for understanding (Van Hove, De Schauwer, & Platel, 2017). In this process, a central place is given to forms of knowledge 'from the margins' which do not fit established research formats, and thus often remain unheard or are considered invalid. In this way, they challenge the dominant

researcher-as-neutral-observer versus research subject-as-passive-object dichotomy and consider the research process itself a political act, aiming to disrupt such power relations (Rogers, 2012).

Whilst the concept of bricolage offered us some theoretical and practical guidance during and after our research process, we also made our own interpretations of some of its core ideas. The methodological flexibility that is an important feature of bricolage is also characteristic of our research process, in which there was no predetermined research plan to determine the course of our journey and no interview guide to structure our conversations. Instead, each step of the process was allowed a dynamic of its own and shaped the next step. This flexible, step-by-step approach generated a creative dynamic between us, in which we freely reflected out loud, generated and discussed hypotheses and shared our thoughts and doubts about the subject matter. These dynamics added to the unpredictability and openness of the research process but at the same time meant that we gradually developed a common language with which to talk about Pete's experiences of recovery and mental health care. This common language made it possible for us as co-writers to continuously learn from each other, refine our own viewpoints and enrich each other's writing. Importantly, this common language neither represents the researcher as the knowing observer nor the untouched lived experiences of the research subject. Of course, our research relationship remained asymmetrical – the study focused on Pete's lived experiences, not Clara's – but was not characterized by an epistemological hierarchy. Instead, we would describe our relationship as one of colleagues in a multidisciplinary cooperation. As Clara is a qualified researcher in Special Needs Education, her staff/researcher perspective contrasts with Pete's experiences of mental health care as service user. Additionally, although we are both writers, we differ in age, gender, social class, academic schooling, native language and lifestyle. Rather than trying to neutralize or 'objectify' these different subjective perspectives, our research journey can be seen as a relational meaning-making process, as knowledge was constructed precisely in the interplay and tensions between our unique, at times divergent or even contradictory, voices and perspectives (Frølunde, 2013; Phillips, 2011).

## 6.4 Dialogue as ethical imperative

The aim of this paper is to share reflections and experiences on the co-creative research journey that we – Clara and Pete – have traveled together. In that process, aware of the power imbalances at play in mental health care practice and academia, we searched for a research approach that did not reproduce epistemic violence and allowed for more equal ways of relating to each other as researcher and research subject. Along the way, we found theoretical and methodological inspiration in the concept of bricolage,

which can be described as a continuous search for more rigorous forms of knowledge production, working to expose complex social realities and disrupt dominant social discourses by giving a central position to subjugated and marginalized voices (Rogers, 2012). Whereas Kincheloe (2005) argues that such rigor can be achieved through methodological flexibility and the use of critical hermeneutics, we experienced the necessity of a radical and far-going collaboration between us in every step of the research and writing process. It was the ethical imperative to continuously keep an open-ended dialogue between us alive that provided our research process (and the knowledge we produced) with rigor. Based on this experience, we elaborated our own interpretation of the rejection of *monological* research in bricolage. Kincheloe (2005) rejects (positivist) research as monological when it ignores the complexity of lived reality and fails to address research subjects as *things-in-the-world* (rather than static *things-in-themselves*). However, we view research as monological when it fails to disrupt the epistemic hierarchy between the researcher and the research subject and thus reproduces mechanisms of epistemic violence. Applying a dialogical approach to mental health care research is not merely a methodological choice, but above all an ethical responsibility. Building on the work of Bakhtin (1981, 1984), Frank highlights two core characteristics of dialogical research: creating space for the *narratability* of the research subject's experiences (Frank, 2002) and respecting the *unfinalizability* of the research process (Frank, 2005). In what follows, we will reflect on both characteristics in relation to our bricolage journey.

Talking about the dialogical ethics of narrative analysis, Frank (2002) argues that what constitutes a story lies in its *narratability*, i.e. the extent to which *"events and lives are affirmed as being worth telling and thus worth living"* (p. 111). Applied to our research process, the central importance of *narratability* is best illustrated by asking ourselves the following question: what benefits did Pete get from engaging in this collaborative research project? For Pete, researching his own situation made it possible to tell a clearer and more stable story of what happened to him, which was crucial in getting perspective on his own life and recovery process. This is in contrast to previous experiences (both in and out of psychiatry) in which his personal perspectives were trivialized or reduced to a psychiatric label, leaving no room for Pete's actual story. He articulated this in the following way in an email to Clara: *"Writing this article, together with other extensive writing in poetry and quasi-scientific prose has made my recovery possible, and literally on my own terms. My vision of myself and my situation does not begin with a formula urged on me by a psychiatrist".* In other words, creating space for the *narratability* of Pete's perspective on his recovery and treatment did not only make his experiences visible, but also attributed a sense of reality to them. Looking back on our bricolage journey, several factors have contributed to a research dynamic in which this space was continuously (re)shaped and kept open: the methodological flexibility, the openness of our research agenda, and especially the fact that we developed a common language that

allowed us both at any stage to exchange and revisit ideas, add nuance and return to our steps when necessary.

Related to the idea of *narratability*, Frank (2005) also refers to the importance of respecting the principle of *unfinalizability*, i.e. the avoidance of any monological interpretations or fixed descriptions of people's personal experiences and perspectives. Considering dialogue as a process with no predefined beginning or end, he highlights how *"in a dialogical relation, any person takes responsibility for the other's becoming, as well as recognizing that the other's voice has entered one's own"* (p. 967). In other words, in the dialogical process, the researcher and research subject find themselves in an equal and co-creative relationship that is characterized by interdependence, a continuous mutual influence and the recognition of each other's unique perspectives and vulnerabilities (Granek, 2013). Aware of the *unfinalizability* of Pete's experiences and our research process, we did not aim to give a finalized representation of 'who Pete is' nor to seek consensus between Clara's academic perspective and Pete's experiential voice. Although our research is the result of the dynamic that occurred when we came together in a shared space and time and influenced each other, it also cannot be understood as a mere reflection of a personal process between us. Whilst Pete's experiences all involve him, most of them also involve other people or interactions with (his ideas about) society as a whole. Likewise, Clara's ideas on recovery and mental health care are shaped by several professional, personal and academic influences. Consequently, our encounters gave shape to an ever-changing field of arguments, infused by a multitude of perspectives and voices (Frank, 2005; Leong, Wright, Vetere, & Howard, 2010). Characteristic to this field is that the researcher and the research subject do not aim to finalize one another, which makes it hard or even impossible to reach a fixed synthesis; emerging tensions between different perspectives are not resolved but explored and made visible. Instead, in line with the idea that *"the meaning of any present story depends on the stories it will generate"* (Frank, 2005, p. 967), our collaborative research project should be considered a small part of an ongoing process and above all an invitation for readers to join in our dialogue. Drawing a monological portrait of Pete based on his experiences would have been unethical, for it would reduce him to a static description, denying him the right to outgrow or change his perspectives, thus reinforcing power inequalities and mechanisms of epistemic violence.

Looking back on our research process, it was only through discussing Pete's personal experiences so extensively and dialogically that we could expose tensions and gaps in today's mental health care (i.e. the professionalization of recovery) in such depth. Indeed, it has been argued that micro-level experiential knowledge holds the potential to address wider political and social developments and to challenge dominant discourses (Stanhope & Solomon, 2007; Swerdfager, 2016). However, connecting experiential knowledge to wider policy developments is only possible when the experiences of persons

with mental health problems are *narratable*, both to themselves and others, and seen as *unfinalizable*. Assuming that their perspectives are crucial for understanding recovery and should form the foundation of recovery-oriented policy and practice (De Ruysscher, Vandevelde, Vanderplasschen, De Maeyer, & Vanheule, 2017; Stanhope & Solomon, 2007; Velpry, 2008), *narratability* and *unfinalizability* are indispensable principles, as they give dialogical research the potential to unsettle entrenched ideas about other people's realities (e.g., living with mental health problems) and to dismantle them from their static character (Frank, 2005).

## 6.5 Concluding reflections

It was not our intention to present our collaborative journey as a 'best' methodology for conducting co-creative or dialogical research. Rather, by unraveling our research process, we aimed to share reflections on the methodological openness of applying a bricolage approach and the ethical implications of developing a more equal research relationship. Keeping the heterogeneity of lived experience and the diversity of co-creative research trajectories in mind, we want to conclude this article by reflecting on a number of specific circumstances that had an impact on our research process.

A first important factor is the place and context in which we met and had most of our conversations for this research project: Villa Voortman. An essential feature of this meeting place is that it works as horizontally as possible. In Villa Voortman, power inequalities (e.g., between staff, volunteers and service users) are minimized, in strong contrast to the strictly hierarchical structures of other psychiatric settings (De Ruysscher, Vanheule, et al., 2017; Vandevelde et al., 2015). Villa Voortman as a place that facilitates equal encounters has undoubtedly helped shape the dialogical way in which our research relationship (and friendship) was built. In addition, a number of personal factors have shaped our collaboration. Besides the fact that Pete has the lived experience of dealing with psychosis and being a service user of mental health care facilities, he also considers himself in an advanced stage of his recovery process and has followed a training course to become a qualified peer worker. As Clara is in the final stage of her PhD which focuses on recovery of persons with complex mental health needs, her thinking on recovery has developed and progressed under influence of previous research projects, encounters with other (ex-)service users and academics, and critical literature (e.g. Mad Studies). However diverse our backgrounds and experiences may be, they did lead us to a shared strong interest in conceptualizations of recovery and the organization of Flemish mental health care. Also, Pete's competences of being a native English speaker and an active writer (prose and poetry) fit well within the academic standard of writing scientific papers.

Whilst these specific factors brought us together and defined the shape of our research relationship and process, they also made us aware of the singularity of our collaboration. If we want to move from monological research that reproduces epistemic violence to more dialogical ways of knowledge production, we face the ethical responsibility of engaging in an ongoing search for appropriate research approaches in each specific context that respect the idiosyncrasy, *narratability* and *unfinalizability* of (lived) experience. Such approaches can take many shapes and sizes, but all open up dynamic spaces in which knowledge is continuously produced and rethought in the intersections and tensions between multiple voices and perspectives. In our quest for such spaces, it might prove worthwhile to explore methodologies that go off the beaten track of traditional academic approaches.

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# Chapter 7

# General discussion

## 7.1 Outline

This research project aimed to gain understanding of (1) what it means for persons with complex mental health needs to be in recovery and (2) how the recovery processes of persons with complex mental health needs can be supported. The search for answers to these research questions took the shape of a non-linear bricolage trajectory. Reflecting back on this trajectory, however, three distinct research phases can be discerned, both regarding the way recovery was conceptualized and regarding my own position as researcher in this project (cf. Figure 1, p. 13). In the first phase, recovery was studied by means of a systematic review in which I summarized and re-interpreted the findings from existing literature on recovery from the perspective of persons with 'dual diagnosis' (cf. Chapter 2). In the second phase, I studied the roles and functions of two mental health care settings in the recovery processes of persons with complex mental health needs (cf. Chapters 3 and 4). To do so, I immersed myself in the daily practices of these places and conducted in-depth interviews with all actors involved. In the final phase of this research project, I traveled a co-creative bricolage process together with Pete, an expert by experience, in which we shed critical light on the way recovery is conceptualized in today's mental health care (cf. Chapters 5 and 6).

The aim of this general discussion is to reflect on the most important insights from the different studies and their implications for mental health care policy, practice and research. First, I will reflect on the changing perspectives on recovery throughout this work and build a case for relational enactments of recovery. Building on these relational ideas, I will draw parallels between both location-based studies in this work to reflect on the role of mental health care settings in the recovery processes of persons with complex mental health needs. More precisely, I will propose to think of recovery-oriented systems of support as diverse landscapes of enabling places. To conclude this thesis, I will look back on how I experienced my position as researcher throughout this research project, and look forward by sharing some suggestions for future research into mental health care and recovery.

## 7.2 Recovery: a contested framework

One of the main aims of this research project was to unravel what it means for persons with complex mental health needs to be in recovery. During my search for answers through the different studies, my thinking about the recovery framework continuously evolved, as it was questioned, deepened and enriched by other ideas and perspectives. In what follows, I will give a brief overview of these changing perspectives and elaborate on how the insights from this research project can contribute to today's debate on recovery-oriented practice, policy and research.

### *7.2.1 Changing perspectives on recovery*

This research project started with a systematic review (cf. Chapter 2) that offered a zoomed-out perspective on recovery in persons with 'dual diagnosis', by synthesizing existing qualitative research that started from a first-person perspective. In that study, four main themes as facilitators of recovery came to the fore. The first theme, having helpful social relationships, stresses the importance of support from family and peers and having a sense of community belonging. The second theme focuses on the role of treatment and points out the need for an individualized and holistic approach that promotes self-determination and inclusive citizenship. In such a treatment approach, continuity of care and therapeutic relationships are considered to be essential. The third theme focuses on personal beliefs such as installing feelings of hope, gaining a positive sense of identity and having a sense of self-responsibility. The final theme that was identified in the systematic review is the need for meaningful activities as an important catalyst of recovery. These themes fit well with recent conceptualizations of personal recovery in mental health such as the CHIME framework in which Connectedness, Hope, Identity, Meaning in life and Empowerment are put forward as central recovery processes (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). This framework has also been extended by Stuart et al. (2017) with additional processes such as the impact of social difficulties, (dis)empowering experiences, self-compassion, the desire to return to 'normalcy' and concerns regarding treatment. At the same time, the findings from the systematic review remain merely descriptive, as they do not touch upon the way the identified facilitators are interrelated and embedded in the lives of persons with complex mental health needs (e.g. *how* recovery unfolds over time). In other words, although these facilitators provide a sense of the clinical utility of the recovery concept, they still fail to grasp the personal experiences of recovery and *"the diversity of bodies, spaces and objects that facilitate, or otherwise participate in, each recovery event"* (Duff, 2015, p. 59). Stuart et al. (2017) also acknowledge the limitations of such overarching conceptualizations of recovery, as they often insufficiently address the dynamic interactions both within and between different aspects of recovery processes.

It was only in a later phase of the research project, when I embarked on the co-creative trajectory with Pete (cf. Chapters 5 and 6), that I gained a more layered and detailed insight into how recovery ebbs and flows in the lives of persons with complex mental health needs. Pete describes his recovery as a process of life rebuilding in which he considers family life, having a social network and reconnecting with his identity (e.g. father, poet, philosopher) of great importance. Other themes that prominently came to the fore during our many conversations were the role of drugs in his recovery trajectory and the necessity of individualized support and continuity of care. However, the results of our co-creative study went beyond a mere description of Pete's recovery, as it was precisely by going so in-depth into his singular story that a number of striking gaps and inconsistencies between his lived experiences of

recovery and dominant professionalized recovery ideas became visible. For example, it became obvious how in Pete's treatment trajectory, mechanisms of diagnostic overshadowing, a medical gaze and the assumption that mental health problems are of a chronic nature were still (latently) present. Also, despite the fact that the social vulnerabilities that Pete faces (e.g. social isolation, stigma, the struggle to rebuild a social network) have a defining impact on his recovery process, they largely remained out of the picture during treatment. Even more so, Pete experienced how new wordings to describe persons with mental health problems that aim to have a strengths-based orientation (e.g. 'persons with psychological vulnerabilities') in reality still contain deficit-oriented and categorizing connotations.

In short, the findings from the co-creative study with Pete painfully exposed how a subtle but far-reaching shift has taken place in the role of the recovery concept in mental health care. Whereas recovery first emerged as an activist philosophy advocated by (ex-)service users who stood up against stigmatizing practices, the overly medical focus and unequal power dynamics in psychiatry, it now represents a professionalized discourse that contains many contradictions, has lost its activist spirit and is at times far-removed from the everyday realities of persons in recovery (Beresford, 2015; Hunt & Resnick, 2015; Roberts & Boardman, 2013). Acknowledging and problematizing this shift, the question now arises as to how we can think of recovery in a way that is more in harmony with its original service user-led ethos; how we can prevent the concept from being further eroded to a floating signifier; and how we can move forward with recovery as a guiding principle in supporting persons with complex mental health needs. In the following section, I will share a number of overarching insights from this research project regarding recovery that can be seen as sensitizing reflections in search of answers to the above questions.

### *7.2.2 Moving forward with recovery*

It was not the intention of this research project to come up with a 'new', 'better' or 'specialized' framework of recovery in persons with complex mental health needs, as each (professional) conceptualization inevitably entails a reduction of the lived realities of the persons who experience recovery first-hand. Keeping this in mind whilst looking back on my research process, I want to share some reflections regarding recovery that can be traced back to my participants' lived experiences and helped me find clarity in the discursive cobwebs surrounding the concept.

*Enactments of recovery*

If there is one hypothesis that can clearly be confirmed through this research project, it is the following: we (as individual professionals, policy makers, researchers, persons with lived experience) do not all talk about the same thing when we talk about recovery (Stuart, Tansey, & Quayle, 2017). Indeed, several authors have warned that recovery has become a floating signifier that has many divergent connotations and is used to represent a wide variety of visions, expectations and agendas (Hopper, 2007; Pilgrim, 2009). However, thinking about recovery in terms of *enactments* offers an inspiring alternative that holds the potential to overcome this conceptual confusion (McWade, 2015, 2016). More specifically, I can see two ways in which the idea of enactments can help us move forward in thinking about recovery.

First, it is beyond dispute that recovery is a *"deeply personal, unique process"*, to say it with Anthony's (1993, p. 527) words, that is characterized by gaining a sense of self-determination, finding meaning in life, building hope-inspiring relationships and having a sense of self-responsibility (Schrank & Slade, 2007). As a consequence, no two recovery processes are the same. For example, Pete's experiences have shown how he gradually crafts and shapes his recovery trajectory, depending on the resources he has access to, embedded in his specific lifeworld with all its facilitators and pitfalls, and attuned to his personal aspirations and changing needs. Acknowledging this diversity and idiosyncrasy, each individual recovery process can thus be seen as an embodied experience, a unique enactment, of recovery. During our research process, Pete repeatedly reminded me of the importance of respecting this singularity by claiming that he *"wants to be treated as an exception"* rather than a prototype of how recovery occurs. This also puts into perspective the practical use of existing (personal) recovery models and frameworks (e.g. CHIME-D), as they are unavoidably limited in their reach to capture these singularities (Leamy et al., 2011; Stuart et al., 2017). At the same time, acknowledging this singularity implies that the co-creative study with Pete unavoidably has limitations, as the findings from that study are solely rooted in Pete's singular experiences of mental health problems and recovery. Consequently, although other persons in recovery might recognize similarities and overlaps between Pete's story and their own experiences, it is likely that they also divert in some aspects. Rather than presenting the findings as universal insights about recovery, I am aware that, to do justice to these idiosyncratic enactments, there will always be a need for additional research to strengthen, diversify and nuance the patchwork of experience-based research.

Second, particular enactments of recovery cannot only be linked to the idiosyncrasies of persons with mental health problems, but are also brought into being through each context, practice and relationship in which recovery takes place (e.g. mental health care settings, family, neighborhood) (McWade, 2015).

In other words, each mental health context (in the broadest sense) embodies specific ideas on the onset and course of mental health problems, materializes different philosophical stances regarding what recovery should look like, (re)produces certain activities and uses a particular discourse to talk about persons in recovery (Chester et al., 2016; McWade, 2016; Tucker, 2010). For example, the discursive particularities of different enactments can be illustrated by looking at the two mental health care settings that were studied in this research project, i.e. an alternative community-based meeting place and a residential psychiatric ward (cf. Chapters 3 and 4). Although both settings offer support to the same group of persons with complex mental health needs, they are called 'visitors' in the meeting place and 'patients' in the residential ward. Also, zooming in on Pete's experiences during our collaborative case study uncovered how, in the professional support he received, recovery enactments that embody deficit-oriented perspectives, in which persons with mental health problems are seen as chronic and passive patients, are still latently present and keep seeping through more hopeful discourses of empowerment and person-centeredness. Additionally, Pete often experienced that the provided support was disconnected from his lifeworld and focused too much on 'getting better' as an intrapersonal process of transformation. This is problematic in a number of ways. First, processes such as rebuilding one's identity, finding meaning in life and gaining a sense of hope for the future are placed in an intrapersonal vacuum (Rose, 2014). Second, it fails to address the mechanisms of social exclusion (e.g. social isolation), detrimental effects of stigma and difficult living circumstances (e.g. poverty, homelessness) that have a significant impact on the daily lives and recovery processes of persons with complex mental health needs (Harper & Speed, 2012). Even more so, by describing recovery as an individual (rather than a personal) process, the idiosyncratic nature of recovery risks being lost in translation and subtly replaced by a neoliberal notion in which *"the onus of recovery still rests squarely on the shoulders of self-governing consumers, who are implicitly encouraged to modify their personal thoughts, feelings and beliefs"* (Price-Robertson, Obradovic, & Morgan, 2017, p. 4). In other words, individualistic beliefs about mental health problems can be linked to a neoliberal enactment of recovery that promotes autonomous and independent citizenship, instead of collectivist ideals of social justice and inclusive citizenship (McWade, 2016; Vandekinderen, Roets, Roose, & Van Hove, 2012).

The above reflections illustrate how different enactments of recovery have come to the fore in this research project. To think about recovery in today's mental health care from a pedagogical perspective, some crucial characteristics of these enactments need to be stressed. First, all enactments are value-loaded, as they are each underpinned by specific ideas about 'good care', the position of persons with mental health problems in society and, essentially, what it means to be human (Moser, 2008). Consequently, asking which recovery enactments are at play in today's mental health care cannot be separated from the question of which values these enactments are based on. Moreover, these different

enactments are subject to material, institutional and relational power dynamics, causing certain enactments to be more dominant and to risk marginalizing others (McWade, 2019). This power play can most obviously be illustrated by pointing to the fact that, since the early 1990s, original activist enactments of recovery that were rooted in consumer/survivor/ex-patient (c/s/x) experiences have gradually been sidetracked and overpowered by professionalized discourses and enactments. This shift is heavily documented in Mad Studies literature, in which it is criticized as a 'hijacking' or 'colonization' of the recovery concept (Hunt & Resnick, 2015; O'Hagan, 2009; Rose, 2014). Attempts to resist this professionalization even led to the foundation of radical c/s/x collectives (e.g. 'Recovery in the Bin') who openly distance themselves from such medicalized, neoliberal and standardized enactments of recovery (http://recoveryinthebin.org).

It is vital to realize that dominant recovery enactments have a large influence on public opinion and thus hold the power to confirm or disrupt popular perceptions about mental health problems. Therefore, Moser (2008) warns how it is dangerous to reduce the multitude of enactments at play in a given social context to a mere case of differences in interpretation of that context, because they inherently have a deeply political character:

> *"The problem of difference – between different objects enacted in different sets of relations and contexts – is no longer a matter of interpretation and perspective. Instead, it has to do with multiple realities, and how these relate or co-exist. Further, a politics of nature is not simply about the power and politics of different perspectives and actors. If natural realities are enacted differently in different sociomaterial practices and arrangements, then it becomes important to explore the politics of the prevailing realities, the differences and patterns of interference that they make, and which realities we want to live with."* (p. 99)

Moser's warning shows how, by bringing in the idea of enactments, the debate on recovery and recovery-oriented support becomes politicized and moves away from thinking about recovery frameworks and models as incontestable and universal matters of fact. Ultimately, there is no way to position ourselves above or outside these enactments; each mental health experience, practice and context of recovery is inevitably political and loaded with certain values. Therefore, to move forward in our thinking about recovery, we have to ask ourselves the following questions: which values do we want to enact? Which philosophical stance regarding the lives of persons with mental health problems do we want to materialize? Which voices do we want to be resonating the loudest in recovery-oriented mental health care policy, practice and research? This research project has made it clear to me that, if we want to outgrow individualistic, overly medicalized, paternalistic or neoliberal enactments of recovery, we urgently need to move towards more social and collectivist ideas about mental health problems and

support that bring the ambitious and activist spirit of the original recovery ethos back to life. In my perspective, a relational enactment of recovery holds the potential to do so.

*Relational recovery*

From an (ortho)pedagogical perspective, persons are not seen as individual islands within society but as inherently part of complex systems of interactions and relationships (Vandevelde et al., 2017). Likewise, a relational enactment of recovery is rooted in the belief that people are relational beings, inseparably linked to their affective, social, material, structural and economic context (Price-Robertson et al., 2017). This ecological lens is also addressed in the substantial body of literature that focuses on the social and interpersonal aspects and contributors of recovery (e.g. Schön, Denhov, & Topor, 2009; Tew et al., 2012; Veseth, Binder, & Stige, 2017). However, within a relational enactment, the role of a person's context in recovery is taken a step further by asserting that recovery processes such as rebuilding one's identity, feeling hopeful about the future and empowerment are not merely facilitated or undermined by contextual factors, but are fundamentally impossible to imagine outside of these contexts (Price-Robertson et al., 2017). In other words, in the case of persons with complex mental health needs, their recovery processes cannot be disconnected from their complex everyday realities (e.g. street life, substance use, poverty, judicial problems, previous treatment experiences, stigma), as they are the scenes in which recovery comes about (Kavanagh & Mueser, 2007). At the same time, a relational enactment of recovery acknowledges and respects the idiosyncrasies and deeply individual ways in which persons with mental health problems try to build meaningful lives. In that respect, processes such as gaining self-determination, a sense of agency and autonomy are highly valued. However, in a relational approach, the importance of these processes is no incentive to consider recovery the individual responsibility of the ones who experience it first-hand. Instead, recovery is seen as a shared responsibility, materialized in the constantly on-going exchange between persons with mental health problems, informal and professional networks, the community and the wider social context (Hopper, 2007). In line with that, Vandekinderen et al. (2012) point out how such a relational recovery approach embraces inclusive and relational (rather than normative) notions of citizenship in which rights and responsibilities are continuously (re)shaped and (re)negotiated within these contexts.

Based on the above-mentioned arguments, relational recovery enactments hold the promising potential to rebalance power dynamics, to disrupt mechanisms of epistemic violence at play in today's mental health care, and to adopt a more activist attitude regarding the lives of persons with mental health problems. However, at the same time, I am aware that realizing this potential is a highly ambitious task, as medicalized and individualistic recovery logics have deep roots in our mental health care system,

psychiatry is an extremely complex domain that finds itself at the crossroads of several (social, political, economic, medical) developments and agendas, and most importantly, the voices of persons with lived experience remain insufficiently heard in policy and practice decisions. In essence, the original recovery advocates fought – and are still fighting in today's Mad Studies movement – to be seen as individuals with fundamentally similar rights, dreams and aspirations afforded to all. Therefore, I fully agree with del Vecchio (2006) who states that *"recognizing and celebrating this shared humanity should be our foremost priority"* (p. 646) in search of the most adequate ways to support the recovery processes of persons with complex mental health needs.

## 7.3 Building landscapes of support

Today, mental health care is going through a transition towards recovery-oriented systems of support. Therefore, a large part of this research project aimed at gaining understanding of how recovery processes of persons with complex mental health needs can be supported, by unraveling the daily practices of two settings that engage with this group (cf. Chapters 3 and 4). In this section, I will elaborate on the findings from these studies and their implications for mental health care policy and practice.

### *7.3.1 Two location-based studies: searching for common ground*

At first sight, the two locations under study in this work seem to find themselves at opposite ends of the mental health care continuum: an alternative meeting place in the community (i.e. Villa Voortman) and a residential ward located at a psychiatric hospital. However, a number of interesting parallels can be drawn between both studies/places.

A first commonality lies in the fact that both places are experienced as a safe haven, 'a place to be', in which persons with complex mental health needs can catch a breath and feel protected from a threatening outside world (e.g. street life, judicial problems, social isolation) and inner world (e.g. substance use, psychosis). In that sense, both settings fulfill the function of *asylum* or refuge, i.e. a sheltered holding environment in terms of space and time (Bachrach, 1984; Zenoni, 2012). At the same time, however, this asylum function is in a constant dialectic with another primordial function: creating strong links to the community. Both settings are grounded in a strong social orientation in which striving for inclusive and visible citizenship are considered to be essential in supporting recovery (Tew et al., 2012). In that respect, both the residential ward and the meeting place play the important role of

'quarter making' (*'kwartiermaken'* in Dutch), i.e. increasing the participation of their visitors/patients in society through creating niches of hospitality, both inside and outside their daily practices (Kal, 2011). In Villa Voortman, this is done for example by regularly inviting local neighbors and other interested people to get a taste of the meeting place's atmosphere (e.g. through the monthly 'Open Gate' events) and through engaging in artistic and creative projects (e.g. performing theatre, publishing poetry bundles, recording music). In the residential ward, this social orientation comes to the fore in the work of the 'road builders' who actively search and create hospitable niches in the community for their patients, and the case managers who support patients in their own environment. Also, by not providing an obligatory therapeutic program, patients are continuously invited and challenged to engage in meaningful activities in the community. In other words, what both settings have in common is that they are characterized by a high degree of permeability and porosity, as boundaries of what occurs inside and outside the meeting place and the residential ward become blurred (Curtis, Gesler, Priebe, & Francis, 2009; Quirk, Lelliott, & Seale, 2006). An important consequence of this porosity is that the provided support is better attuned to and embedded in the lifeworlds of the visitors/patients. Additionally, this porosity can be related to the strong awareness of both settings that empowering persons with complex mental health needs is next to impossible without fighting stigma and creating enabling environments in which they can have access to recovery resources (e.g. social and material capital) (Bryssinck, 2013; Tew et al., 2012).

Related to this, another parallel that can be drawn between the meeting place and the residential ward is that they apply a particularizing approach in which visitors/patients are encouraged to (re)connect with their identity. In Villa Voortman, this is facilitated by the fact that all activities taking place (e.g. cooking, making music, sculpting, philosophy, language workshops, poetry) are grounded in the personal interests, talents and strengths of the visitors. Consequently, through engaging in these activities, visitors start shaking off stigmatizing aspects of their identity (e.g. being mentally ill, being homeless) in favor of a more positive sense of self (e.g. being an artist, being a philosopher). At the residential ward, from the moment patients arrive at the ward, they are actively invited to formulate their expectations regarding their stay. In dialogue with staff members, patients are given space to shape their trajectories on the ward according to their personal meaning of recovery and aligned with their personal and social aspirations. In that sense, both the meeting place and the residential ward actively stand up against narrow and overly medicalized interpretations of identity and mental health problems. At the ward, however, this tailored and identity-focused approach is at times paradoxically hindered by the very fact that its daily practice is located at a psychiatric hospital, which in itself can have an alienating effect and implicitly confirms the patients' illness identity (Yanos, Roe, & Lysaker, 2010).

In order to work in an individualized, identity-focused and community-oriented way, another aspect that stands out in both daily practices is the need for an improvisational space in which the contours of support can continuously be (re)negotiated and rethought. At the ward, important factors that help creating this space are the lack of a one-size-fits-all therapeutic group program, having a negotiating approach to substance use and the fact that patients are given several opportunities to return to the ward after setbacks. In Villa Voortman, this improvisational space is maintained by the fact that all activities are organized on a voluntary basis and visitors can come and go as they wish. Moreover, rather than trying to control the daily practice by installing a large set of rules, only two rules apply: no violence and no substance use at the meeting place. However, both studies have also shown that this improvisational space can come under pressure. For example, in Villa Voortman, although there is a tolerant atmosphere, the sense of safety can be jeopardized by detrimental group dynamics (e.g. substance-related activities in the meeting place), which creates a difficult balance between the staff's inclination to take more control and the visitors' agency. At the ward, the space to improvise is at times threatened by hospital-level regulations of staffing (e.g. only having one staff member on the ward at weekends), safety (e.g. not allowing pets) and hygiene.

The above-described parallels and overlaps between both settings point us to a number of overarching conclusions. First, based on the experiences of the participants in these studies, it can be stated that both the meeting place and the residential ward play a valuable role in the recovery processes of their visitors/patients, which shows that recovery-oriented support is no exclusive terrain of community-based or outreaching mental health care. Also, in general, the findings from these studies tally well with other literature on recovery-oriented practice in which looking beyond psychiatric labels, providing individualized support, promoting community participation and focusing on inclusive citizenship are put forward as key aspects of support (Chester et al., 2016; Kidd, Kenny, & McKinstry, 2015; Le Boutillier et al., 2011). At the same time, however, it is striking how patients/visitors make use of these places in deeply individual ways, prioritize different functions and circulate between different settings (e.g. during my research I have sometimes encountered the same people in both settings), depending on the ups and downs of their recovery. Also, both studies have shown how their daily practices are shaped precisely in the tensions, harmonies, contradictions and complementarities between different approaches, perspectives and rhythms. For example, although simultaneously fulfilling the function of asylum and actively making connections to the community seems contradictory at first sight, the findings from both studies showed that it is precisely in this on-going dialectic that persons with complex mental health needs find helpful resources for their recovery. Moreover, trying to somehow 'solve' or erase these tensions would narrow down the improvisational space in which these resources are created, facilitated and provided.

The aim of the studies at Villa Voortman and the residential ward was to gain understanding of how the recovery processes of persons with complex mental health needs can best be supported. However, keeping the above reflections in mind (i.e. the deeply individual ways these places are used and the necessity of an on-going interplay of dynamics and tensions), the recovery-supportive contours of such settings cannot easily be captured in a set of active ingredients or clear-cut guidelines for recovery-oriented support. In my search for more guidance to understand and describe how the findings from these studies can help us move forward in thinking about adequate recovery-oriented systems of support, two theoretical lines of thought have been particularly helpful: (1) relational geographies and Duff's conceptualization of *enabling places* and (2) Broekaert's ideas on *holistic-integrative Orthopedagogics*. In what follows, I will briefly introduce both frameworks and use them as foundation to reflect on the implications of the findings from the two location-based studies in this research project for future developments in mental health care.

### *7.3.2 Enabling places*

As stated above, unraveling the daily practices of Villa Voortman and the residential ward did not provide us with ready-to-use recommendations on how recovery-oriented systems of support should be organized to respond to the needs of persons with complex mental health needs. Instead, both studies uncovered how these spaces fulfill multi-faceted functions and are experienced in various ways by their service users. However, insights from the field of relational geographies, in which the focus lies on the enabling (e.g. Moore & Dietze, 2005), restorative (e.g. Hansen-Ketchum, Marck, Reutter, & Halpenny, 2011) or therapeutic (e.g. Milligan, Gatrell, & Bingley, 2004) dimensions of places and environments, open up new lines of thought about this layered reality (Cummins, Curtis, Diez-Roux, & Macintyre, 2007).

Within the field of relational geographies, place is seen as the entanglement of several processes and interactions that *"link varied social, material, affective, symbolic and discursive elements, combining and recombining these elements in the production of durable, dynamic 'lived' place"* (Duff, 2012, p. 1389). In other words, places do not pre-exist as stable entities but are continuously and dynamically being (re)produced through (the interplay of) different human and non-human factors (Deleuze & Guattari, 1988; Tucker, 2010). Within this framework, Duff (2010, 2011, 2012) describes places as *enabling* when they produce resources that support health-related activities (e.g. the recovery processes of persons with mental health problems). More specifically, he identifies three types of enabling factors: material, social and affective resources. Material resources refer to tangible factors such as the fulfillment of basic needs (e.g. access to food, a place to sleep), the provision of important services (e.g. health care and

education) and financial benefits attached to place (e.g. paid employment). Social resources focus on interactions and processes that help build positive social networks. Affective resources include more lived and intangible dimensions such as feelings of belonging, generating hope, feeling optimistic about the future, and feelings of being 'attached' to a certain place (Duff, 2010, 2011, 2012).

All three forms of resources can easily be recognized in the findings from the studies in the meeting place and the residential ward. Also, Duff's division fits well with literature on recovery capital, in which social (e.g. family), physical (e.g. money), human (e.g. skills, aspirations) and cultural (e.g. values, social norms) capital are generally identified as important recovery resources (Best & Laudet, 2010; Cloud & Granfield, 2008; Tew, 2013). However, a fundamental premise within relational geographies is that the enabling properties of a certain place can never be seen as static characteristics: the value of material resources depends on the specific context in which these resources are provided and the intentions with which they are deployed; social resources are produced in the ever-changing dynamics of relationships and social networks; affective resources come about in the fluctuating encounters between an individual and his/her surrounding world (Duff, 2010). Instead, the enabling properties of places such as the meeting place and the residential ward should be seen as experiences that are generated precisely in the unique and dynamic convergence of the different material, affective and social resources of that place (Duff, 2011). For example, the asylum function that both the ward and the meeting place fulfill is constituted in the interplay of material (e.g. having shelter, a bed), social (e.g. the proximity of the staff) and affective (e.g. feeling safe, feeling welcome) resources.

Therefore, summarizing the findings from the two location-based studies in checklists of active ingredients for practitioners and policy makers would be of no added value, as it would fall short in capturing these convergences and dynamics. Instead, through applying a relational geographies perspective, the findings show how practices such as the meeting place and the residential ward can be seen as concentrations of processes and interactions, in which specific enactments of support and recovery are articulated, particular identities and subjectivities are embodied, and different powers and meanings are embedded (Darling, 2011; Parr, 2000). In that sense, to say it in a Deleuzian way, it proves more valuable to think of place in terms of its constant 'becoming', rather than its 'being' (Deleuze & Guattari, 1988).

### *7.3.3 The human prerogative*

Orthopedagogics is a science of action that aims to improve the quality of life, living situations and participation of persons who find themselves in vulnerable situations (Vanderplasschen, De Schauwer, & Vandevelde, 2015). Powered by this emancipatory incentive, Orthopedagogics has grown into a rich

and open field of practice and research that is underpinned by several paradigms of care (e.g. empirical-analytical, phenomenological-existentialist, social critical) and gives shape to a myriad of support modalities (Broekaert, Van Hove, D'Oosterlinck, & Bayliss, 2004). For example, although this research project specifically focused on an alternative community-based meeting place and a residential psychiatric ward, support for persons with complex mental health needs exists in many forms, such as therapeutic communities, pharmacological treatment, self-help, outreaching initiatives, harm reduction and outpatient mental health care (Drake et al., 2001; Horsfall, Cleary, Hunt, & Walter, 2009). On the surface, these different scientific paradigms and support modalities can seem contradictory or exclusive of each other. However, to refute these seeming contradictions, Broekaert (2010) points out that support should be organized starting from a holistic-integrative approach in which different paradigms and modalities are inherently connected and complementary in their endeavor to find the best solution for a given situation. He describes this as the 'human prerogative of care', i.e. the shared dedication to support persons in vulnerable situations in the best possible way. Consequently, in integrated systems of support, no modality can in itself be seen as 'more appropriate' or 'better qualified' to support persons in vulnerable situations. Instead, support takes the shape of a continuous, flexible and meaningful quest in which several modalities, underpinned by any paradigm of care, can be valuable to respond to the service user's needs, expectations and aspirations (Broekaert, Autrique, Vanderplasschen, & Colpaert, 2010).

### *7.3.4 Towards recovery-oriented landscapes of support*

Whilst current mental health care is in full transition towards recovery-oriented systems of support, persons with complex mental health needs are still considered 'hard-to-reach' and risk falling between the gaps of existing support modalities (Bryssinck, 2013; Kidd, McKenzie, & Virdee, 2014). Therefore, one of the central questions of this research project was the following: *How can the recovery processes of persons with complex mental health needs be supported?* The findings from the studies in the meeting place and the residential ward have shown how both settings each fulfill several functions and, likewise, are used and experienced by their service users in various ways. Moreover, inspired by ideas from relational geographies, it became clear how these places cannot be pinned down on these functions, as they are continuously being shaped and reshaped in the interplay of different material, social and affective resources (Duff, 2011). As a result, support modalities can only be labeled as recovery-supportive by persons who are in recovery themselves and who experience the daily practices of these modalities first-hand. Additionally, insights from holistic-integrative Orthopedagogics have pointed us to the necessity of building diverse networks of support that are infused by the human prerogative of

care in order to provide the most adequate support for persons with complex mental health needs (Broekaert et al., 2010).

Based on these insights, I propose to think of recovery-oriented systems of support in terms of diverse landscapes that are dotted with enabling places in which persons with complex mental health needs find appropriate material, affective and social resources, tailored to their recovery process. Although this research project has specifically focused on formal support modalities, these enabling places can be found both in professional and more informal contexts (e.g. parks, private homes, work) (Duff, 2011). Building on the findings from this research project, a number of important underlying principles of mental health care settings within such landscapes of support can be identified: (1) applying a person-centered and holistic approach, (2) maximizing continuity of support, and (3) opening up improvisational spaces.

*Person-centered and holistic support*

The insights from this research project have confirmed that recovery is a multi-dimensional and non-linear, at times fickle, process that takes place in deeply idiosyncratic ways, has an impact on all life domains and is inevitably intertwined with wider social and structural developments. To respond to this complexity, support should be organized from a person-centered and holistic perspective, in which persons with complex mental health needs hold the compass that gives direction to their support trajectories. Also, it should be recognized that persons in recovery can need (a combination of) different and seemingly contradictory forms of support (e.g. harm reduction and admission to hospital) at the same moment in their recovery process. Therefore, persons with complex mental health needs should be able to circulate between different (professional and informal) enabling places, tailored to the ebb and flow of their recovery. Consequently, recovery-oriented landscapes should to be characterized by a diverse array of support modalities. This also requires a specific attitude from mental health care professionals. On the one hand, little room is left for person-centeredness when professionals take on the role of expert and control the support trajectories of service users based on presupposed and professionalized ideas about what recovery means for persons with complex mental health needs. On the other hand, professionals should not take a distant attitude and place all responsibility in the hands of individual service users who ought to fully manage their own recovery trajectories, thus slip into neoliberal notions of care (Vandekinderen et al., 2012). Rather, to apply a person-centered approach, professionals should take the role of travel companions that actively support persons with complex mental health needs by engaging in an on-going dialogue about the latter's needs, aspirations and meaning of recovery in all its facets. Such dialogical relationships should always be grounded in the

belief that persons with complex mental health needs try to give meaning to their lives in fundamentally similar ways as persons without mental health problems (Slade, 2012).

*Maximizing continuity of support*

The recovery processes of persons with complex mental health needs have a slow course and are characterized by intense ups and downs (Priester et al., 2016). As a result, they are often in contact with support modalities for a long period of time, be it at times in fickle and unpredictable ways. To cope with this, it is invaluable to maximize continuity of support, in a number of ways. First, a flexible collaboration and exchange between different support modalities is necessary to avoid landscapes of support turning into fragmented and isolated islands of service provision. Second, provided support should be embedded in and attuned to the lifeworlds of persons with complex mental health needs to keep the alienating and disrupting effects of support (e.g. admissions to psychiatric hospital) to a minimum. Moreover, in doing so, the enabling effects of informal (e.g. family, neighborhood) and professional settings can be better interwoven and thus reinforce each other. Third, and most importantly, persons with mental health needs benefit immensely from having long-standing (formal and informal) supportive contacts and relationships that provide them with a sense of coherence and reassurance throughout their (unpredictable) recovery trajectories. Haggerty (2003) refers to this as *relational continuity*, which can be seen as the glue between past, present and future treatment and support experiences (Haggerty et al., 2003; Naert, Roose, Rapp, & Vanderplasschen, 2017). Providing relational continuity also implies that persons with complex mental health needs feel that support is present, accessible and available at any given moment in their recovery process, not just during moments of crisis. Methods such as case management and Open Dialogue could be helpful in maximizing this relational continuity (Hesse, Vanderplasschen, Rapp, Broekaert, & Fridell, 2007; Seikkula, 2001). Additionally, to provide continuity of support, it is crucial to respond to the needs of persons with complex mental health needs at the moment they arise. In that sense, the detrimental and slowing effects of seemingly endless waiting lists (e.g. for sheltered housing units) and the fact that service users are sometimes refused access to support modalities (e.g. based on past negative experiences) on recovery processes should not be underestimated.

*Opening up improvisational spaces*

In the findings from both location-based studies, it strongly came to the fore that, to be able to provide person-centered support that takes shape in dialogue with service users, organizations need to be granted space to improvise, to continuously rethink the contours of their daily practice and to color

outside the lines of more formal and traditional support options. However, the need for this improvisational space is often at odds with today's mental health care policy logic that is characterized by a desire for effectiveness, causing that organizations are urged to prove that they work in an evidence-based way and subsidies are dependent on measurable successes (Minkoff, 2001; Stanhope & Solomon, 2008). As a consequence of this logic, short-term treatment programs in which service users' progress can easily be evaluated (e.g. by measuring abstinence, treatment adherence, symptom reduction, stable living conditions) risk to be favored over settings that apply a long-term perspective on the recovery processes of persons with complex mental health needs and that leave room for ups and downs and the impact of challenging living circumstances. Moreover, as persons with complex mental health needs have difficulties finding connection to support within such an outcome-oriented logic, their image as 'hard-to-reach' service users or 'worrisome care avoiders' (*'zorgwekkende zorgmijders'* in Dutch) unintendedly gets reinforced (Bryssinck, 2013). To counteract this, and to open up improvisational spaces within recovery-oriented support landscapes, mental health care policy should find other, more creative ways of encouraging and financially supporting organizations in their pursuit of the best possible care for persons with complex mental health needs.

The above principles can be read as sensitizing recommendations for mental health care policy makers and practitioners who play important roles in creating enabling places and shaping recovery-oriented landscapes of support. As these recommendations are essentially rooted in the lived experiences of persons with complex mental health needs themselves, I hope they can broaden the horizon of existing systems of support and help us move towards more relational enactments of recovery. Whilst this research project identified a number of important contours of such landscapes, some limitations can be identified. For example, these location-based studies did not focus on the roles of informal enabling places in the recovery trajectories of persons with complex mental health needs. Another limitation lies in the fact that these studies did not address how persons with complex mental health move between various places over time (e.g. throughout their entire recovery process) and what factors they experience as helping or hindering this 'freedom of movement'. In other words, future research is necessary to gain further understanding of the ways persons with complex mental health needs navigate between enabling places, to build knowledge on the roles of informal enabling places in recovery processes and to further scrutinize how mental health care organizations situate themselves and collaborate with each other within recovery-supportive landscapes.

## 7.4 Rethinking research relationships

*"On the back of desire you fly along rhizomes away from a stable and universal identification as a 'pedagogue', 'support worker', 'activist', 'researcher', 'mother', 'friend', and 'academic'. You discover always new connections and possibilities. You construct and reconstruct yourself over and over. You do not have to look for these processes very hard, they just happen. Desire gives you endless opportunities to keep in movement and continuously become by crossing borders, dichotomies, and categories. You are privileged to meet a multiplicity of differences."*

(De Schauwer & Van Hove, 2010, p. 14)

In the General Introduction of this thesis, I have pointed out how I experienced my research trajectory as a non-linear, unpredictable and challenging process of bricolage, shaped by the different (research) encounters I had and the stories I was privileged to listen to. It is beyond doubt that this research project has left a deep impression on myself as researcher, pedagogue and person. Along the way, an on-going flow of reflections was triggered within me about how I position myself as researcher, what it means to be an action-oriented scientist, and what it means to conduct research in and about psychiatry. Therefore, as final part of this work, I want to (1) look back on my trajectory by reflecting on how it impacted my experience of being a researcher and (2) look forward to future directions by reflecting on implications of this work for further research into recovery and mental health care.

### *7.4.1 Looking back: taking the plunge*

During my research trajectory, it became clear to me how, as an action-oriented scientist working with people in vulnerable situations, you are never a mere researcher. I can best illustrate this by looking back on my experiences in Villa Voortman. Throughout my entire PhD trajectory, I stopped by the meeting place nearly every week to catch up with visitors, worked as a volunteer in the daily practice, took part in team meetings and had the privilege to participate in two big theatre productions ('Utopia' and 'Avanti!') performed by *'De Voortmannen en –vrouwen'*. Although all these facets counted as far-reaching participant observations to back up my research, they illustrate how I fulfill multiple roles in the meeting place: I am a visitor, volunteer, witness, pedagogue, friend, student, and amongst all those roles, also researcher. Although I felt that it was impossible to disentangle these multiple roles, they often also led to feelings of discomfort. For example, because I spent so much time in Villa Voortman and because my participant observations were so far-reaching, it was at times difficult for visitors to understand that I was there with the incentive of doing research. Are they really aware of the way their stories are listened to in the context of my research (Cerwonka & Malkki, 2008)? Does that mean that

my research agenda is a *"dirty secret"*, as Morriss (2016) puts it? Also, at several moments I was confronted with the social exclusion mechanisms that visitors had to put up with on a daily basis. For example, witnessing situations where visitors have to get through the day in 'survival-mode', get stuck in destructive cycles of substance use or have no other option but to spend the night on the street, affected me enormously. Does my research have even the slightest impact on these realities? And, also, does my empathy mean that I am suffering from a *"bleeding heart hyperbole"*, jeopardizing the rigor and reliability of my research (Morriss, 2016)?

During, and thanks to, my co-creative trajectory with Pete, I was confronted with another form of discomfort: the unequal power relationships between researchers and participants (Swerdfager, 2016). In Chapter 6, I have extensively discussed how in dominant academic dynamics, research often slips into a scientific monologue in which the participants' lived experiences become compromised or shifted to the margins (Liegghio, 2013; Russo & Beresford, 2015). Although Pete and I both experienced that, through collaborating in a dialogical way, we somehow managed to disrupt or bypass these dominant logics, it made me question many other facets of my research trajectory that took place in less dialogical ways. In that sense, my collaboration with Pete has provided me with the biggest eye-opener of this research project, but also pointed me to the most pressing limitation of other aspects of this work. How can the dominant monological logic of academia, that I also help sustain, be reconciled with my position as critical orthopedagogue that aims to fight marginalization of suppressed voices in society?

In short, the list of examples and situations in which I was confronted with discomfort during my research is nearly inexhaustible. In literature, this discomfort is often glossed over, problematized or pictured as something that somehow needs to be 'resolved' to deliver high-quality and 'objective' research (Naert, Schiltz, & De Ruysscher, 2018). However, rather than trying to shake off this discomfort, I experienced that it was precisely by fully immersing myself in the daily practices I studied and by allowing myself to feel confused by the combination and collision of different roles, that I was pushed in the direction of the most relevant questions and insights. Embracing this multiplicity of roles made me experience situations in a different light, affected the way I listened to the stories of the participants and opened up new spaces of thought to question preconceived research ideas and theoretical constructs, and more than anything else, sparked the activist in me.

Fully taking the plunge in this research project and allowing my trajectory to take a bricolage course has provided me with a number of evolving insights about what it means to be an action-oriented researcher. I experienced how my position was shaped in a rhizomatic way; different facets of my identity alternated in the foreground and background and the contours of my role as researcher were continuously reshaped and rethought (De Schauwer & Van Hove, 2011). It is clear that my experiences

are not a plea for universalist notions of ('objectivist' or 'neutral') researcher positionality, but nor should they be read as relativist ideas about researcher subjectivity (Fassin, 2011). Instead, I can best describe my own trajectory as a kind of 'reflexivity while becoming' (Berger, 2015), a conscious and on-going relational process of discovering multiple layers in my own researcher positionality; of learning how I am affected by my research contexts and how they in turn impact my experiences as a researcher; of questioning my own moral position; of seeking for ways to maneuver in the direction of new niches that help me understand, address and improve the lived realities of persons in vulnerable situations (Ellis, 2007). Such a 'reflexivity while becoming' thus acknowledges the inevitable but necessary entanglement of knowledge construction and the ethical and political engagement of action-oriented research (Naert et al., 2018). In that respect, I agree with Rancière (2007) in the sense that, as action-oriented researchers, we are never mere privileged spectators of a certain social reality but undeniably become part of it: *"Emancipation starts from the principle of equality. It begins when we dismiss the opposition between looking and acting and understand that the distribution of the visible itself is part of the configuration of domination and subjection. It starts when we realize that looking is also an action that confirms or modifies that distribution, and that "interpreting the world" is already a means of transforming it"* (p. 277).

### *7.4.2 Looking forward: future directions*

This research project aimed to gain understanding of what it means for persons with complex mental health needs to be in recovery and how recovery-oriented support can best take shape. Throughout the different studies it became clear how the recovery concept is increasingly being professionalized and is drifting further and further away from the original activist and service user-led ethos. Moreover, it came to the fore how in mental health care practice, mechanisms of 'psychiatrization' and epistemic violence still have a large impact on the way persons with complex mental health needs experience the support they receive. Unfortunately, these professionalization trends and mechanisms of epistemic violence also echo loudly in academic research into mental health recovery. Being aware of the overpowering impact of these processes on the knowledge that we as researchers produce, presents us with the challenge to disrupt them and to actively search for alternative and more ethically responsible research practices. Based on the insights from this research project, I see two potential but radical ways to do so: (1) by widening the lens on evidence-based practice and giving a more central place to values-based practice, and (2) by conducting research in dialogical ways.

*Values-based practice*

Simultaneously with today's mental health care reform towards recovery-oriented systems of support, there remains an ever-increasing demand to deliver practices that are evidence-based and have proven their effectiveness (Davidson, Drake, Schmutte, Dinzeo, & Andres-Hyman, 2009). However, within these developments, what counts as evidence is often limited to quantifiable and measurable criteria, such as clinical outcome parameters (e.g. abstinence, therapy compliance, symptom reduction) and objective quality of life indicators (e.g. being employed, having a place to live) (Broekaert et al., 2010; Gilburt, Slade, Bird, Oduola, & Craig, 2013; Slade, 2010). On an organizational level, several standardized instruments (e.g. Recovery Oriented Practices Index (Mancini & Finnerty, 2005), Recovery Enhancing Environment Measure (Ridgeway & Press, 2004)) have been developed that aim to map the recovery-orientation of mental health practices and teams (Burgess, Pirkis, Coombs, & Rosen, 2011; Williams et al., 2012). Considering the reflections I made earlier regarding recovery enactments and recovery-oriented landscapes of support, such narrow and objectifying interpretations of evidence-based practice are not without risk. For example, the findings from the two location-based studies in this work have shown that the extent to which a support modality can be seen as effective or recovery-oriented is not a static characteristic that can be attributed to that setting, but instead is continuously (re)shaped in the interaction between that setting, individual service users and the wider context. Moreover, this research project has shown how recovery-oriented support should take the shape of landscapes that are composed of a wide variety of modalities, approaches and underlying paradigms, so that persons with complex mental health problems can navigate them tailored to the ebb and flow of their recovery. However, if we were to solely let us be guided by narrow and positivist interpretations of evidence-based practice, certain support modalities risk being pinned down as 'more' or 'less' effective or recovery-oriented without taking these interactions and the need for diversity into account. Even more so, favoring certain support modalities over others based on clinical outcome parameters or quantifiable criteria might (unintentionally) contribute to the reinforcement of less relational enactments of recovery in today's mental health care.

Stripped down to its essence, asking what recovery entails – be it as process, framework or practice – is a question about values. What values does one find important in his/her life (micro)? By what values are mental health support settings underpinned (meso)? What values do governments enact in their mental health policy (macro)? Also, throughout this research project, it has become clear that there can be discrepancies between the values that a certain setting or policy claims to carry out and the values that are experienced in reality by service users (Khoury & del Barrio, 2015). If we want to gain a deeper understanding of these underlying values, we urgently need to expand our notion of what counts as 'evidence'. As stated above, Broekaert et al. (2010) also reject a hierarchical and narrow vision on

evidence-based practice and argue that an integration of different theoretical perspectives, research paradigms and types of knowledge is both inevitable and invaluable in the pursuit of the best possible support for persons in vulnerable situations. However, in that pursuit, I do not solely interpret Broekaert's *'human prerogative of care'* (2010) as our joint dedication to improve people's living situations and quality of life, but also as a collective striving for a shared values-base in theorizing about and organizing support (Fulford, 2011). In that sense, from my (orthopedagogical) perspective, I view values-based knowledge/practice not merely as a type of knowledge/practice among its evidence-based, theoretical and practice-based counterparts, but as the fundamental base underpinning any type of practice, research and knowledge.

In other words, if we see it as our collective prerogative to build relational recovery practices, these relational values should also be reflected in the research we carry out. Therefore, I join the many authors who have argued that evidence on recovery and recovery-oriented practice should be rooted in the narratives of persons for whom recovery is a lived reality (Beresford & Boxall, 2015; Rycroft-Malone et al., 2004; Tanenbaum, 2006). If we want to advocate relational enactments of recovery, this is of vital importance because, to say it with Faulkner's (2017) words, *"if the roots of the evidence are fundamentally flawed, there are serious implications for the nature of the evidence formulated – and therefore for the treatments and services perpetuated by these methods"* (p. 503).

*Dialogical practice*

It is clear that, to really do justice to the lived experiences of persons with mental health problems and to place them at the heart of mental health care research, we need to rethink traditional research relationships. In recent years, the Mad Studies movement, consisting of (ex-)service user researchers and practitioners, has gained momentum in activist and academic circles (LeFrançois, Menzies, & Reaume, 2013). Some voices in this movement aim to radically claim back ownership over discursive developments in the field by advocating that research into mental health problems and recovery can only be ethical when carried out by people with lived experience themselves (Crepaz-Keay, 2016; Russo, 2016). However, this research project – and especially the collaborative study with Pete – has shown that dialogical research practices, in which persons with lived experience and academics work together in a co-creative way, also hold the power to question and disrupt dominant and professionalized discourses of mental health problems and recovery. In Chapter 6 of this work, I extensively zoomed in on the bricolage characteristics and ethical implications of such dialogical research practices. To conclude this thesis, I briefly want to emphasize a number of insights that I consider of fundamental

importance if we want to move to a more dialogical and co-creative research culture in mental health care.

First of all, for co-creation to take place, experiential knowledge needs to be collectively recognized as a fully valued form of knowledge in the wider debate on recovery and recovery-oriented support. This implies that we (as researchers, professionals, service users) should collectively reject practices in which voices of lived experiences are silenced or marginalized, and challenge academic notions in which experiential knowledge remains situated at the bottom of the evidence hierarchy (Faulkner, 2017). Second, co-creation is much more far-reaching than simply involving the perspectives of persons with lived experience in research (e.g. as data source, executor of research tasks). Instead, conducting research in dialogical ways is an intensive and non-linear process that takes place *between* persons with lived experience and academics. A dialogical research process is one of tinkering and bricolaging together in all phases of the research trajectory; of searching for the most relevant research questions, of seeking out adequate research methods (regardless of whether they are to be found on or off the beaten track of academic standards), of keeping an *unfinalizable* dialogue going about emerging insights and ideas (Frank, 2005; Grey, 2016). Such a dialogical approach tallies well with relational enactments of recovery, as research relationships then become characterized by interdependence and an on-going exploration of tensions between perspectives rather than by a pursuit of one-sided analytical distance and unquestionable conclusions (Price-Robertson et al., 2017). Also, it should be our particular ambition to actively search for ways to engage in dialogical practice with people whose voices often remain unheard or are a priori marginalized because they are considered 'hard-to-reach': persons with complex mental health needs.

I want to conclude by sharing an eye-opening insight from Boevink (2018), an expert by experience and activist academic, who argues that 'experiential expertise' (*'ervaringsdeskundigheid'* in Dutch) should be seen as a competence rather than a personal characteristic of individuals in recovery. As professionals and academics in the field of mental health care (or as family members, friends, colleagues of persons in recovery), we might not have the lived experience of facing mental health problems, social exclusion mechanisms or difficult living circumstances. However, through co-creative practice, we can all build the lived experience of fully engaging in dialogue in all its facets; by taking the plunge, by allowing ourselves to feel affected and overwhelmed by the stories of the people we encounter in the field, by immersing ourselves in their daily contexts, by continuously searching for dialogical ways to keep the debate on the best possible support for persons with mental health problems alive.

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# APPENDIX 1

## English summary

## Research context and aims

Internationally, mental health care policy and practice are undergoing a remarkable shift towards recovery-oriented systems of support, motivated by a growing awareness that support should be tailored to the unique recovery processes and needs of its users (Cruce, Öjehagen, & Nordström, 2012; Slade, Amering, & Oades, 2008). Generally, recovery is described as a personal, non-linear and multidimensional process that is characterized by building self-determination and self-responsibility, having a sense of hope and belonging, feeling empowered, developing of supportive relationships and overcoming stigma (Anthony, 1993; Schrank & Slade, 2007). To support recovery processes, the following principles are often put forward as essential conditions: an individualized and person-centered approach, starting from a holistic rather than a medical perspective and focusing on the strengths and capabilities of the person with mental health problems (Gagne, White, & Anthony, 2007; Slade, Amering, & Oades, 2008; Torrey & Wyzik, 2000).

However, despite these developments, there remains a heterogeneous group that risks falling between the gaps of existing support: persons with complex mental health needs. As their everyday realities are often characterized by multiple personal and social problems (e.g. mental health and substance use problems, poverty, judicial problems, lack of social network, structural exclusion, and social isolation), the recovery processes of persons with complex mental health needs have a slow and unpredictable course, and are characterized by many ups and downs (Ness, Borg & Davidson, 2014).

Whilst there is consensus that support for persons with complex mental health needs should be characterized by an integrated and holistic approach (Minkoff, 2001), existing research mainly focuses on identifying barriers to treatment (e.g. lack of motivation, waiting lists, lack of specialized services) (Priester et al., 2016) and measuring clinical outcome parameters (e.g. symptom reduction, abstinence) (Chow et al., 2013; Hunt et al., 2013). What is often ignored is the way persons with complex mental health needs experience treatment and how it affects their recovery process (Lietz, Lacasse, Hayes, & Cheung, 2014). Even more so, although there exist support modalities that do seem to engage successfully with this heterogeneous group, the daily practices and the actual processes taking place in such places remain largely understudied (Chase et al., 2012; Farkas, Gagne, Anthony, & Chamberlin, 2005). Additionally, the social realities (e.g. homelessness, social exclusion, social isolation) that have a defining impact on the recovery processes of persons with complex mental health needs are heavily underexposed in existing recovery research (Hopper, 2007).

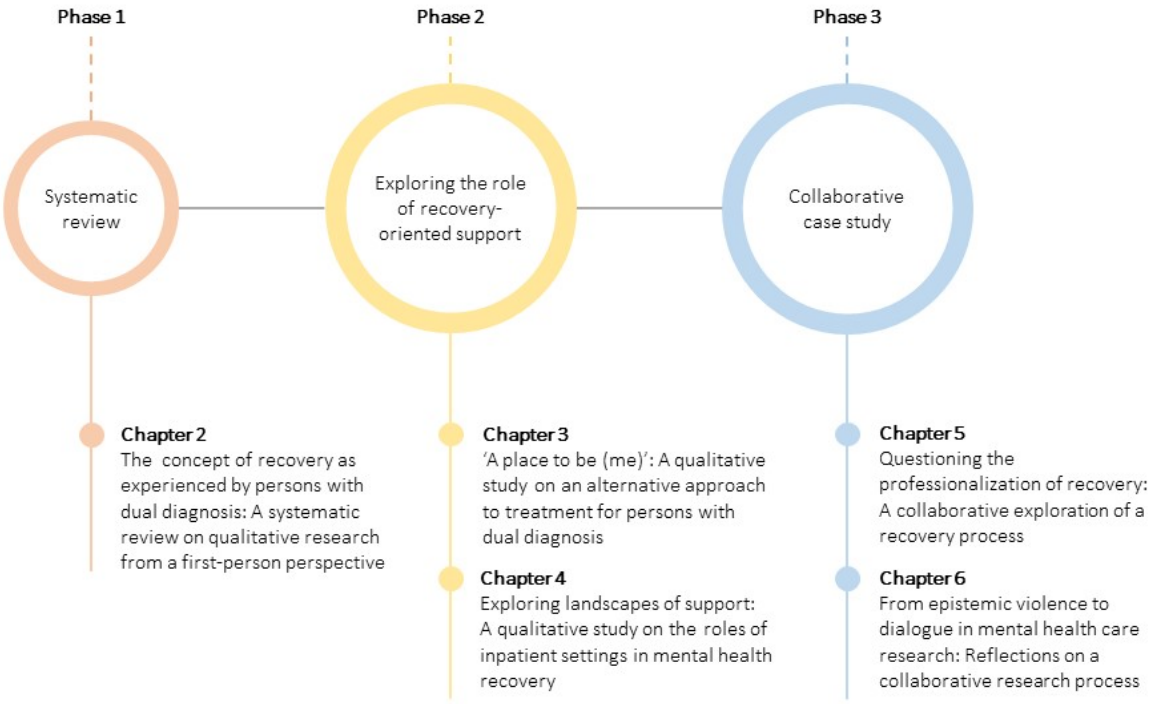
It is only by gaining understanding of the ebb and flow of recovery in the lives of persons with complex mental health needs that it becomes possible to organize more adequate and person-centered support

for this heterogeneous group. Therefore, this research project aims to unravel, in all its complexity, how persons with complex mental health needs experience their recovery, how and where they find helping recovery resources and what roles professional support modalities play in their recovery trajectories. These aims can be translated into the following main research questions:

1. *What does it mean for persons with complex mental health needs to be in recovery?*
2. *How can the recovery processes of persons with complex mental health needs be supported?*

In search of adequate answers to the above research questions, the lived experiences of persons with complex mental health needs are put at the heart of this research project. The reason for this choice is threefold. First, the question of how persons with complex mental health needs experience their recovery is in essence a phenomenological question. Second, it has been argued that qualitative research methods that focus on lived experiences and micro-level processes are the most adequate to gain understanding of recovery in all its complexity (Stanhope & Solomon, 2008). Third, the central position of lived experiences in this work is grounded in the ethical responsibility to give voice to people whose voices have traditionally been marginalized, in their everyday lives, in mental health care practice, and in academia.

More precisely, data are collected by means of (1) a systematic review of existing recovery literature based on first-person perspectives, (2) two qualitative studies focusing on recovery-oriented support as perceived by different stakeholders involved, and (3) a collaborative case study together with an expert by experience. The figure below provides a schematic outline of the three research phases of this PhD and how they relate to the different studies and chapters included in this thesis.




## Overview of the studies

Throughout the entire research process, three perspectives can be distinguished from which I studied recovery in persons with complex mental health needs: (1) from a bird's-eye view, (2) by visiting places that engage with this group, and (3) by going *en route* with a travel companion.

### *A bird's-eye view: zooming out on lived experience*

In the first step of this research project, that is described in *Chapter 2*, a systematic review was conducted that aimed to synthesize existing qualitative research on personal recovery that started from the lived experiences of persons with 'dual diagnosis' (in the first phase of the research, I still used that terminology instead of 'complex mental health needs'). Based on the analysis of 16 selected empirical articles (published between 1993 and 2016), four major themes could be identified: social relationships (i.e. the role of family support, peer support and community belonging), treatment (i.e. the importance of a holistic and individualized approach, having good therapeutic relationships, the role of medication), personal beliefs (i.e. hope, identity, self-determination and spirituality), and meaningful activity. Although these themes tally well with dominant conceptualizations of recovery (e.g. the CHIME framework), a number of research gaps came to the fore in this systematic review (Leamy et al., 2011). For example, the results failed to give insight into role of social and structural factors (e.g. having access to recovery resources) in the recovery processes of persons with dual diagnosis. Also, based on the

results, it remained difficult to understand the actual lived experiences of persons with dual diagnosis in recovery, as the found studies primarily focused on facilitators and barriers to recovery instead of experiential components (how does recovery come about?). In that respect, this systematic review study provided a bird's-eye view, a zoomed-out perspective, on the lived experiences of persons with dual diagnosis in recovery.

*Visiting places: exploring the role of recovery-oriented support*

In the second phase of this research project, the aim was to gain understanding of how the recovery processes of persons with complex mental health needs can best be supported. Two ethnographic studies were conducted that aimed to unravel the daily practice of two diverse support modalities, that seem to successfully engage with this population: (1) a community-oriented meeting place, and (2) a residential ward located in a psychiatric hospital.

*Chapter 3* describes the first location-based study that took place in a community-based meeting place. Data were collected by means of participatory observations and 12 in-depth interviews with visitors (as service users are called), staff members, volunteers and persons that are involved in the daily practice of the meeting place from outside. Data were analyzed by means of thematic analysis, inspired by Interpretative Phenomenological Analysis (IPA) principles (Smith Flowers, & Larkin, 2009). The results showed how on the one hand, the meeting place is experienced as *a place to be*, i.e. a safe place where visitors feel welcome and accepted, and gradually even start to feel 'at home'. On the other hand, the meeting place also functions as *a place to be me*. Through creative activities that are rooted in personal interests and talents, visitors find a language to re-engage in dialogue with others. In doing so, they start rebuilding positive identities that move away from other stigmatizing identities and become visible citizens in society.

*Chapter 4* focuses on the second location-based study that took place at a residential psychiatric ward that engages with a similar group of persons with complex mental health needs. Again, data were collected by means of participatory observations and 17 in-depth interviews with patients and staff members. In accordance with the other study, data were analyzed by means of thematic analysis, based on IPA principles. In this study, three important functions of the ward were identified. First, the ward functions as an *asylum*, i.e. a safe haven in terms of both space and time that for some patients even functions as a 'second home'. Second, the ward is experienced as a *particularizing space* in which support is organized tailored to patients' individual needs and is focused on finding anchor points outside the hospital walls. Related to this, the ward's third function is that of a *transitional space* towards a meaningful community life (e.g. through searching for adequate housing).

*En route with a travel companion: a collaborative case study*

In the wake of the study I conducted in the community-based meeting place, my communication with one of the participants intensified: Pete, an experienced visitor and peer worker. During these conversations, we discussed Pete's experiences regarding psychosis and recovery, my doubts and worries regarding my research and our thoughts regarding the way the concept of recovery in mental health care policy and practice, amongst other things. Eventually, this continuous exchange of ideas formed the foundation of the third phase of this research project, as Pete and I jointly decided to start recording our conversations. In doing so, our exchange of ideas turned into a study of its own: a collaborative case study that aims to capture in all its complexity what it means for Pete to be in recovery.

*Chapter 5* provides a detailed overview of our collaborative research trajectory in which we adopted a bricolage approach. This allowed us to let the context shape our research questions and to creatively combine different data sources (e.g. nine recorded conversations, emails, Pete's poetry, existing literature). Through this co-creative bricolage process, four important themes regarding Pete's recovery were discussed: life rebuilding, identity, continuity of care and the role of substance use. By exploring these themes, a number of contradictions related to the way recovery is operationalized and professionalized in today's mental health care came to the fore. Although recovery is promoted as a hopeful and empowering process towards a meaningful community life, current mental health care still seems to be characterized by a medical gaze that considers mental health problems to be chronic and fails to address the social realities of persons in recovery. Consequently, recovery risks being reduced to a tokenistic model that is shaped by an expert-driven discourse and holds low expectations of recovery for persons with complex mental health needs.

*Chapter 6* specifically zooms in on the methodological and ethical implications of this collaborative research process, in which my perspective on the role of lived experience shifted, as Pete was not only the research subject but also became my travel companion as co-researcher and co-writer. Pete and I became aware of the power imbalances at play in both mental health care practice and research, and searched for more equal ways of relating to each other. The concept of bricolage helped us give shape to a more dialogical research approach that can be seen as an open-ended and relational meaning-making process, rather than an academic monologue in which the researcher claims the final word about the research subject's experiences.

## Implications for research, policy and practice

In *Chapter 7*, the General Discussion, I reflect on the most important insights from the different studies and their implications for mental health care policy, practice and research. These reflections can be clustered around three themes: (1) moving towards relational enactments of recovery, (2) building recovery-oriented landscapes of support, and (3) rethinking research relationships.

### *Relational recovery*

Several authors have warned that recovery has become a floating signifier that has many divergent connotations and is used to represent a wide variety of visions, expectations and agendas (Hopper, 2007; Pilgrim, 2009). However, thinking about recovery in terms of enactments, i.e. discursive practices, offers an inspiring alternative that holds the potential to exceed this conceptual confusion (McWade, 2015, 2016). Also, by bringing in the idea of enactments, the debate on recovery and recovery-oriented support becomes politicized and moves away from thinking about recovery frameworks and models as incontestable and universal matters of fact. Ultimately, there is no way to position ourselves above or outside these enactments; each mental health experience, practice and context of recovery is inevitably political and loaded with certain values. Therefore, to move forward in our thinking about recovery, we have to ask ourselves the following question: which values do we want to enact? If we want to outgrow neoliberal or overly medicalized enactments of recovery, we urgently need to move to more social and collectivist ideas about mental health problems and support. In my perspective, a relational recovery approach holds the potential to do so. Through a relational lens, people are seen as relational beings, inseparably linked to their affective, social, material, structural and economic context (Price-Robertson, Obradovic, & Morgan, 2017). Consequently, rather than an individualistic process, recovery is considered a shared responsibility, materialized in the constantly on-going exchange between persons with mental health problems, informal and professional networks, the community and the wider social context (Hopper, 2007).

### *Landscapes of support*

The aim of the studies at the meeting place and the residential ward was to gain understanding of how the recovery processes of persons with complex mental health needs can best be supported. Despite the diversity of the two locations under study, the results of both studies showed a remarkable overlap regarding the functions they fulfill in the lives and recovery processes of persons with complex mental health needs. Through applying a relational geographies perspective, practices such as the meeting place and the residential ward can be seen as concentrations of processes and interactions, in which

specific enactments of support and recovery are articulated and different power dynamics and meanings are embedded (Darling, 2011; Parr, 2000). Therefore, I propose to think of recovery-oriented systems of support in terms of diverse landscapes that are dotted with enabling places in which persons with complex mental health needs find appropriate material, affective and social resources, tailored to their recovery process (Duff, 2012). Building on the findings from this research project, a number of important underlying principles of mental health care settings within such landscapes of support can be identified: applying a person-centered and holistic approach, maximizing continuity of support and opening up improvisational spaces.

*Rethinking research relationships*

Throughout the different studies, it became clear how the recovery concept is increasingly being professionalized and is drifting further and further away from the original activist and service user-led ethos. Moreover, it came to the fore how in mental health care practice, mechanisms of 'psychiatrization' and epistemic violence still have a large impact on the way persons with complex mental health needs experience the support they receive. Unfortunately, these professionalization trends and mechanisms of epistemic violence also echo loudly in academic research into mental health recovery. Being aware of the overpowering impact of these processes on the knowledge that we as researchers produce, presents us with the challenge to disrupt them and to actively search for alternative and more ethically responsible research practices. Based on the insights from this research project, I see two potential but radical ways to do so. First, stripped down to its essence, asking what recovery entails – be it as process, framework or practice – is a question about values. If we want to gain a deeper understanding of these underlying values, we urgently need to expand our notion of what counts as 'evidence' and give a more central position to values-based practice. Even more so, if we see it as our collective prerogative to build relational recovery practices, these relational values should also be reflected in the research we carry out. Therefore, evidence on recovery and recovery-oriented practice should be rooted in the narratives of persons for whom recovery is a lived reality (Beresford & Boxall, 2015; Rycroft-Malone et al., 2004; Tanenbaum, 2006). Second, we should move to a more co-creative and dialogical research culture in mental health care. To do so, experiential knowledge needs to be collectively recognized as a fully valued form of knowledge in the wider debate on recovery. Also, co-creation should be seen as a dialogical research process in all phases of the trajectory; of searching for the most relevant research questions, of seeking out adequate research methods, of keeping an unfinalizable dialogue going about emerging insights and ideas (Frank, 2005; Grey, 2016). In doing so, it should be our particular ambition to actively search for ways to engage in dialogical practice with people

whose voices often remain unheard or are a priori marginalized because they are considered 'hard-to-reach': persons with complex mental health needs.

# APPENDIX 2

## Nederlandstalige samenvatting

## Context en doelstellingen van het onderzoek

Op internationaal vlak worden het beleid en de praktijk van de geestelijke gezondheidszorg gekenmerkt door een verschuiving naar het uitbouwen van meer herstelondersteunende hulpverlening, gemotiveerd door het groeiende besef dat ondersteuning op maat dient te zijn van de unieke herstelprocessen en noden van cliënten (Cruce, Öjehagen, & Nordström, 2012; Slade, Amering, & Oades, 2008). In de literatuur wordt herstel beschreven als een persoonlijk, niet-lineair en multidimensionaal proces dat wordt gekenmerkt door zelfbepaling en zelfverantwoordelijkheid, gevoelens van hoop en belonging, empowerment, het ontwikkelen van ondersteunende relaties en het overwinnen van stigma (Anthony, 1993; Schrank & Slade, 2007). De volgende principes worden vaak naar voor geschoven als essentieel in het ondersteunen van herstelprocessen: een geïndividualiseerde en persoonsgerichte aanpak, het hanteren van een holistisch eerder dan een medisch perspectief, en een focus op de sterktes en capaciteiten van personen met een psychische problematiek (Gagne, White, & Anthony, 2007; Slade et al., 2008; Torrey & Wyzik, 2000).

Ondanks deze ontwikkelingen blijft er evenwel een heterogene groep die vaak tussen de mazen van bestaande hulpverlening valt: personen met complexe psychische ondersteuningsnoden. Doordat hun dagelijkse werkelijkheid vaak bepaald wordt door de samenloop van diverse persoonlijke en sociale problemen (bv. psychische problemen, middelengebruik, armoede, juridische problemen, een beperkt sociaal netwerk, structurele uitsluiting en sociale isolatie), kennen de herstelprocessen van personen met complexe ondersteuningsnoden een traag en onvoorspelbaar verloop en zijn ze gekenmerkt door veel ups en downs (Ness, Borg, & Davidson, 2014).

Terwijl er consensus bestaat over het feit dat hulpverlening aan personen met complexe ondersteuningsnoden best op een integratieve en holistische manier vormgegeven wordt (Minkoff, 2001), beperkt huidig onderzoek zich hoofdzakelijk tot het identificeren van barrières tot hulpverlening (bv. gebrek aan motivatie, wachtlijsten, gebrek aan gespecialiseerde diensten) (Priester et al., 2016) en het meten van klinische uitkomstparameters (bv. symptoomreductie, abstinentie) (Chow et al., 2013; Hunt et al., 2013). Wat vaak buiten beschouwing blijft is de manier waarop personen met complexe psychische ondersteuningsnoden zelf hun ondersteuning ervaren en wat de invloed is van hulpverlening op hun herstelproces (Lietz, Lacasse, Hayes, & Cheung, 2014). Meer nog, ondanks het feit dat er plaatsen zijn die op een succesvolle manier aan de slag lijken te gaan met deze heterogene groep, worden de dagelijkse praktijken en de eigenlijke processen die er plaatsvinden nauwelijks bestudeerd (Chase et al., 2012; Farkas, Gagne, Anthony, & Chamberlin, 2005). Daarnaast worden de sociale factoren (bv. thuisloosheid, sociale uitsluiting, sociaal isolement) die een bepalende impact hebben op de

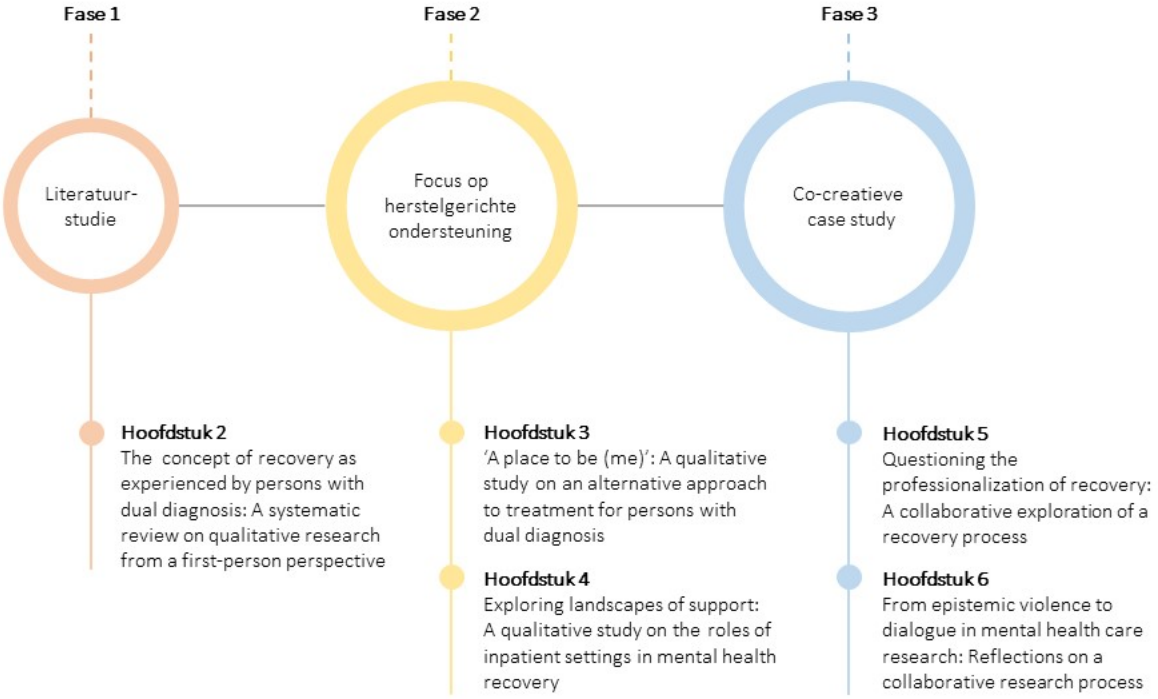
herstelprocessen van personen met complexe ondersteuningsnoden sterk onderbelicht in bestaand onderzoek naar herstel (Hopper, 2007).

Enkel door meer inzicht te krijgen in de manier waarop herstel precies plaatsvindt in het leven van personen met complexe ondersteuningsnoden wordt het mogelijk om hulpverlening op een meer gepaste en persoonsgerichte manier vorm te geven. Daarom is het doel van dit onderzoeksproject om te ontrafelen hoe personen met complexe psychische ondersteuningsnoden hun herstel ervaren, hoe en waar ze hulpbronnen vinden voor hun herstel en welke rol professionele ondersteuningsmodaliteiten spelen in hun hersteltrajecten. Deze doelstellingen kunnen vertaald worden naar de volgende hoofdonderzoeksvragen:

1. *Wat betekent het voor personen met complexe psychische ondersteuningsnoden om in herstel te zijn?*
2. *Hoe kunnen de herstelprocessen van personen met complexe psychische noden ondersteund worden?*

In de zoektocht naar antwoorden op bovenstaande onderzoeksvragen krijgen de doorleefde ervaringen van personen met complexe ondersteuningsnoden een centrale plaats in dit onderzoeksproject, omwille van drie redenen. Eerst en vooral is de vraag naar *hoe* personen met complexe ondersteuningsnoden hun herstel ervaren in essentie een fenomenologische vraag. Ten tweede wordt in literatuur aangegeven dat kwalitatieve onderzoeksmethoden die focussen op doorleefde ervaringen en processen op microniveau het meest gepast zijn om recht te doen aan de complexiteit van herstel (Stanhope & Solomon, 2008). Ten derde is de centrale plaats van ervaringen in dit werk gegrond in de ethische verantwoordelijkheid om stem te geven aan mensen wiens stem vaak niet gehoord wordt, zowel in hun dagelijks leven als in de geestelijke gezondheidszorg en de academische wereld.

Data werden verzameld aan de hand van (1) een systematische review van bestaande herstelliteratuur die vertrekt vanuit persoonlijke perspectieven, (2) twee kwalitatieve studies die focussen op herstelondersteunende hulpverlening zoals ze ervaren wordt door verschillende actoren, en (3) een co-creatieve casestudy samen met een ervaringsdeskundige. Onderstaande figuur geeft een schematisch overzicht van de drie onderzoeksfasen in dit doctoraatsonderzoek en hoe ze zich verhouden tot de verschillende studies en hoofdstukken in dit werk.




## Overzicht van de studies

In het onderzoeksproces kunnen drie perspectieven onderscheiden worden van waaruit ik herstel bij personen met complexe ondersteuningsnoden onderzoek: (1) vanuit een vogelperspectief, (2) door plaatsen te bezoeken die aan de slag gaan met deze groep, en (3) door samen op weg te gaan met een ervaringsdeskundige.

### *Een vogelperspectief: uitzoomen op doorleefde ervaringen*

In de eerste fase van dit onderzoeksproces, dat wordt beschreven in *Hoofdstuk 2*, werd een systematische review uitgevoerd die tot doel had om bestaand kwalitatief onderzoek over herstel vanuit de ervaringen van personen met een 'dubbele diagnose' (in de eerste fase van het onderzoek gebruikte ik deze terminologie in plaats van 'complexe psychische ondersteuningsnoden') te bundelen. Gebaseerd op de analyse van de 16 geselecteerde empirische studies (gepubliceerd tussen 1993 en 2016) werden vier hoofdthema's geïdentificeerd: sociale relaties (de rol van familie, ondersteuning door peers en belonging in de gemeenschap), behandeling (het belang van een holistische en geïndividualiseerde aanpak, therapeutische relaties, de rol van medicatie), persoonlijke overtuigingen (hoop, identiteit, zelfbepaling en spiritualiteit), en betekenisvolle activiteiten. Ondanks het feit dat deze thema's goed aansluiten bij dominante conceptualiseringen van herstel (bv. het CHIME-kader), kwamen er ook een aantal leemtes in het bestaand onderzoek naar voor (Leamy et al., 2011). De resultaten gaven ons

bijvoorbeeld weinig zicht op de rol van sociale en structurele factoren (bv. toegang tot hulpbronnen voor herstel) in de herstelprocessen van personen met een dubbele diagnose. Daarnaast bleef het op basis van de resultaten moeilijk om de eigenlijke doorleefde herstelervaringen van personen met complexe ondersteuningsnoden te begrijpen, aangezien de geselecteerde studies vooral focusten op facilitators en barrières van herstel, eerder dan op ervaringscomponenten (*hoe* vindt herstel plaats?). In dat opzicht gaf deze systematische review een uitgezoomd vogelperspectief op de doorleefde ervaringen van personen met complexe psychische ondersteuningsnoden.

*Plaatsen bezoeken: op zoek naar de rol van herstelondersteunende hulpverlening*

Het doel van de tweede fase van dit onderzoeksproject was om inzicht te krijgen in de manier waarop de herstelprocessen van personen met complexe noden het best ondersteund kunnen worden. Twee etnografische studies hadden tot doel om de dagelijkse praktijk van twee uiteenlopende hulpverleningsvormen, die op een succesvolle manier aan de slag lijken te gaan met deze populatie, te ontrafelen: (1) een laagdrempelige ontmoetingsplaats in het midden van Gent (België) en (2) een residentiële afdeling in een psychiatrisch ziekenhuis.

*Hoofdstuk 3* beschrijft de eerste etnografische studie, die plaatsvond in de ontmoetingsplaats. Data werden verzameld aan de hand van participerende observaties en 12 diepte-interviews met bezoekers (zoals cliënten daar genoemd worden), begeleiders, vrijwilligers en personen die van buitenaf betrokken zijn bij de werking van de ontmoetingsplaats. De data werden geanalyseerd aan de hand van thematische analyse, geïnspireerd door de principes van Interpretatieve Fenomenologische Analyse (IPA) (Smith, Flowers, & Larkin, 2009). De resultaten tonen aan hoe de ontmoetingsplaats enerzijds wordt ervaren als '*a place to be'*, een veilige plaats waar bezoekers zich welkom en geaccepteerd voelen en zich zelfs 'thuis' beginnen te voelen. Anderzijds functioneert de ontmoetingsplaats ook als *'a place to be me'*. Aan de hand van creatieve activiteiten die geworteld zijn in persoonlijke interesses en talenten vinden bezoekers opnieuw een taal om in dialoog te gaan met anderen. Daardoor bouwen ze een positieve identiteit op die hen helpt afstand te nemen van stigmatiserende identiteiten en worden ze zichtbare burgers in de maatschappij.

*Hoofdstuk 4* focust op de tweede etnografische studie die plaatsvond op een residentiële afdeling die aan de slag gaat met een gelijkaardige groep van personen met complexe ondersteuningsnoden. Opnieuw werden data verzameld aan de hand van participerende observaties en 17 diepte-interviews met patiënten en begeleiders. Naar analogie met de andere studie werden data geanalyseerd aan de hand van thematische analyse, gebaseerd op IPA-principes. Drie belangrijke functies van de afdeling werden geïdentificeerd. Ten eerste vervult de afdeling de functie van *asiel*, een veilige haven in termen

van ruimte en tijd die door sommige patiënten zelfs ervaren wordt als 'tweede thuis'. Daarnaast wordt de afdeling ervaren als een *particulariserende plaats* waar ondersteuning wordt geboden op maat van de individuele noden van iedere patiënt en die focust op het vinden van aansluiting buiten de ziekenhuismuren. Ten derde wordt de afdeling ervaren als een *plaats van transitie* naar een betekenisvol leven in de gemeenschap (bv. door het zoeken naar een gepaste woonvorm).

*Op weg met een ervaringsdeskundige: een co-creatieve casestudy*

Gedurende de studie die ik uitvoerde in de ontmoetingsplaats werd mijn communicatie met één van de participanten steeds intensiever: Pete, een vaste bezoeker en ervaringsdeskundige. Tijdens deze gesprekken bespraken we onder andere Pete's ervaringen op vlak van psychose en herstel, mijn twijfels en bezorgdheden omtrent mijn onderzoek en onze ideeën over de manier waarop het herstelconcept wordt gebruikt in de geestelijke gezondheidszorg. Op een bepaald moment hebben Pete en ik samen beslist om onze gesprekken op te nemen, waardoor onze voortdurende uitwisseling een studie op zich werd: een co-creatieve casestudy die tot doel had om in alle complexiteit te vatten wat het voor Pete betekent om in herstel te zijn.

*Hoofdstuk 5* geeft een gedetailleerd overzicht van ons onderzoekstraject. Doordat we een bricolage-benadering hanteerden, konden de onderzoeksvragen gaandeweg vormkrijgen en konden we op een creatieve manier verschillende databronnen (negen opgenomen gesprekken, e-mails, Pete's poëzie, literatuur) combineren. Op die manier werden vier belangrijke thema's met betrekking tot Pete's herstel besproken: het heropbouwen van je leven, identiteit, continuïteit van zorg en de rol van middelengebruik. Door deze thema's te verkennen kwamen er een aantal contradicties naar voor over de manier waarop herstel wordt geoperationaliseerd en geprofessionaliseerd in de huidige geestelijke gezondheidszorg. Terwijl herstel wordt uitgedragen als een hoopvol en empowerend proces naar een betekenisvol leven in de gemeenschap, lijkt de huidige geestelijke gezondheidszorg nog steeds gekenmerkt te worden door een medische kijk die psychische problemen als chronisch beschouwt en er niet in slaagt om sociale problemen van personen in herstel aan te kaarten.

*Hoofdstuk 6* zoomt specifiek in op de methodologische en ethische implicaties van dit collaboratief onderzoeksproces, waarin mijn perspectief op de rol van doorleefde ervaringen veranderde, omdat Pete niet enkel participant was maar ook mijn metgezel werd als co-onderzoeker en coauteur. Pete en ik werden ons bewust van de machtsongelijkheden die meespelen in zowel de praktijk als het onderzoek binnen de geestelijke gezondheidszorg en gingen op zoek naar een meer gelijkwaardige manier om ons ten opzichte van elkaar te verhouden. Het *bricolage*-idee hielp ons vorm te geven aan een meer dialogische onderzoeksaanpak die gezien kan worden als een open en relationeel proces van

betekenisgeving, eerder dan een academische monoloog waarin de onderzoeker het laatste woord heeft over de ervaringen van de participant.

## Implicaties voor onderzoek, beleid en praktijk

In *Hoofdstuk 7*, de Algemene Discussie, reflecteer ik over de belangrijkste inzichten van de verschillende studies en hun implicaties voor beleid, praktijk en onderzoek. Deze reflecties kunnen geclusterd worden rond drie thema's: (1) een verschuiving naar een relationele opvatting van herstel, (2) het uitbouwen van herstelgerichte ondersteuningslandschappen, en (3) het herdenken van onderzoeksrelaties.

### *Relationeel herstel*

Verschillende auteurs hebben gewaarschuwd dat herstel een paraplubegrip is geworden dat veel uiteenlopende connotaties heeft en ingezet wordt om een grote diversiteit aan visies, verwachtingen en agenda's te representeren (Hopper, 2007; Pilgrim, 2009). Echter, nadenken over herstel in termen van *enactments*, nl. discursieve praktijken, biedt een inspirerend alternatief dat het potentieel heeft om deze conceptuele verwarring te overstijgen (McWade, 2015, 2016). Door het idee van *enactments* binnen te brengen wordt het debat gepolitiseerd en verschuift het weg van denken over bestaande herstelkaders als onbetwistbare en universele modellen. Uiteindelijk is het onmogelijk om onszelf buiten of boven deze *enactments* te plaatsen; elke ervaring, praktijk en context waarin herstel plaatsvindt is onvermijdelijk politiek en geladen met waarden. Daarom moeten we onszelf de volgende vraag stellen: welke waarden willen we naar voor schuiven? Als we ons willen verzetten tegen neoliberale en overmatig medische *enactments* van herstel, moeten we dringend gaan naar meer sociale en collectieve ideeën over psychische problemen en ondersteuning. Naar mijn mening draagt een relationale benadering van herstel dat potentieel in zich. Vanuit een relationeel perspectief worden mensen gezien als relationele wezens, onlosmakelijk verbonden met hun affectieve, sociale, materiele, structurele en economische context (Price-Robertson, Obradovic, & Morgan, 2017). Als gevolg wordt herstel niet gezien als een individualistisch proces, maar als een gedeelde verantwoordelijkheid, gematerialiseerd in de voortdurende uitwisseling tussen personen met psychische problemen, informele en professionele netwerken, de gemeenschap en de wijdere sociale context (Hopper, 2007).

### *Ondersteuningslandschappen*

Het doel van de studies in de ontmoetingsplaats en de residentiële psychiatrische afdeling was om inzicht te krijgen in de manier waarop de herstelprocessen van personen met complexe noden het best

kunnen ondersteund worden. Ondanks de diversiteit van de twee onderzoekslocaties vertoonden de resultaten van beide studies een opvallende overlap met betrekking tot de functies die ze vervulden in de levens en herstelprocessen van hun cliënten. Vanuit het perspectief van *relational geographies* kunnen praktijken zoals de ontmoetingsplaats en de afdeling gezien worden als concentraties van processen en interacties waarin specifieke *enactments* van ondersteuning en herstel worden gearticuleerd en verschillende machtsdynamieken en betekenissen zijn ingebed (Darling, 2011; Parr, 2000). Daarom stel ik voor om te denken over herstelgerichte ondersteuningssystemen in termen van gedifferentieerde landschappen die bezaaid zijn met uiteenlopende plaatsen waar personen met complexe ondersteuningsnoden de gepaste materiële, affectieve en sociale hulpbronnen vinden op maat van hun herstelproces (Duff, 2012). Voortgaand op de bevindingen van dit onderzoeksproject kunnen een aantal belangrijke onderliggende principes van hulpverleningsmodaliteiten binnen zo'n landschappen geïdentificeerd worden: het hanteren van een persoonsgerichte en holistische aanpak, het maximaliseren van continuïteit van zorg en het creëren van ruimte voor improvisatie.

*Het herdenken van onderzoeksrelaties*

Doorheen de verschillende studies werd duidelijk hoe het herstelconcept steeds meer wordt geprofessionaliseerd en steeds verderaf staat van het originele activistische ethos dat werd aangevuurd door psychiatrische (ex-)patiënten. Meer nog, het werd duidelijk hoe mechanismen van 'psychiatrisering' en epistemisch geweld in de geestelijke gezondheidzorg nog steeds een grote impact hebben op de manier waarop personen met complexe ondersteuningsnoden de hulpverlening ervaren. Jammer genoeg vinden deze professionaliseringstrends en mechanismen van epistemisch geweld ook veel weerklank in academisch onderzoek naar herstel. Wanneer we ons echter bewust worden van de overweldigende impact van deze processen op de kennis die we als onderzoekers produceren, worden we geconfronteerd met de uitdaging om deze te doorbreken en om actief op zoek te gaan naar alternatieve en meer ethisch verantwoorde onderzoekspraktijken. Gebaseerd op de inzichten van dit onderzoeksproject zie ik twee mogelijke maar radicale manieren om dit te doen. Ten eerste is de vraag naar wat herstel is – zij het als een proces, kader of praktijk – in essentie een vraag over waarden. Als we beter inzicht willen krijgen in deze onderliggende waarden, moeten we ons begrip van wat telt als 'evidentie' dringend verruimen en een meer centrale plaats geven aan *values-based practice*. Meer nog, als we het onze collectieve verantwoordelijkheid vinden om relationele herstelpraktijken uit te bouwen, dan zouden deze relationele waarden ook weerspiegeld moeten zijn in het onderzoek dat we voeren. Daarom zou evidentie over herstel en herstelondersteunende praktijken geworteld moeten zijn in de narratieven van personen voor wie herstel een dagelijkse realiteit is (Beresford & Boxall, 2015; Rycroft-Malone et al., 2004; Tanenbaum, 2006). Ten tweede zouden we moeten gaan naar een meer co-

creatieve en dialogische onderzoekscultuur in de geestelijke gezondheidszorg. Om dit te doen moet ervaringskennis collectief erkend worden als een waardevolle vorm van kennis in het debat over herstel. Daarnaast moet co-creatie gezien worden als een dialogisch onderzoeksproces in alle fasen van het traject, dat gekenmerkt wordt door een zoeken naar de meest relevante en gepaste onderzoeksvragen en –methoden en vertrekt vanuit het idee dat dialoog altijd een open einde heeft (Frank, 2005; Grey, 2016). Hierbij zou het onze specifieke ambitie moeten zijn om actief op zoek te gaan naar manieren om dialogisch aan de slag te gaan met mensen wiens stemmen vaak ongehoord blijven of a priori gemarginaliseerd worden omdat ze als 'hard-to-reach' beschouwd worden: personen met complexe ondersteuningsnoden.

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# APPENDIX 3

## Data storage fact sheets

Data Storage Fact Sheet 1
**Systematic review (Chapter 2)**

Clara De Ruysscher
29 March 2019

## 1. Contact details

*1a. Main researcher*

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

## 2. Information about the datasets to which this sheet applies

– Reference of the publication in which the datasets are reported:

  De Ruysscher, C., Vandevelde, S., Vanderplasschen, W., De Maeyer, J., Vanheule, S. (2017). The concept of recovery as experienced by persons with dual diagnosis: A systematic review. *Journal of Dual Diagnosis, 13*(4), 264-279. doi: 10.1080/15504263.2017.1349977

– Which datasets in that publication does this sheet apply to?

  All data used in the corresponding article and chapter.

## 3. Information about the files that have been stored

*3a. Raw data*

– Have the raw data been stored by the main researcher? [X] YES / [ ] NO
  If NO, please justify:

– On which platform are the raw data stored?
  - [X] researcher PC
  - [ ] research group file server

- [X] other (specify): All data are also stored on a UGent-share managed by DICT. All articles that have been used as data in this systematic review are stored both in digital format and on paper.

– Who has direct access to the raw data (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

*3b. Other files*

– Which other files have been stored?
  - [ ] file(s) describing the transition from raw data to reported results. Specify: ...
  - [ ] file(s) containing processed data. Specify: ...
  - [X] file(s) containing analyses. Specify: ...
  - [ ] files(s) containing information about informed consent
  - [ ] a file specifying legal and ethical provisions
  - [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...
  - [ ] other files. Specify: ...

– On which platform are these other files stored?
  - [X] individual PC
  - [ ] research group file server
  - [X] other: Files containing analysis are also stored on a UGent-share managed by DICT and in paper version in a locked cupboard in the office of the main researcher at the Department of Special Needs Education (Begijnhoflaan 464, 9000 Ghent).

– Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [ ] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

## 4. Reproduction

– Have the results been reproduced independently?: [ ] YES / [X] NO

– If yes, by whom (add if multiple):
  - Name:
  - Address:
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Data Storage Fact Sheet 2
**Qualitative study in a meeting place for persons with dual diagnosis (Chapter 3)**

Clara De Ruysscher
29 March 2019

## 1. Contact details

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

## 2. Information about the datasets to which this sheet applies

– Reference of the publication in which the datasets are reported:

  De Ruysscher, C., Vanheule, S., & Vandevelde, S. (2017). 'A place to be (me)': A qualitative study on an alternative approach to treatment for persons with dual diagnosis. *Drugs: Education, Prevention & Policy*, 1-10. doi: 10.1080/09687637.2017.13756461

– Which datasets in that publication does this sheet apply to?

  All data used in the corresponding article and chapter.

## 3. Information about the files that have been stored

*3a. Raw data*

– Have the raw data been stored by the main researcher? [X] YES / [ ] NO
  If NO, please justify:

– On which platform are the raw data stored?
  - [X] researcher PC
  - [ ] research group file server
  - [X] other (specify): The raw data are also stored on a UGent-share managed by DICT.

- Who has direct access to the raw data (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

*3b. Other files*

- Which other files have been stored?
  - [X] file(s) describing the transition from raw data to reported results. Specify: The main researcher's thoughts and coding schemes, as recorded in her research diaries.
  - [X] file(s) containing processed data. Specify: Verbatim transcriptions of the in-depth interviews
  - [X] file(s) containing analyses. Specify: ...
  - [X] files(s) containing information about informed consent
  - [X] a file specifying legal and ethical provisions
  - [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...
  - [ ] other files. Specify: ...

- On which platform are these other files stored?
  - [X] individual PC
  - [ ] research group file server
  - [X] other: Transcribed interviews, files containing analysis and the researcher's diaries are (also) stored on a UGent-share managed by DICT and in paper version in a locked cupboard in the office of the main researcher at the Department of Special Needs Education (at Begijnhoflaan 464, 9000 Ghent).

- Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

## 4. Reproduction

- Have the results been reproduced independently?: [ ] YES / [X] NO

- If yes, by whom (add if multiple):
  - Name:
  - Address:
  - Affiliation:
  - E-mail:

Data Storage Fact Sheet 3
**Qualitative study in a residential psychiatric ward (Chapter 4)**

Clara De Ruysscher
29 March 2019

## 1. Contact details

*1a. Main researcher*

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*1b. Responsible Staff Member (ZAP)*

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

## 2. Information about the datasets to which this sheet applies

– Reference of the publication in which the datasets are reported:

  De Ruysscher, C., Vandevelde, S., Tomlinson, P., & Vanheule, S. (submitted). Exploring landscapes of support: A qualitative study on the roles of inpatient settings in mental health recovery. (Chapter 4)

– Which datasets in that publication does this sheet apply to?

  All data used in the corresponding article and chapter.

## 3. Information about the files that have been stored

*3a. Raw data*

– Have the raw data been stored by the main researcher? [X] YES / [ ] NO
  If NO, please justify:

– On which platform are the raw data stored?
  - [X] researcher PC
  - [ ] research group file server
  - [X] other (specify): The raw data are also stored on a UGent-share managed by DICT.

- Who has direct access to the raw data (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

*3b. Other files*

- Which other files have been stored?
  - [X] file(s) describing the transition from raw data to reported results. Specify: The main researcher's thoughts and coding schemes, as recorded in her research diaries.
  - [X] file(s) containing processed data. Specify: Verbatim transcriptions of the in-depth interviews
  - [ ] file(s) containing analyses. Specify: ...
  - [X] files(s) containing information about informed consent
  - [X] a file specifying legal and ethical provisions
  - [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...
  - [ ] other files. Specify: ...

- On which platform are these other files stored?
  - [X] individual PC
  - [ ] research group file server
  - [X] other: Transcribed interviews, files containing analysis and the researcher's diaries are (also) stored on a UGent-share managed by DICT and in paper version in a locked cupboard in the office of the main researcher at the Department of Special Needs Education (at Begijnhoflaan 464, 9000 Ghent).

- Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

## 4. Reproduction

- Have the results been reproduced independently?: [ ] YES / [X] NO

- If yes, by whom (add if multiple):
  - Name:
  - Address:
  - Affiliation:
  - E-mail:

Data Storage Fact Sheet 4
**A collaborative case study (Chapters 5 and 6)**

Clara De Ruysscher
29 March 2019

## 1. Contact details

*1a. Main researcher*

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*1b. Responsible Staff Member (ZAP)*

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

## 2. Information about the datasets to which this sheet applies

– Reference of the publication in which the datasets are reported:

De Ruysscher, C., Tomlinson, P., Vanheule, S., & Vandevelde, S. (2019). Questioning the professionalization of recovery: A collaborative exploration of a recovery process. *Disability & Society,* 1-22. doi: 10.1080/09687599.2019.1588708

Tomlinson, P., & De Ruysscher, C. (submitted). From epistemic violence to dialogue in mental health care research: Reflections on a collaborative research process. (Chapter 6)

– Which datasets in that publication does this sheet apply to?

All data used in the corresponding article and chapter.

## 3. Information about the files that have been stored

*3a. Raw data*

– Have the raw data been stored by the main researcher? [X] YES / [ ] NO
If NO, please justify:

– On which platform are the raw data stored?
  - [X] researcher PC

- [ ] research group file server
- [X] other (specify): Some of the raw data (e.g. email correspondence, poetry, literature) are also stored on the PC of the co-researcher of this study. The raw interview data are only stored on the main researcher's PC and on a UGent-share managed by DICT.

– Who has direct access to the raw data (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [X] other (specify): The co-researcher of this study also has access to the raw data.

*3b. Other files*

– Which other files have been stored?
  - [X] file(s) describing the transition from raw data to reported results. Specify: The main researcher's thoughts and coding schemes, as recorded in her research diaries.
  - [X] file(s) containing processed data. Specify: Verbatim transcriptions of the in-depth interviews
  - [ ] file(s) containing analyses. Specify: ...
  - [ ] files(s) containing information about informed consent
  - [X] a file specifying legal and ethical provisions
  - [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: ...
  - [ ] other files. Specify: ...

– On which platform are these other files stored?
  - [X] individual PC
  - [ ] research group file server
  - [X] other: Transcribed interviews, files containing analysis and the researcher's diaries are (also) stored on a UGent-share managed by DICT and in paper version in a locked cupboard in the office of the main researcher at the Department of Special Needs Education (at Begijnhoflaan 464, 9000 Ghent).

– Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [X] other (specify): The co-researcher of this study also has access to the processed data.

## 4. Reproduction

– Have the results been reproduced independently?: [ ] YES / [X] NO

# APPENDIX 4

## List of publications

## Publications in journals

*Published*

De Ruysscher, C., Tomlinson, P., Vanheule, S., & Vandevelde, S. (2019). Questioning the professionalization of recovery: A collaborative exploration of a recovery process. *Disability & Society*, 1-22. doi: 10.1080/09687599.2019.1588708

Vandevelde, S., Vander Laenen, F., De Ruysscher, C., Bryssinck, D., De Maeyer, J., Meesen, D., & Broekaert, E. (2017). Reflections on a Service User Perspective in Supporting Persons with Dual Diagnosis: The Case of Villa Voortman. *International Journal of Mental Health & Addiction*, 16(5), 1189-1192. doi: 10.1007/s11469-017-9840-1

De Ruysscher, C., Vanheule, S., & Vandevelde, S. (2017). 'A place to be (me)': A qualitative study on an alternative approach to treatment for persons with dual diagnosis. *Drugs: Education, Prevention & Policy*, 1-10. doi: 10.1080/09687637.2017.1375461

De Ruysscher, C., Vandevelde, S., Vanderplasschen, W., De Maeyer, J., Vanheule, S. (2017). The concept of recovery as experienced by persons with dual diagnosis: A systematic review. *Journal of Dual Diagnosis, 13*(4), 264-279. doi: 10.1080/15504263.2017.1349977

De Ruysscher, C, Claes, C., Lee, T., Cui, F., van Loon, J., De Maeyer, J., & Schalock, R.L. (2017). A Systems Approach to Social Entrepreneurship. *VOLUNTAS: Journal of Voluntary and Nonprofit Organizations*, 1-16. doi: 10.1007/s11266-016-9704-5

Vanderplasschen, W., Vandevelde, S., De Ruysscher, C., Vandevelde, D., & Broekaert, E. (2017). In Search of Evidence-Based Treatment in TCs for Addictions: 40 Years of Research in TC De Kiem. *Therapeutic Communities, 12*(2-3), 177-195. doi: 10.1080/1556035X.2017.1312656

De Ruysscher, C., Annicq, P., Vandevelde, S., & Claes, C. (2015). The perception of persons with Anorexia Nervosa about Quality of Life: An initial investigation. *Applied Research in Quality of Life*, 1-18. doi: 10.1007/s11482-015-9425-8

De Ruysscher, C., Annicq, P., Vandevelde, S., & Claes, C. (2015). Anorexia Nervosa: een integratief behandelmodel. *Tijdschrift voor Psychotherapie, 41*(2), 87-100. doi: 10.1007/s12485-015-0015-x

Vandevelde, S., De Maeyer, J., De Ruysscher, C., Bryssinck, D., Vanderstraeten, J., & Broekaert, E. (2015). Villa Voortman: carte blanche or not? *Therapeutic Communities, 36*(2), 62-73. doi: 10.1108/TC-12-2013-0035

*Submitted*

De Ruysscher, C., Vandevelde, S., Tomlinson, P., & Vanheule, S. (submitted). Exploring landscapes of support: A qualitative study on the roles of inpatient settings in mental health recovery.

Tomlinson, P., & De Ruysscher, C. (submitted). From epistemic violence to dialogue in mental health care research: Reflections on a collaborative research process.

## Books and book chapters

De Ruysscher, C., Bryssinck, D., Vanheule, S., & Vandevelde, S. (2017). Ondersteuning en behandeling van personen met een dubbele diagnose. In W. Vanderplasschen & F. Vander Laenen (Eds.), *Naar een herstelondersteunende verslavingszorg: Praktijk en beleid* (pp. 201-212). Leuven: Acco.

Morisse, F., Dosen, A., De Ruysscher, C., De Neve, L., Audenaert, L., Zevenbergen, H., Roskam, S.,… & Claes, C. (2015). *SEO-R²: Schaal voor Emotionele Ontwikkeling van mensen met een verstandelijke beperking – Revised*. Antwerpen: Garant.