Stigma and the psychiatric enterprise:

An ethnographic study of stigma in
the Belgian mental health care context

Charlotte Sercu

Voor mama
Omdat niemand ooit meer in mij geloofde
Voor Didier en Annabelle
Die me laten dromen

Table of contents

Acknowledgements

Eerst en vooral wil ik Piet Bracke bedanken, voor het aanwakkeren van mijn sociologische verbeelding. Jouw kennis en passie voor sociologie hebben me steeds opnieuw aangespoord om nieuwsgierig te blijven en om door te zetten.

Mieke Verhaeghe, bedankt om me warm te maken voor onderzoek naar stigma en mentale gezondheidsproblemen. Jouw energie en gedrevenheid waren aanstekelijk en lieten me vol overgave starten met mijn project.

Peter Stevens, Lesley Hustinx, Job van 't Veer en Elise Pattyn, bedankt voor jullie bijdrage als leden van mijn examencommissie en voor het nemen van de tijd om mijn proefschrift ten gronde door te nemen.

Carine en Deborah, bedankt om de administratie rondom mijn doctoraat vlekkeloos te laten verlopen.

Bedankt aan alle zorggebruikers, zorgverleners en stafmedewerkers wiens bijdrage fundamenteel was om dit onderzoeksproject te doen slagen.

Bedankt ook aan alle collega's die voor de nodige ontspanning en versnaperingen zorgden tijdens de talrijke koffiepauzes, lunches en after work activiteiten.

Verder heb ik in die 5 jaar heel veel plezier en steun beleefd aan mijn bureaugenoten. Mieke, voor de aanstekelijke energie die je in de bureau verspreidde. Elise, voor de inspirerende kleurencombinaties en de vele gezellige babbels. Lore, voor de etnografische discussies, gedeelde fantasie en humor. Sarah, voor de fantastische trip naar Marokko waar ik mijn hoogtevrees overwon, voor het leren kennen van mijn sportieve kwaliteiten en voor de vele babbels. Pieter, voor het creëren van de groene omgeving en de vele lekkere koffies. Rozemarijn, om mijn creativiteit aan te wakkeren en voor de vele moestuinpraatjes (van compost tot bereklauw en groenblijvende kersttomaatjes). Veerle, om me met MDD te diagnosticeren en voor de vele aanmoedigingen.

Bedankt ook aan alle vrienden en familie die op regelmatige tijdstippen eens polsten waar ik nu precies mee bezig was en hoe lang dat nog zou duren.

Dankjewel zus, voor alle steun, hulp en de culinaire hoogtepunten.

Murakoze cyane Didier, om er voor mij te zijn.

PART I

GENERAL INTRODUCTION

CHAPTER 1

INTRODUCTION

Mental health problems account for about 20% of the total burden of ill health in Europe (WHO, 2004). The wide impact of mental health on all aspects of life and the high level of stigma associated with mental health problems make the promotion of good mental wellbeing and tackling mental health stigma major priorities for health policymakers across Europe (McDaid, 2005). Stigma and discrimination have been identified as the chief enemies to progress in providing proper care and helping people with mental health problems to live a life of acceptable quality (WHO, 2013).

There is a great deal of debate among academics, policymakers and care providers about the role of mental health care organizations and care providers in both shaping and tackling mental health stigma. Schulze (2007) points to the complexity of the relationship between stigma and mental health care in her review of the intricate connection between providers and stigma, where she identified providers as de-stigmatizers, stigmatizers and stigmatized. This complex relationship can be linked to the dynamics between the different levels at which stigma operates in the context of mental health care (Henderson et al., 2014). For example, how does structural discrimination, such as the allocation of limited resources for mental health care, have a negative effect on the social position of providers and their work experiences, and what are the implications for their relationships with service users? The interplay between different levels of stigma, which ultimately shapes the relationship between it and mental health care, has nevertheless largely been ignored.

Most empirical studies on stigma and mental health care concentrate on providers as potential stigmatizers and involve quantitative research into their knowledge, attitudes and behaviours. This work, based on survey population studies and informed by a social psychological approach to stigma – locating the study of stigma primarily within the larger context of general social psychological processes (Dovidio, Major, & Crocker, 2000, p.9; Schulze, 2007) – has been criticized for its narrow focus on the individual level (Link & Phelan, 2001). Only a few recent

studies approach stigma as a multidimensional issue, in which structural factors at the societal or organizational level are related to interpersonal interactions and stigma experiences in care settings. A study on the stigma experiences of Chinese service users explicitly focuses on the role of power differences in the social production of stigma and discrimination during treatment (Lee, Chiu, Tsang & Kleinman, 2006). This study illustrates how an unbalanced health policy, resource allocation and service organization may create power differences between service providers and users, and ultimately result in stigma experiences.

New theoretical developments further stress the role of norms and power relations in stigma processes. Pescosolido and colleagues (2008) developed their Framework Integrating Normative Influences on Stigma (FINIS), which includes different levels of social life that set the normative expectations, which in turn inform the process of stigmatization. Their endeavour is in line with more-recent efforts to stress the normative character of stigma. Link and Phelan (2014) likewise encourage viewing public conceptions of mental health problems as indicators of the cultural context, rather than questioning their value as a predictor for individual behaviour. Other recent work on the role of structural stigma for individual stigma perceptions and experiences further stresses the fact that stigma is not just a question of the knowledge and experience of individuals, but also a matter of structure and culture (Hatzenbuehler & Link, 2014). Accordingly, this theoretical evolution fits in with the appeal by Link and colleagues (2004) to study stigma as a social phenomenon, rooted in the power relations that structure society.

To advance the understanding of stigma, I draw on these recent developments to contribute to the awareness of what stigma means in relation to mental health care. In line with earlier work concerning the social arrangements used to manage people with mental health problems (e.g. Goffman, 1961), this dissertation uses an ethnographic research design, by combining interviews with participant observations. As Link and colleagues (2004) describe, the added value of qualitative methods of investigation involves the fact that these can offer rich insights into subjective stigma experiences and the complexity of the social systems that produce stigma. Local value systems can be explored in far greater depth than is possible through standard survey instruments (Kleinman & Hall-Clifford, 2009). Therefore, in this thesis it is my aim to value this contextual nature by singling out several topics that appeared during the fieldwork and analysis, and which are lacking in relevant literature. Furthermore, the attention paid to the context, makes

it possible and necessary to transcend the dominant offensive approach of psychiatry in sociological work on stigma, starting my research with an open and respectful attitude to mental health care and its professionals.

The objective here is to provide an understanding of stigma in mental health care as a social phenomenon, with its roots in social structures. In empirical work, the incorporation of structure is often reduced to the integration of an additional level of stigmatizing institutions. The empirical value of the structural antecedents of stigma has not been elaborated on to date. In this thesis, I explore the different relationships through which stigma is given shape, paying specific attention to the impact of structural elements such as social roles, social positions, institutions and cultural knowledge systems, and their systemic relationships (Bonnington & Rose, 2014). Therefore, I first contextualize the historical basis of the intricate relationship between stigma and mental health care, going back to the complex history of sociology's relationship with psychiatry. This complexity provides the structure for an outline of the theoretical basis of the stigma concept in the third chapter. Subsequently, I discuss how research on stigma in mental health care builds on these underpinnings. Lastly, I present my research aims. This general contextualization, together with an extensive discussion of my research methodology, forms the basis for different empirical studies on stigma in mental health care. These studies do not focus on specific levels of stigma, but instead explore how different levels come together in the lived experiences and perceptions of both service users and care providers.

CHAPTER 2

MENTAL ILLNESS, SOCIOLOGY AND PSYCHIATRY

Introduction

In sociological work, psychiatric stigma has often been linked to the role and organization of mental health care. Pioneers of stigma theory identify the psychiatric discipline as being critical to the development of stigma. Moreover, the most influential work on stigma draws on ethnographic research in a mental hospital setting, permeated by the psychiatric approach with its dominant illness framework (Goffman, 1961, 1963). Subsequently, most stigma research has been built on Goffman's (1963, p.3) definition of stigma as '*an attribute that is deeply discrediting*' and '*that reduced the bearer from a whole and usual person to a tainted, discounted one*' and likewise embraces the approach of mental health care as being detrimental for service users' social identity.

The sociological approach to stigma adopted criticism of the psychiatric approach and discipline, in close connection with the emergence of the anti-psychiatry movement (Cooper, 1967). In particular, the two share a concern about the social control function psychiatry performs in society, and both challenge the medicalization of mental health problems (Crossley, 1998). Accordingly, in mental health stigma research, the organization of mental health care is not only understood as reflecting the character of mental health, but also serves as the constitution of what mental health problems are (Prior, 1993, p.1). Scheff (1966) draws partly on this constitutive component of mental health care in his well-known labelling theory of mental illness, in which he identifies the psychiatric label as a compelling starting point for the development of a devalued illness identity.

In spite of the depiction of this critical approach of psychiatry as unilateral and lacking attention to the positive implications of psychiatric knowledge and treatment (Fabrega, 1991), the rapid decline in support for the antipsychiatry movement in the 1980s (Rissmiller & Rissmiller, 2006), the existence of different discourses – such as the biopsychosocial model developed by Engel

(1980) – and associated changes in the organization of care, the critical gaze concerning the role of the psychiatric discipline and mental health care professionals in stigma processes remains among sociological researchers and is reflected in the growing number of studies that point to the detrimental role professionals play in stigma processes (Link & Phelan, 2014b; Schulze, 2007).

In the following section, I first provide a concise account of the development and perceptions of the psychiatric discipline through history, and its relatedness to stigma. Next, I discuss the most prominent features of the contemporary mental health care field – in which I particularly consider the notion that psychiatry is in crisis – and its relatedness to incentives from the sector to promote an inclusive approach to people with mental health problems. The implications of these evolutions for the Belgian mental health care context are discussed in the last part.

Social perceptions of mental health problems and the psychiatric discipline

The psychiatric approach, with the allied assumption that mental health problems originate in the biological malfunctioning of individuals, has been the most commonly accepted and supported understanding of mental health problems in the last five decades (Pearlin, Avison, & Fazio, 2007). Although different discourses relate to mental illness, and notwithstanding the capacity of the psychiatric approach to accommodate multiple explanatory factors, the biological emphasis remains (Pilgrim & Rogers, 2014, p.4). The rise of this psychiatric discipline was stimulated by the Age of Reason and became tangible in the beginning of the nineteenth century with the invention of the term 'psychiatry' by the German doctor Reil, by which he referred to a medical science and discipline (Kaiser, 2007, p.23).

Interest in mental health problems nevertheless predates the development of the psychiatric discipline. Throughout history, all societies recognized and developed specific ways to deal with abnormal behaviour. The methods were characterized by a common belief in the connection between physiological and mental processes (Tausig, Michello & Subedi, 1999, p.158). Social historians of psychiatry describe how the perceptions of mental health problems changed over time, reflecting sociocultural and economic developments in society. In the Western World,

evolutions such as population growth, economic distress and the consolidation of the state in early-modern times were identified as foundational for contemporary approaches to mental health problems (Busfield, 1986; Fabrega, 1991). Although troubled behaviour was previously believed to originate in the natural order, and therefore somehow accepted in society, early-modern times were characterized by the developing idea of mental illness or 'madness' as a social problem (Tausig et al., 1999, p.163). Together with poor, deviant and sick people, individuals with mental health problems were now qualified and treated as 'lower than human', creating a social and economic danger to the 'normal' community (Fabrega, 1991). This perceived threat led to their placement in work or correction houses, and induced the devaluation of their social identity. In his book *Les Règles de la Méthode Sociologique*, Durkheim (1894) was the first to describe this tendency of societies to categorize people as deviant and to treat them as inferior, as a means to enforce the norm. His perspective profoundly influenced labelling theorists, who linked his understanding of norm enforcement to the development of stable mental illness (Scheff, 1966).

After the French revolution, these custodial practices were denounced and physicians such as Reil became interested in 'the mentally ill', who were now believed to be fundamentally human. The exposure to brutal treatment in 'madhouses' led to changing social values, which permitted a greater willingness to accept a medical approach to mental health problems (Pilgrim & Rogers, 2014, p.125). Furthermore, with the development of his *traitement moral*, doctor Pinel based his treatment on the belief that individuals retain a sense of reason (Hinshaw, 2007, p.66). Accordingly, state supported hospitals were initially designed from a humanitarian point of view and were, among other institutions, set up to offer an alternative environment in which abnormal behaviour could be reversed or cured (Fabrega, 1991). However, the idea of moral treatment in asylums was quickly abandoned. The state was reluctant to direct any funds to asylum care. This led to the development of large, obscure hospitals in remote areas. Although their isolated location was initially meant to provide rest, away from the pathogenic character of the city, this seclusion became a synonym for cutting ties with the civilized world (Hinshaw, 2007, p.68).

With the rise of asylums and the medicalization of deviance, mental health problems became a clearly distinct social problem; badness turned into sickness (Schlosberg, 1993). Although psychiatry assumed a specialized medical healing role with regard to people with mental health

problems, the psychiatric profession was identified as a discipline charged with the handling of socio-political dilemmas (Fabrega, 1991). This is particularly clear in the differential approach of psychiatric practice to people with different socioeconomic backgrounds. The tradition of academic medical psychiatry was only applied to upper-class people and the poor were excluded. Where the work of psychiatrists was marked by tolerance and acceptance in 'private practice', impoverished people with mental health problems received the worst forms of care (Fabrega, 1991; Hinshaw, 2007, p.64). The segregation in special asylums led to their visibility, and in the age of reason – with a focus on objective disease markers – the uncertainty and intangibility that characterize their problems were important catalysts for the further stigmatization and marginalization of these individuals.

Early biological psychiatrists explained the disproportionally high number of people from lower social classes in the asylums through the existence of a tainted gene pool in these milieus. This explanation lost credibility due to the impossibility of explaining it, and led to the development of the psychoanalytic discourse on mental health problems. The focus on individuals' personal history contributed to the development of a more eclectic social psychiatry (Pilgrim & Rogers, 2014, p.110) and led to the emergence of an interdisciplinary collaboration between psychiatry and sociology. The rise of psychoanalysis, in which 'we are all ill to some degree', made alternative views to that of the biological illness model acceptable to psychiatrists, who shared an interest in the social conditions of mental health problems (Rogers & Pilgrim, 2011).

From the 1950s onwards, several psychoanalytic psychiatrists explicitly challenged the biological underpinnings of institutional psychiatry, through the identification of mental illness as a mere construct, used as a tool for the maintenance of social order (Cooper, 1967; Laing, 1967; Szasz, 1970). With their anti-psychiatry movement, they put a heavy burden on psychiatric practice (Prior, 1993, p.14), and identified it as a function of economic efficiency (Scull, 1977) and the preserver of bourgeois morality (Foucault, 2004), controlling in both cases the threat from the poor underclass. Through his concept of governmentality, Foucault (1991) pointed to the role of the psychiatric discipline – knowledge produces expertise – used by professionals and institutions as a mechanism for the regulation and control of the population, replacing former physical means of control. In his identification of a change in practice from inquiring about what is done, towards examination of the (potential) abnormality, he perceived the constitution of the

domain of the abnormal as the power and the fundamental basis for the existence of human sciences (Davidson in Foucault, 2004). Scholars like him promoted the idea that personal experiences are independent from any supreme definition of normalcy imposed through psychiatry (Rissmiller & Rissmiller, 2006).

The popularity of social psychiatry was temporary. The biopsychosocial model was relegated to the margins of the medical profession and bio-determinism regained popularity. This 'decade of the brain' is reflected in the third edition of the Diagnostic and Statistical Manual of Mental Disorder (DSM III),[1] published in 1980, where a focus on causality is replaced by behavioural descriptions of disorders, representing the elimination of service users' biographical and social context (Mirowsky & Ross, 1989; Rogers & Pilgrim, 2011). At the same time, the popularity of the anti-psychiatrist movement declined. However, its impact did last with regard to sociological work on psychiatric stigma, as most contemporary research is still built on labelling theorists, who linked the ideas of anti-psychiatrists to the idea that norm enforcement is decisive for the development of stable mental illness (Scheff, 1966).

Similar to the anti-psychiatrists, sociologists such as Ervin Goffman and Thomas Scheff, were concerned about the social control function psychiatry performed in society, reflected in the 'bias in the collective wisdom of professionals', as they are socialized to deal with the abnormal in a socially acceptable way (Scheff, 1966, p.36). Goffman (1961, pp.14-23) points to the centrality of power differentials between inmates and staff, and how this imbalance of power leads to disculturation and the mortification of the self, or the increasing loss of valuable roles in society. Although Goffman does point to the possibility of finding relief in hospital for those who have lost control over themselves (p.130), he particularly stresses the detrimental consequences of the loss of identity due to inpatient care, stressing the reality of stigmatization once inmates return into society (p.70).

While Goffman has been criticized for his unilateral and hostile approach to mental hospitals (Weinstein, 1983), the origin of stigma research can be traced back to his sceptical accounts about the psychiatric institution. Sociologists drew on ethnographic fieldwork in psychiatric

---

[1] The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the standard reference for clinicians and researchers for the evaluation of mental health problems. The fifth edition of the DSM was published by the American Psychiatric Association in 2013.

hospitals to conceptualize stigma, pointing to the harmful effects of both formal care and the negative stereotypes that guide social reactions towards those who are termed (ex-) inmates (Link & Phelan, 2014b). They primarily focus on interpersonal and intergroup (service users vs professionals) relationships to identify the psychiatric system as the primordial source for the development of a stigmatized illness identity. Although individuals who exceed behavioural norms have always occupied marginal positions in society, it is this critical approach of sociologists to the role of psychiatry – a product of its time – which forms the basis for the current research into people with mental health problems as a negatively marked social category.

Contemporary challenges

The sceptical approach of the psychiatric discipline in sociology only gained popularity after the start of the de-hospitalization movement in the second half of the twentieth century. The landscape was characterized by institutional change in mental health treatment, altering the definition of mental illness, treatment modalities and structures of institutions to provide care, and transforming the entire organization of the treatment system (Pavalko, 2007). Many countries have followed the trend of hospital run-down, often referred to as de-institutionalization (Rogers & Pilgrim, 2014, p.95). After previous efforts to change the custodial practices and structures in hospitals through the development of therapeutic communities – small wards or units in which the social environment is the main therapeutic tool – de-hospitalization was believed to be the most efficient way to achieve these goals (Davidson, Rakfeldt & Strauss, 2010). However, the particular reasons for the start of the trend towards de-hospitalization are equivocal. Explanations relate to advances in the medical treatment of mental health problems, the financial burden of inpatient care, the identification of stress as a cause of disorder that led to the dual responsibility between medical and social services, a shift in the psychiatric focus from chronic to acute and less serious problems, and the observation that mental health problems are widespread in the general population (Pilgrim & Rogers, 2014, pp.93-95; Prior, 1993, p.105; Tausig et al., 1999, p.168).

Apparent crisis of psychiatry?

Informed by the critical gaze of the anti-psychiatry movement, the shift towards de-hospitalization brought with it an apparent crisis in psychiatry. In the changing mental health care landscape, multiple alternative care settings – such as sheltered housing initiatives and other living arrangements in the community – undermined the territorial basis for psychiatry. Furthermore, the psychiatric team, which is now commonly composed of a psychiatrist, social worker, psychologist and nurses, replaced the absolute power of the psychiatrist alone. This went together with an expanded range of mental health problems, as non-physical factors such as social relationships and other potential stressors entered the domain of psychiatry (Prior, 1993, p.77). With the expansion of both the spectrum of mental health problems and the psychiatric team, psychiatrists experienced difficulty in claiming a monopoly over both the definitions of mental health problems and the specific therapeutic approaches.

The authority of psychiatry was not only challenged through the changing conceptualizations of mental health problems. Partly under the influence of the consumerist movement, power relations between providers and users were reconceptualized through shifts in the terminology concerning the recipients of psychiatric services. The promotors of the 'client', 'consumer' and 'survivor' paradigm expressed their shared concern regarding the empowerment of service users. Through their rejection of the traditional term 'patient', they renounced the medical approach to mental health problems and care, and associated it with negative features such as paternalism and authoritarianism (McGuire-Snieckus, McCabe & Priebe, 2003; Sharma et al., 2000). This focus on the empowerment of service users is further reflected in the current popularity of the recovery approach, which echoes the belief in the strengths of people with mental health problems as social beings, with their own specific network relationships and social roles (Anthony, 1993; Pilgrim, 2008).

Further medicalization of the abnormal?

The whole movement towards de-hospitalization and community care, however, together with the described transformations in both the professional organization and the scope of mental health problems, has also been interpreted as a further colonization of the social space by the psychiatric discipline. Although these changes are at first glance in line with the anti-psychiatrist

appeal for de-institutionalization, theorists such as Szasz (1970), identify the developments as a further medicalization of the abnormal. This involves the transformation of initially normal human events – such as ageing or mourning – into medical conditions, and implies the growing penetration of medicine into daily life (Conrad, 2007). The shift in focus onto social relationships and stressful conditions has been interpreted by critics as a means to give anyone the possibility of being in need of psychiatric care.

The conclusion of the World Health Organization (WHO) that mental ill health accounts for almost 20% of the burden of disease in the WHO European Region and that mental health problems affect one in four people at some time in their life (WHO, 2004; 2011), has been perceived as a result of the tripling of the number of diagnostic categories in the DSM since its official release in 1952, a means to sustain psychiatry's medical identity, rather than a departure from biomedical determinism (Kawa & Giordano, 2012). The solution of psychiatry for the growing complexity in the field, comes down to the strengthening of its identity as truly 'applied neuroscience', providing an affirmative answer to the enduring question of whether 'medicine of the mind' can work with the same epistemology as 'medicine of the tissues' (Bracken et al., 2012).

Although every individual should now be attentive to signs that may alert them to mental health problems, the concern exists that community care only serves the new and the less-severely ill individuals instead of those with serious problems (Fakhoury & Priebe, 2002). Moreover, community care is believed to prolong the differential treatment of individuals who occupy different social positions. In the great majority of cases, middle-class service users with acute or mild disorders are those who benefit the most from the new community system (Novella, 2010).

Critics of the de-hospitalization process not only reject the claim that it implies a reduction of the medical authority in mental health and that it comprises a more inclusive approach to care, but they also point to its lack of attention to the societal culture with regard to mental health problems. Have people changed their attitudes? Community care can only be successful in relation to a society with an inclusive attitude, in which individuals with mental health problems experience respect and acceptance. Population research on beliefs and attitudes suggests that much work remains to be done with regard to pointing out the prevailing existence of misconceptions about mental health problems (Angermeyer & Dietrich, 2006). Anti-stigma

campaigns, which are now often based on the approach that mental illness is an illness like any other, have not achieved univocally positive results (Read et al., 2006; Pescosolido et al., 2010).

Moreover, these efforts to promote a bio-deterministic conceptualization of mental health problems in anti-stigma campaigns reflect the lost credibility for voices such as that of Scheff (Pilgrim & Rogers, 2005b), which criticize the psychiatric discipline (Hinshaw, 2007, p.90). Solutions to the ambivalence inherent to psychiatry seem to come down to the strengthening of psychiatry's biomedical identity (Bracken et al., 2012). This is, for instance, illustrated by the current dominance of acute hospital units in the development of community models (Nicaise, Dubois, & Lorant, 2014). Rogers and Pilgrim (2014, pp.96-97) point to the similarity between the old Victorian asylums and these units, noting their ability to segregate and their inability to provide a proper care environment, marking a trend towards re-institutionalization rather than in the direction of community care.

The Belgian context

The Belgian mental health care landscape illustrates the statement of Rogers and Pilgrim, (2014, p.96) that the complex set of interrelationships between the medical profession, public morality, the state and the political economy restricts the opportunities to arrive at a more inclusive and diverse care landscape. The multitude of authorities responsible for the planning and legitimization of different care settings has, for example, been indicated as a reason for the difficulty to provide a coherent mental health care policy (Vandeurzen, 2010). As Hermans, de Witte and Dom (2012) state, the collection of epidemiologic data is problematic due to the differences in recording within different care systems.

In Belgium, the organization of mental health care can be traced back to the development of the first 'modern' asylum or large public hospital for medical and moral treatment in Western Europe, built in Ghent in the 1850s by Doctor Joseph Guislain (Kaiser, 2007). Together with the religious Josef Triest, Guislan played a decisive role in the development of mental health care in Belgium (Stockman, 2000). The first asylums were controlled by the administration of justice. In

1948, supervision was transferred to the administration of public health. From 1963 onwards, the specific financing for the treatment of the 'mentally ill' was provided by the *Rijksinstituut voor Ziekte- en Invaliditeitsverzekering* (RIZIV). In parallel with international efforts to reorient and restructure mental health care, new treatment methods led to the replacement of asylums by specific treatment units in psychiatric hospitals, the development of psychiatric units in general hospitals and the start-up of therapeutic communities. Furthermore, in 1975 the first Centre for Mental Health Care (CGG) was established (Stockman, 2000).

The growing diversity in the organization of care and the high prevalence of mental health problems made it necessary to restructure treatment settings, which led to a second period of reconversions in the 1990s. The first reform in 1990 was intended to increase the quality of inpatient care, and led to a reduction in the number of psychiatric hospital beds. People with stabilized chronic problems were transferred to sheltered accommodation and psychiatric nursing homes. Furthermore, 12 'dialogue platforms' were developed, in which all types of services in mental health care took part, aiming to support dialogue about the regional co-ordination of the different existing and new services (Gerkens & Merkur, 2010). A second reform in 1999 promoted intensive and specialized treatment within psychiatric hospitals, setting up co-operation between the care settings, and further shifting hospital and elderly care beds to psychiatric nursing homes and places for sheltered accommodation. Today, innovation of care in the mental health care sector is still on the agenda, in which the most comprehensive development concerns the regulation that allows psychiatric hospitals to test the organization of care circuits (programmes and services) and networks of services, which should lead to a more integrated and individualized approach to service users' problems. This is based on Article 107 of the Hospital Act of 2008 (Gerkens & Merkur, 2010).

In line with the international trend, these changes in the structure and organization of mental health care coincide with a high prevalence of mental health problems. According to the WHO (2011), it is estimated that one out of three Belgian citizens will face psychological troubles throughout the course of their life. In the last 25 years, attempts have been made to respond to this need through the establishment of a demand-oriented care system, with respect for the whole person and with the aim of informing the general population. The Flemish government has subsidized initiatives, for example for a psychiatric hospital (Te Gek!?) and the Flemish

Association for Mental health (Anders gewoon), to counter the negative representation of people with mental health problems. Furthermore, the website *Geestelijk Gezond Vlaanderen. Tijd om normaal te doen over psychische problemen* was recently launched in an effort to make mental health problems discussable. The site informs people about health problems and treatment options.

Notwithstanding the set-up of a multitude of services with the intention of working in an individualized and demand-driven way, the actual legitimization of different care settings and initiatives is progressing relatively slowly. Mental health issues are still badly served at the policy level. This structural disfavour is reflected in the 6.1% of all health expenditure that went to mental health care in 2012, which is small compared with other European countries. Moreover, psychiatrists are the most poorly paid specialists in Belgium, which has led to a lack of qualified people. This is also the case for mental health nurses, for whom the choice to work in psychiatric care is an unpopular one. The attention paid to mental health issues is extremely poor in medical training programmes, resources for research are limited and mental health professionals' working conditions are less favourable compared with other specialities (Hermans, 2012).

In addition, efforts towards community-based care remain minor compared with the residential centres linked to psychiatry (Nicaise, Dubois, & Lorant, 2014). In 2010, there were 38 psychiatric hospitals in Flanders, 10 in Brussels and 20 in Wallonia, with almost 177 beds per 100,000 inhabitants, whereas the European average is 61 beds. Furthermore, between 2005 and 2011, the number of beds in psychiatric hospitals actually increased (Samele, Frew & Urquia, 2012). Furthermore, the number of hospital beds for psychiatric service users in general hospitals and the high consumption of psychopharmacological drugs (19.1% of the population) in Belgium are indicative of the embeddedness of the de-hospitalization movement in the biomedical enterprise. The growing number of service users who are involuntary committed (economist) is also notable. Lorant and colleagues (2007) identify the high number of compulsory admissions as being a function of the lack of less-restrictive alternative care settings for people with a specific diagnostic and – particularly striking – social profile. This involves individuals with psychotic problems, foreigners or people without a private household. The social position of service users has furthermore been found to be related to differences in treatment quality, to the

improvement in service users' functioning and in their psychological symptoms (Lorant et al., 2003).

In parallel with international trends, the relocation of resources from inpatient to outpatient care initiatives, together with the increase in compulsory admissions among individuals with limited socioeconomic resources, firstly suggests a shift in focus onto those who are less severely ill and who have sufficient resources at their disposal to manage their life in society (Van Hecke et al., 2011). It may equally indicate the start of a re-institutionalization movement, which seeks to boost the role of psychiatry as an institution for the preservation of social order.

Conclusion

Today, both mental health policy and research into services focus on developments in community care and embrace empowerment-oriented approaches to care. However, the multiple meanings and conceptual haziness emphasize the need to situate these views of mental health problems and care in a historical perspective, locating the role of mental health care in relation to the broader social context. This embeddedness is the necessary starting point to explore the relationship between the notion of stigma and mental health care in depth.

The current evolutions in psychiatry have been identified as a function of the extending scope of what is termed mental illness, pointing to the incorporation of social relationships, and with this, growing diversity in the team of mental health professionals and the fragmentation of services. However, this evolution has also been identified as a sign of the expansion of psychiatric power and its control over different spheres of social life, by those who distance themselves from the psychiatric rationale.

Sociological stigma research was set up at a time when these sceptical voices were at their peak, partly due to the fit of their claim with the start of the de-hospitalization era. Stigma researchers adopted the critical viewpoint of the anti-psychiatry movement, in denouncing the social control function of psychiatry and its iatrogenic effects. However, empirical work on stigma has moved away from this critical view. The dominance of survey research in contemporary work on stigma, which often adopts a social epidemiological approach to mental health problems in

which the psychiatric illness approach is not put into question, underlines the necessity to re-write this chapter on the history of the perception of mental health problems. It shows how stigma is ultimately a function of the same historical trends and social context that design the particularities of the psychiatric discipline.

In the current work, I explore the meaning of stigma in the everyday world of mental health care. By starting from the perceptions of service users and professionals, I intended to go beyond value judgements about mental health professionals and institutions in relation to stigma. By situating the study of stigma in the wider discordant relationship between psychiatry and sociology, I attempt to exceed the often-evident duality between stigma and the psychiatric discipline, in order to show how the contextualization of experiences makes it all a matter of degree. In the following section, I discuss the different conceptualizations of stigma in greater detail. I claim that the gap between sociological stigma theory and empirical work is closely related to, and a consequence of, the ambivalent relationship between sociology and psychiatry in their shared ambition to appropriate the topic of mental health stigma.

CHAPTER 3

THE STIGMA OF MENTAL HEALTH PROBLEMS

Introduction

Mental health problems have had various conceptualizations, which can all be situated on the continuum between the purely physical notion and its approach as a mere social construct (e.g. Wakefield, 1992). Although on the one hand biological psychiatry defines mental illness as a physical condition, independent of social and economic circumstances (Pearlin et al., 2007), on the other hand social constructionism emphasizes that mental health problems are social conditions, shaped through social interactions, shared cultural traditions, shifting frameworks of knowledge and power relations (Conrad & Barker, 2010).

In sociological (stigma) research, this continuum has often been reduced to a simple discord between the medico-psychiatric and the sociological view of mental health problems (Weinberg, 2005, p.xi). The collaborative history of the psychiatric discipline and sociology seems to have been banished from the minds of sociologists. It was in particular social constructivism that brought distance into the common interest in the social causes of mental health problems in the area of social psychiatry – informed by the growing legitimacy of psychoanalysis – and the perception of the psychiatric discipline as an integrative social force, through structural-functionalist sociologists such as Parsons and Durkheim (Cockerham, 2007; Pilgrim & Rogers, 2002 p.81). With the 'sick role' concept, Parsons viewed illness, for instance, as dysfunctional to the social system, preventing the performance of valuable social roles. In his sick role, the person is relieved of responsibility and expected to seek appropriate professional help, which will result in a return to full social functioning (Parsons, 1975; Shilling, 2002). With the growing popularity of social constructivism, mutual interest in social factors that influence illness trajectories was replaced by strong arguments against bio-determinism. The now guiding sociological perspective explicitly emphasises that any statement about mental health problems comprises a social

judgment of behaviour, shaped by the wider, social, cultural and historical context, and opposes its conceptualization as an individual pathology (Rogers & Pilgrim, 2014, p.19, p.186). This understanding of mental health problems as a form of residual deviance is the basis for the study of psychiatric stigma in sociology, hence identifying psychiatry as a part of the problem rather than a solution in the fight against stigma (e.g. Ungar & Knaak, 2013).

The dominance of this attacking approach of psychiatry, due to the affiliation of pioneers in stigma research with the anti-psychiatry movement (see Chapter 2), obscures the interfaces between the two disciplines, the necessary basis for a significant study of the relationship between stigma and psychiatry. As Becker (1967) states in his controversial text on the position of sociologists via-à-vis their research topics, the refusal to recognize and respect the power of a given status order, through which knowledge is produced in a subfield such as mental health care, makes it difficult to take a credible and constructive position in the discussion of interdisciplinary issues such as mental health stigma.

Furthermore, this theoretical clinging to the critical stance towards psychiatry led to a conceptual gap between theoretical and empirical work on stigma in sociology, as the latter mostly concerns population studies on stigmatizing attitudes and beliefs, in which the highly criticized disease categories are adopted as the backbone of most analyses. This fact first points to the impossibility of discussing psychiatric stigma independently from the psychiatric enterprise in empirical work. Second, the lack of mutual recognition between sociology and psychiatry seems to imply an inconsistency between theoretical and empirical work on stigma.

In the following paragraphs, I first discuss definitions of psychiatric stigma. I examine the conceptualizations that I have found the most relevant to this work. In the adoption of models that are primarily informed by symbolic interactionist theory and social psychological work, the (competing) conceptualizations can be situated at the micro level. Second, recent efforts to broaden the perspective with macro-structural and cultural approaches are discussed, with a focus on how these may offer the possibility to arrive at a more encompassing and empirically useful understanding of stigma.

Stigma: a symbolic interactionist approach

During the last 50 years, stigma has been conceptualized by different disciplines, ranging from sociologists to political scientists and disability theorists, and has been applied to a multitude of issues, such as mental health problems, smoking and HIV/AIDS. Nevertheless, all conceptualizations link stigma to some extent with deviations from the normal, acceptable states of being for the self and others (Scambler, 2009).

Sociological investigation of mental health stigma primarily builds on the work of Goffman (1961; 1963). In his description of stigma as a discrediting attribute, he insists on the inherent relational nature of stigma, requiring both perceivers and recipients of devaluation. Stigma connotes a deep mark of shame and degradation carried by a person as a function of being a member of a devalued social group. It involves the interpersonal processes whereby members of society come to devalue the group or characteristics in question and begin to interpret all of a person's attributes and characteristics in terms of this flawed identity (Hinshaw, 2007, p.24; Pescosolido & Martin, 2007).

This focus on stigma as a social experience with other people, resulting in the development of a devalued self-concept, stresses the influence of symbolic interactionism for sociological stigma theory. This micro-sociological perspective views people as constructing meaning and making it real through social interaction (Charmaz & Belgrave, 2013). In line with this theory, no objects, events or situations carry intrinsic meanings, as all meaning is created through interactions in particular contexts and is constantly renewed (Blumer, 1969). Herewith, Goffman perceived stigma as having an ebb and flow in concord with other aspects of an individual's moral progress and the larger society (Hinshaw, 2007, p.24).

The work of Goffman influenced the labelling debate on the role of labels in the construction of stable mental illness. In line with Goffman, Scheff (1966) agrees that labelling mental health problems induces stigmatization, due to the unfavourable status it entails. In his application of the labelling theory to mental illness, he situates the origin of stable mental illness in the social reactions of observers. Unlike Goffman (1963, p.140), who was rather sceptical of the use of the term 'deviance' to refer to the identified abnormality of all types, Scheff (1966) uses it to refer to

the social reactions to characteristics and behaviour. He distinguishes between rule breaking, or acting in an abnormal way, and the reactions of others towards it, or the official labelling of norm violations. He refers to unclassifiable abnormal behaviour as 'residual rule breaking'. Depending on the social characteristics of both the labellers and those who are being labelled, and the specificity of the context in which interactions take place, residual rule breaking becomes officially labelled and individuals enter a positive feedback loop (Pescosolido & Martin, 2007). A stable pattern of mental illness, or the continuation of residual rule breaking (termed secondary deviance) is encouraged by the rewards for acting in conformity with existing stereotypes about people with mental health problems and leads to a fundamentally changed identity for the labelled person. Accordingly, Scheff refers to stigma as a consequence of the label, referring to the latter as the prime cause of mental illness.

While Scheff (1966) includes two types of labelling – the informal labelling process by, for instance, spouses or acquaintances, and formal labelling through treatment contact – he primarily focuses on the latter in pointing to the detrimental role of ascribed diagnoses or more generally being subjected to official treatment. These diagnoses or labels refer to the culturally dominant ways of knowing, evaluating and dealing with people with mental health problems and involve boundary settings that are very difficult to ignore or to contest (Charmaz & Belgrave, 2013; Phelan & Link, 1999).

Therefore, labelling theory builds on the approach to reality as socially constructed and focuses on social forces that define mental illness experiences at the micro level (Rogers & Pilgrim, 2014, p.11). This approach places the emphasis on social reactions as causes of sustained, disturbing behaviour and minimizes the assumption that those who are mentally ill are experiencing true underlying disorders (Link & Phelan, 2013; 2014). Although social reactions or labelling theory to some degree recognize multilevel causation through the acknowledgement of (residual) rule breaking, critics primarily point to the undervaluing of the role of symptoms for the progression of the illness. Authors such as Gove (1970, 1975, 2004), agree about the existence of negative stereotypes and associated attitudes and beliefs, but they emphasize the role of the behaviour of the mentally ill as the prime determinant of the progression of mental illness, rather than the social reactions of others. They denounce the lack of attention paid to the biological origin of mental health problems and the treatment benefits of diagnostic

categorization (Chauncey, 1975; Kirk, 1974; Weinstein, 1983). Notwithstanding the evidence about the way an individual's psychiatric history predicts social rejection (Link & Cullen, 1983), and reduces access to housing (Page, 1977) and employment (Farina & Felner, 1973), the lack of user attitude studies that confirm the detrimental effects of treatment, diminished the popularity of the social reaction theory in the late 1970s and the 1980s (Link & Phelan, 2014b; Weinstein, 1983).

The suggestion of Gove and others that labelling does not lead to social rejection or devaluation has been contested by Link and colleagues (1987; 1989; Thoits, 1985). These researchers attempt to rehabilitate the labelling theory through a shift in focus towards the devaluation and discrimination of those labelled as mentally ill. They stress the role of negative stereotypes that are associated with a label. These lead to increased vulnerability and the further development of mental illness through self-fulfilling prophecy. The knowledge of negative cultural conceptions makes individuals anticipate the reactions of others, which induces an expectation of rejection by the labelled person and may lead to the avoidance of social contact, keeping treatment secret or educating others (Link, Mirotznik, Cullen, 1991). This can in turn result in the loss of social ties or job opportunities, lower self-esteem, etc. Accordingly, the modified labelling theory signifies an important turning point, as the focus on internal role expectations and social psychological processes takes attention away from broader societal reactions. Furthermore, Link and colleagues (1997), in line with Rosenfield (1997) and Perry (2011), recognize the possible positive consequences of formal treatment for individuals, pointing to the 'package deal' or 'labeling paradox', the occurrence of two independent and opposing processes affected by the label.

A social psychological approach to stigma

In addition to their specific critique of the labelling theory, proponents of the psychiatric perspective have equally contributed to the study of stigma through the development of several stigma models. In sociological and social psychological studies, these researchers focus on the social reactions of the public towards mental health problems, and do not question the origin of mental illness itself. In their conceptualization of stigma as both an interpersonal and an

intergroup phenomenon, they use insights from the social cognitive approach (Fiske, 1998) – which seeks to explain the relationship between discriminative stimuli and consequent behaviour by identifying the knowledge structures that mediate them – and attribution theory (Weiner, Perry & Magnusson, 1988) – a model of human motivation and emotion based on the assumption that individuals search for causal understanding of everyday events, which focuses on the identification of constructs that affect causal attributions – to explore the links between stereotypes, prejudice and discrimination (Corrigan et al., 2005; Dovidio, Major, & Crocker, 2000, p.12). Stereotypes refer to the shared cognitive representations of a social group, suggesting for instance that people with mental health problems are dangerous, childlike or unpredictable (Steele, Spencer & Aronson, 2002). These attributes are not necessarily negative, but are always reductionist and inaccurate. Prejudice refers to an affective or emotional evaluation, such as the development of fear as a consequence of believed dangerousness. Discrimination in turn points to the negative behaviour that may accompany prejudice. Feelings of fear can result in avoidance, for example refusing to employ someone with a history of mental health problems for babysitting (Ottati, Bodenhausen, & Newman, 2005).

In work with a social psychological orientation, stigma is described as function of a person's membership of a devalued social category or group (Crocker, Major, & Steele, 1998). Intergroup processes were initially believed to induce inevitable distortions in the self-esteem of the stigmatized person (Dovidio et al., 2000, p.2). Although contemporary work still focuses on the affective, cognitive and behavioural consequences of stigma for the individual, it also acknowledges a role for the social context in the consideration of stigma as a situational and dynamic process (Major & O'Brien, 2005).

The most prominent stigma model in the present-day social psychological work of Corrigan (2005) is equally built on the aforementioned trinity – the cognitive, affective and behavioural component - and applied to both public and self-stigma. Public stigma refers to the general public's response to people with mental health problems in terms of stereotypes, prejudice and behaviour. Self-stigma refers to the internalization of this public stigma (Corrigan & Watson, 2006). Corrigan stresses that the succession of the different levels is not a self-evident negative process, either in the responses of perceivers or recipients of stigma. As in their situational model

26

of personal response, Corrigan and Watson (2002) suggest that self-stigma entails issues of perceived legitimization and group identification, which questions the approach to self-stigma as an obvious process. These researchers reason that individuals make sense of their stigmatizing condition, firstly through an evaluation of the legitimacy of the negative reactions of others. Only those people who perceive the social reactions as correct will develop self-stigma. Those who do not agree with the social reaction will develop anger or indifference, depending on their identification with the stigmatized group.

This focus on the core components of mental illness stigma is highly instrumental when examining the different elements of stigmatizing attitudes and behaviour, and is useful for anti-stigma initiatives. As Rusch, Angermeyer and Corrigan (2005) state, the added value of the model concerns its appropriateness for unravelling the different components of stigma in empirical work. This mostly involves general population studies, in which knowledge, attitudes and beliefs about individuals with mental health problems are researched (Link et al., 2004). A review of population-based attitude research shows that most of these studies are descriptive in nature and focus on conceptions, attitudes and beliefs related to specific disease categories (Angermeyer & Dietrich, 2006). Moreover, these studies identify disease characteristics as important mediators of individuals with mental health problems with regard to their reactions to stigma. Rusch and colleagues (2005) make, for instance, an appeal to account for the impact of disease and stigma awareness, as well as for the impact of mood disorders for self-esteem in the study of (self-)stigma.

In their recognition of the impact of disease characteristics, these researchers share the psychiatric conceptualization of mental health problems as an illness situated in the brain. Their adoption of notions such as disease awareness refer, for example, to the service users' recognition of the disease categories employed by the psychiatrist. The focus on psychiatric knowledge as an important means to reduce stigma further stresses the adoption of the psychiatric framework by these researchers. Although they hold on to the continuity between normal and abnormal states, they accept diagnoses as appropriate; as accredited facts in themselves (Rogers & Pilgrim, 2014, p.4). They further recognize the social context as a framework for interaction, but suffer from limiting the conceptualization of contextual elements

27

of stigma to those that intrude the individual, who is viewed as the primary locus in which stigma processes take place (Yang et al., 2007). They do not reflect on the complexities of (historical) discriminating mechanisms in society, which form the constitutive force for stigma processes (Rusch et al., 2005).

Accordingly, from the social psychological approach, stigmatization does not require major social injustices or structural inequalities. It concerns entirely normal, but nonetheless harmful patterns of everyday social cognition in any society, based on the psychological tendency to categorize social worlds, equally reflected in intergroup processes of identification, which primarily refer to in-group enhancement and outgroup denigration (Hishaw, 2007). Although its value for empirical work and the set-up of anti-stigma initiatives have been proven (Corrigan, 2000), the uncritical incorporation of social and institutional structures and policies, and the adoption of diagnostic categories as a natural given, also stress its ahistorical nature. In focusing too narrowly on forces located within the individual, it is impossible to account for social power and the issue of who determines the social norms that define the abnormal at certain times and places. Therefore, the dominance of these social psychological conceptualizations has led to a clear-cut individualistic focus for research on stigma.

Towards an encompassing approach

In an effort to develop a more encompassing sociological understanding of psychiatric stigma, Link and Phelan (2001; Link et al., 2004) combine basic ideas of the labelling theory and the social-psychological approach, and further incorporate macro-sociocultural structures reflecting access to social power. They define stigma in the relationship between interrelated components, notably the identification and labelling of differences, the construction of stereotypes, the separation of 'us' from 'them', and the emotional reactions and experiences of status loss and discrimination. The final aspect concerns the dependence of this stigma process on access to social, economic and political power, as it takes power to stigmatize. Accordingly, the conceptualization represents a critical step towards the approach of stigma as processual and created by structural power. Although sociology is preoccupied with social structures and issues

of social power, these factors have only recently regained attention in work on mental illness stigma.

Parker and Aggleton (2003) equally call for an analysis of stigma that acknowledges its key role in the production and reproduction of relationships of power and control. Together with Scambler (2006), they perceive stigma as reflexive of social and structural inequalities in society. Based on Goffman's (1963) work on stigmatizing interactions, in which he identified structure through the rules that regulate face-to-face interactions, Scambler (2006) points to the reproductive role of stigmatizing interactions at the interpersonal level. While Goffman barely referred to the issue of power, the reproduction of structural inequalities in interpersonal or intergroup relations informs current efforts to frame the ways stigma works to the disadvantage of those targeted by it (Hatzenbuehler & Link, 2014). This in turn, is informed by the work of sociologists such as Bourdieu and Foucault, who conceptualize symbolic systems as a function of social and structural inequalities in society. Foucault (2004) wanted to understand how different forms of knowledge, such as cultural systems (for example psychiatry and biomedicine), offer different claims to truth, which are social products linked to powerful groups in society. In their description of symbolic violence, Bourdieu & Wacquant (1992, pp.272-273) equally refers to the role of symbolic systems in promoting the interests of dominant groups, legitimizing the hierarchical distinctions with other social groups.

The term 'stigma power', is for instance based on Bourdieu's concept of 'symbolic power' and has been used by Link and Phelan (2014a; 2014b) to refer to the function and meaning of stigma as a means to achieve aims such as exploitation, management and control. Phelan and colleagues (2008) previously pointed to the possible function of stigma as a power mechanism of choice: as a means to achieve desired ends. The adoption of the concept of 'stigma power' makes it now possible to link these functions of stigma to actual cultural distinctions in value and worth in a particular time and place, experienced by an individual. Concepts such as 'stigma power' seem to fulfil the call of Scrambler (2006) for explicit attention to be paid to the ways in which face-to-face interactions are reflective of structural logics, including those of class or status. However, in the sole focus on the structural logic that promotes the stigma of people with mental health problems, the question of how to exceed the duality between constructivist conceptions of mental illness and stigma, and psychiatric notions remains. The influence of Foucault's work, in which

he opposes a single valid account of disease and appeals for a rethinking of the relationship between medical experts and lay people, enforces the perception of psychiatry and biomedicine as part of the problem rather than the solution for stigma, increasing rather than diminishing the gap (Cockerham, 2007).

Researchers who adhere to the social psychological approach have also called for a focus on the macro-structural determinants of stigma. In their definition of intentional and unintentional forms of discrimination, Corrigan Markowitz and Watson (2004) refer to policies that restrict the opportunities of people with mental illness. They perceive structural discrimination as an additional level of stigma that complements the social-psychological triad of stigma components. This involves the view that stereotyping and stigmatization are to an important extent driven by the greater aim of system justification, achieved through cultural beliefs and social institutions that are mutually reinforcing (Hinshaw, 2007). Structural stigma is thereby perceived as an institutional issue. This view stems from work on racial stigma and discrimination, adding the distinction between justified restrictions based on people's illness condition, and discrimination based on the mental illness label. The conceptualization of macro-level units involves the suggestion for the aggregation of individual properties, serving as a proxy for the macro-level constructs, in addition to negative media representations of people with mental health problems or government rules. Accordingly, this conceptualization neglects to include the multiple ways in which structure constructs and is constructed through social interactions at a particular time and place (Bonnington & Rose, 2014).

With the set-up of the Framework Integrating Normative Influences on Stigma (FINIS), Pescosolido and colleagues (2008) seem to make a valuable effort to unite the different forces that inform stigmatization (see Figure 1). They primarily adopt the socially constructed nature of stigma as a starting point, referring to the normative expectations that set the stage for stigmatizing interactions, and distinguish between individual and contextual factors. At the macro level, they account for forces that set normative expectations, including the media, economic developments, welfare state ideology, the health care system, globalization and cultural values. Social network characteristics and organizations, such as those providing treatment, are situated at the meso level. The micro level contains concepts that fit into a social psychological focus, including disease and social characteristics. Accordingly, this framework

accounts both for the structural rules that set the normative expectations and the social psychological factors, including disease conditions. The framework responds to the call of Perry (2010) for sociologists to participate in integrative research, in which discussions can be set up with the mental health care community, through the acknowledgement of their knowledge system. The empirical utility of the FINIS framework remains relatively unexplored, as most research holds on to the psychosocial models that are easily applicable to population surveys. Lee and colleagues (2006) are unique in their work regarding the stigma experiences of Chinese service users with schizophrenia in Hong Kong, which focuses on the ways contextual factors, such as an unbalanced health policy and service organization, explain the social production of stigma and discrimination during treatment.

Figure 1. Framework Integrating Normative Influence on Stigma (FINIS)
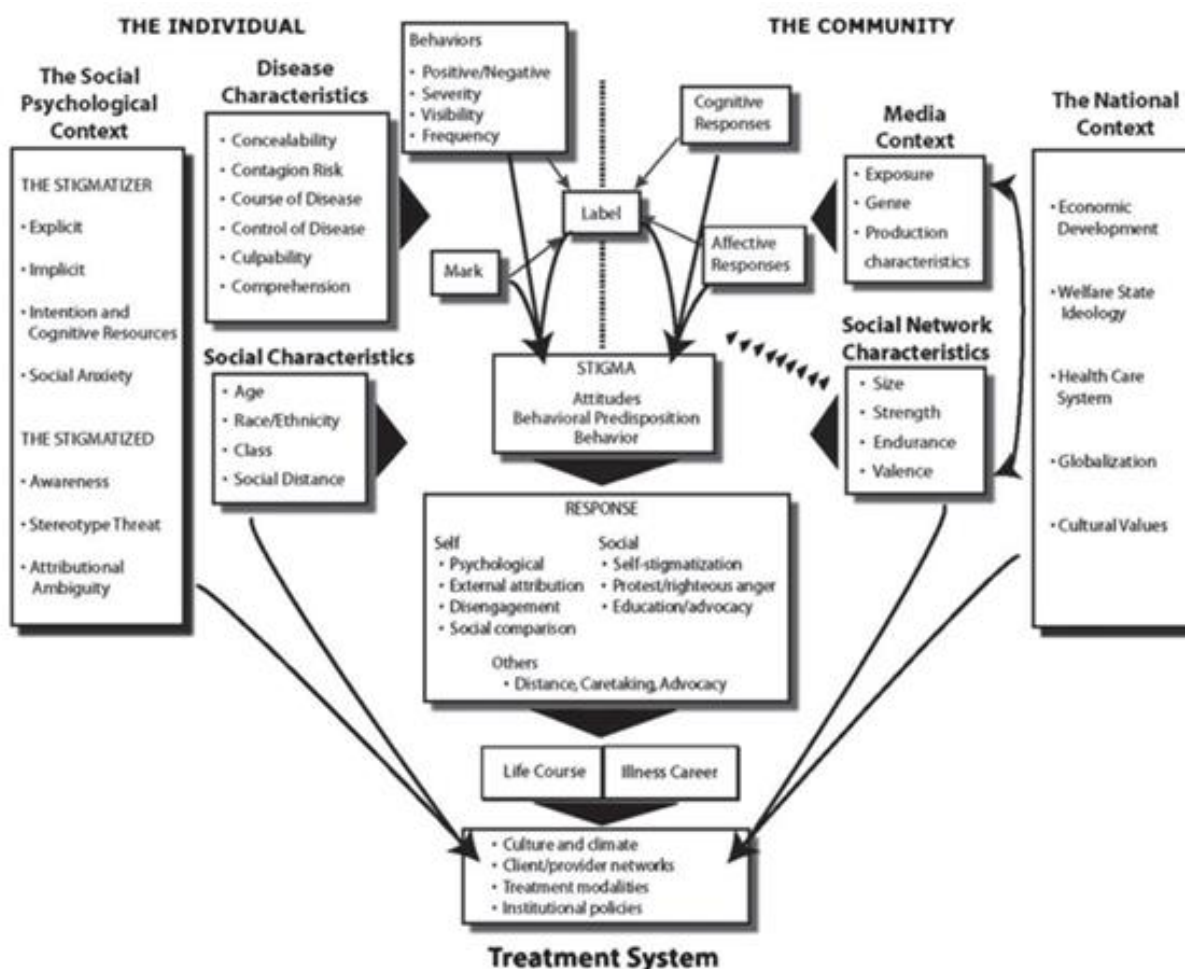
In reasoning from a critical realist perspective, Scambler (2006) suggests the empirical value of the structural antecedents of stigma. A focus on relationships of class, ethnicity or status might offer the possibility to capture stigma processes that take place at an interpersonal level. This lens could provide meaningful insight into the dynamics of what is most at stake for actors in a local, social world and its interrelatedness with stigma (Yang et al., 2007; Scambler, 2009). What is more, the premise of the critical realist, that both the existence of things independent of human will and action, and the impossibility to know things untainted by human action, seems to offer an opportunity to investigate mental illness stigma sociologically, avoiding questions concerning the ontological status of mental health problems.

Conclusion

The social reaction theory has been directive for stigma research in sociology. Shifting the essence of mental health problems from behavioural abnormalities and their social circumstances to the conceptualization of mental illness and its consequences as a mere product of social (stigmatizing) reactions, overlaps with the outset of stigma research in sociology. The switch from Durkheimian positivism, with its focus on the social origins of distress, to a neo-Weberian examination of the way in which illness is socially negotiated, was accompanied by a sociologist claim to stigma as paradigmatically 'theirs', with little attention paid to other conceptualizations in and beyond sociology. The fact that most empirical work adopts a more social psychological approach to stigma has only recently motivated some researchers to search for a more-integrative framework.

Sociological theorists such as Link and Phelan (2001; 2004), and Pescosolido and colleagues (2008), have made important efforts to bridge the gap between the different conceptualizations of stigma. However, efforts to capture this multidimensionality in empirical work are scarce. Reasoning from a critical realist perspective (Scambler, 2006), with a focus on relationships of class and status, may offer the possibility to capture stigma processes that take place at an interpersonal level. Leaving aside judgements concerning the adequacy of psychiatric

qualifications, the focus on dynamics between this classification and structural relationships, may firstly offer an insight into stigma dynamics, especially in relation to mental health care.

CHAPTER 4

STUDYING STIGMA IN MENTAL HEALTH CARE

Introduction

Regardless of their theoretical underpinnings, different stigma models identify a role for psychiatric services and mental health professionals in stigma processes. Sartorius (1998; 2007) claims that stigma is the core issue faced by the entire mental health field, reflected in the difficulties people with mental problems experience in attaining ultimate life goals, the poor access to treatment, the marginal priority given to mental health research and the low status with the mental health professions. There is a fast growing body of literature documenting this 'vital' position of mental health professionals and institutions in the stigma process (Byrne, 2000; Horsfall, Cleary, & Hunt, 2010; Sartorius, 2010; Schulze, 2007; Wahl & Aroesty-Cohen, 2010). However, although these studies indirectly refer to the normative context that places a heavy burden on the mental health field, current empirical work is characterized by a narrower focus on the identification of professionals and mental health care as stigmatizing forces, both in comparative survey research (e.g. Hansson et al., 2011; Hugo, 2001; Lauber et al., 2004; Wahl, 1999) and qualitative work on service experiences (e.g. Schulze & Angermeyer, 2003). With a focus on the prevalence and characteristics of stigmatizing beliefs, attitudes and experiences, most contemporary work on the position of providers and mental health care institutions applies a social psychological view of stigma, whereas work on stigma experiences is based on the labelling theory through the identification of stigma in the use of diagnoses, linked to negative prognosis and the side effects of medication. Accordingly, there is a current call for research from a more encompassing perspective, in which cultural and normative rules are combined with individual and contextual factors, paying attention to the underlying roots of stigma, which guides face-to-face interactions in particular situations (Pescosolido et al., 2008; Scambler, 2009).

In the following section, I discuss the conceptual understandings of stigma that guide research into stigma and mental health care. In line with the previous chapter, I discuss the theoretical underpinnings of this research field, stressing the quasi-absence of empirical work in which the study of stigma in mental health care explicitly refers to the intricacy that characterizes the relationship between the subjects. After a short description of the seminal work on stigma and mental health care, contemporary work on the topic is discussed.

The roots of work on stigma and mental health care

Half a century ago, the rise of mental health stigma research was to an important extent informed by the identification of both professionals and institutional policies as stigmatizing (e.g. Cohen & Struening, 1962). Although institutional care had been previously identified as helpful and functional (Parsons, 1975), the dominance of the labelling theory led to an unbalanced approach to mental health care as being harmful, in which professionals were depicted as agents of social control (Verhaeghe, 2008, p.35). Scheff (1966) identifies professionals as executers of 'the regime of power' and psychiatry as a cultural system with a specific claim to truth. He recognizes an 'important bias in the collective wisdom of professionals who regularly deal with deviants' (p.36), as professionals have the responsibility to deal with the mentally ill in a way prescribed by society (p.36). Because mental health problems always implicate uncertainty, professionals must deal with this uncertainty without violating social norms (p.44). They develop informal norms to handle this, so that all uncertainty on the status of the deviant can be avoided (p.101), to never let a service user be dismissed if there is doubt concerning their illness status (p.104). This leads to a social situation where the 'apostolic mission', informed by social norms, decides the outcome of the medical examination and constitutes the core of the clinical encounters (p.118). Therefore, Scheff (1966) situates the role of mental health professionals in their accountability function towards the larger society, paying central attention to the meaning and use of (diagnostic) labels for this duty.

Goffman (1961) equally identifies hospital treatment as damaging. Through the moral pathway (Chapter 2, p.125), hospitalization ultimately results in a spoiled identity. Similar to Scheff

(1966), he identifies sources of distance from and control over 'inmates' by hospital staff, such as concealing diagnoses (Goffman, 1961, p.19). However, rather than focusing on professionals' liability, he is primarily occupied with the issue of what he calls 'mixed contacts' (p.12). This involves times when a stigmatized and a non-stigmatized person share the same social situation. He stresses the ambiguity of the positions of staff during these clinical encounters, in pointing to the continuous danger that an inmate will 'appear human' (p.79). The circle of involvement and withdrawal marks the continued relational negotiation of the position of the professional and their time. Mental hospital staff are identified as marginal men; as wise men, whose special situation makes them potentially sympathetic others, making it possible for service users to see themselves as ordinary others (Goffman, 1963, p.20). Therefore, referring to the process of negotiating interpersonal distance, he stresses the power of care providers to negotiate the border of professionalism in a social situation.

Goffman further points out the courtesy or associative stigma that professionals are confronted with, due to their close association with people having mental health problems. In relation to mental health professionals, this concerns the sharing of the discrediting status of the service users they work with (p.43). In his recognition of professionals as potentially stigmatizing, stigmatized and the 'wise', he explicitly points to the complex position of care providers in the stigma process.

This complex position has only recently regained attention. Although early sociologists of mental health focused on the structure and functioning of care settings, that interest was not maintained during and after the transition towards community care (Pescosolido, McLeod, & Avinson, 2007). Most contemporary research on stigma in mental health care is dominated by a unilateral focus on the harmful nature of mental health care, identifying the careless use of diagnostic labels as the most obvious source of stigmatization (Sartorius, 2002), entailing the postponement of help-seeking as a way of label avoidance (Corrigan & Wassel, 2008), and a more general negative impact on the objective and subjective quality of life (e.g. Page, 1977; Link, 1982). It is quite obvious that professionals have an intricate relationship with stigma, which is related to the previously mentioned multidimensionality of stigma. However, research rarely adopts a multilevel approach in which both normative structural and practical policy issues of the mental health care context and interpersonal processes are taken into account.

These partial approaches to stigma in mental health care appear to be underpinned by the hostility between mental health sociology and the psychiatric discipline with regard to stigma (see Chapter 3). The naturalness of paying attention to multidimensionality when studying stigma in context seems to fade away, because of the dominance of the two, rarely united perspectives with their specific preoccupations. While adherers to the labelling perspective focus on the detrimental effect of stigma in recent empirical work on the stigma experiences of service users, research from a social psychological view runs parallel to comparative survey research, with a focus on professionals' potentially stigmatizing attitudes and beliefs, leaving aside the context to an important extent.

Disillusioned service users: building on the labelling theory

Attention paid to the stigma experiences of service users grew under the increasing impact of the culture of consumerism following the 1990s (Rogers & Pilgrim, 1993). The critical voices of Sheff and Goffman regained attention from the new social movement of disillusioned service users. Through their accounts concerning the deterioration of their identity due to treatment in mental health care, these users depict the psychiatric discipline as opposing freedom and biographical sensitivity (Pilgrim, 2008). In challenging the dominant medical ideology and specialist hospital-based mental health care, they advocate service users' empowerment in mental health care and a more radical relocation from the hospital to the community (Rogers & Pilgrim, 1993).

Policy measures have met these users' demands through the implementation of reforms in the organization of mental health care. Based on the ideas of labelling theorists and Goffman's work, the further replacement of inpatient hospital care by community initiatives was intended to reduce stigma, a barrier to and antecedent of empowerment. This became a major issue, and sending people to psychiatric hospitals became rapidly approached as the prototype of disempowerment (Corrigan, 2002). Care providers' fear of the unknown, their paternalistic attitudes, their unwillingness to listen and accept criticism, and their reluctance to share power were all identified as opposing service users' empowerment in mental health care (Ajoulat,

d'Hoore & Deccache 2007; Finfgeld, 2004; Laugharne & Priebe, 2006). Service users sought to oppose the labelling and institutionalization they had encountered, demanding respect and equal citizenship, the promotion of a sense of self and hope, client choice and client involvement in planning and providing services and social support (Anthony, 1991; Boney & Stickley, 2008).

This approach to mental health care as part of the problem, rather than part of the solution for people with mental health problems is reflected in empirical studies (e.g. Charles, 2013; Corker et al., 2013; Gabham et al., 2010). In the limited number of studies on service users' stigma experiences in mental health care, specific diagnostic labels are identified as a catalyst for the lack of interest in the personal history of mental health problems, for impersonal psychiatric treatment, for negative prognoses or for the reduction of service users to their illness-related deficits (e.g. Brohan et al., 2010; Schulze & Angermeyer, 2003; Wahl, 1999). How mental health care is embedded in the normative order and how its specific constellation may induce stigma is, however, seldom central in empirical work (Pearlin et al., 2007).

Verhaeghe and Bracke (2007; 2008) are among the few who explicitly link contextual features with service users' stigma experiences in their study of the treatment context. In addition to their comparison of different care settings in Belgium – for example general and psychiatric hospitals – their study on ward features that affect stigma experiences explicitly analyses whether differences in size and in the level of individualization of treatment have an impact on stigma experiences among service users. Service users from larger hospitals – which surprisingly appear to offer more-individualized treatment – report more self-rejection. Similar to other contemporary studies, in which hospital settings are compared with alternative community settings, such as sheltered housing initiatives (e.g. Depla, 2005) or psychiatric departments in general hospitals (e.g. Chee & Kua, 2005), there appears to be no univocal decrease in stigma expectations and self-stigma among service users. Other recent work that integrates contextual factors at the macro level, for example unbalanced health policy and resource allocation, shows how the focus on the role of these contextual factors in creating power differences between users and providers, can help to explain the social production of stigma and discrimination during treatment. Lee and colleagues (2006) illustrate how the adoption of a multilevel approach, in which both structural and practical policy issues of the mental health care context and

interpersonal processes are taken into account, is a necessary step to address the complex position of mental health care in relation to stigma.

Harmful professionals: a social psychological conceptualization

The recent efforts to incorporate characteristics of the profession and the work setting equally characterize work on professionals' role in stigma processes. Researchers, including Flanagan, Miller and Davidson (2009) have analysed, for example, how structural, contextual features may lead to devaluing behaviour by professionals. By means of a mixed qualitative/quantitative design, these researchers identified systemic pressure on practitioners at a community mental health centre to label service users, and describe a culture in the mental health setting that emphasizes symptoms, problems and compliance, while neglecting the potential of service users. As Berry and colleagues (2010) state, the failure of professionals to combat stigma is not only related to the personal beliefs of individuals, but is also due to the fundamental tensions underlying the policies that shape their practices. In their explicit reference to the cultural context, Des Courtis and colleagues (2008) show for example that differences in the level of industrialization among countries have an impact on social acceptance and stigmatization among different professional groups.

These studies, however, stand alone in their effort to contextualize professionals' relationship to stigma. Research on the stigmatizing potential of mental health care and professional care increased after the recognition of the negative public response to de-institutionalization and community care (Henderson et al., 2014). The move to community care seems to have diverted stigma towards a social psychological conceptualization, with the prime focus on the attitudes and experiences of professionals, minimizing the attention paid to issues of structure and organization (Schulze, 2007). The majority of these studies address professionals' attitudes compared with those of the general public (e.g. Hori et al. 2011; Loch et al., 2013). Nearly three quarters of the relevant publications report that the beliefs of mental health providers do not differ from those of the population, or are even more negative (e.g. Caldwell & Jorm, 2001). Their attitudes are in line with the negative public attitudes and the desire for social distance.

Better knowledge about mental illness, identified in the 'contact hypothesis' as a means to reduce stigma (Couture & Penn, 2003), does not seem to act as a protective factor against stigma. Pessimistic beliefs regarding service users' chances of recovery are explained by the shared socialization process of professionals and the lay public (Hansson et al., 2011), and by 'physician bias' (Thornicroft, Rose & Kassam, 2007). Physician bias refers to the accumulated experiences of professionals concerning service users who do not fully recover or who relapse, whereas the professionals do not keep in touch with those service users who get well. Therefore, it appears that mechanisms identified as reducing stigma, such as contact with people who have mental health problems and knowledge about mental illness (Corrigan & Penn, 1999), can act in a counterproductive way for professionals, increasing rather than reducing stigmatizing beliefs. These findings suggest the need for more in-depth research on the dynamics that inform professionals' attitudes and beliefs in mental health care, and the need to move beyond the focus on sociodemographic characteristics and features such as familiarity with and knowledge about mental health problems by professionals as the main explanations.

The suggestion has been made that stigmatizing beliefs need to be approached as a function of professionals' relationship with the psychiatric discipline. The recognition of their strong approval of compulsory admission could, for example, be seen as a reflection of trust in the potential of treatment and not simply as a restrictive attitude (Nordt, Rosseler, & Lauber, 2006). However, the relationship between professionals and their working context has rarely been mentioned. Furthermore, Bates and Stickley (2013) stress the need to incorporate the public view about mental health in the study of professionals' stigma. Rather than suggesting a comparison between the lay public and professionals at the aggregate level, the public view could be approached as an indication of the cultural, normative understanding of mental health in society as a whole.

Research in which different professional groups – including nurses, psychologists, social workers and psychiatrists – are compared with regard to their attitudes and beliefs, equally focus on the differential impact of sociodemographic characteristics such as age, type of profession, working hours and professional experience (e.g. Bjorkman, Angelman, & Jonsson, 2008; Gras et al., 2014; Hugo, 2001; Scheerder et al., 2010). Although the incorporation of characteristics of the profession and the work setting implies accounting for contextual features (e.g. Lauber,

Nordt, Braunschweig, & Rossler, 2006), this research lacks a focus on the reasons why these characteristics have a particular impact. Accordingly, although all research takes a generally critical stance concerning the role of psychiatric care for stigma, the studies on professionals' beliefs and attitudes are characterized by an inconsistency. They simultaneously build on a psychiatric logic for their study, while at the same time identifying it to some extent as a harmful endeavour.

Acknowledging the intricate relationship

The initial focus of researchers such as Rabkin (1974) on the ways the beliefs and attitudes of professionals are linked to issues including professional status and the broader institutional policies and practices (e.g. Rabkin, 1974; Goffman, 1961), finds very little response in present-day studies on stigma and professionals. However, the recent attention paid to the stigma service providers face (e.g. Halter, 2008, Natan, Drori & Hochman, 2015), indicates a growing interest among researchers to move beyond the social psychological approach to the topic, stressing the importance of the normative, cultural context in which professionals work. Although Goffman's (1963) note on courtesy stigma – also termed stigma through association – has primarily been used in work on the stigma experiences of family members (Angermeyer, Schulze & Dietrich, 2003; Francis, 2012; Larson & Corrigan, 2008), professionals are also exposed to stigma, because they are working in a discipline with a low status and are less valued than staff working with other users groups in health care. Negative stereotypes of people with mental health problems – such as being blameworthy, dangerous, and unpredictable – were found to be associated with the mental health professions and led to the depiction and perception of professionals as ineffective and unskilled (Halter, 2008; Schulze, 2007). Verhaeghe and Bracke (2012) point to the necessity of being aware that the phenomenon exists as it appears to effect the well-being of service users. While it remains unclear to what extent this situation may carry over in actual behaviour in their daily work with service users, the topic nonetheless broadens the understanding of stigma in mental health care, as it both exceeds the unilateral approach of mental health care as a stigmatizing force and reorients the attention toward the broader context in which stigma and mental health care come together.

As such, it is clear that the different positions of both users and professionals in relation to stigma need to be contextualized. In their development of the Mental Illness Clinicians Attitude (MICA) scale, Kassam and colleagues (2010; Gabbidon et al.; 2013) made an effort to incorporate the different positions of providers, through the measurement of their attitudes and beliefs/behaviour about people with mental illness, their position toward the helpfulness of psychiatric care and their beliefs related to associative stigma. Like Heflinger and Hinshaw (2010) argued, the acknowledgement of this intricacy is important and should be further completed with explicit references to the relatedness of stigma to structural features of the organisation of care and its role in the broader society, referred to in early studies on the position of mental health care (e.g. Scheff, 1966) and care professionals (e.g. Cohen & Streuning, 1962).

Conclusion

While stigma research got its roots in mental health care research, which payed central attention to the role of mental health care in social structure and the ambiguous position of professionals who have to combine their intend to help with their accountability function toward the larger society, these sociological underpinnings are limited in contemporary work on stigma. Under the influence of the consumerist movement and the turn toward community care, there was a general tendency to stress the stigmatizing potential of mental health care and its professionals. While the work on service users takes a more sceptical stance toward the psychiatric discipline as a whole, compared to comparative survey research on professionals attitudes and beliefs, the absence of a focus on the relational nature of stigma, in which care relationships are analysed and situated in broader mental health care context, creates a partial image and appreciation of psychiatry in relation to stigma, leaves the possibility to unravel the complex relation of stigma and psychiatry unused.

CHAPTER 5

RESEARCH AIMS

Contemporary international literature about stigma in the context of mental health care is univocal in recognizing the role of professionals and mental health care settings in stigma processes. The original interest of symbolic interactionist researchers in the stigma experiences of service users and the role of mental health care has been revived in the last decade. Under the influence of the consumerist movement and the movement towards community care, both service user research and comparative research on provider populations mainly focus on the stigmatizing potential of mental health treatment. However, since this revival, little attention has been paid to the theoretical underpinnings of the stigma concept. As Link and Phelan (2001) state, stigma has a decidedly individualistic focus, informed by the dominance of the psychosocial model in the field. Although stigma was initially conceptualized as a language of relationships, not attributes (Goffman, 1963, p.3), current research often transforms stigma into individual beliefs and experiences. Before stigma can be tackled effectively, it is necessary to move beyond this narrow, individualistic focus and consider what stigma means in relation to mental health care (Henderson, 2014).

Several theoretical efforts have been made to capture the multidimensionality of stigma (e.g. FINIS), and recent work on structural stigma and health further stresses the need to conceptualize and measure stigma as a social phenomenon, with its roots in social structures. In empirical work, the incorporation of structure is often reduced to the integration of an additional level of stigmatizing institutions. The empirical value of the structural antecedents of stigma has not yet been elaborated on. In this thesis, I explore different relationships through which stigma is given shape, paying specific attention to the impact of the structural elements – such as social roles, social positions, institutions and cultural knowledge systems – and their systemic relations (Bonnington & Rose, 2014). The literature overview, with the identified deficiency, forms a basis for theoretical sampling and helped to increase the sensitivity of the employed concepts and theories to the data I gathered during my fieldwork in mental health care.

It is not my aim to reach a full answer to the question of what stigma means in relation to different mental health care processes. When discussing 'stigma in mental health care', the focus is on two core elements that are of crucial importance. The first refers to the relational nature of the concept, as Goffman (1963) refers to the 'language of relationships' as the essence of stigma. The second factor concerns the necessity to approach stigma as a situated concept, defined by the context through which it is given shape. In this thesis, it is my aim to value this contextual nature, by singling out several topics that became evident during my fieldwork and analysis, and which are lacking attention in existing literature. Furthermore, the attention paid to the contextual nature in mental health care, makes it possible and necessary to surpass the attacking approach of psychiatry in sociological work on stigma, requiring an open and respectful attitude towards mental health care and its professionals.

Accordingly, particular attention is paid in this thesis to the different relationships through which stigma is formed and becomes meaningful in the context of mental health care. Several associations are incorporated, out of which the most central one concerns the relationship between the service user and the care provider. Through the choice to include the accounts of mental health problems and care from both groups via interviews, together with carrying out participant observations in which the specific moment of these relationships can be observed, I hope to derive more insights into the dynamics through which stigma is given shape. Starting from this interactional view at the micro level, informed by the symbolic interactionist approach of Goffman, it is my aim to gain more insight into the structural antecedents of these interactions – including social positions and cultural knowledge systems – going beyond the discussion of professionals as good or bad actors in relation to the stigma process. Stigma is accordingly studied as a social dialectic of interpretation, informed by macro-structural forces (Yang et al., 2007).

Moreover, through the incorporation of the context I want to go beyond the discussion about the stigmatizing or helpful nature of mental health care, and instead question why and how its relationship with stigma is so complex. As Becker (1967) said, the acknowledgement and respect for the dominant framework through which knowledge and relationships are produced makes it possible to take a constructive position in the discussion of interdisciplinary issues like mental health stigma.

CHAPTER 6

METHODOLOGY

A research methodology is more than a technique used to answer a research question. It contains inherent assumptions and values regarding the studied subject and determines the questions that can be asked as well as the formulation of satisfactory answers (Rapley, 2014). I chose for a qualitative enquiry in this thesis, because of the specificity of my research aims. Qualitative research seeks to answer questions that concentrate on the way social experiences are created and given meaning to (Denzin & Lincoln, 2011). As Link et al. (2004) stated, the set of methodologies provided by the qualitative approach permits the researcher to gain rich insights in how stigma is given shape in social interactions, how people experience stigma and how the complexity of social systems produces stigma. These locate the researcher as observer in the world, studying things in their natural setting, trying to capture phenomena in terms of the meanings people attribute to them (Denzin & Lincoln, 2011). As such, measuring what matters the most is facilitated by ethnographic methods, as these make it possible to explore local value systems in far greater depth than what is possible through standard survey instruments (Kleinman & Hall-Clifford, 2009). It concerns these value systems who determine the moral standing of an individual or group and therefore the experience of stigma. In what follows the methodological framework of this study is set out. First, the different factors on which the sampling procedure is based are discussed in detail. The second part contains a description of the period of ethnographic fieldwork in which participant observations and semi-structured interviews were combined. Third, the data analysis, informed by constructivist grounded theory are explained and illustrated. In the fourth part reflexive thoughts and ethical questions are discussed. The strategies employed to realize a certain research quality in this work are discussed in the last section of this chapter.

Sampling decisions

Based on the specific concern to study stigma as a contextual issue, the selection of cases is of crucial importance. I choose for theoretical sampling, a type of purposive sampling proposed by Glaser and Strauss (1967, p.45) in their grounded theory. The theoretical overview of the previous chapters served as the main guide for the theoretical sampling procedure. The initial sampling decision was based on the basic theoretical understanding of stigma in mental health care and once some data were collected and the coding began, several new insights further guided the work in apparent relevant directions (Draucker et al., 2007; Glaser, 1978).

In considering the research aims and intensive nature of ethnographic research in mental health care, two inpatient mental health care settings in the region of Ghent were eventually selected. As already mentioned, the Belgian mental health care context is characterized by a very high number of hospital beds compared with other Western countries. Furthermore, at the time of my fieldwork Ghent had five psychiatric hospitals in its territory (from which two recently merged) and is therefore characterized by a very high and concentrated supply of hospital beds. Moreover, I chose to select hospital settings for my fieldwork, as they remain the main specialist care suppliers for people with mental health problems in Belgium, and in several other countries (see Table 1). As the contemporary movement towards community care is financed and directed by psychiatric hospitals, insight into their relationships with stigma can only lead to a better understanding of the dynamics that inform stigma processes in other mental health care contexts.

Table 1: Availability of mental health facilities in Belgium

	Total number of facilities/beds	Rate per 100,000 population
Mental health outpatient facilities	89	0,83
Day treatment facilities	136	1,27
Psychiatric beds in general hospitals	2737	25,58
Community residential facilities	UN	UN
Beds/places in community residential facilities	UN	UN
Mental hospitals	68	0,64
Beds in mental hospitals	14385	134,47

Source: WHO Atlas 2011

The hospitals were chosen based on their geographical location, their equivalent size and their approaches to mental health problems and care. Both are situated in Ghent, on the outskirts of the city. They are relatively small, with a similar number of hospital beds (+/-190). This involves hospitals in which theoretically divergent notions of care for people with mental health problems had been reported earlier, based on interviews with staff and written material on their care approaches (Sercu et al., 2010). This earlier study focuses on service users who were difficult to transfer between care settings, and its findings suggest that service users were perceived as 'difficult' due to a mismatch between their needs – related to their diagnostic and sociodemographic profile – and the notion of residential psychiatric care based on which the care supply was organized.

One hospital (A) adhered to a more social explanatory model in the definition of its service users, by which the hospital renounced the distinction between the ill and the healthy, based on diagnostic categorizations. They opted for a social explanatory model, which identifies the less healthy as socially marginalized and misfortunate. This approach has its roots in the French psychoanalytic tradition, viewing all people as mentally ill to a certain degree. In general, the

movement towards community care has progressed relatively slowly in these settings, as there is no general method at a supra-local level (Morant, 2006). This hospital had a high prevalence of long-term inpatient care. In the other hospital (B), service users were primarily perceived and approached from a diagnostic point of view and the care approach was founded on the dichotomized categorization of healthy versus ill. This involves a setting that can be situated in the Anglo-Saxon tradition, which takes a more cognitive/behavioural approach and in which mental health care reforms are part of the political process (Morant, 2006). Hospital B served as an institution providing primarily short-term care.

This background was crucial to orient the hospital sample, because it is recognized that the understanding of mental health problems and care – such as for instance the process of dichotomized categorization between illness and health – is at the core of stigma processes (Link & Phelan, 2001; Scheff, 1966). Choosing research settings with a different conceptualization of mental health problems further implies that service providers and users are exposed to particular theoretical paradigms, professional identity conceptions, practices, etc. These conceptualizations reflect cultural processes in the broader society, which sustain, for instance, the idea that people with mental health problems comprise a distinct cultural category (Handy, 1991; Van der Geest & Finkler, 2004).

Two treatment wards in each hospital were selected as the specific units for observation: wards A1 and A1 in Hospital A, and B1 and B2 in Hospital B. These were specifically one ward for people diagnosed with mood disorder in each hospital, namely ward A1 (20 beds) and ward B1 (24 beds). Whereas A2 (15 beds) was a ward for individuals dealing with a combination of psychosis and substance abuse, ward B2 (24 beds) was for people with problems related solely to substance abuse. The initial aim was to select two wards in each hospital that focused on exactly the same diagnostic target group, namely two wards for people with depression and two wards for people suffering with psychotic episodes. In practice, it appeared that not all professionals were keen to welcome a researcher without training in psychiatry in their ward. A co-ordinator expressed concern about an 'outsider' making contact with individuals who were paranoid. Someone else stated that the use of interviews as the research method opposed the treatment approach of the ward, as one-to-one interactions were not carried out. After multiple meetings and discussions with providers, the choice of the above-mentioned wards was made.

Accordingly, the initial statement that the theoretical sampling procedure guided the selection of cases is only partially correct. In taking the remarks of professionals into account, pragmatic considerations led to convenience sampling (Charmaz, 2006; Patton, 2002), stressing the ultimate importance of practical issues in the sampling procedure.

Furthermore, it is important to note that the selection of wards based on their diagnostic target group, means that the study is somewhat inscribed in the dominant diagnostic logic. Although this has been identified as an important catalyst in stigma research, it was impossible to move beyond this leading organization principle as a starting point for my ethnographic work if I wanted to start my research in a considerate way.

Table 2 : Hospital characteristics in 2011 - 2012

	Hospital A		Hospital B	
Ward	A1	A2	B1	B2
Diagnostic target group	depressive mood disorder	psychotic disorder & substance abuse	depressive mood disorder	substance abuse
Official duration of treatment	12 months	12 months	5 months	5 months
Number of hospital beds	20	15	24	24

At the time of the fieldwork, Hospital A housed service users who had multiple psychiatric problems, who were homeless or who were facing juridical procedures. In ward A1, it was remarkable that the profile of service users rarely matched the official description of the ward as one for people suffering from depression. While service users' medical profiles differed, they all had precarious socioeconomic conditions, meaning that they had a homeless, solitary and/or financially uncomfortable life. This observation fits with the adherence of the hospital to a more social explanatory model of mental health problems, in which the less healthy are identified as socially marginalized and misfortunate. In Hospital B, the official description of the wards was reflected in the ascribed diagnoses of the hospitalized service users. Similar to ward A1, ward B1 was described as a department for people with depression. The problems of most service users were framed as symptoms of major depressive disorders. Although professionals expressed their dissatisfaction with the growing number of service users whose symptoms did not fit the strict criteria of major depressive disorders, there was an enormous difference with the other ward

oriented towards depression, were people with symptoms of major depressive disorders were relatively exceptional. By contrast with the service users in ward A1, most of those in ward B1 could be situated in the middle class.

The differences in the approach to mental health problems and care were further reflected in the organization of care, which implied for instance different admission criteria or the time people were 'allowed' to stay in the ward. Furthermore, both the organization of inter-professional relationships and those between professionals and service users were dissimilar in the wards. In Hospital A, the organization of care was rather fuzzy. Inter-professional relationships were characterized by tensions, reflected in endless, troublesome decision-making processes. The authority of the psychiatrist was continuously questioned. Relationships with service users were intimate and intense, and encounters were not framed by an apparent treatment framework. The organization of care in Hospital B was characterized by a clear professional framework, in which hierarchical relationships and responsibilities were quite explicit. Relationships with service users were in general characterized as those between provider and user. The framework for treatment was set by the providers and with their support, the user was supposed to employ the tools offered in order to get better. Furthermore, the variation in the approaches to mental health problems and care appeared to be important in the professionals' motivation to work in a particular hospital. They identified a match between their view and the broader treatment framework in which they worked. Accordingly, the choice of hospitals with a different approach to service users and a different organization of care also imply the selection of professionals who differ in their understanding of mental health problems and of good care for people with mental health problems.

Table 3: Organizational features of hospitals and wards based on field notes

	Hospital A		Hospital B	
Ward	A1	A2	B1	B2
Geographical location	Outskirts of Ghent.		Outskirts of Ghent.	
Number of hospital beds	Around 190.		Around 190.	
Explanatory model	Social model (renounced the distinction between the ill and the healthy, identification of the less healthy as socially marginalized and misfortunate, rooted in French psychoanalytic tradition).		Biomedical model (medical language use, diagnoses crucial in evaluation of service users and organization of treatment, the therapeutic programme, rooted in Anglo-Saxon tradition, holds to more cognitive/behavioural approach).	
Target group	Low SES (very low level of educational attainment, most people were unemployed or were receiving an invalidity allowance).		Higher SES (most users had completed at least secondary education, were self-employed or on sick leave).	
Inter-profesisonal relationships	Informaly organized, limited authority psychiatrist, autonomy nurses (in decision making processes during team meetings, or in case of unacceptable behavior of service users; relationships were characterized by tensions and reflected in endless, troublesome decision making processes).		Formally organized, authority psychiatrist (takes final decision during team meetings), limited authority nurses.	
User-provider relationships	Relationships with service users were intimate and intense, and encounters were not framed by an apparent treatment framework, difficult to identify who was user or provider, partly due to organization of space, seldom separate eating places, providers were often sitting/smoking/playing with service user, nursing room was often frequented by service users looking for company or who wanted to say something.		Relationships with service users intense, encounters framed as therapeutic, nurses rarely sit with service users during the day, or participate in users' activities during idle times, only during the evening/night. when providers sit together with users to smoke. Nursing room is not a place users can enter easily.	

In sum, it appears that the difference in the perception of mental health problems and care in the hospitals implies variations in a multitude of organizational characteristics, reflected in interpersonal and intergroup relationships in the different settings.

In the four selected wards, all the professionals (43) were included in the research design, which implies that they were observed and were invited to participate in an interview. This mainly

concerns psychiatric nurses, as they comprised the majority in the multidisciplinary teams. Each team contained one psychiatrist, one social worker, one or two psychologists and on average eight nurses. All the nurses (33) who participated in an interview were graduates from university colleges, and who had followed professional nursing education for three years. In Flanders, nurses can opt to specialize in mental health and psychiatry in the third year of higher education. Some had an additional master's degree in philosophy or psychology. Nurses who were interviewed in this study were aged between 26 and 58 years. In all the wards, nurses in their twenties and thirties were accompanied by nurses in their forties and fifties. Some 61% of the nurses were women, and both sexes were represented in every ward. In addition three psychiatrists, four psychologists and three social workers were interviewed. Whereas nurses regularly met to discuss service users (up to three times a day), the contact of nurses with psychiatrists was often limited to one or a few times per week. This variation in presence was reflected in the time spent in interactions with service users. Nurses had the most intense contact, spending some time with service users every day. Consultations with a psychologist or doctor were mostly scheduled once a week.

Out of a total of 83 service users who were present at the time of the fieldwork, 42 self-selected for an interview, on average 10 in each ward. The sample of participants is 64% male (n=27), their age ranges from 20 to 60. Ten of them were on sick leave and six were taking a career break, all the others were unemployed (n=8) or living off an allowance (n=18). A minority were living with a partner (n=11), as most participants were divorced (n=12), single (n=18) or widowed (n=1). It is interesting that both the level of educational attainment of service users and their occupational status differed between the hospitals. In the wards of Hospital A, only three users had followed higher education and in Ward A1, more than half of them had not completed secondary education. However, in Hospital B, nine service users had a higher education degree and in Ward B2, 10 out of 12 had completed at least general secondary education. Most of the people who were on sick leave or who were self-employed resided in Hospital B, whereas Hospital A contained mostly people who were unemployed or were receiving an invalidity allowance. A minority of 36% had been hospitalized for the first time. Four individuals were subject to compulsory admission. Service users were labelled with (multiple) diagnoses, specifically 33% with mood disorders, 2% with psychosis, 69% with dependency and one person with an acquired brain impairment. However, during the fieldwork period, I did not focus on

54

service users' clinical diagnoses, unless they discussed it with me or if it was the topic of conversation during team meetings. I wanted to move beyond the diagnostic label as a starting point for the study of stigma. Instead, the focus was on the conceptualization of the service users and providers regarding their problem and the importance of this biomedical view in the perception of their problems.

Service users (n=41) who did not agree to participate in interviews, did so primarily because of their discharge before the start of the interviews or because of the severity of their problems. Incoming service users during the time of the research were informed of the goals and methods of the research and were invited to give their 'consent-to-observation'. They were not invited for an interview. As the objection of one service user would mean the end of my fieldwork in that particular ward, a great deal of time and energy was invested in informing service users and answering their questions related to the research and the presence of a fieldworker. Eventually, none of the fieldwork periods was cut short due to the objection of a service user.

Researcher reflexivity and ethical questions

Reflexivity

Carrying out research contains the implicit idea that issues external to the researcher are being investigated. However, research topics and questions do not develop independently from the researcher's interests and affinities, making all researchers to some degree connected to the object of their research (Davis, 2008, p.3). Therefore, the impact of the specific characteristics of the researcher on the research process needs to be considered, especially in ethnographic work in which more intimate, long-term engagements are made with the subjects and settings for research. Reflexivity therefore refers to a process of self-reference, focusing on the ways in which personal characteristics and history, together with the sociocultural context in which they work, affect the research process (Davis, 2008, pp.4-5). These aspects more particularly influence how data is constructed through interviews and observations. Davis (2008, p.5) suggests that the integration of this reflexive movement can best be obtained through the

elaboration of research in which subjective experiences and reflections on it are an intrinsic part of the research. The constant negotiation of my unnatural position as participant observer in mental health care settings made this reflexivity an integral part of the research process. In the following part, I discuss some reflexive thoughts about the ways the presence and the personal characteristics of the researcher influenced the data.

First, during the initial days of my presence on the wards, efforts were made by professionals to structure and time team consultations and meetings. Furthermore, overt discussions and the venting of frustrations were limited during my presence in the meetings. Service users made remarks about the abnormal 'schoolish' character of certain therapeutic sessions, which they thought had something to do with my presence. After several days, these effects diminished and the particular dynamics of the different wards re-emerged. Prudence was replaced by overt discussions. Jokes were made about service users, their families, psychiatrists and other absent care providers. My presence was now reflected in providers joking about my presence, such as 'be careful, our researcher writes everything down', and the daily functioning of the team seemed to embrace my presence. However, some providers retained a feeling of being evaluated, and repeatedly asked me how I perceived their work on the ward. I always told them that the purpose of my fieldwork was not to judge them, but that I was instead interested in their work-related perceptions and experiences. Rather than being cautious, service users were curious about my presence and asked me many questions about the purpose of my presence. Most service users were enthusiastic and showed me around the ward or hospital, and several used me as a sounding board to express their opinions and frustrations about the staff and the treatment they received. After a few days, this 'sounding board' function diminished, and reciprocal, informal conversations were established.

Second, my status as a mentally 'healthy' and medically untrained person positioned me as an outsider in the wards (Gair, 2012). In qualitative studies, researchers are regularly part of the social group they study (or 'insiders'). This position has several benefits, specifically familiarity with the setting and the culture being studied. Furthermore, issues of gaining access and dealing with ethical concerns become minor concerns (Bonner & Tolhurst, 2002). However, being an insider makes it difficult to grasp routine care procedures, as it is easy to overlook the experiences of day-to-day events. As an outsider, it was possible to observe and question the way

routine processes were given shape; aspects that could easily be overlooked by people who are familiar with mental health care. In participant observations, this position was further identified as a useful method to build trusting relationships with participants and therefore to increase in-depth reflections on, for instance, the daily functioning of the ward (Adler & Adler, 1994). As mentioned in the previous paragraph, service users were enthusiastic about my outsider position, and perceived my presence as an opportunity to express their experiences.

Third, the relatively young age of the researcher may have formed a barrier for some older service users to talk openly. Especially because some service users explicitly mentioned their dissatisfaction about being expected to express their feelings and tell their history to providers of a young age. The remark of Jeanne (pseudonym) about age during the interview illustrates this:

I also find it important that several nurses are my age; are from the same generation. Others are younger, that's different, I find them very engaged, but they are not the first I will go to if I have a problem. And I have to say, someone like Bjorn? That's difficult for me. It has nothing to do with the person as such, but it is just that he could be my son so to say, and that's not .[…] If someone is younger than my daughters, then I think, is it necessary that she knows everything about me? I do not find that evident.

My status as an outsider, who was not in a position to make them better or to help them, appeared to remove this age barrier to an important extent, making them report difficulties such as that described above. For some professionals, my age, together with a lack of psychiatric training, appeared to give them the feeling that they had to teach me about their work, perceiving me as a trainee, rather than a researcher. This perception offered me insights into the content and way they presented the ward to potential professionals, and in the issues they did not talk about, evaluating these as less important to future care providers. Due to the mixed gender composition of both the groups of service users and the professional teams, gender did not appear to play an important role.

Fourth, my own emotions as a researcher equally affected the research. My unfamiliarity with mental health care confronted me first of all with my own prejudices and emotions concerning people with mental health problems and stereotypes in general. I caught myself thinking in a

stigmatized way in the build-up to my fieldwork. Experiences during my first visit to the first hospital in which I was going to carry out fieldwork are illustrative:

In taking the bus to the hospital, I wondered who else had the same destination as me. I caught myself thinking that those people who I perceived as marginal, with poor personal hygiene, were people with mental health problems. While several of them got off the bus with me at the hospital, other did not. Once I entered the hospital and waited for the professional I had an appointment with, the confrontation with my own stereotypical thoughts was complete. I was waiting for about a minute when someone presented himself to me as Gert, after passing several times in front of the entrance of the waiting room: 'Hi, I am Gert, and you are probably Charlotte from the university who will do research here.' I confirm, surprised. Did the staff tell the service users that I would pass by today, or is this man a professional and not a service user? He carries on and tells me that he talked with me on the phone and I respond that I cannot remember this and that I do not think it is the case. He says: 'I probably mistook you for someone else', and says goodbye. He lights a cigarette up at the entrance, taking a look at me from time to time through the window. I did not pay visible attention to him.

On my first entrance, I was immediately confronted with my own stereotypes and prejudices when I entered the world of psychiatry. The fuzziness in the distinction between ill and healthy, provider and service user, self and other, made it a confronting and very instructive starting point for my fieldwork.

In addition to my own negative stereotypes and emotions, facing service users who were having a very hard time with their particular problem and further asking them to participate in my research, gave me a somewhat guilty feeling. In the midst of their problems, I was asking them for a favour, in an effort to make my own research project succeed. This guilt diminished through the experience that service users were mostly positive about my interest in psychiatry – in contrast to most people for whom negative experiences dominate – and were willing to and interested in participating. As well as feelings of guilt, feelings of fear equally overcame me several times. I was especially afraid when the staff were very restless after aggressive incidents, after a suicide attempt or when the police came to pick up a service user who had broken his conditions in order to take him back to prison. These situations created commotion, which affected me too. When I heard that a woman had attempted suicide the day after finishing the

interview with her, feelings of fear and guilt overwhelmed me. By writing things down, I could somehow take a step back from these emotions. The fact that I did not sleep in the ward during my fieldwork equally helped me to stay emotionally balanced, offering me the necessary distance to reflect on my experiences during the day. These breaks made it possible to become aware of my own emotions, to reflect on them and to diminish their impact on my fieldwork.

Ethical issues

Different requirements have been identified for ethical research in mental health studies, referring to moral principles to prevent harmful actions and to promote respectful attitudes and behaviour towards the research subjects (Dubois, 2008). The underlying premise for the consideration of research ethics in mental health care is based on the notion of the vulnerability of psychiatric service users (Oeye, Bjelland, & Skorpen, 2007). As previously described in the paragraph concerning gaining access, these guidelines are based on medical ethical guidelines, such as informed and voluntary consent and an estimation of the risks and benefits. These factors modified the research design to an important extent. The lack of experience of the Ethics Committee of Ghent University Hospital with the ethnographic method meant that the research design had to be adapted to some positivist standards in order to be approved.

A serious challenge concerned the voluntary informed consent of the service users for the participant observations. Every service user had to agree to my presence by completing a written consent form. If one service user did not sign the form, the ethnographic fieldwork in the ward could not commence. This involved being expected to work together with the professionals, who decided if and when people were able to give their consent. Although the professionals made great efforts to make the fieldwork possible, this instruction by the committee shows that they perceived service users as vulnerable and potentially not competent to give their consent. The roots of this protective action lies in a paternalist attitude, while at the same time making absolute respect for service users' autonomy a central issue. This duality made the ethical approval problematic in advance.

Informed by existing stereotypes about mentally ill individuals, service users were considered as potentially incapable of giving their informed consent. The capacity to give consent refers to an individual's ability to make a meaningful decision about whether to participate in the research or

not, and is therefore related to their understanding, appreciation, reasoning and voluntarism (Zayas, Cabassa, & Perez, 2005). These concepts do not have clear meaning, and the focus of ethnographic work is on the different meanings of these concepts for service users in their specific contexts. However, the 'positive care experiences of service users' had to be transformed by the 'better care', suggesting a positivist and universal definition of good care. Eventually, three written informed consent forms were distributed respectively to service users, professionals and the board of the different wards. With regard to service users, this form sometimes created distance: they asked why they had to sign their name, who these informed consent forms were for, etc. After consultation with the professionals, it was sometimes decided to give newly-admitted service users a few days in the ward before I presented myself and my research project, in an effort not to burden service users with additional, confusing information during their first days. These minor deviations from the ethical prescriptions made the fieldwork more respectful in a certain sense.

With regard to voluntariness, the sampling procedure – which implies the selection of settings – meant that service users and professionals were not entirely free to make the choice of whether or not to be a research subject. The coincidence of their hospitalization and the planning of my fieldwork made them potential research subjects. However, the fact that they could choose not to be interviewed gave them somehow an additional choice to decide on their participation. This was equally the case for care providers. Participant observations are therefore somewhat intrusive, in the sense that service users do not choose to be part of a given setting at a given moment. Nevertheless, participation at this moment, by interacting with them to get to know how they experience it, is the only way to learn to know about care experiences in day-to-day interactions (Oeye et al., 2007).

Several measures were taken to guarantee the privacy of all research participants. I explained that I was the only people who would listen to the interviews and that pseudonyms would be given to all the interviewees. Any information that could lead to their identification would never be published in relation to specific quotes.

As previously mentioned, feelings of guilt accompanied me as a researcher when I invited service users to participate in my research in the midst of very difficult times in their life. Although I conjectured that only the researcher would truly benefit from the fieldwork, it

60

appeared that the professionals and service users also had an interesting time, after reflecting together with them on my observations and their own perceptions and experiences. Accordingly, I could suggest that it was an enriching experience for all the parties who participated in the research project, and at the end of each period of fieldwork also participated in my sister's homemade patisserie.

Ethnographic fieldwork

Negotiating access

The described sampling procedure – in its multiple stages – is closely related to issues of negotiating and gaining access. It refers to a continuous process, in which the presentation of oneself and the building and maintaining of relationships are central (Reeves, 2010). In the process of gaining access to the hospitals, those selected for the research were contacted by means of an invitation letter. Both settings were willing and were interested in participating. An appointment was made for an explorative discussion with the manager of patient care and co-ordinators of different wards, during which the research proposal was detailed. In an effort not to put them off, the focus on stigma was framed in a broader interest in the understanding of the construction and role of care relationships in the treatment process. Both hospitals were enthusiastic to participate and the next step was to gain approval from the Ethics Committee of Ghent University Hospital and both hospitals before the fieldwork could begin. The process of gaining permission for ethnographic research in hospitals was very difficult. It involved a rather discouraging period, but at the same time it was a vital time for me, as their comments and demands provided me with the first insights into the way mental health care is related to the broader biomedical framework of care, based on positivist notions of illness, health and research. The first remark of the committee regarding the title of my information form is telling. I had to change the title 'A sociological study into the aspects of care relationships *which contribute to positive care experiences of service users* in a psychiatric hospital setting' into '*… which contribute to better care for service users…*', which implies that the essence of my work, concerning the experiential aspect of care relationships and stigma, had to be replaced by a

61

positivist and previously decided-on notion of better care, perceiving service users as passive recipients of care. Other comments related to my lack of medical schooling as a sociologist, such as the suggestion to incorporate a psychiatrist into the research team to improve the quality of the research team and to *protect* the service users and the researcher. With regard to my research method, the use of in-depth interviews was for instance perceived as problematic, because as the committee stated 'it is impossible to predict where the conversation will end' and 'what will you do if someone starts to tell the story of their life'. This implied that my topic list had to be replaced by a semi-structured interview to obtain the necessary approval. In the end, I provided two semi-structured interviews, one for service users and one for professionals, and different information forms for the hospital board, the care providers and the service users. Providers were invited to give their informed consent for an interview. Two different consent forms were prepared for service users, one of which invited them to agree to my presence in the ward and the second to participate in an interview. The understanding was that if one service user did not agree to my presence in the ward, I had to stop my fieldwork immediately. This aspect of the fieldwork made the continuous process of building and maintaining relationships with service users, as well as the constant reflection on how I presented myself and interacted with others, as both a methodological and a practical necessity in the elaboration of the fieldwork.

The impossibility of the ethical committee to reason from a qualitative, explorative viewpoint – influenced by their positivist biomedical approach – had consequences for the style and content of the interviews, the organization of my presence in the different wards and the negotiation of my researcher role. Moreover, the experience that hospitals and wards take different forms and hold different orientations towards mental health problems, care and service users implied that the process of gaining access and the negotiation of the researcher role differed considerably between wards, and even in my contact with different service users and professionals.

After the approval of my adapted research proposal by the Ethics Committees, I had to advise the research foundation of where and when I was going to carry out my fieldwork. This procedure further confronted me with the alienated character of the psychiatric hospital in contemporary social and academic life. Although it took me only about 20 minutes to travel to each place, I was obliged to officially report each period of fieldwork as a stay abroad. Despite the geographical proximity, my fieldwork appeared to be comparable to a stay in a foreign country.

Research roles and relationships

Once I effectively entered the field, it was essential to establish my identity and position. Although I had no choice regarding my official insured status in the hospital – as a trainee (Hospital A) and a volunteer (Hospital B) – as a researcher, there were basically three positions I could choose from if I wanted to appear to be a 'natural' person in the ward. This involved accompanying the professionals, the service users, or positioning myself as a visitor. However, my aim to approach stigma as a relational issue, focusing on the different relationships and interactions that inform stigma processes in the ward, made it necessary for me to try to establish my 'unnatural' position as a researcher. I repeatedly told users and providers about the aims of my presence. Based on my intent to participate as much as possible in the daily functioning on the wards, I chose to take the role of 'participant as observer'. With this role, Gold (1958) means that the field worker and the participants are aware of their role, but that the fieldworker develops relationships with the participants, through which any unease and initial reactions to the presence of the fieldworker are likely to disappear over time. Much of my work in each of the wards was therefore related to the overt creation of a new role or position in the social system of the setting, as all the information I could gather during the fieldwork depended on this effort.

In the beginning of each period of fieldwork, the build-up of trusting relationships with professionals was easier than expected and progressed smoothly in the different settings. They were interested in my work and helped me to make sure that the fieldwork could be carried out. They helped me to organize the information sessions for service users, to make sure that all the users agreed to my presence in the ward. They were very open, sharing the complexities and pleasures of their work with me. However, I was sometimes approached as an ombudswoman. Several providers took me to one side to tell me about their frustrations concerning collaborating with the psychiatrist, or about their work with certain service users. Furthermore, jokes about my presence during team meetings, such as 'be careful about what you are saying, she writes down everything', illustrated that my presence never went completely unnoticed. I developed a great deal of respect for the professionals' dedication to care. The easiness of these contacts made it possible to follow team meetings, to have lunch with the professionals, to reflect together on the observations I made, etc. Moreover, they often asked me for feedback, discussing their perceptions, ideas and difficulties. Although in stigma research, professionals are often pointed

to as harmful, egoistic individuals, I had easy contact with professionals who were generally very concerned about their service users. The time I spent with the professionals in their office, during team meetings and information transfers (up to three times a day), made it sometimes difficult not to be viewed as a professional in the eyes of service users.

Initially, it was more difficult for service users to position me in their social-interpersonal world, because they knew that I was not like them. The ease with which I could build researcher relationships with the service users appeared to be influenced by the organization of the relationship between user and provider. The greater the fuzziness in the distinction between provider and service user, between the healthy and the mentally ill, the easier it was to move into the ward as a researcher, without the feeling of constantly switching from one side to the other. I could sit, walk and talk where I wanted, as there were almost no spaces or organizational features that indicated a clear division of individuals in the function of their status as professionals and service users. This is illustrated in the following note:

When I enter the ward on this first day of my fieldwork, I am immediately invited to go and smoke a cigarette together with other people. In the lift, I wonder who the service users and providers are. Once we are outside, they start talking about the thesis of one of the individuals, which includes a piece of art. Once the morning meeting starts, I still do not have a clue about who the service users and professionals are. I sit among others and only after the meeting, when service users are invited by the creative therapist to join her in the 'creation' room, I understand that she is a care provider.

In wards with a clear organizational structure, I had the feeling of constant switching between perspectives, between spaces. The fact that users and care providers seldom sat together during moments of idle time and ate in different buildings, made it difficult to position myself as a researcher. Users and providers equally tried to put me in a staff position in order to benefit from my presence. I tried to avoid this wherever possible. For example in wards where I had a key, I kept this a secret and never used the key in the presence of service users. On other occasions, I could not escape, such as when professionals put me in their position during therapeutic activities. During a trip in the neighbourhood, the professionals told me that they were going back to the hospital by car, and that I could take the train with the service users. Although I felt uneasy and responsible, I ultimately used this time with the service users for a collective

reflection on certain health care aspects, which made it a very informative moment. Service users equally tried to push me into a provider position, for example by asking me for permission to leave, when I could only refer them to the professionals. The most difficult challenges were related to interpersonal conflicts I witnessed during my presence on the ward. At these times, the different parties explained the conflict to me and it was not always easy to maintain my position as a 'neutral' observer. Such as the case of Simon, and the discussion about his non-compliance with medication:

Simon has not taken his medication for three weeks. On the one hand, the doctor says that he has to leave the ward if he does not take medication. Nurses, on the other hand, appear to 'take Simon's side', telling me that the doctor only sees Simon's violation of the rules, and does not question the reason for his refusal to take it. They tell me that multiple side effects, such as bed-wetting, made it impossible for Simon to continue with the medication. They suggested that the doctor give it a try, and she answered with the statement: 'Then it is no longer my responsibility if things go wrong'.

Service users knew that I participated in staff sessions and the providers knew that I participated in activities outside the therapeutic programme, for example playing volleyball in the evening or eating with service users at noon. My transparency about these instances never led to difficulties in relation to one or the other. On the contrary, my 'cross-border' position was highly valued, and professionals as well as service users often asked me if I perceived things differently, based on my position. Accordingly, I was able to see and began to understand mental health care as a multifaceted phenomenon. Having a glimpse of the perspective of both provider and service user, I started to uncover the complexity of stigma in mental health care.

Participant observations and field notes

The typicality of participant observations is the long-term personal involvement in the context, and with those being studied (Tedlock, 2005). Participation in the context serves to expand the researchers' understanding of the culture in which research subjects live their daily life. Although participant observation is seldom the main data-gathering technique, it facilitates research in important ways (Davies, 2008, p.77). First, participant observations increase the mutual familiarity between the researcher and the research subjects. Informal talks made the

eventual interview a more informal event, in which service users were no longer reluctant to express their perceptions. Accordingly, it enabled more open and meaningful discussions with professionals and service users. This combination of observations and interviews has also been recommended as a strategy to maximize the quality of data when dealing with individuals who might have difficulty in reporting their experiences (Kirkewold & Bergland, 2007). Second, the technique makes it possible to move beyond the analysis of the information being obtained and to explore the social dynamics that make this information central to the study. This possibility goes hand in hand with the third advantage, namely the reflection on the researcher's own positions. More specifically, this concerns the awareness of the fact that gathered information is always affected by the position of both the ethnographer and the informant within their own personal relationships and social worlds (Davis, 2008, p.83). The researchers' sensitivity to the nature of the conditions governing their own participation, form a part of developing an understanding of the studied individuals and settings. The constant negotiation of my researcher's position with the professionals and service users and the organizational barriers I experienced in the handling of my researcher role (see the previous paragraph), provided me with important insights into the organization of care relationships in the different settings. Trained as a sociologist, I needed time to try and uncover the unspoken logic that shaped the clinical reality of each ward, and at the same time, my training also made it possible to reflect on this clinical logic from a different perspective than professionals or service users, which enriched the data-gathering process.

Eight consecutive weeks of participant observations were conducted in each ward. Fieldwork was mainly organized during the day and mostly on four days a week. Several evenings were spent in each ward, in an effort to observe a different logic between the various actors when the formal therapeutic programme came to an end. The distinctiveness between formal relationships during the day and more intimate contacts during the evening was remarkable in some places, as observed in ward B1.

After five, at the end of the official therapeutic programme, nurses seem to replace the formal distance from service users by another, more intimate relationship. While they eat or take a break at a separate providers' table during the day, professionals sit together with service users

66

at night, they eat together and play a game in the living area. Service users and care providers sit together in the smoking room at night.

I also spent a few nights in the wards on the advice of professionals. During the nights, the use of space was different, as service users were for instance free to spend a few hours in the nurses' office, a space that was primarily reserved for professionals during the day. The different use of space, and more generally the 'contrast' between formal and informal moments/contacts told a lot about the organization of care and how both professionals and service users were related to this framework. It made me question the self-evidence of interactions or dynamics I might have overlooked during the day.

During the participant observations, I tried to understand the service users' ways of perceiving themselves, their problems, the professionals who were working with them and how they acted on the basis those perceptions; trying to comprehend their expressed reactions regarding what had happened to them. If there is a central question I seek to answer, it is how stigma comes into play in the perceptions and actions of the users, and what this might mean in relation to inpatient care relationships in contemporary mental health care settings. Field notes therefore refer to reconstructions of conversations, my own thoughts and feelings, descriptions of events and individual behaviours, discussions, and information from a variety of sources.

The writing up of field notes seemed rather uncomfortable initially. Team meetings were the only moments where taking notes was practical. Most of the day I was busy, observing and participating in activities, eating together, etc. From time to time, I withdrew to the bathroom or an empty room to write down observations. The professionals and service users knew that I made notes, but I avoided doing so in the presence of others, as it stressed my function as an external observer, which might have increased any unease about my presence. During team meetings I was not the only one making notes, which therefore made it a less remarkable act. I completed and wrote out my notes in the train on my way back home, immediately after leaving the field. It took approximately two hours to write the notes down on the computer after each day of fieldwork.

In each ward, field notes were made about professional-service user, inter-professional and inter-service user interactions during therapeutic activities – when smoking together, eating together,

in the corridor, etc. – about organizational features, professional approaches and practices, etc. During the first days of a new period of fieldwork in a new ward, I received documents about the therapeutic and organizational approach of the ward. I spent time trying to get to know service users and professionals. I divided my time between accompanying service users during lunch and their idle time in an effort to build rapport with them, and with professionals in their office and during lunch. In every ward, descriptive notes were made about the daily functioning of the ward; writing down how, where and when interactions occurred. The unfamiliarity with mental health care implied that some extra time was needed to try and uncover the unspoken logic that shaped the clinical reality of each ward. However, this 'outsider' position made it equally possible to reflect on the clinical logic from a different perspective than that of a trained nurse, which enriched the data-gathering process. These notes tried to capture how daily routines structured life in the ward, as illustrated by a note on informal interactions related to the transfer of keys:

The key is passed on to service users when doors have to be opened. I think most of the doors were opened by service users and not by professionals. This observation stands in sharp contrast with the message of the screensaver on the computers in the ward: 'never pass the key on'.

Observations like these formed a basis for further discussions with providers on their relationship with the formal framework for the organization of care in the ward. During formal meetings between professionals, field notes were made about the features of conversations between professionals, their power relations and the different approaches to care. In discussions on the future of service users in the ward between team meetings, the inter-professional positions became clearer, as the following observation of a discussion about the orientation of a service user illustrates:

The question is where he wants to be oriented. He wants a social housing arrangement, but the nurses do not believe that is possible. A sheltered housing arrangement seems more plausible to them. The doctor thinks that is not possible, as he was living in such an arrangement before he was admitted to the ward. The doctor says that he's ready for a psychiatric nursing home. She believes that the nurses are thinking too positively when they believe that he can live in a sheltered housing arrangement. And then she said: 'But I don't believe I have a choice, I will

68

have to follow them'. It has been decided that he will be oriented to a sheltered housing arrangement when he has found volunteer work.

The doctor bears the official responsibility, but in practice, the collectivity of nurses seems to steer decisions in a certain direction.

When field notes became increasingly repetitive after about 200 hours of observations, the participant observations in a ward were concluded.

Semi-structured interviews

After three weeks of participant observations in each ward, I started to conduct interviews with in total 42 service users and 43 care providers. Interviewing, as the most widely-used method of investigation in the social world, has various formats (Davis, 2008, p.106). In this research, semi-structured interviews were conducted. This involves interviews that are not similar to natural conversations, but that are also not completely structured by a series of predetermined questions. The researcher starts the interview with an interview schedule. In the case of this research, this involved a number of written questions that were approved by the Ethics Committee (listed in Appendix 1). In contrast to structured interviews, the researcher can change the wording and order of the questions, or add new topics when others seem to be inappropriate or inadequate (Davis, 2008, p.106). In the case of this research, informal conversations during participant observations gave insights into service users' personal history and emotive subjects. This information guided the interviews, in the sense that some topics were addressed in the second part of the interview, or only very vaguely. For example, when I was interviewing Frederik, I knew he had a very hard time realizing that his family (which refers to his mother and grandmother) had broken off all contact with him. Direct questions about the contact he had with his family, what they did together, etc. were therefore avoided. It was only when he started to talk about searching for his mother whom he could not find, and the fact that she always hid the fact that her son was admitted to a psychiatric setting, that I could continue with some small questions, such as asking him if he had any idea why she was hiding his admission.

The interviews were conducted during moments of idle time, during lunch breaks or when the therapeutic program was finished. Most professionals and service users were keen to participate in an interview, as they perceived it as an opportunity to express their frustrations, to explain

their approach in detail or to tell more about themselves in private. The remarks of service users that they were familiar or had the necessary experience with interviews and the way questions are asked due to the multiple interviews they had with professionals, again pointed to the need to stress and continuously negotiate my researcher role.

The interviews lasted between 30 minutes and two hours. Most interviews were audio recorded. However, in one ward, my proposal to record the interviews with service users created confusion. Although several professionals tried to discourage me, stating that it was dangerous to record the voices of people who hear voices and referring to an incident where a journalist had been beaten up by a service user, others told me that they did not expect any particular difficulties. This lack of consistency in the approach not only gave me a difficult time deciding how to record interviews, but it also further illustrated the diversity in professionals' approaches to service users and their mental health problems. I eventually decided to work with hand-written notes. These interviews progressed relatively slowly, and service users saw me writing things down, which could have been a barrier to speaking freely. However, in the end, I did not experience having to write during interviews as a major obstacle for the interview process. Once written down, the interviews were shorter than those recorded, but they equally approached most of the topics in depth.

First, a short questionnaire was presented, both to providers and service users. Service users were asked about their socioeconomic and educational background, their family composition and treatment history. Providers were particularly asked about their educational background and their professional experience (see appendix). In some cases, the answers to these questions, similar to reflections on observations, formed a starting point for the interview.

Based on the approved interview structure, questions for service users included the history of their admission, their social network and work relationships, their expectations of mental health care in general and of the different care providers, their experiences and evaluation of the care they received from different professionals, their experiences with medication and their view of the recovery process. During the interview, service users were invited to reflect on their perceptions and expectations. When service users were asked if they had told their employer about their hospitalization, the subsequent question concerned the reason for their behaviour. The stigma topic followed more general questions about service users' care experiences; in order not

to distort the interview process towards a focus on negative stigmatizing experiences, but to try to capture the broader picture of care experiences in which this stigma could be situated. Interviews with professionals followed a similar process. They were asked to explain what it meant to be a mental health care provider and why they had chosen the job, to describe the functioning of the ward and their perception of it, and to describe general and more specific care-giving experiences. They were also invited to reflect on these experiences, asking themselves why they experienced aspects of the care-giving process in a particular way. Here again, the stigma concept was introduced at the end of the interview for the reason previously mentioned. However, several professionals referred to stigma from the beginning of the interview, when discussing their motivation to become a mental health care worker, during issues of service users, family and context or when the issue of de-hospitalization was approached.

All the participants were assured that their accounts were anonymous and that nobody but me would listen to the interviews. After every period of fieldwork, I transcribed all the interviews for further analysis.

Constructivist grounded theory

The process of analysis is a continuous one, inherent to all stages of the ethnographic endeavour (Davis, 2008, p.231). Accordingly, the previous paragraphs – in which the fieldwork methodology and sampling decisions are detailed – also contain important material about analysis. This section focuses on the analysis of the collected data, once the researcher had withdrawn from the field, taking the distance and time to identify patterns and structures in the data (Davis, 2008, p.231). The data analysis started from the carefully-collected data in fieldwork notebooks, together with the corpus of the interviews, systemized by using the computer software application Nvivo. This offers the opportunity to make an electronic database of field notes and interview transcripts, facilitating the organization of data through the creation of categories, the integration of data from observations and interviews, and the application of the grounded theory principles (Coffey & Atkinson, 1996; Davis, 2008, p.247).

71

One of the major expectations of ethnographic analysis is that the theory is grounded in the data, emerging from a constant comparative process inherent to the grounded theory method (Davis, 2008, p.247). This method is mostly used as specific method of analysis, which offers a set of general rules that help researchers to focus data collection and to execute successive levels of data analysis and conceptual development (Charmaz, 2011). For this thesis, data analyses are in line with the general coding processes formulated by grounded theory, and are structured using a derivate of the approach: the constructivist grounded theory approach (Charmaz, 2005; Mills, Bonner, & Francis, 2006).

This method adopts the general guidelines of grounded theory, but does not subscribe to the objectivist, positivist assumptions of the theory, referring to the discovery of data or theories (Charmaz, 2011). However, the constructivist version stresses that data is the result of a co-construction between the researcher and participant, or more generally between the researcher and the research field, influenced by their values, positions, interactions, etc. The method is in line with the critical realist perspective (Bhaskar, 2008), in the sense that it recognizes both a pre-existing reality, and multiple realities and perspectives on these realities. The approach has been used in social justice research, in which the integration of subjective experiences and social conditions is central to the analysis (Charmaz, 2011). The approach stresses the studied phenomenon and not primarily the methods. In the current thesis, this refers to the focus on the empirical realities in which stigma processes evolve. Through this approach, the researcher is positioned as the author of a reconstruction of perceptions, experiences and meaning, uncovering the implicit values and beliefs that have a meaningful implication to that end (Charmaz, 2008). Furthermore, this approach not only allows the researcher to gain awareness of the experiences and value systems of users and providers, but also how these are framed by the context of care and society as a whole.

Data analysis used open coding (Strauss & Corbin, 1990), applied during and after each period of data collection in each ward. This involves a type of thematic coding, from which the emerging topics were further explored and evaluated during the fieldwork. The data from the notebooks was also coded and linked to the coding scheme of the interview data. With regard to the accounts of service users, the coding scheme included for example general and more specific codes related to the perception of their admission (see Figure 2).

Figure 2. Coding scheme 'Admission
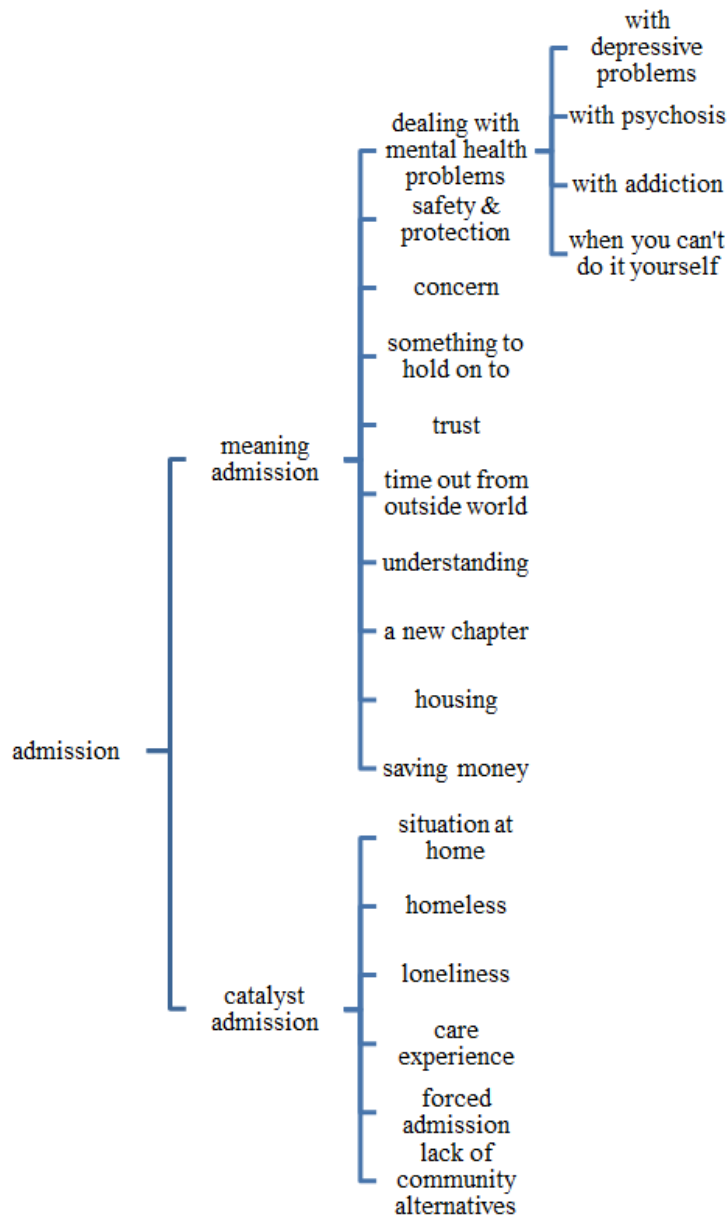
This process was influenced by the use of sensitizing concepts, such as identity, social status, power, stereotypes, diagnosis and labelling. The focus was on if, when, how, to what extent and under which conditions these concepts were relevant to the research, which led to approaching these concepts as lived and understood (Charmaz, 2011). Starting from the theoretical background on stigma, professionals were, for example, asked to describe individuals who meet the selection criteria of the ward, based on the idea that the approach to mental illness and people facing it would inform the professionals' attitudes and behaviour to these people (e.g

Angermeyer & Matschinger, 2005; Pattyn et al., 2013). Further attention was paid to the professionals' specific frame of reference for the perception of service users after their initial answer to this question. Codes including diagnostic categorization emerged, in which the use and perception of diagnoses were then identified in detail with sub codes. In addition, memos were written, which helped to identify some patterns in the data. Consequently, in the next period of fieldwork, new data could be gauged against these preliminary findings and ideas.

The detail of the initial findings was enhanced by so called 'member-checking' (Cresswell, 2007), where the researcher reflects on codes and findings in informal conversations with respondents during the fieldwork. Throughout the data-gathering process, codes were adapted and readjusted (Patton, 1999). The general themes were expanded with more specific sub codes for the interview data of service users, namely the image of mental health problems (including codes such as self-image, image of psychiatry and image of acquaintances), diagnosis, recovery, medication, admission, cause of problem, relationship with professionals, social network, treatment trajectories and acquaintances. These codes formed the starting point for the actual data analysis, in which codes were related to contextual factors, frames of reference, relationships and background characteristics. During the coding process, substantive and theoretical memos were written about the ways service users and providers perceived and experienced mental health care (relationships) in the different settings. This involved, for example, a memo on the relationship between providers' perceptions of mental health problems and the perception of their job. It involved a process of constant reconsideration of previously-made codes and memos, which led to elaborated memos on specific issues, resulting in research articles.

Research quality

There are no standard measures to control the quality of qualitative research data. Issues of quality are inevitably related to the research purposes and to the public who consult the research. However, the qualitative researcher has a duty to report sufficient details about the data collection and processes of analysis to permit others to judge the quality of the research (Patton,

1999). In general, qualitative data is expected to be detailed, varied and contextualized, and reflect the human experiences, actions and perceptions of the participants that are encountered in specific situations (Kirkevold & Bergland, 2007). First, detailed information about the different research settings and the reasons for choosing them were provided. This made it possible to gain insight into the motivation and approach of the researcher at the start of the research process. Further, the fact that these settings and the participants working and living there were limited to the region of Ghent – due to practical considerations – should not be problematic. As Prior (1993, p.19) states, from a sociological point of view, it is only of marginal significance that individuals, with their perceptions and experiences, are limited by geographical boundaries, as their lives, like all others, are organized in terms of the cultural categories and structural arrangements that transcend these frontiers to an important extent. This extended description of these research settings further heightens the credibility of the research, showing that the researcher achieved a degree of familiarity with the settings and subjects. These 'thick descriptions' make it easier to show how particular observations and data can be situated in and linked to the broader context, to cover them within larger categories and easily link them to the researchers' arguments and analysis (Charmaz, 2011). Furthermore, the information concerning the researcher's process of gaining access, negotiating their role, reflexivity and ethical issues, further increases the credibility, as it recognizes the researcher as an important instrument in the qualitative inquiry (Patton, 1999). With regard to the credibility of data obtained in interaction with service users – who can be perceived as vulnerable and having difficulties in providing detailed accounts of their experiences – particular attention has been given to strategies that can maximize the quality of the data (Kirkevold & Bergland, 2007). This involves the time taken for participant observations, through which service users could get used to the presence of the researcher; time used to establish rapport with them in an informal way. Accordingly, the combination of observations and interviews meets the need for an adaptive approach. Informal discussions based on the researchers reflections on observations and interview data further increase the credibility of the research (Cresswell, 2007).

As mentioned previously, different types of triangulation were applied. This combination of different perspectives helps to enhance confidence in the research process and findings. Denzin (1978) and Patton (1999) identify different forms of triangulation. Data triangulation was applied through the selection of settings, which differed considerably with regard to the understanding of

mental health problems and care. Furthermore, the sampling of both service users and providers makes it possible to study stigma and mental health care from different perspectives, and avoids a unilateral approach to mental health care in relation to stigma. Methodological triangulation was used through the combination of ethnographic observations and semi-structured qualitative interviews. As already stated, this offers a multiplicity of perspectives and enhances the quality of interviews with people who may have difficulties in accounting for their experiences in a detailed way. With regard to theoretical triangulation, different theoretical perspectives were contrasted with the data in order to gain a deeper understanding of the research topic.

In the following four chapters, different empirical studies illustrate how ethnographic research can be useful to answer questions that concentrate on the way social experiences are created and are given meaning in relation to stigma and mental health care. In these papers, more detailed accounts are given about the specific analyses performed. Accordingly, different interview and field note extracts are used to exemplify stigma, care perceptions and experiences in the different settings. All the participants are given pseudonyms and any information that could lead to their identification has been removed.

PART II

EMPIRICAL STUDIES

CHAPTER 7

HOW DOES STIGMA INFLUENCE MENTAL HEALTH NURSING IDENTITIES? AN ETHNOGRAPHIC STUDY OF THE MEANING OF STIGMA FOR NURSING ROLE IDENTITIES IN TWO BELGIAN PSYCHIATRIC HOSPITALS

Charlotte Sercu, Ricardo A. Ayala & Piet Bracke

Stigma constitutes a threat for professionals who work in mental health care, through their association with mental illness as a discrediting attribute. Together with nurses' unclear self-perception, recent insights suggest that stigma may inform the apparent identity crisis within the mental health nursing profession. This article explores how stigma may give meaning to mental health nursing identities. The nursing role is built upon official labels, a prime trigger of stigma. Therefore, due to nurses' ambiguous relation with the psychiatric/medical care and their own stigma experiences due to their association with mental health problems, they can be considered as a stigmatizing, de-stigmatizing and stigmatized group. Dynamics which inform this intricate relation between stigma and mental health nursing identity are the focus of this article. Accordingly, this article points to the importance of including stigma in the overall study of mental health nursing identity. This research uses a qualitative case-study design. Ethnographic data were gathered from 33 nurses in 4 wards in two psychiatric hospitals in the region of Ghent (Belgium). Participant observation and semi-structured interviews were combined to access the meaning of being a mental health nurse in these specific care contexts and its possible interference with mental health stigma. The findings suggest that tackling stigma is a particularly important personal motive for nurses to work in mental health care. The meaning of stigma is closely entangled with nurses' troublesome relationship with the medical model of care. Variations between hospitals regarding the extent to which stigma informs the professional role constructs and identity of nurses are found to be related to the degree of formalization of the

nursing roles in these different hospitals. The present study points to the relevance of the integration of stigma in mental health nursing identity research. Furthermore, the focus on stigma may offer an opportunity to link contexts of illness and care, and nurses' identity construct.

Introduction

The process of identity formation has been a topic of interest among scholars of nursing since the mid-1970s. In mental health nursing in particular, the continuous search for distinctiveness has always been at the core of the profession (Nolan, 1993; Tilley, 2005; Holmes, 2006; Hurley, 2009). This endeavor has become more evident due to the process of deinstitutionalization, which has seemingly produced a loss of the mental health nursing identity (Cleary, 2004, Fitzpatrick, 2005; Loukidou, Ioannidi, & Kalokerinou-Anagnostipoulou, 2010; McCabe, 2000).

Research on mental health nursing identity, or what it means to be a nurse, often comes down to the study of nurses' intricate relationship with the medical, psychiatric model of care. Nurses, including nursing students (Mior & Abraham, 1996), were found to claim their liberation from the medical discourse, arguing a paradigm shift in psychiatric nursing from paternalism toward the idea of partnership between nurse and service user (Bray, 1999; Tilley, 2005), the adoption of a more empathic approach (Handsley & Stocks, 2009), and the engagement with expanding roles, such as talk-based therapy (Crawford et al., 2008; Hurley, 2009).Yet, some researchers (Barker & Buchanan-Baker, 2011; Clarke, 1999; Cutcliffe & Happell, 2009) pointed to the remaining dominance of traditional psychiatric discourse in contemporary mental health nursing. Nurses' efforts not to define mental health nursing in medical scientific terms were then identified as a means to construct a distinctive professional identity, rather than to be the result of fundamental changes in mental health work.

Moreover, the vagueness about their professional identity concept has been linked to the unpopularity of the specialty and to negative attitudes toward mental health nursing among nursing students in most Western societies (Happell & Gaskin, 2013; Holmes, 2006). In fact, Halter (2002) identified the combination of this unclear identity concept and social stigma as the basis for the current identity crisis within the mental health nursing profession. Stigma appeared to constitute a threat for professionals who work in mental health care, through their association with mental illness as a discrediting attribute (Goffman, 1963). Negative stereotypes of people with mental health problems – such as being blameworthy, dangerous, and unpredictable – are associated with the mental health nursing profession, which has led to the depiction and

81

perception of nurses in this field as neurotic, ineffective, and unskilled (Gouthro, 2009; Halter, 2008; Schulze, 2007) and to negative reactions and jokes nurses have to face when they tell people in their environment about their job (Sercu, Bracke & Ayala, 2012).
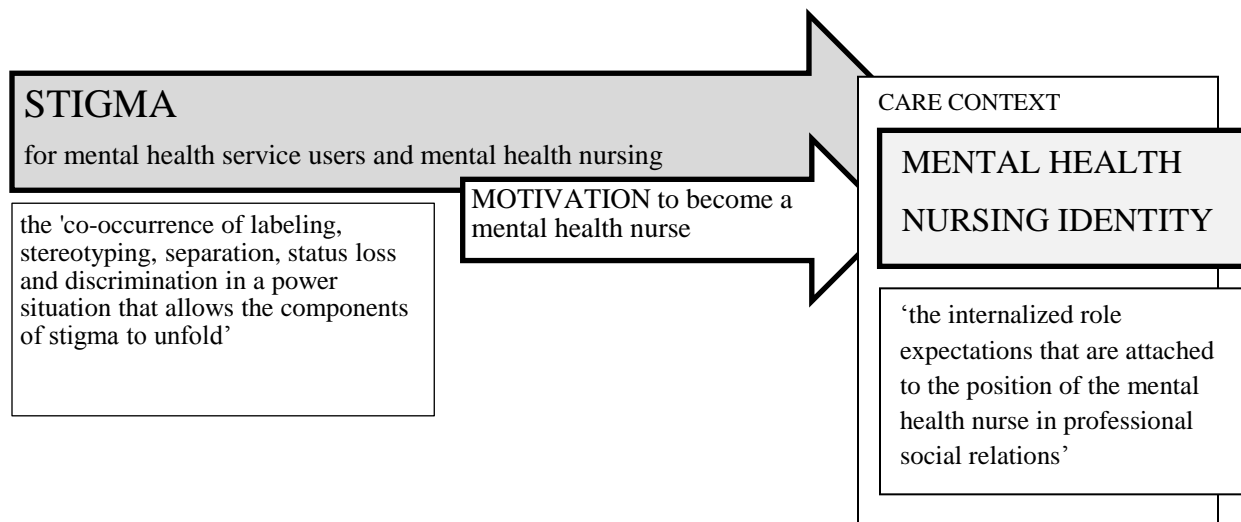
Furthermore, the psychiatric framework has equally been depicted as a barrier for an empathic and respectful relationship between mental health professionals and service users in research on mental health stigma (e.g. Scheff, 1966). This focus on the possible negative impact of official diagnosis and formal mental health care in stigma research (e.g. Link et al., 1989), gave rise to studies of possible stigmatizing beliefs and attitudes of nurses, such as the perception of individuals with mental health problems as dangerous, bizarre, or unpredictable in contemporary studies on mental health nursing and stigma (Ross & Goldner, 2009). These studies are equivocal in the sense that some report no clear differences between the attitudes and beliefs of nurses and those of the general public (Schulze, 2007), while others have found that nurses may hold more negative attitudes and beliefs than the general population (e.g. Caldwell & Jorm, 2000).

However, the definition of stigma as the 'co-occurrence of labelling, stereotyping, separation, status loss and discrimination in a power situation that allows the components of stigma to unfold' (Link & Phelan, 2001, p367), suggests mental health nurses to occupy a more complex position in relation to stigma. On the one hand their professional context and work are built upon the official labels which are often depicted as the prime trigger for stigma to occur (Crowe, 2006). Moreover, Ross & Goldner (2009) found psychiatric nurses to be a stigmatizing group, in having negative attitudes of blame and fear and discriminatory behaviours themselves. On the other hand, their ambiguous relation with the psychiatric/medical care model (see above), combined with their own stigma experiences due to their association with mental health problems (Halter, 2008), also led to the consideration of nurses as a stigmatized and de-stigmatizing group (Ross & Goldner 2009; Schulze, 2007). Negative stereotypes of people with mental health problems – such as being blameworthy, dangerous, and unpredictable – are associated with the mental health nursing profession, which has led to the depiction and perception of nurses as neurotic, ineffective, and unskilled (Gouthro, 2009; Halter, 2008; Schulze, 2007). Yet, nurses also have the power and motivation to alter the stigma of mental health problems, for instance by increasing awareness of stigmatizing nursing practices (Bates & Stickley, 2013; Schulze, 2003). However, this power to de-stigmatize was found to be closely

intertwined with the structural barriers and organizational demands – related to professional responsibility and accountability - which frame nurses' roles and practices (Bates & Stickley, 2013; Berry, Gerry and Chandler, 2010).

Notwithstanding the observation of the intricate relation of mental health nurses and stigma, possible dynamics which inform the relation between stigma and mental health nursing identity were rarely reported. Accordingly, this article points to the importance of including stigma in the overall study of mental health nursing identity (see Fig. 1). In line with the premises of symbolic interactionism (Blumer, 1969; Stryker & Burke, 2000), nursing identity is understood in this study as 'the internalized role expectations that are attached to the position of the mental health nurse in professional social relations.' Ethnographic data collected in two psychiatric hospitals in the Belgian region of Ghent, is used to explore dynamics which may inform the relation between stigma and mental health nursing identity, and how these dynamics are given shape in specific care contexts.

Fig. 1. Conceptual framework

STIGMA
for mental health service users and mental health nursing

the 'co-occurrence of labeling, stereotyping, separation, status loss and discrimination in a power situation that allows the components of stigma to unfold'

MOTIVATION to become a mental health nurse

CARE CONTEXT

MENTAL HEALTH NURSING IDENTITY

'the internalized role expectations that are attached to the position of the mental health nurse in professional social relations'

Methods

Approach

This research uses a qualitative case-study design, aimed at increasing the understanding of the way stigma is entangled with mental health nurses' identity and the broader functioning of psychiatric wards. As Link et al. (2004) stated, a qualitative design is appropriate for studying stigma, as it can disclose how stigma is constructed and enacted in social interactions. Accordingly, the ethnographic approach was chosen as the most appropriate way to study the topic of concern.

Case selection

This article is based on case-study research on stigma in mental health care, conducted between 2011 and 2012 in two psychiatric hospitals in the region of Ghent, Belgium. We chose two hospitals in which theoretically divergent notions of care for people with mental health problems had been reported earlier (Sercu et al., 2010). This earlier study focused on service users who were difficult to transfer between care settings in the region of Ghent, and its findings suggested that service users were perceived as 'difficult' due to a mismatch between their needs – related to their diagnostic and socio-demographic profile – and the notion of residential psychiatric care based on which the care supply was organized.

These hospitals approached the categorization of people with mental health needs from divergent positions. In one hospital service users were primary perceived and approached from a diagnostic point of view and the care approach was founded on the dichotomized categorization of healthy versus ill. The other hospital adhered to a more social explanatory model in the definition of its service users, by which the hospital renounced the distinction between the ill and the healthy, based on diagnostic categorizations. They opted for a social explanatory model which identified the less healthy as socially marginalized and misfortunate.

This background was crucial to orient the hospital sample, because it is recognized that such dominant processes of dichotomized categorizations are at the core of stigma processes (Link &

Phelan, 2001; Scheff, 1966). They reflect cultural processes in the broader society which sustain the idea that people with mental health problems are a distinct cultural category (Handy, 1991; Van der Geest & Finkler, 2004; Sercu, Bracke & Ayala, 2012).

At the time we designed our methodology, a significant proportion of the first hospital's (Hospital A) users had multiple psychiatric problems, were homeless, or faced juridical procedures. This setting had a high prevalence of long-term inpatient care. The second hospital (Hospital B) focused on the treatment of people with acute mental health problems, and served as an institution providing primarily short-term care. Both were rather small (190 beds per hospital). Furthermore, professionals identified the match between their view of mental illness and care and the general care approach of the hospital as crucial for their motivation to work in the hospital. Therefore, the choice for hospitals with a different approach of service users (as mentioned above) and a different organization of care also implies the selection of professionals who differ in their understanding of mental health problems and good care for people with mental health problems. Besides, almost all nurses were graduates from the university colleges who followed professional nursing education for 3 years. In Flanders, nurses may opt for the specialization of mental health and psychiatry in the third year of higher education. Some had an additional master's degree in philosophy or psychology. Nurses who were interviewed for this study were aged between 26 and 58 years. In all wards nurses in their twenties and thirties were accompanied by nurses in their forties and fifties. 61 per cent of all nurses were women and both sexes were represented in every ward.

We selected two treatment wards in each hospital as the specific units for observation. These were specifically one ward for people diagnosed with mood disorder in each hospital namely ward A1 (20 beds) and ward B1 (24 beds). While A2 (15 beds) was a ward for those dealing with a combination of psychosis and substance abuse, ward B2 (24 beds) was for people with problems related solely to substance abuse.

Data gathering

After approval from the Ethics Committee of Ghent University Hospital and both hospitals, one of the authors, who is a sociologist, conducted semi-structured interviews and intensive participant observation (Tedlock, 2005). To ease the socialization process, every ward and the

people treated there, were visited before starting the observations. All were personally informed about the goals and methods of the research and received a prospect. The observation was only undertaken once all service users and professionals agreed on the researcher's presence. During the fieldwork, the main fieldworker chose to take the role of 'participant as observer' (Gold, 1958), by which is meant that both field worker and informant are aware of their role, yet the field worker develops relationships with informants, through which their uneasiness and initial reactions to the presence of the fieldworker are likely to disappear with time. Observations took place mainly during team meetings, therapeutic activities, and at meal times. During idle periods, time was used to approach staff through informal conversations, examining cautiously the organization of care, stigma and identity conceptions. This period of observation was further necessary, as the fieldworker was trained as a sociologist and needed time to try to uncover the unspoken logic that shaped the clinical reality of each ward. However, the researcher's training made it also possible to reflect on this clinical logic from a different perspective than trained nurses, which enriched the data gathering process. When field notes became increasingly repetitive after about 200 hours of observations, the research in one ward was finalized.

Throughout the observation period, we also conducted semi-structured interviews (Fontana & Frey, 2005) with nurses, once they became familiar with the ongoing observations. This helped us to challenge and critically revise the findings arising from the observations. Individual interviews were undertaken with all nurses of the different wards (33), lasting between thirty minutes and one hour, which were recorded and transcribed. Nurses were asked to respond to questions such as: 'How would you describe your job as mental health nurse?' and 'How would you describe the problems individuals are dealing with in the ward?' In addition, we incorporated the thematization arising from the fieldwork.

Data analysis

Once the saturation point had been reached, the data gathered in fieldwork notebooks, together with the corpus of the interviews, were systematized by using Nvivo CAQDAS. Data analyses were in line with the general coding processes formulated by grounded theory and structured using a constructivist grounded theory approach (Charmaz, 2005; Mills, Bonner, & Francis, 2006). Through this approach, the researcher is positioned as the author of a reconstruction of experiences and meaning, uncovering the implicit values and beliefs that have a meaningful

implication to that end (Charmaz, 2008). This allowed us to gain awareness of nurses' subjective meanings and experiences and how care contexts and society at large frame them. Open coding (Strauss & Corbin, 1990) was applied during and after each period of data collection in each ward.

In addition, memos were written, which helped to identify some patterns in the data. Consequently, in the next period of fieldwork, new data could be gauged against these preliminary findings and ideas. Throughout the data gathering process, codes were adapted and readjusted (Patton, 1999). These general explanations and themes were used as initial, provisory categories for actual data analysis.

Results

Reasons for becoming a mental health nurse

Close analysis reveals that most nurses found it difficult to define how they perceived their mental health nursing role. In interviews, some even asked to start by discussing another topic and keeping the question about their understanding of their role to the end. However, they had no difficulty in explaining their motivation to become a mental health nurse when they were asked why they chose to work as a mental health nurse. In addition to prior familiarity with the profession due to family members who practiced mental health nursing, their wish to treat and approach individuals with mental health problems in a respectful way was the core argument to choose for mental health nursing in most nurses, as Hanne said:

'In the beginning I wanted to become a general nurse, but my internship was so disappointing. I thought for example to pass by some service users to say hello, but I noticed that they [the nurses] didn't appreciate it. Afterwards I chose psychiatry and that was it. Just the fact that you don't wear a uniform, that you can't differentiate between service user and care provider sometimes, that they are not focusing on differences and especially the way they dealt with service users, really working with them, that's what attracted me.' (Hanne, B1)

Moreover, almost two thirds of all nurses explicitly linked their quest for a respectful approach to their negative perceptions of and experiences with the treatment of individuals with health problems in general health care. These nurses contrasted mental health nursing with general nursing, which they depicted as dehumanizing. In particular, they disapproved of the reduction of individuals with health problems to the technicalities of the illness they were confronted with and the lack of time to listen to service users' personal experience. By contrast, nursing in mental health care was understood as a human, empathic, and holistic endeavour, through which individuals with mental health problems could be cared for with respect for the whole person, as the following interview extracts illustrate:

Researcher: 'Why did you choose to work as a mental health nurse?'

Ringo: 'Because general nursing is very technical. The contact with the people [service users] is medicalized, and because of the efficiency policy you have a lot of short, often too short, hospitalizations, which means that people are approached in a less human way [than in mental health nursing]. It makes it impossible to encounter the person as a human being. And here you can do this [approaching people in a human way].' (Ringo, A2)

'I worked for three years in a general hospital and I wasn't happy. The contact with service users was different, everything had to go fast and the people were numbers. Individuals became their disorder, they didn't know service users names.' (Yves, B2)

Their perception of the reduced impact of the medical model in mental health nursing was not only perceived as an opportunity for more human nurse-service user interactions, it was also understood by several nurses as a way through which nurses could obtain responsibility and autonomy in decision-making processes. In other words, the particularity of the power relations between professionals attracted them. As Erno explained:

'You can make plans on your own in mental health nursing. If you want to sit together with someone to see how he's doing, you can. In general hospitals it's the doctor who decides and you will carry it out in practice.' (Erno, B2)

Furthermore, nurses not only referred to general health care when they pointed to the disrespectful attitudes toward and treatment of individuals with mental health problems, but also

to the stigma people are confronted with in society. They understood mental health nursing as encountering these individuals in a respectful way, in an effort to oppose the societal trend. As nurses said:

'The most important thing is that you can let the other [the service user] be himself the way he presents himself. I try to be there for them, [people with mental health problems] while most people turn their back on them. (…) When something goes wrong in society, people with mental health problems are easily identified as the guilty party.' (Peter, A1)

'That's what I want, to be there for them, knowing that society has given up on them.' (Lore, B1)

The meaning of stigma for mental health nursing identities

The personal motivation of most nurses to counteract the discrediting treatment of individuals with mental health problems in health care and broader society, by means of a holistic and empathic approach of service users, was not equally reflected in nurses' actual internalized role expectations. These were questioned during the interview and observed in the ways nurses positioned themselves in their relationships with service users and other health professionals. The findings make clear that the impact of nurses' initial motivation for their actual internalized role expectations differs considerably between nurses. Moreover, it appeared that the specificity of the care contexts informed the diversity in reflections of nurses' motivations in their nursing identity.

Being their equal

Nurses in ward A1, which accommodated mostly individuals with a poor socio-economic status, gave meaning to their nursing role first and foremost by emphasizing the discrepancy between their role and the discrediting way in which people with mental health problems are approached in society. It appeared that their nursing identity was rooted in the 'unwell-being' of service, caused by the stigma they were confronted with. The nurses perceived their role as an opportunity and a means to counteract this stigma.

They took an explicit stance against the depiction of individuals with mental health problems as being abnormal or essentially different. They instead perceived them as people who had lost their balance at a certain moment in life. Through the fieldwork, it became clear that these nurses were

very sensitive to the approach of seeing service users as their equals. This equity approach characterized the relationships between nurses and service users in ward A1, as observed:

During the morning meeting, Nurse Ines asked everyone, if they had slept well. She asked me first. I was surprised and I responded: 'Yes, actually, I did.' She asked all the service users and professionals [the other nurses]. When I asked her why she had asked the other nurses and I if we slept well, she answered: 'Who am I to pretend to have the right to know if they [service users] slept well, without giving them information on my condition? I want to show them that we are all equal.' (Fieldwork, A1)

Further, information transfers between nurses were time intensive and diagnoses were almost never mentioned in interactions with service users and heavily discussed or opposed when used by the doctor. They believed that 'diagnoses are never complete' and as Peter said:

'It is very important that people can be who they are, with their undefined problems. (…) When you talk about people with a personality disorder, you talk about all of us, I don't know anyone in this world who's not having a personality disorder.' (Peter, A1)

It appeared that nurses perceived their role as opposing/countering the different stigma components, as they actively tried to avoid the use of diagnostic labels and us-them thinking. They clearly watched over the definition of their relationship with service users as one between fellow human beings in an effort to avoid power situations which they believed would limit the respect and attention for the whole person. They rather understood their role as a key position for valuing individuals with the mental health problem.

Living a nursing dilemma

In the other ward of hospital A, a residential setting for people with the ascribed double diagnosis of psychosis and addiction (A2), service users were sometimes identified as 'other' and 'severely ill.' during interviews. Several nurses explicitly referred to the diagnosis and the associated particularity of their target group in the descriptions of their role. They preferred to work with service users with psychosis, because they were believed to be 'straightforward,' 'not intrusive,' and 'essentially different, which seem to fit their nursing expectations better than other diagnostic groups.' As Zohra and Gregory said:

'I really like psychotics. You can deal with them in a pleasant way. You don't have to mother them. (…) I am also not very patient with people when they are not seriously ill. I think both Brad and Leon are troublesome. But I know Brad is really ill and therefore I can support him more than Leon, who just lacks social skills. (…) A psychosis is something completely different from my personal life, which makes it easier for me to distance myself from their problems.' (Zohra, A2)

'I'm more tolerant toward 'psychotics' because they have no sense of reality, they don't realize it. It is said that 'personality disorders' do have a sense of reality and that they are testing borders. They are also ill, but it is different. I think it would frustrate me and I would do a bad job I believe.' (Gregory, A2)

However, nurses account were equivocal, in the sense that they used diagnoses in de description of their role, while they also said to be against the use of diagnosis in their communication with service users, as Mario first described his role on the basis of the diagnosis of his service users, not much later he expressed his disagreement about the use of diagnostic labels:

'I rather prefer the psychotic double diagnosis patient than the junky. I think it is because I started working in a ward for psychosis. (…) I'm really against the use of diagnosis. I don't see the use of telling someone that he's schizophrenic. I prefer to work with someone's behavior. That's understandable for our public, more tangible.' (Mario, A2)

Furthermore, this ambiguity in nurses' accounts on stigma and diagnosis was also reflected in the daily functioning in ward A2, marked by many discussions and tension between the nurses. These appeared to be induced by the tension some nurses experienced between their aspiration to take up the role of a fellow human being who approaches service users in a personal and empathic way and the increasing dominance of the diagnostic approach which led to a focus on disorder characteristics and diverted the attention from service users personal illness experiences, as the following observation illustrates:

Nurse Marleen mentioned that a service user finds it dirty that people play volleyball, after they have dinner and then they continue the game without washing their hands. She thinks he's suffering from bacillophobia. Nurse Seppe reacts by saying that they always search for an a disorder definition in service users for normal things. (Field notes, A2)

This tension between the diagnostic/medical frame of reference and nurses' belief in their human approach also surfaced in nurse-psychiatrist interactions. Several nurses were sensitive for the experience of service users and overtly distanced themselves from psychiatrists' opinions, which appeared to be informed by disorder characteristics and not by service users' personal stories, as the following observation illustrates:

Simon [pseudonym, service user] told the psychiatrist that he no longer used medication. The psychiatrist said that he would have to look for another hospital if he did not want to follow the rules. The nurses did not agree with the psychiatrist. They knew that he was suffering from side effects like incontinence, which were very intrusive for his self-worth. They told Simon that they would talk to the psychiatrist about it. They believed that the psychiatrist had to give Simon the chance to try it without medication. Finally, the psychiatrist decided that he could stay, but she said that she would not be responsible if anything were to go wrong. (Field notes, A2)

Notwithstanding nurses' clearly referred to service users 'specific' diagnostic profile in their role prescription, the majority of the nurses appeared to struggle with the fact that colleagues hung on to this frame of reference in the fulfilling of their role as they perceived the use and communication of diagnosis as a sign of diminished respect for the totality of the individual. Furthermore, nursing advocacy for service users and against the diagnostic interpretation of service users behaviour, appeared to be particularly present when there was disagreement between nurses and a psychiatrist (for example about medication use). This seemed to be, at least in part an effort of nurses to preserve their responsibility in their relationship with service users. As they did use the diagnosis in the interpretation of their own nursing role during interviews, it may be that the call for an empathic relationship between nurse and service user, which may keep stigma away, was partly employed to preserve the impact of the nurses' voice vis-à-vis the psychiatrist in decision-making processes.

Nursing and stigma in a therapeutic framework

This discontinuity between nurses' motivations to take an alternative stance in relation to general health care with its medicalized approach of service users, and their actual nursing identity was also present in the nurses of hospital B. However, nurses did not seem to experience the lack of consistency between their motivation and the diagnostic framework as an insurmountable

obstacle to take their role as mental health nurse. Moreover, in both wards of hospital B, the nursing role was shaped in the context of a incontestable therapeutic framework, rooted in the singularity of the illness characteristics of specific diagnostic target groups. This frame guided the treatment of service users and the allocation of tasks between the different professional groups.

Nevertheless, nurses in B1 stressed their belief that diagnoses were not used to narrow people's problem down to their DSM definition (the Diagnostic and Statistical Manual of Mental Disorders). Instead, they were only used to construct a therapeutic program and to make the communication between professionals workable. Referring to this, Tilde explained:

'When everything has to be discussed in detail, it takes too much time, so we use diagnoses as a means to make our work more efficient.'

During information transfers, nurses reflected most of the time on (un)met treatment goals. Acknowledging the limitations of the treatment and transferring a service user when necessary were identified by nurses as important indicators of professionalism. The mismatch between the therapeutic framework and a service user's needs was often identified as the main cause for the lack of improvement in that service users' condition and nurses' professionalism implied a focus on treatment goals and their attainment, a vision which they all seemed to subscribe:

'Every ward has a diagnostic target group, so I think that's a starting point, and I think that's useful, but I also believe that it should be possible to complete the program with more interpersonal moments.' (Nelle, B1)

'I think it's good to focus on a specific diagnostic profile, because people with a pure depression often say that they didn't find help in a places with a mix of different diagnostic profiles. Of course it's the doctor who decides on someone's diagnostic profile, an after a few months you can learn to know someone completely different. (…) I think and I hope that we look at them as different individuals, who we not just qualify under the same diagnosis.' (Lore, B1)

As illustrated in the previous quotes, the dominance of a therapeutic and diagnostic framework did not necessarily suppress nurses' belief that mental health nursing implies a respectful, empathic and personalized approach toward individuals with mental health problems. Yet,

implicit tensions between nurses' internalized role expectations were omnipresent, as they were passionate to integrate their personal drive to approach service users in a holistic and empathic way and their professional role expectations. This became especially visible during technical tasks, like their interpretation therapeutic nursing talks or the distribution of medication:

When Marjan [service user] came to the nurses' table to ask for her medication she took the medication from the medication box herself. Nurse Asterie joked: 'We will make a note of that in your record: Marjan takes over nursing tasks.' Marjan answers: 'Or [you can write] patient does not know her place in the system.' They laughed. (Field notes, B1)

Nurse Asterie made no problem of the fact that a service user took over her task, a task through which she could define her professional role and her powerful position vis-à-vis the service user. However, the joke which follows the action indicates the possibility and at the same time sensitivity of cross-border actions in the ward and the implicit dominance of the medical framework in the organization of care and professional tasks there. Moreover, when nurses in ward B1 were having therapeutic talks with service users, most of them always invited the service users to go outside. In this way, they could escape the clinical reality that defined their role in terms of treatment goals and actualize the motivation to bring human contact at the center of their relationship with service users.

This duality was rather absent in the nursing identity of nurses in ward B2. Their internalized role expectations appeared to be totally designed by the diagnostic and therapeutic framework they were working with. They were involved in giving therapy and psycho-educative activities, which appeared to strengthen the integration of their nursing role in the formalized psychiatric system of care. Explicit disagreements between nurses and the psychiatrist rarely occurred. Further, the functioning of service users was often interpreted by referring to their ascribed diagnosis. In this regard, it is possible to identify a clear pattern that surfaced in the form of recurrent comments or expressions such as 'if she's honest,' 'I believe him,' or 'I don't believe her,' referring to the assumed fabrications of service users. Nurses understood this behaviour as a typical trait of people with an addiction and founded their own role on the base of this diagnostic and often negative interpretations of service users' behaviour. Rather than questioning their position or approach, they easily called people mentally challenged, as observed:

Service users supposed to express their experiences and difficulties in relation to substance abuse during the group session. After the session, the nurse who led the session described almost half of the group as retarded, lacking the capacity to understand their problem and to get better. At a certain moment a service users who talks difficult was imitated and laughed with. (B2)

Besides, for nurses like Anna, the diagnosis and the therapeutic framework seemed to provide the necessary distance to perform their role. During the interview, she clarified:

'Our approach is very clear concerning the total abstinence we stand for. I think that's the easiest, the more human you are, the more difficult and complex it [nursing] becomes.' (Anna, B2)

The nursing identity of nurses in both wards of Hospital B distilled meaning from the formalized therapeutic framework they were working in. Diagnosis informed their nursing role expectations in important ways, as the therapeutic framework was built on these diagnosis. This diagnostic categorization, identified by the same nurses as means which induces a medicalized an reductionist approach of service users did however not necessarily lead to internal role conflicts in nurses. Nurses in ward B1 believed in both the utility of the diagnostic therapeutic framework, and their role in giving service users the respect they deserve. Nurses in ward B2 seemed to have fully absorbed the role expectation prescribed by the framework and their aspiration to work with service users from a more empathic, holistic perspective appeared to be pushed aside.

Discussion

Existing literature concerning mental health nursing identity provides a concise idea about the way nursing identity seems to be trapped between the quest for an autonomous profession and the difficulties of detaching itself from its roots in psychiatric medicine. This article builds on previous literature, integrating stigma into the study of mental health nursing identity. Because of the particular nature of stigma, this dimension may add value to a closer analysis of mental health nursing identity. Particularly the shared ambivalent relationship with the medical psychiatric system of care in both stigma and mental health nursing research forms an interesting

starting point. Accordingly, we have analyzed how nurses give meaning to their nursing identity or their internalized role expectations in Belgium and how stigma inform this process, drawing on data from two psychiatric hospitals in the region of Ghent (Flanders). The key question in this discussion is: How does stigma inform mental health nursing identities?

The effect of nurses' stigma attitudes toward individuals with mental health problems, their beliefs concerning recovery, and their own stigma experiences have been cited in previous studies as a threat to better care. Whereas previous research has seldom explicitly pointed to the possible impact of stigma on nursing identity, in the present analysis stigma seems to profoundly affect the choice of nurses to work in mental health care. The meaning of stigma appears to be intimately intertwined with the stance of nurses concerning the medical concept of care. The choice of nurses to work in mental health was described as a means to counteract stigmatizing practices in general health care, which were believed to be induced by a medicalized, reductionist approach of service users. Furthermore, their hope to distance themselves from the medical model and its inter-professional interactions has also been reported. The findings reflect the issue of adopting a more empathic, holistic, and respectful approach to detach the specialty from its historical psychiatric framework (Clarke, 1999).

Working as a mental health nurse is thought of as overcoming the ambivalence inherent in the relationship between psychiatric stigma and the psychiatric system. However, the impact of stigma on mental health nurses' identity differed between wards. Most nurses in Hospital A saw their role in counteracting the stigma they perceived elsewhere. In ward A1 nurses actively tried to avoid all aspects which may lead to the discrediting treatment of service users and perceived their role as a key position in the fight against mental health stigma. In this endeavour, their use of non-medical language may be considered as a strategy, which questions both the relational asymmetry between service user and professional and the power of the medical model over mental health nursing, as diagnoses were identified as the prime classification tools of medicine (Cuttcliffe & Happell, 2009; Jutel, 2009, Scheff, 1966).

Notwithstanding nurses' reference to diagnostic categories in the description of their nursing identity in ward A2, they experienced the same unease in relation to both the meaning of diagnosis in the treatment process and the hierarchical organization of inter-professional and user-provider relationships. Nurses in both wards identified their activism to distance mental

health nursing from its original psychiatric frame of reference – with its diagnostic categorization, us-them thinking, and asymmetric power relations which create a partial and sometimes devaluing approach of people with mental health problems - as an essential aspect of their nursing role. In this motivation, nurses' complex relation with their psychiatric background (Clark, 1999) and the role of this psychiatric framework for labeling theorists in stigma research (Link & Phelan, 2001; Scheff, 1966) come together.

This interrelatedness makes it difficult to distinguish between the different functions of stigma for nurses' identities in these wards, as it concerns both a pursuit of professional independence and valorisation of people with mental health problems. Moreover, this connectedness between nurses' motivation to tackle stigma and their internalized role perceptions appears to be partly due to the absence of a clear organizational framework which shapes the organization of treatment, including professional role identities and care relationships. Therefore it appears that other frames are looked for like the existence of mental health stigma.

Conversely, the nursing identity of nurses in hospital B was given shape in the context of a clear diagnostic and therapeutic framework. This implied that nurses did not oppose the use of diagnosis in their role, which they rather identified as a useful tool to structure and orient their therapeutic interventions. However, contrary to the assumption of the labeling theory that this diagnostic framework forms a starting point for a reductionist and devaluing perception of service users (Scheff, 1999), nurses of ward B1 also held to their aspiration to approach service users in a respectful way. As nurses were not involved in therapeutic activities themselves, they had the space to 'escape' the clinical reality of the ward which defined the nursing' role in terms of treatment goals, placing the human contact at the centre of their nursing identity and relationship with service users. These cross-border actions, or nurses 'bending the rules,' were also identified by O'Brien (1999) as a means to minimize the visibility of the clinical professional role of nurses.

However, the nursing identity in ward B2 appeared to be completely determined by the diagnostic and therapeutic framework, which sometimes made room for the development of stigmatizing attitudes in nurses. There was a clear discontinuity between their expressed dedication to tackle stigma as a basis for the adoption of their nursing role and their actual internalized role expectations. Nurses' participation in therapeutic activities seemed to intertwine

their identities in a quite intense way with the guiding framework, which may imply that countering stigma was no longer essential for their nursing identity. Moreover, having this framework was also a means to distance themselves emotionally, a conclusion reported earlier by Handy (1991). In her study on the relationship between the structure and ideology of psychiatric systems and the nursing endeavour, therapeutic frameworks seemed to be not only an articulation of a common organizational perspective, but also a frame for emotional immunity concerning the conflicts inherent to the psychiatric systems.

This study provides new insights concerning the extent to which the meaning of stigma, affecting nursing identity, appears to be closely intertwined with nurses quest for an independent profession, or their aspiration to detach from their psychiatric frame of reference. Furthermore, the (dis)continuity between nurses' motivation to tackle stigma in the build-up to their role and their actual internalized role expectations seems to be linked to the degree of formality of the role of nurses in a given institution. When nurses did not depend on a therapeutic, goal-oriented framework in the construction of their relationships with service users, the stigma they observed in society and their hope to detach nursing from its medical-psychiatric framework informed their internalized role expectations. This appears to be the reason for the observed continuity between their personal motivation to counteract stigma and their nursing identity.

Contrarily, when nurses worked in a setting with a clear diagnostic and therapeutic framework they distilled less meaning from possible external frameworks like mental health stigma. The more nurses were absorbed in the therapeutic framework, the lesser the impact of their initial aspiration to counter stigma.

Yet, the finding that the existence of a diagnostically based therapeutic framework, which embodies medicine's authority in the ward (Jutel, 2009) not necessarily implies that nurses accept a reductionist approach of their service users, clearly argues with the idea that the use of clinical diagnosis cannot go together with an respectful and empathic nursing endeavour. Nurses not necessarily experience an intense role conflict in combining their diagnostic team-talk, with a holistic and empathic approach of individuals with mental health problems.

Furthermore, the observed impact of the therapeutic framework is consistent with Stryker and Burkes' (2000) structural symbolic-interactionism argument, which states that social structures

affect individuals' identity, made up of 'interdependent and independent, mutually reinforcing and conflicting parts' (p. 286). The discrepancy identified between on the one hand challenging stigma as a personal motivation to become a psychiatric nurse, and on the other hand, nurses' internalized role expectations, may be analysed with reference to the concept of commitment. In identity theory, this concept points to 'the degree of importance of a particular role or identity for persons interactions in a certain group or network' (Stryker & Burke, 2000, p. 286). Nurses' professional role taking appeared to be particularly relevant in those wards with clear-cut therapeutic goals and a formalized organization of professional tasks. In turn, those wards with a less formalized structure offered nurses the freedom to install more consistency between their nursing aspiration and their nursing identity, in which case stigma appeared to be a relevant frame of meaning for the construction of their nursing identity. This may also support Porters' (1993) discussion on the relationship between structure and action in psychiatric care – an adequate examination of the reasons for prevalent role-taking mechanisms in mental health nursing needs accounts of both the organizational structures where the practice takes place and nurses' attitudes and beliefs about their practice.

Although this comparative study is limited to the experiences and accounts of nurses in only two psychiatric hospitals, it may bring fresh insights to the stigma theory, in particular for the study of stigma as a framework from which mental health professionals extract meaning for both their identity construction and their daily work. Our research may thus illuminate future exploration of a better understanding of the meaning of stigma in the mental health sector as a whole. A critical part of this exploration might be how the (dis)continuity between nurses' aspirations and their role identity informs their nursing experiences, which may further point to the relevance of this topic for the delivery of quality care. As Hummevoll & Severinsson (2001) stated in their study of nurses balancing tensions between ideals and the reality of daily work, demands for effectiveness may create stress, as these seem to conflict with nurses' understanding of their role. Clearly, in an effort to integrate stigma in the study of nurses' search for identity, this (dis)continuity must be addressed with other related issues such as the unpopularity of mental health nursing and prejudicial attitudes toward the specialty among nursing students.

Finally, the study of stigma in mental health nursing contexts using another approach to care and in outpatient care settings may result in a greater understanding of its relevance. It is recognized

that nurses' identity crisis becomes more manifest in contexts of deinstitutionalization (Loukidou et al., 2010) and accordingly, stigma needs to be incorporated in the exploration of this phenomenon. Likewise, research on the meanings of stigma for mental health nursing in countries with deinstitutionalized mental health care, could be valuable for the ongoing nursing identity debate.

CHAPTER 8

EXPLORING THE MEANING OF STIGMA IN HELP-SEEKING DYNAMICS OF INPATIENT SERVICE USERS IN TWO BELGIAN PSYCHIATRIC HOSPITALS

Charlotte Sercu, Elise Pattyn & Piet Bracke

Using an ethnographic approach, in combining interviews with forty-two inpatient service users and participant observations, this research explored service users' experiences of their help seeking trajectories in an effort to uncover identity dynamics by which these are informed. They described both identity dynamics which made them postpone their search for help, like their belief in the essential difference between themselves and mental health service users; and dynamics which catalysed their hospitalization, like the loss of social roles. Their accounts illustrate how experiences of barriers and facilitators for help seeking are closely intertwined with identity and therefore context related dynamics.

Introduction

Help-seeking has been identified as a socially embedded process, not only informed by symptom severity, socio-demographic and cultural characteristics (Greenely & Mechanic, 1976) and other personal aspects like their previous illness episodes or help-seeking trajectories (Pavalko, Harding & Pescosolido, 2007), but also by social context dynamics. It particularly concerns the contextual dynamics by which social meanings of illness and care inform the relations between individuals with a mental health problem and their social network members (Pescosolido & Boyer, 2010).

Social meanings on the effectiveness of formal care and the singularity of its users have an impact on individuals' need expression and therefore their pathways to care (Pescosolido. Gardner & Lubell, 1998) (see fig. 1.). Depending on the labelling of peoples' problems as medical or non-medical in their social network (Freidson, 1960; Pattyn, Verhaeghe, Sercu & Bracke, 2013) and the social support and familiarity with the mental health care system of network members (Thoits, 2011), people will be encouraged to seek help or not. Furthermore, negative stereotypes about individuals with mental health problems may prevent them from seeking help, as the expression of their need may result in changing role relations (Perry & Pescosolido, 2012) (see fig. 1.). They may for instance lose their job or status as custodial parent once they express their need for help, as they are believed to be irresponsible or unpredictable. As the modified labelling theory suggests, the fear of individuals' with mental health problems for changing role relationships – based on these stereotypes - can make them hide their problem for their social environment and therefore prevent them from seeking help (Link & Phelan, 1989).

Fig. 1. Conceptual framework

Social meanings of mental illness and care ~ stigma
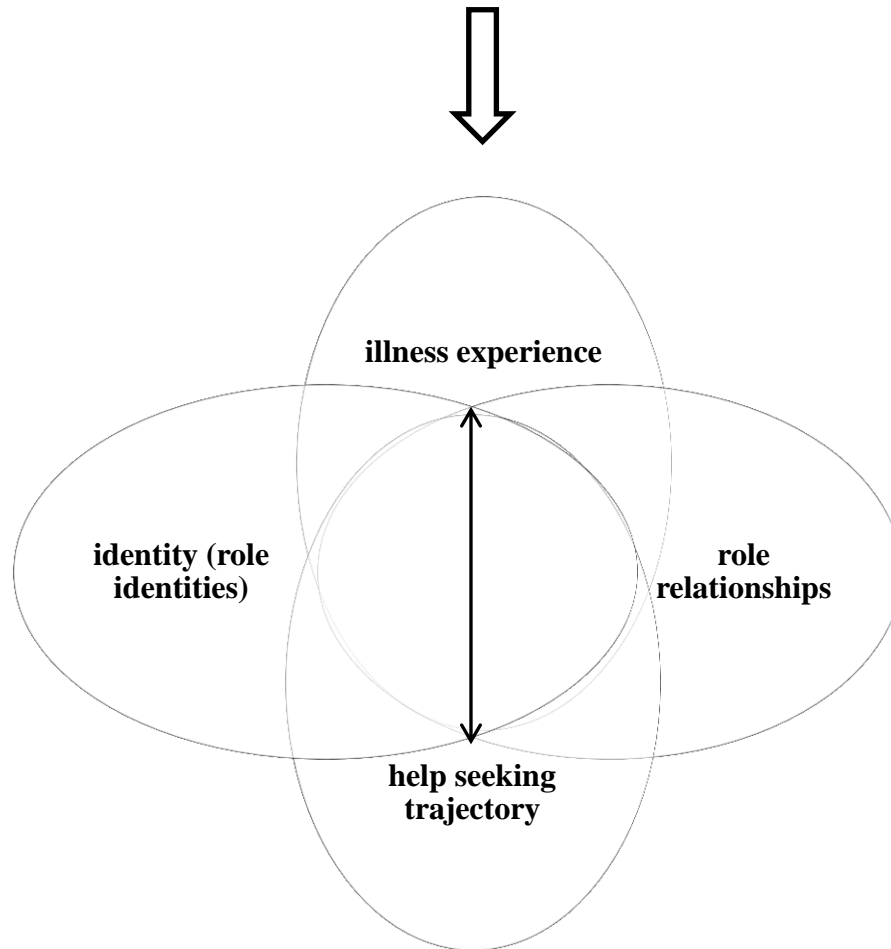
With the development of the 'sick role' concept, Parsons (1951) set the tone for the study of this link between health problems, social role and identity dynamics and help-seeking. He observed that people who express a certain illness behaviour, are pushed into a 'patient' role once this behaviour is manifested in social relations. Individuals are then forced by their entourage to seek help and to get better, based on the meanings of illness, recovery and health in society (Shilling, 2002). Contrary to Parsons' understanding of the sick role as an imposed means to recover, stigma researchers perceived the search for help and the 'forced' adoption of a patient role as a starting point for the construction of a definite devalued illness identity. For instance in Rosenhans' (1973) experiment on the pathogenic character of psychiatric hospitals and Scheff's

(1999) labelling theory, entering mental health services was identified as a crucial step toward the appropriation of a devalued identity. Current stigma researchers still identify help-seeking as a turning point in peoples self-concept (Schomerus & Angermeyer, 2008) and therefore as a prime reason for the existence of non-help-seeking and unmet need in people with mental health problems (Cooper, Corrigan, & Watson, 2003; Kessler, Berglund et al. 2005). Individuals are found to postpone their search for help as they anticipate possible discrimination by others (perceived stigma) and/or apply negative stereotypes to themselves (self-stigma) (Schomerus & Angermeyer, 2008).

Yet, in several contemporary studies about the impact of social and cultural context dynamics on individuals' illness-identity and help-seeking behaviour, researchers adopt a less deterministic and more agency oriented perspective. In these studies the focus lays on the strategies by with individuals form their illness experience, and stigma is therefore not approached as a general barrier in their help-seeking trajectories. Biddle, Donovan, Sharp & Gunnel (2007) developed for instance an explanatory model for the non-help-seeking of young adults with mental health problems. The interplay between social meanings of health and illness and individuals' strategies of normalization are at the core of the study, rather than the identification of negative stereotypes as an inevitable barrier in individuals' help-seeking career. Verouden, Vonk & Meijman (2010) found a similar dynamic in university students who did not seek help for their mental distress. These students interpreted the distress they experienced as a part of their student life – which took a central place in their identity construct - and not as a mental health problem.

In an effort to contribute to this discussion on the ways social context and identity dynamics inform help-seeking trajectories, service users' help-seeking experiences were studied from a qualitative approach. Through semi-structured interviews, respondents described their help seeking process, from the moment they noticed the first signs of their illness experience till the time they were admitted in a psychiatric hospital. During the data analysis different identity dynamics which informed service users' help-seeking trajectories were identified. Particularly the dynamics between individuals' sick role perception and the evolving meaning of other role identities were found to be crucial in the help-seeking process. Furthermore the finding that a hospitalization can be perceived as an opportunity for individuals to give meaning to their

'selves' adds to both the body of research on help-seeking and identity and to the discussion on the meanings of health care services for identity dynamics in service users.

Methods

Case selection

The qualitative data, used for the present analysis contains first-person accounts of inpatient service users (n=42), combined with participant observations (750 hours in total). The data were gathered between 2011 and 2012 in four wards from two psychiatric hospitals in the region of Ghent, Belgium. After approval from the Ethics Committees of Ghent University Hospital and both hospitals, each of the four wards and the people being treated there were visited before the start of the research. All service users and care providers were personally informed on the goals of and methods involved in the research. The procedure to inform service users was decided by the fieldworker in close consultation with the care providers, in an effort to adapt the procedure to the broader functioning of the ward. As a primary consideration, the research was only undertaken once all the care providers and service users had agreed to the researcher's presence, including those who chose not to participate in the interview.

Out of a total of 83 service users who were present at the time, 42 self-selected for an interview, on average 10 in each ward. The sample of participants was 64 per cent male (n=27), their age ranged from 20 till 60 years. 10 participants were currently on sick leave and 6 were taking a break in their career as independent, all others were unemployed (n= 8) or living from their allowance (n=18). Only a minority was living with a partner (n=11), as most participants were divorced (n=12), single (n=18) or widowed (n=1). A minority of 36 per cent was hospitalized for the first time and four individuals were subjected to a compulsory admission. Service users were labelled with (multiple) diagnosis, namely 33 per cent mood disorder, 21 per cent psychosis, 69 per cent dependency and 1 person with an acquired brain impairment.

Service users (n = 41) who did not agree to participate in the interview, did so primarily because of their discharge before the start of the interviews or because of the severity of their illness. Incoming patients during the time of my research in each of the wards were informed on the goals and methods of the research and were invited to give their 'consent-to-observation'. They were not invited for the interview. As the disagreement of one service user would mean the end of my fieldwork in that particular ward, much time and energy were invested in informing service users and answering their questions related to the research and the presence of the fieldworker. Eventually, none of the fieldwork periods was cut of due to the objection of a service user.

Data gathering

Interviews lasted for about one hour, most interview were recorded and subsequently transcribed. However, after the consultation of the staff in the department for people with psychosis, we decided to work with handwritten notes during these interviews. As staff members mentioned, hearing and recording their own voice could confuse individuals who were hearing voices. During the interview, respondents were asked to talk about the way they had ended up in the psychiatric hospital. This general question made it possible to obtain information on the different dynamics that informed their eventual admission. By the use of a topic guide, topics that were not mentioned by service users themselves were also introduced and discussed. The main topics were service users' understanding of their mental health problem and of psychiatric care, the communication around their problems in their social network and their experiences concerning the care they receive.

The fieldworker, who's a sociologist, also conducted intensive participant observation. She chose to take the role of "participant as observer" (Gold, 1958). This means that the field worker and the participants are aware of their role, but the fieldworker develops relationships with the participants, through which any uneasiness and initial reactions to the presence of the fieldworker are likely to disappear over time. This role made it possible to talk about individuals help-seeking trajectories in an informal way and to make the interview a more informal moment in which service users were asked to talk about their help-seeking and service use experiences in detail. This combination of observations and the interview has also been recommended as a

strategy to maximize the quality of data when dealing with individuals who might have difficulties reporting their experiences (Kirkewold & Bergland, 2007).

Observations were brought to an end when the researcher was confronted with a kind of field fatigue, as new information concerning illness experiences and help-seeking trajectories became very rare and field notes became increasingly repetitive (after about 180 hours in each ward). Observations took place mainly during therapeutic activities and at meal times. Idle periods were used to approach service users through informal conversations, cautiously examining their illness and treatment experiences, and their identity conceptions. Field notes were taken in the toilet, in the living room or outside, when service users took some rest, or in the train on the way back home.

Data analysis

During the fieldwork period, the data gathered in fieldwork notebooks, together with the corpus of the interviews, were systematized by using NVivo CAQDAS. This facilitated comprehensiveness and the application of the principles of grounded theory, such as constant comparative techniques (Coffey & Atkinson, 1996). Data analyses were in line with the general coding processes formulated by grounded theory and were structured using a constructivist grounded theory approach (Charmaz, 2005; Mills, Bonner, & Francis, 2006). In this approach, the researcher is positioned as the author of a reconstruction of experiences and meaning, uncovering the implicit values and beliefs that are significant in this regard (Charmaz, 2008). This allowed us to gain awareness of service users' subjective meanings of their illness experiences and illness behaviour, and the dynamics that framed these meanings. Thematic coding of illness and care experiences, and help-seeking dynamics, as well as the links between these provided a detailed report of the interview data. Throughout the analysis, the theme codes were expanded with sub codes, adapted and readjusted. The data from the notebooks were also coded and linked to the coding scheme of the interview data. The coding process resulted in the construction of abstract concepts, like 'otherness', 'shame', 'hope', 'temporary illness identity', 'devalued identity'.

In the following section, we focus on different identity dynamics which informed service users' help-seeking trajectories, identified during the analysis. Accordingly, we work with interview

extracts that exemplify the help-seeking experiences of service users. All participants are given pseudonyms and any information that could lead to their identification has been removed.

Results

Most participants entered into treatment after a period of acute crisis, which involved serious problems such as a suicide attempt, an acute psychotic episode, the dysfunction of vital organs after years of alcohol abuse, or other problems that constituted a threat to themselves and their direct social environment. However, several of them mentioned that they experienced previous episodes of acute need in which they did not seek help. How identity dynamics informed participants (postponement of) help-seeking trajectories is discussed below.

Otherness and shame

Most participants said they did not start with their search for help when they were first confronted with their mental health problem. For many this decision was related to the existing stereotypes in society about people with mental health problems. Many could not imagine being part of the group which they depicted as crazy people:

Lena: 'I fought against it [her problems] for two years. Without properly realizing that I was suffering from depression. (…) I tried to find someone who could help me but it was so difficult. The way to this place was so ponderous.'

Researcher: 'But you were aware of the existence of mental health care institutions?'

Lena: 'Not really, actually I wasn't. I have lived my whole life ten kilometres from the hospital, and the hospital has always been the clinic for the crazy [pause] and when you are young, you think the place houses only crazy people [pause] Yes, until you are confronted with mental health problems yourself, then the step is huge.'

Like others, Lena did not place her illness experience in the field of mental health, nor did she think of mental health care as a solution for her problem. The fact that she associated the care

settings with the "otherness" of its users, who she described as "crazy people," made it impossible for her to imagine that she had a mental health problem, or to say that she would label herself as mentally ill.

Furthermore, for half of the participants, the confrontation with their need for help led to feeling of shame as they applied the negative stereotypes to themselves. The idea that they belonged to the group of 'weak', 'irresponsible' people, following the common stereotypes in society, clearly affected their self-image in a negative way:

'I've been confronted with these depressive episodes for ten years now. Before, I was always strong enough to get myself out of these situations. But this time it didn't work and then I had to accept hospitalization.' (Martin)

'I was scared about the way people would react to my hospitalization. Yes, I'm responsible for little children in my job and if the parents found out about it [his hospitalization], what would they say? I was supposed to be responsible for their children and I was going to be hospitalized.' (Wim)

'I told my best friend that I was going on holiday [when he accepted the hospitalization that his parents wanted] . I was ashamed.' (Robert)

Most participants were struggling with the idea that they would belong to the group of the 'crazy people', which led to the postponement of their search for care and the development of an negative self-image and shame.

Changing role identities

Additionally, participants indicated that their changing role identities were crucial for their help-seeking trajectories. Most respondents said that the time had come to seek help. Several described this "right time" as a moment in their life when there was room for care and the adoption of an illness identity.

For those who were seeking help for the first time, the disappearance of other role identities appeared to be a turning point in their help-seeking behaviour. Frieda for instance, went through different depressive episodes over the previous 22 years. She always postponed her search for

help because she was unfamiliar with and afraid of psychiatric care, but when her daughter was 18, she made the decision to seek help. She distanced herself from her role as a mother and this seemed to create space for an illness identity. Just like Elise who always postponed her admission because she did not want to give up her mother role:

'You want to do it [to get better] yourself, because I didn't want to leave my child on his own. That's why it was so important for me to do it [to get better] myself.' (Elise)

For others, the fact that they no longer had a job was important in their decision to accept care:

Fanny: 'I was addicted to Temesta for eight years, because I had to work, I was single and I had to do my part in society, but I lost my job [pause] three months before I decided to search for help.'

Researcher: 'And these days you are searching for a job?'

Fanny: 'Yes, because I say, Fanny, you have to get on with your life. I want to go outside [be discharged], but I first need a job. If not I will be back soon.'

It seems that individuals' loss of their job and their working role identity, made help-seeking a more realistic proposal. Three people also identified their recent change to life without a partner as a reason for seeking admission. The fact that individuals were no longer a husband or wife, mother, or employee, appeared to initiate the search for care. Individuals lost valuable roles or distanced themselves from these roles, which led to feelings of incapability, but which also made room for the start of the help-seeking process, as their illness identity became more prominent in their self-construct.

Taking a break

Others who had experienced previous hospitalizations were less reluctant to seek help when they were confronted with new or recurring problems. This was in part related to their increased familiarity with the functioning of the settings and their experience of treatment as helpful. Moreover, they perceived their admission as a possibility to distance themselves from daily life and the role expectations that go with it, or like Jeanne said: "It's like a time out from the outside world", or as others mentioned:

111

'From the last time, I know that it is necessary to step out of the situation. And for that, it's good to come here. Outside [the hospital], the daily tasks, a fulltime job combined with a family life – then you don't have the time to reflect on your problem.' (Rita)

'I really wanted to handle my problem [pause] and this is a protected environment [pause] It was also a way to escape from my partner, with who I was fighting all the time. Here you find rest. I really want to handle my problem.' (Brecht)

Like Rita and Brecht, who decided on hospitalization to deal with their alcohol dependence, participants perceived help-seeking as a way to bring her illness identity to the forefront. Inpatient care was depicted as the only way they could totally focus on their problem, without being distracted by the expectations of others at work or at home.

Hope for new valuable roles

Moreover, some participants defined their decision to seek care not really as an opportunity to focus on their illness experience, but rather as a chance to acquire new valuable roles and to build up a life in society. For example Jef, he hoped that his admission would give him the opportunity to work and earn something to build a life in society:

'I could only leave prison when I chose a residential setting. But that's what I was going to look for anyway. Living alone from the moment you leave prison is too (pause) I could live in a home for homeless people or something like that. I think I will stay for six months, then I can work and save money. They [the staff] will try to keep me here as long as possible, to be sure [that he does not take illegal drugs]. For me, I want to stay here long enough to work and to save enough money for the deposit and rent of a house and for furniture.' (Jef)

It mostly concerned individuals who chose for hospitalization instead of imprisonment and people who were homeless at the time of their admission. These were people living at the margins of society, with a limited number of valued role identities that constituted their self. For people like Elise, who stated that it was her homeless status which made her eventually opt for admission, or Rik, who had the choice between life on the street and inpatient care, the choice of hospitalization was in part informed by their miserable socioeconomic living conditions:

'I always wanted to do it [to get better] myself, but now, I don't have a place to live and that's why. If I had my home, I would still postpone my search for help.' (Elise)

Nonetheless, the finding that these respondents perceived their admission as a step toward life in society does not imply that they all easily adopted an illness identity as the case of Ann illustrates:

'I asked for a hospitalization because I cannot stay with my boyfriend. And I was following day-care sessions and I asked if I could stay here. Not as a patient, but as a social residence.'

She had been hospitalized several times for psychotic problems. This time she ended up in hospital because she was homeless. She found it very important to stress that she was not a "patient," but that her stay should be interpreted as a "social residence." She was familiar with the institution and hospitalization was the only way for her to claim social housing benefits and not to live in the street.

Some participants, however, experienced their illness identity not as a temporary role/identity to get better and to take up (again) more valuable roles in society. They rather constructed their life around their illness identity. Bart for instance, perceived hospitalization and his illness identity as means to escape situations in which he did not feel at ease:

'I started adult secondary education, but I was not doing well. Then I told the psychiatrist that I didn't feel well, so I could stop going to school (…) One day my father was angry, because I had been living with him for two months without doing anything, and he told me that I could leave the house. I thought it was for real and therefore I chose hospitalization. I wasn't psychotic, I just needed peace. I told them I was psychotic, but that wasn't true.'

'Every time he experienced difficulties in the construction of other roles, such as being a student, living on his own, or finding a job, he fell back on his illness identity and chose for a hospitalization.'

Discussion

The preceding analyses confirm the crucial role of social context and identity dynamics in individuals' help-seeking careers. It was found that the negative social meanings of mental health care use, seemed to make people reluctant to seek help. Participants described their proper prejudice toward mental health service users, their appropriation of stereotypes and the development of feelings of shame which all led to the postponement of their admission. This finding is consistent with previous qualitative research on help-seeking experiences (e.g. Taskanen et al., 2011), and in line with the finding that individuals' own stigmatizing perceptions of service users and mental health care (see also Corrigan, Markowitz, & Watson, 2004), together with their lack of familiarity with mental health problems (e.g. Jorm, Christensen, & Griffiths, 2006; Wright, Jorm, Harris, & McGorry, 2007) negatively affect their search for treatment. Furthermore, respondents' accounts of anticipated negative reactions and shame can be explained with reference to the modified labelling theory (Link et al., 1989), which states that individuals with mental health problems are aware of existing stereotypes in society and adjusted their behaviour, for example by delaying or hiding their hospitalization, out of shame and the fear of stigmatizing social reactions.

Furthermore, the present study affirms the finding of Perry & Pescosolido (2012) that individuals fear for changing role relations on the basis of negative stereotypes of people with mental health problems. They appeared to worry about degrading reaction of network members and the loss of social bonds based on mutual confidence and respect based on their own belief that people with mental health problems are weak or irresponsible.

The present study further elucidates the impact of changing role identities for individuals their help-seeking trajectories. The finding that the disappearance of other role identities can be crucial in help-seeking trajectories supports the premise of the role identity theory (Stryker & Burke, 2000), that devalued role identities, like the illness identity, which usually occupy a low position in individuals' identity hierarchy, become more salient in the identity hierarchy with the loss of important role identities, such as being a mother, husband, or employee. As Thoits (2011) mentioned in her study on the conditions which inform stigma resistance, the impact of the

114

illness-related identity on the self is lesser when individuals possess more role identities. In our study, the loss of valuable roles led to feelings of incapability and the loss of self-image (see also Charmaz, 1983), but made also room for the start of the help-seeking process as individuals' illness identity became more prominent. This finding confirms the idea that the loss of role identities should not only be studied as a possible source of mental health problems or as a result of mental health problems, but also as a dynamic which gives meaning to individuals' illness experiences (Thoits, 2013). It appears that a divorce can not only be a source of alcohol abuse or depression, the loss of the 'partner-role' seems to make room for the focus on one's illness identity and for the start of a recovery process. Besides, it could be interesting to question the extent to which the balance between the loss of self-image and the start of the help-seeking process is influenced by the existing stigma in the broader society.

The analysis further revealed that several individuals who experienced previous hospitalizations, perceived their admission as an opportunity to distance themselves from daily life and the role expectations that go with it. The conclusion is that their decision to seek help was informed by their experience that only a hospitalization could allow them to concentrate on their illness. The adoption of an illness identity to free oneself from other social roles and responsibilities, fits the reasoning behind Parsons' (1951;1975) conceptualization of the "sick role," in which he describes the sick role as a legitimized social role which enables people to focus on their recovery, setting other social roles aside for the duration of the illness. This was however only the case for participants who were previously admitted and who occupied multiple other demanding social roles in society.

It was also interesting to observe that some participant depicted their search for help and their admission as a starting point for the construction of valuable roles in society. It concerned people with a low socioeconomic status and a limited number of valued role identities. Socioeconomic status has previously been identified in relevant literature as a predisposing factor, which influences both peoples' susceptibility to mental health problems (Andersen, 1995) – because of a lifestyle that contains more risks of differential disorders (Gove, 1982, in Thoits, 2005) – and because of their illness behaviour (Young, 2004). Differences in socioeconomic status have also been linked to differences in access to qualitative care settings and treatment (e.g. Lorant et al., 2003). Yet, this study does not affirm the double jeopardy hypothesis, which states that multiple

devalued identities like being homeless and mentally ill lead to the experience of multiple disadvantages (Beale, 2008; Purdie-Vaughns & Eibach, 2008), because service users did not experience their hospitalization and illness identity as a reinforcement of their devalued identity, but instead as an opportunity to acquire other, more valued identities. Most of them accepted the illness identity as a temporary role in an effort to build up a life in society, while some chose for an admission, but refused 'to be a patient'.

Finally, some individuals had constructed their life around their illness identity, which as Estroff (1981) mentioned, can provide a sense of identity and a resource in the absence of other sustainable rewarding roles.

Although this analysis is limited to the accounts of 42 service users, it may bring fresh insights to the study of identity dynamics in mental help-seeking trajectories. Our research may illuminate further understanding of the way dominant social meanings of mental health care and the specific roles people occupy in their social context impact the way identity dynamics and help-seeking trajectories inform each other. Why identity dynamics differ between people with a lower socioeconomic status requires additional exploration in an effort to understand the meaning of other devaluing social identities for illness experiences in the help-seeking process of individuals with mental health problems.

Besides, it should be stated that the accounts of participants' help-seeking experiences are informed by the experiences of their current hospitalization. As every reconstruction of the past can be seen as a way of making sense of present beliefs and experiences (Charmaz & Belgrave, 2013), the assistance and tools to resume occupational and family roles they received during hospitalization certainly influenced the story of the respondents' care-seeking experiences. Nevertheless, the fact that individuals could perceive inpatient care as an opportunity and a means to take new valuable roles in society has seldom been suggested. This finding is of particular interest in the light of the current movements towards community treatment, which are at least partly based on the recognition of negative effects of inpatient care like the build-up of chronically ill people (Fakhoury & Priebe, 2002).

For the purpose of this study, we did not consider the – often relevant – disorder labels and their symptomatic differences, which have been found to effect help-seeking behaviour in different

ways (e.g. Wang et al., 2005). Instead, we studied all the respondents as individuals living a certain illness experience, because our prime intention was to study the meaning of these encompassing experiences and identity dynamics for service users' help-seeking trajectories.

Moreover, we found that the so called lack of illness insight and the lack of recognition of their mental health problems, did not only inform the help-seeking trajectory of people suffering from psychosis (David, 1990) as almost all participants had difficulties with the recognition and the acceptance that they had a mental health problem. This at least partly due to the existing stereotypes about people with mental health problems. Furthermore, not only schizophrenia was found to be an 'I am illness' (Estroff, 1989), as all participants were confronted with a redefinition of their identity during their help-seeking process.

CHAPTER 9

STIGMA, SOCIAL STRUCTURE AND THE BIOMEDICAL FRAMEWORK: EXPLORING THE STIGMA EXPERIENCES OF INPATIENT SERVICE USERS IN TWO BELGIAN PSYCHIATRIC HOSPITALS

Charlotte Sercu & Piet Bracke

The study discusses the stigma experiences of service users in mental health care, within the debate on the role of the biomedical framework for mental health care and power relations in society. Interview data of inpatient users (n= 42) and care providers (n=43) from two Belgian psychiatric hospitals were analysed using a constructivist grounded theory approach, in which the researcher is positioned to reconstruct experiences and meaning. Findings offer insight on how stigma experiences are affected by social structure. While the role of social position for the perception of mental health problems has been stated earlier, this study shows how it affects stigma experiences. Stigma was found to be related to the relation between care providers and service users their position. The concept 'mental health literacy' is used to frame this finding. In paying attention to the specific cultural and normative context which influences the relationship between mental health literacy and stigma, it is further possible to move beyond the approach of the biomedical framework in mental health care as merely a stigmatizing approach, casting some light on its meaning for the construction and maintenance of power relations in mental health care and broader society.

Introduction

About one in four stigma experiences of individuals suffering from mental health problems are directly related to mental health care (Schulze, 2007; Wahl, 1999). In places individuals visit in search of understanding, relationships with care providers can be experienced as stigmatizing, for example due to infantilizing contacts and a lack of respect for and interest in one's person (Schulze & Angermeyer 2003; Thornicroft, Rose & Kassam 2007; Wahl, 1999). The sociological study of these stigma experiences rests on the premise that stigma is a deeply discrediting attribute (Goffman, 1963, p.3). However, as Goffman emphasizes, the attribute is not discrediting as such. It may only lead to stigmatizing interactions and the development of a 'spoiled identity', when linked to specific cultural rules and power relations in a particular context (Parker & Aggleton, 2003; Pescosolido et al., 2008; Yang et al., 2007).

In the context of mental health care, these cultural rules and power differences are determined to an important extent by the biomedical model. The psychiatric approach allied with the assumption that mental health problems originate in the biological malfunctioning of individuals. This biomedical approach which situates the cause of mental health problems in the brains, has been the most commonly accepted and supported understanding of mental health problems in the last five decades (Pearlin, Avison, & Fazio, 2007). While psychiatry, as a medical science and discipline contains different discourses relate to mental illness; and notwithstanding the capacity of the psychiatric approach to accommodate multiple explanatory factors, the biological emphasis remains (Pilgrim & Rogers, 2014, p.4). This emphasis is reflected in the dominant biomedical definition mental health problems, described in the DSM-IV (Kawa & Giordano, 2012) and in the authority of the psychiatrist.

This biomedical approach has been extensively criticized by sociologists. In relation to mental health care, sociologists have identified the adoption of the model–and therefore the diagnostic categorization of people with mental health problems–as an important catalyst for the stigma process (Scheff, 1999). Further, the ideology has been found to mirror middle-class values and resources (Crawford, 2006; Pescosolido, 2006). This means that people with limited resources often lack the power to benefit from the care offered in mental health treatment contexts.

Accordingly, the biomedical approach in mental health care can be seen as a source for the reproduction of social inequalities in society as a whole (Conrad and Barker, 2010).

Therefore, it appears crucial to incorporate the role of social structures in the analysis of stigma in mental health care. Moreover, this focus may help to capture the dynamics that shape users' stigma experiences in mental health care, moving beyond the approach of psychiatry with its biomedical underpinnings (Mirowsky & Ross, 1989) as a harmful (e.g. Thachuk, 2011; Ungar & Knaak, 2013) rather than helpful approach in the context of stigma, instead questioning why and how its relationship with stigma is so complex. As Becker (1967) states, in the discussion about interdisciplinary issues such as mental health stigma, it is only possible to take a constructive position by acknowledging and respecting the dominant framework through which knowledge and relationships are produced. Like Perry (2012) argues, discussions can only be set up with the mental health care community through the participation in integrative research, with acknowledgement of their knowledge system.

In an effort to respond to the recent call for more research that pays attention to the underlying roots of stigma, or the cultural and normative rules that guide behaviour in particular situations (Pescosolido et al., 2008; Scambler, 2009), this study explores how power structures that permeate mental health care, may affect stigma processes in inpatient care settings. The accounts of service users and providers are analysed with reference to Smith's (2007) stigma communication theory, in which she focusses on the way stigma is manifested through communication, serving its function in the production and reproduction of relations of power and control (Parker & Aggleton, 2003; Link & Phelan, 2014a). This study builds on the concept of mental health literacy (Jorm, 1997; Papen, 2009) to explore how the dominant understanding of mental health problems in forms stigma experiences in the context of mental health care. Mental health literacy reflects the knowledge and related ability to obtain, understand and use the information to make appropriate decisions with respect to their mental health (problem) (Jorm et al., 1997; Nutbeam, 2008), for which the term 'correct' refers to the dominant biomedical definition of a disorder. The suggestion of Smith (2007) to work with particular cues which characterise stigma communication, like the use and meaning of diagnoses formed a starting point for the analysis of the way stigma experiences in mental health care are informed by the system of social stratification and its relation to the biomedical framework.

Accordingly, we analyse users' stigma experiences with reference to both users and providers understanding regarding mental illness and care, with specific attention paid to the particular care setting and broader social context in which their interactions take place. Drawing from interviews with 43 service providers and 42 service users, the stigma experiences of service users appears to be related to the match (or mismatch) between users' and providers' expectations and understanding of mental health care. The mapping and analysing of these accounts of stigma experiences illustrate how stigma perceptions are influenced by society's power structures, and more particularly by the role of mental health care and its providers in the preservation and contestation of these power structures.

Iatrogenic stigma experiences

Iatrogenic stigma experiences refer to the stigma experiences that are shaped by the user's encounter with treatment settings, arising from particular treatment practices and actions (Lee et al., 2006). Despite the emphasis on the situatedness of the interaction between the service user and the care provider in this conceptualization, most research has not explicitly investigated how and why this encounter may lead to stigma experiences. In both survey research and in qualitative studies on service users' stigma experiences, care settings and providers have been identified as sources of stigma, in addition to communities and policy measures (e.g. Schulze & Angermeyer, 2003; Wahl, 1999). Schulze (2007) focuses on the various ways through which professionals are entangled in the stigma process. Although in her review she identifies the complex relationship between stigma and the psychiatric profession, the extent to which her study focuses on the contexts of power that affect this intricacy is limited. Other studies on user experiences primarily refer to accounts of a lack of interest in personal illness trajectories and personalized psychiatric treatment (e.g. Angermeyer & Schulze, 2003) and link these reports, for instance, to clinical determinants such as diagnosis (e.g. Dinos et al., 2004).

Research on iatrogenic stigma experiences often only takes a partial approach to the subject by neglecting the contextual dynamics that guide care interactions. Even though, as Kusow (2004) states, in order to make empirical sense it is important to go beyond individually-based analysis

and to identify the cultural rules and structural conditions in which these stigmatizing encounters are given shape. In their work regarding the iatrogenic stigma experiences of Chinese service users with schizophrenia in Hong Kong, Lee and colleagues (2006) clearly show how focusing on the role of contextual factors (such as an unbalanced health policy, resource allocation and service organization) in creating power differences between users and providers, can help to explain the social production of stigma and discrimination during treatment.

Differences in power

The way in which stigma experiences are influenced by power relations was recently examined by Link and Phelan (2014), through the concept of 'stigma power'. They identify stigma as a form of symbolic power (Bourdieu, 1989), which refers to the capacity of people or institutions to impose their legitimized vision of the social world in order to achieve the ends they desire. With reference to psychiatric stigma, this concerns the–often subtle–exercise of stigma to keep people down, away or in (Link & Phelan, 2014; Phelan, 2008). As such, service users experience stigma, while professionals do not have any conscious intention to stigmatize (Link & Phelan, 2001).

Health and its meanings have been described as sources of symbolic capital for strategies of distinction and stigmatization (Crawford 2006). In relation to mental health care, sociologists have identified the adoption of the biomedical model, and therefore the diagnostic categorization of people with mental health problems, as an important constituent of symbolic power and stigma (Scheff, 1999), reflecting ultimately the unequal distribution of power between the stigmatizers and the stigmatized (Link & Phelan, 2001).

This conceptualization of mental illness as a brain disease–embodied in the responsibility of the psychiatrist, the use of diagnostic labels during the caring process and the pharmacological treatment of mental health problems (Deacon 2013; Jutel 2009)–has further been identified as a source of symbolic power, used by psychiatrists to maintain their status. Through the biomedical approach, they define their higher status vis-à-vis other mental health professionals and service

users (Pilgrim & Rogers, 2005). Like Jordan (1993) suggests, while equally legitimate knowledge systems exist - like the believe in social stressors or supernatural phenomena as causes of illness - the biomedical understanding of mental health problems can be seen as a form of authorities knowledge which organizes power relations during the treatment process.

In this context Alden, Merz and Thi (2010) emphasis the need to focus on the differences in service users decision making preferences and how these are related to peoples relation with the biomedical model and broader societal culture. As Hofstede (1983) states, power distance concerns a set of values, like the emphasis on hierarchic values, which define the importance of power in a particular culture. As such, depending on individuals' cultural values, providers' adherence to the medical model may lead to the appreciation of the expertise and control in treatment relationships, rather than leading to experiences of a lack of interest in the personal values and interpretations.

Furthermore, it does not only concern the preservation of status in the context of mental health care, as the culturally dominant ideology of medicalization has been found to mirror middle-class resources and opportunities, reflecting middle-class culture (Crawford 2006; Francis 2012). As Crawford (2006) argued, the meaningful practice of health is clearly linked to the meaning of biomedicine as a means to establish authority and other marks of distinction. The professional project was instructed by a social movement of aspiring middle class men with a scientifically oriented worldview (Pescosolido, 2006). As such, this growing middle class was privileged in its ability to adopt a healthy lifestyle which mirrors and reinforces the values of middle class culture (Crawford, 2006). With respect to (mental) health, it concerns the pursuit of health as a very valuable activity in contemporary life, characterised by the multiple prevention campaigns in which 'healthy lifestyles' are promoted. As Crawford (2006) argues, personal responsibility for health is widely considered the ultimate condition of good citizenship and individuals are expected to acquire the necessary knowledge and practices or literacy to live their healthy life.

Keeping body and mind in balance through sports, healthy food or seeking out health information stress values of personal responsibility and agency. Furthermore, this ability depends on the social and economic capital, the access to education and information and further confirms the shared middle class values of science education and progress (Pescosolido, 2006). Therefore, providers their adherence to and promotion of the biomedical view, may therefore be seen as a

means to preserve their social standing or as Pescosolido (2006) called it, their 'consulting status', which fits these middle class values of science, education and progress, all reflected in the concept of 'mental health literacy'.

Mental health literacy

The idea that holding a powerful position in society may help a person to benefit from mental health care and may diminish stigmatizing perceptions and experiences, has been further confirmed by work on mental health literacy in mental health promotion research (Jorm et al. 2006). The concept of mental health literacy, builds on research on the relation between ill health and low levels of education and understood as the degree to which people have the ability to obtain, understand and use health information to make appropriate health decisions' (Nutbeam, 2008). The term mental health literacy was then developed to capture the knowledge and beliefs about mental disorders in the community, and focusses on individuals' personal resources that aid the correct recognition to manage mental health problems in the appropriate way (Jorm et al., 1997; Lauber et al., 2003). Jorm and colleagues (2000) point to the particular relevance of mental health literacy for interactions between service users and care providers. They argue the specific description of symptoms as reflecting a mental health problem will benefit the detection and effective treatment of the problem. In relation to health promotion research, it primary concerns the altering of the belief in non-biological causes for serious mental health problems, for which individuals identify social stressors (Angermeyer & Matschinger, 2005; Pattyn et al., 2013) or supernatural phenomena like witchcraft or possession in non-western cultures (Razali, Khan & Hasanah, 1996). The reference to the dominant biomedical definition described in the DSM-IV (Kawa & Giordano, 2012) of a disorder as its correct recognition, can for instance be compared to the dominance of the BMI index, which was identified by Anderson (2012) as an illustration of how the biomedical model has the power to define the correct, healthy body and functions as a classification system with particular moral, ethical and political consequences.

This conception of (mental) health literacy as a personal skill or ability has been criticized. Papen (2009) argued for instance that it neglects the relevance of the context in which the knowledge

126

and resources, defined as literacy, become meaningful, through her definition of health literacy as a social practice. She describes how literacy functions as a form authoritative knowledge through which relations of power are established. In practise, health care environments are 'textually-mediated' social worlds in which individuals are supposed to engage with various sorts of text, related to diagnoses, treatment or prognoses. Therefore, through the incorporation of mental health literacy as a social practise, which incorporates the relationship between individual literacy, the health care system and the broader society, the role of the medical framework in the reproduction of health inequalities and stigma through mental health care interactions can be studied in a meaningful way (Baker, 2006; Smith, 2007). While Anderson & Bresnahan (2012) did study the way this biomedical model informs stigma communication in relation to body size, how mental health literacy may influence stigma experiences in mental health care has not yet been studied. However, research into the meaning of insight and of treatment compliance (Kravetz et al., 2000; Mishra et al., 2009) for stigma experiences in care interactions, suggests that these are to an important extent influenced by the degree to which individuals recognize and endorse the dominant, biomedical explanation for their mental health problem (Kravetz et al., 2000).

In sum, when approaches to mental illness are influenced by the social positions and the systems of meaning that people employ (Kleinman, Eisenberg & Good, 1978), treatment interactions might be characterized by major discrepancies regarding therapeutic engagements, expectations and goals. As Pattyn and colleagues (2013) state, while some individuals uphold the biomedical model, a significant proportion of the population views mental illness instead as a life crisis, caused by social circumstances. While a disease-oriented patient role may be beneficial for service users who identify and agree with the ascribed diagnoses and medical treatment (e.g. Alden et al., 2010), people who hold other views about mental illness may not profit from treatment in the same way. It often concerns people with fewer social and economic recourses (Crawford, 2006), who lack the power to question or counter the dominant understandings of illness and care in health care contexts. In both health care relationships and empirical studies, these service users are often identified as individuals who lack the insight, or capacity and 'know how' to recognize an illness that requires treatment (Kravetz et al., 2000). Accordingly, the medical approach in mental health care may induce feelings of misunderstanding and inferiority,

and can be seen as a source for the reproduction of social inequalities in society (Conrad & Barker, 2010).

This article discusses why some service users do experience stigma in their relationship with certain care providers and contexts, and others do not, within the debate on the role of the biomedical framework for mental health care and power relations in the broader society. The current article explores the variation in service users' stigma experiences by positioning their accounts as affected by the health literacy of service users and service providers, and more generally their social position in society. The study offers an idea of how stigma research can be more than the study of a barrier to good health, a risk factor to overcome. The focus on the dynamics between context and personal experience makes it further possible to view users and providers as social agents, who employ different levels of resources, rather than to focus on the 'goodness or badness' of the actors.

Methods and participants

As part of a research project on stigma in mental health care, qualitative data was gathered through semi-structured interviews of inpatient service users (n = 42) and service providers (n = 43), combined with participant observations (750 hours in total). The data was collected between 2011 and 2012 in four wards of two psychiatric hospitals in the region of Ghent, Belgium. The hospitals were chosen based on their geographical location, their equivalent size and their approaches to mental health problems and care. Both are situated in Ghent, on the outskirts of the city. They are relatively small, with a similar number of hospital beds (+/-190). This involves hospitals in which theoretically divergent notions of care for people with mental health problems had been reported earlier, based on interviews with staff and written material on their care approaches (Sercu et al., 2010). This earlier study focuses on service users who were difficult to transfer between care settings, and its findings suggest that service users were perceived as 'difficult' due to a mismatch between their needs – related to their diagnostic and

sociodemographic profile – and the notion of residential psychiatric care based on which the care supply was organized.

Hospital A adhered to a more social explanatory model in the definition of its service users, and identified the less healthy as socially marginalized and misfortunate, while in Hospital B, service users were primary perceived from a diagnostic point of view and the care approach was based on the dichotomized categorization of healthy versus ill. This background was crucial to orient the hospital sample, because it is recognized that dominant processes of dichotomized categorizations are at the core of stigma processes (Link & Phelan, 2001).

Once the Ethics Committees of Ghent University Hospital and both hospitals had given us permission to start the fieldwork, all service users and care givers were informed of the course of the research. The way to advise participants was determined in collaboration with the care givers, in an effort to adapt the procedure as much as possible to the functioning of the wards. The fieldwork started once all individuals, including those who did not participate in the interview, had agreed to the researcher's presence.

The analysis is based on field notes and the accounts of both service users and care providers. Providers were invited to give their informed consent for an interview. Almost all the care providers in the four wards were also interviewed, totalling 33 nurses, 3 psychiatrists, 4 psychologists and 3 social workers. Two different consent forms were prepared for service users, one of which invited them to agree to my presence in the ward and the second to participate in an interview. The understanding was that if one service user did not agree to my presence in the ward, I had to stop my fieldwork immediately. This aspect of the fieldwork made the continuous process of building and maintaining relationships with service users, as well as the constant reflection on how I presented myself and interacted with others, as both a methodological and a practical necessity in the elaboration of the fieldwork. Out of a total of 83 service users who were present at the time, 42 self-selected for an interview, on average 10 in each ward: 27 male and 15 female, aged between 20 and 60. It is interesting that both the level of educational attainment of service users and their occupational status differed between the hospitals. In the wards of Hospital A, only three users had followed higher education and in Ward A1, more than half of them had not completed secondary education. However, in Hospital B, nine service users had a higher education degree and in Ward B2, 10 out of 12 had completed at least general secondary

education. Most of the people who were on sick leave (11) or self-employed (6) resided in Hospital B, whereas Hospital A contained mostly people who were unemployed (6) or were receiving an invalidity allowance (12). Furthermore, 36 per cent of all the individuals had been hospitalized for the first time and four were subject to compulsory admission. Service users were labelled by (multiple) diagnosis: 33 per cent mood disorder, 21 per cent psychosis, 69 per cent dependency and one person with an acquired brain impairment.

Service users (n = 41) who did not agree to participate in the interview, did so primarily because of their discharge before the start of the interviews or because of the severity of their illness. Incoming patients during the time of my research in each of the wards were informed on the goals and methods of the research and were invited to give their 'consent-to-observation'. They were not invited for the interview. As the disagreement of one service user would mean the end of my fieldwork in that particular ward, much time and energy were invested in informing service users and answering their questions related to the research and the presence of the fieldworker. Eventually, none of the fieldwork periods was cut of due to the objection of a service users and at the end of each period of fieldwork all users and providers participated in my sister's homemade patisserie.

Data gathering

Each interview lasted for approximately one hour, and they were recorded and subsequently transcribed. However, in the department for people with psychosis, we followed the suggestion of the staff to work with handwritten notes during interviews with service users. Different staff members argued that hearing and recording their own voice could confuse individuals who were hearing voices, based on the previous aggressive reaction of a service user toward a journalist who recorded an interview. The topic guide for interviews with service users covered experiences and understanding of mental health problems, the meaning of mental health care and care expectations, experiences of the treatment program, experiences of contacts with care providers, and an overall care evaluation. Care providers were asked about their understanding of their job as a mental health care provider and were asked to describe the problems and the treatment for these problems that service users were confronted with in the ward.

The first author also conducted participant observations, in which she took the role of "participant as observer" (Gold,1958). This made it possible to develop a relationship with both the providers and the service users, and to reduce any unease regarding the presence of the researcher at the start of the fieldwork. Further, this role made it possible to discuss individuals' illness and care experiences in an informal way and to make the interview a more informal event. Combining observations and interviews has also been suggested as a strategy to heighten the quality of data when dealing with individuals who can find it difficult to express their experiences (Kirkewold & Bergland, 2007). When new information about illness and care experiences became scarce, the observation period was concluded. Observations took place mainly during therapeutic activities and at meal times. Rest periods were used to approach service users through informal conversations. Field notes were taken in the bathroom, in the living room or outside, when service users took some rest, or in the train on the way back home. It was surprising how quickly service users accepted the researcher's presence and understood her 'extra-organizational' role. They showed her around and invited her to participate in informal sporting activities, etc.

Data analysis

During the fieldwork, the interactional complexity of stigma experiences became clear. The divergence in the described types and occasions of stigma in mental health care, and dynamics which formed or affected experiences, were uncovered. Data analyses were structured using a constructivist grounded theory approach (Mills, Bonner & Francis, 2006). This perspective offers the possibility to uncover understandings of mental health problems and mental health care, as the researcher is there to reconstruct experiences and meaning. Data analysis used open coding (Strauss & Corbin, 1990), applied during and after each period of data collection in each ward. To define codes for organizing the data principles of the constant comparative method were used, being the systematic combination of data collection, coding and analysis at the same time (Glaser, 1965). This involves a type of thematic coding, from which the emerging topics were further explored and evaluated during the fieldwork. The detail of the initial findings was enhanced by so called 'member checking' (Cresswell, 2007), where the researcher reflects on codes and findings in informal conversations with respondents during the fieldwork. The data

from the notebooks was also coded and linked to the coding scheme of the interview data as a form of methodological triangulation (Denzin, 1978)

Throughout the data-gathering process, codes were adapted and readjusted (Patton, 1999). The general themes were expanded with more specific sub codes. The coding scheme included for example general and more specific codes related to participants understanding of mental illness. One of the general codes "cause of problem" was subdivided in more specific codes like "context/circumstances", "real psychiatric problem/brain disease", "personal history" which were again subdivided. With respect to "context/circumstances", it concerned the codes "family", "housing", "money", "prison". These codes formed the starting point for the actual data analysis, in which codes were related to contextual factors, frames of reference, relationships and background characteristics. During the coding process, substantive and theoretical memos were written about the ways service users and providers perceived and experienced mental health care (relationships) in the different settings.

The following sections draw on the analysis of the accounts of service users and care providers, in order to clarify the meanings of mental health literacy in the stigma experiences of inpatient service users. We work with interview extracts that exemplify the stigma experiences. Several measures were taken to guarantee the privacy of all research participants. I explained that I was the only people who would listen to the interviews and that pseudonyms would be given to all the interviewees. Any information that could lead to their identification would never be published in relation to specific quotes.

Findings

In this section, the stigma experiences of service users during their hospitalization are explored. Service users' stigma experiences varied to the extent that some individuals experienced stigma in their relationship with a specific professional, while others experienced these relationships in a positive way. In an effort to study how and why interactions between users and providers influence stigma experiences in a particular way, we analysed the accounts of both users and

providers on their perceptions of illness and care. The first part provides a concise discussion on care providers' conceptualizations of service users and care. The second part builds on this, to discuss service users' stigma experiences in their interactions with care providers.

Care providers' approaches to illness and care

Care providers, and especially the nurses in Hospital A, were influenced to a significant extent by the social explanatory model of mental health problems in their perception of service users. Rather than distinguishing between individuals with different diagnostic profiles, the social position of service users was identified as a criterion for their classification. In particular, they focussed on the social fragility of service users who experienced difficulties surviving in society, and sometimes contrasted their profile with that of service users who were seriously ill, mostly suffering from severe psychotic episodes:

'There are people who do not find a connection with society, and are therefore marginalized, and then you have the real, well… real, it's not like all the others are false, but the really sick people, like someone with severe schizophrenia. That's a real psychiatric disorder, which means that they can't function in society. But I believe the opposite exists too, people who are marginalized due to circumstances and who can't get out of the situation. (…) I don't see diagnoses, you learn to know people with a story, a past history. I find it very interesting to listen to people's stories and then you often understand why they are who they are, why they have difficulties with certain things.' (Nurse Sophie, A1).

'How many marked people live in the streets because there is no place in psychiatry for them. They need care, a bed, a shelter, safety, whatever it may be.' (Nurse Ines, A1)

'It [inpatient care] concerns a possibility for people who can't handle life in society, and it not necessarily concerns sickly individuals. I often think and tell people that we all have something. When I read the DSM, I have many problems too.' (Nurse Karen, A1)

In Hospital A, the providers' conceptualization of service users appeared to be influenced by their experiences with the target group for the ward, which mostly comprised people with a low socioeconomic position. Most of these individuals had not completed secondary education, were socially isolated and/or did not have a job. They often lacked the culturally-valued skills and

resources or mental health literacy to find connection with the broader society. Accordingly, care providers in the setting were used to working with individuals who were socially marginalized. The nurses stressed their intention to value these people as their equals, and perceived the use of non-medical language and the focus on equity and equality in caring relationships as prime tools to achieve this goal (see Sercu, Ayala & Bracke, 2014). Further, several (n= 13) care providers portrayed the hospital as a setting for 'all' people. The admission of the socially marginalized was presented as a kind of hallmark. The care context was also characterized by a high level of autonomy for the nurses and limited authority for the psychiatrist. There was no clear organizational framework for the integration of the different professions. It seemed that nurses and the psychiatrist differed considerably in their language use and their approach to service users. The medical language of the psychiatrists was often objected to during team meetings. Accordingly, the presumed symbolic power of the medical model was actively countered in the specific care setting. Nurses in the hospital actively touched on the role of diagnoses and more generally the DSM-IV as a source of stigma (Pilgrim, 2002).

The approach to people with mental health problems appeared to be more influenced by the medical understanding of mental illness in Hospital B. The accounts of the care perception of service users were to a significant extent based on their ascribed diagnosis. The constant evaluation of the diagnostic fit between the treatment setting and the service users' diagnostic profile was striking. Nurses (n= 15) stressed the usefulness of diagnosis, among which they described the labelling process as 'taking a position' in order to deal with the problem in a 'logical way':

'Things [illnesses] exist and names were invented, names that cover the meaning of it. On the other side, in general medicine, they use this. This person has this, and therefore needs this or that medication or operation. Maybe things are more clear there, and less obvious here, but in a way you have to take a position, if not, you can't react in a logical way to a problem.' (Boudewijn, nurse, B2).

'People have to realise that they have problem, if you don't realize it… I think it is necessary to have that insight.' (Els, psychologist, B2)

'I believe that naming things is helpful, it helps individuals with the interpretation. You can explain that symptoms are part of someone's illness and it may help them to understand their problem.' (Walter, nurse, B1)

This 'logical way' refers to the psychiatric approach and is therefore a reflection of the culturally dominant, middle-class approach to psychiatric problems. Further, in their evaluation of service users during team meetings and in their interview accounts, care providers (un)consciously differentiated between those individuals who possessed the social resources and skills to benefit from their diagnostic line of approach–the majority of the service users present at the time, as the setting has the informal status of a 'middle-class' hospital–and those who lacked the engagement or capacities to do so. While the social position of care users was not an actual evaluation or classification criterion, in taking a position or treatment approach that favours people who have the resources to benefit from the programme, providers indirectly classified service users on the basis of their social position.

While the biopsychosocial model was represented as the official organising framework for care in both settings, the accounts of providers in the two hospitals clearly show the different viewpoints through which mental health problems were approached and understood. The care approach in the wards was characterized by a limited compatibility between the social and biomedical approach to mental illness. Especially in Hospital A, the opposition to the use of diagnostic labels and psychiatric authority clearly reflected the gap in understanding and the rivalry between psychiatry and social explanatory models. As Rogers and Pilgrim (2011) suggest, the depiction of psychiatric theory as part of the problem of stigma in mental health care by care providers, may be influenced by their search for their own professional identity. This seems to be supported by the finding that those providers who work in a clear organizational framework perceive their biomedical viewpoint as a relatively 'logical' approach. Furthermore, the link between the health literacy of their target group and providers' accounts of the value or detrimental effects of the biomedical approach, echoes the influence of social structure in shaping and maintaining the specific approaches and classifications in the different settings. In what follows, service users' care experiences are discussed in relation to the care approaches of providers.

Stigma experiences

Service users' care experiences appeared to be influenced by the congruity of their own views of illness and care, and those of care providers. The majority expressed their satisfaction with the care provided and their care relationships. As mentioned in the previous section, this finding is related to the observation that providers develop their understandings of care partly based on their experiences with the service users or target group they treat. Most of the interviewed service users belonged to this group–(in)formally defined in both diagnostic and socioeconomic terms–which resulted in agreeable and helpful care relationships. In the following part, identified dynamics which influence (non)stigmatizing experiences are discussed.

Health-related attitudes

Throughout the interviews, the match or mismatch between the expectations about the health-related attitudes of care providers and users' actual attitudes, seemed to influence their stigma experiences. The users who were satisfied with their hospital stay (n=25), described this contentment as being a result of the specific care approach in the ward, referring to respecting providers for their understanding of illness and care, and their general view on life. As Marie (A1) explained:

'I love the freedom. They don't have to tell me what to do. I'm happy that there are no obligations here; when I feel like sleeping, I just do it. Now I feel like looking for a job, and I can do that. When I feel like smoking a cigarette, I just do it. Therapy, sports, that's not for me. I never did sports. I have always worked a lot, since I was 14 years old. I never knew something like relaxation, what that would mean. (…) I always took Temesta[2] for the last months, two in the morning, at noon and in the evening. Just to keep on functioning in society, and that way I could keep my place in society.'

The absence of obligatory therapy and the time provided for relaxation fitted her understanding of illness and care, as she attributed her condition to the societal demands on single women. Furthermore, the care approach clearly matched her lifestyle. She had never relaxed or reflected on her own health before she entered mental health care. She had depended on unhealthy

---

[2] Temesta is a trademark for Lorazepam, a drug used to treat anxiety disorders and with a high addiction potential.

practices, such as the use of drugs, to remain stable in society. In common with most service users in Hospital A, she did not have many health-related habits or resources that could be mobilized to benefit from specific treatment programmes. However, the fact that the prime aspects of care in the ward were providing free time, protection and rest, gave Marie a positive feeling about her admission.

By contrast, two individuals experienced this approach as stigmatizing (Ward A1). Jeanne (A1) for instance, who explained that she had been hospitalized because she had felt that she needed help with her depression:

'I was confronted with symptoms of depression and I didn't know how to deal with it. And yes, I knew I needed professional help and then I said I really need to be hospitalized somewhere. I felt that I had to do something and I went to the emergency department of the University Hospital and then they sent me here. They don't ask you if it's OK, they just look for a free place.'

In her story, Jeanne stressed her own active decision-making process, which preceded her hospitalization. Her attitude clearly reflects a culturally-valued agency and empowerment-oriented character. Furthermore, she defined her condition in diagnostic terms and looked for a place where they could offer her professional help to deal with her problem. During the interview, she expressed frustration about the lack of therapy and other sessions through which she could actively engage in her recovery process:

'I slept almost the whole day and I didn't know how to deal with it. And it was difficult for me, you can stay here without taking any initiative. Because you are free to do what you want here, that's what I did for a while. It was very heavy and not that obvious. I have to say that I don't feel good in this setting. The hospital as such, it's not just people with a depression, it's everything. And the hospital has a bad name, it's a place for marginal people. (…) I feel different to most of the people who are here. Just in the group, when you suggest something to do, or to watch a movie, nobody is interested.'

Jeanne appeared to be one of the two people in the ward who felt misrecognized in their active engagement to recover, an attitude that also characterized other spheres of their life. They had a higher educational degree and a job that required them to work autonomously, which was an attitude that did not match the care approach in the ward. Jeanne felt stigmatized by her

impression of being reduced to the presupposed marginal status of a service user. Jeanne's experience of status loss, or the downward placement of an individual in a status hierarchy, was identified as a core component of the stigma process, a direct consequence of the process of labelling and stereotyping (Link and Phelan 2001). However, Jeanne's experiences of stigma appeared to be related to her association with people from a lower social class, and not directly with her mental health condition being a discrediting status characteristic. As someone with a middle-class background, she experienced a lack of recognition for her health literacy in relationships with providers, who seemed to adapt their expectations to the resources and capacities of their socially-marginalized target group. As a result, she experienced the 'failure' of providers to appreciate her medical knowledge as a lack of respect for her social standing.

Medical knowledge, social position and stigma

Service users such as Jeanne, who anticipated that providers would expect to see motivated service users who actively engaged in the treatment programme, often adhered to the dominant medical conceptualization of health and illness. In general, they experienced their relationship with a psychiatrist in a positive way. These service users experienced the necessary recognition that they had a medical problem, rather than being a social case in these relationships:

'I like to go to the doctor. She approaches your problem from a different angle, from a medical angle, and I think she's doing a good job.' (Jeanne, A1).

In the different hospitals, service users' adherence to the medical approach, and their appreciation of the psychiatrist's expertise, were the main reasons for being on good terms with them:

'He's good for me. This is a doctor who knows his job. He knows a lot about medication. I don't think there are many doctors who know it that well. And I believe that's important. His knowledge, his experience. Of course, depression is not something measurable, so it's always difficult. And I react quite strongly to medication, so that's not easy. But I think I'm doing better, and that's also because of him.' (Lena, B1).

'I have a weekly contact with the doctor. He's an intelligent man with a lot of experience. I have the feeling that he knows everything and yes, he looks at you from a medical perspective. And he

checks the medication, whether it's working well. And you can always ask him questions. He has no problem with this.' (Tom, B1).

The majority (n=13) of these service users said they asked questions when things were unclear, and situated difficulties during the treatment process, for example, in the framework of 'medical uncertainty'. These individuals could be defined as having mental health literacy (Jorm, 2000), as they possessed the necessary knowledge and skills to benefit from the care approach in order to get better. This concerns individuals who often had a higher education degree, with an occupation at the time such as entrepreneur, researcher, teacher, civil servant or economist. This positive evaluation was also identified in individuals who had low social status, but who previously had a career, such as Tom, who had been an entrepreneur, but lost everything. Notwithstanding his actual status, it appeared that the skills and value system he had originally learned and employed, shaped the construction and evaluation of his relationships with care providers at the time. This is an observation that further suggests the usefulness of a concept such as mental health literacy for research on stigma experiences in mental health care, as it becomes possible to focus on more than service users' actual social position in the study of stigma and care experiences. However, as the case of Jeanne illustrates, the extent to which this literacy appears to influence the care experience in a positive way are provider and ward specific. Nevertheless, the majority of the service users (n= 22) mostly those in Hospital A) experienced a stigmatizing relationship with the psychiatrist. They referred to situations in which they had the feeling of not being listened to and not being taken seriously by the psychiatrist. Some service users, such as Ann (A1), felt intimidated when the doctor used the technical medical framework to motivate and prescribe medication use:

'We also had a row about medication. I wanted to stop and she said no, you can't stop anymore. And then I said OK, I will take the medication. But she should explain why, what the medication is for. She just said the medication is good for your head. And then I looked up on the computer what the medication is for. And I found that it's medication against drug addiction. Why didn't she tell me? Why did she lie to me? (…) It is difficult because the doctors use these special words, and I just stop thinking about what these could mean, maybe I misunderstood, or I did understand, but decided that I didn't want to talk anymore.'

These findings reflect the idea that in sticking to the authority of the medical model and even using it as an instrument to impose medication use, a psychiatrist may induce feelings of devaluation or stigmatizing experiences in some service users. This appeared to be especially the case for people like Ann. She explained her admission and psychological problems as consequences of her status as a homeless person, and her difficult youth and marriage. In addition, she did not have the medical knowledge and capacities to understand how she might benefit from the medical approach. Her attitude towards the psychiatrist was very defensive and she clearly perceived the authoritarian attitude as a personal threat. Moreover, while communication in medical terms was experienced as a source of appreciation of their identity by people who shared the medical model with care providers, individuals who held other understandings of mental illness experienced communication in medical terms as a form of misrecognition and devaluation of their identity.

The meaning of mental health literacy

The findings show that in all wards, providers had expectations concerning service users' resources and performances, directly or indirectly based on the status characteristics of their target group. Service users were supposed to reason, speak and behave in accordance with the ward culture and the care approach of providers, in order to build a constructive relationship with them.

These expectation seemed to shape service users' experiences. Stigma was accounted for in instances where users could not meet providers' expectations. In wards with a well-defined therapeutic and diagnostic framework, such as Ward B2, the specificity of expected language use and therapeutic skills made service users (n= 6) complain that they felt they were forced to adopt the language of the ward if they wanted to stay and receive treatment. As Rik (B2) explained the necessity to define his and other users problems in accordance with the ward culture:

'Nurses said that I was hiding my drinking problems. I regularly heard nurses talking about it, but they didn't realise that I had heard it. I think it's sad that they thought about me like that. (...) I always wanted to be honest, but they were so paranoid. Yet, the day I told them that someone else had been drinking, I couldn't do anything wrong anymore.'

It appeared that individuals in this ward could only get the trust and respect they needed when they mastered the language and logic of the medical, therapeutic framework in the ward. Rik found out that when he adopted the language of the ward and acknowledged the powerful position of the care providers, his relationship with the latter changed. This concerned speaking in terms of suspicion, accusation or admitting abuse. Like Smith (2007) argued, multiple accounts concerning language issues of users point to the power differentials in care relationships and how care providers use their language as a means of symbolic power to enforce a particular view of illness and care. Several service users did not have the expected competences to build a constructive and helpful relationship with care providers. The expectation to be reflexive, both verbally and in writing, led to feelings of mistrust and frustration for service users who did not possess these capacities. As Valerie (B2) stated:

'They always ask you so many questions. What happened and why? And then I had to write it down, what happened and how I dealt with it. I had to write two pages, but me and writing, they do not go together, so…'

Or Rob (B2), who explained that he did not feel good in the ward, due to his lack of verbal competences and an assertive attitude. He said:

'I have had three talks with my nurse in the three months that I have been here. And two of the three times we did not even have a private talk. I have the feeling that the social background and the attitude of the people who enter this place, the skills people have who enter the place… if you don't have all of these… you have to be very assertive, taking the initiative and then you get what you need … maybe it's just that I am not like that. I wanted them to work in a more individual way.'

Rob clearly refers to his lack of knowledge and capacities, or literacy, which he perceived as the reason for the little attention and respect he received. He felt that specific skills such as assertiveness were a necessary condition to benefit from treatment and it seemed that he lacked the power to question the scarce attention to his case. He linked the valued competencies to a group of service users with a specific social background, to which he did not belong. In accordance with the finding that professionals' understanding of mental health problems and care is based on the health literacy of their target group, echoing the influence of social structure in

141

their approaches, service users refer to these specific systems of knowledge and the attitudes that go with it as crucial for their experience of stigma in relation to mental health care.

Discussion

In this study, we explore how the dominant understanding of mental health problems, reflected in the concept of mental health literacy (Papen, 2009), informs stigma experiences in the context of mental health care. Although this concerns a small-scale qualitative study of the stigma experiences of inpatient service users, their accounts of stigmatizing encounters with care providers offer insights into how experiences are affected by social structure. The research builds on previous work which emphasizes the link between health literacy and socio-economic status (Papen, 2009) and on research which considers the role of this status in stigma processes (e.g. Thoits, 2008).

For most service users, the understanding of their mental health problem as either a medical or a social issue, reflected their social position. In accordance with the claim of Crawford (2006) and others, socially-marginalized service users mainly explained their problems as social issues, whereas service users with a higher socioeconomic status upheld a medical explanation for their problems, and reflect the idea that ideology of medicalization mirrors middle-class resources and opportunities (Crawford, 2006).

However, the social position of service users itself was not found to determine if and how they experienced stigma during their hospitalization. Moreover, stigma experiences were influenced by the mismatch between users' understanding of illness and care, and the dominant approach in the ward. As such, this article points to the added value of a relational approach to social inequalities for research on mental health care outcomes, and more particularly for work on stigma in mental health care.

In settings with a medical model of care, frustrations about the lack of involvement and information were prominent among service users who focussed on the social stressors, like relational or economic issues for their problems. In these cases, the analysis of the medical

model as an important catalyst for the stigma process makes sense (Scheff, 1999). However, in the wards where individuals shared the medical view of their problems with, for example the psychiatrist, the users experienced these encounters as helpful and non-stigmatizing. Further, the absence of an approach that framed service users' problems as a medical issue was felt to be discrediting for most of these users. In the cases of service users with a higher socioeconomic status, ignorance about their resources, skills, knowledge and values–which are also valued in society in general–made them feel reduced to the socially-marginalized status of those who blamed society for their problems. As Pescosolido (2006) suggested, in framing their mental health care encounters in a medical framework, they confirm their middle class status or valued position in society. Accordingly, it appears that the medical approach is used by both professionals and service users as a strategy to stress their social status. It seems that the unilateral approach of the biomedical model as a source of symbolic power owned by professionals (Rogers & Pilgrim, 2011), distracts attention from the value of this model for certain individuals with mental health problems, as it appears that they draw social status from it, rather than losing it, making it a source of symbolic power for themselves.

Moreover, our analysis equally revealed the necessity to be cautiously about the naturalness of professionals adhering to a biomedical oriented care approach, as mental health providers were found to believe in different causal mechanisms with respect to mental health care. The study stresses the importance of stigma processes in professionals' struggle with their role in mental health care and the broader society. The relational approach to stigma processes in mental health care draws attention to the efforts of professionals to create or maintain their own professional identity. In the two hospitals we investigated, care providers–except for psychiatrists–held somewhat different views concerning the true nature of mental health problems and the role of mental health care. The orientation towards target groups with a particular social position seems to confirm the idea that the continuous quest for a well-defined professional identity influenced their approach to mental illness and care.

Therefore, the value of the 'correct' understanding of mental health problems, reflected in the concept mental health literacy (Jorm et al., 1997; Nutbeam, 2008), did not always appear as a precursor for satisfying and non-stigmatizing relationships. It appears that research on stigma processes in mental health care should pay attention to the strategies through which professions

negotiate their status, to social class dynamics and how these inform mental health care experiences and stigma in particular.

Rather than questioning who is using symbolic power (by means of, for instance, diagnoses) it is necessary to identify dynamics pointing to the social structures that put in place specific power relations between users and providers. The dominant focus in stigma research on the way in which illness is socially negotiated in interpersonal interactions, influenced by symbolic interactionism, has limited the attention paid to the larger normative context in which stigma experiences are given shape (Pescosolido, 2008; Scambler, 2009). Based on the findings of this article, more research that incorporates both the structural and relational dynamics of care experiences is needed, in order to further understand stigma in mental health care.

CHAPTER 10

STIGMA AS A STRUCTURAL POWER IN BELGIAN'S MENTAL HEALTH CARE REFORM: AN ETHNOGRAPHIC STUDY AMONG MENTAL HEALTH CARE PROFESSIONALS

Charlotte Sercu & Piet Bracke

The growing interest among scholars and professionals in mental health stigma is closely related to different mental health care reforms. This article explores professionals' perceptions of the de-hospitalization movement in the Belgian context, paying particular attention to the meaning of stigma. Combined participant observation and semi-structured interviews were used to both assess and contextualize the perceptions of 43 professionals. The findings suggest that stigma may function as a structural barrier to professionals' positive evaluation of de-hospitalization, depending on the framework they are working in. It is important to move beyond a unilateral understanding of the relationship between stigma and de-hospitalization in order to attain constructive health care reform.

Introduction

Care for people with mental health problems has undergone major changes since the construction of the first mental asylums in the 19th century (Fakhoury & Priebe, 2007). In particular, the second half of the 20th century was characterized by a landscape of institutional change in mental health treatment, with alterations to the definition of mental illness, treatment modalities and the structures of institutions providing care, together with transformation of the entire organization of the treatment system (Pavolka, 2007). Many countries have followed the trend of psychiatric hospital run-down, often referred to as deinstitutionalization (Rogers & Pilgrim, 1993, p126). Although it is certain that numerous developments are related to this evolution – such as advances in the medical treatment of mental illness and the identification of stress as a cause of disease – the shift toward de-hospitalization has been equally informed by the critical gaze of the anti-psychiatry movement (Cooper, 1967). This movement has expressed concern about the social control function psychiatry performs in society, and has challenged the medicalization of mental illness (Crossley, 1998). The criticism of psychiatry has been adopted as the central premise of the sociological approach to stigma by seminal authors, such as Ervin Goffman for example in his works on institutional life (1961) and stigma (1963). Moreover, the rise of mental health stigma research has to an important extent been informed by the identification of both professionals and institutional policies as stigmatizing (e.g. Cohen & Struening, 1962). Hospital treatment has been identified as a damaging enterprise, which ultimately results in a 'spoiled identity' (Goffman, 1961; 1963).

The previously dominant inpatient stays have nowadays been lessened and community mental health care facilities established, because community-based care is assumed to be intrinsically more humane, more therapeutic and more cost effective than hospital-based care (Thornicroft & Bebbington, 1989). Partly under the influence of the consumerist movement, these changes have been accompanied by a focus on the empowerment of service users. This is further reflected in the current popularity of the recovery approach, echoing the belief in the strengths of people with mental health problems as social beings, with their specific network relationships and social roles (Anthony, 1993; Pilgrim, 2008).

147

Stigma is conceptualized by Link and Phelan (2001) as the co-occurrence of labels, negative stereotypes, separation of us from them, discrimination and status loss in a context of power that allows these components to unfold. In relation to stigma, the guiding idea is that increased contact between the public and people with mental illness, due to the de-hospitalization of care, will provide an opportunity to diminish stigma and facilitate the social reintegration of people with mental illness into the community (Novella, 2010). Furthermore, the community mental health ideology scale (CMHI) of Baker, Herbert and Schulberg (1967) has become an important subscale of the Community attitudes toward the Mentally Ill scale (CAMI), the most widely used scale for the study of stigma in both the general population and (mental) health professionals (Wahl & Aroesty-Cohen, 2010). This scale was constructed by Baker and colleagues (1967) to understand and measure the new community mental health ideology, and makes it possible to differentiate between groups who are differently oriented to this ideology. An individual's degree of adherence to the community mental health ideology is accordingly understood as an indication of stigma. In line with the critical approach to psychiatry by influential stigma theorists of the 1960s, more tolerant attitudes to community mental health care are understood as less stigmatizing (Pattyn, Verhaeghe, Sercu & Bracke., 2013).

However, the unilateral approach of community care as a positive alternative to hospital care, and the belief in the community ideology as a simple indication of less stigmatizing attitudes, have also been criticized. The whole movement toward de-hospitalization, together with the described transformations in both the professional organization and the scope of mental health problems, has been interpreted as a further colonization of the social space by the psychiatric discipline. Although these changes at first glance appear in line with the anti-psychiatrist appeal for de-institutionalization, theorists such as Szasz (1970) identify the developments as a further medicalization of the abnormal. The shift in focus onto social relationships and other stressful conditions has been interpreted by critics as a means to classify anyone as having the possibility to be in need of psychiatric care. Further, although every individual should now be attentive to signs that may alert them to mental health problems, the concern exists that community care only serves the newly diagnosed and less severely ill individuals, instead of those with serious problems (Fakhoury & Priebe, 2002; Van Hecke et al., 2011). Moreover, community care is believed to prolong the differential treatment of individuals who occupy different social

positions; in the great majority of cases, middle-class patients with acute or mild disorders are those who benefit the most from the new community system (Novella, 2010).

The critics of the de-hospitalization movement from within the profession first illustrate a certain reluctance to believe in the movement. Research into professionals' attitudes and beliefs confirm that professionals do not differ notably from other people in their evaluation of community care (e.g. Lauber et al., 2004). Second, it is found that psychiatrists rate it more positively than nurses do (Prior, 1993, p.83), which indicates the need to contextualize professionals' beliefs. This concerns, for example, the relevance of their relationship to the medical psychiatric framework and how this framework is questioned or reinforced through the current movement.

Third, it appears that the proponents and opponents of the community ideology differ considerably in their approach to mental health stigma. Although the reform toward community care intuitively implies change at the organizational level, the conceptualization of stigma in the ideology concerns an individual-level approach, with a prime focus on changing stereotypes and negative beliefs through the increase of interpersonal contact, in line with the contact hypothesis (Couture & Penn, 2003). This lack of attention to the broader picture, in terms of the position and role of both mental health care and stigma, forms the main issue for the critics of the community ideology. They severely criticize ignorance of the power context in which both care and stigma processes take place (see Link & Phelan, 2001), and ignorance of the structural component in the debate on community care and stigma. This structural dimension of stigma has recently gained increased attention by sociological stigma theorists, who denounce the unilateral individual focus, stressing the essentially social nature of stigma, rooted in social structure, and the need to go beyond one-to-one stigmatizing interactions (e.g. Parker & Aggleton, 2003). Hatzenbuehler and Link (2014, p.2) define this focus as one on the "societal-level conditions, cultural norms and institutional policies that constrain the opportunities, resources and wellbeing of the stigmatized".

This article focuses on professionals' perception of the de-hospitalization movement. Rather than studying it as an indicator of stigma by professionals, the focus is on the dynamics that influence these perceptions, and on the ways these are related to stigma in the Belgian mental health care context and the broader social structure. Instead of studying stigma as an individual attitude or belief, the focus in this paper is on its role as a contextual feature in the situation of de-

hospitalization. This involves the perceptions of professionals working in different inpatient care settings, who are these days exposed to the idea of de-hospitalization.

The Belgian context

In Belgium, innovation in the mental health care sector is still on the agenda. Within this, the most comprehensive development concerns the regulation that allows psychiatric hospitals to test the organization of care circuits (programmes and services) and networks of services, which should lead to a more integrated and individualized approach to service users' problems. This is based on Article 107 of the Hospital Act of 2008 (Gerkens & Merkur, 2010), aiming at both the establishment of community care and enhancement of the integration of care (Nicaise, Dubois, & Lorant, 2014). However, efforts in terms of community-based care remain minor compared with the residential centres linked to psychiatry (Report of the Economist Intelligence Unit, 2014). In 2010, there were 38 psychiatric hospitals in Flanders, 10 in Brussels and 20 in Wallonia, with almost 177 beds per 100,000 inhabitants, whereas the European average is 61 beds. Furthermore, between 2005 and 2011, the number of beds in psychiatric hospitals actually increased (Samele, Frew, & Urquia, 2012). The number of hospital beds in general hospitals and the high consumption of psychopharmacological drugs (19.1% of the population) in Belgium also indicate the embeddedness of this de-hospitalization movement in the biomedical enterprise. In addition, the growing number of service users who are involuntary committed (Report of the Economist Intelligence Unit, 2014) is notable. Lorant and colleagues (2007) identify the high number of compulsory admissions as a function of the lack of less-restrictive alternative care settings for people with a specific diagnostic and – particularly striking – social profile. The multitude of authorities responsible for the planning and legitimization of different care settings has been indicated as a reason for the difficulty in providing a coherent mental health care policy (Vandeurzen, 2010). However, in parallel with international trends (see Priebe & Fakhoury, 2007), the relocation of resources from inpatient to outpatient care initiatives, together with the increase in compulsory admissions among individuals with limited socioeconomic resources, is in line with a general shift of focus toward those who are less severely ill and who have sufficient resources to manage their life in society (Van Hecke et al., 2011). It may equally indicate the start of a re-institutionalization movement, which seems to boost the role of psychiatry as an institution for the preservation of social order.

In this article, we discus professionals' perceptions of the de-hospitalization movement. More specifically, we analyse why professionals believe, or do not believe, in the community mental health ideology, within the debate on the role of stigma as a contextual feature in the situation of de-hospitalization. Therefore, we explore the variation in professionals' perceptions by positioning their accounts within the broader functioning of mental health care in society. The focus on the dynamics between context and personal experience makes it further possible to view professionals as social agents who employ different levels of resources, rather than categorizing them as good or bad actors.

Methodology

Case selection

This article is based on case-study research into stigma in mental health care, conducted between 2011 and 2012 in two psychiatric hospitals in the region of Ghent, Belgium. For this study, qualitative data was gathered through semi-structured interviews with service providers (n = 43), combined with participant observations (750 hours in total). Based on the specific intent to study stigma in the context of mental health care as a contextual issue, theoretical sampling was chosen as the main sampling strategy; a type of purposive sampling proposed by Glaser and Strauss (1967, p.45) in their grounded theory. We chose two hospitals with different notions of care for people with mental health problems. Hospital A adhered to a more social explanatory model in the definition of its service users, and identified the less healthy as socially marginalized and misfortunate. In Hospital B, service users were primary perceived from a diagnostic point of view and the care approach was based on the dichotomized categorization of healthy versus ill. This background was crucial to orient the hospital sample, because it is recognized that dominant processes of dichotomized categorizations are at the core of stigma processes (Link & Phelan, 2001).

At the time we designed our methodology, a significant proportion of the users in Hospital A had multiple psychiatric problems, were homeless or faced juridical procedures. This setting had a

high prevalence of long-term inpatient care. Hospital B focused on the treatment of people with acute mental health problems, and served as an institution providing primarily short-term care. Both were relatively small (190 beds per hospital). Furthermore, professionals identified the match between their view of mental illness and care and the general care approach of the hospital as crucial to their motivation to work in the hospital. Therefore, the choice of hospitals with a different approach to service users (as mentioned above) and a different organization of care, also implies professionals who differ in their understanding of mental health problems and proper care for people with these issues. We selected two treatment wards in each hospital as the specific units for observation. This involves one ward for people diagnosed with mood disorder in each hospital: ward A1 (20 beds) and ward B1 (24 beds). Ward A2 (15 beds) was for those dealing with a combination of psychosis and substance abuse, and ward B2 (24 beds) for people with problems related solely to substance abuse.

Data collection

After approval from the Ethics Committee of Ghent University Hospital and both hospitals, one of the authors, who is a sociologist, conducted semi-structured interviews and intensive participant observation (Tedlock, 2005). To ease the socialization process, each ward and the people treated in it, was visited before starting the observations. All participants were personally informed about the goals and methods of the research and they received a prospectus. Observations were only carried out once all the service users and professionals had agreed to the researcher's presence. During the fieldwork, the main fieldworker chose to take the role of 'participant as observer' (Gold, 1958), which implies that both field worker and informant are aware of their role, yet the field worker develops relationships with informants, through which any unease and initial negative reactions to the presence of the fieldworker are likely to disappear over time. Observations took place mainly during team meetings, therapeutic activities and at meal times. During idle periods, time was taken to approach staff through informal conversations, cautiously examining the organization of care, and stigma and identity conceptions. This period of observation was further necessary, as the fieldworker was trained as a sociologist and needed time to try to uncover the unspoken logic that shaped the clinical reality of each ward. However, the researcher's training also made it possible to reflect on this clinical logic from a different perspective than that of trained professionals, which enriched the data

gathering process. When field notes became increasingly repetitive after about 200 hours of observations, the research in a ward was concluded.

Throughout the observation period, we also conducted semi-structured interviews (Fontana & Frey, 2005) with care providers once they became familiar with the ongoing observations. This helped us to challenge and critically revise the findings arising from the observations. Individual interviews were undertaken with all professionals, comprising 33 nurses, 3 psychiatrists, 4 psychologists and 3 social workers. These interviews lasted between thirty minutes and one hour, and were recorded then transcribed. Professionals were asked to respond to questions such as: 'How would you describe your job?', 'How would you describe the problems individuals are dealing with in the ward?' and 'How do you perceive the current efforts to develop community care by means of Article 107?'

Data analysis

Once the saturation point had been reached, the data gathered in fieldwork notebooks, together with the corpus of the interviews, was systematized using Nvivo CAQDAS. Data analysis was carried out in line with the general coding processes formulated by grounded theory and structured using a constructivist grounded theory approach (Charmaz, 2005; Mills, Bonner, & Francis, 2006). This method adopts the general guidelines of grounded theory, but does not subscribe to the objectivist, positivist assumptions of the theory, referring to the discovery of data or theories (Sage Handbook, 2011, p.509). Nevertheless, this constructivist version stresses that data is the result of a co-construction between the researcher and participant – or more generally between the researcher and the research field – influenced by their values, positions, interactions, etc. The approach stresses the studied phenomenon and not primarily the methods. In the current research, this refers to the focus on the empirical realities in which perceptions and beliefs regarding community care and stigma evolve. Through this approach, the researcher is positioned as the author of a reconstruction of perceptions, experiences and meaning, uncovering the implicit values and beliefs that have a meaningful implication to that end (Charmaz, 2008). Furthermore, this approach allows the researcher to gain awareness of the ways professionals' perceptions and value systems are framed by the context of care and society at large. Data analysis was based on open coding (Strauss & Corbin, 1990), applied during and after each period of data collection in each ward. This involves a form of thematic coding, from which the

emerging topics were further explored and evaluated during fieldwork. In addition, memos were written, which helped to identify some patterns in the data. Throughout the data gathering process, codes were adapted and readjusted (Patton, 1999). These general explanations and themes were used as initial, provisory categories for the actual data analysis.

The following section draws on the accounts of care providers, in order to clarify their perceptions of the community ideology and stigma. We work with interview extracts that exemplify the perceptions. All the names of participants have been changed and any information that could potentially lead to their identification has been removed.

Results

Close analysis shows that most professionals believe the current discussion on de-hospitalization and the strengthening of community care is a good thing. They believe it is a necessity to focus on the outside world when discussing the modalities of mental health care. However, when looking more closely at the accounts of most professionals, these somehow reflect a dichotomy about the system reform.

Asterie: I think it can be positive for people to return more quickly to their normal environment, but I am also a little scared. Everyone has their own limitations. If I can detect something over the years, it is the tendency to force, the reduced respect when hospitalization time diminishes. But anyway, I think it can be a good system […] And maybe a depressive disorder is a diagnostic profile that does not need this de-hospitalization. One of the interventions for people with serious depression is their removal from home, which opposes the idea of de-hospitalization.

Ines: How many broken people will end up on the street because they are no longer welcome in psychiatry? There is a demand for aid, for a bed, for shelter, for some safety, whatever that could be […] and I totally agree that people have to be back in society, but I think there is not enough supply in society to take care of everybody […] I think many people will be excluded. Where is

the safety net for them? But the shortening of hospitalization is a good thing, telling people that their hospitalization is temporary.

As the accounts by these nurses illustrate, most professionals' positive evaluation of the de-hospitalization movement appears primarily related to the idea that people should not lose connection with their home environment and the functioning of society in general. Accordingly, their positive approach is line with the general argument of the initial critics of psychiatry who designated the institution as a place of alienation or disculturation, in which a long stay may lead to the loss of the capabilities to manage certain aspects of daily life (Goffman, 1961, p.23).

However, contrary to the perception of the movement as a menace to the psychiatric enterprise through the subversion of the territorial basis for psychiatry, the professionals – those with a more medical background such as psychiatrists and equally those working in a medical framework – do not seem to consider this de-hospitalization as being disruptive to their professional expertise or authority. At first glance, it appears that belief in the value of community care does not imply opposition to the usefulness of the psychiatric viewpoint, together with its institutional framework. This observation opposes the understanding of stigma theorists who suggest that adherence to the community ideology stands against belief in the psychiatric enterprise. However, professionals' positive evaluation of the movement are clearly accompanied by critical and crucial remarks concerning the feasibility of de-hospitalization.

Critical remarks

Throughout the analysis of these sceptical accounts, it became clear that two general arguments can be identified for reluctance about de-hospitalization. On the one hand this concerns issues related to the diagnostic characteristics of service users, and on the other hand, involves a negative evaluation of society's social structure and general attitude to people with mental health problems.

Diagnostic misfit

Different professionals, including psychiatrists, psychologists and nurses, supported the community ideology, but remarked that 'their' diagnostic target group did not fit the approach, referring primarily to people suffering from mood-related disorders.

Chiel: Depressive disorder is a diagnostic profile that is less in need of community care. If people are depressed, it is sometimes crucial to have some distance from the home environment, where they are confronted daily with the fact that they cannot make progress. They wake up and see the dishes they couldn't do, they can't run the home, they can't work anymore. When people are confronted with this day after day, they become suicidal. So one of the interventions for people with major depressive disorder is their removal from the home environment, which is at odds with de-hospitalization.

Nelle: I absolutely believe in the idea of de-hospitalization. But I don't see it [as suitable] for the target group I am working with. I think that for people with depression, the acute phase cannot be treated at home. When people are suicidal. I think you put huge pressure on the family life. This concerns people who really need residential treatment. And depression lasts a lot longer than for instance a psychotic episode, which may clear up more quickly with medication and counselling.

Miriam: It is also related to the fact that people with double diagnosis have difficulties completing the trajectory in community centres, sheltered housing initiatives or job counselling. It is more difficult than for someone with, for instance, depressive problems due to relational difficulties.

These professionals' evaluation of the feasibility of community care is clearly founded within the medical framework. Professionals specifically point to diagnostic characteristics, symptoms and prognoses that are incompatible with the organization of community care for this group of users. Accordingly, it appears that most people who expressed their hesitation with regard to the applicability of the community ideology for different diagnostic target groups, approached health, illness and care from a more medical viewpoint. Therefore, professionals to some extent confirm the fit between the medical approach to mental illness and the value of inpatient institutional psychiatric care, by stressing the necessity of inpatient settings for people with specific diagnostic profiles. At first sight, community care is thus viewed as an insufficient alternative to the appropriate inpatient medical approach for people with serious mental health problems. The observed reluctance of these professionals is therefore in line with the dominant idea that the build-up of mental health care in the community threatens the medical psychiatric conceptualizations of mental illness and care.

156

However, when looking in detail, the professionals did not seem to experience the movement as a threat to their professional identity. Instead, they interpreted its usefulness from a medical point of view and stressed their belief that community care would not fulfil the needs of individuals with a specific diagnostic profile, although they believed in its usefulness for people with different diagnostic profiles. They did not identify de-hospitalization as a threat to the psychiatric model, which may indicate that for these professionals, community care does not stand for a mere run-down of the psychiatric model in mental health care.

Need for structural changes

Different professionals also expressed some criticism of the community mental health ideology for not offering an alternative approach to the medical view of care. Rather than offering a more socially-embedded approach to mental health work, the narrow transfer from hospital beds to community alternatives, together with the shortening of inpatient stays, was believed to increase exclusion and discrimination instead of diminishing it. For these professionals, who generally stressed and focused on the social dimension of mental health care, the lack of attention to structural changes in society that should accompany institutional transformations, led to distrust and disbelief in the community project. As nurse Ringo expressed:

Ringo: What do you have to do with a society that does not want to support it [real community care], with its neoliberal backbone? What will you do about it? Like the sheltered living arrangements. They say that is community care, but it concerns islands of people who do not fit into the system. […] It concerns pseudo-community care, in which people do not obtain access to social life, from which they are excluded by the structure. Not by those people who try, but by the structure.

His account exemplifies the belief of different professionals that the current efforts to introduce community care are hypocritical, as no fundamental change has taken place in society that could lead to the acceptance and integration of people with mental health problems, or to reducing the stigma. Furthermore, several professionals identified this hypocrisy through the observation that one type of institutionalization of care is simply replaced by another, rather than being replaced by collaboration with the community. As Nicola stated:

I believe it is a fact that many people stayed too long in this place and that something had to happen. But I also believe that more people will miss the boat, people who really need a psychiatric bed, and who no longer have that opportunity. It is already so disintegrated. Where can they go? And when you look at what happens, you see that new small institutions or group practices have come into existence, which try to give people a place, which in essence comes down to the same institutionalization.

Professional accounts such as that of Nicola are in line with the argument that a new area of institutionalization has begun, among other things characterized by a rising number of places in supported housing initiatives. In line with the account of the professionals, Priebe and colleagues (2005) suggest that this tendency may be interpreted as an outcome of a general ideology, which highly values risk containment in 21st century Europe. Initiatives such as sheltered housing are seen as an excuse to impose a particular policy, disconnected from the needs of most people with mental health problems. Or as Marjon, who was questioning the demand-driven character of the community ideology, stated:

I wonder if it will not be too interfering. […] I think most people don't like it when other people come into their home. The thing many psychiatric service users suffer from is loneliness and it is difficult to change that, because everything is expensive and they do not have much money, which makes it difficult.

In addition to her appeal for attention to the other functions of inpatient psychiatry apart from psychiatric treatment – such as the importance of peer contacts and support to break through their isolation or to increase their self-esteem (see also Verhaeghe, Bracke, & Bruynooghe, 2008) – she stressed the lack of attention paid to service users' demands and experiences. This involves the accounts of professionals, which resemble the statements of anti-psychiatrists who describe community care as a further colonization of the social space by the dominant paradigm. Although the professionals do not explicitly refer to the psychiatric view as the evildoer, they accuse the initiators of a lack of a more encompassing approach to mental health care, for which structural measures outside the strict medical realm are of central importance.

This lack of attention to structural social measures essentially comes down to blaming policymakers for their lack of attention to the structural backbone of stigma in society. As Ines stated:

Ines: How many damaged people will be on the street, because they can no longer come to psychiatry? There is a demand for health care, a demand for a bed, for shelter, for safety, whatever this could be. [...] Like Paul said: "If I break my arm or leg, I can tell the outside world about it, I can take a period of sick leave, but what can I tell the outside world now?" It is difficult. It is not just about in here, it is about the outside world.

In referring to the outside world, professionals such as Ines perceive inpatient care as a necessary alternative for what is lacking in society due to structural stigma. The lack of opportunities offered to, and respect for, people with mental health problems, makes inpatient care a necessary substitute for external support and care.

Structural stigma

When referring to structural stigma in relation to community care initiatives, the accounts of most professionals are related to the lack of socioeconomic opportunities for people with mental health problems, and more particularly their housing and job opportunities:

Mario: It has to do with a societal phenomenon and problem. We feel that people are ready, but when there is no house […] we had fake students for a shile, who could live in a student room for some time, but that was a problem too, living together with students. But on the housing market it is very difficult. […] And before, there was an employment agency, Instant A, where you could go with people from here, and those people searched and found work. Today it no longer exists. You are forced to lie. […] I do not support the idea that everyone has to return into society, because it is not the ideal place.

Marleen: Society has to be ready for it [community care]. It is very difficult for people to be part of a normal sports club. It's not easy. And working? Employers are very reluctant toward people who have been mentally ill for a long time.

These experiences of professionals show how the loss of life opportunities related to employment and comfortable and safe housing are still a central concern for people with serious

mental health problems and for service providers working with them (e.g. Farina & Felner, 1973; Page, 1977). It was especially through encountering service users who were homeless and unemployed that several professionals were confronted with the ignorance of the social dimension of the community ideology. Similar to the critics of the movement, they identified a lack of attention to structural barriers, which only increases the inequality between those people with few socioeconomic resources and those who live under better circumstances.

It appears that although supporters of the community ideology consider community care as a catalyst for the reduction of stigma, motivated by the contact hypothesis, professionals who work with service users on a daily basis are confronted with this stigma as an insurmountable obstacle. They are inhibited in their belief in community care due to regularly dealing with the difficulties of redirecting service users to a life in society. This observation may form an explanation for Baker, Herbert and Schulberg's (1967) finding that the professionals who are most strongly oriented toward community mental health are those who are less involved in direct patient treatment, working primarily in administration, teaching or community consultation. It therefore seems that there is a duality in professionals' accounts about the community ideology. On the one hand, both factions support the idea that the current mental health care system needs to undergo a fundamental reform. On the other hand, their confrontation with structural stigma and more generally the structural barriers to make this reform successful, mean that professionals hold a more critical stance concerning the implementation of the community ideology.

Discussion

Beliefs and perceptions regarding community care have been integrated into most studies on stigma in both the general population (e.g. Pattyn, Verhaeghe, Sercu, & Bracke, 2014) and (mental) health professionals (e.g. Wahl & Aroesty-Cohen, 2010) by means of the community mental health ideology scale (Baker et al., 1967). In relation to stigma, this scale allows researchers to distinguish between groups that are differently oriented toward this ideology, and it has been used and accepted as an indicator of stigma. In line with influential stigma theorists,

tolerance of community mental health initiatives and the renouncement of inpatient care are understood as less stigmatizing (e.g. Pattyn et al., 2013).

The current study builds on existing literature by analysing and discussing professionals' perceptions of the community ideology, within the debate on the role of stigma in the situation of de-hospitalization. Because of the particular nature of stigma as a multidimensional concept (e.g. Pescosolido et al., 2008), focusing on the dynamics between context and personal experience may help us to understand how stigma acquires meaning in the context of de-hospitalization. Accordingly, we analysed the perceptions and beliefs of professionals about the community ideology, and how stigma could inform this process. The key question in this discussion is: How does stigma interfere with professionals' perceptions of de-hospitalization?

Studies show that professionals' attitudes and beliefs toward community care do not differ considerably from those of the general population and in some cases are actually more negative (Schulze, 2007). Although this negative stance toward community care has been cited as an indication of stigma, previous research has never explicitly pointed to the context in which these perceptions and beliefs are given shape. In the present analysis, the understanding of professionals seems to be profoundly connected to both the framework in which they work and – depending on this framework – to the continuing existence of structural stigma in society.

The analysis in this study confirms the absence of explicit positive beliefs and attitudes among health care professionals. However, all the professionals exhibit an equivocal viewpoint, in which they attribute both positive and negative characteristics and consequences to the community perspective. This implies that their appreciation of inpatient care does not necessarily oppose the usefulness of community care. In line with the general argument of the community ideology, all professionals hold the idea that individuals should not lose connection with their home environment and the functioning of society in general, as this could lead to the loss of skills necessary to manage daily life outside the ward. Accordingly, all the professionals generally follow the argument of adherents to the community ideology, stressing the idea that community care is necessary to facilitate social integration.

Although the community ideology presumes a degree of openness and tolerance in society in order to reach the goal of social integration, it equally presents the community role as a catalyst

in the struggle for a more tolerant and inclusive society with regard to people with mental health problems. This theoretically-driven incentive, based on the contact hypothesis (Courture & Penn, 2003), is identified by a proportion of the professionals as somewhat hypocritical, as structural changes in society are an absolute precondition in their view to make the community a success story rather than a hoped-for consequence.

For these professionals, who primarily focus on the social dimensions of mental illness and care, the unilateral rundown of hospital beds and their replacement by community initiatives such as sheltered housing or homecare, are believed to increase the exclusion of and discrimination against people with mental health problems. They denounce the lack of social embeddedness of the whole movement. These professionals therefore share the concern of critics of the community ideology, that it will prolong and reinforce the differential treatment of individuals with different social positions. Furthermore, this group of professionals perceive stigma primarily as a structural barrier and a condition to overcome, rather than an aggregate of individual attitudes in the population, as supposed by those who base their adherence to the community ideology on the contact hypotheses as a means to challenge and change individual stigmatizing attitudes and beliefs. Accordingly, they confirm the concern of stigma theorists such as Parker and Aggleton (2003), that stigma is approached in a much too individualistic way to capture its impact and to develop ways to reduce it.

This study provides new insights about the necessity of contextualizing the beliefs and behaviours of professionals. It subscribes to the suggestion of Link and Phelan (2014) to approach population attitudes as a proxy for structural issues. The explicit reference to these stigmatizing structures as a frame of reference for experiences has previously seldom been integrated in empirical work, although most service users and professionals are clearly confronted with this structural component of stigma. It seems necessary to integrate this component of stigma into work on community care if policymakers want to enforce organizational reform aiming for the proper establishment and protection of all citizens with mental health problems (Pilgrim & Rogers, 2005b).

The identified lack of attention paid to structural stigma as a barrier to effective community care by professionals may be related to the general positive connotation of community in (sociological) work on stigma. As this essentially refers to natural human relationships, founded

162

on co-operation and commitment, unfavourable features of community are rarely highlighted and communities are always seen as resources (Prior, 1993, p.169). In its definition as opposed to inpatient care (Prior, 1993, p.169) – in which people's user identity and everyday life are both dominated by the 'illness' – the community ideology reconstructs the institutionalized and disempowered service user as an independent consumer (Prior, p177). However, the current study illustrates the importance of a more nuanced image of community care, in which the community should be approached as more than a resource, and equally as a context for care, which incorporates particular barriers such as structural stigma.

Furthermore, this study provides new insights into the relevance of the professional framework for care providers' perceptions of community care and their relationship to stigma. In analogy with previous work on the importance of professionals' relationship with the framework for their stigma perceptions (Sercu, Ayala, & Bracke, 2014), it appears that the link between stigma and their perception of community care is related to their relationship with the medical psychiatric framework. Care providers who primarily work from a medical, diagnostic frame of reference, rarely identify the community ideology as hypocritical, as they do not focus on the inherent contradiction between the supposed openness of society and the structural stigma it incorporates. They are equally equivocal regarding the community ideology, but clearly frame their doubts within the medical framework. The misfit between particular clinical pictures and the community alternatives, such as homecare or sheltered housing, inform their doubt about the feasibility of the community model. Accordingly, stigma – and more particularly, structural stigmatizing features – in society do not seem to inform their perception of community care. By contrast, as discussed in the previous paragraphs, for those professionals who hold a more social point of view, structural stigma in society is presented as an essential barrier to overcome before they can truly believe in the community role.

Although population research makes the 'evident' decision to compare different professions, resulting for instance in the finding that psychiatrists' evaluation of community care appears to be more positive than nurses' evaluation (e.g. Prior, 1993, p.83), this study illustrates the need to contextualize these differences in order to make them meaningful. The research incorporates a broad range of professionals, from social workers to psychiatrists, and it appears that

professionals' link with the medical framework, or their socialization in a particular professional setting, seems to be more influential than their professional status as such.

In an area of deinstitutionalization, this study of professional perceptions illustrates why stigma should be approached as a multidimensional concept. The unilateral approach of stigmatizing attitudes and beliefs on which the link between stigma and community care is primarily based, misses the huge impact of structural stigma on professionals' beliefs and practices concerning community care. The observation that the relevance of different stigma components in the discussion depends on the frame of reference of professionals, further stresses the need for a contextual approach.

Although this study is limited to the accounts and perceptions of professionals in two psychiatric hospitals, it may bring fresh insights into the meanings of stigma in the context of de-hospitalization, in particular the relevance of structural stigma (see Hatzenbuehler & Link, 2014) and the meaning of stances toward the community ideology as an indication of stigma in population research. Our research may thus illuminate future exploration of a better understanding of stigma, both for population research and for a mental health sector in transition. Finally, the choice to study in a hospital context the perceptions of professionals about community care may at first glance seem contradictory. However, the remaining power of psychiatric hospitals in both the provision and the organization of mental health care in Belgium (Nicaise, Dubois, & Lorant, 2014), makes it necessary to include their approaches and positions in work on de-hospitalization. Furthermore, as Scull (1989, p.302) states, no discussion about community care can occur without major attention being paid to psychiatric hospitals, as these were initially built for the provision of care in a community setting. A statement that confirms the necessity to overcome the duality between institutional and community life in discussions on de-hospitalization.

CHAPTER 11

CONCLUSION AND DISCUSSION

Introduction: general background and research aims

International literature about mental health stigma shows that increasing attention is being paid to the effects of formal, specialized mental health treatment on the development of stigma processes (Schulze, 2007). Currently, this work is characterized by two dominant fields of interest. First, building on the original work of symbolic interactionists – and more particularly labelling theorists – concerning the detrimental role of formal treatment (e.g. Scheff, 1966), there is growing interest in the stigma experiences of service users (e.g. Schulze & Angermeyer, 2003; Wahl, 1999). Second, research into the roles of professionals in these stigma processes is booming. This research mostly involves population studies, in which different (non-)professional populations are compared with regard to their stigmatizing attitudes, primarily building on an implicit social psychological conceptualization of mental health stigma (e.g. Hugo, 2001) . Although the role of mental health care organizations and providers in relation to stigma is recognized as complex, the primary focus lies on their stigmatizing potential. Through the influence of the consumerist movement and the shift towards community care, both service-user research and comparative research on provider populations mainly focus on the capacity of mental health treatment to be harmful.

Following this renewed interest, however, little attention has been paid to the theoretical underpinnings of the stigma concept. As Link and Phelan (2001) state, empirical work on stigma has a decidedly individualistic focus, informed by the practical advantages of both comparative survey research and the social psychological approach in the research field. Although stigma was initially conceptualized as a language of relationships, not attributes (Goffman, 1963, p.3), current research into stigma and mental health care frequently transforms stigma into individual beliefs and experiences. However, before stigma – as one of the chief enemies in the provision of proper care – can be tackled effectively, it is necessary to move beyond this narrow

individualistic focus and to consider what stigma means in relation to mental health care (Henderson et al., 2014).

To date, ethnographic work on stigma in mental health care has been relatively rare, due to the difficulty researchers experience in obtaining access to care settings and the people being treated in them. Having been granted permission by the relevant ethical committees, I was able to carry out my research in two settings, working with professionals and service users. Through my ethnographic work, it was possible to incorporate the different relationships through which stigma is formed and becomes meaningful in the context of mental health care, allowing me to move beyond the criticized individual conceptualization of stigma. This study is further unique in its focus on the structural antecedents of stigma, such as social roles, social positions, institutions and cultural knowledge systems, and their systemic relationships in the context of mental health care (Bonnington & Rose, 2014). In this last chapter of my thesis, I provide an overview of the main findings of my study, followed by some suggestions for further research. I conclude with a discussion of the implications of my work for policymakers, mental health professionals and sociologists working on (mental) health related issues.

Main findings and theoretical conclusions

It is not my aim in this work to reach a full answer to the question of what stigma means in relation to different mental health care processes. When discussing 'stigma in mental health care', the focus is on two core elements that are of crucial importance. The first concerns the relational nature of the concept, in which regard Goffman (1963) refers to the 'language of relationships' as the essence of stigma. Second, and evolving out of its relational nature, is the necessity to approach stigma as a situated concept, defined by the context through which it is given shape. The choice to carry out ethnographic research in inpatient care settings – working with users and providers – led to a basic focus on the meanings of stigma in the relationship between user and provider, and on the way in which the care context informs the significance and structure of these relationships. On a theoretical level, approaching stigma as a situated, relational concept directed my attention towards the significance of its different structural

166

antecedents. This appears relevant in the context of mental health care. Furthermore, this viewpoint made it both possible and necessary to go beyond the duality between sociology and psychiatry.

General findings

Researchers contend that stigma can only be understood when the institutions through which it operates are well characterized, the history of their relationship with the stigmatized group understood, the policies of the institutions examined and the attitudes of the leaders explored (Link et al., 2004; 2014). Methodologically, the call by these researchers for the context to be incorporated in work on stigma is addressed in my work through the specificity of the sampling procedure. The theoretical sampling procedure, in which the different levels for analysis – here, the hospitals and wards – were determined, started off from the finding that the particularity of care contexts, with their specific service organization and health policy, affects stigma experiences (Flanagan et al., 2009; Lee et al., 2006; Verhaeghe & Bracke, 2008). For my research, the procedure involved a selection based on the dominant notions of care for people with mental health problems in the different settings, which were characterized by a primarily social or medical and therapeutic approach.

In my analysis, I began from the finding that several users and professionals perceived and/or experienced stigma during the time I was carrying out the fieldwork, whereas others did not. In exploring why and how these variations exist, the findings here suggest that stigma is indeed essentially a social dialectic of interpretation, informed by structural forces (Yang et al., 2007). The third empirical study included in the thesis, suggests that stigma experiences are a result of the differences in power between provider and service user, in combination with the stance of both parties vis-à-vis expert knowledge, relating to a primarily medical approach (Pearlin, Avison, & Fazio, 2007). In line with work on the association between socioeconomic status and mental health problems – which uses social stratification measurements such as education or literacy for the study of mental health outcomes (Muntaner et al. 2013) – for most service users, the understanding of their mental health problem as either a medical or a social issue, reflects their socioeconomic position. The role of social structure is therefore reflected in the finding that the culturally-dominant medical ideology seems to be owned by the middle class, whereas

people with limited social and economic resources hold less-beneficial beliefs in the context of mental health care (e.g. Francis, 2012). As Pescosolido (2006) an Crawford (2006) argue, the key to the success of the medical ideology lies in the network relationships of a growing middle class, with shared cultural values regarding science, education and progress. Like Thoits (2008) suggests in her evaluation of the differential labelling theory, it is possible that this effect of structural inequalities remains hidden, as two counterbalancing processes may occur: the inability of individuals with lower resources to avoid unwanted labelling and treatment, and the ability of the more privileged to have better access to mental health services.

The socioeconomic position of service users, however, has not been found to determine if and how they experience stigma during hospitalization. This appears to be related to the (mis)match between the understanding of users and that of professionals regarding mental health problems and care. The approach of professionals to mental health problems and care differed between wards and even more so between hospitals. The particular orientation of professionals appeared to be influenced by the culture and structure of the ward and hospital, as many professionals said they would never be able to work in a different hospital. Whether they adhered to the medical or 'illness' model, identified as the dominant ideology, appeared to depend on the role of this framework in the hospital culture. Furthermore, the level of formalization of care relationships seemed to influence the extent to which mental illness stigma, and more generally the marginalization of people with mental health problems in society, affected their role perception.

Therefore, users who adhered to a social explanatory model felt that their problem was recognized, through the experience of their relationship with care providers who perceived the situation from a similar viewpoint. These findings support (structural) symbolic interactionists (Goffman, 1963; Stryker & Burke, 2000) in their argument that stigma, as a social identity issue, should be approached from a relational perspective, because it appears to be the situated relationship between user and provider that influences their experiences. However, although the medical approach can be perceived as a source of stigma, the argument based on labelling theory (Scheff, 1966) does not hold in instances where the user and provider are like-minded regarding the value of the approach. In these instances, critique of the labelling theory – which stresses the treatment benefits of the illness approach (e.g. Gove, 1970; 1975) – seems to fit the observations. Accordingly, the findings suggest that both arguments are valuable for a better understanding of

care relationships, informed by the framework of the (perceived) social position of users and providers that gives meaning to their role.

The findings therefore support the suggestion of theorists such as Hatzenbuehler and Link (2014) that stigma research should be given a structural focus. The results of the fourth study should also be considered in this regard. Community mental health initiatives have been understood as offering an opportunity to diminish stigma and facilitate the reintegration of people with mental health problems into the community (Novella, 2010). Furthermore, the community mental health ideology scale (CMHI) of Baker, Herbert and Schulberg (1967) has become an important subscale of the Community Attitudes Toward the Mentally Ill scale (CAMI) which is the most widely used for the study of stigma in both the general population and (mental) health professionals (Wahl & Aroesty-Cohen, 2010). This is in addition to other scales, such as Authoritarianism, Benevolence and Social Restrictiveness scale (Link et al., 2004). An individual's degree of adherence to the community mental health ideology is accordingly understood as an indication of stigma, defined as a score on the 'not in my backyard' attitude (Taylor & Dear, 1981). The findings therefore suggest the need to study the evaluation of this community ideology as a contextual issue, which takes into account the broader policy structures and cultural stereotypes with regard to mental health problems. It appears that a specific proportion of the professionals – those who held a more critical stance towards the community – to some extent identified the broader society, with its particular ideology, as one of the prime sources of stigma. They perceived their work in the hospital as a way of somehow distancing themselves from this dominant ideology, and were able to offer people the alternative they needed.

The findings further support the suggestion of Scambler (2006) to study stigma in context, through a focus on structural antecedents such as users' social roles (Bonnington & Rose, 2014). This is illustrated in the second empirical paper where people's decision to seek help seems to be related to the status of other role identities, such as being a mother, husband or employee. Respondents' accounts of anticipated negative reactions and the reluctance to seek care were partly explained by referring to the modified labelling theory (Link et al., 1989), which states that individuals with mental health problems are aware of existing stereotypes in society and adjust their behaviour accordingly (e.g. Corrigan, Markowitz, & Watson, 2004). However, in

line with Pescosolido and Perry (2012), it appears crucial to look at individuals, their social positions and the roles they hold, in order to gain a better understanding of the mechanisms of blame and shame in relation to their eventual admission. For the participants in this research, the particularity of their social role perceptions was crucial in their help-seeking trajectory. The loss of these roles was a pivotal starting point for several individuals' help-seeking trajectory, whereas others with previous care experiences and differing role expectations – for example, a demanding work or mother role – perceived their admission as an opportunity to distance themselves from these situations in an effort to concentrate on their mental health problems. Therefore, the function of social roles and positions seems crucial to understanding how the social meanings of mental health problems and care affect help-seeking trajectories.

Theoretical conclusions

With regard to research into stigma and mental health care, this study illustrates the added value of a relational approach. Starting from this relational viewpoint at the micro level, informed by the symbolic interactionist approach of Goffman, it became possible to gain understanding of the structural antecedents of interactions, including the meaning of the social positions and cultural knowledge systems of providers and users. Flanagan and colleagues (2009) and Lee and colleagues (2006) illustrate in their research that adopting a multilevel approach – in which structural, contextual features and interpersonal processes are both taken into account – can help to address the complex position of mental health professionals in relation to stigma. This focus on the norms that frame relationships in mental health care makes it possible to capture the complex ways in which stigma works to the disadvantage of those affected by it.

This involves the finding that perceptions of stigma for both users and providers are always related to their perceived social identity. This not only confirms the basic premise of symbolic interactionism – that all meaning lies in relationships (Charmaz & Belgrave, 2013) – but also further stresses the need to study stigma as a contextual issue, because people's relationships with different frameworks of care at multiple levels inform their perceptions and expectations.

Stigma and social structures

This thesis emphasizes the need to conceptualize and measure stigma as a social phenomenon, with its roots in social structures. Here, this primarily refers to the way socioeconomic positions are structured and linked to different cultural understandings of mental health problems and care. In line with the many theoretical efforts to stress and capture the multidimensionality of stigma (e.g. Pescosolido, 2008), this structural dimension has recently attracted the attention of sociological stigma theorists. They denounce the unilateral individual focus, stressing the need to go beyond one-to-one stigmatizing interactions (e.g. Parker & Aggleton, 2003). Hatzenbuehler and Link (2014, p.2) define this focus as one on the "societal-level conditions, cultural norms and institutional policies that constrain the opportunities, resources and wellbeing of the stigmatized". In empirical work, the incorporation of this structural aspect is often achieved by the integration of an additional level of stigmatizing institutions. However, in the context of mental health care, these structural factors have never been linked to concrete stigma perceptions. It nevertheless appears that in relation to stigma, paying particular attention to the relationships between the social roles and positions of professionals as well as service users makes it possible to study and capture the multidimensionality in mental health care. It seems that the use of concepts such as mental health literacy – referring to the personal resources of individuals that aid the correct recognition and management of mental health problems (Jorm et al., 1997; 2000; Lauber et al., 2003) – can be beneficial. Although literacy has been identified as solely a 'personal asset', I follow Nutbeam (2008) among others (Baker, 2006; Papen, 2009) in the suggestion that the added value of mental health literacy lies in its framing as a contextual, relational issue rather than a personal asset. In work on stigma, this makes it possible to incorporate the specific context and social structures through which interactions occur and services are organized and delivered, paying attention to the cultural, normative context for stigma perceptions in mental health care (Smith, 2007).

Other issues have been investigated, such as the 'evident' decision to compare different professions, resulting for example in the finding that psychiatrists appear to be more positive than nurses in their evaluation of community care (e.g. Prior, 1993, p.83) . I have specifically illustrated the need to contextualize these inter-professional differences in order to make them meaningful. My research subjects include a wide range of professionals , from social workers to

171

psychiatrists, and it appears that with regard to stigma, professionals' perception of their role in the medical psychiatric framework, as well as in the broader society, seems to be more influential than their professional status itself. Nurses primarily working from a medical, diagnostic frame of reference, rarely assessed the community ideology as hypocritical, as they did not focus on the inherent contradiction between the supposed openness of society and the structural stigma it incorporates. Nurses with a more critical stance towards this medical approach primarily defined their role in relation to the broader societal dynamics and structures, in caring for those who are marginalized in society. Based on their frames of meaning, these professionals saw structural stigmatizing features in society as an essential barrier to overcome. Therefore, my research strongly underlines the call by Link and colleagues (2001; 2004) for contextualization in work on mental illness stigma.

Going beyond the duality between psychiatry and sociology

Notwithstanding the explicit attention paid to the ways in which face-to-face interactions are reflective of structural factors (such as socioeconomic position), in work on stigma the question remains of how to go beyond the duality between constructivist conceptions of mental health problems and psychiatric notions. As Becker (1967) states, in the discussion about interdisciplinary issues such as mental health stigma, it is only possible to take a constructive position by acknowledging and respecting the dominant framework through which knowledge and relationships are produced. As a sociologist, it was therefore necessary for me to go beyond the false dichotomy of mental health problems as being either a human construct or an independent reality, in order to study stigma in mental health care in a meaningful way (Estroff & Weinberg, 2005).

Accordingly, my choice to carry out ethnographic work in a context dominated by the psychiatric framework made it necessary to transcend the combative approach to psychiatry in sociological work on stigma, as it required an open and respectful attitude to the settings. Furthermore, this initial intention was soon augmented by a firm appreciation of the professionals' dedication to helping and supporting individuals with mental health problems. Rather than approaching the framework they were working in as being either harmful or benign, the focus was on how it informed their role perception and on the ways stigma became meaningful in this framework. Accordingly, by incorporating and acknowledging the psychiatric

172

model as the guiding framework in mental health care, I hope to go beyond the discussion about its either stigmatizing or helpful nature, instead questioning why and how its relationship with stigma is so complex.

Through the different empirical studies, it became apparent that the effort I expended with regard to contextualization helped me to reach a more nuanced view . Both the premise of the (modified) labelling theory – that labelling as a normative act triggers stigmatizing reactions and may sustain sick roles – and the focus of social psychological work on the harmful patterns of everyday cognition, appear to add fundamental value to the study of stigma in mental health care. More specifically, the study of stigma as a function of group dynamics (involving membership of a devalued group) was instrumental in the planning and execution of my fieldwork (Crocker, Major, & Steele, 1998).

As already mentioned, I selected professionals and service users, whom I initially treated as two different groups and whose interactions would lead to me understanding what stigma means in the context of mental health care. During my work, these 'logic' categorizations between users and professionals formed a frame of reference, or a starting point for the research on how and why these became real in the daily functioning of the ward , and how they were then related to perceptions and experiences of stigma. In this way, I eventually went beyond a social psychological viewpoint, as the fieldwork and data rapidly prompted me to reflect on the broader complexities and mechanisms in society, such as the structural inequalities through which stigma is given shape (Rusch et al., 2005; Yang et al., 2007).

This thesis was inspired by the work of Pescosolido and colleagues (2008), who created a multidimensional conceptualization of stigma through their FINIS framework. By paying attention to the mechanisms in society – such as social stratification – that structure interactions in the context of mental health care, I align with Scambler (2006) in stressing the reproductive role of stigmatizing interactions. Furthermore, his suggestion to capture stigma-related dynamics through structural antecedents appeared to offer the possibility to link stigma with actual cultural distinctions in value and worth at a particular time and place, experienced by the individual. This involves, for example, the association between stigma perceptions and the understanding of mental health problems as either a medical or a social issue. Through the introduction of what is termed 'mental health literacy' (Nutbeam, 2008) owned by the middle class (Pescosolido, 2006),

and the less beneficial explanations for mental health problems held by those with limited social and economic resources (e.g. Francis, 2012), stigma perceptions can be understood within the broader framework of the social structures that organize daily life at the macro level. Rather than being right or wrong, the illness approach is then put into context, making it possible to go beyond the question of the 'goodness' or 'badness' of mental health care in stigma processes.

Limitations and suggestions for further research

As with any research endeavour, this ethnographic work has some limitation s. These follow on from the choices made about the research design and methodology, the choice to elaborate certain research questions and to leave others aside – in view of the limited time at my disposal – and other practical considerations. In the following part, I discuss what I believe to be the main limitations of this work and how the work nevertheless offers opportunities for future research.

First, the ethnographic approach in this study was aimed at exploring the different dynamics through which stigma becomes meaningful in the context of mental health care. Specifically, this methodology made it possible to explore factors related to the ward and hospital culture, professionals' and service users' perception of mental health care and stigma, and the particular relationships involved in it. However, these different dynamics were studied in one type of setting: that of an inpatient psychiatric hospital. The mental health care landscape is changing, characterized by alterations to the definition of mental illness, treatment modalities and the structures of institutions providing care, together with the complete transformation of the organization of the treatment system (Pavolka, 2007). Accordingly, the hospitals I selected are among many different types of institutions in the Belgian mental health care context (Hermans et al., 2012). There is a current aim to organize care circuits and networks of services to arrive at a more integrated, individualized and demand-driven care approach, based on Article 107 of the Hospital Act of 2008 (Gerkens & Merkur, 2010). This suggests the value of additional ethnographic work in alternative settings, such as day-care centres or community mental health centres, in which psychologists rather than nurses are for instance the prime care providers, and where service users go for consultation s. This appears important, as it involves settings that

occupy different positions vis-à-vis their integration in broader societal dynamics, as users combine participation in treatment with the continuation of their societal role – such as an employee, parent or player in a sports team. This will certainly influence both professionals' and service users' perception of stigma in relation to a specific mental health care setting. Exploring how service users in these alternative settings experience their care relationships with providers may help to provide greater insight into the relative importance of the duality between inpatient and outpatient care in relation to stigma (e.g. Linden & Kavanagh, 2011).

Second, as suggested in recent theoretical studies on mental health stigma (e.g. Link et al., 2001; Pescosolido et al., 2008), and strengthened by the results presented in this dissertation , more attention should be paid to the way mental health stigma is embedded in social, economic and cultural power relations, which are among other things reflected in the organizational structure and culture of mental health care settings. For example, this concerns the culturally dominant medical ideology in (mental) health care that sets the boundaries for the hierarchical relationships between professionals, and between service users and providers (Jutel, 2009). Nevertheless, only a few studies take note of this dimension of power in relation to stigma and mental health care (e.g. Flanagan et al., 2009; Lee et al., 2006). The relevance of this approach became clear in the study of the way nurses gave meaning to their professional role in relation to stigma. The meaning of stigma appears to depend on the embeddedness of the nurses' role in the medical framework, characterized by a focus on diagnosis and a clear inter-professional hierarchy, and the centralization of authority and responsibility in the psychiatrist (Pescosolido, 2006; Schneider, 1993). It appears that in a more decentralized system, in which professionals share responsibilities and in which they have a more holistic approach to service users, stigma becomes part of the frame of reference from which care relationships are constructed. This appears rarely the case in more centralized systems. In this dissertation, discussions on the meaning of power are, however, based on only two hospitals and four different wards. Therefore, comparative research that considers the structural and cultural features of a wider range of mental health care settings could be very enriching. The work of Verhaeghe and colleagues (2007; 2008) – in which features of care settings, such as their size and level of individualized care, were linked to service users' feelings of self-efficacy and self-worth – could function as a starting point for further research into the way the organizational design of mental health care

settings may form an intermediary level that influences the ways stigma is perceived by professionals and service users.

Third, the selection of hospitals and wards was based on a theoretical sampling procedure, which finally resulted in the participation of 43 professionals and 42 service users. Only around half of the service users I met during the fieldwork participated. This primarily comprised users who had been resident for at least four weeks before my interview with them. This makes it possible that the sample was affected by selection bias (Collier & Mahoney, 1996), and primarily consists of participants who were relatively positive about their stay, as others could have left the inpatient setting before the time of the interview. At first sight it could be that this involves individuals who were characterized by treatment compliance. The study by Sirey and colleagues (2001) suggests that service users who do not adhere to their treatment may be those who have experienced stigma. Furthermore, users who are characterized by treatment compliance are generally supposed to endorse the dominant understanding of mental health problems in the ward (Kravetz et al., 2000).

However, the adoption of a relational approach, paying particular attention to contextual dynamics, shows that service users seek help and follow their treatment regime for multiple reasons. Although several individuals in the study were convinced of the helpfulness of treatment in terms of getting better, others stayed primarily because they had no other choice, due to social or economic circumstances. Others were constantly on the horns of a dilemma; they were frustrated about the course of their treatment, but also believed there was no alternative to staying in the ward at the time. Accordingly, the contextualization made it possible to reflect on the possibility of this selection effect. In this regard, it could be interesting to carry out ethnographic research for a longer period in a ward, in order to be able to interview service users at multiple points in time. However, this investment in terms of time would not preclude the fact that people are often not able to participate in research during the first days of their stay.

Fourth, throughout my research, analysis of the data started from the accounts of service users and providers about their experiences and perceptions regarding stigma and mental health (care). In particular with regard to people with mental health problems, these accounts often remain unheard and may even be assessed as inaccurate or irrelevant. Their experiences are supposed to be biased by their problem, and it is the professionals – in particular the doctor – who know

176

what is best for them (Faulkner & Thomas, 2002). Furthermore, the lack of a trusting relationship with the researcher may result in incomplete accounts. However, in this research I wanted to come as close as possible to the professionals' and users' perceptions of mental health problems and stigma. The choice to combine semi-structured interviews with intensive participant observations, in which I took the role of 'participant as observer' (Gold, 1958), was used to maximize the quality of the data. As suggested by Kirkewold and Bergland (2007), this methodological triangulation may augment the quality of data, because it may first of all help to build a rapport between the researcher and the participants, through which a trustful relationship can be built. The opportunity to reflect on particular accounts during informal moments also helped me to capture the details and background of the participants' experiences.

Fifth, concerns about the quality of ethnographic data go together with another potential limitation of this research, which is that I am an outsider in the field of mental health care (Hellawel, 2007). Being familiar with the field would offer the advantage of not having to learn the jargon used. However, I quickly became familiar with the vocabulary – which also differed between wards – and I experienced my position as valuable for several reasons. As mentioned in the methodological section, it offered the possibility to question the self-evidence of each ward's daily functioning . Furthermore, it appeared that the professionals and the service users were enthusiastic about expressing and discussing their opinions and frustrations, which they would normally not do, for example about issues concerning the role and authority of the psychiatrist in the ward. They were just relieved to talk, or were interested in my point of view as someone outside of the care relationships in which they were engaged. I always tried to answer their questions by mentioning an observation I had made. This offered me the possibility to reflect on things together with someone else, therefore minimizing any impact of my personal opinion. Based on the information obtained, I believe that my position offered the opportunity to collect rich data. As I have mentioned, the ethnographic research in this field gave me the ability to reflect on my own prejudices as a sociologist, for instance my scepticism about the medical approach to mental health problems. It was through these reflections that I became truly convinced of the need for a contextual approach to stigma, in which different understandings are valuable.

Lastly, when exploring mental health stigma and care perceptions, I primarily focused on their contextualization, paying particular attention to the structural antecedents. This made it possible to link personal experiences and identity perceptions to the broader mental health care and societal framework in which they are given shape. This does not seem to be in line with the current focus on users' empowerment (e.g. Corrigan, 2002), stigma resistance (Thoits, 2011; 2015) and other more agency-oriented approaches, going hand in hand with a changing mental health care landscape aimed at more individualized and demand-driven provision of care. However, as Devish and Vanheule (2015) remark, it is necessary to reflect profoundly on the basic principles of this shift towards empowerment in (mental) health care. As they state, research on empowerment in this context focusses on how to achieve individualized and demand-driven care, and often ignores the more fundamental questions of what it means and why it is the new goal in mental health care.

It appears that the promotion of a sense of self and of hope, client choice and client involvement in planning (Anthony, 1991; Anthony & Liberman, 1986) perfectly fits the cultural trend in which self-realization is of crucial importance (Crawford, 2006). It is therefore important to pay attention to the interplay between individual demands and motivations, and the broader structure in which they function. As Rush and colleagues (2010) argue, it remains vital to keep in mind how the focus on personal responsibility and self-realization is related to mental illness stigma, and more specifically to implicit, guilt-related stereotypes. As I propose in this dissertation, it is fundamental to put both providers' and users' perceptions of mental health problems, care and stigma into context. It seems that stigma can only be unravelled and incorporated in contemporary efforts to build a balanced care model through recognition of the interplay between the broader context of social stratification and the cultural approach to mental health problems and care.

To conclude: research and policy recommendations

Research on stigma in mental health care

This dissertation primarily builds on the social constructivist approach to stigma developed by Goffman (1963) and Scheff (1966), and further discusses and elaborates on some recent critiques related to the study of mental health stigma. The findings confirm the suggestion of theorists such as Link and Phelan (2001; 2004), that mental illness stigma should be studied as a multidimensional concept. Furthermore, it endorses their opinion that qualitative research may add value to this approach, as it permits the researcher to gain deep insights into how stigma is given shape in social interactions, how people experience it and how the complexity of social systems produces it.

Recent efforts to incorporate this multidimensionality have often started from a social psychological approach. They follow Corrigan and colleagues (2004) in their approach to structural stigma as comprising policies that restrict the opportunities of people with mental health problems. This involves a level of stigmatizing policy measures in addition to the prime dimensions of the stigma model: the cognitive (stereotypes), affective (prejudice) and behavioural (discrimination) responses through which individuals may (self-)stigmatize or anticipate stigma (Corrigan & Watson, 2002). This approach has led to important insights into the prevalence and functions of stigma at different levels in society, but does not provide the necessary understanding of how stigmatizing dynamics and experiences at these different levels are intertwined; a necessary condition to reach a more encompassing understanding of stigma in mental health care. Based on my research, I recommend following the suggestion of Scambler (2006) to focus on the structural antecedents of stigmatizing perceptions, as it has proven its value in reaching an integrative perspective. As suggested by Link and Phelan (2014), this involves for instance the way professional roles are embedded in social structure and how they function to preserve particular power relations in the context of care. In my research, professionals' perceptions of stigma appear to be related to their evaluation of their professional role within the medical, culturally dominant care system. This appears to be a function of the extent to which the organizational culture and structure adhere to this powerful model, reflected

in the centralization of authority and responsibility in the person of the psychiatrist, within a clear inter-professional hierarchy (Schneider, 1993). Therefore, it seems important for future stigma research to pay particular attention to the way the social roles and positions of both users and providers are constructed and reconstructed in relation to cultural systems of care and the aligned organizational structures. For example, it might be interesting to investigate to what extent the organizational structure (e.g. the level of centralization) of inpatient and outpatient provider teams differs, and how this influences the meaning of stigma in the professional role perception of team members. This focus makes it possible to value both the relational dynamics – which are of crucial importance in the social constructivist approach to stigma – and the guiding (medical) concepts that structure mental health care in its contemporary form. The findings equally show that it is fundamental to be cautious regarding the generalization of findings in relation to stigma. It is the interplay between contextual dynamics at different levels in individuals' personal experiences that inform their perceptions.

Policy makers

While the prime aim of this thesis concerns the development of insights on the meaning of stigma in mental health care from a sociological point of view, my approach of stigma forms the basis for the suggestion of some cautious reflections of policy implications. As Sayce (1998) stated, the particular view of stigma has specific implications for the understanding of responsibilities, actions and solutions.

Most practical efforts to tackle stigma can be situated at the level of public opinion, such as for example the recent launch of the website Geestelijk Gezond Vlaanderen. Tijd om normaal te doen over psychische problemen and anti-stigma campaigns such as Te Gek!? and Anders Gewoon. These have been prompted by the need to counter the negative stereotypes, attitudes and beliefs about mental health problems in society (e.g. Henderson & Thornicroft, 2009; Vaughan & Hansen, 2004) and are aimed at increasing awareness and factual knowledge about mental health problems (Corrigan et al., 2012; Rusch, Angermeyer, & Corrigan, 2005). In addition to these efforts to diminish the myths and misconceptions about mental health problems, increased contact with people suffering from these issues forms a strategy to tackle stigma in the general population. The idea that negative stereotypes and beliefs may change through increased

interpersonal contact (Couture & Penn, 2003; Novella, 2010) is one of the motivations for the current mental health care reform, in which the further expansion of community care is central. Increased contact between the public and people with mental health problems should provide an opportunity to reduce stigma and facilitate the reintegration of affected people into the community. This dissertation does not offer the opportunity to make any recommendations about efforts to challenge stigma in the general population, as I have concentrated on stigma in mental health care, and more specifically in inpatient hospital settings.

However, the observation that care providers are influenced by the general tendency in society to marginalize people with mental health problems in their role construction illustrates the necessity to keep focussing on these perceptions in the general population. For several care providers, their awareness of stigma in society appeared to inform the perception of their duty. They were devoted to offering a caring and safe alternative to society at a particular time in the life of service users. They were also professionals who held a critical view of the de-hospitalization of care. Their concern about the lack of respect and opportunities in society for people with mental health problems also guided this scepticism. Although this only involves the accounts of a small number of care providers, it can be useful to take this relationship between providers and societal attitudes into consideration in the quest for better care, provided by dedicated care providers. First, this is relevant in light of the current development in Belgium regarding the organization of care circuits (programmes and services) and networks of services, in which community care will be an important part (Gerkens & Merkur, 2010; Nicaise, Dubois, & Lorant, 2014). Second, it seems particularly important to pay attention to the interplay between stigma and professional role perceptions in the training programme for future care providers (e.g. Sadow & Ryder, 2008). As other studies on associative stigma illustrate (e.g. Cutler et al., 2009, Malhi et al., 2003), students face the multiple dimensions of mental stigma even before the start of their professional career, through for instance negative reactions to their choice to work in mental health care. It seems important to consider these issues during training programmes in an effort to make care providers even more reflective about the meaning of stigma for their professional role.

Although this dissertation is based on the accounts of individuals in only four wards, service users' accounts about the different roles hospital care had for them may equally inform the

ongoing reform. It appears that the current efforts being made by policymakers to find a balance between hospital and community care is of crucial importance, as hospital settings appear to have multiple functions. These include the provision of safety for people who are confronted with domestic problems, or a place to stay for people with combined mental health and economic and/or housing difficulties. These functions illustrate the necessity to co-operate more intensely with adjoining sectors, such as welfare and employment.

Furthermore, the hospital setting also provides an opportunity for people to obtain some distance from their demanding life – with children, work, etc. – in order to concentrate fully on their recovery. The try-out of flexible housing models for people with enduring mental health problems to some extent addresses the concern of Van Hecke and colleagues (2011) that people with severe problems may be helped in a more efficient way in inpatient settings. However, it remains important to take into account the value of temporary inpatient care for people who are not necessarily dealing with enduring problems.

Furthermore, the identified differences in the social position of service users who experienced stigma during their treatment in the different wards show that psychiatric hospital settings should not be considered as a homogenous type of care. As Verhaeghe and colleagues (2008) state, the identified differences may offer policymakers the opportunity to learn how to optimize inpatient care. In relation to this dissertation, this particularly concerns the challenge of working with people who occupy different positions in the social structure, with accompanying differences in their care expectations, language use and perception of mental health problems and care. These findings firstly suggest an appeal for the intensification of personalized care, with a reflective attitude towards concepts such as empowerment and personal agency (see Devish & Vanheule, 2015). As Crawford (2006) argues, it is important to pay attention to the way health(care) and its meanings function as a sources of symbolic capital for strategies of distinction and stigmatization.

Furthermore, the findings suggest the mental health care sector faces the challenge of how to combine the further individualization of care with the organization of care institutions whose structure is based on work in community or group settings. I found that settings have a tendency

to organize their treatment for people with a particular socioeconomic and/or cultural background. As a result, people without this background feel they are not heard, and even worse, not helped. For example, although I observed during my fieldwork how creative therapy can form a helpful means of expression in a ward with a strong focus on group talks and self-reflectivity, the proportion of these sessions in the organization of care and the evaluation during team meetings, remained negligible. In this particular case, these forms of therapy appear very valuable to reach people with different backgrounds and skills.

In general, a personalized approach has the potential to diminish stigmatizing experiences in mental health care and even beyond. Nevertheless, the challenge of how to organize it in hospital and other community settings remains, to a certain degree. It therefore seems important to keep history and context in mind. The first psychiatric hospitals were constructed based on a humanitarian point of view (Jones, 1960). However, as described in the first chapter, this benignancy resulted in a differential approach between individuals with a different social status and appeared to reinforce stigma for those from the lower strata with mental health problems. In the light of this dissertation, it seems central to keep in mind how social structure affects the organization of mental health care and the perception of mental health problems.

Mental health professionals

Last but not least, I would like to offer some suggestions for mental health professionals. They are at the core of this story and are often the most important people in the life of service users, due to the users' limited social network (Borge et al., 1999), occupying a role as 'wise others', through which the professionals 'appear human' (Goffman, 1963, p.20). During this research project, the care providers I worked with were characterized by their dedication. They all had a mission to care for people with mental health problems in the best way they could. As Cook and colleagues (2014) argue, care providers can play a crucial role in tackling the stigma perception of service users they encounter, by means of counselling sessions, education or value affirmation, through which they remind people that they are much more than just their mental health problem. In this context, my work illustrates the importance for providers to be aware of their approach to care when they take this role, as it is not always the same as that of the user. It

is of crucial importance to contextualize all information – for example the use of diagnosis – and to reflect together with the service user on the meanings of it.

Overall, this dissertation invites professionals to be aware of and reflective about their own professional background, their language use and the expectations that go with it, and how this informs their use of notions such as treatment compliance and insight (Kravetz et al., 2000; Mishra et al., 2009). As Dobransky (2009) illustrates, the danger exists that a misfit between the background and expectations of professionals and users may lead to differential labelling, in which people who do not seem to fit the organizational and cultural system of the ward may be identified as difficult or bad. I suggest that different initiatives could help to trigger this reflectivity. For instance, it could involve collaboration or regular consultation with acquaintances of service users during the treatment process, or the integration of experienced experts into multidisciplinary teams. As Schulze and Angermeyer (2003) suggest, insight into the varying perceptions of mental health problems on the part of users, relatives and mental health professionals may help to increase awareness about the professionals' own point of view and may further allow consideration of aspects of stigma that might not be seen by either group alone.

It equally remains important to pay attention to and to discuss among professionals why a particular approach works for a particular service user. During my fieldwork, it was striking that individuals who were not doing well were talked about most of the time, which led to a pessimistic atmosphere. As Thornicroft and colleagues (2007) mention, professionals primarily deal with service users who do not fully recover or who relapse, whereas they do not maintain contact with those who get well. The resulting accumulation of negative experiences may lead to pessimistic attitudes concerning an individual's prognosis. It seems crucial to pay more attention to positive dynamics, as these may help to provide insights into the difficulties encountered with other service users, and reorient attention to the relationship between care context/provider and service users/context, rather than a sole focus on the 'progression' of the service user.

With regard to the relationship between care providers and the identified stigma in society, the focus on providing safety and rest may create a risk to their dedication to help and fully respect

184

people with mental health problems. Moreover, this attitude has been identified by Cohen and Struening (1962) as a kind, paternalistic view of people with mental health problems, informed by humanistic motives (Link et al., 2004). This approach may therefore involve the danger of reinforcing rather than tackling the power relations that induce mental health stigma. Viewing stigma as the embodiment of a fearful and excluding society should therefore not just lead to the protection of those who are marginalized. It appeared that professionals' their reflection on the role of healthcare in the preservation of a system of stratification may lead to the further consolidation of the system. Therefore, in the current constellation of our society, their awareness should be accompanied by a continuous effort to strengthen the social position of users to escape from a vicious circle, starting from their understanding of their problems and care.

In sum, considering stigma as a very detrimental force and noting the crucial position of mental health care in both the start-up and tackling of stigma processes, it is crucial for professionals and policymakers to reflect on their role in relation to stigma in the changing mental health care landscape. The further integration of care in the community will intensify the need for reflection. Professionals and policymakers will be confronted with society's approach to mental health problems and the expected role of mental health care in this regard. Therefore, they should be supported in dealing with the issue of stigma in a reflective and resilient way, as they do make a difference to people with mental health problems.

REFERENCES

Adler, P. A. and Adler, P. (1994). Observational techniques. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 377–392). Thousand Oaks, CA: Sage Publications.

Alden, D. L., Merz, M. Y. and Thi, L. M. (2010). Patient decision-making preference and physician decision-making style for contraceptive method choice in an Asian culture: Does concordance matter? *Health Communication, 25*, 718-724.

Andersen, R.M. (1995). Revisiting the behavioral model and access to medical care: does it matter? *Journal of Health and Social Behavior, 36*, 1-10.

Anderson, J. (2012). Whose voice counts? A critical investigation of discourses surrounding the Body Mass Index (BMI). *Fat Studies, 1*, 195-207.

Anderson, J., & Bresnahan, M. J. (2012). Communicating stigma about body size. *Health Communication, 28*, 603-615.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11–23.

Angermeyer, M.C., Schulze, B. and Dietrich, S. (2003). Courtesy stigma: A focus group study of relatives of schizophrenia patients. *Social Psychiatry and Psychiatric Epidemiology, 38*, 593–602.

Angermeyer, M.C. and Matschinger, H. (2005). Causal beliefs and attitudes to people with schizophrenia. Trend analysis based on data from two population surveys in Germany. *The British Journal of Psychiatry, 186*(4), 331-334.

Angermeyer M.C. and Dietrich S. (2006). Public beliefs about and attitudes towards people with mental illness: a review of population studies. *Acta Psychiatrica Scandinavia,113*(3), 163-79.

Aujoulat, I., d'Hoore, W. and Deccache, A. (2007). Patient empowerment in theory and practice: polysemy or cacophony? *Patient Education and Counseling, 66*(1), 13-20.

Baker, F., and Schulberg, H. C. (1967). The development of a community mental health ideology scale. *Community Mental Health Journal, 3*(3), 216–225.

Baker, D.W. (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine, 21*(8), 878–83.

Barker, P. & Buchanan-Barker, P. (2011). Myth of mental health nursing and the challenge of recovery. *International Journal of Mental Health Nursing, 20*, 337-344.

Bates, L. and Stickley, T. (2013). Confronting Goffman: how can mental health nurses effectively challenge stigma? A critical review of the literature. *Journal of Psychiatric and Mental Health Nursing, 20,* 569-575.

Beal, F.M. (2008). Double jeopardy: to be black and female. *Meridians: Feminism, Race, Transnationalism, 8*(2), 166-176.

Becker, H. (1967). Who's side are we on ? *Social Problems, 14*(3), 239-24.

Bell, K., A. Salmon, M. Bowers, J. Bell, and L. McCullough. 2010. Smoking, stigma and tobacco 'denormalization': Further reflections on the use of stigma as a public health tool, a commentary on Social Science & Medicine's Stigma, prejudice, discrimination and Health Special Issue (67,3). *Social Science and Medicine, 70,* 795–99.

Berry, C., Gerry, L., Hayward, M. and Chandler, R. (2010). Expectations and illusions: a position paper on the relationship between mental health practitioners and social exclusion. *Journal of Psychiatric and Mental Health Nursing, 17*, 411–421.

Bhaskar, R. (2008). *A realist theory of science.* London: Routledge.

Biddle, L., Donovan, J., Sharp, D. and Gunnell, D. (2007). Explaining non-help-seeking amongst young adults with mental distress: a dynamic interpretive model of illness behavior. *Sociology of Health and Illness, 29*, 7, 983-1002.

Bjorkman, T., Angelman, T., and Jonsson, M. (2008). Attitudes towards people with mental illness: a cross-sectional study among nursing staff in psychiatric and somatic care. *Scandinavian Journal of Caring Sciences, 22*, 170-177.

Blumer, H. (1969). *Symbolic Interactionism: Perspective and method*. Englewood Cliffs, New Jersey: Prentice Hall.

Bonner, A. and Tolhurst, G. (2002). Insider-outsider perspectives of participant observation. *Nurse Research, 9*(4), 7-19.

Bonney, S. and Stickley, T. (2008). Recovery and mental health: A review of the British literature. *Journal of Psychiatric and Mental Health Nursing, 15,* 140–153.

Bonnington, O. and Rose, D. (2014). Exploring stigmatization among people diagnosed with either bipolar disorder or borderline personality disorder: A critical realist analysis. *Social Science and Medicine, 123*, 7-17.

Bourdieu, P. (1989). Social space and symbolic power. *Sociological Theory, 7*(1),14–25.

Bourdieu, P. and Wacquant, L. (1992). *An Invitation to Reflexive Sociology.* Chicago: The University of Chicago Press.

Bracken, P., Thomas, P., Timimi, S., Asen, E., Behr, G., Beuster, C., Bhunnoo, S., Browne, I., Chhina, N., Double, D., Downer, S., Evans,C., Fernando, S., Garland, M.R., Hopkins, W., Huws, R., Johnson, B., Martindale, B., Middleton, H., Moldavsky, D., Moncrieff, J., Mullins, S., Nelki, J., Pizzo, M., Rodger, J., Smyth, M., Summerfield, D., Wallace, J. and Yeomans, D. (2012). Psychiatry beyond the current paradigm. *The British Journal of Psychiatry, 201*, 430–434.

Bray, J. (1999). An ethnographic study of psychiatric nursing. *Journal of psychiatric and Mental Health Nursing, 6*, 297-305.

Brohan, E., Slade, M., Clement, S., and Thornicroft, G. (2010). Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *Health Services Research, 10*(80).

Busfield, J. (1986). *Managing madness: changing ideas and practice.* New York: Unwin Hyman.

Byrne, P. (2000). Stigma of mental illness and ways of diminishing it. *Advances in Psychiatric Treatment, 6*, 65–72.

Caldwell, T. M. and Jorm, A. F. (2000). Mental health nurses' beliefs about interventions for schizophrenia and depression: a comparison with psychiatrists and the public. *Australian and New Zealand Journal of Psychiatry, 34*, 602-611.

Caldwell, T. M. and Jorm, A. F. (2001). Mental health nurses' beliefs about likely outcomes for people with schizophrenia or depression: a comparison with the public and other healthcare professionals. *Australian and New Zealand Journal of Mental Health Nursing, 10*, 42-54.

Charles, J.L.K. (2013). Mental health provider-based stigma: understanding the experience of clients and families, *Social Work in Mental Health, 11*(4), 360-375.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5*(2), 168-195.

Charmaz, K. (2005). Constructing grounded theory in the 21st century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd Ed.), (pp. 507-536)). Thousand Oaks, California: Sage.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* London: Sage Publications.

Charmaz, K. (2008). Constructionism and the grounded theory method. In J.A. Holstein & J.F. Gubrium (Eds.), *Handbook of constructionist research*, (pp. 397-412). New York: The Guilford Press.

Charmaz, K. (2011). Grounded theory methods in social justice research. In N.K. Denzin & Y.S. Lincoln. *The Sage Handbook of Qualitative Research*, (pp. 359-380). California: Sage.

Charmaz, K. and Belgrave, L.L. (2013). Modern symbolic interaction theory and health. In Cockerham (Ed.) *Medical sociology on the move: new directions in theory,* (pp. 11-39). Dordrecht: Springer.

Chauncey, R. L. (1975). Labelling theory of mental illness - Comment. *American Sociological Review, 40,*248-252.

Chee, C. Y. I., Ng, T. P., and Kua, E. H. (2005). Comparing the stigma of mental illness in a general hospital with a state mental hospital - A Singapore study. *Social Psychiatry and Psychiatric Epidemiology, 40,*648-653.

Clark, L. (1999). *Challenging ideas in psychiatric nursing.* London: Routledge.

Cleary, M. (2003). The challenge of mental health care reform for contemporary mental health nursing practice: relationships, power and control. *International Journal of Mental Health Nursing, 12,* 139-147.

Cleary, M. (2004). The realities of mental health nursing in acute inpatient environments. *International Journal of Mental Health Nursing, 13*, 53-60.

Cockerham, W. (2007). *Social causes of health and disease*. Cambridge: Polity Press.

Coffey, A. and Atkinson, P. (1996). *Making sense of qualitative data.* Thousand Oaks, California: Sage.

Cohen, J., and Struening, E. L. (1962). Opinions about mental illness in the personnel of two large mental hospitals. *The Journal of Abnormal and Social Psychology, 64*(5), 349–360.

Collier, D. and Mahoney, J. (1996). Insights and pitfalls: selection bias in qualitative research. *World Politics, 49*(1), 56-91.

Conrad, P. (2007). *The medicalization of society: On the Transformation of Human Conditions into Treatable Disorders.* Baltimore: The Johns Hopkins University Press.

Conrad, P. and Barker, K.K. (2010). The social construction of illness: key insights and policy implications. Journal of Health and Social Behaviour, 51, 67–79.

Cook, J.E., Purdie-Vaughns, V., Meyer, I.HH. and Busch, J. (2014). Intervening within and across levels: A multilevel approach to stigma and public health, *Social Science and Medicine, 103*, 101-109.

Cooper, A., Corrigan, P., and Watson, A. (2003). Mental illness, stigma and care seeking. *The Journal of Nervous and Mental Disease, 191*(5), 339-341.

Cooper, D. (1967). *Psychiatry and Anti-Psychiatry.* London: Tavistock Publications.

Corker, E., Hamilton, S., Henderson, C., Weeks, C., Pinfold, V., Rose, D., Williams, P., Flach, C., Gill, V., Lewis-Holmes, E. and Thornicroft, G. (2013). Experiences of discrimination among people using mental health services in England 2008–2011. *The British Journal of Psychiatry, 202*, 58–63.

Corrigan, P. W. and Penn, D. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist, 54*(9), 765-776.

Corrigan, P. (2000). Mental health stigma as social attribution: implications for research methods and attitude change. *Clinical Psychology: Science and Practice, 9*(1), 48-67.

Corrigan, P. W. (2002). Empowerment and serious mental illness: Treatment partnerships and community opportunities. *Psychiatric Quarterly, 73*, 217-228.

Corrigan, P. and Watson, A.C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9(1), 35-53.

Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist, 59,* 614–625.

Corrigan, P.W., Markowitz, F. E., and Watson, A.C. (2004). Structural levels of mental illness stigma and discrimination. *Schizophrenia Bulletin, 30*, 481-491.

Corrigan, P.W., Kerr, A. and Knusdsen, L. (2005). The stigma of mental illness: Explanatory models and methods for change. *Applied and Preventive Psychology, 11*, 179–190.

Corrigan , P.W. and Wassel, A. (2008). Understanding and influencing the stigma of mental illness. *Journal of Psychosocial Nursing and Mental Health Services, 46*(1), 42-8.

Corrigan, P.W. and Watson, A.C. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology, 25*(8), 875-884.

Corrigan, P., Morris, S.B., Michaels, P.J., Rafacz, J.D. and Rüsch, N. (2012). Challenging the public stigma of mental illness: A meta-analysis of outcome studies. *Psychiatric Services, 63*(10), 963-973.

Couture, S. M., and Penn, D. L. (2003). Interpersonal contact and the stigma of mental illness: A review of the literature, *Journal of Mental Health, 13*(3), 291–305.

Crawford, R. (2006). Health as a meaningful social practice. Health: An interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 10(4), 401–20.

Crawford, P., Brown, B., and Majomi, P. (2008). Professional identity in community mental health nursing: A thematic analysis. *International Journal of Nursing Studies, 45*, 1055-1063.

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five traditions* (2nd ed.). California: Sage.

Crocker, J., Major, B., and Steele, C. (1998). Social stigma. In D.T. Gilbert, S.T. Fiske and G. Lindzey, (eds.) *Handbook of Social Psychology* (pp.504-553). Boston: McGraw-Hill.

Crossley, N. (1998). R. D. Laing and the British anti-psychiatry movement: a socio-historical analysis. *Social Science and Medicine, 47*(7), 877–889.

Crow, M. (2006). Psychiatric diagnosis: some implications for mental health nursing care. *Journal of Advanced Nursing, 53*(1), 125-133.

Cutcliffe, J. and Happell, B. (2009). Psychiatry, mental health nurses, and invisible power: Exploring a perturbed relationship within contemporary mental health care. *International Journal of Mental Health Nursing, 18*, 116-125.

Cutler, J.L., Harding, K., Mozian, S., Wright, L.L., Pica, A.G., Masters, S.R. Graham, M.J. and Davis, A.S. (2009). Discrediting the notion ''working with 'crazies' will make you 'crazy''': addressing stigma and enhancing empathy in medical student education. *Advances in Health Sciences Education : Theory and Practice,14*(4), 487-502.

David, A.S. (1990). Insight and psychosis. *British Journal of Psychiatry, 156*, 798-808.

Davidson, L., Rakfeldt, J. and Strauss, J. (2010). *The Roots of the recovery Movement in psychiatry: lessons learned.* West Sussex: Wiley-Blackwell.

Davies, C.A. (2008). *A research guide to researching selves and others*. London: Routledge.

Deacon, B.J. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility and effects on psychotherapy research. *Clinical Psychology Review, 33*, 846–861.

Denzin, N.K. (1978). *Sociological Methods*. New York: McGraw-Hill.

Denzin, N.K. and Lincoln, Y.S. (2011). Introduction: The discipline and practise of qualitative research. In N.K. Denzin & Y.S. Lincoln. *The Sage Handbook of Qualitative Research* (pp. 1-20). California: Sage.

Depla, M. F. I. A., de Graaf, R., van Weeghel, J. and Heeren, T. J. (2005). The role of stigma in the quality of life of older adults with severe mental illness. *International Journal of Geriatric Psychiatry, 20,*146-153.

Des Courtis, N., Lauber, C., Costa, C. T., and Cattapan-Ludewig, K. (2008). Beliefs about the mentally ill: a comparative study between healthcare professionals in Brazil and in Switzerland. International Review of Psychiatry, *20*, 503-509.

Devisch, I. and Vanheule, S. (2015). Foucault at the bedside: a critical analysis of empowering a healthy lifestyle. Journal of Evaluation in Clinical Practice, 21(3), 427–432.

Dinos, S., Stevens, S., Serfaty, M., Weich, S. and King. M. (2004). Stigma: the feelings and experiences of 46 people with mental illness. Qualitative study. *The British Journal of Psychiatry, 184,* 176–81.

Dobransky, K. (2009). The good, the bad, and the severely mentally ill: Official and informal labels as organizational resources in community mental health services. *Social Science and Medicine, 69*, 722-728.

Dovidio, J. F., Major, B., and Crocker, J. (2000). Stigma: Introduction and overview. In T. F. Heatherton, R. E. Kleck, M. R. Hebl & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 1-28). New Yor: Guilford Press.

Draucker, C. B., Martsolf, D. S., Ross, R. and Rusk, T. B. (2007). Theoretical sampling and category development in grounded theory. *Qualitative Health Research, 17*, 1137-1148.

Dubois, J.M. (2008). *Ethics in mental health research. Principles, guidance and cases.* Oxford: Oxford University Press.

Durkheim, E. (1894). *Les Règles de la méthode sociologique*, Paris, Payot.

Engel, G.L. (1980). The clinical application of the biopsychosocial model. *American Journal of Psychiatry, 37*(5), 535-544.

Estroff, S.E. (1981). *Making it crazy: an ethnography of psychiatric patients in an American Community.* California: University of California Press.

Economist Intelligence Unit (2014). *Mental Health and Integration. Provision for supporting people with mental illness: A comparison of 30 European countries. Geneva: Switzerland.* Retrieved from: http://www.mentalhealthintegration.com/media/whitepaper/EIUJanssen_Mental_Health.pdf

Samele, C., Frew, S. and Urquía, N. (2013). Mental Health Systems in the European Union Member States, Status of Mental Health in Populations and Benefits to be Expected from Investments. Nottingham: European commission. Retrieved from: http://ec.europa.eu/health/mental_health/docs/europopp_full_en.pdf

Fabrega, H. (1991). The culture and history of psychiatric stigma in early modern and modern western societies: A review of recent literature. *Comprehensive Psychiatry, 32*(2), 97-119.

Fakhoury, W. and Priebe, S. (2002). The process of deinstitutionalization: an international overview. *Current Opinion in Psychiatry, 15,* 187-192.

Fakhoury, W. and Priebe, S. (2007). Deinstitutionalization and reinstitutionalization: major changes in the provision of mental healthcare. *Psychiatry, 6*(8), 313–316.

Farina, A. and Feliner, R. D. (1973). Employment interviewer reactions to former mental patients. *Journal of Abnormal Psychology, 82*, 268–272.

Faulkner, A. and Thomas, P. (2002). User-led research and evidence-based medicine. *The British Journal of Psychiatry, 180* (1), 1-3.

Finfgeld D.L. (2004). Empowerment of individuals with enduring mental health problems: results from concept analyses and qualitative investigations. *Advances in Nursing Science, 27*(1), 44-52.

Fiske, S. (1998). Stereotyping, prejudice, and discrimination. In D.T. Gilbert, S.T. Fiske and G. Lindzey, (eds.) *Handbook of Social Psychology* (pp.357-411). Boston: McGraw-Hill.

Fitzpatrick, J. (2005). Editorial: Launching a velvet revolution in psychiatric-mental health nursing. *Archives of Psychiatric Nursing, 19*, 203-204.

Flanagan, E. H., Miller, R., and Davidson, L. (2009). Unfortunately, we treat the chart: sources of stigma in mental health settings. *Psychiatry Quarterly, 80*, 55-64.

Fontana, A. and Frey, J. H. (2005). The interview: From neutral stance to political involvement. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd Ed.), 695-727. Thousand Oaks, California: Sage.

Foucault, M. (2004). *Abnormal: lectures at the Collège de France 1974–1975* V. Marchetti, A. Salomoni (Eds.). London and New York: Verso.

Foucault, Michel (1991). Governmentality, In G. Burchell, C. Gordon, and P. Miller (Eds.), *The Foucault Effect: Studies in Governmentality*, (pp.87-104). Hempstead: Harvester Wheatsheaf.

Francis, A. (2012). Stigma in an era of medicalisation and anxious parenting: how proximity and culpability shape middle-class parents' experiences of disgrace. *Sociology of Health and Illness, 34*(6), 927–42.

Freidson, E. (1960). Client control and medical practice. *American Journal of Sociology, 65*(4), 374-382.

Gabbidon J., Clement, S., van Nieuwenhuizen, A., Kassam, A., Brohan, E., Norman, I. and Thornicroft, G. (2013). Mental Illness: Clinicians' Attitudes (MICA) scale-psychometric properties of a version for healthcare students and professionals. *Psychiatry Research, 206*(1), 81-7.

Gabham, L.M., Lakeman, R., McGowan, P., Parkinson, M., Redmond, M., Stevenson, C. and Walsh, J. (2010). *Hear My Voice: The experience of discrimination of people with mental health problems in Ireland.* Dublin: Dublin City University.

Gair, S. (2012). Feeling their stories: contemplating empathy, insider/outsider positioning, and enriching qualitative research. *Qualitative Health Research, 22*(1), 134-143.

Gerkens, S., and Merkur, S. (2010). Belgium: health system review. *Health Systems in Transition, 12*(5).

Glaser, B. G. and Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*, New York: Aldine de Gruyter.

Glaser, B.G. (1978). *Theoretical sensitivity: advances in the methodology of grounded theory*. California: Sociology press.

Goffman, E. (1961). *Asylums. Essays on the social situation of mental patients and other inmates.* New York: Anchor Books

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs: Prentice Hall.

Gold, R. (1958). Roles in sociological field observation. *Social Forces, 36*, 217-213.

Gouthro, T. J. (2009). Recognizing and addressing the stigma associated with mental health nursing: a critical perspective. Issues in Mental Health Nursing, 30(11), 669-676.

Gove, W. R. (1970). Societal reaction as an explanation of mental illness: an evaluation. American Sociological Review, 35,873-884.

Gove, W. R. (1975). Labelling Theory of Mental Illness - Comment. *American Sociological Review, 40*, 242-248.

Gove, W. R. (2004). The career of the mentally ill: An integration of psychiatric, labeling/social construction, and lay perspectives. *Journal of Health and Social Behavior, 45*, 357-375.

Gras, L.M., Swart, M., Slooff, C.J., van Weeghel, J., Knegtering, H. and Castelein, S. (2014). Differential stigmatizing attitudes of healthcare professionals towards psychiatry and patients with mental health problems: something to worry about? A pilot study. *Social Psychiatry and Psychiatric Epidemiology, 50*, 299–306.

Greenley, J.R and Mechanic, D. (1976). Social selection in seeking help for psychological problems. *Journal of Health and Social Behavior, 17*(3), 249-262.

Halter, M. J. (2002). Stigma in psychiatric nursing. *Perspectives in Psychiatric Care, 38*(1), 23-29.

Halter, M.J. (2008). Perceived characteristics of psychiatric nurses: Stigma by association. *Archives of Psychiatric Nursing, 22*(1), 20-26.

Handsley, S. and Stocks, S. (2009). Sociology and nursing: Role performance in a psychiatric setting. *International Journal of Mental Health Nursing, 18*, 26-34.

Handy J. A. (1991). The social context of occupational stress in a caring profession. *Social Science and Medicine, 32*(7), 819-830.

Hansson, L., Jormfeldt, H., Svedberg, P. and Svensson, B. (2011). Mental health professionals' attitudes towards people with mental illness : Do they differ from attitudes held by people with mental illness? *International Journal of Social Psychiatry, 59*(1), 48-54

Happel, B. and Gaskin, C.J. (2013). The attitudes of undergraduate nursing students towards mental health nursing: a systematic review. *Journal of Clinical Nursing, 22*(1-2), 148-158.

Hatzenbuehler, M.L., Phelan, J.C. and Link, B.G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health, 103*(5), 813–21.

Hatzenbuehler, M. L. and Link, B. G. (2014). Introduction to the special issue on structural stigma and health. *Social Science and Medicine, 103*, 1–6.

Heflinger, C.A. and Hinshaw, S.P. (2010). Stigma in child and adolescent mental health services research: Understanding professional and institutional stigmatization of youth with mental health problems and their families. *Administration and Policy in Mental Health and Mental Health Services Research, 37*(1), 61-70.

Hellawel, D. (2006). Inside–out: analysis of the insider–outsider concept as a heuristic device to develop reflexivity in students doing qualitative research. *Teaching in higher education, 11*(4), 483-494.

Henderson, C., and Thornicroft, G. (2009). Stigma and discrimination in mental illness: time to change. *Lancet, 373*, 1928-1930.

Hermans, M.H.M., de Witte, N. & Dom, G. (2012). The state of psychiatry in Belgium. *International Review of Psychiatry, 24*(4), 286-294.

Henderson, C., Noblett, J., Parke, H., Clement, S., Caffrey, A., Gale-Grant, O., Schulze, B., Druss, B., and Thornicroft, G. (2014). Mental health-related stigma in health care and mental health-care settings. *Lancet Psychiatry, 1*, 467–482.

Hinshaw, S.P. (2007). *The mark of shame: stigma of mental illness and an agenda for change.* Oxford: Oxford University Press.

Hofstede, G. (1983). National cultures in four dimensions. *International Studies of Management and Organization, 13*(2), 46–74.

Holmes, C.A. (2006). The slow death of psychiatric nursing: what next? *Journal of Psychiatric and Mental Health Nursing, 13*, 401-415.

Hori, H., Richards, M., Kawamoto, Y. and Kunugi, H. (2011). Attitudes toward schizophrenia in the general population, psychiatric staff, physicians, and psychiatrists: A web-based survey in Japan. *Psychiatry Research, 186*, 183–189.

Horsfall, J., Cleary, M. and Hunt, G.E. (2010). Stigma in mental health: Clients and professionals. *Issues in Mental Health Nursing, 31*,450–455.

Hugo, M. (2001). Mental health professionals' attitudes towards people who have experienced a mental health disorder. *Journal of Psychiatric and Mental Health Nursing, 8*, 419-425.

Hurley, J. (2009). A qualitative study of mental health nurse identities: Many roles, one profession. *International Journal of Mental Health Nursing, 18*, 383-390.

Jordan, B. (1997). Authoritative knowledge and its construction. In R. E. Davis-Floyd & C. F. Sargent (Eds.). *Childbirth and authoritative knowledge: Cross-cultural perspectives* (pp. 55–79). Berkeley, CA: University of California Press.

Jorm, A.F., Korten, A.E., Jacomb, P.A., Christensen, H., Rodgers, B. and Pollitt. P. (1997). Mental health literacy': A survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. Medical Journal of Australia, 166,182–86.

Jorm, A.F. (2000). Mental health literacy. Public knowledge and beliefs about mental disorders. The British Journal of Psychiatry, 177(5), 396–401.

Jorm, A.F., Barney, L.J., Christensen, H., Highet, N.J., Kelly, C.M., and Kitchener, B.A. (2006). Research on mental health literacy: what we know and what we still need to know. Australian and New Zealand Journal of Psychiatry, 40, 3–5.

Jorm, A.F., Christensen, H., and Griffiths, K.M. (2006). The public's ability to recognize mental disorders and their beliefs about treatment: changes in Australia over 8 years. *Australian and New Zealand Journal of Psychiatry, 40*(1), 36-41.

Jutel, A. (2009). Sociology of diagnosis: a preliminary review. Sociology of Health and Illness, 31(2), 278–99.

Kaiser, L. H.W.M. (2007). *Psychiatrie toegelicht*. Antwerpen: Garant.

Kassam, A., Glozier, N, Leese, M., Henderson, C. and Thornicroft, G. (2010). Development and responsiveness of a scale to measure clinicians' attitudes to people with mental illness (medical student version). *Acta Psychiatrica Scandinavia, 122*, 153–161.

Kawa, S. and Giordano, J. (2012). A brief historicity of the Diagnostic and Statistical Manual of Mental Disorders: Issues and implications for the future of psychiatric canon and practice. *Philosophy, Ethics and Humanities in Medicine, 7*(2).

Kirk, S. A. (1974). Impact of labeling on rejection of mentally ill - experimental study. *Journal of Health and Social Behavior, 15,*108-117.

Kirkewold, M. and Bergland, A. (2007). The quality of qualitative data: issues to consider when interviewing participants who have difficulties providing detailed accounts of their experiences. *International Journal of Qualitative studies on Health and Well-Being, 2,*68-75.

Kleinman, A., Eisenberg, L. and Good. B. (1978). Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine, 88*, 251–8.

Kleinman, A. and Hall-Clifford, R. (2009). Stigma: a social, cultural and moral process. *Journal of Epidemiology and Community Health, 63*, 418-419.

Kravetz S., Faust, M. and David, M. (2000). Accepting the mental illness label, perceived control over the illness, and quality of life. *Psychiatric Rehabilitation Journal, 23*(4), 323–32.

Kusow, A.M. (2004). Contesting stigma: on Goffman's assumptions of normative order. *Symbolic Interaction, 27*(2), 179–97.

Laing, R.D. (1967). *The Politics of Experience and The Bird of Paradise*. Penguin, England.

Larson, J. and Corrigan, P. (2008). The stigma of families with mental illness. *Academic Psychiatry, 32*(2), 87-91.

Lauber, C., Nordt, C., Falcato, L. and Rössler ,W. (2003). Do people recognize mental illness? Factors influencing mental health literacy. *European Archives of Psychiatry and Clinical Neuroscience, 253,* 248–51.

Lauber, C., Anthony, M., Ajdacic-Gross, V., and Rossler, W. (2004). What about psychiatrists' attitude to mentally ill people? *European Psychiatry, 19*, 423–427.

Lauber, C., Nordt, C., Braunschweig, C., and Rossler, W. (2006). Do mental health professionals stigmatize their patients? *Acta Psychiatrica Scandinavia,* Supplement, 51-59.

Laugharne, R. and Priebe, S. (2006). Trust, choice and power in mental health: a literature review. *Social Psychiatry and Psychiatric Epidemiology, 41*(11), 843-852.

Lee, S., Chiu, M.Y., Tsang, A., Chui, H. and Kleinman, A. (2006). Stigmatizing experience and structural discrimination associated with the treatment of schizophrenia in Hong Kong. Social Science and Medicine, 62,1685–96.

Linden, M. and Kavanagh, R. (2011). Attitudes of qualified vs. student mental health nurses towards an individual diagnosed with schizophrenia. *Journal of Advanced Nursing 68*(6), 1359–1368.

Link, B. G. (1982). Mental patient status, work, and income - an examination of the effects of a psychiatric label. *American Sociological Review, 47*, 202-215.

Link, B. G. and Cullen, F. T. (1983). Reconsidering the social rejection of ex-mental patients - Levels of attitudinal response. *American Journal of Community Psychology, 11*, 261-273.

Link, B. G., Cullen, F. T., Frank, J., and Wozniak,J. F. (1987). The social rejection of former mental patients - Understanding why labels matter. *American Journal of Sociology, 92*,1461-1500.

Link, B.G., Struening, E., Cullen, F.T., Shrout, P.E., and Dohrenwend, B.P. (1989). A Modified Labeling Theory Approach to Mental Disorders: An Empirical Assessment. *American Sociological Review, 54*, 400-423.

Link, B., Mirotznik, J. and Cullen, F. (1991).The effectiveness of stigma coping orientations: can negative consequences of mental illness labeling be avoided? *Journal of Health and Social Behavior, 32*, 302-32.

Link, B. G., Struening, E. L., Rahav, M., Phelan, J. C., and Nuttbrock, L. (1997). On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior, 38*, 177-190.

Link, B. G., and Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363–385.

Link, B. G., Yang, L. H., Phelan, J. C., and Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin, 30*, 511-541.

Link, B. and Phelan, J. (2013). Labeling and stigma. In Aneshensel C.S., Phelan, J. & Bierman, A. (eds.), *Handbook of the Sociology of Mental Health,* (Second Edition), Springer Dordrecht

Link, B. G. and Phelan, J. C. (2014a). Stigma Power. Social Science and Medicine, 103, 24–32.

Link, B.G. and Phelan, J.C. (2014b). Mental illness stigma and the sociology of mental health. In R.J. Johnson, R.J. Turner, B. Link (Eds*) Sociology of Mental health: Selected Topics from Forty Years 1970s-2010s,* (pp. 75-100), Springer.

Loch, A.A., Michael Pascal Hengartner, M.P., Guarniero, F.B., Lawson, F., Yuan-Pang Wang, Y., Gattaz, W.F. and Rössler, W. The more information, the more negative stigma towards schizophrenia: Brazilian general population and psychiatrists compared, *Psychiatry Research, 205*,185–191.

Loukidou, E., Ioannidi, V. and Kalokerinou-Anagnostipoulou, A. (2010). Institutionalized nursing staff: planning and developing a specialized educational framework that enhances psychiatric nurses' roles and promotes de-institutionalization. *Journal of Psychiatric and Mental Health Nursing, 17*, 829-837.

Lorant, V., Kampfl, D., Seghers, A., Deliège, D., Closen, M.C. and Ansseau, M. (2003). Socio-economic differences in psychiatric in-patient care. Acta Psychiatrica Scandinavia, 107, 170-177.

Lorant, V., Depuydt, C., Gillain, B., Guillet, A. and Dubois, V. (2007). Involuntary commitment in psychiatric care: what drives the decision? *Acta Psychiatrica Scandinavia, 107*, 170–177.

Major, B. and O'Brien, L. (2005). The social psychology of stigma. *Annual Review of Psychology, 56*, 393–421.

Malhi, G. S., Parker, G. B., Carr, V. J., Kirkby, K. C., Yellowlees, P., Boyce, P., et al. (2003). Attitudes toward psychiatry among students entering medical school. *Acta Psychiatrica Scandinavica, 107*, 424–429.

McDaid, D. (2005). *Mental health I: Key issues in the development of policy and practice across Europe.* Geneva: World Health Organization.

McGuire-Snieckus, R., McCabe, R. and Priebe, S. (2003). Patient, client or service user? A survey of patient preferences of dress and address of six mental health professions. *Psychiatric Bulletin, 27*,305-308.

Mills, J., Bonner, A., and Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods, 1*(5).

Mior, J. & Abraham, C. (1996). Why I want to be a psychiatric nurse: constructing an identity through contrasts with general nursing. *Journal of Advanced Nursing, 23*, 295-298.

Mirowsky, J. and Ross, C. (1989). Psychiatric diagnosis as reified instrument. *Journal of Health and Social Behavior, 30*, 11-25.

Mishra, D.K., Alreja, S., Sengar, K.S. and Singh, A.R. (2009). Insight and its relationship with stigma in psychiatric patients. Industrial Psychiatry Journal, 18(1), 39–42.

Morant, N. (2006). Social representations and professional knowledge: The representation of mental illness among mental health practitioners. *British Journal of Social Psychology, 45*, 817–838.

Muntaner, C., Ng, E., Vanroelen, C., Christ, S. and Eaton, W.W. (2013). Social stratification, social closure and social class as determinants of mental health disparities. In C.S. Aneshensel, J.C. Phelan, and A. Bierman (Eds.) *Handbook of the Sociology of Mental Health* (2nd. ed), (pp. 205–27). Dordrecht: Springer.

Natan, M.B., Drori, T. & Hochman, O. (2015). Associative stigma related to psychiatric nursing within the nursing profession. *Archives of Psychiatric Nursing, 29* (6), 388-392.

Nicaise, P., Dubois, V. and Lorant, V. (2014). Mental health care delivery system reform in Belgium: The challenge of achieving deinstitutionalisation whilst addressing fragmentation of care at the same time, *Health Policy, 115,* 120–127.

Nolan, P. (1993). *A history of mental health nursing*. Cheltenham: Stanley Thomas.

Nordt, C., Rossler, W., and Lauber, C. (2006). Attitudes of mental health professionals toward people with schizophrenia and major depression. *Schizophrenia Bulletin, 32*, 709-714.

Novella, E.J. (2010). Mental health care in the aftermath of deinstitutionalization: A retrospective and prospective view. *Health Care Analysis, 18,* 222–238.

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine, 67*, 2072–2078.

O'Brien, A. J. (1999). Negotiating the relationship: Mental health nurses' perceptions of their practice. *Australian and New Zealand Journal of Mental Health Nursing, 8*(4), 153-161.

Oeye, C., Bjelland A.K. and Skorpen, A. (2007). Doing participant observation in a psychiatric hospital-- research ethics resumed. *Social Science and Medicine, 65*(11), 2296-2306.

Ottati, V., Bodenhausen, G.V. and Newman, L.S. (2005). Social psychological models of mental illness stigma. In P.W. Corrigan (Ed.) *On the stigma of mental illness: practical strategies for research and social change* (pp. 99-128). Washington DC.: American Psychological Association

Page, S. (1977). Effects of the mental illness label in attempts to obtain accommodation. *Canadian Journal of Behavioral Sciences, 9*, 85–90.

Papen, U. (2009). Literacy, Learning and Health – A social practices view of health literacy. *Literacy & Numeracy Studies, 16*(2), 2009.

Parker, R., and Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine, 57*, 13–24.

Parsons, T. (1975). The sick role and role of physician reconsidered. *Health and Society, 53*, 257-278.

Patton, M.Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*(5), 1189-1208.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, California: Sage.

Pattyn, E., Verhaeghe, M., Sercu, C. and Bracke, P. (2013). Medicalizing versus psychologizing mental illness: what are the implications for help seeking and stigma? A general population study. *Social psychiatry and Psychiatric Epidemiology, 48*, 1637-1645.

Pattyn, E., Verhaeghe, M., Sercu, C., and Bracke, P. (2014). Public stigma and self-stigma: Differential association with attitudes toward formal and informal help seeking. *Psychiatric Services, 65(2*), 232–238.

Pavalko, E.K., Harding, C.M., and Pescosolido, B.A. (2007). Mental illness careers in an era of change. *Social Problems, 54*(4), 504-522.

Pearlin, L.I., Avison, W.R. and Fazio, E.M. (2007). Sociology, psychiatry, and the production of knowledge about mental illness and its treatment. In W. R. Avison, J. D. McLeod and B. A. Pescosolido. *Mental Health, Social Mirror*, ,(pp. 33-53). New York: Springer.

Perry, B.L. (2010). Taking the medical sciences seriously: Why and how medical sociology should incorporate diverse disciplinary perspectives. B.A. Pescosolido, J.K. Martin, J.D. McLeod, A. Rogers (Eds.), *Handbook of the Sociology of Health, Illness, and Healing: A Blueprint for the 21st Century, Handbooks of Sociology and Social Research* (pp.543-56), New York: Springer.

Perry, B.L. (2011).The Labeling Paradox: Stigma, the sick role, and social networks in mental illness. *Journal of Health and Social Behavior, 52*(4), 460-477.

Perry, B.L. and Pescosolido, B.A. (2012). Social network dynamics and biographical disruption: the case of 'first-timers' with mental illness. *American Journal of Sociology, 118*(1), 134-175.

Pescosolido, B.A., Gardner, C.B. and Lubell, K.M. (1998). How people get into mental health services: stories of choice, coercion and 'muddling through' from 'first-timers'. *Social Science and Medicine, 46*(2), 275-286.

Pescosolido, B.A. (2006). Professional Dominance and the Limits of Erosion. *Society, 43*(6), 21-29.

Pescosolido, B. A. and Martin, J. K. (2007). Stigma and the sociological enterprise. In W.R. Avison, J. D. McLeod, & B. A. Pescosolido (Eds.), *Mental health, Social mirror.* (pp. 307-328). New York: Springer.

Pescosolido, B.A., McLeod, J.D. and Avinson, W.R. (2007). Through the looking glass: the fortunes of the sociology of mental health. In W.R. Avison, J. D. McLeod, & B. A. Pescosolido (Eds.), *Mental health, Social mirror.* (pp. 3-32). New York: Springer.

Pescosolido, B. A., Martin, J. K., Lang, A., and Olafsdottir, S. (2008). Rethinking theoretical approaches to stigma: a Framework Integrating Normative Influences on Stigma (FINIS). *Social Science and Medicine, 67*, 431–440.

Pescosolido, B.A., Martin, J., Long, J.S., Medina, T.R., Phelan, J.C. and Link, B.G. (2010) "A Disease Like Any Other"? A Decade of Change in Public Reactions to Schizophrenia, Depression, and Alcohol Dependence. *American Journal of Psychiatry, 167,* 1321–1330.

Pescosolido, B.A. and Boyer, C.A. (2010). Understanding the context and dynamic social processes of mental health treatment. In T.L. Scheid & T.N. Brown (Eds.), *A Handbook for the Study of Mental Health* (2nd Ed.), 420-438. Cambridge: Cambridge University Press.

Phelan, J. C. and Link, B. G. (1999). The labeling theory of mental disorder: the role of social contingencies in the application of psychiatric labels. In A.Horwitz and T. L. Scheid (Eds.), *A handbook for the study of mental health* (pp. 139-160). Cambridge: Cambridge University Press

Phelan, J.C., Link, B.G., and Dovidio, J.F. (2008). Stigma and prejudice: one animal or two? *Social Science and Medicine, 67*,358–67.

Pilgrim, D., and Rogers, A. (1993). *A sociology of mental health and illness*. Buckingham: Open University Press.

Pilgrim, D. and Rogers, A. (2002). Mental Health and Inequality. Basingstoke: Palgrave Macmillan.

Pilgrim, D. and Rogers, A. (2005a). Social psychiatry and sociology. *Journal of Mental Health, 14*(4), 317–20.

Pilgrim, D. and Rogers, A. (2005b). Psychiatrists as social engineers: A study of an anti-stigma campaign. *Social Science & Medicine, 61*, 2546–2556.

Pilgrim, D. (2008). 'Recovery' and current mental health policy. *Chronic Illness, 4*, 295–304.

Porter, S. (1993). The determinants of psychiatric nursing practice: a comparison of sociological perspectives. *Journal of Advanced Nursing, 18*(10), 1559-1566.

Priebe, S., Badesconyi, A., Fioritti, A., Hansson, L., Kilian, R., Torres-Gonzales, F. et al. (2005). Reinstitutionalisation in mental health care: comparison of data on service provision from six European countries. *British Medical Journal, 330*, 123–126.

Prior, L. (1993). *The social organization of mental illness*. London: Sage.

Purdie-Vaughns, V. and Eibach, R.P. (2008). Intersectional invisibility: the distinctive advantages and disadvantages of multiple subordinate-group identities. *Sex Roles, 59*, 377-391.

Rabkin, J.G. (1974). Public attitudes toward mental illness: a review of the literature. *Schizophrenia Bulletin, 10*, 9-33.

Rapley, T. (2014). Sampling strategies in qualitative research. In U. Flick (ed.). *The Sage handbook of qualitative data analysis* (pp.49-63). London: Sage.

Razali, S.M., Khan, U.A. and Hasanah, C.I. (1996). Belief in supernatural causes of mental illness among Malay patients: impact on treatment. *Acta Psychiatrica Scandinavica, 94*, 229-233.

Read J, Haslam N, Sayce L. and Davies E. (2006). Prejudice and schizophrenia: a review of the mental illness is an illness like any other approach. *Acta Psychiatrica Scandinavia, 114*, 303-318.

Reeves, C.L. (2010). A difficult negotiation: fieldwork relations with gatekeepers. *Qualitative Research, 10*(3), 315-331.

Rissmiller, D.J. and Rissmiller, J.H. (2006). Evolution of the antipsychiatry movement into mental health consumerism. *Psychiatric Services, 57*(6):863-6.

Rosenfield, S. (1997). Labeling Mental Illness: the effects of received services and perceived stigma on life satisfaction. *American Sociological Review, 62*, 660-672.

Rosenhan, D. L. (1973). Being Sane in Insane Places. *Science, 179,* 250-258.

Rogers, A. and Pilgrim, D. (1993). Service users' views of psychiatric treatments. *Sociology of Health & Illness, 15*(5), 612-631.

Rogers, A. and Pilgrim, D. (2011). Medical sociology and its relationship to other disciplines: the case of mental health and the ambivalent relationship between sociology and psychiatry. In B.A. Pescosolido, J.K. Martin, J.D. McLeod, and A. Rogers (Eds.). *Handbook of the Sociology of Health, Illness, and Healing: A Blueprint for the 21st Century*, (pp. 21–37), New York: Springer.

Rogers, A. and Pilgrim, D. (2014). *A sociology of mental health and illness.* Berkshire: Open University Press.

Ross, C. A. and Goldner, E. M. (2009). Stigma, negative attitudes and discrimination towards mental illness within the nursing profession: a review of the literature. *Journal of Psychiatric and Mental Health Nursing, 16*, 558-567.

Rusch, N., Angermeyer, M.C. and Corrigan, P.W. (2005). Mental illness stigma: concepts, consequences, and initiatives to reduce stigma. *European Psychiatry, 20* (8),529-39.

Rusch, N., Todd, A. R., Bodenhausen, G. V. and Corrigan, P. W. (2010). Do people with mental illness deserve what they get? Links between meritocratic worldviews and implicit versus explicit stigma. *European Archives of Psychiatry and Clinical Neuroscience, 260*, 617-625.

Sadow, D. and Ryder, M. (2008). Reducing stigmatizing attitudes held by future health professionals: The person is the message. *Psychological Services, 5*(4), 362-372.

Samele, C., Frew, S., and Urquía, N. (2012). *Mental health systems in the European Union member states, status of mental health in populations and benefits to be expected from investments into mental health.* Brussels: European Commission.

Sartorius, N. (1998). Stigma: what can psychiatrists do about it. *The Lancet, 352,* 1058-1059.

Sartorius, N. (2002). Iatrogenic stigma of mental illness. *British Medical Journal*, 324,1470 – 1471.

Sartorius, N. (2007). Stigma and mental health. *The Lancet, 370*(8), 810-811.

Scambler, G. (2006). Sociology, social structure and health-related stigma. *Psychology, Health and Medicine, 11*(3), 288-295.

Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness, 31*, 441–455.

Sharma, V., Whitney, D., Kazarian, S. and Manchanda, R. (2000). Preferred terms for users of mental health services among service providers and recipients. *Psychiatric Services, 52*(2), 203-209.

Scheerder, G., Van Audenhove, C., Arensman, E., Bernik, B., Guipponi, G., Horel, A., Maxwell, M., Sisask, M., Szekely, A., Värnik, A. and Hegerl, U. (2010). Community and health professionals' attitude toward depression: a pilot study in nine EAAD countries. *International Journal of Social Psychiatry, 57*(4): 387–401.

Scheff, T.J. (1966). *Being mentally ill: A Sociological Theory.* London: Weidenfeld and Nicolson.

Scheff, T.J. (1999). *Being mentally ill: A Sociological Theory* (third edition). New York: De Gruyter.

Schilling, C. (2002). Culture, the 'sick role' and the consumption of health. *The British Journal of Sociology, 53*(4), 621-638.

Schlossberg, A. (1993). Psychiatric stigma and mental health professionals (stigmatizers and de-stigmatizers). *Medicine and Law, 12*, 409-416.

Schomerus, G. and Angermeyer, M.C. (2008). Stigma and its impact on help-seeking for mental disorders: what do we know? *Epidemiologia e Psichiatria Sociale, 17*(1), 31-37.

Schulze, B. and Angermeyer, M.C. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. Social Science and Medicine, 56, 299–312.

Schulze, B. (2007). Stigma and mental health professionals: A review of the evidence on an intricate relationship. International Review of Psychiatry, 19, 137–55.

Scull, A.T. (1977). Madness and segregative control: The rise of the insane asylum. *Social Problems, 24*(3), 337-351.

Sercu, C., Verhaeghe M., Pattyn, E. and Bracke, P. (2010). *Onderzoek naar moeilijk doorverwijsbare zorggebruikers in de GGZ Regio Groot Gent*. Eindrapport. Universiteit Gent, Vakgroep Sociologie.

Sercu, C., Ayala, R. A., and Bracke, P. (2014). How does stigma influence mental health nursing identities. An ethnographic study on the meaning of stigma for nursing role identities in two Belgian psychiatric hospitals. *International Journal of Nursing Studies, 51*(1), 307–316.

Sercu, C., Pattyn, E. and Bracke, P. (2015). Exploring identity dynamics in mental help-seeking trajectories: an ethnographic study among inpatient service users of two Belgian psychiatric hospitals. *Archives of psychiatric nursing, 29*, 114-119.

Sirey,J., Bruce, L., Alexopoulos, G., Perlick, D., Friedman, S. and Meyers, B. (2001). Stigma as a barrier to recovery. Perceived Stigma and Patient-Rated Severity of Illness as Predictors of Antidepressant Drug Adherence. *Psychiatric Services, 52*(12), 1615-1620.

Smith, R. A. (2007). Language of the lost: An explication of stigma communication. *Communication Theory, 17*, 462-485

Steele, C.M., Spencer, S.T. and Aronson, J. (2002). Contending with group image: the psychology of stereotype and social identity threat. *Advances in Experimental Social Psychology, 34,* 379-440.

Stockman, R. (2000). *Van nar tot patiënt. Een geschiedenis van de zorg voor geesteszieken.* Leuven: Davidsfonds.

Strauss, A. and Corbin, J. (1990). *Basics of qualitative research: grounded theory procedures and techniques.* Newbury Park, California: Sage.

Stryker, S. and Burke, P.J. (2000). The Past, Present, and Future of an identity theory. *Social Psychology Quarterly, 63*, 284-297.

Szasz, T. (1970). *The manufacture of madness: A comparative study of the inquisition and the mental health movement.* Syracuse: Syracuse University Press.

Taskanen, S., Morant, N., Hinton, M., Lloyed-Evans, B., Crosby, M., Killaspy, H., et al. (2011). Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study. *BMC Psychiatry, 11*(157).

Tausig, M., Michello, J. and Subedi, S. (1999). *A sociology of mental illness*. Upper Saddle River: Prentice-Hall.

Taylor, S. M., and Dear, M. (1981). Scaling community attitudes toward the mentally ill. *Schizophrenia Bulletin, 7*, 225-240.

Tedlock, B. (2005). The observation of participation and the emergence of public ethnography. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd Ed.), 467-482. Thousand Oaks, California: Sage.

Thachuk, A.K. (2011). Stigma and the politics of biomedical models of mental illness, International Journal of Feminist Approaches to Bioethics, 4(1), 140-163.

The Economist Intelligence Unit. (2014). Mental health and Integration. Provision for supporting people with mental illness: a comparison of 30 European countries. Geneva: The Economist.

Thoits, P.A. (1985). Self-labeling processes in mental illness - the role of emotional deviance. *American Journal of Sociology, 91*,221-249.

Thoits, P.A. (2005). Differential labeling of mental illness by social status: A new look at an old problem. *Journal of Health and Social Behavior, 46*, 102-119.

Thoits, P.A. and Evenson., R.J. (2008). Differential labeling of mental illness revisited: Patterns before and after the rise of managed care. *Sociological Forum 23*, 28–52.

Thoits, P.A. (2011). Resisting the Stigma of Mental Illness. *Social Psychology Quarterly, 74*, 6-28.

Thoits, P.A. (2013). Self, identity, stress and mental health. In C.S. Aneshensel, J.C. Phelan, & A. Bierman (Eds.), *Handbook of Sociology of Mental Health* (2nd Ed.), (pp.357-378), Dordrecht: Springer.

Thornicroft, G. and Bebbington, P. (1989). Deinstitutionalisation – from hospital closure to service development. *British Journal of Psychiatry, 155*(155), 739–753.

Thornicroft, G. and Tansella, M. (2004). Components of a modern mental health service: a pragmatic balance of community and hospital care: overview of systematic evidence. *British Journal of Psychiatry, 185*, 283-290.

Thornicroft, G., D. Rose, and A. Kassam. (2007). Discrimination in health care against people with mental illness. *International Review of Psychiatry, 19*, 113–122.

Tilley, S. (2005). *Psychiatric and mental health nursing: the field of knowledge.* Oxford: Wiley-Blackwell.

Ungar, T. and Knaak, S. (2013). The hidden medical logic of mental health stigma. *Australian and New Zealand Journal of Psychiatry, 47*(7), 611 –612.

Van der Geest, S. and Finkler, K. (2004). Hospital ethnography: introduction. *Social Science and Medicine, 59*(10), 1995-2001.

Vandeurzen, J. (2010). *Beleidsplan geestelijke gezondheidszorg Vlaanderen.* Brussel: Vlaamse Regering.

Van Hecke, J., Joos, L., Daems, J., Matthysen, V., & De Bruyne, S. (2011). Reorganisatie van de Belgische GGZ; betere zorg voor mensen met ernstige psychiatrische aandoeningen? *Tijdschrift voor Psychiatrie, 53*, 917–926.

Vaughan, G., and Hansen, C. (2004). 'Like minds, like mine': a New Zealand project to counter the stigma and discrimination associated with mental illness. *Australasian Psychiatry, 12*, 113-117.

Verhaeghe, M. and Bracke, P. (2007). Organizational and individual level determinants of stigmatization in mental health services. *Community Mental Health Journal, 43*(4), 375-399.

Verhaeghe, M., Bracke, P. and Bruynooghe, K. (2007). Stigmatization in different mental health services: A comparison of psychiatric and general hospitals. *The Journal of Behavioral Health Services and Research, 34*(2), 186-197.

Verhaeghe, M., Bracke, P. and Bruynooghe, K. (2008). Stigmatization and self-esteem of persons in recovery from mental illness, the role of peer support. International *Journal of Social Psychiatry, 54*(3), 206–218.

Verhaeghe, M. (2008). *Stigma, een wereld van verschil? Een sociologische studie naar stigma-ervaringen in de geestelijke gezondheidszorg*. Gent.

Verhaeghe, M. and Bracke, P. (2012). Associative stigma among mental health professionals: implications for professional and service user well-being. *Journal of Health and Social Behavior, 53*(1), 17-32.

Verouden, N.W., Vonk, P. and Meijman, F.J. (2010). Context guides illness-identity: a qualitative analysis of Dutch university students' non-help-seeking behavior. *International Journal of Adolescence Medicine and Health, 22*(2), 307-20.

Wahl, O.F. (1999). Mental health consumers' experience of stigma. Schizophrenia Bulletin, 2, 467–478.

Wahl, O., and Aroesty-Cohen, E. (2010). Attitudes of mental health professionals about mental illness: A review of the recent literature. *Journal of Community Psychology, 38*, 49–62.

Wakefield, J.C. (1992). The concept of mental disorder: On the boundary between biological facts and social value. *American Psychologist, 47*(3), 373-388.

Wang, P.S., Berglund, P., Olfson, M., Pincus, H.A., Wells, K.B., and Kessler, R.C. (2005). Failure and delay in initial treatment contact after first onset of mental disorders in the national comorbidity survey replication. *Archives of General Psychiatry, 62*, 603-6013.

Weinberg, D. (2005). *Of Others Inside: Insanity, Addiction And Belonging in America*. Philadephia: Temple University Press.

Weiner, B., Perry, R. P., and Magnusson, J. (1988). An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology, 55*(5), 738-748.

Weinstein, R.M. (1983). Labeling theory and the attitudes of mental patients: a review, *Journal of Health and Social Behavior, 24*,70-84.

WHO (2004). *The World Health Report 2004. Changing History*. Geneva: World Health Organization.

WHO (2013). *Mental health action plan 2013 – 2020*. Geneva: World Health Organization.

Wright, A., Jorm, A.F., Harris, M.G., and McGorry, P.D. (2007). What's in a name? Is accurate recognition and labelling of mental disorders by young people associated with better help-seeking and treatment preferences? *Social Psychiatry and Psychiatric Epidemiology, 42*, 244-250.

Yang, L.H., Kleinman, A., Link, B.G., Phelan, J.C., Lee, S. and Good. B. (2007). Culture and stigma: adding moral experience to stigma theory. *Social Science and Medicine 64*, 1524–1535.

Young, J.T. (2004). Illness behaviour: a selective review and synthesis. *Sociology of Health & Illness, 26*(1), 1-31.

Zayas, L.H., Cabassa, L.J. and Perez, M.C. (2005). Capacity-to-consent in psychiatric research: development and preliminary testing of a screening tool. *Research on Social Work, 15*(6), 545-556.

APPENDIX

Appendix 1: Short questionnaire service users

VRAGENLIJST HULPVERLENING IN DE PSYCHIATRIE

centrum/ziekenhuis	
Afdeling	

OVER JEZELF

1. U bent een … :

   O vrouw   O man

2. Uw leeftijd: … jaar

3. In welke regio woont u?

………………………………………….

4. Staat uw domicilie op het adres van het ziekenhuis?

O neen   O ja

5. Welk is uw hoogst behaalde diploma?

O lager middelbaar onderwijs   O hogeschool korte type (max. 3 jaar)

O hoger middelbaar onderwijs BSO zonder 7^e jaar   O hogeschool lange type (4 jaar)

O hoger middelbaar onderwijs BSO met 7^e jaar   O universitair

O hoger middelbaar onderwijs TSO   O andere: …………

O hoger middelbaar onderwijs ASO

6. Wat is de naam of titel van uw hoofdberoep?

    …………………………………………………..

7. Wat is uw werksituatie op dit moment ….

O voltijds werkend

O halftijds werkend

O minder dan halftijds werkend

O tijdelijk afwezig van het werk

O zelfstandige

O huisvrouw/huisman

O werkeloos

O student

O gepensioneerd

O steuntrekkend

O andere: …

8. Wat is uw burgerlijke staat?

O gehuwd

O weduwnaar/weduwe

O wettelijk gescheiden

O feitelijk gescheiden

O samenwonend met partner

O ongehuw

9. Wat is het beroep van uw partner? (indien u een partner hebt)

………………………….

10. Heeft u kinderen? Zoja, hoeveel?

....

11. Wat is de leeftijd van uw kinderen?

……………………

12. Is het de eerste keer dat u in een psychiatrisch centrum verblijft?

O ja   O neen

13. Waar verbleef u eerder al (indien 12. Neen)?

……………………..

14. Hoe lang verblijft u al op deze afdeling?

…………………………

Appendix 2: Short questionnaire professionals

VRAGENLIJST HULPVERLENING IN DE PSYCHIATRIE

centrum/ziekenhuis	
Afdeling	
hoofdberoep	

OVER JEZELF

1. U bent een … :

 O vrouw O man

2. Uw leeftijd: … jaar

3. Welk is uw hoogste behaalde diploma?

 O lager middelbaar onderwijs O hogeschool korte type (max. 3 jaar)

 O hoger middelbaar onderwijs BSO zonder 7^e jaar O hogeschool lange type (4 jaar)

 O hoger middelbaar onderwijs BSO met 7^e jaar O universitair

 O hoger middelbaar onderwijs TSO O andere: ….

 O hoger middelbaar onderwijs ASO

4. Welke diploma('s) hebt u?

 O psychiatrisch verpleegkundige O kinesitherapeut

 O sociaal verpleegkundige O psycholoog

 O ziekenhuisverpleegkundige O psychiater

 O ergotherapeut O andere: …

 O maatschappelijk werker

 O opvoeder

5. Op welke afdeling en met welke behandelgroep werkt u? Indien meerdere, graag aanduiding % van je tijd: bv. 30% in afdeling A en 70% in afdeling B.

………
…………….

6. Hoeveel uren werkt u per week (overuren niet inbegrepen)?   ...   uur

7. Hoe vaak maakt u overuren?

   O nooit

   O één of enkele keren per jaar

   O één of enkele keren per maand

   O één of enkele keren per week

   O (bijna) dagelijk

8. Hoe lang werkt u al in het ziekenhuis?
……………….

9. Hoe lang werkt u al op de afdeling?
…………........

10. Werkte u vroeger nog op andere afdelingen of in andere ziekenhuizen? (zo ja, waar?)

   …………………………………………..

Appendix 3: Information form

UNIVERSITEIT GENT

Informatieformulier voor deelnemers aan het onderzoek

Titel onderzoek:

> Studie naar aspecten van hulpverleningsrelaties die bijdragen tot een positieve
> hulpverleningservaring van patiënten in een psychiatrisch ziekenhuis.

Verantwoordelijke onderzoeker: Piet Bracke

Beste,

Charlotte Sercu nodigt u uit om deel te nemen aan een wetenschappelijk onderzoek van de Universiteit Gent. Zij is doctoraatsstudente aan de vakgroep sociologie en dit onderzoek maakt deel uit van haar doctoraatsonderzoek. Het onderzoek wordt volledig door Charlotte Sercu uitgevoerd en staat onder het promotorschap van professor Piet Bracke. Het is belangrijk dat u weet waarom dit onderzoek wordt gedaan, wat het inhoudt en wat concreet van u wordt gevraagd als deelnemer. Daarom vindt u alle informatie over het onderzoek in de tekst hieronder.

1. Wat is het doel van het onderzoek en wat houdt het in?

De komende 3 jaar wordt in dit project onderzocht welke aspecten van hulpverleningsrelaties in het psychiatrisch ziekenhuis bijdragen aan een positieve hulpverleningservaring bij patiënten.

2. Beschrijving van de inhoud van de studie?

Om de onderzoeksvraag uit de vorige paragraaf te beantwoorden wordt ten eerste bestudeerd hoe patiënten hun begeleiding door hulpverleners ervaren. Hiervoor zal Charlotte Sercu informatie verzamelen over:

- de motivaties van patiënten om zich te laten begeleiden

- de algemene verwachtingen die patiënten hebben van de behandeling en begeleiding

- de specifieke verwachtingen die patiënten hebben van hulpverleners

- de redenen voor bepaalde verwachtingen van patiënten

- de manier waarop patiënten de hulpverlening evalueren

- de activiteiten die patiënten doorbrengen samen met een hulpverlener

- de ervaren moeilijkheden tijdens de behandeling en het leven op de afdeling

- de positieve ervaringen tijdens de behandeling en het leven op de afdeling

Ten tweede zal bestudeerd worden hoe hulpverleners de begeleiding van patiënten zien en ervaren. Hiervoor zal informatie verzameld worden over:

- de methodiek die de begeleiding en behandeling stuurt

- de professionele doelstellingen en taken van de hulpverleners

- de persoonlijke motivatie van de hulpverleners om hun job uit te oefenen

- de verwachtingen die hulpverleners hebben tegenover patiënten

- de manier waarop hulpverleners hun relaties met patiënten evalueren

- de ervaren moeilijkheden bij het begeleiden van patiënten

- de positieve ervaringen in de begeleiding van patiënten

- de betekenis van informele contacten met patiënten, bijvoorbeeld: op de gang, tijdens lunchpauzes

- de samenwerking tussen hulpverleners

Ten derde zal bestudeerd worden hoe de relatie hulpverlener – patiënt wordt georganiseerd.

3. Beschrijving van de uitvoering van de studie?

Om de ervaringen van patiënten en hulpverleners te onderzoeken, wordt ervoor gekozen om op drie afdelingen van het ziekenhuis onderzoek te doen: een afdeling angst en stemmingstoornissen, een afdeling psychosenzorg en een dagcentrum.

Omdat het belangrijk is, dat de onderzoeker bij de start van zijn onderzoek de werking op de afdelingen leert kennen; en de hulpverleners en de patiënten leert kennen, wordt ervoor gekozen om de afdeling een kijk- en luisterstage volgen (3 tot 5 dagen per week gedurende 6 à 8 weken). Tijdens deze stage zullen zo veel mogelijk activiteiten op de afdeling gevolgd worden. Ook zullen de vergaderingen van hulpverleners bijgewoond worden.

Naast de kijk – en luisterstage zullen ook semigestructureerde interviews afgenomen worden bij hulpverleners en patiënten die dit willen. Met patiënten zal gepraat worden praten over hun ervaringen met de begeleiding en behandeling op de afdeling. Met hulpverleners zal gepraat worden over de inhoud van hun job en over hun motivatie om de job te doen.

4. Verloop van het onderzoek

Concreet zal het eerste deel van het onderzoek (week 1&2) besteedt worden aan participerende observatie. Dat betekent dat de onderzoeker op de afdeling aanwezig zal zijn en samen met jullie zal deelnemen aan de geplande activiteiten. Tijdens het tweede deel van de studie (week 3 tot 7) zullen patiënten en hulpverleners uitnodigt voor een interview tijdens mijn aanwezigheid. Iedereen op de afdeling die wil deelnemen aan het interview zal geïnterviewd worden.

Schema studieverloop

Week 1 &2	Participerende observaties (3 à 5 dagen per week)
Week 3 tot 7	Participerende observaties (3 dagen per week)
	Semigestructureerde interviews met hulpverleners
	Semigestructureerde interviews met patiënten

5. Wat wordt verwacht van de deelnemers

Er worden geen specifieke verwachtingen gesteld tegenover de deelnemers.

6. Vrijwillige deelname en vertrouwelijkheid

Iedereen kan vrij kiezen of hij/zij wil deelnemen aan het semigestructureerd interview. Als u beslist hebt om deel te nemen kunt u op een later moment nog altijd uw mening herzien.

Het semigestructureerde interview kan eventueel op een recorder opgenomen worden, maar dit kan enkel als u hiervoor toestemming geeft. Na de verwerking van de informatie worden de opnames vernietigd.

De privacy van alle informatie die geeft, wordt strikt gerespecteerd. Enkel de onderzoeker mag de informatie inkijken.

Het verwerken van de informatie die de onderzoeker verzamelt voor het onderzoek gebeurt anoniem. Dit betekent dat personen en afdelingen niet herkend kunnen worden in het verslag van het onderzoek. Iedereen krijgt een andere naam of 'pseudoniem' en persoonlijke informatie wordt nooit samen met het pseudoniem in het verslag opgenomen.

7. Kosten

De deelname aan het onderzoek brengt geen kosten met zich mee.

8. Letsel ten gevolge van deelname aan de studie.

De onderzoeker voorziet in een vergoeding en/of medische behandeling in het geval van schade en/of letsel tengevolge van deelname aan de studie. Voor dit doeleinde is een verzekering afgesloten met foutloze aansprakelijkheid conform de wet inzake experimenten op de menselijke persoon van 7 mei 2004. Op dat ogenblik kunnen uw gegevens doorgegeven worden aan de verzekeraar.

9. Bedanking

Op het einde van de onderzoeksperiode zullen alle personen die op de afdeling werken of begeleid worden, bedankt worden met een presentje.

10. Contactpersoon

Als u na het lezen van deze tekst of tijdens het onderzoek nog vragen hebt over de inhoud van de studie of over uw rechten en plichten als deelnemer, mag u deze altijd aan Charlotte Sercu stellen. Dit kan tijdens haar aanwezigheid op de afdeling.

Appendix 4: Informed consent form

FACULTEIT POLITIEKE EN SOCIALE WETENSCHAPPEN

UNIVERSITEIT GENT

Vakgroep Sociologie

Verklaring tot toestemming voor deelname aan het onderzoek:

Titel onderzoek:

Studie naar aspecten van hulpverleningsrelaties die bijdragen tot een positieve hulpverleningservaring van patiënten in een psychiatrisch ziekenhuis.

Verantwoordelijke onderzoeker: Piet Bracke

Ik, ondergetekende, heb een exemplaar van de informatieformulier ontvangen. Ik ben op de hoogte gebracht van het doel van het onderzoek en de manier waarop de onderzoeker tewerk zal gaan. Ik heb het informatieformulier voor deelnemers aan het onderzoek gelezen. Ik doe vrijwillig mee aan dit onderzoek en ik kan op elk moment beslissen om niet meer mee te werken.

Ik werd ingelicht over het bestaan van een verzekeringspolis in geval er problemen zou ontstaan dat aan de studieprocedures is toe te schrijven.

Ik weet dat deze studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent.

Ik mag op elk moment beslissen om toch niet deel te nemen zonder hier een reden voor op te geven.

Naam vrijwilliger:

Datum:

Handtekening:

Faculteit Politieke en Sociale Wetenschappen – Vakgroep Sociologie
Korte Meer 5 – 9000 Gent   I

Ik bevestig dat ik de aard, het doel, en de procedure van de studie heb uitgelegd aan de bovenvermelde vrijwilliger.

De vrijwilliger stemde toe om deel te nemen door zijn/haar persoonlijk gedateerde handtekening te plaatsen.

Naam van de persoon
die voorafgaande uitleg
heeft gegeven: _____

Datum: _____

Handtekening:

Appendix 5: Interview scheme (service users)

1. **Vragen die peilen naar de 'motivatie' van de patiënt om zich te laten begeleiden.**

- *Hoe bent u op deze afdeling terecht gekomen?*

2. **Vragen die peilen naar de contacten die patiënten onderhouden met familie, vrienden en het werk.**

- *Heeft u contact met familie tijdens uw opname? Hoe vaak?*
- *Wat doen jullie samen? Komen ze op bezoek?*

- *Heeft u contact met vrienden? Komen ze op bezoek?*
- *Hoe reageren ze op je opname?*

- *U bent op dit moment aan het werk?*
- *Vertelde u uw werkgever dat u psychiatrische problemen hebt? Waarom (niet)?*
- *Wanneer bent u gestopt met werken? Wat was hiervoor de aanleiding?*

3. **Vragen die peilen naar verwachtingen van patiënten over de begeleiding.**

- *Kan u zeggen wat u verwachtte van de opname toen u hier werd opgenomen?*

- *Kan u zeggen wat voor u een goeie verpleegkundige is?*
- *Waarom vindt u 'de aspecten die u aanhaalt' belangrijk?*
- *Kan u zeggen wat voor u een goeie psychiater is?*
- *Waarom vindt u 'de aspecten die u aanhaalt' belangrijk?*
- *Kan u zeggen wat voor u een goeie maatschappelijk werker is?*
- *Waarom vindt u 'de aspecten die u aanhaalt' belangrijk?*

4. **Vragen die peilen naar de evaluatie van de begeleiding door patiënten.**

- *Kan u zeggen wat u goed vindt aan de begeleiding die u hier krijgt?*
- *Waarom vindt u 'de aspecten die u aanhaalt' belangrijk?*
- *Zijn er elementen van de begeleiding die volgens u beter kunnen? Welke?*

- *Welke activiteiten die hier georganiseerd worden vindt u goed? Waarom?*
- *Welke activiteiten vindt u minder goed? Waarom?*

5. **Vraag die peilt naar de ervaringen met medicatie.**

- *Hoe ervaart u het gebruik van medicatie?*

6. **Vraag die peilt naar de betekenis van herstel voor de patiënt.**

- *Wat betekent herstel voor u?*

Appendix 6: Interview scheme (professionals)

1. **Vragen die peilen naar de motivatie van de hulpverlener om zijn/haar job uit te oefenen.**

- *Kunt U uw job omschrijven?*
- *Waarom hebt u gekozen voor deze job?*
- *Wat wil u persoonlijk bereiken in u job?*

2. **Vragen die peilen naar de werking van de afdeling en de visie van de hulpverlener op deze werking.**

- *Hoe zou u een patiënt omschrijven die op deze afdeling behandeld kan worden?*
- *Welke zijn de inclusiecriteria?*
- *Welke zijn de exclusiecriteria?*
- *Is de groepssamenstelling belangrijk voor de opname van een nieuw persoon?*

- *Hoe wordt een profiel van een patiënt opgemaakt en door wie?*
- *Hoe belangrijk is de psychiatrische diagnose voor u in de opmaak van dit profiel?*

- *Waarvan is het gebruik van ziektebeelden in uw communicatie met andere hulpverleners afhankelijk?*
- *Waarvan is het gebruik van ziektebeelden in uw communicatie met patiënten afhankelijk?*

- *Waarom heeft de afdeling gekozen voor … therapeutische benadering? Hoe draagt deze benadering volgens u bij aan een goede hulpverlening voor de patiënten?*

- *Wat zijn volgens u de rol en het belang van medicatie in de begeleiding?*

3. *Vragen die peilen naar hulpverleningservaringen van de hulpverlener*

- *Hoe zou u een succesvol begeleidingstraject omschrijven?*
- *Welke zijn volgens u de factoren die dit traject succesvol maken?*
- *Welke zijn volgens u de factoren die voor problemen kunnen zorgen?*
- *Hoe belangrijk is volgens u de aanwezigheid van een sociaal netwerk (familie, vrienden) in de begeleiding van patiënten?*
- *Waarom vindt u de aanwezigheid van een sociaal netwerk wel/niet belangrijk?*
- *Is het volgens u anders werken met mensen die geen woonst hebben? Waarom?*
- *Is het anders werken met mensen geen job hebben? Waarom?*

- *Wat vindt u leuk aan uw job als 'functie'? Waarom?*
- *Wat vindt u het minder leuk aan uw job als 'functie'? Waarom?*
- *Wat vindt u het moeilijkste aan uw job als 'functie'? Waarom?*

- *Hoe ervaart u het werken in team in het algemeen?*
- *Wat vindt u positief aan het werken in team?*
- *Wat vindt u minder positief aan het werken in team?*

- *Is de manier van werken veranderd in de periode dat u hier werkt?*
- *Wat zijn volgens u de huidige sterke punten van de afdeling?*
- *Wat kan er volgens u nog verbeterd worden aan de werking?*

- *Wordt u met stigma geconfronteerd in uw job? Op welke manier?*

4. Vragen die peilen naar uw visie op vermaatschappelijking van zorg.

- *Wat zijn volgens u voorwaarden voor een succesvolle vermaatschappelijking van zorg in België?*
- *Kan Artikel 107 volgens u bijdragen tot een succesvolle vermaatschappelijking van zorg?*
- *Welke zijn vandaag de grootste barrières voor deze vermaatschappelijking volgens u?*
- *Hoe zijn deze te overkomen? Hoe ziet u uw rol daarin?*