

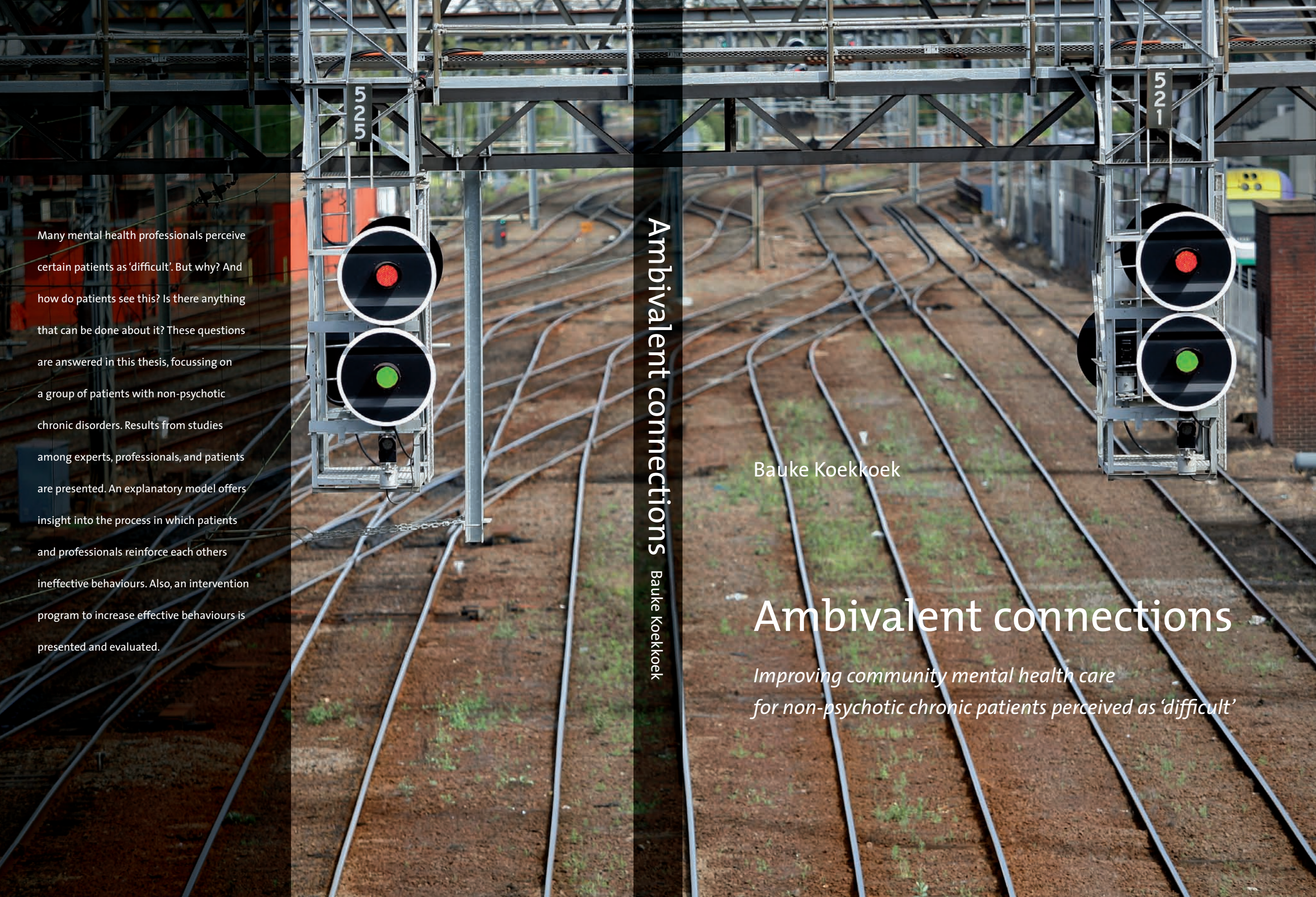
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Many mental health professionals perceive certain patients as 'difficult'. But why? And how do patients see this? Is there anything that can be done about it? These questions are answered in this thesis, focussing on a group of patients with non-psychotic chronic disorders. Results from studies among experts, professionals, and patients are presented. An explanatory model offers insight into the process in which patients and professionals reinforce each others ineffective behaviours. Also, an intervention program to increase effective behaviours is presented and evaluated.

Ambivalent connections Bauke Koekkoek

Bauke Koekkoek

Ambivalent connections

*Improving community mental health care
for non-psychotic chronic patients perceived as 'difficult'*

voor
mijn onverstoorbare dochters
Renske en Noor

'As a matter of fact, nothing I might write could make any difference whatever. It would only be a 'book' at the best. If it were a safely dangerous one it would be 'scientific' or 'political' or 'revolutionary.' If it were really dangerous it would be 'literature' or 'religion' or 'mysticism' or 'art,' and under one such name or another might in time achieve the emasculation of acceptance. If it were dangerous enough to be of any remote use to the human race it would be merely 'frivolous' or 'pathological,' and that would be the end of that.'

James Agee & Walker Evans, *Let us now praise famous men*, 1941

'Overmoed is net zo belangrijk als talent: ik *kan* het niet maar ik *doe* het toch.'

Tommy Wieringa, *Joe Speedboot*, 2005

Bauke Koekkoek

Ambivalent connections

*Improving community mental health care
for non-psychotic chronic patients perceived as 'difficult'*

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Ambivalent connections

*Improving community mental health care
for non-psychotic chronic patients perceived as 'difficult'*

Een wetenschappelijke proeve op het gebied van de

SOCIALE WETENSCHAPPEN

Proefschrift

Ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. mr. S. C. J. J. Kortmann,
volgens besluit van het college van decanen
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Introduction

This thesis concerns patients that are perceived as 'difficult' by professionals in mental health care. It is a study of an interpersonal phenomenon with moral implications (judging patients) related to a specific context (community mental health care), taking place between a subgroup of professionals (community mental health professionals, among whom psychiatric nurses in particular) and a subgroup of psychiatric patients (non-psychotic chronic patients). Labelling patients as 'difficult' runs contrary to past and current developments of jointly shaped care arrangements that focus on patients' autonomy, empowerment, shared decision making, rehabilitation, and recovery (e.g. Slade, 2009). Yet in daily mental health practice, certain patients are easily and frequently referred to as 'difficult', not just by one but by several distinct professionals. There appears to be some logic in perceiving patients with certain characteristics, such as aggressive or demanding behaviour, as 'difficult' (Groves, 1978). The process and context of this phenomenon, however, is poorly researched but is highly relevant in daily practice for patients and professionals alike, since the 'difficult'-label may be detrimental to patients' health and social outcomes (e.g. Colson et al., 1985), as well as to the professional's work satisfaction and well-being (e.g. Hinshelwood, 1999).

In this introductory chapter, three pertinent issues in mental health practice that form the background of this research will be described. After defining the problem and the research aims, the structure of this thesis will be outlined.

Issues in mental health practice

Three interrelated issues are of importance to this research project. First, the presence of patients perceived as difficult by professionals working in mental health services. Second, the increasing specialization of mental health services and professionals along the lines of diagnostic categories. Third, the limited content and specificity of (community) psychiatric nursing interventions in mental health services.

> *'Difficult' patients*

Patients that are perceived as 'difficult' exist across all health care settings, including primary (Steinmetz et al., 2001) and specialist care (Hahn et al., 1996). The 'difficult' patients in physical health care, of whom many may be diagnosed with a psychiatric disorder (Schafer et al., 1998; Hahn et al., 1996), generally have many physical symptoms and are high – but often discontent – care users (Lin et al., 1991). In mental health services, certain patients are also found 'difficult' but their clinical symptoms are less obviously described. They are often intensively discussed among professionals in both formal team meetings and informal contacts. While discussing them, patients' characteristics and professional emotional attributes are easily mixed, resulting in a very unclear picture of the patient and his or her (need for) treatment (e.g. Santy et al., 1984). Some of them tend to be disliked and preferably discharged or referred to elsewhere. Often, however, these options are hard to pursue due to the patient's unwillingness to be discharged, or the targeted service's reluctance to accept the patient (e.g. Neill, 1979). Such patients may be characterised as 'difficult', while it is unclear on what exact grounds.

In older studies it is clear that the 'difficult' patient receives care of less quantity and quality than the non-'difficult' patient. 'Difficult' patients lack a key clinician, a treatment plan, and proper documentation of treatment contracts and history, while referral elsewhere is haphazard and uncoordinated (Neill, 1979). Also they tend to be hospitalized longer, to be prescribed more medication and have poorer treatment outcome (Colson, 1990; Modestin et al., 1986). In spite of these significant findings, research into 'difficult' patients in mental health care has been minimal over the last decades.

> *Increasing specialization*

Since the introduction of the DSM-III (1980) and DSM-IV (1994), diagnostic manuals that describe the observable phenomena of psychiatric disorders in detail, researchers have increasingly focused on diagnostic categories (e.g. Wilson, 1993; Mayes et al., 2005). The reliability of psychiatric diagnoses has greatly improved, while research into the effectiveness of treatments for well-delineated disorders has blossomed, resulting in a stronger base of evidence of psychiatric treatment for certain disorders (e.g. Nathan et al., 2007). In several countries, the practical organisation of mental health care services has followed this example. Dutch mental health care, for instance, has seen a move from regionally based generic community mental health services towards diagnosis-based services. Homogeneity of patients and specialized treatments have become more important than geographic proximity. Last, patients are increasingly adopting this

principle by organising themselves into diagnosis-specific associations and seeking help for particular disorders from specialized professionals (e.g. Schene et al., 2001).

There are several potential advantages to this approach, such as improved diagnostics, tailored interventions, and more evidence in practice, yet many remain to be evaluated. In practice, however, this organising principle has also brought along some problems. The first problem is due to the high comorbidity among patients, especially in those with severe and persistent mental illness (Weaver et al., 2003). The diagnosis-specific model asks for patients to fit into one specific category, which is hard when many complex problems and potential diagnoses are present. A second problem is the availability of long-term care for patients that have not recovered after a, usually short-term, diagnosis-driven treatment. In many diagnosis-specific programs long-term treatment or care is absent or poorly developed, with the exception of programs for patients with psychotic disorders (e.g. Olfson et al., 2009). These programs, however, are often difficult to access to those with long-term non-psychotic disorders. Moreover, long-term care is increasingly rationed due to policy attempts to reduce overall health care costs, which especially affects patients with non-psychotic disorders who are seen as less severely ill and potentially curable in a limited amount of time.

Thus, in spite of the possible advantages of increasing specialization, there are some drawbacks for certain patients, specifically for those with long-term disorders, who may become the victims of the current organising principle. While these drawbacks appear to be the mostly organisational in nature, it must be noted that they accurately reflect the changes in the larger field of mental health research and mental health care as described in the first paragraph of this section. As such, patients that are perceived as 'difficult' and previously were described as such before, may now be diagnosed along the categories of DSM-IV. This appears to be a step forward since any diagnosis is more specific than the label 'difficult', if only certain diagnoses are not overused for previous 'difficult' patients. There is, however, some evidence that certain disorders, especially the personality disorders on DSM-Axis II, are highly unpopular among professionals (e.g. Lewis et al., 1988; Markham et al., 2003). A practice of relabeling 'difficult' long-term patients, such as people with chronic depression or chronic anxiety, as personality disordered patients would decrease the objectivity of diagnostic categorization. Even more important, it could potentially obscure the reasons – which are not necessarily patient-related only – for the subjective judgement of these patients as 'difficult'. Difficulties in the patient-professional interaction or the service organisation would then be individualized and renamed as psychiatric disorders.

➤ *Community psychiatric nursing interventions*

Aforementioned long-term mental health care, often also referred to as community mental health care, is largely offered by psychiatric nurses in the capacity of so-called home-care nurses, case-managers, community psychiatric nurses, or clinical nurse specialists. Of those, community psychiatric nurses (CPNs) form the largest professional group in community mental health care in The Netherlands and many other countries (van Hoof et al., 1995; WHO, 2007). In spite of their large numbers, long history in, and high value to Dutch mental health care (Oosterhuis, 2004), these psychiatric nurses still make use of poorly described, generic interventions in their patient care (MacNeela et al., 2010). These interventions, for instance termed offering ‘structure and support’ (Koekkoek, 2004) and ‘structured engagement’ (MacNeela et al., 2010), generally lack a solid methodical, theoretical, and empirical base.

While this lack of evidence is not limited to community mental health care but also applies to hospital-based care, it is especially problematic to CPNs. These nurses are, either officially or unofficially, individually responsible for the treatment of patients, yet have little resources to design and carry out such treatments (for a more detailed analysis of these issues, see also Koekkoek et al., 2009a). Their role in community mental health care can be difficult to define. On the one hand they offer psychosocial treatment that may be closely related to more concrete forms of (supportive) psychotherapy (Koekkoek et al., 2010a), while on the other hand they offer practical support that may resemble social work (Brown et al., 2000). Research findings offer little support for psychiatric nursing practice. In a recent systematic review of interventions led or co-led by psychiatric nurses, only few were methodologically sound and applicable in daily outpatient care (Curran et al., 2007), showing the need for development and evaluation of interventions for use by CPNs.

➤ *Problem definition and research aims*

Aforementioned issues amplify one another and result in the following problem definition. Problems in the care of ‘difficult’ patients have not decreased, despite the fact that these patients and their treating professionals receive little attention in the literature. While this may be due to previous ‘difficult’ patients now receiving a ‘difficult diagnosis’ (e.g. a personality disorder), we note that patients that poorly fit the current diagnosis-based treatment programs run the risk of ending up in a type of psychiatric care that lacks evidence and direction. This care is generally offered by psychiatric nurses, which is one of the least developed professions in mental health care in terms of evidence-based approaches. As such, psychiatric nurses, especially those working in

community mental health care, do not know how to offer care to 'difficult' patients.

Therefore, the aims of the current research project are: (1) to describe and understand the problems in the community mental health care for non-psychotic chronic patients perceived as 'difficult', as experienced by experts, professionals, and patients, (2) to develop an intervention program tailored to the needs of non-psychotic chronic patients perceived as 'difficult', to be used in non-specialized community mental health care, and (3) to evaluate the applicability and preliminary effectiveness of this program when carried out by community psychiatric nurses.

Outline of the thesis

This thesis chronologically follows the three aforementioned aims in seven separate chapters, followed by a general discussion.

- *Aim 1: to describe and understand the problems in the community mental health care for 'difficult' patients (chapters 1 to 5)*

In a review of the literature (chapter 1), we answer the questions *what the defining characteristics of 'difficult' patients are, how difficulty may be explained, and how it may be managed*. The results of this study are further built on in subsequent chapters, for which reason we briefly summarize some outcomes here. Out of three groups of 'difficult' patients, people with non-psychotic chronic disorders were perceived as most difficult. This group, apart from being perceived as 'difficult', meets the criteria for severe mental disorder (Ruggeri et al., 2000), namely (1) suffering from a psychiatric disorder, (2) using mental health care for 2 years or more, (3) having a score at or below 50 on the Global Assessment of Functioning-scale (GAF; a broad measure of psychosocial functioning).

For reasons that will be described in more detail in chapter 1, foremost the limited availability of treatment options for this group, we restricted the target group of this research project to patients with non-psychotic severe mental disorders. Among those are people with long term depressive, anxiety, substance abuse, and personality disorders while it excludes people with organic, psychotic and bipolar disorders. Since certainly not all patients in this group are 'difficult', an additional criterion applied. To qualify as 'difficult', patients had to have had – according to professionals involved – disagreement over form or content of treatment with at least two professionals, at least once in the previous two years.

In the second study (chapter 2), using the Delphi-procedure, we answer the question *which problems do community mental health experts' experience in the care of non-*

psychotic chronic patients perceived as 'difficult'. In chapter 1 it was found that among non-psychotic chronic patients, three diagnostic groups were in particular perceived as 'difficult': patients with chronic depression, patients with borderline personality disorder, and patients with an unclear diagnosis or multiple diagnoses. In chapter 2 we report on the outcomes of this research across these groups.

In the next paper (chapter 3), the perspective of general community mental health professionals on 'difficult' patients is subject of investigation. Using a large scale survey among community psychiatric nurses, the primary professionals in community mental health care, the question is answered *which patient, professional, treatment and social variables are associated with perceived patient difficulty*.

The third perspective, that of perceivedly 'difficult' patients themselves, is examined in chapter 4, in which we report on a qualitative Grounded Theory-study using individual interviews. The questions were *which difficulties do patients perceived as 'difficult' experience in their contact with psychiatric clinicians, which explanations do they have for these difficulties, and what change should be made to decrease these difficulties*.

In the next paper (chapter 5) aforementioned perspectives, respectively that of experts, general professionals, and patients, are compared within a theoretical framework. The question was *how the different perspectives of experts, professionals, and patients can be integrated into one explanatory model*. This analysis results in a preliminary theoretical model that explains the occurrence and persistence of 'difficult' patients within community mental health services.

- *Aim 2: to develop an intervention program tailored to the needs of 'difficult' patients, to be used in non-specialized community mental health care (chapter 6)*

Based on the theoretical model from the previous chapter, and guided by the structured method of Intervention Mapping, an intervention program is built. The question was *how current research findings, evidence-based treatment strategies, and findings from best-practices can be built upon an explanatory theoretical model and result in an evidence and practice based program*. Using elements from evidence-based treatments and insights from current best practices, Interpersonal Community Psychiatric Treatment (ICPT) is developed for use by community psychiatric nurses in their care for non-psychotic chronic patients perceived as 'difficult' (chapter 6).

- *Aim 3: to evaluate the applicability and preliminary effectiveness of an intervention program when carried out by community psychiatric nurses (chapter 7)*

In the final paper (chapter 7), the implementation and evaluation of aforementioned intervention program is described in community mental health care. The question was *how applicable and effective, both in terms of outcome and process, the intervention program (ICPT) is according to patients and community psychiatric nurses*. Hereto a pilot study is carried out with 6 community psychiatric nurses and 20 patients in which quantitative and qualitative data are collected.

In the concluding chapter, the General Discussion, the various studies are analysed and weighed in relation to the aims of this research project. Apart from that, we look back on the issues that motivated this research project. We assess to which extent this study contributes to solutions for the problems regarding the community mental health care for patients perceived as 'difficult'.

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57:795-802



> *Objective*

This article provides an overview of what is known about 'difficult' patients in mental health care. It aims to answer three main questions: what are the defining characteristics of 'difficult' patients, how is the difficulty explained, and which treatment strategies are available?

> *Methods*

A search of the MEDLINE, PsycINFO, and CINAHL databases was conducted for articles published between 1979 and 2004 that had 'difficult' patients as their main topic, resulting in 94 eligible articles.

> *Results*

Characteristics of 'difficult' patients in psychiatric care were consistent across several studies. Explanations for these difficulties widely varied: individual, interpersonal, and social factors were identified. Interventions were described in little detail and offered relatively few specific guidelines for daily

practice, although some general principles are summarized. Difficult patients are classified into three subgroups, and some prevailing discourses on 'difficult' patients in mental health care are discussed.

> *Conclusions*

Treatment strategies or settings exist for two of the three groups of 'difficult' patients – those with severe non-psychotic mental illness (unwilling care avoiders) and those with the least severe psychiatric symptoms but the most difficult behaviours (demanding care claimers). The remaining group (ambivalent care seekers), which consists of those who seek care but exhibit ambivalent behaviours that could be interpreted as both difficult and ill, is not supported sufficiently by effective treatment strategies. Further development and research into effective interventions is suggested for this group.

Introduction

The 'difficult' patient is a well-known figure in everyday mental health care yet is underrepresented in research reports. The adjective difficult often refers to the lack of cooperation between patient and professional: although the patient seeks help and care, the patient does not readily accept what is offered. The frequent use of the term seems to indicate a well-known and well-distinguished group of patients. This is not the case, however: 'difficult' patients are hard to describe and characterize as a group. Since the first attempt over 25 years ago to empirically assess characteristics of 'difficult' patients (Neill, 1979), numerous non-empirical and few empirical articles have been published. This review aims to highlight important findings that may be used in daily practice.

Methods

For this literature review, we conducted a search of the MEDLINE, PsycINFO, and CINAHL databases for articles published in English between 1979 and 2004 about patients between 18 and 65 years of age. The title words 'difficult patient' or 'problem patient' were combined (with Boolean AND) with keywords 'mental disorders' and the following terms (with Boolean OR): 'mental health services', 'psychiatric hospitals', 'treatment', 'psychotherapy', 'therapeutic alliance', 'therapeutic processes', 'physician-patient relations', or 'nurse-patient relations'. Selection took place according to various criteria. An article was excluded when it did not have 'difficult patient' as its main subject, it primarily focused on a specified non-mental health setting (for example, a surgical ward of a general hospital), it related difficulty only to one specific diagnostic category (for example, difficulties in the treatment of eating disorders), or it presented a case study without any reflection or theory building apart from the particular case. Cross-references were used extensively to find additional publications. In doing so, four frequently cited articles published earlier than the studies within the range of the database search (Groves, 1978; Maltsberger et al., 1974; Burnham, 1966; Main, 1957) were assessed as relevant for this literature review. In all, 94 titles were included.

Type DP ▾	Unwilling care avoider	Ambivalent care seeker	Demanding care claimer
Characteristics ▾			
Diagnosis	Paranoid psychosis Personality disorder cluster A, especially PPD	Chronic depression Personality disorder, clusters B and C, especially BPD	Substance abuse Personality disorder, cluster B, especially APD and severe NPD
Sex (predominant)	Male	Female	Male
Difficult behaviours	Withdrawn, hard to reach, aggressive	Demanding, claiming, self-destructive, dependent	Attention seeking, manipulating, aggressive and destructive
Acceptance of sick role by patient	No	Yes	When opportune and expedient
by professional	Yes ('mad')	Alternating ('mad' or 'bad')	No ('bad')
Prevailing discourse	Medical-psychiatric ('difficult-to-treat patient')	Mixed ('difficult' patient)	Social-moral ('difficult non-patient')
Probable treatment setting	Mental health care	Usually mental health care; risk of no care	Justice department

Table 1

Characteristics of 'difficult' patients in a review of 94 articles published between 1979 and 2004

Results

> *Characteristics*

Most data came from quantitative studies published before 1991 (Neill, 1979; Colson et al., 1985; Colson et al., 1986a; Colson et al., 1986b; Allen et al., 1986; Colson, 1990; Modestin et al., 1986; Gallop et al., 1987; Robbins et al., 1988) that, except for two studies (Neill, 1979; Modestin et al., 1986), did not provide control groups. In these studies, most of the 'difficult' patients were between 26 and 32 years of age, whereas control patients were either of the same age (Neill, 1979) or somewhat older (Modestin et al., 1986). More than control patients, 'difficult' patients were unemployed and poorly educated. In most studies, 'difficult' patients were predominantly men (between 60 and 68 percent). Diagnoses of psychotic and personality disorders were the most common. Prevalence of the former varied (19 to 44 percent), and prevalence of the latter was consistently high (32 to 46 percent) across all studies. Mood disorders (8 to 24 percent) and other disorders (4 to 16 percent) were less frequently found. Data on comorbidity of DSM Axis I and II disorders were absent across all studies.

Together, the studies refer to four dimensions of difficult behaviours: withdrawn and hard to reach, demanding and claiming, attention seeking and manipulating, and aggressive and dangerous. The first category is found mostly among patients with psychotic disorders, the second and third mostly among those with personality disorders, and the fourth appears with both diagnostic groups. Estimates of relative or absolute frequency of 'difficult' patients were available from only one study, in which 6 percent of all 445 inpatients in a psychiatric hospital were considered difficult by at least two members of an inpatient nursing team (Modestin et al., 1986).

Difficult patients appear in both inpatient (Colson et al., 1985; Colson et al., 1986a; Colson et al., 1986b; Allen et al., 1986; Colson, 1990; Modestin et al., 1986; Gallop et al., 1987) and outpatient (Neill, 1979; Robbins et al., 1988) settings, yet no data were found on the prevalence of 'difficult' patients in these subgroups, except for the study previously mentioned. One study (Robbins et al., 1988) found a high correlation between 'difficult' patients, the number of hospital admissions, and inpatient days, which indicated a higher prevalence of 'difficult' patients among inpatients. All studies considered psychiatric treatment centers at general psychiatric hospitals and outpatient clinics.

Most 'difficult' patients are offered a pragmatic, eclectic form of psychiatric treatment. Because of their easy accessibility, both financially and physically, general mental health centers tend to attract a greater number of 'difficult' patients, especially when emergency

care is delivered (Neill, 1979). Neill (1979) also found significant differences regarding a treatment plan and a primary caregiver. All control patients had both, whereas the 'difficult' patients had neither. Difficult patients' files were updated less thoroughly, and communication between professionals of different treatment programs about these patients was minimal (Neill, 1979).

From the data reviewed, we hypothesize three subgroups of 'difficult' patients, as presented in table 1. In this scheme the first group of 'difficult' patients, care avoiders, consists of severely psychotic patients who do not consider themselves ill and who view mental health care as interference. The second group, care seekers, consists of patients who have chronic mental illness yet have difficulty maintaining a steady relationship with caregivers. The third group, care claimers, consists of patients who do not need long-term care but need some short-term benefit that mental health care offers, such as housing, medication, or a declaration of incompetence.

> *Theoretical explanations*

Individual factors

Four major theoretical explanations were frequently identified in the articles reviewed: chronicity, dependency, character pathology, and lack of reflective capabilities.

The first, chronicity, considers the course of the 'difficult' patient's psychiatric disorder, which almost always is chronic and renders the patient dependent on mental health institutions (GAP, 1987; Bachrach et al., 1987; Bachrach, 1983; Menninger, 1984). Chronic patients experience problems that are difficult to resolve by the psychiatric system, which leads to labelling these patients as problematic and difficult. Although chronicity of a mental disorder is a patient's personal matter, chronicity is also considered problematic for mental health professionals: 'the sufferer who frustrates a keen therapist by failing to improve is always in danger of meeting primitive behaviour disguised as treatment' (Main, 1957). Apart from being one explanation for patients' difficulty, chronicity induces specific responses by the psychiatric treatment system and is covered in more detail later.

Dependency on care is a second reason for perceived patient difficulty. Severe, unmet dependency needs lead the patient to project a lack of stable self and basic trust onto the caregiver (Neill, 1979; Powers, 1985; Groves, 1978; Groves et al., 1998; Fiore, 1988). The caregiver then experiences the patient as demanding and claiming, which makes the interpersonal contact difficult. Underlying the difficult behaviours of so-called hateful patients there seems to be a strong need for dependency (Groves, 1978). These patients,

who exhibit clinging, denying, entitled, or self-destructive behaviours, all have problems in tolerating a normal dependency (Fiore, 1988). In qualitative interviews with nurses, a clear difference was found between 'good' and 'difficult' dependent patients (Strandberg et al., 2003). Good patients were described as reasonable and thankful; 'difficult' patients were described as unreasonable, selfish, and not able to appreciate the value of given care. Power struggles arose easily with the latter category (Wright et al., 1990). The relationship with the mental health professional becomes so important for many 'difficult' patients that terminating it seems impossible, both for patient and professional (Kirsch, 1986).

A third, psychodynamic view is that 'difficult' patients have character pathology. Specifically, paranoid, borderline, narcissistic, and antisocial (Wong, 1983; Silver, 1983) personality disorders would make for 'difficult' patients. Psychiatrists mentioned the diagnosis borderline personality disorder up to four times more often than any other diagnosis when asked about characteristics of 'difficult' patients. Less frequent were paranoid, antisocial, sociopathic, obsessive, and narcissistic disorders (Bongar et al., 1991). According to several authors (Fiore, 1988; Schwartz et al., 1981), almost all 'difficult' patients have a so-called borderline personality organization, which would explain why so many 'difficult' patients have a highly ambivalent relationship with mental health care. People with this kind of personality organization perceive reality accurately yet feel overwhelmed by it, resulting in intense feelings of suffering and a need to seek help. In combination with so-called primitive defences, such as splitting, idealizing, and projective identification, this lack of a clear self is considered a major source of the often confusing and negative interactions with professionals (Fiore, 1988; Waska, 1999; Waska, 2000; Shapiro, 1992).

The fourth explanation for patients' being difficult is related to their perceived lack of reflective capacities. Reflection lies at the core of most psychotherapies; therefore, an incapability to reflect will easily turn the patient into a not-so-suitable (difficult) patient. People who are not securely attached in their younger days especially seem to lack these reflective or 'mentalizing' capacities (Fonagy, 1998). This insecure attachment may have many causes, one of which is trauma (Chrzanowski, 1980), and easily creates problems in interpersonal relations, including those with caregivers (Shapiro, 1992; Freedman et al., 1995).

Interpersonal factors

Some authors emphasized that it is not the patient but the therapeutic relationship that is difficult, thus taking the blame off the patient and situating problems in an interpersonal context. Traditional concepts of transference and countertransference

are often used in this context, yet in a broader sense than in classic psychoanalytic theory. Countertransference in this context refers to the emotional struggles that emerge while working with 'difficult' patients (Colson, 1990). Transference is defined as the unconscious feelings the patient has toward the therapist, based on earlier experiences in the patient's life (with therapists in general or with this particular therapist). Countertransference is, likewise, defined as the unconscious feelings the therapist has toward the patient, either based on the patient's present behaviour or on the therapist's earlier professional and personal experiences. Examples of professionals' countertransference feelings toward 'difficult' patients are anger, guilt, helplessness, powerlessness, dislike, and disappointment (Colson et al., 1986a; Colson et al., 1986b; Main, 1957; Groves, 1978; Burnham, 1966; Maltzberger et al., 1974; Gallop et al., 1993; Podrasky et al., 1988; Santamaria, 1995; Santamaria, 2000).

Transference and countertransference issues between professionals and 'difficult' patients are sometimes described in vivid detail (Main, 1957; Groves, 1978; Burnham, 1966; Maltzberger et al., 1974). Although the concept of transference and countertransference is interpersonal, some authors maintained that the patient is responsible for evoking strong countertransference reactions (Arlow, 1986). Some critics have indicated that early psychoanalysts, who were unable to maintain a transference relation used the transference concept to blame the patient for therapy failure (Noonan, 1998; Bromberg, 1992). Others assumed that the 'difficult' patient exists only because of a lack of professionalism among caregivers. In other words, if all caregivers were properly psychoanalyzed, these interpersonal problems would not occur (Fine, 1984). Moreover, the transference relation is not a static one-way interaction but an intersubjective undertaking. In this view, two worlds need to meet, which is possible only if the therapist is able to put his or her own subjective views into perspective (Stolorow et al., 1983). A strong working alliance can be reached only by mutual understanding and giving meaning to difficult behaviours displayed by the patient and to the nature of the therapeutic relationship (Laskowski, 2001).

Countertransference in a multidisciplinary treatment setting has a different character, often strongly influenced by the so-called phenomenon of splitting. The 'difficult' patient is considered a specialist in behaving differently with various team members, resulting in mutual disagreement (Main, 1957; Burnham, 1966). At the same time, the literature indicates that multidisciplinary teamwork with 'difficult' patients is highly necessary, yet complex. Such teamwork leads to less trouble and fewer mistakes, because countertransference issues can be shared (Menninger, 1998). Feelings that emerge in countertransference may lead to distinctive reactions – extra care on the one hand, active neglect on the other – and different professionals may experience distinctive feelings of

countertransference (Colson et al., 1985; Colson et al., 1986b; Gallop et al., 1987; Gallop et al., 1993). For example, physicians are challenged when medication fails, when patients manipulate, or when treatment is difficult (Gallop et al., 1987). Nurses experience annoyance and anger when their caring attitude and competence are questioned (Gallop et al., 1987; Breeze et al., 1998). Both doctors and nurses get irritated when patients challenge their authority (Neill, 1979; May et al., 1982). Distinctions also have been noted between nurses' experiences on different types of psychiatric wards. Difficult behaviours were less easily interpreted as deliberate on wards with a psychodynamic orientation than on wards with a psychopharmacological orientation (Lancee et al., 1995). Perceived difficulty differed between on-floor staff and off-floor staff. The former group experienced patients' difficulty more intensely because on-floor staff has closer physical and emotional interaction with them (Munich et al., 2003).

We found no studies that solely focused on the role of the professional. Yet some authors pointed out that some personality traits may increase the risk of difficult relationships with patients: a strong wish to cure, a great need to care, trouble with accepting defeat, and a confrontational and blaming attitude (Main, 1957; Maltsberger et al., 1974; Smith et al., 1983; Najavits, 2001). Research on therapist variables that may account for good and bad treatment is still in its infancy (Najavits, 2001). Given the previously discussed concept of 'blaming the patient', such variables appear to be closely linked to patients' being called difficult.

Systemic and sociological factors

We next review the social environment as the major explanation for the existence of 'difficult' patients. In general, authors who supported this view assumed that different forms of social judgment are responsible for patients being called difficult, including prejudice, labelling, and exclusion.

Prejudice takes place largely within the individual, although it often is influenced by societal beliefs. Psychiatric literature, especially, covers the negative effects of certain diagnoses on professionals' attitudes. In this review, these negative attitudes were found among psychiatrists working with patients with personality disorders (Lewis et al., 1988) and among psychiatric nurses treating patients with borderline personality disorder (Gallop et al., 1989). In these studies, professionals were asked to rate the difficulty of certain behaviours, dependent on the patient's diagnosis. Patients who were diagnosed as having borderline personality disorder were judged more negatively than were patients with other diagnoses – schizophrenia, for example – although their difficult behaviours, such as expressing emotional pain or not complying with the ward routine, were equal. This difference seems to imply that certain difficult diagnoses evoke negative

reactions from professionals, independent of the patient's actual behaviour. However, only a few articles on this matter were identified with the search terms used.

Labelling differs from prejudice in that it implies a form of action rather than a mere attitude. In group-therapeutic practice this phenomenon is specifically documented (Yalom, 1995). It is not the diagnosis but deviancy from the particular group culture that leads to patients' being called difficult. This scapegoating may induce counter-therapeutic reactions by therapists (Gans et al., 1998), which refer to actions and reactions that reinforce the characterization of an individual as the 'difficult' patient in a group. Intersubjective theory, in which patients' and professionals' beliefs and actions are considered as equally subjective input into the therapy process, highlights the risk of negative labelling of particular patients. This theory contrasts with some psychoanalytic views in which individual behaviours tied to specific diagnostic terms, such as borderline and narcissistic disorders, are held responsible for patients' difficulty in groups (Leszcz, 1989; Roth et al., 1990).

The phenomenon of labelling is especially present in nursing literature. Behaviour that deviates from what may be expected in a specific context, such as a hospital ward, risks being labelled as difficult, sometimes resulting in withdrawal of necessary care (Trexler, 1996). The difficult-patient label is easily and rapidly communicated among nurses and may lead to care of less quantity or quality (Carveth, 1995). Some authors claimed that 'difficult' patients are socially constructed in a complex web of social influences, including power, status, the management of uncertainty, and negotiation (Johnson et al., 1995). Also the term stigma, first introduced by sociologist Erving Goffman as a superlative form of labelling, is used in this context (Macdonald, 2003). Nurses tend to label patients as bad when they do not express gratitude for the help they receive (Kelly et al., 1982; Jeffery, 1979), yet patients who do not improve but try hard are regarded positively (May et al., 1982). Feelings of incompetency and powerlessness among professionals may lead to labelling patients as difficult, consequently leading to power struggles over control and autonomy (Breeze et al., 1998; May et al., 1982; Russel et al., 2003).

A step beyond labelling is the exclusion of patients from mental health care. Creating barriers to specific forms of treatment or care legitimizes the denial of care. Critics have gone so far as to state that mental health providers deny the very existence of severe and disabling diseases, such as schizophrenia, by constantly being too optimistic about patients' opportunities to conduct their lives outside psychiatric hospitals (Coid, 1991). As a result, responsibility for 'difficult' patients is fended off, and patients may be passed on to another institution. Patients who do not fit into the system, because their problems differ from those of the mainstream, run a high risk of being labelled as difficult. This

situation also occurs with patients who have alternative, nonmedical explanations or solutions for their health problems, such as maintaining a healthy lifestyle instead of using medication (Wright et al., 1990). Chronic patients run a high risk of encountering this problem, because their complex and long-term needs often do not fit into the psychiatric care system (Bachrach et al., 1987; Bachrach, 1983; Menninger, 1984). According to this view, many difficult interactions are explained by the interpersonal stances of professionals and patients and by the mental health care system's tendency to consider atypical demands as difficult.

From an organizational perspective, the ongoing replacement of inpatient care by outpatient care is considered as possibly harmful for the 'difficult' patient (Holmes, 1992). When the psychiatric hospital ceases to be a safe haven that offers long-term stay and therapy, the pressures on both patient and professional in outpatient care increase. This situation may have negative consequences for the working alliance and the patient's health situation, especially when busy community mental health centres can devote little time to difficult, long-term therapies (Holmes, 1992). Recent studies have stressed that the psychiatric hospital increasingly becomes a last resort for very specialized care or treatment of more disturbed 'difficult' patients (Munich, 2003; Fisher et al., 2001).

One study (Maltsberger, 1995) showed that patients whose treatment borders on different health care terrains – specialized medical care or addiction treatment – run a greater risk of being considered difficult. Iatrogenic damage may be the result of the diffusion of responsibility among different health care professionals. Comparable matching problems are likely to occur when a patient shows or threatens criminal behaviour. Subsequent exclusion from the mental health system may have a detrimental effect on the patient. In general, professionals appear to be reluctant to set limits and tend to diffuse responsibility with patients who violate or do not know the 'rules of the game' in the mental health system (Neill, 1979).

> *Interventions*

Many interventions suggested in the literature are rather standard and could therefore be characterized as common practice. Examples include respecting the patient, careful listening, validating feelings and behaviours, and being nonjudgmental (Juliana et al., 1997; Nield-Anderson et al., 1999). Yet 'difficult' patients, as described in previous sections, seem to be very attentive to professionals' attitudes and behaviours. Therefore, these common practices are more important with this population than with patients who are not difficult. Apart from these standard interventions, some specific interventions are listed next, as well as interventions that consider the professional instead of the patient. Unfortunately, none of these interventions have been evaluated for effectiveness in empirical studies.

First, as stated earlier, a supportive and understanding attitude is suggested. A so-called holding environment, in which the patient may feel safe to experience different feelings and experiment with different behaviour, is encouraged. To maintain the safety of this holding environment, setting limits for the patient is suggested. Other structuring interventions include assigning the patient the responsibility for his or her own safety, framing a clear treatment structure and contract, and maintaining one professional as a case manager for both patient and other professionals (Neill, 1979; Silver, 1983; Berman, 1990). Interpretation of transference and countertransference issues as they arise is necessary and effective and may serve to ameliorate the doctor-patient relationship (Weiler, 1987). Others have recommended that modes of treatment or attitudes be modified according to different types of 'difficult' patients, with different strategies for dealing with denying, dependent, and demanding patients (Groves et al., 1998). Also mentioned are the need for a non-authoritative attitude and power sharing (Breeze et al., 1998), forgiveness as a counterpart of a judgmental attitude (Scheurich, 2002), and consciousness of the patient's situation and situational factors (Sledge et al., 1997). Some more specific therapeutic techniques include slowly decreasing the amount of care (Frayn, 1986), modifying dialectical behaviour therapy (Linehan, 1993; Huffman et al., 2003), creating a very strict and clear treatment contract in behavioural terms (Taylor et al., 1980), using strategic and paradoxical interventions (Johnson, 1988), and establishing a specialized aftercare program for former inpatients considered to be difficult (Wasylenski et al., 1981).

Additional interventions that professionals may use consist of two major categories: individual supervision and interdisciplinary team consultation. Through supervision, the attitude of the supervised professional may improve and treatment quality may increase. On the other hand, a parallel process may occur: the supervisor may consider the supervisee as a difficult person because none of the suggested interventions seem to work (Fiore, 1988; Laskowski, 2001; Lauro et al., 2003). Other options on a personal level include collaborating and consulting instead of working alone and maintaining balance in both private and personal life (Smith et al., 1983). Multidisciplinary meetings are suggested as a way to form a collective vision. In such meetings, staff feelings are channelled into more professional modes, and development of consistent treatment plans is endorsed (Munich, 2003; Santy et al., 1984). Sessions that value the views of different professions and lack the need of forming immediate solutions offer the best insight in team troubles and processes (Colson, 1990). Outside consultation by a third-party professional is a useful variant that may help immersed treatment teams to gain a fresh perspective (Silver et al., 1983; Silver et al., 1987). Last, reading literature on patient care is suggested to help students and trainees to gain perspective on the 'difficult' patient's vantage point (Shapiro et al., 2000; Batchelor et al., 2001).

In summary, the professional should maintain a validating attitude and strict boundaries within a clear treatment structure. Consciousness of the patient's background and one's own limitations helps the professional to see different perspectives, and consultation and supervision may strongly reinforce the importance of different perspectives.

Discussion

As in daily practice, there is consensus in the literature about who 'difficult' patients are and what they do. Yet why these patients are difficult and how they might best be treated are less clear according to the results of this review. We considered over 90 articles, but most of them contained few empirical findings. Quantitative empirical studies were limited to the characteristics of 'difficult' patients, and qualitative studies mostly considered social processes, whereas the articles on explanations and interventions were theoretical in nature. Contributions from different mental health professions varied widely. Medical-psychiatric literature almost exclusively considered symptoms, behaviours, and diagnoses. Psychological literature largely focused on explanations of difficult behaviour and the relationship between patient and professional. Nursing literature mainly considered the occurrence of 'difficult' patients in a social context, the result of specific social processes such as labelling and exclusion. All considered treatment options, yet not in much detail.

The large variation in results is probably the consequence of the conceptual problem that underlies the term 'difficult' patient: being difficult is not an observable disease or symptom but a judgment made by mental health professionals. Moreover, the label seldom refers to a difficult treatment but almost always to a patient who is hard to be with (Staley, 1991; Daberkow, 2000; Allen et al., 1987).

The adjective 'difficult' suggests the existence of a model patient who lives up to certain unwritten beliefs that seem to exist in and about mental health care. Some of these characteristics are covered in more detail by sociologists in writing about the sick role (May et al., 1982; Hartman, 1999; Parsons, 1951), yet here are some of the most important: the patient is not responsible for being ill; the patient makes a great effort to get better; the disease is clearly delineated, recognizable, and treatable; the disease, after treatment, is cured, and the patient leaves the system; the therapeutic encounter is pleasant and progressively effective; and the system is not responsible if the disease is not successfully treated.

Clearly, the typical 'difficult' patient does not behave according to these sick role expectations. The 'difficult' patient we have discovered through the literature is either

not, or ambivalently, motivated for treatment and has a disorder that does not neatly fit into one diagnostic category, which also does not gradually improve. The 'difficult' patient is often unpleasant to be with, and although our patient may sometimes be out of sight, he or she almost always returns to start treatment all over again and sometimes blames the mental health system for taking too little or too much care before. In many of the articles reviewed, the question of whether the patient is deliberately behaving in a difficult manner is implicitly raised but seldom explicitly answered. This important question may have some major implications. If a patient is purposely difficult, does that mean that he or she is not ill? Should other standards be applied when the patient is not ill? Or is this particular behaviour proof of a very serious disorder that gravely affects the free will of the patient? And if this is so, should there be new definitions of certain disorders, and should new treatments be invented? Some authors seemed to favour this view, suggesting that over time effective treatments for 'difficult' patients will emerge. These treatments will transform 'difficult' patients into regular patients who are treated instead of judged (Kendell, 2002). In a recent volume on difficult-to-treat patients, this optimism was endorsed by several treatment strategies (Dewan et al., 2001), although critics have contended that such an approach is too narrow (Hinshelwood, 1999; Nathan, 1999).

This dichotomy between ill and not ill does not, however, seem helpful in either this review or daily practice. In order to differentiate among different patients, we suggest a gliding scale between a medical-psychiatric and a social-moral approach. The first approach largely excuses difficult behaviours because ill people cannot be held accountable for them. The second approach holds people accountable for their actions, independent of their health status. Though these two extremes are not very useful in everyday care, they may help to clarify the two attitudes that are often competing in the minds of professionals. Balancing these two approaches is necessary to prevent ineffective either-or discussions.

To illustrate this approach, a closer look at the three subgroups may help (table 1). The 'unwilling care avoiders' (group 1) have the most objective psychiatric symptoms, such as hallucinations and delusions, and therefore will be considered ill ('mad'). They will be treated in mental health care with the use of methods that take the patients' vulnerable health status into account, such as Assertive Community Treatment. The 'demanding care claimers' (group 3), on the other hand, exert the most difficult behaviours and experience the least severe psychiatric symptoms and therefore are easily considered as non-patients (or 'bad' patients). Often, however, they are also treated, albeit within the justice system in which a social-moral attitude plays a larger role. An example of this kind of patient is one undergoing involuntary treatment that is focused on preventing recidivism

to protect society. Both groups and settings have undergone major developments in recent years, resulting in clearer treatment approaches. Yet it is the group of 'ambivalent care seekers' (group 2) that is the most challenging. Even more than the other groups, patients in this group show psychiatric symptoms, such as depression and suicidality, as well as difficult behaviours. Therefore, they are constantly subject to different judgments about their health status by professionals and thus are most at risk of facing either-or discussions.

Conclusions

Because of its conceptual nature, the 'difficult' patient is not a new DSM category but is a result of professionals' implicit and explicit judgments about patients. When a professional calls a patient difficult, he or she says something about the degree to which a patient complies with the role of the ideal patient. The so-called 'difficult' patient is always at risk of not being considered a real patient, in need of and deserving of care. Illness may be denied or exaggerated, both with detrimental results.

The second subgroup that has been described, of non-psychotic 'ambivalent care seekers', is especially at risk of poor treatment because a rigid approach to treatment (either medical-psychiatric or social-moral) may be harmful. With these patients, health care providers find it hard to maintain a clear strategy, as patients' behaviours evoke concern as well as annoyance. Concern refers to a caring attitude, whereas annoyance induces harsh judgments. Although these patients are ill, they do not benefit from a medical-psychiatric approach alone because they need more limits than are usually placed on psychiatric patients. On the other hand, the strict social-moral approach is also insufficient because it does not meet this group's need for care. Balancing the two approaches will help professionals work effectively with this type of 'difficult' patient. Although some interventions for this subgroup have been highlighted in this review, they are merely free-standing actions that lack a unifying frame of reference. Unlike the other two groups, the group of ambivalent care seekers lacks overall treatment strategies and specific treatment settings. Apart from that, the effectiveness of the proposed interventions has not been researched. Future studies of 'difficult' patients therefore should focus on describing, implementing, and evaluating interventions for the group of ambivalent care seekers. In these future studies, both the medical-psychiatric and social-moral approach should be favoured within a clear conceptual framework.

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> *Aim*

'Difficult' patients may evoke strong feelings in health professionals. The ambivalent attitude of, especially, non-psychotic chronic patients towards psychiatric care may be frustrating and burdensome to professionals. Many of these patients are cared for in non-specialized services, where professionals are often more used to working with psychotic patients. Specific problems with 'difficult' non-psychotic patients may occur, and hamper the quality of care offered. The aim of this research is to determine precisely what problems psychiatric professionals perceive in contact with non-psychotic chronic patients in order to identify starting points for alternative or improved care in non-specialized services.

> *Methods*

A modified five-phase Delphi study with three groups of eight participants from was used to identify and prioritize experts' judgments.

> *Results*

46 problems were identified of which some were relevant to one or two subgroups and some were relevant to the entire group.

> *Conclusions*

A program that combines a coherent view at services level, with support and increased communication at the interprofessional level (e.g. through regular supervision, sharing of case-loads) may be highly beneficial to non-specialized services.

Introduction

'Difficult' patients may evoke strong feelings in health care professionals: frustration, helplessness dislike, anger and even hatred (e.g. Hinshelwood, 1999; Groves, 1978). The noun 'difficult' is debated though: some find the term displaying a current lack of knowledge (Kendell, 2002), in need of differentiation (Dewan et al., 2001), stigmatizing (Corrigan, 2006), or just plain unsatisfactory (Tyrer, 2008). In a recent review, we distinguished three 'prototypes' of 'difficult' patients: paranoid psychotic patients ('difficult-to-treat patients'), antisocial and abusive patients ('difficult people') and non-psychotic chronic patients ('difficult' patients). Especially the latter patients puzzle psychiatric professionals by their often ambivalent way of help-seeking. It does not comply with what professionals expect from 'good' patients, namely to ask for help and accept it, get better and gradually become autonomous again (Koekkoek et al., 2006). These patients may find or engage themselves in risky circumstances or behaviours, be high and ad-hoc users of psychiatric services yet without establishing an effective alliance but meanwhile being highly dependent on the institution at large (Kent et al., 1995a; Kent et al., 1995b; Roick et al. 2002).

There is evidence that a substantial number of these non-psychotic chronic patients receives care in non-specialized psychiatric services such as community mental health teams (Greenwood et al., 2000; Keown et al., 2002). These services are often more tailored to the needs of chronic patients with psychotic disorders than to those with non-psychotic disorders. Evidence-based practices are less available and professionals may experience the care for these patients as burdening. This burden, just as the 'difficult'-qualification, may easily result in substandard care or treatment.

To identify starting points for alternative or improved care in non-specialized services, the aim of this study is to precisely determine the difficulties mental health professionals perceive in contact with non-psychotic chronic patients. The following three research questions were stated: (1) which problems occur in the care for 'difficult' non-psychotic chronic patients?, (2) which differences exist in these problems between subgroups of 'difficult' non-psychotic chronic patients?, and (3) which similarities exist in these problems between subgroups of 'difficult' non-psychotic chronic patients?

Methods

> *Design*

To elicit and prioritise experts' views on the problems occurring in the care of 'difficult' non-psychotic chronic patients, we used a modified five-phase Delphi design with three

groups of eight participants. The Delphi-procedure is well-known and often used to explicate tacit knowledge and reach consensus on a little-researched subject (Fiander et al., 1998; Jones et al., 1995a; Hasson et al., 2000). We modified the regular procedure by the use of a focus group (Knudsen et al., 2000) in the 1st round instead of anonymous generation of items, followed by thematic analysis of the group interview and a 2nd round in which participants validated the items derived from this analysis. The 3rd and 4th rounds were used to score the items with regard to urgency and changeability. The 5th and final round again was a face-to-face group meeting with representatives of each of the three subgroups. Rounds 2 through 4 took place by e-mail communication, rounds 1 and 5 were face-to-face meetings.

> *Definitions*

The target group of our research into 'difficult' patients is substantially narrowed by only including non-psychotic chronic patients, as highlighted before. However, defining chronicity (and severity and duration of mental illness in general) has proven to be a complicated subject and many definitions have been presented throughout the years (Schinnar et al., 1990). Here, we limit the group of non-psychotic chronic patients to those with a severe mental illness (SMI), using the broad definition of Ruggeri et al. (2000). This includes all patients that have been in psychiatric care longer than two years and that have a GAF-score at or below 50. Further diagnostic specification was based on our review (Koekkoek et al., 2006) and resulted in three major 'difficult' subgroups of non-psychotic chronic patients. First, patients with chronic depression (CD), defined as (1) major depression with a duration longer than two years, or (2) dysthymia or (3) recurrent major depression with incomplete remission, all according to DSM-IV criteria. Second, patients with borderline personality disorder (BPD), defined according to DSM-IV criteria. Third, patients with an unclear diagnosis (often deferred 799.9), multiple diagnoses or diagnoses shifting within or across Axis I and II (further defined according to criteria based on a review and relevant national literature sources on such patients; details available from the first author). We will refer to this latter group as not otherwise specified non-psychotic chronic patients (NOS).

> *Participants*

National experts in non-psychotic chronic disorders were purposively approached for this study, specifically for each subgroup. The three panels each consisted of eight mental health experts from different disciplines, treatment settings and educational backgrounds (see table 1). To be considered an expert, participants had to meet two criteria: (1) having at least three years of working experience with the patient group, and (2) being employed in a nationally-recognized centre of expertise or being a nationally-

recognized expert through publications, lectures or academic excellence. We selected experts by searching recent literature for authors on the three distinct patient groups and through consultation of key figures in nationally recognized centres of expertise.

> *Data collection and analysis*

Data collection and analysis took place between June 2006 and June 2007 in an iterative process, typical to the Delphi-procedure. In round 1 we used a focus group interview in each subgroup, to elicit data about the problems in the care for non-psychotic chronic patients. Focus groups allow interaction between participants, which we considered useful and necessary in this sparsely illuminated subject. We expected more diverse results from this exercise than through an anonymous generation of items or individual questionnaires (see also Kitzinger, 1995). The focus group interviews were facilitated by the 1st and 2nd author in a neutral space (unrelated to a psychiatric facility) and lasted 90-100 minutes. Discussion items were partly generated by the researchers using a literature review (Koekkoek et al., 2006) and partly introduced by the experts (in response to the initial question ‘what are the problems in the psychiatric care for this patient group?’). We audio taped and fully transcribed the focus group interviews, and coded all text manually through thematic analysis (Joffe et al., 2003), using qualitative data analysis software (MAXQDA). Three preliminary lists of short items (problems) were constructed.

In round 2, the three item-lists were sent to the participants for validation of the accuracy of the descriptions. All participants returned the list and comments were discussed in the research team, resulting in one final list per group.

In round 3, these items were scored by all participants of each subgroup. They were asked to rate the *urgency* (‘to what extent you rate this an urgent problem in the daily psychiatric care for this patient group?’) and the estimated *changeability* (‘to what extent you rate this problem to be amenable for positive change through professional intervention’) of the identified problems. Ratings were given on a 7-point Likert scale, with 1 being a very low and 7 a very high rating. Results were analyzed using SPSS, considering the data to be on an interval level of measurement. We fed back the group mean scores of all items to the participants. Participants whose scores differed substantially from the group mean were, according to Delphi-procedure, asked to elucidate these. We summarized their statements for each item.

In round 4, all participants again received the item list for their respective subgroup, together with the summarised statements from round 3. We asked them to reconsider

their own scores in the light of these clarifications. After round 4, mean scores and standard deviations of each item were calculated. Since the literature on the Delphi-procedure is inconsistent about the establishment of consensus, we choose to use the standard deviation to establish variation in the scores. The smaller the standard deviation, the more consensus there was on that item. The cut-off point was set at 1.5: items with a higher standard deviation were interpreted as items about which there was dissension.

In the 5th and final round, three experts from each subgroup were invited to discuss and interpret the results of the Delphi-procedure. Selection of these 5th round participants was guided by the level of participation in the 1st round focus group: clear and outspoken participants were invited from each subgroup. This meeting again was chaired by the 1st and 2nd authors in the same facility and lasted 100 minutes. We made audio-recordings and summarized these in a report of the meeting which we sent out to the eight participants for validation.

Analysis of the final quantitative results was performed using analysis of variance (ANOVA) with Bonferroni-corrected post-hoc testing of observed differences.

		CD	BPD	NOS	Total
Age	<30	–	–	2	2
	30–39	3	–	2	5
	40–49	4	6	2	12
	50–59	1	2	1	4
	59>	–	–	1	1
Sex	male	5	4	6	15
	female	3	4	2	9
Profession	psychiatric nurse	4	4	4	12
	psychiatrist	2	2	2	6
	psychologist	2	2	2	6
Experts criteria	criterion 1	8	8	8	24
	criterion 2	6	7	5	18
Treatment setting	outpatient	4	4	5	13
	inpatient	2	2	2	6
	day treatment	2	2	1	5
Educational setting	general	5	6	7	18
	academic	3	2	1	6

Table 1

Characteristics of Delphi-participants (n=24)

CD: Chronic Depression, BPD: Borderline Personality Disorder, NOS: Not Otherwise Specified Non-psychotic Chronic Disorder

Criterion 1: having at least three years of working experience with the patient group

Criterion 2: being employed in a nationally-recognized centre of expertise or being a nationally-recognized expert through publications, lectures or academic excellence

Description	CD		BPD		NOS	
	Mean (SD)	rank	Mean (SD)	rank	Mean (SD)	rank
Undertreatment	6.38 (0.74)	1	4.75 (1.39)	28	4.38 (1.41)	29
No view on problems and treatment	5.88 (1.13)	2	5.25 (0.89)	12	4.50 (1.60)	24
Relapses	5.75 (1.28)	3	5.38 (0.92)	9	-	
No clear distinction between cure and care	5.75 (1.16)	4	-		4.63 (1.41)	20
No treatment offered at all	5.50 (1.20)	5	-		-	
Demoralization (in patient and professional)	5.50 (1.20)	6	4.63 (1.60)	31	4.75 (0.89)	18
Pessimistic attitude	5.38 (1.06)	7	5.50 (1.07)	6	4.88 (1.25)	16
Lack of structured treatment	5.38 (1.85)	8	5.50 (1.07)	5	5.00 (1.51)	15
Negative view of patients/stigma	5.25 (1.28)	9	-		4.63 (1.69)	22
Only 'pampering and dithering'	5.13 (1.46)	10	5.13 (1.36)	15	5.00 (1.20)	13
Lack of long-term treatment	5.13 (1.73)	11	4.88 (1.55)	25	4.75 (1.28)	19
Lack of organisational support	5.00 (1.51)	12	5.63 (1.06)	4	6.13 (0.83)	1
High expectations (in patients)	5.00 (1.31)	13	-		-	
Dependency	4.88 (1.36)	14	5.75 (0.71)	2	4.38 (1.85)	30
Poor alliance of family carers and professionals	4.88 (1.36)	15	4.88 (1.46)	22	5.13 (0.92)	9
Poor social functioning	4.88 (1.36)	16	4.38 (1.06)	32	5.13 (0.64)	8
Lack of clear diagnosis	4.88 (1.64)	17	-		4.13 (0.99)	32
Personality problems	4.88 (1.64)	18	3.88 (1.46)	35	5.38 (0.74)	4
Lack of congruence in expectations	4.88 (1.55)	19	3.75 (1.04)	36	3.38 (1.41)	39
Fearful attitude with suicidality	4.75 (1.58)	20	5.38 (0.92)	10	-	
Lack of family support	4.63 (1.06)	21	4.88 (1.46)	23	4.38 (0.92)	27
Lack of gratefulness/success (by patient)	4.50 (1.69)	22	4.38 (1.19)	33	4.25 (0.71)	31
Complex problems	4.50 (1.31)	23	5.13 (1.36)	16	5.00 (1.31)	14
Patients limited role in the family	4.50 (1.41)	24	4.38 (1.30)	34	4.38 (0.74)	26
Patients poor parental functioning	4.50 (1.69)	25	4.88 (1.36)	21	4.38 (1.30)	28
Limited cooperation professionals	4.50 (1.41)	26	5.13 (1.13)	14	5.38 (1.19)	5
Lack of intensive treatment	4.50 (1.70)	27	4.88 (1.96)	26	5.50 (1.20)	2
Lack of treatment contracts	4.25 (1.67)	28	5.00 (1.41)	18	3.75 (1.49)	36
Limited skills with suicidality	4.25 (1.49)	29	-		-	
Suicidality	4.25 (1.28)	30	4.88 (1.13)	20	-	
Urgent problems	4.00 (0.76)	31	5.38 (1.06)	11	5.25 (1.28)	7
Lack of diagnostics	4.00 (1.51)	32	-		5.13 (1.46)	11
Feeling pressured (in professional)	3.88 (1.13)	33	4.88 (1.46)	24	4.50 (1.77)	25
Considering patient as being able but unwilling (in professional)	3.50 (1.60)	34	5.75 (1.04)	3	5.50 (1.20)	3
Interference with time/agenda	3.38 (1.30)	35	5.38 (0.74)	8	5.13 (1.55)	12
Attachment disorders	-		6.13 (0.64)	1	3.75 (1.49)	37

Description	CD		BPD		NOS	
	Mean (SD)	rank	Mean (SD)	rank	Mean (SD)	rank
Lack of reflection	-		5.50 (1.20)	7	-	
Limited general therapeutic skills	-		5.25 (1.04)	13	5.13 (0.99)	10
Powerlessness (in patient)	-		4.88 (0.99)	19	4.50 (1.31)	23
High but inefficient use of services	-		4.75 (1.28)	27	3.75 (1.39)	35
Diffusion of responsibility	-		4.75 (1.39)	30	4.63 (1.41)	21
Large amount of problems	-		4.75 (1.28)	28	4.13 (1.46)	33
Lack of accumulation of knowledge	-		-		5.25 (1.16)	6
Limited professional ambitions	-		-		4.00 (0.93)	34
Low professional status	-		-		3.63 (1.19)	38

Table 2

Urgency scores and ranking
orders of identified problems
in the care for three subgroups
of 'difficult' non-psychotic
chronic patients

Rank	Problem	Urgency	Changeability
1	Lack of organisational support	5.58 (1.21)	5.63 (1.06)
2	Lack of structured treatment	5.29 (1.46)	5.75 (1.26)
3	Pessimistic attitude	5.25 (1.11)	5.21 (1.32)
4	No view on problems and treatment	5.21 (1.32)	5.46 (1.22)
5	Undertreatment	5.17 (1.47)	5.58 (1.35)
6	Only 'pampering and dithering'	5.08 (1.28)	5.38 (1.31)
7	Limited cooperation professionals	5.00 (1.25)	5.33 (1.13)
8	Dependency	5.00 (1.45)	4.58 (1.53)
9	Poor alliance of family carers with professionals	4.96 (1.12)	4.46 (1.06)
10	Demoralization (in patient and professional)	4.96 (1.27)	4.96 (1.49)

Table 3

Aggregated urgency and
changeability scores of
problems in the care for
'difficult' non-psychotic
chronic patients

Results

> *Problems in the care of non-psychotic chronic patients*

Response rates were optimal throughout the entire procedure, with all participants responding in all rounds. Combining the lists for the three groups, a total number of 46 problems was identified. The problems and their urgency scores are displayed in table 2, including a ranking order that differs between groups. Of these 46 problems 26 appeared in all three groups, 14 in two groups and 6 in only one group. Problems in the care for BPD-patients scored the highest on urgency (mean 4.99, sd 0.52), followed by those in the care for CD-patients (mean 4.81, sd 0.65) and NOS-patients (mean 4.68, sd 0.59). None of these differences were statistically significant.

> *Specific problems: subgroup profiles*

Based on the ranking of the five most urgent problems per subgroup (table 2, bold print) the specific difficulties in the care for each subgroup of patients can be clarified. The Delphi-procedure showed that problems in the care for patients with chronic depression (CD) primarily have to do with the form and content of the treatment offered. Undertreatment is the single most important problem, largely caused by demoralization of both patient and professional: both parties simply lose faith in further treatment due to frequent relapses and limited progress. The lack of a coherent view on both problems and treatment may be detrimental in such cases. The experts state that there is no generally accepted model that explains the treatment resistance of some depressive patients. This may result in ascribing the lack of effect and patient's dependency on mental health services to his or her unwillingness to get better, or to underlying personality characteristics. All problems have one thing in common: the notion that it is very difficult to stay motivated in working with chronic depressive patients. As a consequence it is hard to assess when treatment should become long-term care, or should be terminated at all. In the latter case, the question is if this is an objective decision based on the patient's situation or if it is based on the professional's subjective state of demoralization.

For patients with borderline personality disorder (BPD), other problems are scored the most urgent. The problems these patients have with attachment and dependency place a heavy burden on the professional. It is very difficult for borderline patients to become attached to a professional, yet once this has happened it is just as hard to reclaim independence. Experts describe the charged therapeutic relationship, which is often the consequence, as burdening. This burden is increased and complicated by

professionals' tendency to consider patients as able but unwilling to behave differently, thus suggesting that the patient is purposively sabotaging help. Two more problems consider the organisation of mental health care. Professionals experience little support in working with these patients, neither from management nor from colleagues. Structured treatments may exist but are often inaccessible due to their limited capacity or implementation. Other than with chronic depressive patients, for whom treatments are more available but are underused because of mutual demoralization, professionals are eager to try these treatments. Another difference between CD and BPD patients is the stronger emphasis on interpersonal problems with borderline patients, which makes professional more inclined to consider them unwilling instead of unable. As a result, borderline patients are blamed more for their lack of improvement than chronic depressive patients.

The third group, that of not otherwise specified non-psychotic chronic patients (NOS), often defies diagnosis or classification and combines multiple psychiatric problems into an undistinguishable amalgam of misery. Many problems with this group are, according to experts, related to the mental health system itself. The most urgent item is the lack of organisational support: facilities to work properly with these patients are lacking, (intensive) treatments are unavailable and cooperation with co-workers is poor since most are unwilling to accept, or be responsible for these patients. Although it may well be very difficult to design proper services for these multi-problem patients, it currently are the patients that are blamed for this mismatch. The second most urgent problem in this group is the professional qualification of patients as able but unwilling to change their behaviour. The urgency of personality problems is illustrative in this matter, exemplifying that not so much the possible Axis I-disorder or practical problems are considered explanatory but that merely the patient's personality is. Certainly more than in chronic depressive and somewhat more than in borderline patients, lack of treatment success and interpersonal difficulties are attributed to the patient. The lack of a clear and stable diagnosis apparently makes professionals and organisations powerless towards the care needs of these patients that often are so clearly present or vividly articulated. Unlike for the other groups, there simply is no treatment available for this NOS group. Concluding, their presentation and help-seeking behaviour does not fit the current diagnostic and therapeutic structure of mental health care.

> *Generic problems*

Since all three groups together were earlier described as one, we also analysed the most urgent problems across all groups. We selected the 10 most urgent overall problems (table 3). Here, most of the items are related to an overall lack of knowledge about the

necessary content of treatment, the evidence of 'what works' and the organisational embedding within the total mental health care system. As such, professionals, regardless of the non-psychotic chronic patient group they work with, experience problems that are not directly related to the patient's specific psychopathology or disorder. Describing the central dilemma as briefly as possible, it comes down to: psychiatric professionals lack a view on how to understand and structurally treat non-psychotic chronic patients, with whom dependency (on part of the patient) and pessimism (on part of the professional) are particularly problematic, resulting in demoralization and limited therapeutic ambitions within an organisation that does not support the work with these patients very well, while professionals experience limited cooperation with each other and a limited alliance with family carers.

Considering many problems not to be related to patient characteristics but to the functioning of mental health care itself, we expected experts to be quite optimistic about the changeability of these problems. Indeed, organisational problems attract the highest changeability scores, while professionals' pessimism and demoralization score lower and problems related to the patient (dependency) and his or her social system (poor alliance with family carers) typically score lowest. Although present in all groups, the perceived changeability of problems differed between groups. The chronic depression group evoked most optimism, shown through a high mean changeability-score over these 10 most urgent items (mean 5.70, sd 0.67). The NOS-group evoked least optimism (mean 4.94, sd 0.47), while the borderline group scored somewhat higher (mean 5.02, sd 0.41). The difference between the CD-group and the other two groups was significant (ANOVA $F=6.384$, $df=2, 27$, $p=0.005$). The same pattern was found when the mean changeability scores of all problems, not just the 10 most urgent, were compared: CD scored highest (mean 5.25, sd 0.74), NOS lowest (mean 4.71, sd 0.59) and BPD in between (mean 4.86, sd 0.39) (ANOVA $F=7.998$, $df=2, 107$, $p=0.001$). In terms of clinical significance it may be stated that the CD-group evokes up to three-quarters of one point, on a 7-point Likert-scale, more belief in possible change than the BPD and NOS-groups do.

The 5th Delphi-round supported this outcome. In the final group discussion the changeability of the identified problems was thoroughly discussed, regarding the experts' observation that most patients with severe and persistent mental illness receive care in non-specialized services. Many were critical of such services: CD-experts strongly favoured more therapeutic options, while NOS-experts were somewhat sceptical of therapeutic endeavours and stronger supported needs-focussed care arrangements. All agreed that if non-specialized psychiatric care was better structured and more focussed on problems like chronicity and dependency, care could be improved. However, all experts also agreed that evidence-based treatments (if existent and available) should be tried first.

Discussion

Regarding our research questions, we have identified 46 problems in the care for three groups of non-psychotic chronic patients. The largest differences were found in patient-related problems. Descriptions of the particular problems in these groups have given insight in how these variables contribute to perceived difficulty by professionals, and possible effects on subsequent care. The most important generic problems across all three groups, considered the organisation and provision of mental health care, professional's pessimism and demoralization of both patient and professional.

The use of aggregated scores of the larger group of non-psychotic chronic patients, is somewhat at odds with the present scientific focus on disorder-oriented treatments and dedicated services. It did, however, show that some problems are more generic than estimated beforehand. Although generic, differences between diagnostic groups were present: problems in patients with an Axis I-diagnosis (CD) were perceived much more changeable than problems in patients with an Axis II-disorder (BPD) or no clear diagnosis at all (NOS). This suggests that the better patients fit into the (diagnostic) mental health system, the less pessimistic professionals become. An alternative explanation is that the larger number of effective treatments for depressive disorders, compared to BPD and NOS, evokes more optimism in professionals. Experts are truly optimistic about changes in the mental health system to reduce problems in the care of 'difficult' patients. The patient-professional interaction remained largely out of sight, which is surprising since substantial research is directed towards the therapeutic alliance and a large part of treatment effectiveness is ascribed to its quality. As such it appears that, additional to blaming the patient, experts blame mental health care for systemic failure with these patients.

Our list of most urgent items (table 3) points to such systemic failure at three different levels. First, the scientific level at which there exist relatively few treatments for many of these patients. Second, the services level at which the existent treatments may not be available to patients, either because of scarcity of means or because of poor fit (as a result of e.g. diagnostic uncertainty, co-morbidity, repeated no-show, recurrent crises). In such cases, patients are often referred to services with few treatment options for patients, little appeal to professionals and limited resources in general. Within such services, a coherent view on the care for these patients is often lacking. It is unclear how intensive professionals may follow patients, how long care may continue, how problems in treatment should be understood or from which therapeutic framework care should take place at all (Koekkoek et al., 2010a). The third systemic level is the interprofessional level, at which cooperation and support are hard to find, leaving professionals relatively

isolated with their 'difficult' patients. All aforementioned elements of systemic difficulties may find their way into the patient-professional interaction and result in professionals' insecurity, pessimism and demoralization.

While the search for more refined diagnoses and specialized treatments continues, it appears useful to also develop strategies for practical problems regardless of diagnosis (e.g. frequent no-show, chronic suicidality, dependency, demoralization). A program that combines a coherent view at services level, with support and increased communication at the interprofessional level (e.g. through regular supervision, sharing of case-loads) may be highly beneficial to non-specialized services (e.g. Tyrer, 2007; Tylee et al., 2007). It goes beyond doubt that an evidence-based treatment that fits the patient's problems and needs, should be provided first if available. However, the non-specialized services that patients are referred to in the case that this is not an option, need support to offer proper care. More so, they may even need to become specialized services for non-psychotic chronic patients, analogous to specialized services for 'difficult' psychotic chronic patients (e.g. Assertive Community Treatment). Then, they can incorporate evidence-based strategies for specific problems without requiring patients to fit an entire treatment program or a specific diagnostic category.

> *Strengths and limitations of the study*

The Delphi-procedure was beneficial in increasing our understanding of difficulties in the care for non-psychotic chronic patients. The focus groups in the 1st round were useful because of their interactive nature, helping experts to explore their explanations beyond what is commonly said about 'difficult' patients. Furthermore, the validation of summarized items in the 2nd round improved both the reliability and validity of the statements used in the following rounds. The diverse sample in terms of professional background and working setting may have further improved the validity of the results. However, participants came from only one country and all were experts. Even though the Dutch mental health system resembles that of most highly developed countries, we cannot rule out that 'regular' professionals would have come to other conclusions than our experts did. Bias in the selection of experts may have occurred, yet we have put in maximal effort to ensure that participants met the preset objective expertise-criteria. Last, generalization of the three subgroups of 'difficult' non-psychotic chronic patients researched here, to all non-psychotic chronic patients is not readily possible.

Dividing a Delphi-panel into three smaller groups is not a regular procedure. In this case, it resulted in small numbers per subgroup and the absence of some items in one or two groups, making it impossible to calculate aggregated scores of all problems across three

groups. This procedure may have introduced a bias towards more general and less specific items. However, the selected items do represent a large part of the urgent problems in each of the three groups.

Conclusions

To state that mental health care produces its own 'difficult' non-psychotic chronic patients may be too strong. Yet it is clear that 'turfing' patients to under-resourced services is more likely to reinforce than to diminish professional's pessimistic attitudes towards these patients. This and other problems have been exemplified through this research. The results may be helpful in developing increasingly tailored strategies to deal with these problems in non-specialized services.

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What makes community psychiatric nurses label non-psychotic chronic patients as 'difficult': patient, professional, treatment and social variables

> *Purpose*

To determine which patient, professional, treatment and/or social variables make community psychiatric nurses (CPNs) label non-psychotic chronic patients as 'difficult'.

> *Methods*

A questionnaire was designed and administered to 1946 CPNs in the Netherlands. Logistic regression was used to design models that most accurately described the variables that contributed to perceived difficulty.

> *Results*

Six variables were retained in the final logistic model. Perception-related variables (feeling powerless, feeling that the patient is able but unwilling to change, and pessimism about the patient's change potential) dominated treatment-related variables (number of contacts per week and admission to a locked ward in the last year) and social variables (number of psychosocial problems).

> *Conclusion*

This research shows that perceived difficulty is related to complex treatment situations, not so much to individual patient characteristics. If the constructed model has good predictive qualities, which remains to be tested in longitudinal research, it may be possible to accurately predict perceived patient difficulty. When used as a screening tool, such a model could improve treatment outcomes.

Introduction

Health care professionals do perceive certain patients as 'difficult', both in physical (Groves, 1978; Lin et al., 1991; Jackson et al., 1999; Hahn et al., 1996; Steinmetz et al., 2001) and mental health care (Hinshelwood, 1999; Koekkoek et al., 2006). In general medicine, perceived difficulty has found to be associated with multiple somatic complaints and psychiatric disorders (Lin et al., 1991; Jackson et al., 1999; Hahn et al., 1996; Steinmetz et al., 2001). In psychiatry, patients with severe mental illness in general are often considered difficult to treat (Rössler et al., 2006), but few empirical studies have been undertaken to clarify the underlying reasons for this perceived difficulty (Koekkoek et al., 2006). Small studies of earlier date show that patients with psychotic or personality disorders are most likely to be perceived as difficult, with patients with mood disorders ranking next. 'Difficult' psychotic patients are characterized by professionals as 'withdrawn' and 'hard-to-reach', 'difficult' patients with personality disorders as 'demanding' and 'claiming', and 'difficult' patients with mood disorders as 'dependent' and 'demoralizing' (Koekkoek et al., 2006).

The label 'difficult' is pejorative, stigmatizing, and imprecise (Corrigan, 2006) but often used in everyday mental health care, especially in services that are not highly selective such as public and community mental health centres (Neill, 1979). From earlier work, we can distinguish three different meanings of the term. The first meaning refers to patients that do not improve or relapse repeatedly, so-called 'difficult-to-treat' patients (Koekkoek et al., 2006; Koekkoek et al., 2008a; Dewan et al., 2001). The second refers to patients that are interpersonally challenging, so-called 'difficult' patients that supposedly have a complex character or personality (Koekkoek et al., 2006; Koekkoek et al., 2009b). The third meaning refers to patients who find themselves in complex social and treatment situations, patients that have numerous social problems, frequently use inpatient and outpatient emergency services, and have difficulties in finding the right helping agency to have their needs met (Koekkoek et al. 2009c; Koekkoek et al. 2009d). The label 'difficult' thus represents a complex interplay of several factors and may refer to patient characteristics in terms of illness, behaviour or character. It may, however, also reflect professionals' lack of skills and motivation, or environmental factors such as patients' social system or clinicians' professional system (Koekkoek et al., 2009c).

In general, the 'difficult'-label is associated with a low quality of the therapeutic alliance between patient and professional, which in itself is a predictor of a more negative treatment outcome (Horvath et al., 1993; Martin et al., 2000). Also, 'difficult' patients more often lack a treatment plan, a key clinician and continuity of care in general, than other patients (Neill, 1979). Service use of these patients is high and thus costly (Kent

et al. 1995a; Kent et al. 1995b, Roick et al., 2002). Therefore, it is relevant to understand which variables account for the perception of patients as difficult by professionals. Timely recognition of these variables may prevent perceived difficulty and thus result in improved treatment outcome. Currently, however, many of these factors are theorized or hypothesized only, and not empirically assessed in a larger study. In this study, we focused on patients with severe non-psychotic mental illness. The percentages of non-psychotic patients in long-term community mental health services are estimated between 20 and 50% (Arvidsson, 2003; Keown et al., 2002; Greenwood et al., 2000; Hunter et al., 2002; Ruggeri et al., 2007). The key clinicians in long-term care for these patients often are community psychiatric nurses (CPNs), the most numerous professionals in community mental health in several countries (Greenwood et al., 2000; van Hoof et al., 1995; WHO, 2007; Koekkoek et al., 2009a). In this paper, we report on the perception of CPNs in community mental health care for non-psychotic chronic patients. The aim of this study is to determine which patient, professional, treatment and/or social variables make CPNs label non-psychotic chronic patients as 'difficult', in order to define this term more accurately, and eventually improve care for patients labelled as such.

Methods

> *Design and participants*

A cross-sectional survey design was used to describe community psychiatric nursing care for non-psychotic chronic patients, assessing several patient, professional, treatment and social variables. The sampling frame was the database of the Dutch Association for Community Psychiatric Nurses (DACPN). This database includes 1946 CPNs, about 70% of the total estimated number of 2900 Dutch CPNs. An electronic questionnaire was developed and was available online between mid-December 2007 and late January 2008. CPNs were invited to participate by a postal letter in which the study was introduced as a general survey into current CPN-practice. Two weeks and 4 weeks after this letter, non-responders received a reminder in the form of a postal card.

> *Measures*

The questionnaire was constructed by the authors, based on previous research among CPNs and previous Delphi-research on problems in the care of difficult patients among community mental health experts (Koekkoek et al., 2009c). It consisted of 19 questions related to the CPN and the service he or she worked in. Another 23 items (rateable on a 7 point Likert-scale) were about the perceptions of the care for a selected patient. Furthermore, it included 23 questions about clinical, treatment and social characteristics of the

selected patient in care. The first paper version of the questionnaire was tested by 27 CPNs after which some questions were omitted and text phrasing was altered. A second, internet-based version was tested by another six CPNs after which technical software-related errors were corrected.

Before answering the questionnaire, CPNs were asked to select a patient meeting the criteria for non-psychotic severe and persistent mental disorder (Ruggeri et al., 2000): a non-psychotic diagnosis (excluding psychotic, bipolar and organic disorders), two or more years in psychiatric care and a GAF-score at or below 50. To ensure random sampling of patients, a fixed procedure was used. CPNs should select the first eligible patient on their next working day from their agenda (or progress as far ahead in time as necessary to encounter a patient meeting the criteria).

Degree of perceived difficulty, the dependent variable in this study, was measured by the question 'to which extent do you rate this patient as 'difficult'?', scored on the same 7-point Likert-scale as the other perception-related items. At the time of the study, we were unaware of validated measures of psychiatric patients' difficulty. Furthermore, single-item questions such as ours have been used widely before (Lin et al., 1991; Steinmetz et al., 2001; Neill, 1979; Modestin et al., 1986).

> *Analysis*

Due to a bimodal distribution (table 1), the dependent variable was dichotomized into two values: no perceived difficulty (score 1–4) and perceived difficulty (5–7). Logistic regression was used to determine the effects of the patient, professional, treatment and social variables on perceived difficulty. Linearity of the relation between each variable and the dependent variable was assessed using cross tables for dichotomous and categorical variables, and scatter plots for continuous variables. Since some variables did not have a linear association with the dependent variable, these were categorized using dummy variables. Non-linearity was also found in 7 of the 23 continuous variables related to the professional's perception that were measured on the Likert-scale. These seven variables were omitted since categorization of the Likert-scale was not considered a valid way to interpret this non-linearity. Bivariate analyses were used to reduce the number of variables, since this was too high after categorisation for the number of cases to produce a stable model. A significance value of $p \leq 0.20$ was used to select variables to be included in the further analysis.

Two models were made, one for the continuous perception-related variables and one for the (predominantly) dichotomous and categorical other variables. A third and final model was constructed by combining all variables retained in the previous models. In the first two models, variables stayed in the model at $p \leq 0.10$ to prevent preliminary exclusion of relevant factors. In the final model, variables remained in the model at $p \leq 0.05$. For all models, backward procedures were followed. Interaction effects of the variables included in the final models were explored ($p \leq 0.10$), which was also done for collinearity (Twisk, 2007). Goodness-of-fit was established using the classification table, and the Hosmer and Lemeshow test to test the models' accuracy of predicting perceived difficulty (Hosmer et al., 1989). All analyses were performed with SPSS version 15.

Likert-score (perceived difficulty 1=low, 7=high)	Number of selected patients (%)
1	10 (2.1)
2	74 (15.8)
3	165 (35.2)
4	83 (17.7)
5	100 (21.3)
6	29 (6.2)
7	4 (9)
	465 (99.1)¹

1: Of the 469 patients described by 469 CPNs, of
4 patients data on perceived difficulty was missing

Table 1

Distribution of perceived
difficulty over selected
patients on 7 point Likert-
scale

		n=469 (%)
Sex	Female	248 (52.9)
Age	mean (sd)	46.9 (7.3)
	20-29	10 (2.1)
	30-39	53 (11.3)
	40-49	225 (48.0)
	50-59	175 (37.3)
	>60	6 (1.3)
Education	CPN	412 (87.8)
	CPN+	204 (43.5)
	CPN + Master	11 (2.3)
Work setting	Mental health care	411 (87.6)
	Addiction services	35 (7.5)
	Private practice	34 (7.2)
	Forensic psychiatry	10 (0.6)
	General hospital or academic psychiatry	6 (1.3)
	Otherwise	15 (3.1)
Mean years of CPN-experience (sd) [range]		11.4 (8.6) [0-35]
Type of care	Emergency services	133 (28.4)
	Community-based <2 years	301 (64.2)
	Community-based ≥2 years	307 (65.5)
	Partial hospital	17 (3.6)
	Inpatient <2 years	21 (4.5)
	Inpatient ≥2 years	9 (1.9)
Evidence-based practice	Method described in the work setting	202 (43.1)
	Method described in the literature	110 (23.5)
	No or non-described method	157 (33.5)
Mean hours of supervision (sd) [range]		1.5 (1.15) [0.2-8]
Case load size	Mean total number (sd) [median & range]	52.2 (31.7) [50 (1-250)]
	Mean number of non-psychotic chronic patients (sd) [median & range]	12.4 (13.6) [8 (1-95)]

Table 2

Characteristics of surveyed

Community Psychiatric

Nurses (CPNs)

Results

The 1946 CPNs answered 776 questionnaires (response rate: 40%). Of these participants, about 20% did not carry their own case-load of patients between 18 and 60 years of age. Another 20% did not have non-psychotic chronic patients under their care, resulting in 469 CPNs describing a patient (table 2). Most CPNs were between 40 and 50 years of age. They predominantly worked in long-term care departments (≥ 2 years) of mental health institutes. They had a mean case-load size of 52.2 (sd 31.7, median 50) of which 12.4 (sd 13.6, median 8) were non-psychotic chronic patients (23.8% of the total case-load).

The selected patients (table 3) show a high prevalence of mood disorders (48.6%), cluster-B personality disorders (44.8%), and a somewhat lower prevalence of anxiety (22.8%) and substance abuse disorders (21.7%). Furthermore, over 32.4% of them had a diagnosis on Axis III, the mean number of psychosocial problems on Axis IV was 3.3 and most patients (71.9%) had a GAF-score on Axis V between 41 and 50. Of all 465 described patients, 28.4% was perceived difficult by their treating CPNs.

After bivariate screening of patient, professional, treatment and social variables ($p \leq 0.20$), 39 variables were selected to be included in two logistic regression models (table 4). The first model contained all variables except the 16 perception-related items. Perceived difficulty showed a moderate to strong relation to the GAF-score, the number of Axis I diagnoses, the presence of an Axis III-diagnosis and the number of psychosocial problems on Axis IV (table 5, model 1). Apart from these patient and social variables, the number and type (especially intensive and acute care) of psychiatric treatment used by the patient were related to the label 'difficult'. The second model (table 5, model 2), in which the 16 items related to the professional's perception of patient and treatment were entered, yielded a compact model of five continuous variables of which 'feeling powerless' had the strongest relation to perceived difficulty. The third model (table 5, model 3) combined the variables retained in the previous two models, resulting in a final model with six variables. Patient variables were no longer present in this model while treatment, social and perception-related variables remained. The number of psychosocial problems proved to have the strongest relation to perceived difficulty with feelings of powerlessness being almost as strongly related.

In terms of goodness-of-fit, this model classified patients correct in 74.2% of cases and the Hosmer and Lemeshow test was not significant ($\chi^2=11.92$, $df=8$, $p=0.16$), indicating support for our model. The previous two models classified patients correct in 70.3 and 69.9% of cases, respectively, with Hosmer and Lemeshow tests neither being significant.

		n=467 (%) ¹
Sex	Female	269 (57.4)
Age	18–24	43 (9.2)
	25–34	78 (16.6)
	35–44	143 (30.5)
	45–54	138 (29.4)
	55–60	65 (13.9)
In psychiatric care ≥3 years		349 (74.5)
No legal confinement		387 (82.5)
Diagnosis (DSM IV)	Axis I	
	Substance abuse disorder	102 (21.7)
	Mood disorder	228 (48.6)
	Anxiety disorder	107 (22.8)
	Somatoform disorder	8 (1.7)
	Factitious Disorder	1 (0.2)
	Dissociative disorder	30 (6.4)
	Sexual disorder	7 (1.5)
	Eating disorder	14 (3.0)
	Impulse control disorder	43 (9.2)
	ADHD/autism	48 (10.2)
	Adjustment disorder	61 (13.0)
	No or deferred diagnosis	33 (7.0)
	Other	23 (4.9)
	Primary diagnosis on Axis I	208 (44.3)
	Mean number of Axis I diagnoses (sd) [range]	1.5 (0.81) [1–5]
	Axis II	
	No or deferred diagnosis	89 (19.0)
	Cluster A	33 (7.0)
	Cluster B	210 (44.8)
	Cluster C	83 (17.7)
	NOS	52 (11.1)
	Axis III any diagnosis	152 (32.4)
	Axis IV mean number of problems (sd) [range]	3.3 (1.8) [0–9]
	Axis V GAF–score	
	41–50	337 (71.9)
	31–40	98 (20.9)
	21–30	18 (3.8)
	10–20	15 (3.2)
Social contacts ≤3		387 (82.6)

Table 3
Characteristics of
patients described by
Community Psychiatric
Nurses (CPNs)

1: Due to missing data
on characteristics
of 2 of 469 patients
described by CPNs

Professional variables	p
Sex	.682
Age category	.055
Educational level	.194
Number of working hours	.741
Work setting	.068
Years of CPN-experience	.030
Type of care	.073
Evidence based practice	.869
Hours of supervision	.273
Case-load size	.064
Perception-related items	
'I expect that this patient will not improve much as a result of my care'	0.00
'I feel powerless towards this patient'	0.00
'I do not experience success in the care of this patient'	0.00
'I feel pressured by this patient'	0.00
'This patient is dependent on me'	0.00
'This patient has too high expectations of his/her contact with me'	0.00
'This patient is not hopeful about the care offered'	0.00
'There is no clear view on the problems and the treatment of this patient'	0.00
'I feel that this patient is able but unwilling to change'	0.00
'This patient is not offered intensive treatment while he/she should be'	0.00
'This patient's treatment is not consistent'	0.00
'I do not have faith in the treatment of this patient'	0.00
'I am pessimistic about the patient's change capacities'	0.00
'People around this patient think that he/she is able but unwilling to change'	0.00
'This patient causes trouble within his/her family or social system'	0.00
'This patient plays hardly any role in his/her family or social system'	0.22
Patient variables	
Sex	.738
Age category	.045
Years of psychiatric care	.487
Legal confinement (once, repeatedly or constantly during last year)	.019
Axis I diagnosis	5x $p \leq 0.20$
Axis II diagnosis	.054
Number of Axis I diagnoses	.006
Primary diagnosis on Axis I or Axis II	.837
Axis III diagnosis (nolyses)	.002

Table 4
Significance of
variables in bivariate
screening (n=465)

Social variables		
Number of psychosocial problems (Axis IV)		.000
GAF-score (Axis V)		.000
Number of social contacts (≤ 3 > 3)		.045
Treatment variables		
Number of mental health contacts per month (≤ 1 > 1)		.000
Regularity of contacts (regular, irregular)		.471
Treatment goal (recovery, prevent relapse, structure life, monitor risk behaviour, unclear)	2x	$p \leq 0.20$
Number of mental health professionals involved		.435
Cooperation of mental health professionals involved (none, irregular, regular)		.414
Additional psychiatric services (emergency services, admission, partial hospital)	3x	$p \leq 0.20$
Number of additional psychiatric services		.006
Number of non-psychiatric institutions involved		.302

Table 5	1: bivariate OR, not corrected for other variables
Multivariable logistic regression models for perceived difficulty using three sets of variables (descriptive variables, perception-related variables and combined) (n=465)	2: adjusted OR, corrected for other variables in the model
	3: ORs of continuous variables increase with each unit increase on given scale or number

	OR ¹	95% CI	AOR ²	95% CI	p
Model 1: patient, professional, treatment and social variables (p≤0.10)					
<i>Dichotomous/categorical</i>					
Substance abuse disorder (no/yes)	1.42	0.89–2.28	0.50	0.27–0.94	.031
Diagnosis Axis III (no/yes)	1.97	1.30–3.00	2.02	1.25–3.27	.004
CPN contacts per week (≤1/>1)	2.65	1.75–4.02	2.07	1.27–3.37	.003
Use of crisis intervention services during last year (no/yes)	2.10	1.38–3.19	1.97	1.05–3.68	.033
Use of open closed ward during last year (no/yes)	1.84	1.17–2.88	1.90	0.97–3.76	.063
Use of locked admission ward during last year (no/yes)	2.06	1.23–3.44	2.34	1.13–4.82	.021
GAF-score (reference category = 41–50)	1	–	1	–	.00
31–40	2.90	1.80–4.65	3.07	0.94–10.09	.064
21–30	2.84	1.08–7.46	3.23	1.08–9.69	.036
10–20	3.11	1.09–8.86	2.52	1.44–4.41	.001
Number of diagnoses Axis I (reference category = 1)	1	–	1	–	.088
2 diagnoses	1.78	1.11–2.88	1.80	1.01–3.20	.047
>2 diagnoses	2.22	1.24–3.98	1.80	0.87–3.75	.113
<i>Continuous³</i>					
Number of psychosocial problems Axis IV (0–9)	1.34	1.20–1.51	1.25	1.08–1.43	.002
Number of used psychiatric services during last year (0–7)	1.22	1.06–1.40	0.79	0.61–1.04	.095
Model 2: perception-related variables (p≤0.10)					
<i>Continuous³</i>					
'I feel powerless towards this patient' (1–7)	1.75	1.51–2.20	1.51	1.27–1.81	.000
'I feel that this patient is able but unwilling to change' (1–7)	1.35	1.17–1.56	1.18	0.99–1.40	.072
'I am pessimistic about the patient's change capacities' (1–7)	1.37	1.21–1.56	1.30	1.07–1.59	.009
'This patient causes trouble within family or social system' (1–7)	1.29	1.16–1.44	1.20	1.02–1.41	.027
'This patient should but does not receive intensive treatment' (1–7)	1.57	1.31–1.80	1.30	1.13–1.49	.000
Model 3: all remaining variables combined (p≤0.05)					
<i>Dichotomous</i>					
CPN contacts per week (≤1/>1)	2.65	1.75–4.02	1.25	1.09–1.44	.001
Use of locked admission ward during last year (no/yes)	2.06	1.23–3.44	2.81	1.70–4.66	.000
<i>Continuous³</i>					
Number of psychosocial problems Axis IV (1–9)	1.34	1.20–1.51	2.18	1.20–3.97	.011
'I feel powerless towards this patient' (1–7)	1.75	1.51–2.20	1.67	1.42–1.98	.000
'I feel that this patient is able but unwilling to change' (1–7)	1.35	1.17–1.56	1.27	1.06–1.51	.008
'I am pessimistic about the patient's change capacities' (1–7)	1.37	1.21–1.56	1.19	1.01–1.39	.035

Discussion

From this study, we may conclude that Community Psychiatric Nurses (CPNs) label about a third to a fourth of their total patient caseload as 'difficult'. We found that a relatively small number of (six) characteristics accounts for the perception of non-psychotic chronic patients as 'difficult'. To our knowledge, this is the first study that investigates such characterization of non-psychotic chronic patients.

> Findings

The 28% of patients perceived as difficult is quite high compared to findings from other research: 6% among psychiatric inpatients with both psychotic and non-psychotic disorders (Modestin et al., 1986) and 15% of ambulatory patients with physical disorders (Jackson et al., 1999; Hahn et al. 1996). It is, however, lower than the 37% of high medical service-using patients of a health maintenance organization perceived as 'frustrating' by providers (Lin et al., 1991). Unfortunately, since these populations differ substantially from ours, prevalence percentages cannot be readily compared.

In the final logistic model, six variables were independently related to the outcome of 'difficulty', none of which were related to the patient's diagnosis. Weakly significant correlations of certain diagnoses (e.g. substance abuse disorder, dissociative disorder, cluster-B personality disorder) were lost in the multivariable analyses. Of the six variables, three were related to professionals' perceptions of patients and their interactions with them (feeling powerless, feeling that the patient is able but unwilling to change, and pessimism about the patient's change potential). Two other variables were treatment-related (number of contacts per week and admission to a locked ward in the last year), showing that high service use correlates with perceived difficulty. The strongest relation, however, existed between the current number of psychosocial problems and perceived difficulty. In summary, the model shows the domination of professionals' subjective perceptions of patients, followed by social and treatment variables. These findings lend most support to our previously described explanation of 'difficult' as referring to a complex treatment situation in which the patient has many social problems and uses services intensively, and the professional has several negative perceptions related to these patient problems. These outcomes fit in well with what is generally considered the designated role of CPNs in mental health care, namely to treat long-term patients with many complex psychiatric and psychosocial problems that have been unsuccessful in earlier treatment. They also show, however, that this is not an easy task.

In previous research, an important factor in the qualification of non-psychotic patients as difficult was the professional's perception of patients as 'able but unwilling to change or behave differently' (Koekkoek et al., 2009c). In the present study, this perception-related variable was also retained in the multivariable model. Patients that are considered able to make changes in their lives may easily be considered in less need and less deserving of care than others. Irrespective of its correctness, this notion may add to a discrepancy of perceived need between patient and professional, which has been found to be persistent (Lasalvia et al., 2007), associated with lower quality of life (Wiersma, 2006), and predictive of disagreement and negative therapeutic alliance (Junghan et al., 2007). There is some evidence that, for instance, patients with substance abuse (Ruggeri et al., 2004) and personality disorders (Hayward et al., 2006; Lasalvia et al., 2000) have higher needs than patients with psychotic disorders. Also, non-psychotic patients reported more needs than their treating staff did, whereas in psychotic patients this was exactly the opposite (Lasalvia et al., 2000). Recent studies confirm this picture of higher staff-rated needs in psychotic patients (Arvidsson, 2001; Foldemo et al., 2004; Fleury et al., 2006), others do not (Slade et al., 1998; Slade et al., 1996). Hence, patients may want more from professionals than these think is necessary. This incongruence may be the root for perceived difficulty by professionals, which will be exemplified in the next paragraph.

The oft-noted differences between professionals' views of 'difficult' patients with psychotic disorders (as 'hard-to-reach') and non-psychotic disorders (as 'dependent' or 'claiming') may be explained by disagreement over needs for care. Professionals tend to see patients with psychotic disorders as more or 'really' sick, compared to patients without a psychotic disorder. Thus, the needs of the latter patients are scored lower by professionals, while patients themselves score them higher. Our research, however, shows a high number of psychosocial problems (mean 3.3) among patients with non-psychotic disorders. As such, high needs may be present, yet the judgement of needs as 'justified' remains partly arbitrary and agreement over care needs is unlikely to be reached through 'objective' measures. Recent research consistently suggests that negotiation over needs for care results in better outcomes (Junghan et al., 2007; Lasalvia et al., 2005; Lasalvia et al., 2008; Joosten et al., 2009). Even when professionals perceive needs to be lower than patients, as in non-psychotic patients, it may be wiser to negotiate than to ignore patient-rated needs.

➤ *Strengths and limitations*

There are some methodological limitations to this research. Selection bias may have occurred through differential non-response to the CPN-survey. Yet, responders did not differ from non-responders on demographic variables. Furthermore, the subject of

the questionnaire was generally stated, and therefore is it highly unlikely that non-responders would have perceived non-psychotic chronic patients differently than responders. The sampling of patients, through selection of the first patient meeting the criteria in the CPN's agenda, was beyond our direct control but since CPNs were unaware of the content of the following questions, it is unlikely that they have deliberately chosen more or less 'difficult' patients. Furthermore, information bias is a risk since information about patients is provided by their CPNs and errors cannot be ruled out. Although we do not know if these are random or systematic errors, we have reason to believe that the large number of observations largely evens out these possible errors. Last, in bivariate screening some variables (e.g. 'evidence-based practice') unexpectedly failed to reach statistical significance. However, these variables were few in number, their p value was well above the preset level of 0.20, and the number of observations was sufficiently high, thus indicating a very low probability of non-detection of true associations.

The strength of this study lies in the large number of CPNs involved and the patients described. To our knowledge, similar research into the relevant clinical problem of 'difficult' non-psychotic patients has not been carried out on this scale. The electronic format of the questionnaire strongly reduced missing and inaccurate data to an absolute minimum (only 1.6% of the returned questionnaires were partly invalid). Through this design, we were able to reach CPNs evenly spread out over the Netherlands, thus representing different mental health institutions. The Delphi-variables were valid translations of data provided by community mental health experts in an extensive Delphi-study that has been reported on in detail before (Koekkoek et al., 2009c). We have reason to believe that the results of our study also apply to CPNs outside the Netherlands since their role is relatively comparable worldwide (Koekkoek et al., 2009a). They often, if not always in long-term care, work in close collaboration with psychiatrists. Psychiatrists tend to largely depend on the information provided by CPNs, which makes CPNs' perception of the patient highly relevant to psychiatrists' own role and care in relation to the patient. The extent to which our results apply to other front-line professionals (e.g. other psychiatric nurses, social workers or occupational therapists) is uncertain and warrants more research, but as of yet we have no reason to assume that these key clinicians perceive patients very differently.

➤ *Practice implications*

The implications for clinical practice partly depend on the predictive qualities of our models, to be assessed in longitudinal research. If it is possible to accurately predict perceived patient difficulty, the predictive variables may be used in a screening tool. Then, preventive actions may be taken to prevent possible future perception of these patients as difficult. Such preventive actions may consist of, for instance, increased attention for the therapeutic alliance between patient and professional, a focus on congruence of patient-rated and professional-rated needs for care, and organizational changes that facilitate high-quality care for patients in complex treatment situations. The overall purpose of these preventive measures, implemented through training and supervision, would, in line with our findings, be to redefine difficulty from an individual patient characteristic into a characteristic of the treatment situation.

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4

Ambivalent connections: a qualitative study of the care experiences of non- psychotic chronic patients who are perceived as 'difficult' by professionals.

> *Background*

Little is known about the perspectives of psychiatric patients who are perceived as 'difficult' by clinicians. The aim of this paper is to improve understanding of the connections between patients and professionals from patients' point of view.

> *Methods*

A Grounded Theory study using interviews with 21 patients from 12 outpatient departments of three mental health care facilities.

> *Results*

Patients reported on their own difficult behaviours and their difficulties with clinicians and services. Explanations varied but could be summarized as a perceived lack of recognition. Recognition referred to being seen as a patient and a person – not just as completely 'ill' or as completely 'healthy'. Also, we found that patients and professionals have very different expectations of one another, which

may culminate in a difficult or ambivalent connection. In order to explicate patient's expectations, the patient-clinician contact was described by a stage model that differentiates between three stages of contact development, and three stages of substantial treatment. According to patients, in each stage there is a therapeutic window of optimal clinician behaviour and two wider spaces below and above that may be qualified as 'toxic' behaviour. Possible changes in clinicians' responses to 'difficult' patients were described using this model.

> *Conclusions*

The incongruence of patients' and professionals' expectations may result in power struggles that may make professionals perceive patients as 'difficult'. Explication of mutual expectations may be useful in such cases. The presented model gives some directions to clinicians how to do this.

Background

Across all healthcare settings, clinicians perceive particular patients as 'difficult' (Groves, 1978). High users of medical services, these patients are generally unsatisfied with the care they receive (Lin et al., 1991; Jackson et al., 1999; Hahn et al., 1996; Steinmetz et al., 2001; Koekkoek et al., 2006) and may evoke strong negative emotions in clinicians (Groves, 1978; Hinshelwood, 1999). Although clearly a subjective and imprecise term, the perception of patients as 'difficult' may result in worse care for patients involved (Cornic et al., 2007; Koekkoek et al., 2009d) and increased stress and burn-out among professionals (Stacey et al., 2009; An et al., 2009). In the scarce empiric research into patients perceived as difficult in psychiatric services, prevalence varies between 6 and 28% (Modestin et al. 1986; Koekkoek et al., 2010b). Earlier, we found that especially patients who do not comply with the obligations of the sick role as defined by sociologist Parsons (1951), run the risk to be perceived as 'difficult' (Koekkoek et al., 2006). People have the right to be relieved from their routine social obligations and not be held accountable for their illness, if only they seek and accept professional help, and do their utmost best to restore good health as soon as possible (Parsons, 1951).

Among patients perceived as 'difficult', patients with long-term non-psychotic disorders may be seen as not complying with the latter obligation. Unlike patients with psychotic disorders – who are more obviously out of contact with reality – they may be held accountable for their behaviours (Koekkoek et al., 2006). Among long-term non-psychotic patients, no particular psychiatric diagnosis is associated with difficulty, while the number of psychosocial problems, psychiatric service use, and ways in which clinicians perceive these patients are (Koekkoek et al., 2010b). Clinician variables, such as a dominant focus on medical problems over interest in psychosocial issues, however, repeatedly have been found to be associated with perceived difficulty (Lin, 1991; Jackson et al., 1999; Hahn et al., 1996; Koekkoek et al., 2010b), clearly showing that 'difficult' is defined within the relationship of patient and clinician.

Although substantial research into the patient-clinician alliance has taken place (Stewart, 1995), the perspectives of patients in general, and of long-term non-psychotic patients in particular have hardly been explored (Svanborg et al., 2008). Also we are aware of only one (small) study that explored the care experiences of 'difficult' patients (Breeze et al., 1998). Here, we focussed on the alliance between the perceivedly 'difficult' patient and the clinician with the purpose to understand why certain patients – according to their accounts of receiving care – come to be perceived as difficult. Thus, we hoped to shed a different light on the labelling of patients as difficult and the possibly poor patient-clinician interactions resulting from it. We stated three research

questions: (1) which difficulties do patients who are perceived as ‘difficult’ experience in their contact with psychiatric clinicians, (2) which explanations do they have for these difficulties, and (3) what changes should be made to decrease these difficulties?

Methods

> *Design*

To answer the research questions we used a qualitative Grounded Theory (Strauss et al., 1998) research design with individual interviews of long-term non-psychotic patients perceived as ‘difficult’ by clinicians. Grounded Theory is a qualitative research method developed for social scientific research, that aims to develop theory grounded in empirical data. It is also widely used in health sciences, mostly – like other qualitative methods – in areas in which current (theoretical) knowledge is limited. Grounded Theory is considered particularly useful in the study of roles and interpersonal processes due to its origin in symbolic interactionism (Holloway et al., 2002).

> *Participants*

We included patients in community mental health care meeting the following requirements, based on a widely accepted definition of severe mental disorder (Ruggeri et al., 2000): (1) being in psychiatric care for at least two years, (2) having high psychiatric symptomatology and low social functioning (Global Assessment of Functioning [GAF] score ≤ 50 (Jones et al., 1995b)), (3) suffering from a non-psychotic disorder on DSM Axis I and/or a personality disorder on DSM Axis II. One subjective criterion regarding difficulty as perceived by treating clinicians was added. Participants had to have had disagreement over form or content of treatment with two or more professionals at least once in the past two years, as assessed by at least two clinicians. A similar criterion has been used in earlier studies (e.g. Modestin et al., 1986) and, as imperfect as it is, adds concretization (disagreement), quantity (at least once in past two years), and intersubjectivity (two clinicians).

> *Procedure*

We selected 12 outpatient departments in three mental health institutes in The Netherlands, striving for a differentiated sample of locations, according to degree of treatment specialization, nature and severity of psychopathology, and geographical dispersion. Key figures of these departments were informed about the research project and were asked to invite clinicians to participate. Treating clinicians (community

psychiatric nurses, psychiatrists, psychologists, and social workers) introduced the research to eligible patients as an investigation into difficult relations between psychiatric patients and clinicians. After patients gave consent to establish contact, the first author checked their eligibility with the clinician and then called or e-mailed the patients to arrange an individual interview at their preferred location. After getting acquainted and having explained the project, informed consent, basic socio-demographic, and clinical data were obtained prior to the interview. Each participant received a gift certificate to the equivalent of €35/£30.

› *Data collection*

Two experienced qualitative researchers (BK & JvO) carried out open-ended interviews between March 2008 and September 2009. The research team (BK, JvO, RP, BvM, AK) spent two instructional meetings to immerse in the subject, to design the interview structure and to practice its application. A topic guide, based on a literature search of relevant databases and patient literature was flexibly used. In the first series of eight interviews, participants were asked after certain topics if they had not mentioned them at all. In the following series of interviews, these checking questions were replaced by questions originating from the analysis of previous interviews.

Participants were invited to start their account by the general question: 'Which problems do you experience in contact with psychiatric clinicians, both now and in the past?'. Next, the interviewers invited participants to tell in detail about each of these problems and suggest possible explanations for them. Patients were also invited to suggest solutions or alternatives for the present care. All interviews were electronically recorded and transcribed verbatim. Transcripts were analysed in their original language, Dutch, while relevant quotations were translated into English for this paper.

› *Data analysis*

Data analysis took place between March 2008 and October 2009 in an iterative process, typical to the Grounded Theory-method of constant comparison (Strauss et al., 1998). Each member of the research team independently coded two out of the first four interviews and checked it against coding by the others (Pope et al., 2000). This procedure was followed to construct a mutually agreed on initial code tree, from which further coding could be done by one person (BK), using MAXQDA-software (Kuckartz, 2007).

The research team met after respectively 4, 8, 11, 14 and 21 interviews to discuss progress, monitor interviewers' techniques and congruence, evaluate and conceptually

analyze coded interviews, select and explore emerging categories and their mutual relationships, and design theoretical sampling strategies for following interviews. After eight interviews, six main large descriptive categories were constructed to order data. Each category fell apart in three to seven sub-categories. After 11 interviews, a tentative theoretical model of the care process was constructed and a preliminary core category ('incongruous expectations and perceptions of needs') was identified. After 14 interviews, an extensive thick description of data was written, structured according to the six descriptive categories. It was discussed and commented on in the research team, resulting in a number of additional questions used in the following interviews to clarify, refine, and expand the categories. Also after 14 interviews, intermediate results were sent to the participants interviewed, for a member check, and were accepted as they were. In addition to the existing questions, in interviews 15 through 21 the tentative model was presented to participants and their feedback was elicited. A summary of the research findings and the final theoretical model was discussed in the final meeting after 21 interviews. Methods and results were discussed with external supervisors (AS & GH) after 8, 14 and 21 interview.

An example of the analytical process is the *in vivo* (1st order) code 'clinician feels offended', that was categorized under 'clinicians' accountability', then under 'clinicians' professional characteristics', that finally became part of one of the six main categories 'professionals'. Furthermore, because of the both personal and professional qualities of this characteristic of clinicians, which was believed relevant to further analysis, a memo (called 'mixing up of personal and professional characteristics') was added to this fragment. Next, other clinician characteristics were explored and coded in detail, paying attention to for instance causes and consequences (*axial coding*). When clinicians' characteristics became part of the central theme of this research, it was further explored in relation to the model later reported on (*selective coding*).

As posited by Lincoln et al. (1985), qualitative research should show sufficient rigour, or 'trustworthiness' in their words. In order to enhance this project's credibility and dependability, member checking was used to validate intermediate findings. Also, peer debriefing was done with the external supervisors, and a thick description was made to allow co-researchers to assess the research' transferability. A detailed log book, consisting of memo's about data collection, analysis, and interpretation, was kept to ensure confirmability.

Results

In total, 29 patients recruited by clinicians were approached by the researchers. Eight refused (lack of time, lack of interest, or too much stress), 21 were interviewed (duration 26-75 minutes, mean 61 minutes). Almost all participants were socially isolated: living alone, having no (paid) work, having very few meaningful social contacts, and having several psychosocial problems (table 1).

From the 17th interview we did not collect data that added significantly to our findings. Thus, we carried out four additional interviews (18-21) to ensure that we reached theoretical saturation, and concluded data collection after interview 21. Overall, interviews proceeded relatively smoothly. Some patients expressed substantial grief, anger, or despair about current or past mental health contacts. The interviewers then paused, validated these emotions, and inquired whether the participants wanted to terminate the interview – which did not happen in any instance.

Our qualitative analysis was guided by six large categories of which four referred to actors: patients, clinicians, psychiatric services, and the patient’s social system. Two other categories referred to interpersonal processes: contact between patient and professional, and treatment of the patient’s problems by the clinician. These six categories are used to structure the answering of the three research questions in the results below, and specifically to construct a model of the patient-professional interaction in the second part of this section.

Table 1
.....
Characteristics of
participants
.....

		n	%
Age (mean, sd and range)		38.6 (9.8) [22–60]	
Gender	male	10	47.6
	female	11	52.4
Living arrangement	Alone	19	90.5
	With partner	2	9.5
	Else	0	–
Housing arrangement	Rental	17	81.0
	Owned	2	9.5
	Living with others	2	9.5
	Else	0	–
Day-time activity	Work	2	9.5
	Volunteer work	5	23.8
	Education/college	0	–
	None	14	66.7
	Else	0	–
Present mental health contact	None	1	4.7
	Outpatient	18	85.7
	Day treatment or inpatient	2	9.5
Years of mental health contact (mean, sd, range)		15.2 (7.6) [3–31]	
Number of significant and supportive contacts (mean, sd, range)		1.7 (1.2) [0–4]	
Number of psychosocial problem areas (DSM Axis IV) (mean, sd, range)		3.2 (2.0) [0–5]	
Diagnosis	<i>Axis I</i>		
	Chronic depression/dysthymia	5	23.8
	Post Traumatic Stress Disorders	5	23.8
	Bipolar Disorder II	3	14.3
	Attention Deficit Hyperactivity Disorder	1	4.7
	Any substance abuse disorder	3	14.3
	<i>Axis II</i>		
	Borderline Personality Disorder	12	57.1
	Personality Disorder Not Otherwise Specified	7	33.3
	Axis I only	2	9.5
	Axis II only	7	33.3
	Both	12	57.1

> *Difficulties experienced by 'difficult' patients*

Almost all participants described themselves as being 'difficult' for professionals, either because they knew they were perceived as such or because they said that they were not 'regular customers'. Participants described: (1) challenging behaviours exhibited by themselves towards clinicians and services, (2) difficulties in contact with individual psychiatric clinicians, and (3) difficulties with mental health care services.

Patients described behaviours that could be perceived as 'difficult' in quite some detail. These varied from not showing up on or walking away from appointments, to disqualifying and offending professionals, to shopping around for help, or claiming, threatening, fighting and stalking professionals. With regard to these behaviours, many acknowledged their heightened sensitivity for interpersonal rejection, personal history of problematic relationships, and high expectations of psychiatric services. These services are a last resort for many of them, often related to the absence of substantial social support. Patients' sometimes very outspoken expectations of clinicians and services are, in their view, repeatedly not being met. The following citation exemplifies an expectation that may not be particularly high, but clearly very different from what psychiatric clinicians are able or willing to offer.

In the beginning I had this ideal picture of day treatment, that they would comfort me and such things. That did not happen though, instead when I laid down on the couch they said that I could not do so. [P15]

But you do have a preset expectation (...), like they will start helping me now. You do not think that you will have to do the work, no, you believe they will do it. [P19]

The expectation 'to be helped' is recurrent in many participants' accounts. Patients feel a strong need for help but actually do not know what can be done. Clinicians in turn, in complex cases, do not know either which tends to culminate in mutual powerlessness.

Can we do anything else for you, they asked. I don't know, I said. (...). I mean if I all knew so well then I would not be here, would I?? [P11]

The second kind of difficulties are those regarding interpersonal contact with clinicians, in which participants differentiate between 'personal characteristics' and 'professional characteristics'. On the personal level, participants in particular miss true interest and authenticity. This stretches farther than politeness or professional courtesy, farther than just being listened to. For many participants, clinicians' merely professional interest

seems insufficient, possibly related to their aforementioned high expectations. Some participants make a direct link between their own difficult behaviours within the mental health contact and the lack of 'right interest' from clinicians. If there is no such true interest, these participants tend to stay away or start acting in a way that may be perceived as 'difficult'.

When I say something out of personal experience some doctors reply 'well who has went to school for this?'. Those kind of remarks make me very, very angry. [P13]

Professional characteristics participants search for in clinicians, are taking the lead, accepting responsibility, and setting out a clear course of treatment. An empathic and understanding attitude does not suffice, participants also want their clinician to assess them correctly, to look beyond their initial presentation and confront their easy excuses. While the aforementioned personal characteristics (true interest and authenticity) are most important to the interpersonal process of contact, clinicians' professional qualities are most important for the treatment process. Participants clearly state that these professional characteristics, however important, come into play only when a good-enough contact with the clinician has developed. At the same time, in many of the participants' accounts, personal and professional characteristics are not so clearly distinguishable. For instance, taking responsibility is not only seen as a strong professional asset but also as a sign of personal involvement, of real interest, and even of warmth.

They decided to take me by the scruff of the neck and help me. They did not give up on me. And that is what I am enormously grateful for now. [P2]

In some cases the desire for warmth and responsibility goes as far as one participants wishing for a long-term compulsory admission.

But for a psychiatric patient, who has no-one, an involuntary admission may mean that there is still one person on the earth, even though it is an institution, that at least cares a bit about her fate. [P12]

The wish for clinicians' personal involvement, however, is limited by the extent to which clinicians bring their own emotions into the contact. Clinicians' strong emotions are perceived as a source of potential difficulties by participants. For instance, one participant described a therapist that addressed the patient's noticeable alcohol odour due to drinking the night before. She expressed her personal feelings about the patient coming to their first appointment hung over and kept on repeating her discontent.

She did not ask one single question, all she did was whine about what I had done to her. Yeah, right. Well, now I go home and hang myself – how would that make her feel? [P3]

In line with this, several participants state that clinicians tend to interpret 'difficult' behaviours far too easily as personally directed towards them. They want clinicians to be more neutral in such cases, to understand certain behaviours as part of the patient's disabled behavioural repertoire and to assess it correctly as meaningful or functional. Yet at the same time participants loathe this neutrality when it turns into a distant, objectifying attitude. This puts the professional in a one-up position which many patients find hard to tolerate.

The third kind of difficulties are those with psychiatric services, which tend to hamper access by all kinds of complex organisational procedures, such as low contactability of clinicians, limitation of care, and high thresholds for certain treatments. Also there are unwritten rules, so they say, considering themes that are apparently not appropriate to discuss or do. These issues are at odds with the involvement participants desire. At a more abstract level, participants note collective negative attitudes in psychiatric clinicians, exemplified by the negation of patients' positive characteristics and pessimism about recovery opportunities. While participants feel that their illness, deviance, and difficulty is focussed on constantly in psychiatric services, they also experience that in order to maintain their contact or to receive treatment, they should behave as 'good' patients (i.e. seek and accept help and do their best to get better as soon as possible).

Professionals continuously laid demands on me about what I could or should not do. Never positive about what I could or should do. That I can draw strength from. Not from demands or expectations of what I should or could not do. [P15]

Participants state that in psychiatric services, patients' failures and pathology are constantly paid attention to and pointed out. Yet at the same time these pathological behaviours (e.g. using illicit drugs, self-mutilating or attempting suicide) are not tolerated and may be reasons to refer or discharge patients, which may be one of the unwritten rules referred to above.

I came there and could not smoke marihuana, I could not self-mutilate, I could not... But what I could do was unclear to me. I did not understand it. [P15]

Another participant tells about her admission to a hospital because of suicidal intentions, where she had to hand in her medication. After refusing this, she was discharged (still in possession of the pills).

That serious they took the problem, they put you back on the street. (...). Try to keep someone inside and to make contact with where someone's at, do not start a struggle over pills or self harm. That I still find so strange that people are put on the street because they do that [self harm]. No, I find that cruel, truly cruel. [P14]

Or another such account:

I grew only more suicidal and destructive. All the time I got some sort of slap in my face: you better leave, we can't do anything for you. All it was, was a confirmation that I did not belong there, that I was nothing. [P19]

> *Explanations for perceived difficulties: lack of recognition*

We now move to possible explanations for the difficulties in the patient-clinician relationship. All patients want clinicians to recognize their suffering and their needs. This recognition of needs, however, does not automatically mean that patients want to be seen as *patients in need*. Many find it hard to accept the patient role, or even concur with their given diagnosis. A distant and strictly medical approach (i.e. being offered diagnosis, prognosis and treatment by a skilled doctor) was endorsed by none of the participants. While they believed this to be a necessary but not sufficient element of care, it was once again pointed out that treatment cannot exist without contact. For some, receiving a diagnosis meant recognition of the genuineness of their problems and suffering.

But if you have an appointment with a psychiatrist who does not say what is best for you than you do not have it. You don't have that little paper that says what is exactly wrong with you. [P5]

Well, I was happy that I finally could, well, give it a name. That it was truly something. A personality disorder, or whatever you want to name it. [P11]

For others, receiving a diagnosis exemplified the inequity of the patient-professional interaction. With personality disorders, participants often resented their given diagnosis since they believed it actually hampered access to health care. Some expressed the wish to receive a diagnosis unburdened with the notion of 'being guilty' of their behaviour, in order to have better access to services. As such, different notions by patients and professionals of both the function and type of diagnosis may be partly explanatory for difficulties.

Independent of diagnosis, all participants expressed a deep need to feel understood, and in some cases, to be cared for by health professionals. The mental health system was described as a far from ideal but still the best environment to have this need met, better than their – so often absent – social system or other helping agencies. In other words, mental health care offers the least bad environment, shown by the statements of two participants that express their feeling to be relegated to mental health care. They express both their fundamental discontent and their intention to remain in psychiatric services in one single sentence.

People don't understand that [vulnerability] at all. It is such a lack of recognition. (...) Then, psychiatry is the lesser of two evils. That is why I stay there, I believe. I do occasionally have a good conversation, or I am sometimes able to find some relief. Otherwise I only start doing crazy things and become more sad. [P14]

From this point of view we may understand difficulty partly as a consequence of patients' ambivalence towards psychiatric care: needing it without wanting to. This perceived need merits further attention, since in spite of previous negative experiences and expressed discontent with several clinicians' characteristics, participants do remain in psychiatric care.

It [psychiatry] does not bring me any further, it does not offer any grip. It is not something one can pull oneself up on like for instance work is. Once again, I will always keep on going there [mental health care] without wanting to. [P8]

They appear to be looking for exceptions to the rule, for the one clinician that does understand them. Some are able to find this person but many are not and keep on fighting the misunderstanding they experience. Many clinicians appear to be unable to truly identify and validate the needs of these patients. At the same time, these needs may be so existential that psychiatric services will never be able to accommodate them, as exemplified below.

I expect, and that appears to be undeliverable, my basic problem is that I just want my mother. But that one simple thing is not available in psychiatry. [P12]

Instead of 'tender loving care', patients get 'distant' advice and structure. Many deeply resent the 'doctor knows best'-attitude of some clinicians, and do not want to be told what their life is, or should be like. Such active, but often also strict and formal clinicians, are easily perceived as bringing about a power imbalance that takes away the patient's control over the treatment encounter, and even the patient's life. Yet, not having to be

in control also relieves patients from their obligations and clearly acknowledges their needs and limitations in doing things themselves. Two participants exemplify this paradox in vivid terms.

These power relations feel very safe on the one hand because you just don't have anything to say anymore. Really, that security from when you were a child. Everything is being done for you and you just have to do this at that time and nothing else really. But on the other hand, it is not good since you cease to be a person. [P4]

At the moment I am not right, I feel very dependent, really very small. Then I think, oh no, I really need them. Yet, when I feel better, I am annoyed about them and their idea that they can decide what is good for me. [P13]

Patients once again appear very ambivalent about truly accepting help and the patient role. They express their difficulties with being either a person who is competent and autonomous, or a patient who is incompetent and dependent, and appear unable to combine those. Yet, according to participants not only patients have difficulties relating to this polarized notion of autonomy and helplessness. Clinicians also have difficulties to tolerate these two sides of one person, and tend to respond paradoxically to patients that display either one of them. Whenever a patient appears able to communicate his or her needs clearly, professionals see this as a sign of good mental health. So, when the patient asks for help in a 'normal' way, that is without dramatizing, threatening or without visibly being shattered, clinicians tend to believe that help is not actually required.

They said: 'you can articulate it so clearly, we believe that nothing is necessary'. That I found so bizarre, since I was doing everything to articulate myself clearly since otherwise I could not bring the message across. I would not receive help when I articulated it poorly, nor when I articulated my needs clearly. [P11]

Implicit notions about help-seeking behaviour are suggested by these examples. Clinicians expect patients to ask for help in a non-dramatic, rational, but still indigent way. Patients should thus not come up too autonomous or dependent, since clinicians seem to hold unspoken views of what is the right way to ask for help. When the patient is highly autonomous, the clinician appears to be unnecessary and may feel unseen him or herself. When the patient is overly dependent or 'needy', the clinician sees this as overreacting or even manipulative, and as potential risk of dependency. Patients desire a special kind of understanding and compassion from clinicians, that incorporates both their personal qualities and their difficulties, and not solely focuses on what is wrong, or easily concludes that nothing is wrong. Clinicians, on the other hand, are easily

confused over patients' presentations and tend to take adequate help-seeking behaviour for the absence of problems and needs. Margins for both patients' and clinicians' behaviour appear very narrow, which we will further exemplify in the next paragraph.

I am afraid that it is a mixture of my own paranoia and hostility towards health professionals, and the way I interpret what they say. And the interaction that comes from this. (...). Plus that they have this panic-like fear for dependency of patients. [P12]

➤ *Changes in patient-clinician contact: using the 'therapeutic window' through different stages*

The narrow margins of 'right' behaviour of both patients and clinicians described above, returned across many interviews and categories. Also, they were not static entities but changed over time. This closely relates to the core category we came to construct: incongruence of expectations and perceptions of needs. Participants repeatedly described wanting something else than professionals: more or another kind of care, more (or less) personal involvement, or a more structured approach to problems. Combining this with another recurring finding, that of contact and treatment as two separate dimensions, we tentatively constructed a stages model in the contact process with 'required' clinician behaviour per stage (figure 1). In each stage, there is a 'therapeutic window' of optimal clinician behaviour, and two wider spaces – both below and above the therapeutic dosage – of 'toxic' behaviour.

The first three stages of this model (figure 1) all concern 'contact', while the latter three concern 'treatment'. In the first stage ('acquaintance') patient and professional meet and get basically acquainted. Patients expect some basic interest of the professional at this stage, while rapid over-involvement or clear disinterest may be toxic and prevent the patient from returning for a next meeting. The second stage ('clique/fit') requires more closeness from the professional, but not over-disclosure of personal information or too much distance. A clique refers to a certain level of personal contact that shows the patient that the clinician cares.

I think it's a clique, it has to do with a clique. A clique between professional and patient is very important. Because if it cliques, then you gain trust. [P2]

The third stage ('true contact') is a crucial one, in which the clinician needs to recognize and genuinely understand the patient with both his or her qualities and shortcomings, as well as the patients' suffering. In this stage most difficulties tend to arise, since expectations are up from the previous stages. Patient and clinician must

navigate themselves through all the ambivalent demands described in the previous paragraphs. Toxic responses by clinicians include over-identification with the patient, and trivialization of problems and needs since this reinforces patients' earlier experiences of uncaring clinicians. In this stage, toxic clinician behaviour may result in more intense patient responses than not returning for another appointment (e.g. becoming disqualifying, angry, clinging, or threatening).

I believe that because when you are recognized, you are heard, and then you don't start fighting all the time to be heard. [P14]

The next three stages all concern 'treatment'. The fourth stage ('mutual strategy'), is the one in which the content of treatment becomes involved. A mutual agreement over goals and a treatment strategy need to be developed. In order to do this, more than just understanding is required, the clinician needs to be active and directive. This solidity should not be too rigid, or be too weak, since both are toxic to patients that look for a clear course.

And then the conversations start to dilute into something I can't define any more. (...). Then I have completely lost track. There is no structure any more, no direction. Yeah, at a certain moment, yeah, you just stop going. [P3]

In the fifth stage ('active help') the clinician should show not to be afraid to take responsibility for the patient's well-being and show continued involvement. Participants state that it is important that clinicians show their willingness to do some work for their patients. Failure to find a non-toxic level of intervention may result in patients perceiving the clinician as paternalistic or non-committed.

And if there's some time left, they ask me if they should join me to social services or anything. And that is really great sometimes, because it makes me more motivated to do start doing such things again by myself. [P9]

In the sixth and final stage ('continuation of fitting help') clinicians must carefully monitor the care process for recurring or new difficulties in the contact. The clinician needs to be perseverant in focussing on treatment goals, and vigilant for possible breaches in the contact. Too much persistence can result in rigid insistence, which like its opposite – negligence – is toxic to the patient.

So there is little attention for the progress one has made. Is he feeling better, is it right what we are doing here? [P5]

Stage 1: Acquaintance	Stage 2: Clique/fit	Stage 3: True contact	Stage 4: Mutual strategy	Stage 5: Active help	Stage 6: Continuation of fitting help
Over-involvement	Over-disclosure	Over-identification	Rigidity	Paternalization	Insistence
Interest	Closeness	Understanding & Recognition	Solidity	Responsibility	Perseverance
Disinterest	Distance	Trivialization	Weakness	Noncommittal	Negligence

Figure 1
.....
Stages of contact,
interventions, and respective
therapeutic windows
.....

We may state that the therapeutic window for interventions with ‘difficult’ patients is very narrow. In each stage things can go wrong due to either the lack of, or the excess of this required behaviour by clinicians. In both cases, such behaviour may be toxic to patients who are in substantial need of recognition of their problems and needs as described before.

Discussion

This research explored the views of patients perceived as 'difficult' on their contacts with psychiatric clinicians and services, in order to improve our understanding of difficult treatment encounters. We found that patients have difficulties with a variety of clinicians' and services' characteristics, of which disinterest, noncommittal, and a general negative view are the most important. The interpersonal process of perceived lack of recognition, grounded in the incongruence of expectations of one another, may be considered the major explanation for difficulties between patients and professionals. We constructed a staged model in which the development of personal contact is crucial to patients during the first three stages, and to which substantial treatment is added in the next three stages. The stage in between personal contact and substantial treatment is pivotal and concerns the recognition of patients as both genuinely ill, and valuable human beings with capacities and shortcomings.

> *Substantial findings*

Although the starting point of this research, and the premise of our sampling strategy, it cannot be upheld that 'difficult' is an attribution that can be objectively made upon patients. The findings of this study thus deserve interpretation on different levels.

A first important finding on patient level is that perceived difficulty may partly be explained by the ambivalence of these patients to fully assume the patient role. This appears to be a central feature of all participants and explains why such patients are found among people with quite different diagnoses. Not specific disorders themselves, but the way people perceive them and the way they want health clinicians to respond to them, appears associated with difficulty. Also, it explains why these patients evoke such strong and ambivalent emotions in health professionals. If the patient is unwilling to accept the patient role, a clinician cannot take up the designated role of genuine helper. It is quite well established that any health professional whose help is denied, questioned, ridiculed or whatsoever, feels frustrated (e.g. Groves, 1978; Lin et al., 1991). To a certain extent, the 'difficult' patient who feels unseen, unheard and unrecognized, is mirrored by the clinician who remains unrecognized as a genuine helper.

A second important finding, on professional and services level, is that mental health care does not very well know how to respond to patients that behave different and less predictable than other patients. The response of choice to patients that are ambivalent about being a patient, seems to be an intensification of efforts to make him or her fit the 'normal' patient frame – which in fact has the opposite effect. For instance, assuming

the expert role to convince the patient to behave differently, is exactly what will exacerbate the patient's unpreparedness to do so. It may be much more effective for the professional to recognize, voice, and discuss the patient's ambivalence.

A third finding, that encompasses different levels, is that patients who are perceived as 'difficult' and their clinicians who perceive them as such, have very different expectations about the contact with one another. The expectations patients have in different stages of the interaction with health professionals have been exemplified in the model. This model offers insight into the various expectations and allows clinicians to discuss these with patients in different treatment stages. Clinicians may thus use this knowledge to explicate mutual expectations and set up mutually agreed on goals and actions.

› *Limitations and strengths*

There are limitations to our study. First, the results need careful interpretation since they potentially suffer from a self-serving bias of participants. Very much like clinicians in earlier research (Koekkoek et al., 2010b), patients primarily report behaviours of the other they have trouble with. Second, our findings do not apply to psychiatric patients that are sent, or even sentenced, to mental health care. Third, we were unable to use alternative data sources to verify our findings (triangulation (Mays et al., 2000)). Despite several invitations, none of the participants was willing to attend a focus group discussion to verify intermediate findings and collect new data. Fourth, sampling proved to be complicated during the entire research for which reason selection bias is a risk. Many clinicians did not readily enrol possible participating patients, notwithstanding the description of this project as research into difficult interactions. Also, the requirements of both purposive sampling (to allow variation of socio-demographic characteristics, psychiatric diagnosis and health care settings) and theoretical sampling (following from intermediate analyses) limited the number of suitable participants. Moreover, initially enrolled patients did not always follow through when the interview date came closer. The period of data collection was therefore substantially extended. Potential undersampling of the most 'difficult' patients, however, is countered by the fact that participants, who were announced as 'really difficult' patients by clinicians, proved to be willing and even eager to participate. We believe that refusing research cooperation is not a primary characteristic of this population, thus suggesting the absence of selection bias on these grounds. Although our sample size was smaller than intended, theoretical saturation appeared relatively soon, and was followed by four additional interviews to ensure validity. To our knowledge, this is the first qualitative study into the experiences of 'difficult' patients using a sufficient sample size and rigorous qualitative methodology.

> *Current and future research*

Our findings, and especially the model, concur quite well with, and add some detail to, the literature on the importance of the therapeutic alliance in psychiatric treatment and the required focus on bonds, goals, and tasks (Bordin, 1979; Martin et al., 2000). The importance of true interest in, and recognition of, the patient and his or her suffering, is under different names also found in modern care models for different non-psychotic disorders (Bateman et al., 2004; Linehan, 1993; McCullough, 2003). More surprisingly, findings from studies of ‘difficult’ patients with medically unexplained symptoms in general health care, are quite consistent with ours (e.g. Sumathipala et al., 2008). In this study, patients expectations also differed from those of doctors, while in another study (Salmon et al., 1999) the recognition of suffering, followed by a open discussion of treatment options was a finding comparable to our findings. Future research into difficult alliances may sample pairs of patients (both perceivedly ‘difficult’ and ‘non-difficult’) and professionals, investigating their mutual expectations, interactions, and progress over time.

Conclusions

The incongruence of some patients’ and professionals’ expectations may result in power struggles that may make professionals perceive patients as ‘difficult’. Explication of mutual expectations may be useful in such cases. Additionally, clinicians may first wholeheartedly acknowledge and recognize the needs of such patients, only to proceed with more formal treatment procedures (such as clarification of expectations, setting of goals, and choosing of interventions) from there. The presented model may be helpful to navigate through the different stages of the patient-professional contact.



5

How do patients become to be seen as ‘difficult’?: a mixed-methods study in community mental health care

> *Objective*

Across all health care settings, certain patients are perceived as ‘difficult’ by clinicians. This paper’s aim is to understand how certain patients come to be perceived and labelled as ‘difficult’ patients in community mental health care, through mixed-methods research in The Netherlands.

> *Methods*

A literature review, a Delphi-study among experts, a survey study among professionals, a Grounded Theory interview study among ‘difficult’ patients, and three case studies of ‘difficult’ patients were undertaken. Analysis of the results of these qualitative and quantitative studies took place within the concept of the sick role, and resulted in the construction of a tentative explanatory model.

> *Results*

The ‘difficult’ patient-label is associated with professional pessimism, passive treatment and possible discharge or referral out of care. The label is given by professionals when certain patient characteristics are present and a specific causal attribution (psychological, social or moral versus neurobiological) about the patient’s behaviours is made. The status of ‘difficult’ patient is easily reinforced by subsequent patient and professional behaviour, turning initial unusual help-seeking behaviour into ‘difficult’ or ineffective chronic illness behaviour, and ineffective professional behaviour.

> *Discussion*

These findings illustrate that the course of mental illness, or at least the course of patients’ contact with mental health professionals and services, is not determined only by patients’ characteristics. Patient and professional, reinforced by the social and mental health care system, mutually shape the course of care and illness. This model adds to the broader sick role concept a micro-perspective in which attribution and learning principles are incorporated. On a practical level, it implies that professionals need to look into their own role in the perpetuation of difficult behaviours as described here.

Introduction

In various health care settings, health professionals perceive particular patients as 'difficult' (Groves, 1978). These patients often are high users of medical services, may sometimes be violent, demanding, aggressive or rude, and generally are unsatisfied with the care they receive (Lin et al., 1991; Jackson et al., 1999; Hahn et al., 1996; Steinmetz et al., 2001; Koekkoek et al., 2006). In physical health care, no particular medical diagnosis is associated with perceived difficulty, but medically unexplained symptoms and a psychiatric label often are (Jackson et al., 1999). In mental health care, and particularly in community mental health care – due to its easy accessibility for almost anyone with psychological problems – three groups of patients are considered 'difficult'. These are withdrawn patients with psychotic disorders, demanding patients with antisocial personality and addiction problems, and – foremost – ambivalent patients with long-term non-psychotic disorders (Koekkoek et al., 2006).

'Difficult' patients run the risk to be treated less respectfully, less effectively, and to be excluded from health services because of their failure to comply with its implicit and explicit rules for 'proper' patienthood (e.g. Ring et al., 2005; O'Reilly et al., 2001; Pelet et al., 2005). Professionals working with these patients report more stress and burn-out (Stacey et al., 2009; An et al., 2009). An increased understanding of how patients come to be seen as 'difficult', why these 'difficult' patients remain in mental health care, and what can be done to prevent this may have positive effects on treatment quality, treatment effectiveness and total health care costs. Therefore, the aim of this research project was to understand how certain patients become to be perceived and labelled as 'difficult' patients in community mental health care. By integrating and re-analyzing previous mixed-methods research projects and using social scientific theory to guide our analysis, we describe the various steps towards a tentative explanatory model that offers a possible explanation of the occurrence of 'difficult' patients in mental health care. A theoretical framework – Parsons' sick role concept – will be introduced first, and used throughout to understand empirical findings from various studies.

Background

The most general explanation for the professional perception of patients as 'difficult', regardless of more concrete and specific troublesome behaviours, is that these patients fail to comply with the requirements of the sick role (Koekkoek et al., 2006). Most important, they do not appear to do their very best to get better. Instead, they seem to obstruct their own, and their clinicians' efforts towards, recovery. They may regularly miss out appointments or fail to comply with even the most modest of life style

suggestions, apparently on purpose. Even those that do try hard to get better but do not succeed and relapse often, may be considered 'difficult'. In general, clinicians perceive patients as 'difficult' when they feel denied in their best intentions and obstructed in their curative actions.

Parsons (1951) defined both obligations and rights related to (legitimate) sickness. The individual should do all to get better, as soon as possible, by seeking and accepting help, and by cooperating with health professionals. At this price, the individual may expect not to be held responsible for his sickness and to be relieved from routine social obligations. Notions of 'proper' sick role behaviour, highly consistent with Parson's formulations, have repeatedly found to be present among health professionals (e.g. Glenton, 2003; Werner et al., 2003), including those who care for chronic psychiatric patients (Bachrach et al., 1987), in spite of the limited suitability of the sick role concept with chronic illnesses (e.g. Parsons 1951; Freidson, 1970).

The social dimension of the sick role implies that anyone can at any time decide to be *sick*, that is to stop performing one or more social roles because of perceived non-health. Such self-perceived non-health is usually referred to as *illness* (Marinker, 1975). However, in order to legitimately maintain the sickness status, self-perceived illness is insufficient and a diagnosis by a qualified health professional is required (e.g. Nettleton, 2006). The health professional thus plays an important, if not crucial, role in the reinforcement of a patient's sickness status. This role becomes even more important when objective diagnosis of the patient's condition, for instance through a blood test or X-ray pictures, is impossible. In the absence of a detectable underlying *disease* (that is the physiological substrate of non-health), it is dependent on the professional's response whether or not a diagnosis is made, and subsequently the sick role status is granted (e.g. Werner et al., 2003). This is a notorious problem in the field of medically unexplained symptoms in illnesses such as chronic fatigue syndrome or chronic pain (e.g. Werner et al., 2003) and has resulted in substantial interest in the phenomenon of medical uncertainty (e.g. Fox, 1999; Lillrank, 2003). When no physical cause for symptoms or distress in general is found, doctors may perceive patients as objectively healthy but subjectively unhealthy. The uncertainty about this juxtaposition may be transferred to patients by blaming them for 'illegitimately' claiming the sick role, from which it is but a small step to the use of the 'difficult'-label.

This professional uncertainty, and its possible consequences, is equally relevant in community mental health care. There, behaviour and verbal reports (by the patient and/or others) are the only sources upon which a diagnosis is made, since no physical correlates of specific mental illnesses have been found so far. However, the behaviour of people suffering from mental illness is often very a-specific. For instance a silent and

withdrawn person may suffer from depression, from social anxiety, from psychosis or yet another mental illness. Moreover, it is very complicated to differentiate between primary illness characteristics (symptoms), the way a person responds to illness (illness behaviour), and the person's individual characteristics regardless of a possible illness (character or personality).

In the absence of objectifying tests for diagnosis, and subsequent 'objective' granting of the sick role status, the patient's illness behaviour and interpersonal behaviour, as well as the subsequent interpretation by the clinician, become highly relevant. The role of clinicians in denying or validating patients' illness behaviour, however, has not been fully explored. Ludwig (1971) identified patients' behaviours seemingly aimed at prolonged hospitalization that were 'unwittingly reinforced by complementary ones on the part of the hospital staff' tending to result in a 'perpetuation of chronicity' (Ludwig, 1971; p. 11). Petroni (1972) found that mental health professionals exert a large influence on the acceptance and the continuation of patients' sick role behaviour. Estroff (1981) found that many severely mentally ill patients were ambivalent about improving their social functioning. For instance, they did not actively seek a job, which was reinforced by staff through support of patients' applications for disability benefits. She stated that since the diseases status of mental illness is ambiguous, 'significant others and the patient play important parts in determining each others' ideas of the cause, nature, course, and consequences of being mentally ill' (Estroff, 1981; p. 243).

Along these lines it may be argued that professionals, by reinforcing the sick role status of those who do not show clear evidence of a disease, facilitate the future construction of 'difficult' patients. That is, when these patients fail to cooperate with professionals but do claim the sick role, they become 'difficult' patients in the eyes of professionals. To our knowledge, however, no research has been undertaken into this subject with the exception of Barrett's anthropological study of the social construction of schizophrenia in a psychiatric hospital (1996). Therein he describes the career of 'good' and 'bad' patients in relation to chronicity and recovery. Overall, little research since Estroff's study has focussed on the role of professionals in reinforcing patients' sick role status. Much more attention, however, has been paid to the therapeutic alliance between patients and professionals, and its relation to treatment outcomes (e.g. Martin et al., 2000a; Mead et al., 2000). Likewise, the general concept of illness behaviour has received substantial attention in physical health, but much less in mental health (e.g. Rief et al., 2003).

In summary, we have argued that the 'difficult'-label some psychiatric patients receive, does not only refer to symptoms of mental illness, but also to patients' illness and interpersonal behaviour. Since it is very hard to differentiate between these three

sources of behaviour in conditions that are diagnosed on the basis of observable behaviour, mental health clinicians have substantial influence on the making of a psychiatric diagnosis, the course of a patient's illness and the patient's sick role status. Since the labelling of patients as 'difficult' is strongly related to use of the sick role, especially when perceived as 'improper' use by professionals, we use the sick role as an analytical frame in this research. As this concept is currently unable to exemplify when and how labelling takes place exactly, we report in detail on the analysis of the patient-professional relationship as seen by experts, professionals, and patients.

Methods

> *Design*

This mixed methods was informed by a previous literature review (Koekkoek et al., 2006) and consisted of four empirical studies: a mixed-methods Delphi-study, a quantitative survey, a qualitative Grounded Theory study, and three case reports on individual patients. The methods of these individual studies will be outlined briefly below.

> *Definitions*

The target group of our research into 'difficult' patients is formed by severely mentally ill, non-psychotic patients in community mental health care. Although certainly not all of these patients are 'difficult', a literature review revealed that most difficulties were perceived in the care for people with chronic and severe, non-psychotic mental illness (Koekkoek et al., 2006). This category includes all patients that do *not* have a psychotic, bipolar or organic disorder according to DSM-IV criteria, that have been in community mental health care longer than two years, and that have a Global Assessment of Functioning score (GAF; a composite score of psychiatric and social functioning) at or below 50 (Ruggeri et al., 2000).

In this study, the qualification 'difficult' is considered a perception of professionals, that becomes a label once it is persistently used by a professional to characterize the patient. It does not refer to a well-defined set of characteristics or symptoms, nor does it qualify as a syndrome or diagnosis. Instead, 'difficult' is defined interpersonally, as imposed on a patient by a professional. Thus, to qualify as 'difficult', patients needed to have had a lack of agreement over form or content of treatment with two or more professionals, at least once over the previous two years. As such, 'difficult' patients studied in our 1st, 3rd and 4th study were patients from the total group of non-psychotic severely mentally ill patients who met the 'difficult'-criterion.

> *Data collection*

1st study:

Delphi-study among experts (researchers, policy-makers and expert-professionals)

The objective of this study was to determine in detail what problems community mental health experts perceive in contact with 'difficult' non-psychotic chronic patients. Experts were professionals that: (1) had at least three years of working experience with the patient group and (2) were employed in a nationally-recognized centre of expertise, or were a nationally-recognized expert through publications, lectures or academic excellence. A modified five-phase Delphi study, an oft-used method to reach consensus in a structured manner over subjects there is little scientific knowledge of, was used. In these focus groups, three subgroups of eight experts from different professional backgrounds each discussed patients with one specific non-psychotic chronic disorder (chronic depression, borderline personality disorder, and not otherwise specified non-psychotic chronic disorder), from which experts' judgments on relevant problems were identified and prioritized using qualitative and quantitative analyses (Koekkoek et al., 2009c).

2nd study:

Survey among community mental health professionals

The objective of this study was to determine which patient, professional, treatment and/or social variables make community mental health professionals label non-psychotic chronic patients as 'difficult'. A questionnaire was designed and administered to 1946 community psychiatric nurses, a group of professionals particularly involved in long-term care of severely mentally ill patients in the Netherlands. Logistic regression was used to design models that most accurately described the variables that contributed to perceived difficulty (Koekkoek et al., 2010b).

3rd study:

A Grounded Theory study based on interviews with 'difficult' patients' who reported on their views on mental health care

The objective of this study was to explore 'difficult' patients' views on their contacts with mental health clinicians and services, in order to improve our understanding of difficult treatment encounters. A qualitative Grounded Theory research design was used to answer three research questions: which difficulties do 'difficult' patients experience in their contact with mental health clinicians, which explanations do they have for these difficulties, and what should change in this contact? A total of 21 in-depth interviews was conducted with patients that were identified by professionals as 'difficult', showing that recognition as both a patient and a person is an important issue for patients (Koekkoek et al., 2010c).

4th study:

Case reports of individual 'difficult' patients in community mental health care

The objective of this study was to analyze difficult care processes with non-psychotic chronic patients in detail, by using three n=1 studies of patients selected from the authors' clinical caseloads. Precise descriptions of patients' biographies and treatment histories, as well as professionals' considerations and interventions, and interaction and social variables were presented to external consultants. These consultants described their considerations and proposed interventions separately from the presented case reports (Koekkoek et al., 2008b; Koekkoek et al., 2010d; Koekkoek et al., 2010e).

Data analysis

For this paper, we analyzed previous findings and compared quantitative and qualitative results across aforementioned studies. From the 1st and 2nd study we were able to calculate which were the five most urgent problems in the community mental health care for non-psychotic chronic patients as rated by both experts and professionals. From the 3rd study, we selected the five most central findings from the patients' interviews, and compared these to aforementioned findings. Apart from quantitative data, we used qualitative data collected from experts in the first Delphi-round to improve our understanding of the contrasting findings between the studies.

In constructing an explanatory model for the development and endurance of 'difficult' patients in community mental health care, we progressed according to the following steps. Five groups of variables were recognized in the 1st (Delphi) study: patient-related, professional-related, interaction-related, mental health care-related, and social system-related. After the Delphi focus group interviews, an early sequence of the model was constructed, based on a qualitative analysis of experts' narratives, particularly about repeated interactions between patients and professionals. The 2nd (survey) and 3rd (interview) study among patients were used to substantiate the model, especially concerning the attributions made by professionals and patients about one another. In the 4th study, three case reports were held against the initial model, resulting in further understanding of patients' help-seeking styles, and confirmation of the sequence. During the entire process, intermediate versions of the model were used in discussions with mental health professionals in training sessions and conferences, resulting in further refinement.

1	diverse and fluctuating psychiatric symptoms (e.g. inconsistent, shifting, and temporal thus prohibiting the making of a clear diagnosis for which treatment can be started)
2	challenging interpersonal behaviour (e.g. violent, demanding, aggressive or rude)
3	unusual help-seeking behaviour that is poorly understood by mental health professionals (e.g. actively seeking help for constantly shifting problems with various agencies, actively seeking continuation and intensification of help, actively seeking but not accepting help)
4	various and complex social problems (e.g. debts/poverty, poor housing, unemployment, difficulties in upbringing of children, legal issues etc.) that cannot be solved by mental health professionals

Results

Table 1
Initial patient behaviours
perceived as 'difficult'

> Difficult behaviours

In all studies patient behaviours perceived as 'difficult' were reported (summarized in table 1). Potentially 'difficult' patients are those that present many symptoms that are not easy to cluster into a meaningful diagnosis. They further present challenging interpersonal behaviour, unusual help-seeking behaviour, and various social problems. Surprisingly, these behaviours were perceived very 'difficult' in certain patients but not in others. The cause of these behaviours, as hypothesized by professionals, appeared to play an important role in the qualification of patients as 'difficult'. Therefore, the explanations, or attributions made by professionals became an explicit focus of analysis.

Differential findings

In the areas of defining the difficult patient, rating important problems, and offering explanations for perceived difficulty, the findings from our studies differ substantially across the three interest groups of experts, professionals, and experts (table 2). Patients see themselves as people in need for help and predominantly blame professionals for not being sufficiently understanding and being too pessimistic.

I never intentionally obstructed treatment, I just felt very desperate and helpless. (...) In my view, mental health professionals should always do their utmost best to understand the sometimes difficult behaviours of their patients, even if this is a lot to ask at times.
[patient's response to case report]

Professionals primarily see patients' large amounts of complex and often interrelated problems (such as poverty, housing problems, family issues, unemployment etc.), and believe that professional pessimism and patients' lack of social support, are

most explanatory for difficulty. Experts, for their part, look more into patients' psychopathology than into their social problems, and further define patients through their unusual help-seeking style.

I think one of the problems is that the problem is not so clear. They discuss housing problems with their mental health professional and their mental problems with the police. It is a large pile of trouble for which help is sought in many ways without you knowing what it is exactly about. [psychiatrist₁ in Delphi study]

Like patients and professionals, experts too believe that professional pessimism is an important explanatory factor for difficulty, especially since some diagnoses (e.g. personality disorder) and help-seeking styles (e.g. ambivalence towards help; see table 1) are viewed negatively by many professionals. Experts, however, look beyond patient and professional characteristics and point to the therapeutic interaction, the mental health service, the development of psychiatric science, and society at large as important factors in the occurrence of the 'difficult' patient.

If we look at the content of this discussion, few patient characteristics come up. A lot is about interaction and context, about the health service and the therapist characteristics. [expert psychiatrist₃ in Delphi-study]

Furthermore, experts noted that patients and professionals shape their behaviours based on their responses to one another. A professional who, for instance, positively responds to an out-of-hours call from a patient that has not shown up at the regular appointment that same day, may inadvertently reinforce this kind of help-seeking behaviour. At the same time, the professional may start to believe that the patient cannot cope without the professional being available out of hours, thus also reinforcing his or her own help-giving behaviour.

Several experts are quite optimistic about therapeutic possibilities with these patients and believe that new, improved, and more structured treatments for delineated disorders will eventually result in the disappearance of 'difficult' patients. Some believe that once a 'difficult' patient has entered and remains in a proper treatment program, he or she will cease to be 'difficult'. Patients, likewise, criticize the lack of structure in many current treatment contacts, as well as the general negative attitude within mental health services.

Actually, during all these 15 years that I have been in contact with mental health services, I have always had the idea that we were sort of aimlessly wandering around, not going anywhere. [patient₅ in qualitative study]

This quote supports the priority experts give to the development of a view on, and specific treatment options for these patients and their problems. They state that currently many professionals work individually with ‘difficult’ patients without knowing what to do, or without receiving support from their co-workers or management. Apart from the obvious disadvantages of working with ‘difficult’ patients, some experts also reported benefits, for instance gaining a certain status because of being able to work with such patients. It was also found, however, that such a status is unofficial and that no such things as a grade in working with ‘difficult’ patients exists. The latter problem outweighs the benefits for most experts.

Summarizing, the perspectives on explanations for ‘difficulty’ of patients, professionals and experts differ substantially (table 2). Although apparently irreconcilable, these different viewpoints can be understood from the different roles these groups have in the treatment encounter. While patients and professionals are the main actors in the difficult relationship, experts maintain a somewhat more distant position. In the following integration of these findings into a staged explanatory model, we include the different perspectives and variables but focus on the dyadic relationship of patient and professional.

	Definition of ‘difficult’ patient	Explanations	Consequences	Suggested strategy
Patients	a person with a strong need for help	<ul style="list-style-type: none">– lack of sensitivity in professional– professional pessimism	unwilling and angry patient	improvement of professional skills
Professionals	a person with many complex problems, poor social function, and consistent failure to improve	<ul style="list-style-type: none">– lack of social support– professional pessimism	demoralization	–
Experts	a person with multiple diagnoses or co-morbidity, and unusual help-seeking behaviour	<ul style="list-style-type: none">– lack of professional skills– lack of view on problems– lack of suitable and structured treatment– lack of organisational support	undertreatment of patient	improvement of quality and quantity of treatments

Table 2
Perspectives of different groups: patients, professionals, and experts

> *Integrating findings into a model*

The heuristic model presented here (figure 1) aims to offer an interpersonal and social explanation, additional to a strictly individual and medical one, to clinicians and researchers. Second, it will be used to design a treatment program that aims to prevent the labelling of patients as 'difficult'. Third, the model may generate hypotheses that can be empirically tested by researchers. The model and its stages will be exemplified below.

Stage 1

In stage 1, the variables resulting in difficult contact are described (resulting from the studies and copied from table 1).

Stage 2

Next, in stage 2, the interpretation process of the professional is exemplified. Once 'difficult' behaviour has been noted by a professional, he or she starts to seek for an explanation of this behaviour. Given the health care context, professionals first of all look for individual, medical explanations of illness, based on a certain psychiatric diagnosis. If no such explanation or causal attribution is found, other attributions may be made. A critical factor in attributing behaviour to a certain non-medical cause, is the degree of control over, and responsibility for difficult behaviour a patient has, according to the professional. Four types of causal attributions were identified: neurobiological, social, psychological, and moral.

The first, neurobiological, attribution is quite straightforward. If the patient's difficult behaviour can be attributed to one presumably neurobiologically disposed disorder such as schizophrenia or bipolar disorder (thus a *disease*), the behaviour is more easily accepted. The patient is seen as not in control, and entitled to the sick role rights and the reception of health care.

The second, social, attribution is more complicated. When professionals believe that problematic behaviours are not caused by an internal mental disorder but rather are the consequence of structural social-economic inequities, a social attribution may be made. On these grounds, problems (e.g. family conflict, unemployment, criminal behaviour) that may be considered pathological in people with high socio-economic status, are considered non-pathological in, and even inherent to people with low socio-economic status. Such social problems are seen as either the responsibility of other agencies or society at large (e.g. church, charity or the state or federal government). If patients remain in mental health care, however, this attribution will result in therapeutic pessimism (or demoralization) among professionals since they feel unable to effectively help these patients.

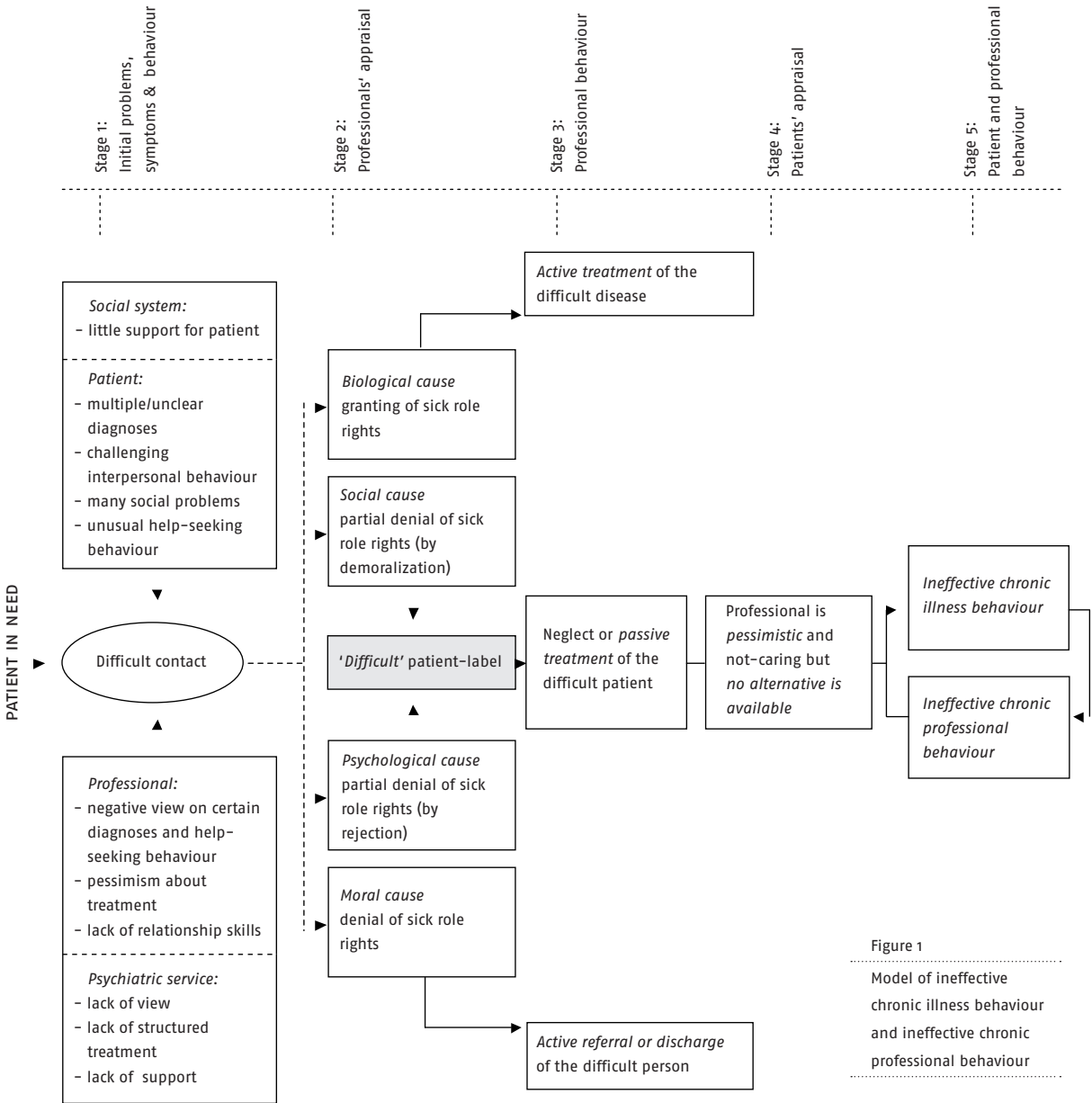


Figure 1

Model of ineffective chronic illness behaviour and ineffective chronic professional behaviour

The third, psychological, causal attribution, results in the perception of difficult behaviour as controllable and originating from poor character or coping skills. Patients may be seen as at least partly responsible for their own behaviour. When difficult behaviour is psychologically attributed, which is often the case in patients with non-psychotic chronic disorders, professionals often are ambivalent about the patient and their own treatment responsibility. They may feel obstructed, frustrated, and wilfully denied in their competency, which easily results in rejection.

The fourth, moral, attribution takes difficult behaviour as caused by a bad character. Patients may be seen as 'wrong' or worse, and unsuitable for mental health care. A moral attribution usually results in plain resentment and rapid discharge from services or referral elsewhere (most often the criminal justice system).

Equal behaviours by different patients are perceived differently by professionals, dependent on the causal attribution they make about the behaviour. Some behaviours are allowed when they are believed to have a neurobiological origin, but not when they are seen as having a psychological cause

In a crisis intervention center, patients with a psychosis were seen as not accountable and in need of support. Borderline patients, however, were considered theatrical, posing, and in need of punishment. [expert psychologist2 in Delphi-study]

We found support for the association of professional demoralization with causal attribution. Professional ratings of perceived changeability of problems differed significantly across diagnoses. Least optimism was found in the care of patients with an unspecified non-psychotic chronic disorder, most in the care for patients with an Axis I-disorder (chronic depression). 'Difficult' patients fit the most pessimistic profile very well since they often receive either several diagnoses (because of their multiple problems), an Axis II-diagnosis (because of their unusual help-seeking or interpersonal behaviour, interpreted as a disturbed personality characteristic), or no clear diagnosis (because of a confusing mixture of multiple problems and unusual help-seeking). Thus, the less the diagnosis resembles a state-like diagnosis (Axis I), the more pessimistic and demoralized professionals become.

Stage 3

In stage 3, aforementioned attributions result in actual responses by professionals. Both demoralization and rejection may lead to early discharge, rapid referral, or – most often – passive treatment described by experts as 'pampering and dithering'. This approach

generally lacks structure, goals, and well-defined actions and is mostly aimed at not letting things get out of hand.

Stage 4

This professional response may result in patients feeling unseen and unheard (stage 4), which was the most important finding of our qualitative research among 'difficult' patients. However, due to limited social support and the unsuitability of other help agencies, patients tend to stay in mental health care since it is the 'least bad alternative'. This paradox, being discontent and having to stay, is a strong impetus for ambivalent behaviour that may easily be perceived as difficult. The noted lack of social support these patients have, reinforces patients' needs for basic contact, sought in mental health care.

All I want is a little human attention, a bit of warmth, and authenticity. And involvement, and not so clinical that one gets the feeling of being sent away. And that will undoubtedly have to do with me not having a partner, nor children, nor a family. I probably find such things a lot more important than someone who has an entire network around her, sure. That certainly makes a difference but I don't want all that much... [patient12 in qualitative study]

As far as I know these patients, they have only one support system left and that is mental health care. [expert psychiatrist4 in Delphi-study]

Yet, the forced collusion of patient and professional results in ineffective behaviours from both parties, as exemplified in table 3. These behaviours tend to become autonomous, unconnected to the initial problems the patient came into treatment for, and unconnected to a possible effective treatment strategy aimed at these problems.

Stage 5

Patients' and professionals' idiosyncratic behaviours lead them into a vicious cycle of ineffective actions (stage 5), for which most often the patient is blamed by the amplification of the 'difficult'-label. Even though professionals find this situation generally unattractive, they often do not know how to change it, which results in the continuation of the difficult contact. Variables on the service level exert substantial influence on this process. In the absence of a true understanding and a coherent view on these patients and their problems, mental health services offer little theoretical and practical support to their workers. The only way professionals often believe they can change it, is to refer or discharge the patient out of their own care, after which this cycle often starts again with a new mental health professional.

The model presented here fitted most cases quite well, though not all. One of the interviewed patients, a reluctant user of mental health care, did not express any desire to remain in mental health services when the contact with his clinician became troublesome. As such, he did not enter the cycle of mutual ineffective behaviours with his clinician, but simply left the service. Although possibly ineffective illness behaviour for himself, since he had had to retrace his steps many times, it did not affect providers.

Ineffective chronic illness behaviour	Ineffective chronic professional behaviour (either in response, or autonomous)
<ul style="list-style-type: none">• claim help frantically• miss scheduled appointments• call frequently between scheduled appointments• threat self-destructive actions• disqualify or seduce professional• intrude in professional's privacy• claim help at multiple institutions• conceal other treatment contacts• refuse to set treatment goals• constantly bring up unsuitable themes	<ul style="list-style-type: none">• deny treatment• ignore non-compliance• be unreachable for the patient• take over all or deny any responsibility• be overly kind or hostile to patient• fail to set limits• refer patient elsewhere• argue with other professionals about patient and his/her treatment• fail to set treatment goals and structure• be overly rigid and formalistic with patient

Table 3
Ineffective behaviours by
patients and professionals

Discussion

In this mixed-methods study we found the 'difficult' patient-label to be associated with professional pessimism, passive treatment, and possible discharge or referral out of health care. The label is given by professionals when certain patient characteristics are present and a specific causal attribution (psychological, social or moral versus neurobiological) about the patient's behaviours is made. The status of 'difficult' patient is easily reinforced by subsequent patient and professional behaviour, turning initial unusual interpersonal or help-seeking behaviour into 'difficult' behaviour. A lack of resources in both the mental health service and the patient's social system negatively influence the patient-professional interaction.

The tentative model we present differentiates between five stages of the treatment process. In stage 1, patient and professionals start their contact, both introducing their individual characteristics, problems, and skills. In stage 2, patient characteristics guide the professional's appraisal process who labels the patient 'difficult' based on his or her attribution of patient behaviour. In stage 3, professional responses to the now-labelled 'difficult' patient prove hardly effective and guide the patient's appraisal process who, in stage 4, sees the professional as being insufficiently caring. In stage 5, patient and professional are reinforcing each others ineffective behaviours based on their previous attributions, and enter a vicious cycle of ineffective chronic illness behaviour and ineffective chronic professional behaviour.

These findings illustrate that the course of mental illness, or at least the course of mentally ill patients' contact with mental health professionals and services, is not determined only by patients' characteristics. Patient and professional, reinforced by the respective forces of the social and mental health care system, mutually shape the course of care and illness. This shaping is the most obvious in situations of uncertainty, in which the diagnosis is unclear, the suitability of mental health care is questioned, and it cannot be established whether the patient is able to control his or her own behaviour (for an in-depth discussion of attribution of control over behaviour, and related uncertainties see for instance Weiner, 1995; Rhodes, 2004).

> *Findings in relation to theoretical and empiric research*

Theoretically, our model is founded upon the sick role concept. Our model adds to Parsons' larger framework a micro-theoretical perspective in which attribution and learning principles are incorporated. The model exemplifies that behaviours that may be perceived as 'difficult' by professionals, truly exist. What happens to patients displaying

such behaviours, however, is dependent on the attribution professionals make. A neurobiological model in which the patient – because of the disease – cannot control, or at least cannot be held responsible for, his or her behaviour leads to legitimization of the sick role. When another explanatory framework (e.g. social, psychological, or moral) is used, the attributions of mental health clinicians hardly differ from those of laymen in the judgement of social conduct (Weiner, 1995). Our mainly qualitative findings are supported by quantitative findings from a recent vignette study among mental health professionals that found high levels of perceived responsibility in patients with a presumed psychological disorder as opposed to low levels in patients with a presumed neurobiological disorder, and intermediate in presumed socially caused disorder (Miresco et al., 2006). It is noteworthy that mono-causal attributions about mental illness, either neurobiological, psychological or social in nature, are highly present among clinicians but lack a scientific base.

Following this attribution, patients' ineffective illness behaviour and professionals' ineffective treatment behaviours are increasingly solidified through social learning principles. These findings match those of a study of psychosomatic patients in which chronic illness behaviour is explained from a social learning perspective (Wooley et al., 1978). In this explanation, adoption of the sick role is rarely a conscious choice but is shaped by vicarious learning, direct social reinforcement of illness behaviour by professionals, family, and friends, and preferred postponement of responsibilities associated with a healthy status (Wooley et al., 1978). Despite the paper's popularity in the practice and research of psychosomatic illness, it has raised little interest outside this field and attempts to validate a social learning program for general psychiatric patients based on this model, have failed (Winstead et al., 1980). Nevertheless, our findings lend support to this model.

> *Implications for practice*

Practical application of our model may improve care for 'difficult' patients or – preferably – prevent the label from being given. The contradictions between patients' and professionals' views in fact offer options for changes.

On service entry, the contradiction between the 'subjective' 'patient in need' and the 'objective' professional in search of a pattern and, preferably, a diagnosis, needs attention. Typically, patients with multiple problems defy a clear diagnosis or are eligible for many diagnoses. The 'difficult' patient-label may be easily given in such cases, obscuring a more useful or valid diagnosis, and possibly harming the patient. In contrast, we found that a clear psychiatric diagnosis 'protects' patients from professional

pessimism, especially one with a perceived neurobiological basis. Thus, not the act of labelling itself is harmful here, but labelling as 'difficult' is. A medical-diagnostic perspective that attributes the behaviour as not under the patient's control, helps to increase professionals' optimism. This finding may seem counter-intuitive, since we identified the 'difficult' patient largely as a socially derived label, but is highly consistent with current studies of social distance and causal attribution among professionals (Markham et al., 2003; Forsyth, 2007) and the lay public (e.g. Martin et al., 2000b). It may therefore be in the patient's best interest to make a valid diagnosis (i.e. that best captures the patient's core symptoms), that at the same time is as 'blameless' as possible.

Along these lines it is often argued that clear organisational or treatment guidelines are impossible to carry out with 'difficult' patients – thus leaving both patients and professionals without any direction. This lack of direction enables the professional to push the care process – and possibly the patient's illness process – in any possible direction. It may explain why the percentage of chronic patients among those with non-psychotic illness varies so widely across mental health services (between 20% and 50%; Ruggeri et al., 2007; Greenwood et al., 2000; Hunter et al., 2002; Keown et al., 2002). Surprisingly, an increasing number of treatment modalities with clear, and sometimes very strict guidelines, succeed in caring for patients that are perceived as 'difficult' by many other health professionals (e.g. Bateman & Fonagy, 2004; Essock et al., 2006). Although it must be noted that such programs are often well-staffed and rely on a team instead of an individual approach, it may be that the absence of guidelines in regular community mental health care actually increases difficulty.

Furthermore, mental health professionals should seriously consider if interpreting the problems as psychiatric in nature, is always helpful. In some cases, a supportive but autonomy-promoting approach may be better than an overly medical one. This implies that professionals need to look into their own role in the perpetuation of difficult behaviours as described here. Treatment modalities that focus on patient autonomy (e.g. relationship management; Dawson et al., 1993), motivation (e.g. motivational interviewing; Milller et al., 2001), and empowerment (e.g. various psychosocial rehabilitation models; Barton, 1999) may be helpful to professionals.

The combination of aforementioned suggestions results in an interesting mixture of strategies. Patients may be labelled as ill and treated according to strict guidelines but still be considered responsible and autonomous individuals. This apparently paradoxical approach is further developed in a treatment program (Koekoek et al., 2010f).

> *Limitations and strengths*

The model presented in this paper is based on secondary analyses of recent research projects, within a framework of social scientific theory. Given the nature of these projects, it necessarily constitutes a mixture of qualitative and quantitative data that is filtered by the authors. Although we have stayed as close to the empirical findings as possible, we have interpreted various data sources and combined those into the presented model. It must also be noted that the generalizability of this model may be limited since it concerns a subgroup of mentally ill patients, those with long-term non-psychotic disorders in community mental health care. This group is, however, quite large and very costly (Kent et al., 1995a; Kent, 1995b). The presented model complements more general models of sick role and illness behaviour by focussing on the social shaping of sick role behaviour within the concrete relationships of patients and professionals in community mental health care.

Some variables have not been incorporated in this model since they were not explicated by the participants in our research projects. An important variable would be the cost of and availability of services. From earlier research it is known that health care expenditures, insurance policies, and social benefit systems may have a large influence on patients' illness behaviour and differ across nations (e.g. Burns et al., 2007). The Netherlands, where this study took place, have universal health insurance with unlimited reimbursement for people with severe mental illness. Since our samples were all-Dutch, we could not assess the differential effect of health care systems and therefore have omitted this variable from our model.

The strength of this research is its focus on various stakeholders in the difficult interaction between patients and professionals, which to our knowledge has not been done so extensively before. These multiple empirical perspectives, complemented with relevant theoretical perspectives, allowed us to appreciate the contribution of different parties in the understanding of difficult behaviours, both by patients and professionals.

Conclusion

A detailed analysis of empirical data using the sick role and other social scientific concepts, provides a better understanding of the perception of patients as 'difficult' by clinicians in community mental health care. Although the 'difficult'-label is socially derived at, it is based on a combination of variables – related to patients, professionals, mental health services and larger social systems.

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6

Development of an intervention program to increase effective behaviours by patient and clinicians in psychiatric services: Intervention Mapping study

> *Background*

Health clinicians perceive certain patients as 'difficult' across all settings, including mental health care. In this area, patients with non-psychotic disorders that become long-term care users may be perceived as obstructing their own recovery or seeking secondary gain. This negative perception of patients results in ineffective responses and low-quality care by health clinicians. Using the concept of illness behaviour, this paper describes the development, implementation, and planned evaluation of a structured intervention aimed at prevention and management of ineffective behaviours by long-term non-psychotic patients and their treating clinicians.

> *Methods*

The principles of Intervention Mapping were applied to guide the development, implementation, and planned evaluation of the intervention. Various empirical findings, theoretical models, and existing evidence were combined to construct a program tailored to the needs of these target groups. Qualitative (individual and group interviews), quantitative (survey), and mixed methods (Delphi-procedure) research was used to gain a broad perspective of the problem.

> *Results*

A structured program to increase effective illness behaviour in long-term non-psychotic patients and effective professional behaviour in their treating clinicians was developed, consisting of three subsequent stages and four substantial components, that is described in detail. Implementation took place and evaluation of the intervention is being carried out.

> *Conclusions*

Intervention Mapping proved to be a suitable method to develop a structured intervention for a multi-faceted problem in mental health care.

Background

In various health care settings, clinicians perceive particular patients as ‘difficult’. ‘Difficult’ is an individual judgment that generally refers to patients who have limited social functioning, make high use of medical services, and generally are unsatisfied with the care they receive (Groves, 1978; Lin et al., 1999; Jackson et al., 1999; Hahn et al., 1996; Hinshelwood, 1999; Steinmetz et al., 2001). The more of these elements are combined and the smaller the perspective of future recovery, the more likely it becomes that a patient is perceived as ‘difficult’ by a professional. In psychiatric services, most ‘difficult’ patients are found among patients with long-term non-psychotic illness as mood, anxiety, substance use, and personality disorders that have not responded well to previous treatments (Koekkoek et al., 2006). Patients perceived as ‘difficult’ may be labelled as such in services, and subsequently be at increased risk to be treated less respectfully, less effectively, and to be excluded from health services because of their failure to comply with its implicit and explicit rules for ‘proper’ patienthood (Ring et al., 2005; O’Reilly et al., 2001; Pelet et al., 2005). Professionals working with these patients report more stress and burn-out (Stacey et al., 2009; An et al., 2009).

It is not unusual for mental health professionals to ascribe problems in treatment to patients through the use of the ‘difficult’-label. This routine has been criticized repeatedly (Rose et al., 2007; Krebs et al., 2006; Corrigan, 2006). Indeed, it is not always clear which patient behaviours must be considered as originating in the psychiatric disorder itself, and which may be the consequence of an ineffective contact with mental health clinicians or services (Koekkoek et al., 2009d). In previous work, for instance, we found no association between any specific non-psychotic psychiatric disorder and clinicians’ ‘difficult’-judgment (Koekkoek et al., 2010b). However, clinicians’ perceptions of the patient (e.g. seeing the patient as able but unwilling to change), the patient’s previous service use and the number of psychosocial problems, were independently associated with clinician-perceived difficulty (Koekkoek et al., 2010b). Thus, patients’ responses to illness and treatment (*illness behaviour*) may prevail over the illness itself. Since the concept of illness behaviour not only refers to the different ways in which people perceive, evaluate, and respond to symptoms (Mechanic, 1986), but also to the ways in which they seek help and to their behaviour in healthcare systems, this concept is highly relevant to the understanding and prevention of perceived difficulty. Recurring behaviours that are perceived as difficult by clinicians may be described as ‘ineffective chronic illness behaviour’, which in part may result in ‘ineffective professional behaviour’ as a response (Koekkoek et al., 2009d). We therefore use these terms to describe certain ‘difficult’ behaviours by long-term patients with non-psychotic disorders (e.g. constant complaining about ever-changing problems, recurrent making of suicidal threats,

repeated denial of financial problems) and certain ineffective responses by professionals (e.g. not listening to patients' long-term problems, responding only to acute problems, failure to intervene in obvious social problem situations).

Currently, prevention of these two types of ineffective behaviour is not a high priority in mental health services. In general, the management of non-psychotic chronic patients in psychiatric care is poorly developed. While evidence-based treatment for various non-psychotic disorders is available, this does not apply to non-psychotic *chronic* disorders. Some treatments exist for specific subgroups, for instance for chronic depression (McCullough, 2000; Keller et al., 2000), and borderline personality disorder (Linehan, 1993; Bateman et al., 2004). Yet, they do not apply to the entire target population (Koekkoek et al., 2010a; Koekkoek et al., 2009b) since some patients may not (yet) be ready for such treatments. The project described in this paper aims at the development of an intervention program to both prevent and manage these ineffective behaviours among long-term non-psychotic patients who have not benefited from previous treatment, and their key clinicians.

Methods

Intervention mapping (IM), a systematic method for the development, implementation and evaluation of health interventions outlined by Bartholomew et al. (1998; 2001), has proven to be a useful way to construct programs grounded both in theory and empirical data (van Oostrom et al., 2007; Ramirez-Garcia et al., 2009). IM proceeds according to the following steps. Step 1 consists of a needs assessment through a review of the scientific literature to analyse the target population, environmental conditions, and determinants of health behaviour. In step 2 the determinants of the health behaviour are used to set objectives for behaviour change, divided in broad performance objectives and concrete change objectives in terms of what a person needs to learn to change his or her behaviour. In step 3, theoretical foundations and empirically evaluated methods and strategies for behaviour change must be assessed. In step 4, the methods and strategies are translated into an organized intervention. In step 5, the adoption, implementation and sustainability of the intervention is planned. In step 6, an evaluation plan must be provided for and carried out. The strategies used in this project for each of the six steps in Intervention Mapping are reported on in detail below.

For step 1 and 2, we carried out a comprehensive review of the literature on 'difficult' patients. The MEDLINE, CINAHL, and PsycINFO databases were searched for English articles published between 1979 and 2004, retrieving 94 eligible papers (Koekkoek et al., 2006). Next we undertook additional research to describe the health behaviour and its

determinants: a qualitative interview study among patients (Koekkoek et al., 2010c), a survey among community mental health clinicians (Koekkoek et al., 2010b), and a Delphi-exercise among scientists/policy makers/expert-professionals (Koekkoek et al., 2008a; 2009b; 2009c; 2009d). We concluded with the formulation of the overall behavioural objective of the intervention, and the more concrete change objectives.

For step 3, we made a theoretical analysis of ineffective chronic illness behaviour (Koekkoek et al., submitted), which forms the foundation of the intervention program. We conducted a review of therapeutic methods available to change determinants (assessed in step 1), reach objectives (formulated in step 2), and confront ineffective behaviours of both patients and professionals [search strategy and results available from the 1st author]. Additionally, since empirical findings were limited, we collected data from current best practice sites. We visited three well-known national best practices, specialized in three important domains of long-term non-psychotic disorders (mood disorders, substance abuse disorders, and personality disorders) for data on possible effective practice-based strategies not yet described in the literature. Selection of these best practices took place by searching national scientific and professional journals, searching conference programs and reports, and inviting leaders in the fields (e.g. professors, directors, educators) to suggest best practices.

For step 4, we consulted an expert group of clinicians, scientists, and policy makers over an extended period of time (two years). Some of these experts were participants in one of the problem analysis studies in step 1, others were invited because of their expertise in a specific therapeutic method (for instance clinical case management or behaviour therapy).

In step 5, implementation was prepared with a steering group of scientists and managers in the psychiatric service the intervention was tested in. Before an agreement was reached, the intervention was first presented to a director, a research psychiatrist, and the psychiatrist of the team the intervention would be implemented in. Next, the intervention and its evaluation were presented to the team members who all agreed to participate. After obtaining ethical permission and the final approval of the institution's chief director, the program was implemented.

In step 6, we designed a mixed-methods pilot study to evaluate the intervention program. This pilot study consists of quantitative and qualitative measurements of outcome and process variables. It is described in more detail later.

Ethical approval was obtained for the patient-related qualitative study and the pilot study from the Institutional Review Board of the organisation the 1st author is affiliated with. Informed consent was obtained from all participating patients in aforementioned patient-related studies.

Results

Outcomes of the Intervention Mapping process will be described according to the six steps .

> Step 1: Needs assessment

Analysis of target population

Non-psychotic psychiatric disorders are highly frequent in the general population: lifetime prevalence in the US is 28.8% for anxiety disorders, 19.1% for depressive disorders, 14.6% for substance use disorders (Kessler et al., 2005) and 9.1% for personality disorders (Lenzenweger et al., 2007). Comparable percentages were found in The Netherlands, United Kingdom, Australia, and other Western countries (Andrews et al., 2001; Kessler et al., 2008; Kohn et al., 2004). Together these disorders account for the majority of mental illness in the community, and some of these become chronic. The percentage of non-psychotic patients in long-term care is estimated between 20 and 50% (Arvidsson, 2003; Keown et al., 2002; Greenwood et al., 2000; Hunter et al., 2002; Ruggeri et al., 2007). Of these patients, about 28% is perceived as difficult by psychiatric clinicians (Koekkoek et al., 2010b).

Analysis of environmental conditions

Even though the prevalence of non-psychotic psychiatric disorders in The Netherlands, where this study took place, is comparable to that of other countries, the availability of services may be somewhat different. The Dutch mental health care system is paid for by a mixture of federal grants, individual health insurance, co-payment and fee-for-service. However, long-term care for patients with non-psychotic disorders is fully paid for by federal budgets, even for those without insurance. Compared to the USA, Canada and Puerto Rico, a substantially higher percentage of people is treated in mental health services, both in general and specialty health care (Alegria et al., 2001). Also financially, there are few limits on the availability of long-term care in The Netherlands, compared to other countries (Sareen et al., 2007).

Analysis of behaviour

We found three types of behaviours to be specific to perceived difficulty in mental

health care. First, the presence of various psychiatric symptoms that are inconsistent, shifting, temporal and thus prohibiting the making of a clear diagnosis for which treatment can be started. Second, the presence of unusual help-seeking behaviour and interpersonal behaviour that is for instance chaotic (actively seeking help for constantly shifting problems with various agencies), dependent (actively seeking continuation and intensification of help), or ambivalent (actively seeking but not accepting help) that is poorly understood by psychiatric professionals. Third, the presence of various social problems (e.g. debts, poverty, poor housing, unemployment, difficulties in upbringing of children, legal issues etc.) that patients appear to consider as mental health problems but that can often not be solved by psychiatric professionals.

Some of these problems (for instance the described forms of unusual help-seeking) may be typical for people with non-psychotic disorders, others may also apply to people with psychotic disorders. In psychiatric services, however, mental health professionals still seem to hold different views on non-psychotic disorders (generally seen as potentially curable, psychological problems) and psychotic disorders (generally seen as chronic, neurobiological problems) (Koekkoek et al., 2006; Koekkoek et al., submitted). As such, professionals tend to see long-term non-psychotic patients largely as responsible for their problems. Subsequently, professionals are ambivalent about labelling these patients as chronically ill, and about reinforcement of their claim to the sick role. This ambivalence about legitimacy of chronic illness may cause friction in the therapeutic relationship, resulting in the qualification of the non-psychotic patient as a 'difficult' patient.

Analysis of behavioural determinants

From our literature review and subsequent research studies we concluded that other than patient-related factors are equally relevant in the occurrence of difficulties in the care of non-psychotic chronic patients (Koekkoek et al., 2006; Koekkoek et al., submitted). While patient-related factors solely focus on, for instance, psychopathology, there are more variables that account for difficulties. Such variables could be categorized in four groups. The 1st is professional-related (e.g. the professional's willingness to engage with long-term patients). The 2nd is interaction-related, (e.g. the quality of the contact between patient and professional). The 3rd is social system-related (e.g. the amount of social support a patient has outside the mental health care system). The 4th is mental health care-related (e.g. the support a professional receives from co-workers and managers to care for long-term patients).

The mental health care-related category was by far the most relevant according to experts. General professionals laid more emphasis on social factors and less on specific

diagnoses, professional skills or mental health care factors. Last, patients stressed the importance of the professional's competencies, the quality of the patient-professional interaction and the views on non-psychotic chronic patients held in psychiatric services. As such, ineffective chronic illness behaviour appears to be the consequence of a complex interplay of factors, while these factors are viewed differently by distinct interest groups. Table 1 shows the determinants from our aggregated results, distinguished by patients, general professionals and experts.

Interest group	Determinant
Patients	- lack of empathy in professional
	- professional pessimism
Professionals	- lack of social support
	- professional pessimism
Scientists/policy makers/expert-professionals	- unusual help-seeking style of patients
	- lack of professional skills
	- lack of view on problems
	- lack of suitable and structured treatment
	- lack of organisational support

Table 1

Determinants of ineffective
chronic illness behaviour
according to research findings
among three interest groups

> Step 2: Matrix of change objectives

Based on the needs assessment, the overall behavioural outcome was defined as '*an increase of effective behaviours in people with long-term non-psychotic mental illness and their treating professionals*'. We established that current ineffective behaviours consist of ineffective chronic illness behaviour by patients, and ineffective professional responses or behaviour by clinicians. These behaviours are caused by several patient-related and non patient-related determinants, and therefore performance objectives should be set on the patient, professional and services level. Next, important and changeable determinants of behaviour need to be chosen. For each of the three target groups (patients, professionals and services), one determinant, taken from table 1, is exemplified in more detail (table 2).

Table 2

Matrix of intervention
objectives for each target
group

Target group	Determinant (selected)	Performance objectives	Change objectives
Patient & Social system	Unusual help-seeking style	<ul style="list-style-type: none"> - Patient decides to negotiate expectations with clinician - Professional and patient reach or maintain a positive working alliance 	<ul style="list-style-type: none"> - Decides to accept increased autonomy offered by mental health care professionals - Uses this autonomy to discuss treatment form and content with professional
Professional	Professional pessimism	<ul style="list-style-type: none"> - Professional expresses a neutral view on behaviour, disorder and treatment results of his/her patients - Professional and patient reach or maintain a positive working alliance 	<ul style="list-style-type: none"> - Decides to consider own view of patient's behaviour, disorder and treatment results as partly responsible for ineffective chronic illness behaviour. - Decides to follow training and supervision on how to look at patient behaviour more neutrally. - Actively participates in supervision meetings on this subject. - Supports colleagues in using such skills
Psychiatric service/ Psychiatric profession	Lack of view on problems	<ul style="list-style-type: none"> - Service or treatment team expresses a coherent view on the treatment (and distinction between cure and care) of non-psychotic chronic patients 	<ul style="list-style-type: none"> - Develops and endorses a view of chronicity of non-psychotic patients as partly caused by mental health care itself - Offers training and supervision to increase professionals' skills and attitudes - Enables regular evaluative meetings of skills of professionals and effects on patients - Enables supervision meetings for professionals to offer mutual support and further development of a mutually shared view

> *Step 3: theoretical methods and practical strategies*

Far most theoretical models of illness behaviour focus on individuals' help-seeking behaviour and decision-making process before entering the health care system (Pescosolido, 2000). Few specifically consider illness behaviour of people with psychiatric problems, which appears to differ qualitatively from illness behaviour related to physical problems (Pescosolido, 2000). A notable exception to this observation is the Network Episode Model (Pescosolido et al., 1999), that combines the perspective of an illness career with social, cultural, medical and economical variables into a dynamic perspective. Developed by social scientists, this model however is still too general to explain the occurrence of ineffective illness behaviour within psychiatric services. We have, therefore, developed a more detailed model to describe the occurrence of ineffective chronic illness behaviour (figure 1 in chapter 5). The model shows that the 'difficult'-patient label is given by professionals when certain patient characteristics are present and a specific causal attribution about the patient's behaviours is made. The status of 'difficult' patient is easily reinforced by subsequent patient and/or professional behaviour, turning initial unusual help-seeking behaviour into 'difficult' or ineffective chronic illness behaviour. Furthermore, a lack of resources in the psychiatric service and the patient's social system negatively influence the patient-professional interaction.

The tentative model differentiates between five stages of the treatment process. In stage 1, patient characteristics guide the professional's appraisal process who labels the patient either or not 'difficult' based on the attribution of patient behaviour (stage 2). As stated earlier, professionals have few resources available on the treatment of these long-term non-psychotic patients (Gournay et al., 1994; Devilly et al., 1995; Koekkoek, 2004) and therefore are easily demoralized about treatment effectiveness. At the same time, both patients and the general public may have high expectations about cure for these patients, who are sometimes referred to as the 'worried well' (Bowers, 1997). Not only does this term underestimate patients' difficulties, it also pays little attention to the conflicting demands (few resources, high expectations) laid upon clinicians. Clinicians tend to respond with limited involvement and pessimism, which may result in (further) undertreatment (stage 3) or blaming the patient for being ill or not getting better. In stage 4, professional responses to the now-labelled 'difficult'- patient may make the patient conclude that the professional is uncaring or unwilling to offer help. Thus, the patient, with many complex problems and a different style of help-seeking, is confronted with a negative and pessimistic attitude of the professional, resulting in a low dosage of help that aims for management, not recovery. This low-dose help reinforces the original behaviour of patients in distinct ways, thus leading to repetition, perpetuation and even aggravation of the initial problems. In stage 5, patient and professional are

reinforcing each others ineffective behaviours based on their previous attributions. These behaviours may have little to do with the problems the patient initially sought help for. In fact, patient and clinician enter a vicious cycle of ineffective chronic illness behaviour (patient) and ineffective chronic professional behaviour (clinician) (Koekkoek et al., submitted). From this theoretical model we have conceptualized the following stages in the intervention program (table 3) – each fitting an important step in the theoretical model.

> *Step 4: Intervention*

In this stage, the theoretical model (described above) and practical methods (described in detail in section 3 of this step) were translated into a manual for the intervention, which we named Interpersonal Community Psychiatric Treatment (ICPT) since the interpersonal contact between patient and professional is the main target of the intervention. From our descriptive studies and the theoretical model we concluded that an intervention program should focus on: (1) a clear treatment structure (to prevent uninformed and haphazard low-dosage help), (2) a phased model (which fits the patient's level of acceptance of help), (3) a therapeutic style that fits the phase the patient is in, (4) a routine monitoring of the interpersonal contact between patient and professional, (5) and support for team professionals.

The intervention is designed for use in departments or programs for long-term ambulatory care, to which patients may be referred when short-term treatment, aimed at cure, has been found unsuitable or unsuccessful. In such departments, long-term care tends to turn into an unstructured, aimless, and sheer endless enterprise. Professionals working within these department are used to working with long-term patients with a severe mental illness. Often they do this autonomously but share the clinical responsibility with a doctor or psychiatrist, who has the final medical responsibility and sees the patient at a low frequency.

(1) *Generic structure*

Based on various evidence-based treatments of specific non-psychotic disorders (McCullough, 2000; Linehan, 1993), we introduced a fixed structure for each session, taking 45 minutes as the standard duration. The first 5 minutes are used by the clinician and the patient to set a mutually agreed on agenda for the session, including themes and goals to be discussed. The next 5 minutes are used to look back from the current to the previous session, allowing a process-oriented discussion of the patient’s current mental state and that of the elapsed time since the last session. In the following 25-30 minutes the themes, subjects and goals that have been set on the agenda, are discussed and summarized. The last 5 minutes are used to look back on the session and to fill out a report form (clinician) and a feedback form (patient), which will be exemplified later.

Treatment Stage	Stage I	Stage II	Stage III
Goal in intervention program	<div>- Alternative understanding of patient's behaviour</div> <div>- Optimization of working alliance</div>	<div>- Clarification of and agreement over goals and tasks</div>	<div>- Improvement of personal and social functioning</div>
Understanding from theoretical model	<div>- Non-blaming attribution of behaviour by clinician increases chances of positive working alliance</div> <div>- Mutual clarification of expectations increases chances of mutually supported conceptualization of sick role</div>	<div>- Active and mutual goal-setting by clinician and patient improve chances of patient's positive attribution and restoration of professional's belief in treatment</div>	<div>- Practical and real help improves chances of patient's effective illness behaviour and professionals' effective behaviour</div>
Empirically validated method	<div>- Team supervision & Monitoring through feedback and report forms</div> <div>- Relationship Management & Motivational Interviewing</div>	<div>- Motivational Interviewing & Shared-decision Making</div>	<div>- Clinical Case Management & Behavioural Analysis</div>

Table 3

.....

Staged intervention program
based on theoretical model
and empirically validated
methods

.....

(2) Stage model

This model is an explication of the three stages described above (table 3), moving from the 1st stage (optimization of working alliance), through the 2nd stage (clarification of and agreement over goals and tasks) to the 3rd stage (improvement of psychiatric and social functioning). In order to optimize the patient-professional interaction across all stages, it is crucial for the clinician to determine in which stage the treatment contact is located. Clinicians may ask themselves 'diagnostic' questions related to each stage. There are two or three such questions per stage, which are thought and asked during the training and supervision sessions. For the 1st stage such a question is for instance 'do I feel the liberty to discuss the nature of the treatment contact with my patient?'. If the answer to this question is 'no', for example because the professional fears that the patient will become very anxious to lose the treatment contact, the clinician knows that the contact still is in the first stage of optimization of the alliance. As such, the change objective of 'being able to discuss form and content of treatment' (table 2) may not have been reached yet. The stage model helps professionals to structure their treatment, using different methods across different stages.

(3) Therapeutic methods per stage

One of the crucial elements of ICPT, in order to prevent ineffective illness and professional behaviour, is the differentiation of therapeutic styles across treatment stages. This approach is a variation of, but consistent with, the trans-theoretical model of change (Prochaska et al., 1992) which differentiates people's readiness to change into various stages. In the 1st stage, in which the working alliance is defined, the suggested methods are *relationship management* (Dawson et al., 1993; Dawson, 1988; Hoch et al., 2006) and *motivational interviewing* (Miller et al., 2002; Burke et al., 2003), of which especially the latter has a firmly established empirical base. Both methods aim to prevent the usual mental health care 'script' in which the clinician is the one who looks for problems in the patient, and suggests improvements of his or her behaviour, while the patient is a passive recipient of help. Instead, in both methods the clinician is a careful and observant listener who elicits timely responses from the patient and strongly promotes autonomy. In relationship management, the basic rule is to do no harm – referring to the adverse outcomes that have been reported with patients that do not respond well to an actively helping clinician (Linehan et al., 2006; Dawson et al., 1993; Fonagy et al., 2006). Motivational interviewing seeks to create and increase patient's ambivalence, for instance by juxtaposing riskfull behaviour with responsible parenthood in a person who loves his or her child but also engages in repeated self-destructive behaviours.

In the second stage of ICPT, motivational interviewing is used again in a generic way, now to set patient-centred goals. It is complemented with *shared decision making* (Joosten et al., 2009). This method, imported from physical health care, makes use of a structured way to make treatment decisions mutually agreed on by patient and professional. We added systematic *goal-setting* to this procedure. After an initial open question to focus the patient on the future ('what do you want your life to look like in one year from now?'), a more detailed analysis follows of the areas where change is desired. Then, aided by a widely used tool to assess care needs (Phelan et al., 1995) which identifies possible unmet needs that may obstruct progress, specific goals are jointly formulated. This careful process of mutual goal setting seeks to avoid common pitfalls: the patient feeling that treatment goals are forced upon him or her, and the clinician feeling that urgent patient needs (e.g. financial problems) have not come under discussion.

In the third stage of ICPT, two different goal-oriented methods are used to improve personal and social functioning. The more practical variant, often required with patients that have many social problems, is *clinical case management* (Ziguras et al., 2000; Kanter et al., 1989; Suber, 1994). This form of psychiatric case-management assumes one responsible clinician who takes an active role to improve the patient's social situation, through helping solving social problems (e.g. problems with housing, income, debts, social activities etc.). This form of case-management is, despite its lower implementation grade than the earlier mentioned Assertive Community Treatment (Ziguras et al., 2000), more suitable to situations in which team-wise treatment is not possible. The second variant, possible with patients who have less severe social problems, is *behavioural analysis*. This generic and empirically supported form of focused behaviour therapy (McCullough, 2000; Cooper et al., 2007), assumes that people with long-term non-psychotic disorders mostly find themselves caught in unsatisfactory interpersonal situations. These situations become object of analysis in a stepwise behavioural protocol (McCullough, 2000) which focuses on the thoughts, feelings, actions and consequences regarding the patient's interpersonal behaviour. This third stage of ICPT, that may not be reached by several patients, aims to offer true, practical help after goal-setting in stage two has been concluded.

(4) Application of feedback forms

Originally intended for research purposes, feedback forms have gained solid ground in mental health care over the last years. In ICPT, both clinician and patient fill out a form about the session they have just had. Both rate items on the Session Rating Scale (Duncan et al., 2003), thereby informing one another on their (dis)content with the working alliance. In addition, clinicians score in which stage of the treatment contact

this session could be located, as well as which methods were used, and if treatment goals were discussed. Patients, on the other hand, rate their own input in the session's content. By these means, both parties are delegated responsibility for the working alliance and their substantive input in the session.

(5) Supervision

Every two weeks, a team-wise supervision takes place in which a treatment situation of two different clinicians is jointly analysed. The stage model is implicitly used by the supervisor, but not forced upon the participants. After a 3-minute description, or through a previously distributed paper sheet with 7 preset questions, the treatment situation is introduced by one of the clinicians. After a 25-minute discussion, the process is finalized by the clinician who introduced the situation, through a short summary and mentioning of learning points. Supervision has been proven to be helpful to reduce stress in community psychiatric nurses (Kilminster et al., 2000; Edwards et al., 2006). We used a brief version of a supervision protocol that has been developed and evaluated in Dutch long-term mental health care (Rotteveel et al., 1993). It focuses on the professionals' feelings that may be evoked by working with patients who seem to miss the capacity to improve their independent functioning, are not able to solve their often broad set of psychosocial problems, and have a high level of demands of which they expect the professional to take the responsibility for

> Step 5: implementation

A community mental health team consisting of six community psychiatric nurses and two psychiatrists, with a case-load of severely mentally ill patients with both psychotic and non-psychotic disorders was selected as suitable for a pilot study of the intervention. This selection was based on three criteria: (1) representativeness of the psychiatric service and its catchment area, (2) preparedness and possibility of implementing a new treatment program in the service, (3) geographical accessibility of the service for the authors. Implementation was supported by the management team early on, the clinical team was invited to two meetings about the content and form of the program before the final consent for implementation was given. The team also expressed their willingness to participate in group supervision sessions during the research period. Although this may not be the case in other teams, many professionals express their wish to participate in supervision in daily practice. The team-leader, one of the participating clinicians with additional management tasks, and the team psychiatrist functioned as the link between the treatment team and the research team.

The intervention was implemented mainly through a 3-day training program, consisting of the following elements: (1) theoretical overview (4 hours), (2) relationship

management skills (8 hours), (3) motivational interviewing and goal setting skills (4 hours), (4) case-management skills (4 hours), and (5) behavioural analysis skills (4 hours). The training was offered by the first author (8 hours), and four specialists in the specific skills (4 hours each). It combined lectures, group discussions, one-on-one and group-wise role-playing, homework assignments, and self-study of provided literature. Substantial effort was put in tailoring the training program to the needs and competencies of the participants. Many of the existing therapeutic approaches for patients with non-psychotic disorders, are aimed at Master-level clinicians, whereas the participating community psychiatric nurses, the key clinicians of patients and also those intended to carry out ICPT, all had Bachelor-level psychiatric nursing qualifications. Tailoring was done by inviting specialists with extensive experience with both the target group of professionals, and the method to be taught.

Report and feedback forms were fully integrated into the institution's electronic patient file, to facilitate easy use of these forms and the intervention program in general. The training program was followed up by biweekly supervision sessions and hands-on support by email, telephone or face-to-face contact, delivered by the first author. Every two weeks, a 30-minute group-wise booster session took place, designated for the answering of questions about, and enhancement of adherence to ICPT.

➤ *Step 6: evaluation*

Scientific evaluation of the intervention is part of the implementation process. For various reasons a pilot study was designed to investigate the feasibility of the intervention. First, little experience has been developed so far with the implementation of community psychiatric nurse-led interventions. We need to consider that the application of ICPT places high demands on professionals' skills. Therefore, biweekly supervision and constantly available coaching by phone, email or live instruction were offered. It is possible though that some of the interventions may not be successfully carried out by nurses. Although we believe, based on prior experience and preliminary results from the pilot study, that nurses are able to do so, a thorough process evaluation is included. Second, likewise, implementation of innovative programs for the target group of patients with long-term non-psychotic disorders has been scarce. Third, the intervention consists of multiple components of which the individual effectiveness is established, yet not in conjunction with other methods. It may be that the application of several treatment strategies within one integral program weakens the effect of the individual interventions – especially when less thoroughly implemented (e.g. through fewer training days) than in the original research studies. Fourth, this implementation will be used to improve the intervention and to assess the applicability of several

patient-administered measures with this patient group, since they are used only with other groups of patients (e.g. patients with psychotic disorders, short-term patients). Positive results of the pilot study may well result in the design and execution of a randomized controlled trial.

This pilot study will have a duration of six months and both quantitative and qualitative assessments will be made at baseline, 3 months and 6 months. Quantitative assessments will include outcome measures (psychopathology, psychosocial functioning, quality of life) and process measures (service use, treatment satisfaction, and quality of the therapeutic alliance) on patient level. It will also include process measures on the professional level (treatment integrity, work satisfaction, and perceived difficulty). Qualitative interviews will be used to assess the feasibility and usefulness of the intervention program among patients and professionals alike. Among clinicians, satisfaction with the training, the program, the support, and the supervision will be investigated quantitatively (through scores) and qualitatively (through interviews).

Discussion

In this paper we described the systematic development of an intervention program aimed at people with long-term non-psychotic disorders, Interpersonal Community Psychiatric Treatment (ICPT), carried out by community psychiatric nurses in order to prevent ineffective illness and ineffective professional behaviour. By following the steps of the Intervention Mapping process, it has become increasingly clear that behaviours by health clinicians and (illness) behaviours by patients are mutually reinforcing. Thus, this intervention aims not only to change patient's behaviours, but also to change clinicians' behaviours. In fact, patient's behaviours should change through different clinicians' behaviours. A three-stage treatment model was developed, with tailored therapeutic interventions applied in each stage. Implementation mainly took place through a training program, evaluation through a pilot study.

Although the stage model and therapeutic modalities used in this intervention program are relatively straightforward, the health problem it targets is quite complex, and may be more precisely described as an interaction problem within health services. More than in descriptions of other programs aimed at prevention of ineffective health behaviour (e.g. Bartholomew et al., 1998; 2001), the patient behaviour in this area is very much influenced by the behaviour of health clinicians, and the organisational arrangements of the health services. Ineffective chronic illness behaviour can certainly not be ascribed to patients alone, and therefore an intervention program should also target other parties involved. Although it may appear unusual to target health clinicians' behaviours

and health services' policies through an intervention program, in fact many patient behaviours are quite strongly associated with clinicians' professional behaviour (e.g. Gilbert et al., 2008; Little et al., 2001). Even though studies into the primary or secondary prevention of ineffective chronic illness behaviour are relatively scarce (e.g. Waddell et al., 1984; Whitehead et al., 1982; Wooley et al., 1978), we believe that in many health settings, mechanism of mutual reinforcement of ineffective behaviours are relevant but poorly recognized and understudied phenomena. However, the consequences of such reinforcement may be stronger in our population of non-psychotic patients in long-term mental health care. For both patients and professionals, several disincentives (e.g. motivational, financial, and social) may be present in long-term mental health care, requiring a program explicitly aimed at prevention of ineffective behaviours.

The program combines effective methods on various levels. First, it is grounded in the principles of systematic care planning. The stage model of treatment and the generic session structure offers an overall systematic framework. Next, effective therapeutic methods fill this framework with content. Another level encompasses structured feedback professionals receive from their patients, which facilitates improvement of care. At another level, patient-professional cooperation and patient empowerment are important principles that place patient's autonomy in the middle ground. Last, mutual professional support through supervision is an essential element to improve quality and inter-professional cooperation. Several elements of ICPT can be found elsewhere in more detail (for instance goal-setting is very well defined in psychiatric rehabilitation (Anthony et al., 2002)). To our knowledge, however, it is the first time that a number of potentially effective methods is combined into one, ready-to-use program tailored to this patient and professional population – which both have been deprived of theoretical and methodological developments for long.

This study has limitations and strengths. First, large-scale research into the determinants of ineffective chronic illness behaviour is absent. Therefore we had to rely on smaller, though well-focussed, studies. Second, the scope of our findings may be limited by the specifics of the Dutch health care system. As has been noted before, long-term mental health care is relatively well reimbursed in the Netherlands, which may not be so in other countries. However, this limitation applies less to European countries than to the United States, since many European nations have some form of public care for severely mentally ill patients. Third, some elements that are considered important by some, are not present in ICPT. For instance, the patient's social functioning is primarily supported indirectly, i.e. through active encouragement and practical help by the professional, yet not through direct involvement of patient's significant others. Although certainly not discouraged, the introduction of significant others into the mental health care contact is

not the program's main goal, which is the optimization of the patient-clinician contact first. Generalization of these improved interpersonal skills is aimed for, however, through the use of behavioural analysis of interpersonal problems. Whether this strategy is sufficiently helpful to improve the patient's social support is to be determined through the pilot study. Fourth, the therapeutic methods chosen for inclusion in ICPT may not be the only ones possible but we have given preference to those methods that best matched the behavioural determinants *and* had most empirical support. Fifth, whether the key clinicians delivering ICPT, community psychiatric nurses, are able to do so effectively after three days of training in a variety of concepts and methods, needs to be assessed empirically. While the intervention program is full, and the training rather short, follow-up is intensive through constant support and biweekly supervision sessions. Sixth, this intervention program might also have been developed using other methods to derive at health care interventions, for instance the MRC Framework (Campbell et al., 2000). In this paper, we have not reviewed this and other methods in detail since at an earlier stage we found that Intervention Mapping's strong emphasis on intervention development in general, and goal setting and explication of target groups in particular, suited the complex background of the health problem well. Still, other models might have been equally applicable.

One of the strengths of this study is the investigation of the health problem from a variety of angles. Also, the patient's perspective has been researched in substantial detail. Furthermore, the theoretical model has been developed over a period of four years and has been exposed to various rounds of feedback from researchers, practitioners, and patients. These measures, to our belief, have greatly increased the validity of our findings.

Conclusions

Systematic development of an intervention program for a complex health behaviour problem is possible with Intervention Mapping although the method places high demands on clarification of targeted behaviours, determinants, and target groups.

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Increasing effective behaviours of long-term non-psychotic patients and nurses in community mental health care: a pilot study of Interpersonal Community Psychiatric Treatment

> *Aim*

This paper is a report of a study of the applicability and effectiveness of an intervention program for use by community psychiatric nurses (CPNs) in the care of 'difficult' patients with non-psychotic chronic disorders.

> *Background*

In psychiatric care some patients are perceived as 'difficult', especially patients with long-term non-psychotic disorders for whom few evidence-based treatments exist. An intervention program, Interpersonal Community Psychiatric Treatment (ICPT), was developed and evaluated with the aim to increase effective behaviours by both patients and CPNs.

> *Methods*

6 CPNs and 20 patients participated in a mixed-methods study between October 2009 and April 2010. Quantitative data included type and severity of psychiatric disorder, psychosocial functioning, care needs, quality of life and social participation. Also, service use, satisfaction with care, and quality of the therapeutic alliance were measured. Qualitative interviews were conducted with all participants.

> *Results*

Patients' quality of life improved and their unmet care needs decreased. Service use also decreased but the quality of therapeutic alliance between patients and professionals did not increase. In qualitative interviews, patients rated ICPT largely positive, although the structure and focus on patient-professional contact did not fit everyone. Professionals rated ICPT positively in terms of applicability and usefulness and gave important suggestions for improvement.

> *Conclusion*

ICPT is a program that can successfully be carried out by CPNs, that is generally experienced as acceptable and useful by patients and CPNs alike, and that results in positive results on both process and outcome. Further, controlled, research is needed.

Introduction

Over the last few decades, community mental health care for patients with severe mental illness (SMI) has developed into a practice with an increasingly solid base of evidence (e.g. Torrey et al., 2001). The definition of SMI varies somewhat over settings and authors but generally conforms to the following criteria (Ruggeri et al., 2000): (1) the presence of a mental disorder, (2) having been a user of psychiatric services for two years or longer, and (3) suffering from substantial psychosocial disability defined as a score below 50 on the Global Assessment of Function (GAF; Jones et al., 1995b). There is, however, some debate about which mental disorders qualify. Some argue that only psychotic disorders should be included, other argue that all disorders should as long as the patient receives long-term care and is psychosocially disabled (Ruggeri et al., 2000). Such non-psychotic disorders are, for instance, long-term depressive disorders, anxiety disorders, substance use disorders and personality disorders.

Not only in general definitions, but also in the allocation of care, non-psychotic disorders are viewed differently than psychotic disorders. Their severity has been questioned, and it has been argued that scarce resources should be spent solely on patients with schizophrenia and other psychotic disorders (Gournay et al., 1994; 1995). Others have shown that non-psychotic disorders may be serious, enduring, and in particular disabling (Barr, 2000; Bowers, 1997). Meanwhile, interventions for patients with non-psychotic disorders have been less developed than those for patients with psychotic disorders (Curran et al., 2007). Even though research shows that non-psychotic patients face serious symptoms, display various riskfull behaviours, have substantial psychosocial problems and little future perspective (Bowers, 1997), they may be considered by professionals as less deserving of psychiatric care (Koekkoek et al., 2006). These patients are seen as more able to control their behaviours, both outside and within psychiatric services, than are patients with psychotic disorders (e.g. Hinshelwood, 1999). When non-psychotic patients display challenging behaviours they may thus be perceived as 'difficult' (Breeze et al., 2002). In the absence of evidence-based interventions, care giving may be highly complex (e.g. Koekkoek et al., 2008a).

In our previous work, we investigated the problems that community mental health experts, community psychiatric nurses (CPNs), and patients experience in current psychiatric care for non-psychotic patients. We found that care for these patients often lacks a focus, a theoretical view, and a methodological structure (Koekkoek et al., 2009c). Although pertinent to this patient group, these issues extend to (community) psychiatric nursing in general (e.g. MacNeela et al., 2010; Goossens et al., 2008). The evidence base for community psychiatric nursing is rather small, while long-term non-psychotic

patients generally receive care from CPNs. Therefore, intervention development and evaluation is highly necessary. In this paper we report on the pilot testing of the applicability and effectiveness of a program of community psychiatric nursing care for patients with non-psychotic chronic disorders, called Interpersonal Community Psychiatric Treatment (ICPT).

Background

The development of ICPT took place over a period of four years and was guided by models for development of nursing interventions (van Meijel et al., 2004) and Intervention Mapping (Bartholomew et al., 1998). After conducting two literature reviews (Koekkoek et al., 2006; 2010a) and empirically investigating the problems in current care from different angles, we integrated these findings into a theoretical model. This model, presented elsewhere in more detail (Koekkoek et al., submitted), explains the problems between patients and professionals from the perspective of learned ineffective behaviour by both parties. Chronic ineffective illness behaviour refers to patient behaviours such as being clinging, disqualifying, and demanding in relation to the CPN, often accompanied by high service use. Chronic ineffective professional behaviour refers to professional behaviours such as ignoring patient needs, failing to set limits, maintain treatment structure, and doing not much more than ‘pampering and dithering’.

The model formed the theoretical fundament for ICPT, upon which interventions extracted from evidence-based treatments and current best practices were built. The program was repeatedly discussed in a working group of community mental health experts (consisting of nurses, psychiatrists, and psychologists). The goal of ICPT is to decrease ineffective behaviours by patients and CPNs. It aims to reach this goal through involving patients more actively into their treatment process, and through supporting CPNs to structure the treatment process more clearly. Hereto, generic interventions (e.g. treatment structure) and specific interventions (e.g. needs assessments and therapeutic techniques) are used. Since mutual ineffective behaviours may decrease the quality of the therapeutic alliance (process) and the likelihood of positive treatment results for patients (outcome), these were important measures in the evaluation of the program in an open study.

Measuring health outcomes in SMI-patients, however, is difficult (Repper et al., 1998; Montgomery, 2009). Since symptomatic improvement is often limited or absent, measures from patients’, professionals’, and important other parties’ perspectives are necessary. We used The World Health Organization (WHO) model (Üstün et al., 2002) to distinguish between disease (body structures and functions), disability (activity

limitations) and functioning (participation limitations). In psychiatry, these three concepts usually are interpreted as the type and severity of psychiatric disorder (body structure), psychosocial functioning (activity limitations), and quality of life and social participation (participation limitations). In addition, important process measures in mental health are service use, satisfaction with care, and quality of the therapeutic alliance.

Methods

> Aim and design

The aim of this study is to assess the outcome and the process, in particular the applicability, of ICPT as seen by patients and CPNs.

Our expectations were that:

- of the outcome measures, psychiatric symptoms would not change, psychosocial functioning might increase, and quality of life may increase
- of the process measures, the program's applicability would be judged positively, and that more fidelity to ICPT would result in a higher rating of the quality of face-to-face contacts by both patients and professionals
- of the other process variables, service use would decrease, while we were unsure about the consequences of a more structured treatment to satisfaction and therapeutic alliance as rated by patients and professionals

A mixed-methods design was used, combining pre-post and longitudinal assessments of outcome in both patients and professionals to establish the effect of the program. Longitudinal process measures and qualitative interviews with patients and professionals were used to establish its applicability.

> Sample/participants

The study setting was a case management team of a community mental health centre (CMHC) of a middle-large Dutch city. Such teams are widespread in Dutch community mental health care, and generally function according to case management principles (e.g. Chan et al., 2000; Ziguras et al., 2000). Inclusion criteria for patients were a main non-psychotic diagnosis, two years or longer in psychiatric care, poor psychosocial functioning (GAF-score ≤ 50), age 18-60 years, and Dutch literacy. Exclusion criteria were current psychotic disorders (except short, reactive psychotic episodes), current bipolar disorders, and organic disorders. Comorbid disorders were allowed, including substance use. Further selection took place through the addition of the criterion of professional-

perceived difficulty, operationalized as the presence of at least one disagreement over content and/or form of treatment with at least two professionals over the last two years. Patients' eligibility was assessed by the team leader (a CPN) and the consulting psychiatrist, and was checked with the 1st author.

Eligible patients underwent a structural diagnostic interview for Axis I-disorders (SCID-I; Williams et al., 1992) and Axis II-disorders (SCID-II; First et al., 1995), based on DSM-criteria for assessment of psychiatric disorders. These interviews were conducted by four Master-level trained psychiatric nurses, two Master-level trained social scientists, and a psychiatrist. All were trained by an experienced interviewer according to the SCIDs' instruction manuals.

The case management team consisted of six CPNs, who offered ICPT in cooperation with the team's two consulting psychiatrists. These CPNs were four men and two women, had a mean age of 48.1 (sd 9.1) years, worked 32.9 (sd 3.6) hours per week, all had postgraduate CPN-training, and had 8.1 years (range 1-18, sd 6.8) of CPN-experience. They had received three days of ICPT-training in the month previous to the start of the study, offered by the developer of the program supported by subject-specific sessions by specialized scientists-professionals.

> *Intervention*

ICPT has been specifically designed for community mental health professional for use with non-psychotic chronic patients (Koekkoek et al., 2010f). ICPT consists of three elements: (1) a general structure of treatment stages, (2) specific therapeutic methods per stage, and (3) general methodical elements per session.

The three distinguishable stages are the 1 ('alliance') stage, in which optimization of the therapeutic alliance is the focus and relationship management (Dawson et al., 1993; Hoch et al., 2006) is the specific therapeutic method. The 2nd ('agreement') stage focuses on the development of, negotiation about, and agreement over treatment goals in which motivational interviewing (Miller et al., 2002; Burke et al., 2003) is the specific method. The 3rd ('working') stage, focuses on improvement of the level of activities and participation, in line with earlier agreed on treatment goals. Two specific methods are used here: clinical case management (Suber, 1994; Ziguras et al., 2000) and structured analysis of interpersonal behaviour (Linehan, 1993; McCullough, 2000; Keller et al., 2000). The general methodical elements are used in each session (see 2nd column of table 4 for a detailed description). The frequency of sessions and the length of the program is dependent on mutually agreed on needs and goals. As a rule of thumb, an ICPT-session takes place every two weeks and has a duration between 20 and 45 minutes.

> *Data collection*

Quantitative measures

In accordance with the aforementioned WHO-model we measured outcomes across three levels, both at baseline and 6 months follow-up:

- *Severity of psychiatric disorder*
 - OQ-45 (Outcome Questionnaire; Lambert et al., 1996): a 45-item patient-rated instrument which assesses treatment outcome, mostly in terms of symptom reduction.
 - HoNOS (Health of the Nation Outcome Scale; Bebbington et al., 1999): a 12-item clinician-rated instrument to assess general mental health in predominantly SMI-patients.
 - *Disability and psychosocial functioning*
 - GAF-score (Global Assessment of Functioning; Jones et al., 1995b): a single-item clinician-rated composite score between 10 and 100 of psychiatric and social functioning.
 - CANSAS (Camberwell Assessment of Need Short Appraisal Schedule; Phelan et al., 1995): a 22-item instrument that measures met, unmet needs and total needs for care as viewed by both the patient and the professional.
 - *Participation and quality of life*
 - MANSA (Manchester Short Assessment of Quality of Life; Priebe et al., 1999): a 16-item patient-rated instrument that assesses quality of life in SMI-patients.
 - extent of social network: a single patient-informed question on the extent of the individual's social network.
- > We assessed process with the following measures:
- *Service use (also at 3 months)*
 - CSSRI-EU (Client Socio-Demographic and Service Receipt Inventory; Chisholm et al., 2000): a patient-informed instrument that captures all health care and social services use, as well as any justice department contacts
 - CMHC's administrative records (AR): the organisation's administrative records that register all care contacts by patients in the CMHC
 - *Satisfaction*
 - CSQ-8 (Client Satisfaction Questionnaire; Attkisson et al., 1982): an 8-item patient-administered instrument that assesses satisfaction with care
 - WSQ (Work Satisfaction Questionnaire): a professional-administered composite instrument, consisting of a 21-item scale measuring satisfaction (Landeweerd et al.,

1996), an 8-item scale measuring autonomy, and a 10-item scale measuring social support (de Jonge et al., 1996).

- *Therapeutic alliance (also at 3 months)*
 - STAR (Scale To Assess the Therapeutic Relationship; McGuire-Snieckus et al., 2007): a 12-item instrument that measures the quality of the therapeutic alliance in community mental health care, administered by patients (STAR-P) and clinicians (STAR-C)
- *Professional-perceived patient difficulty*
 - difficult patient score (Koekkoek et al., 2010b): a professional-rated 7-point score of the patient's perceived 'difficulty'.
- *Relation of ICPT-fidelity and intensity (offered by professional) and session rating (scored by both patient and professional) (each session)*
 - ICPT-form: a professional-administered checklist of the number of ICPT-elements used in each face-to-face contact. The order of the checklist followed the chronological order of the treatment stages in ICPT. The scoring schedule rated the different elements in such a way that, regardless of the treatment stage, scores may vary between 4 and 10 (see 3rd column of table 4 for scoring schedule).
 - SRS (Session Rating Scale; Duncan et al., 2003): a brief instrument using four visual analogue scales to rate (1) the alliance with the other, (2) the fit of the goals and topics worked on, (3) the fit with the other's approach or method, and (4) the session in general. At the end of each face-to-face contact, the SRS was filled out by both the patient and the professional. One item in the professionals' version was modified to tailor it to the professional's perspective ('the therapist's approach is a good fit for me' was changed into 'the client's approach is a good fit for me').

Qualitative interviews

Qualitative data was collected from three different data sources:

- individual patient interviews at 6-month follow up
- individual professional interviews at 6-month follow up
- minutes and recordings of biweekly team supervision meetings during 6 months

Patients' and professionals' experiences with the intervention program were collected through a semi-structured interview that was digitally recorded. The patient interview consisted of a number of closed (yes/no) and open questions. The professional interview consisted of a number of scaling (1-10) and open questions. Team supervision sessions were also digitally recorded and minutes were collected from each meeting.

Data analysis

All statistical procedures were performed with SPSS version 15. After controlling for normal distributions, Poisson-distributions were found necessary for skewed service

use data. Paired t-tests were used to assess differences between baseline and 6-month follow-up scores in all the pre-post measurements. A Wilcoxon Sign-Rank test was used for ordinal social network data. All results are reported based on Intention-to-Treat analyses (all participants included), though Per Protocol analyses were also performed (only completers included). Results were reported as significant when $p < 0.05$ or as a trend when $p < 0.10$. An effect size (ES) was calculated for each paired t-test result with $p < 0.10$, according to Field (2005).

Since service use and therapeutic alliance were measured three times, longitudinal analysis by means of Generalized Estimating Equations (GEE; Twisk, 2003) was used, in which we tested whether there was an effect of time between baseline, 3-month, and 6-month follow-up. GEE-analyses were also used to assess the effect of the professional's ICPT-score (predictor) on both the patient's SRS-score and the professional's SRS-score (outcome). GEE models are able to detect a predictor effect over time, while correcting for correlations between individual longitudinal measurements.

Qualitative interview data was descriptively analyzed per question, using both representative and deviating quotes to describe the range of replies. The scaling questions were analyzed as quantitative data, while explanations of scores were descriptively analyzed as above. Qualitative team supervision data was summarized into a list of issues discussed in supervision sessions, and analyzed to detect generic or recurring themes.

> *Validity/reliability/rigour*

Outcome and process measures

Dutch versions of the measures described above have been psychometrically tested earlier and are highly used in mental health care research. For one instrument (STAR), we used a Dutch version of which the back-translation was approved of by the original developer, but was not validated before use. The work satisfaction questionnaires solely exist in Dutch. Also, we asked professionals to rate sessions with the SRS – an instrument intended for use by patients – which to our knowledge has not been done before, and of which reliability and validity data thus does not exist. The one-item Likert-scale score of perceived difficulty is a subjective measure, that was found useful in previous research (Koekkoek et al., 2010b).

Qualitative interviews

Qualitative data were collected and assessed by a qualitative researcher who was informed of, but unrelated to the development and evaluation of ICPT. His prioritizing of

relevant data was cross-checked with that of the 1st author. Summarized qualitative data from the team supervision meetings was member-checked with the team members and found valid.

> *Ethical considerations*

The study was approved by the local research ethics committee, at the institution the 1st author is affiliated with.

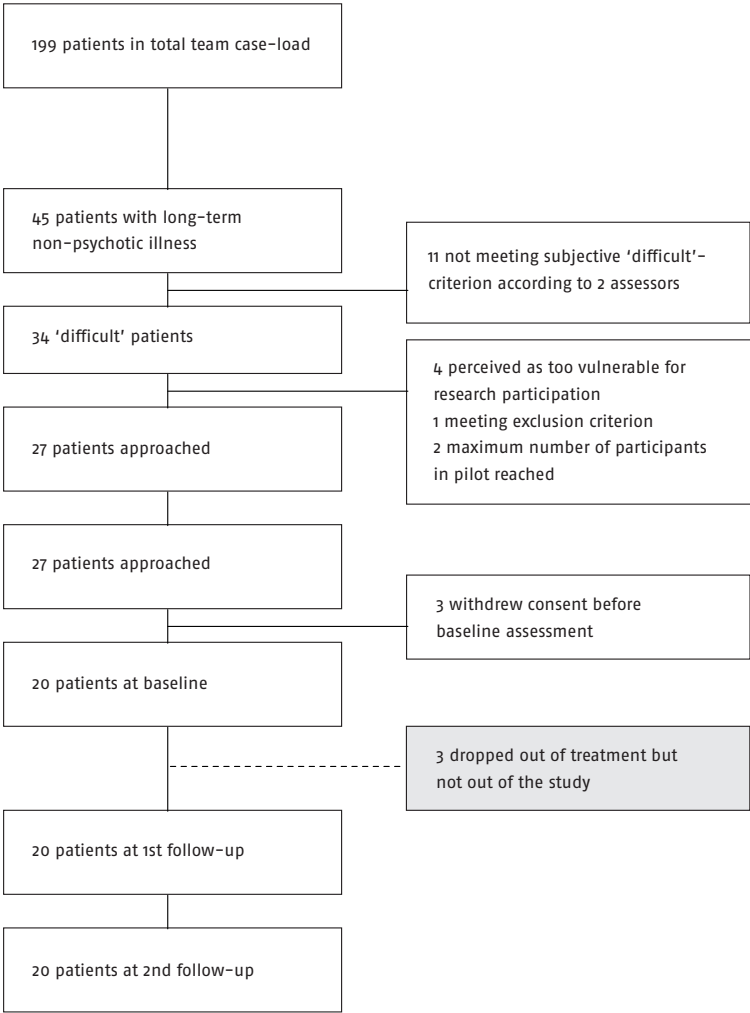


Figure 1
Patient flow into and through intervention

Results

Out of 34 eligible patients, 20 finally participated in the study, whom all could be followed up at 3 and 6 months (see figure 1). Of the 20 participants 3 were treatment drop-outs. Table 1 shows relevant characteristics of patients: participants have many disorders (mean of 6.3 lifetime DSM-IV disorders), poor social functioning (mean GAF-score of 46.4) and have been in treatment for a long time (mean of 9.6 years at the present CMHC). Despite the assessment of some psychotic and bipolar disorders during SCID interviews, concerning patients were not excluded since their main current disorder was of a non-psychotic nature. The mean difficulty score was 4.00 (sd 1.3) at baseline on a 7-point scale, with 25% of patients being scored 5 or higher.

Based on the aforementioned mean frequency of biweekly CPN-contacts in ICPT, we expected 260 contacts during 6 months to take place, while 223 were observed. Per-protocol analyses (with the 17 patients that remained in treatment) showed similar results as Intention-to-treat analyses (with all 20 patients that were followed up), yet with sometimes larger effect sizes but less statistical significance. In the case of some service use measures, decreases were no longer significant.

> Outcome measures

In the first domain of psychiatric symptoms no significant or clinically relevant decreases were found. In the second domain of psychosocial functioning some relevant results were found. Global Assessment of Functioning increased from 46.4 (sd 7.6) to 50.1 (sd 5.9) although only a trend towards statistical significance was detected ($ES=.55$, $p=.099$). Patient-rated unmet needs significantly decreased ($ES=1.23$, $p<.000$), but professional rated unmet needs did not. Yet, professional-rated met needs increased significantly ($ES=.80$, $p=.029$) whereas patient-rated met needs did not. In the third domain (activities and participation), quality of life improved significantly ($ES=.66$, $p=.023$). A trend towards significance was found for the increase in the size of social networks of participants ($ES=.25$, $p=.094$, $z=-1.676$).

Table 1

Socio-demographic and
clinical characteristics of
participants

Characteristics		n	%
Women		15	75%
Marital status	Married/living together with partner	5	25
	Unmarried	12	60
	Divorced	3	15
Ethnicity	Dutch	18	90
	Other	2	10
Education	Elementary school	4	20
	High school	8	40
	College	3	15
	Graduate/Professional	3	15
	Not given	2	10
Employment	Unemployed	6	30
	Volunteer work	1	5
	Housewife/man	3	15
	Retired	1	5
	Student	1	5
	Other	8	40
Source of income	Disability	15	75
	Welfare	5	25
Height of monthly income			
	<1000 euro	14	70
	1000–1500 euro	4	20
	1500–2000 euro	0	0
	>2000 euro	1	5
	Not given	1	5
Lifetime DSM–IV Axis I diagnoses			
	Depressive disorders	17	85
	Psychotic disorders (excluding schizophrenia)	5	25
	Bipolar disorders	4	20
	Substance abuse disorders	10	50
	Anxiety disorders	13	65
	PTSD	5	20
	Eating disorders	2	10

Characteristics	n	%
Current DSM-IV Axis I and II diagnoses		
Depressive disorders	9	45
Psychotic disorders	2	10
Bipolar disorders	4	20
Substance abuse disorders	8	40
Anxiety disorders	9	45
PTSD	5	25
Eating disorders	1	5
Axis II cluster A disorders	8	66.7
Axis II cluster B disorders	12	60
Borderline personality disorder	12	60
Axis II cluster C disorders	12	60
Axis II not otherwise specified	3	15
	Mean [range]	SD
Current Axis I disorders	2.4 [0-5]	1.3
Lifetime Axis I disorders	3.9 [0-6]	1.6
Axis II disorders	2.4 [0-6]	1.8
Age in years	41.1[22-59]	9.7
Number of years in treatment in CMHC	9.6 [2-17]	6.0
Global Assessment of Functioning score	46.4	7.6

> *Process measurements*

Service use decreased in several areas, though only significantly for CPN-contacts over the full 6-month period ($B=-4.06$, $p=.006$), and the number of psychotropic medications ($B=-.45$, $p=.039$).

Findings on the quality of the therapeutic alliance were less consistent. Patients rated the alliance significantly worse after 6 months ($B=-5.46$, $p=.001$). Professionals, however, rated it better after 3 months ($B=2.78$, $p=.013$) but only a trend could be discovered after 6 months ($B=2.05$, $p=.091$). Treatment satisfaction of patients also decreased with a trend towards significance ($B=-2.79$, $p=.065$). No significant changes were found in professionals' work satisfaction and perceived workload, but there was a trend towards significance in the increase of perceived social support.

The ICPT scoring forms allowed measurement of the extent to which distinct ICPT-elements were used. ICPT-forms were filled out in 142 of 223 contacts (63.7%) and showed a range of scores between 4 and 9.5, with a mean of 7.6 (sd 1.3), indicating a relatively high use of ICPT-elements. The frequency of use of ICPT-elements varied widely, with assessing the treatment stage being the most (98.6%) and negotiating goals the least (15.6%) used. The longitudinal relation between ICPT-fidelity and scores on the SRS was also studied, revealing conflicting results among patients and professionals. For patients, an increase of the ICPT-score did not result in a significant change of the SRS-score over time and participants. Higher ICPT- scores, however, resulted in higher professionals' SRS-scores: a significant 18.0% increase with 10 ICPT-points over a 6-month period ($B=.719$, 95% CI [.036 – 1.402], $p=.039$, Wald=4.262, $df=1$). This means that the more ICPT-elements were used, the better the professional rated the session with the patient, while this did not effect the session rating of the patient. Correction for the variable time did not change this association. The professional-perceived difficulty score, however, was a confounder, since the positive effect of a higher ICPT-score on professionals' SRS-scores was magnified by almost a factor three in more 'difficult' patients ($B=1.964$, 95% CI [1.05 – 2.86], $p<.000$, Wald=17.76, $df=1$). This indicates that with more 'difficult' patients, a higher use of ICPT-elements resulted in higher session ratings over time and between patients than in less 'difficult' patients.

Outcome measure	Instrument	Baseline	6-month follow-up	Mean difference [95% CI]	p-value (t-statistic, df)	Effect size
Psychiatric symptoms	Patient-rated					
	OQ-45	74.77 (23.4)	73.91 (22.1)	-.86 [-9.53 – 7.80]	.837 (-.209, 19)	n.s.
	Professional-rated					
	HoNOS	12.5 (5.6)	11.1 (6.2)	-1.47 [-4.82 –1.88]	.366 (-.93, 16)	n.s.
Psychosocial functioning	Patient-rated					
	CANSAS Met needs	4.70 (2.5)	4.65 (2.2)	-.05 [-1.61 – 1.51]	.947 (-.07, 19)	n.s.
	CANSAS Unmet needs	5.10 (3.3)	1.65 (2.3)	-3.45 [-4.81–2.09]	.000 (-5.30, 19)	.77
	Professional-rated					
	CANSAS Met needs	4.17 (2.0)	6.17 (3.0)	2.00 (.23 – 3.77)	.029 (2.39, 16)	.51
	CANSAS Unmet needs	5.12 (3.2)	4.65 (3.0)	-.47 (-.2.20 – 1.26)	.573 (-.58, 16)	n.s.
	Professional-rated					
	GAF	46.4 (7.6)	50.1 (5.9)	3.71 [-.78 – 8.19]	.099 (1.75, 16)	.40
Activities and participation	Patient-rated					
	MANSA Quality of Life	3.61 (.79)	4.17 (.90)	.56 [.090 – 1.02]	.023 (2.505, 17)	.52
Process	Patient-rated					
	CSQ-8 Care Satisfaction	23.63 (5.9)	20.84 (7.1)	-2.79 [-5.78 – .20]	.065 (-1.963, 18)	.42
	Professional					
	Work Satisfaction	2.74 (.19)	2.78 (.21)	.04 (-.15 – .23)	.620 (.528, 5)	n.s.
	Perceived work load	3.29 (.55)	3.19 (.55)	-.10 (-.50 – .30)	.532 (-.671, 5)	n.s.
	Social Support	3.12 (.41)	3.35 (.30)	.23 (-.01 – .46)	.055 (2.49, 5)	.74
	Professional					
	Perceived patient difficulty	4.00 (1.4)	3.59 (1.3)	-.41 [-1.40 – .57]	.386 (-.891, 16)	n.s.

Table 2
Outcome and process
measures at baseline and
6-month follow-up

Table 3
Longitudinal process
measures at baseline,
3-month, and 6-month
follow-up

Outcome measure	Instrument	Mean (SE)	Coefficient (SE)	95% CI of co-efficient	p-value (Wald-statistic, df)
Process measure	<i>All outpatient contacts</i>				
Service use	CSSRI-EU Baseline	10.64 (2.53)	-	-	-
	CSSRI-EU 3 months	6.90 (1.49)	-3.74 (2.46)	[-8.57 - 1.10]	.130 (2.29, 1)
	CSSRI-EU 6 months	8.54 (2.01)	-2.09 (2.21)	[-6.43 - 2.24]	.344 (.895, 1)
	<i>All outpatient contacts</i>				
	AR Baseline	21.70 (2.98)	-	-	-
	AR 3 months	15.95 (2.45)	-4.45 (2.32)	[-11.19 - -.310]	.038 (4.29, 1)
	AR 6 months	17.25 (3.51)	-5.75 (2.78)	[-9.00 - .095]	.055 (3.68, 1)
	<i>CPN-contacts</i>				
	AR Baseline	13.20 (1.91)	-	-	-
	AR 3 months	9.35 (2.12)	-3.85 (1.40)	[-8.43 - .23]	.064 (3.44, 1)
	AR 6 months	9.10 (1.33)	-4.10 (2.21)	[-6.60 - -1.10]	.006 (7.54, 1)
	<i>Number of medications</i>				
	CSSRI-EU Baseline	3.10 (.37)	-	-	-
	CSSRI-EU 3 months	2.82 (.33)	-.280 (.16)	[-.60 - .04]	.086 (2.94, 1)
	CSSRI-EU 6 months	2.65 (.31)	-.450 (-.22)	[-.88 - -.02]	.039 (4.27, 1)
	<i>Inpatient days MHC</i>				
	CSSRI-EU Baseline	10.00 (6.06)	-	-	-
	CSSRI-EU 3 months	4.90 (4.52)	-5.10 (4.64)	[-14.20 - 4.00]	.272 (1.20, 1)
	CSSRI-EU 6 months	3.60 (4.38)	-6.40 (4.53)	[-15.28 - 2.48]	.158 (2.00, 1)
	<i>GP visits</i>				
	CSSRI-EU Baseline	2.45 (.88)	-	-	-
	CSSRI-EU 3 months	0.95 (.34)	-1.50 (.86)	[-3.18 - .18]	.081 (3.05, 1)
	CSSRI-EU 6 months	3.00 (1.19)	.55 (.118)	[-1.77 - 2.87]	.642 (.216, 1)
	<i>Inpatient days GHC</i>				
	CSSRI-EU Baseline	0.20 (.13)	-	-	-
	CSSRI-EU 3 months	0.05 (.05)	-.15 (.15)	[-.44 - .14]	.305 (1.05, 1)
	CSSRI-EU 6 months	0.05 (0.5)	-.15 (.15)	[-.44 - .14]	.305 (1.05, 1)
Therapeutic relationship	<i>Patient-rated</i>				
	STAR Baseline	34.70 (1.71)	-	-	-
	STAR 3 months	35.35 (2.00)	.650 (1.91)	[-3.10 - 4.40]	.734 (11.27, 1)
	STAR 6 months	29.03 (2.45)	-5.46 (1.63)	[-8.650 - -2.273]	.001 (.115, 1)
	<i>Clinician-rated</i>				
	STAR Baseline	35.28 (1.02)	-	-	-
	STAR 3 months	38.05 (.91)	2.775	[.58 - 4.97]	.013 (6.16, 1)
	STAR 6 months	37.32 (.98)	2.049	[-.33 - .443]	.091 (2.85, 1)

> *Qualitative interviews*

In the patient interviews we asked to which extent participants noted changes in their treatment, and if specific well-recognizable ICPT-elements (e.g. agenda setting, goal setting, and SRS-administration) were carried out (see 6th column of table 4). Furthermore, we collected some ordinal data about their usefulness as perceived by patients. In general, out of the 35 judgements by 12 patients who reported changes, 60% (n=21) was positive, 11.4% (n=4) was negative, and 28.6% (n=10) was undecided (see 8th column of table 4 for more details per ICPT-element). Professionals also rated the applicability and usefulness of ICPT, through scale questions (1 to 10) about the training, the support, the program itself, and the supervision (table 4, column 6).

Patients

In the open-ended questions, the overarching themes were ‘feeling heard’ and ‘session structure’. Some patients told they felt hardly listened to by their CPN, while others stated that they took the lead right from the start of the session. Overall, most participants perceived the agenda setting as a useful tool to raise the chances of having their own subjects discussed in the session. They were able to make themselves better heard through the setting of an agenda. Some, however, found agenda-setting overly distant or had difficulties in coming up with subjects to talk about. Goal setting was more universally perceived as helpful in focussing the sessions and the treatment in general. Some stated that even while goals were formulated, they were not worked on, nor evaluated. Another element, the filling out of the SRS at the session’s conclusion, again had a more mixed reception. While most participants saw it as another way to increase the quality of the contact, some others had negative feelings about it. They felt that the SRS was overly formalistic or that they were judging their CPN.

The three patients that dropped out of treatment, all before the start of ICPT, were also interviewed. One had an obvious reason, since he had been hospitalized since the start of the program. A second patient switched from the CMHC to the local general hospital, receiving care at a much lower frequency. The third patient stated that he started thinking about his ‘psychiatric career’ after the diagnostic interviews, subsequently got into an argument with his CPN, and then decided to stay away and seek care from his general practitioner.

Professionals

All CPNs and psychiatrists could be interviewed at 6 month follow up. In general, CPNs found the program sufficiently applicable (mean 7.3, sd 1.3). The usefulness of the program was given a mean score of 7.2 (sd 1.0). The offered support was hardly used,

except in the biweekly team meetings, but the 3 CPNs that did use it, felt well supported (mean 8.5, sd 1.0). The training was well evaluated in general (mean 7.8, sd 0.3) but lower on feeling prepared for practicing ICPT (mean 6.7, sd 0.5). More instruction was felt needed in some areas (e.g. goal setting, filling out of forms). More specific ratings were also given for each ICPT-element, as shown in table 4 (7th column).

Five overarching themes occurred in the data about the program itself: 'treatment structure', 'specific techniques', 'personal discipline', 'responsibility', and 'team support'. All CPNs acknowledged the positive effect of ICPT on structuring each session and treatment in general. Of the specific techniques, agenda setting (mean 7.8, sd 1.0), looking back at the previous session (mean 7.5, sd 1.0), and working towards goals (mean 7.3, sd .6) were considered highly useful. Although time-intensive, CPNs thought that these elements of ICPT enhanced the patient-professional cooperation. An often recurring theme concerned 'personal discipline' to maintain the structure as suggested in ICPT. During the research period in general, and shortly after the training in particular, CPNs reported better fidelity to ICPT than later in the research period. Supervision may have played an important role in maintaining ICPT-fidelity in general. The content of supervision sessions, with few exceptions, concerned issues of responsibility. CPNs wondered to what extent they should interfere with patients lives and decisions, and how they could entice patients to accept more personal responsibility in general. Despite the fact that supervision did not intent to, nor provided clear-cut answers to concrete questions, all CPNs highlighted the support they experienced from both the team and the supervisor, resulting in a score of 8.1 (sd .4) for its usefulness. This resulted in a better practice of what had been learned during the training, and a closer look into CPNs' personal functioning. CPNs valued the focus on the treatment phase the patient they discussed was in, but warned against the easy transition into a patient discussion instead of the analyzing of contact and care patterns and personal involvement.

ICPT element	Goal	Score ¹	Frequency (CPNs)	Usefulness (CPNs) (mean, sd)	Frequency (patients) ⁴	Usefulness (patients) ⁴
Identifying treatment phase	Identification of stage 1 (alliance), 2 (goal setting), 3 (working)	2	98.6% (140)	6.7 (1.4)	-	-
Setting agenda	Joint agenda setting for the session	1	63.1% (89)	7.8 (1.0)	55% (11)	+ : 55% (6) - : 27% (3) ± : 18% (2)
Looking back	Looking back at the previous session to maintain a course	1-1.5 ²	80.9% (114)	7.5 (1.0)	-	-
Clarifying expectations		2 ³	36.9% (52)	6.3 (1.6)	-	-
Inventarizing problems and needs	Inventory of needs according to structured instrument (CANSAS)	2 – 2.5 ²	68.1% (96)	6.7 (2.9)	-	-
Setting goals	Goal setting based upon needs	2	25.5% (36)	7.0 (1.1)	60% (12)	+ : 75% (8) - : 0% (0) ± : 25% (4)
Negotiating goals	Negotiating suitability and ranking order of goals	2	15.6% (22)	7.0 (.6)	-	-
Working towards goals	Active working on goals, using structured methods	2	51.2% (73)	7.3 (.6)	-	-
Using SRS-forms	Collection of structured session feedback	1.5 (patient) 1 (clinician)	62.5% (85) 97.2% (138)	7.0 (1.2) 5.8 (1.5)	60% (12) -	+ : 59% (7) - : 8% (1) ± : 33% (2) -
Using stage-specific methods	Using methods that fit the treatment phase	.5	72.5 (100)	-	-	-

Table 4
Content, frequency of use, and perceived usefulness of ICPT-elements

1 Total maximum score adds up to 10
2 Exact score depends on the extent to which specific elements are used
3 Only one of the score from rows 4-8 may be obtained
4 No data collected on all items since some were hard to observe when unaware of

Discussion

> *Limitations*

This study suffers from some limitations. The small sample size and the lack of a control group warrant careful interpretation of the results. The level of development of the intervention program, however, first required a pilot study. Nevertheless, we have incorporated several strategies to counter these drawbacks, among which longitudinal data collection and non-parametrical data analysis to meet sample size requirements. Analysis of the longitudinal relation between treatment dose (reflected by the ICPT-score) and experienced effect (reflected by patients' and professionals' SRS-score) also meets some of the disadvantages of the lack of a control group. We do have to take into account, though, that social desirability may have induced CPNs to score their use of ICPT-elements higher than justified. Finally, qualitative data collection and analysis was merely descriptive than analytical, but still it facilitated better understanding of some of the outcomes.

> *Findings*

In this pilot study of ICPT, designed for patients with long-term non-psychotic disorders and their treating CPNs, we found, as expected, that patients' quality of life improved and their unmet care needs decreased. Yet, the quality of therapeutic alliance between patients and professionals decreased. Somewhat comparable, professionals' fidelity to ICPT resulted in higher session ratings by professionals but no change in the patients' session ratings. In qualitative interviews, patients rated ICPT largely positive, although the structure and focus on patient-professional contact did not fit everyone. Professionals also generally rated ICPT positively in terms of applicability and usefulness but also gave important suggestions for improvement.

> *Outcomes in relation to the goals and rationale of ICPT*

The treatment evaluated here did better than expected, and resulted in consistently positive outcomes across all outcome measures and some process measures, however not all reached significant p-levels. Briefly stated, patients' content with treatment decreased, but their content with life increased. Looking at the broadly stated goal of ICPT, increase of effective behaviours, we may preliminarily conclude that this was reached. Looking at the same goal for professionals, we note that the more ICPT-elements professionals use, the more content they become with patient contacts, especially with more 'difficult' patients. We may carefully conclude that CPN-treatment

has become more structured over time, which has resulted in positive patient outcomes and a more positive rating of the CPN's contact with the patient.

The findings raise two questions that deserve further attention. First, whether the study participants were truly 'difficult' patients. The mean difficulty score at baseline in this study (4.00 on a 7-point scale) indicated that the participants were perceived somewhat more 'difficult' than those in an earlier large-scale descriptive study (mean 3.48; Koekkoek et al., 2010b). While all subjects were selected because of their perceived difficulty, upon quantitative measurement this difficulty appeared less pronounced. The second question is why patients became less content with the treatment process. Based on the qualitative interviews and the existing literature we are inclined to think that these patients preferred the unstructured nature of previous CPN-care, described elsewhere as 'pampering and dithering'. The stronger emphasis on agenda and goal setting may have scared of some patients. We need to note that the therapeutic approach used in early stages, relationship management, is one in which the professional does not present him or herself as the expert. Instead, patients are invited to become active and responsible while professionals lean backwards. This may be challenging to nurses and patients, who both tend to see the nurse as someone who is able to second-guess what is on the patient's mind and to act upon it (e.g. Jackson et al., 2000). Still, this approach may have served its goal since patients have become more content outside of, than within the CPN-contact.

> *Strengths*

One of the strengths of this study is the focus on both the process and outcome of the evaluated treatment. The treatment itself, ICPT, is outlined and reported on in detail, enabling clinicians and researchers to weigh the potential benefits of the total program and the elements it consists of. The use of modern statistical techniques allows analysis of the treatment process over time, currently still little used in nursing and mental health care research. Another strength is the consistent focus on patient-rated and professional-rated measures, facilitating a comparison between these two viewpoints.

> *Implications for community psychiatric nursing practice and research*

To our knowledge, this is one of the first studies that looks into psychiatric nursing care for patients with long-term non-psychotic disorders. Also, it is one of the first studies, although non-experimental, that reports positive outcomes of community psychiatric nursing treatment with non-psychotic patients (e.g. Kendrick et al., 2005; Gournay et al., 1994). In spite of several initiatives in particularly the UK but also elsewhere towards a

more professional patient-centred practice (Couldwell et al., 2007), a recent study still (MacNeela et al., 2010) found psychiatric nurses to do little shared decision making with their patients. Additional to earlier findings, we were able to show that CPNs may be able to use more structured and goal-oriented strategies within an atmosphere of shared-decision making. Before proceeding any further, a detailed description and standardized training of ICPT are required to facilitate an experimental study into its effectiveness.

Conclusion

ICPT appears to be a program that can successfully be carried out by CPNs, that is generally experienced as acceptable and useful by patients and professionals alike, and that results in positive results on both process and outcome.

Introduction

In this general discussion of the studies presented in this thesis, we first summarize and discuss the findings and the research process. Then, we consider the issues that motivated this research project and the implications for daily practice. In the conclusion of this final chapter, we assess to which extent this study contributes to solutions for the problems regarding the mental health care for 'difficult' non-psychotic chronic patients in daily practice. Also, we make suggestions for further research. The aims of this thesis were:

- 1 to describe and understand the problems in the community mental health care for non-psychotic chronic patients perceived as 'difficult', as experienced by experts, professionals, and patients
- 2 to develop an intervention program tailored to the needs of non-psychotic chronic patients perceived as 'difficult', to be used in non-specialized community mental health care
- 3 to evaluate the applicability and preliminary effectiveness of this program when carried out by community psychiatric nurses.

Summary of main findings

> *Overview of 'difficult' patients*

The foremost reason to undertake this research was the observation that a large part of mental health professionals' time and energy is spent on a relatively small number of patients perceived as 'difficult'. This led to our review of the scientific literature on 'difficult' patients (chapter 1). This review shows that several characteristics of 'difficult' patients in psychiatric care were consistent across studies. Within this population the diagnoses of psychotic disorders and personality disorders were the most common, but more important were functional characteristics. Patients perceived as 'difficult' often are (1) withdrawn and hard to reach, (2) demanding and claiming, (3) attention seeking and manipulating, and/or (4) aggressive and dangerous. The first characteristic is found mostly among patients with psychotic disorders, the second and third mostly among those with personality disorders, and the fourth among both diagnostic groups.

Explanations for these difficult behaviours widely varied: individual (e.g. patients are chronically ill or lack reflective capacities), interpersonal (e.g. patient and professional have a poor therapeutic alliance), and social factors (e.g. patients that do not fit existing care systems are more easily perceived as difficult) were identified. In the literature, strategies to offer care to or treat 'difficult' patients were described in little detail and relatively few specific guidelines were offered for daily practice.

Three subgroups of 'difficult' patients could be identified in the literature, and for two of them treatment strategies or settings were found available. First, those with severe psychotic disorders ('unwilling care avoiders'), second those with low severity psychiatric symptoms but the most challenging behaviours ('demanding care claimers'), and third the remaining group ('ambivalent care seekers'). The latter consists of patients with severe and long-term non-psychotic disorders who seek care but exhibit ambivalent behaviours towards mental health professionals and services. These ambivalent behaviours may be seen by professionals as both purposively obstructive ('bad') and involuntary and unintentional, originating in an illness ('mad'). Mental health care for these patients was found not to be supported sufficiently by effective treatment strategies.

> *Description of problems in daily mental health care*

These conclusions from the literature directed the research project towards a clearer description of 'ambivalent care seekers' and a further understanding of the problems

in the care for these long-term non-psychotic patients. From our review, within this non-psychotic population, three potential diagnostic groups dominated: patients with chronic depression, patients with borderline personality disorder, and patients with multiple or unclear non-psychotic diagnoses (for instance, a person with a major depression, substance abuse and a personality disorder that all are difficult to differentiate from one another). Since most of these patients receive community mental health care, we focussed our research on that particular health care setting.

In chapter 2, we aimed to further investigate what problems psychiatric professionals perceive in their contacts with such 'difficult' patients. Through a modified five-phase Delphi study with three groups of eight experts working in community mental health care, a list of 46 problems was identified. These 46 problems could be grouped into five categories, related to respectively the patient, the professional, the patient-professional interaction, the patient's social system and the professional's mental health care system. Of these, some were relevant to one or two of the three aforementioned diagnostic subgroups while most were relevant to the entire group. The experts identified most problems in the mental health care system itself.

The next step in this project was to complement the view of experts with the scope of general professionals and patients in community mental health care. Chapter 3 reports on a survey among 1946 community psychiatric nurses, which aimed to validate findings from the relatively small group of experts, and to determine which patient, professional, interaction, social and/or mental health care variables make community psychiatric nurses label non-psychotic chronic patients as 'difficult'. While most of the 46 problems identified by experts also applied to general professionals, differences in their relative importance were substantial. Three problems related to the professional ('feeling powerless', 'feeling that the patient is able but unwilling to change', and 'pessimism about the patient's change potential') were highly important. Mental health care-related variables (number of contacts per week and admission to a locked ward in the last year) and social variables (number of psychosocial problems) also were. Thus, the final model of explanatory variables did not contain any patient-related variables but solely professional-related and mental health care-related variables, showing that perceived difficulty is related to complex treatment situations, not so much to individual patient characteristics.

In chapter 4, a next step is reported: qualitative research among 21 'difficult' non-psychotic chronic patients themselves. So far little is known about the perspectives of psychiatric patients who are perceived as 'difficult' by clinicians. Our aim therefore was to improve the understanding of difficult treatment encounters from the point of view

of patients. In a Grounded Theory-study using individual interviews, patients reported on both their own difficult behaviours and their difficulties in the interaction with clinicians and mental health services. Explanations of difficulties varied but could be summarized as a perceived 'lack of recognition'. Recognition referred to being seen both as a patient and as a person, and not just as completely 'ill' or as completely 'healthy'. Patients stated that they perceived their manoeuvrable space in contact with their treating professional as very small, but they also mentioned that they offered little such space to clinicians, highlighting the interpersonal origin of their difficult behaviours. The main explanation for both the perceived lack of space and the perceived lack of recognition was the incongruence of expectations of patients and professionals from the mental health contact.

Using patient-generated data, patients' expectations could be explicated, resulting in a tentative model of the patient-clinician contact. This model consists of three phases of contact development, and three phases of substantial treatment. While contact and a positive therapeutic alliance are necessary conditions for proper treatment, they are not sufficient. Later in the process, the content of treatment becomes more important than the contact or alliance only. According to patients, in each phase there is a therapeutic window of optimal clinician behaviour and two wider spaces below and above that may be qualified as 'toxic' behaviour. This model not only introduced 'time' as an important variable, it also gave us the opportunity to postulate possible changes in clinicians' responses to 'difficult' patients.

➤ *Explanation of the occurrence of 'difficult' patients*

Overlooking these three studies among experts, professionals, and patients, it became clear that there are several different descriptions of, and explanations for the phenomenon of 'difficult' patients. So in chapter 5, a study is described that aims to understand the perception of patients as 'difficult' from all aforementioned perspectives. Analysis of the results of the four studies described in chapters 1 through 4, took place within the theoretical framework of the sick role concept, and resulted in the construction of a tentative explanatory model. The 'difficult' patient-label is given by professionals when the following characteristics are present: (1) many symptoms that are not easy to cluster into a meaningful diagnosis, (2) unusual help-seeking behaviour in particular, and challenging interpersonal behaviour in general, and (3) various social problems. Again, these are required but not sufficient conditions to qualify as a 'difficult' patient. The specific causal attribution professionals make about these conditions, determines whether or not a patient is perceived as 'difficult'. Possible attributions vary from moral, to psychological, social, and neurobiological. The moral attribution ('bad')

most likely results in the 'difficult'-label since it places the largest emphasis on the patient's individual choices and responsibilities. The neurobiological attribution ('ill' or 'diseased') is the least likely to result in the 'difficult'-label since it places most emphasis on physical processes that lie beyond the patient's volatile control. The psychological and social causal attributions tend to oscillate between the aforementioned extremes.

The status of 'difficult' patient is easily reinforced by subsequent patient and professional behaviour (e.g. not accepting any help by patients, or not offering true help by professionals), turning initial unusual help-seeking behaviour into 'difficult' or ineffective chronic illness behaviour. A lack of resources in both the mental health service (e.g. effective methods) and the patient's social system (e.g. sufficient social support) negatively influence this patient-professional interaction. These findings illustrate that the course of mental illness, or at least the course of mentally ill patients' contact with mental health professionals and services, is not determined only by patients' characteristics. Patients and professionals mutually shape the course of care and illness, reinforced by the respective forces of the social and mental health care system.

Aforementioned study shows that while the initial perception of patients as 'difficult' may have much to do with patients' characteristics and professionals' attributions, the continued perception and labelling of patients as such is of a different kind. It appears to be a phenomenon more determined by learned ineffective responses to one another than to the patients' initial behaviours. Comparable to patients' ineffective illness behaviour, clinicians display ineffective professional behaviour. Therefore, an intervention program should focus on increasing effective behaviours by both patients and professionals, rather than on attempting to reduce initial 'difficult' patient behaviours or change professionals' causal attributions.

> *Development and evaluation of an intervention program for 'difficult' patients*

Hereto, in chapter 6 a study is described into the development of a structured program to increase effective behaviours in long-term non-psychotic patients and their treating professionals. The aforementioned model (chapter 5) formed the theoretical fundament for an intervention program that we named Interpersonal Community Psychiatric Treatment (ICPT), upon which interventions extracted from evidence-based treatments and current best practices were built. The program was repeatedly discussed in a working group of community mental health experts (nurses, psychiatrists, and psychologists). The goal of ICPT is to increase effective behaviours by both patients and professionals. It aims to reach this goal through involving patients more actively into their treatment process, and through supporting professionals to structure the

treatment process more clearly. Hereto, generic interventions (e.g. treatment structure) and specific interventions (e.g. needs assessments and therapeutic techniques) are used.

In the final study, described in chapter 7, the intervention program (ICPT) was implemented and evaluated among community psychiatric nurses (CPNs) and their 'difficult' patients. By using quantitative and qualitative methods, the applicability, usefulness, and potential effectiveness of ICPT was assessed. We found that patients' quality of life improved and their unmet needs for care decreased. Yet, according to patients, the quality of the therapeutic alliance with professionals decreased. Somewhat comparable, professionals' fidelity to ICPT resulted in higher ratings of session quality by professionals but no change in the patients' session ratings. In qualitative interviews, patients rated ICPT largely positive, although the structure and focus on patient-professional was experienced as too intensive by some. Professionals also generally rated ICPT positively in terms of applicability and usefulness, and gave important suggestions for improvement. Concluding, ICPT appears to be a program that can successfully be carried out by community psychiatric nurses, that is generally experienced as acceptable and useful by patients and professionals alike, and that shows positive results on both process and outcome.

Discussion of findings

Two major issues emerged during this research project, which are of relevance to both the findings and the methods. The first issue is the lack of objective criteria to describe or define 'difficult' patients. The second issue is the moral connotation of the adjective 'difficult' for patients.

> Objectifying 'difficult' patients

Grounded in daily practice, this project took off from the observation that certain patients are perceived as 'difficult' by professionals. These patients are consequently labelled and discussed with co-workers as such. A broad literature review yielded some behavioural and diagnostic characteristics of 'difficult' patients, yet these were still little precise. We limited our target group to patients with non-psychotic disorders since: (1) few treatments were available for these patients, (2) most difficulties were found among these patients, and (3) it allowed more precision in the definition of the target group. Since we also found that chronicity was an important characteristic of 'difficult' patients, we further restricted the group to patients non-psychotic *chronic* disorders.

Including only chronically, severely mentally ill patients with non-psychotic disorders,

using the broadly accepted definition of severe mental illness by Ruggeri et al. (2000), met some of the problems with defining the target group in terms of diagnosis, severity, and service use. It did, however, not offer any objective criteria for perceived 'difficulty' and therefore another criterion was added to select 'difficult' patients. To be included in the studies, patients had to have had disagreement over form or content of treatment with at least two professionals, at least once in the previous two years. By adding this criterion, perceived 'difficulty' was clearly located in the therapeutic alliance of patient and professional – as perceived by the professional. Though this criterion is still not objective, it is somewhat less subjective to the extent that at least two professionals had to be involved, in at least one disagreement over a given time period. It thus excludes individual, arbitrary and momentary perceptions of patients as 'difficult'.

Results of descriptive studies carried out with this target population of 'difficult' non-psychotic chronic patients yielded differential results over the three groups of participants: experts (chapter 2), general professionals (chapter 3), and patients (chapter 4). These studies further clarified what characteristics 'difficult' patients may have. As summarized in chapter 5, the defining characteristics of patients perceived as 'difficult' were: (1) multiple symptoms and possible diagnoses, (2) challenging interpersonal and unusual help-seeking behaviour, and (3) complex social problems. This chapter also explains why these characteristics make professionals perceive patients as 'difficult'. While the three aforementioned characteristics are necessary conditions, they are not sufficient in themselves. A decisive factor in this perception and labelling is the type of causal attribution professionals make about patients' behaviour. This attribution accounts for the professional's perception of the patient as either 'difficult' or not 'difficult'. It is important to note that an 'objective' or 'behavioural' description of 'difficult' patients is thus impossible.

During this project it became increasingly clear that the 'difficult' patient is not a naturally occurring phenomenon, dependent only on the presence of certain patient characteristics. No patient diagnosis, nor any patient behaviour, nor any other patient problem, or any combination of the aforementioned, fully accounted for perceived difficulty. Thus, perceived difficulty is indeed an interplay of several factors related to the patient, the professional, the interaction, the social system (patient), and the mental health system (professional).

> *Moral judgements and 'difficult' patients*

A second relevant issue during the research process was the moral dimension that the adjective 'difficult' introduced in the supposedly value-neutral context of mental health

care and related research. As we have shown in chapter 5, the attributions professionals make about potentially 'difficult' patients' behaviours, may be more neutral (e.g. neurobiological) or less neutral (e.g. moral). Thus, apart from the argument that the adjective 'difficult' is imprecise, it may also be seen as pejorative, stigmatizing, negative, and counter-effective. According to various critics of the term 'difficult' it would be best to abandon it, and prevent its further use in scientific publications and mental health care (e.g. Corrigan, 2006; Tyrer, 2008). As tempting as this idea is, implying that simply not using the term will result in the disappearance of 'difficult' patients, it appears at odds with our findings and the realities of daily mental health care.

Throughout this project various alternative, less patient-blaming terms have passed, for instance 'countertransference' (defining difficulty as a professional problem), 'poor therapeutic alliance' (an interaction problem), 'multi-problem situations' (a – possibly – social system problem), and 'lack of effective methods' (a mental health care or scientific problem). While none of these alternatives are incorrect, and in fact even are quite accurate descriptions of elements of the problem under study, they all offer more 'technological' alternatives to the value-laden term 'difficult' patient. While we endorse the use of less pejorative and patient-blaming vocabulary, such as used throughout chapters 6 and 7 ('ineffective illness behaviour' and 'ineffective professional behaviour'), we think it is important to not downplay the moral dimension of the highly used adjective 'difficult'.

This moral dimension is little valued in current mental health care and related research (e.g. Scheurich, 2002). Technical neutrality and objective empiricism are required – even though these are values themselves – but hard to maintain in a complex context such as mental health care. While we do not believe that talking about patients as 'difficult' does them much good, we do believe that the term has a strong appeal to professionals in daily care and that it – more importantly – uncovers some hidden non-rational elements in the delivery of care. These non-rational elements include ineffective behaviours by professionals related to for instance uncertainty, anxiety, guilt, or anger. They also concern other elements, including systematic bureaucratic procedures such as high barriers preventing patients' access to treatment. The model presented in chapter 5 exemplifies, without blaming either one of the parties involved, these and other elements and the process through which the 'difficult'-patient label may occur and persist in psychiatric services.

Since this model incorporates both objective and subjective variables and pays attention to rational and non-rational processes, it includes the moral dimension without exclusively blaming the patient. Therefore, at this time, we consider it wise to replace the

term ‘difficult’ patient by the more neutral and inclusive term ‘ambivalent connection’ or ‘ambivalent therapeutic situation’. The presented model (chapter 5) allows a systematic analysis of such situations, while the treatment program presented (chapter 6) facilitates a structured approach. The treatment goal in such situations then is to increase effective behaviours by both patients and professionals.

Practice implications

Due to various causes – i.e. an unclear diagnosis, the patient’s challenging (help-seeking) behaviour and various social problems – patients may be perceived as too complex to fit a structured, diagnosis-specific, evidence-based treatment. For many patients with chronic and severe non-psychotic mental illness this has resulted in receiving no (structured) treatment at all, from professionals with little knowledge and skills in evidence-based approaches. This research project has shown, however, that it is possible to offer structured treatment, which is not diagnosis-specific but based on a generic theoretical model. Below we will discuss the practice implications of structured treatment in more detail, and look towards the professionals that may offer it.

> *Structured treatment*

In the generic approach of Interpersonal Community Psychiatric Treatment (ICPT), the therapeutic alliance and the setting of a mutually shared agenda for treatment receives more attention than signs and symptoms related to specific psychiatric diagnoses. Also we have complemented this process-based approach with substantial treatment elements by focussing on concrete problems and goals. Concrete problems, identified as needs for care by using a validated instrument, are even less important than the goals mutually agreed on by patient and professional. Thus, goals and concrete needs for care have priority over signs and symptoms, without overlooking the latter. This type of approach originates largely from different practical (community mental health care) and scientific (social psychiatry) fields, than the diagnosis-specific approach. These fields have lagged behind in their focus on evidence-based treatments but are becoming more rigorous in their attempts to validate treatments that focus for instance on problem solving (e.g. Malauff et al., 2007), social support (e.g. Davidson et al., 2004), and supported employment (e.g. Burns et al. 2007). Developing and evaluating a generic (i.e. not diagnosis-specific) and structured treatment may be seen as another such attempt.

Apart from the distinction of separate treatment stages, and methods linked to each stage, structured treatments such as ICPT should make optimal use of monitoring of process and outcome through scientifically validated instruments. In fact, such

instruments may be used in treatment itself, as we for instance did by applying a needs for care assessment, and a session rating scale. We may conclude that for patients who have already (unsuccessfully) underwent a diagnosis-specific treatment, or for those unsuitable for such treatments, a structured approach is possible. Contrary to the apparent belief among certain groups of professionals, a structured approach that combines several evidence-based instruments and methods, is very well feasible. Implementation of such approaches effectively in daily practice, though, requires considerable effort and knowledge of professionals.

➤ *Professionals offering long-term care to patients with severe mental illness*

We have shown that, in general, professionals offering long-term care are not academically trained, and come from a professional background that lacks well-developed and evidence-based treatments (also see Kerr et al., 2007). While most long-term care in the Netherlands is offered by (community) psychiatric nurses, professionals such as social workers, occupational therapists, and others may also offer it – and in fact do so to a larger extent in some countries (for instance in the United States; Mechanic, 2006).

Looking at community psychiatric nurses (CPNs), the professionals most studied in this project, we see that they feel that their work lacks structure, a theoretical base and empirical support (Couldwell et al., 2007). At the same time, CPNs play an important role – if not the most important role – in the offering of community mental health care to patients with severe mental illness. While many patients, nurses, non-nursing co-workers and managers feel that CPNs do valuable and highly necessary work, aforementioned discontent is echoed in our research findings. Experts describe long-term treatment by CPNs somewhat disqualifying as ‘pampering and dithering’ (chapter 2). Patients, when asked in individual interviews, claim they have good contact with CPNs but also state that nothing much happens in these contacts (chapter 4).

In our studies that concerned CPNs (chapters 2, 3, 4 and 7), we consistently found that they consider the therapeutic alliance with their patients as the most important element of their care, turning it into a goal itself rather than a means to achieve goals. Patients and non-nursing professionals, however much they value the therapeutic alliance, have been critical about the domination of process (i.e. contact) over content of treatment (i.e. setting of goals and application of interventions). This lack of focus on content may result in long-term, agreeable contacts between patients and CPNs without much improvement in the patient’s mental or social functioning. Furthermore, there is a substantial risk that once the therapeutic alliance does not develop smoothly, which is

often the case with potentially 'difficult' patients, the negative interpersonal process will completely come to dominate the patient-professional encounter. In other words, when there is no agreeable contact and there is no substantial treatment to fall back on, CPNs may be tempted to blame the patient for this discomfort by calling him or her a 'difficult' patient.

This project has offered an alternative to the exclusive focus on the therapeutic alliance, and the subsequent risk of introducing the 'difficult'-label in challenging situations. A theoretical model that explains difficulties between patients and professionals was constructed from research into daily mental health practice. Next, an intervention program with both a theoretical rationale and empirical support for its content was developed. Finally, CPNs were trained to effectively apply this program. The pilot results (chapter 7) show that CPNs become less 'caring', and more 'motivating' towards patients to take up personal responsibility and to work towards goals in life outside of mental health care.

> *Implementation*

Both for CPNs, implementation specialists, and researchers it will be a challenge to maintain the profits as shown by the application of ICPT. Working according to a structure, staying focussed on maximizing the patient's potential for personal responsibility and development, and not getting caught up in collusive, long-term contacts are complex skills to be asked from CPNs. Also for other professionals, it may be hard to refrain from introducing moral judgements and calling patients 'difficult'. Even though ICPT has incorporated strategies to facilitate the acquisition and maintenance of such skills, for instance through regular supervision and collegial feedback, further steps in the development of the program are required. Participating CPNs have given valuable feedback that may increase the applicability and effectiveness of ICPT in the future. The development of a practical handbook that combines theoretical background and practical methods will facilitate further learning and enable implementation on a larger scale, for instance to carry out a controlled study of ICPT.

Furthermore, successful implementation and continuation of ICPT also requires some changes in the organization of mental health care. First, it must be acknowledged that the pivotal role CPNs and other such professionals play in the mental health care for severely mentally ill patients, puts them under substantial strain. In many cases, few alternatives but CPN-care are available to patients. Thus, 'dumping' of chronic, complex and potentially 'difficult' patients on CPNs is a serious risk. The availability of alternatives, either within mental health care or in primary care, may facilitate

CPNs to remain hopeful and committed to a structured method such as ICPT. Second, CPNs may need more support from colleagues and be more able to share the burden of their individual case-load. While the full team approach of Assertive Community Treatment may be somewhat too intensive, dual treatment (by two CPNs) and easier access to supervising psychiatrists could be facilitated. Team-wise supervision, as provided during this research, should be structural. Third, it must be noted that many of the processes described in the explanatory model in chapter 5, such as either or not legitimizing the sick role, do not only apply to individual professionals but to mental health care as a whole. In spite of impressive developments in the care for severely psychotically disordered patients, for instance Assertive Community Treatment for the most vulnerable patients, many high thresholds remain in place for patients with chronic and severe non-psychotic mental illness. Almost any treatment program requires a clear diagnosis, somewhat agreeable behaviour and a stable social situation, thus effectively excluding patients that are so often perceived as 'difficult'.

Limitations and strengths

The lack of a fully objective definition or description of the 'difficult' patient may be considered a limitation of this research project. This limitation is of most significance when considered in the light of the present focus on behavioural descriptions of psychiatric disorders. The current classificatory system (DSM-IV), its predecessors and future successor (DSM-V), all are based on the categorization of observable phenomena. Although the dominance of this paradigm may be debated, the problems with selecting patients partly based on non-observable phenomena are obvious. First of all, selection always needs to take place by professionals involved, since without their 'difficult'-qualification these patients would not exist. Bias is thus a substantial risk, since our 'objective' criterion 'disagreement over form or content of treatment' may be interpreted very differently by professionals. Second, the selected group may still be quite heterogeneous in terms of diagnosis (many non-psychotic disorders exist and combinations are abound), behaviour and interaction (disagreement over treatment may have various forms and sources). While heterogeneity is not necessarily a problem, it may be when these research outcomes are generalized to other – possibly different – groups of people with non-psychotic disorders. Third and possibly most importantly, the current definition of the target group – using an additional professional-perceived criterion – implies that 'difficulty' cannot be measured objectively.

This limitation, as problematic as it is to be unable to detect 'difficult' patients solely by measuring patient characteristics, is also an important strength of this research. While we have maintained the use of the adjective 'difficult' throughout the studies, since this

was the criterion upon which patients were included, this project has in fact revealed various causes for the occurrence and continued presence of 'difficult' patients. These sources could not have been uncovered without the use of multiple research methods and informants. To our knowledge, this project is the first to study perceived difficulty among experts, general professionals, and patients alike. Furthermore, the model presented in chapter 5 is the first attempt to integrate various sources of information and social scientific theory into one explanatory framework.

Another limitation is that the findings from the last (pilot) study (chapter 7) are only preliminary indicators of the intervention program's effectiveness. However, it was beyond the aim of our study to undertake an additional controlled trial and the naturalistic study described in chapter 7, fitted the level of development of the intervention program quite well. Also, though this program has preliminary proven to be feasible and effective (chapter 7), as well as useful in decreasing patients' perceived difficulty, we need to acknowledge that moral judgements are not necessarily prevented through this program, rather they may be tackled more promptly and more strategies are available to handle them. Future research is required to address aforementioned issues.

Further research

Considerations about further research are made in three separate areas, congruent with the issues discussed in detail above: (1) the objective description of 'difficult' patients, (2) the moral dimension in complex treatment situations, and (3) the implementation and use of the treatment program.

In this project we have exhaustively sought for patient characteristics that are both necessary and sufficient conditions for the universal perception of patients with such characteristics as 'difficult'. However, we did not find such characteristics and in fact found that difficult patienthood may, in general, not be attributed to patients alone. Therefore, we suggest future research to focus on the entire treatment situation, including variables related to patient, professional, interaction, social system, and mental health system. While research into interaction variables is relatively commonplace, much less emphasis is placed on professional and social system variables. Also, research into the organisation of mental health services is very limited. Although some organisational models (e.g. Assertive Community Treatment) appear to work better than traditional models, it is unknown whether better outcomes may be ascribed to organisational or other factors. Social scientific research into the prevalent culture in mental health services may uncover differences in systematic responses to certain types of patients.

Concerning the moral dimension introduced by the use of the 'difficult'-label, we think that more research into professionals' attributions of patients' behaviour and problems may be useful. During this project we have made a crude distinction between types of causal attributions, but have not investigated those in detail, nor have we looked into the extent to which professionals are inclined to make these attributions. For daily practice, it may also be very useful to know how negative attributions may be changed.

Last, it is important to repeat the pilot study into the feasibility and effectiveness of ICPT in a different setting. The design then needs to be strengthened by including more patients and a control group. Before doing so, improvements to the program, based on participants' comments, will be made.

Conclusion

Individuals with long-term non-psychotic disorders and difficult behaviours may evoke a moral response. We have been able to disentangle some of the consequences of this and other responses, for the contact of patients and their caregivers. A model that incorporates the variables currently known, has proven to be helpful to analyze complex treatment situations from multiple perspectives. The results of the evaluation of the intervention program that was developed from this model, exemplify that improvements are possible once a theoretical framework and evidence-based interventions are combined. A generic structured approach, such as used in this program, may be useful for people with long-term disorders. Application of a program such as ICPT may be a viable future for long-term mental health services to people with chronic and severe non-psychotic illness, since they strike a bridge between the required use of evidence-based interventions (which are scarcely available for people with non-psychotic chronic disorders) by professionals, and the challenges and needs presented by patients. Further research into the intervention program, but also into complex treatment situations is required.

Introductie

In deze algemene discussie over de studies in dit proefschrift, vatten we eerst de bevindingen samen en bespreken deze gezamenlijk met het onderzoeksproces. Dan besteden we aandacht aan de aanleiding voor dit project en de implicaties voor de praktijk. Aan het einde van dit hoofdstuk, stellen we vast in welke mate dit proefschrift bijdraagt aan oplossingen voor problemen in de psychiatrische zorg aan 'moeilijke' niet-psychotische chronische patiënten. Ook doen we suggesties voor verder onderzoek.

De doelen van dit onderzoek waren:

- 1 tot een beschrijving en begrip komen van de problemen in de sociaal-psychiatrische zorg aan 'moeilijke' niet-psychotische chronische patiënten, zoals ervaren door experts, professionals en patiënten
- 2 ontwikkeling van een interventieprogramma, toegesneden op de behoeften van 'moeilijke' niet-psychotische chronische patiënten, dat bruikbaar is in de algemene sociaal-psychiatrische zorg
- 3 evaluatie van de bruikbaarheid en voorlopige effectiviteit van het interventieprogramma, wanneer uitgevoerd door sociaal-psychiatrisch verpleegkundigen

Samenvatting

> Overzicht van 'moeilijke' patiënten

De belangrijkste reden om dit onderzoek te starten was de constatering dat een groot deel van de tijd en energie van hulpverleners besteed wordt aan een relatief kleine groep patiënten, die beschouwd wordt als 'moeilijk'. Dit leidde tot een literatuurstudie (hoofdstuk 1) die laat zien dat de kenmerken van 'moeilijke' patiënten redelijk vergelijkbaar zijn in verschillende studies. In deze populatie kwamen de diagnoses psychotische stoornis en persoonlijkheidsstoornis het meest voor, maar belangrijker waren de gedragingen van patiënten. Als moeilijk gepercipieerde patiënten waren vaak (1) teruggetrokken en moeilijk te benaderen, (2) eisend en claimend, (3) aandachtvragend en manipulatief, en/of (4) agressief en gevaarlijk. Het eerste gedrag kwam het meest voor onder psychotische patiënten, het tweede en derde het meest onder patiënten met een persoonlijkheidsstoornis en de vierde onder beide groepen.

De verklaringen voor moeilijk gedrag liepen erg uiteen: we vonden individuele (bv. patiënten zijn chronisch ziek of missen reflectieve vermogens), interpersoonlijke (bv. patiënten en professionals hebben een slechte therapeutische relatie) en sociale factoren (bv. niet in het systeem passende patiënten worden eerder moeilijk gevonden). In de literatuur werden zorg- en behandelstrategieën slechts globaal beschreven.

We konden drie subgroepen van 'moeilijke' patiënten onderscheiden in de literatuur, en voor twee daarvan vonden we behandelstrategieën. De eerste groep bestond uit patiënten met ernstige psychotische stoornissen ('zorgwekkende zorgmijders'), de tweede uit patiënten met relatief milde psychiatrische symptomen maar zeer lastig gedrag ('hinderende hulpeisers'), en een derde groep van 'ambivalente aandachtvragers'. Deze laatste groep bestond uit patiënten met ernstige en langdurige niet-psychotische stoornissen die op een ambivalente manier hulp zoeken bij psychiatrische professionals. Dit ambivalente gedrag kan door hulpverleners zowel gezien worden als bewust dwars ('slecht'), of als onbedoeld en onvrijwillig, veroorzaakt door een ziekte ('gek'). Voor de begeleiding van deze patiënten bleken nauwelijks effectieve behandelstrategieën voorhanden.

> Beschrijving van problemen in de dagelijkse praktijk

De conclusies uit de literatuurstudie stuurden het onderzoek in de richting van een duidelijker omschrijving van 'ambivalente aandachtvragers' en de noodzaak meer te begrijpen van de problemen in de zorg aan deze niet-psychotische chronische patiënten. Uit de literatuurstudie bleken drie subgroepen in deze niet-psychotische populatie de

meest ‘moeilijke’: patiënten met een chronische depressie, patiënten met een borderline persoonlijkheidsstoornis en patiënten met een onduidelijke diagnose of verschillende niet-psychotische diagnoses (bv. een depressie, middelengebruik en een persoonlijkheidsstoornis, waarvan de symptomen moeilijk te onderscheiden zijn). Aangezien de meeste van deze langdurige patiënten zorg ontvangen op afdelingen voor ambulante langdurige zorg, voorheen sociale psychiatrie, deden we ons onderzoek in die setting.

In hoofdstuk 2 hadden we als doel om duidelijker te krijgen welke problemen psychiatrische professionals ondervinden in contacten met bovengenoemde groep ‘moeilijke’ patiënten. Door middel van een aangepaste Delphi-studie met drie groepen van acht experts in de sociaal-psychiatrische zorg aan deze niet-psychotische chronische patiënten, werden 46 problemen gevonden. Deze 46 problemen waren onder te verdelen in vijf groepen: problemen gerelateerd aan de patiënt, aan de professional, aan de interactie, aan het sociale systeem van de patiënt en aan het zorgsysteem van de professional. Van deze 46 problemen was een aantal relevant voor één of twee patiëntgroepen, maar de meeste waren relevant voor de totale groep van niet-psychotische chronische patiënten. De meeste problemen bevonden zich volgens de experts in het geestelijke gezondheidszorgsysteem zelf.

De volgende stap in dit project was om de visie van experts aan te vullen met die van algemene professionals en patiënten in de ambulante langdurige zorg. In hoofdstuk 3 wordt verslag gedaan van een enquête onder 1946 sociaal-psychiatrisch verpleegkundigen (SPV-en), die als doel had om de bevindingen van de kleine groep experts te valideren, en om te bepalen welke variabelen (gerelateerd aan de patiënt, de professional, de interactie, het sociale systeem van de patiënt en het zorgsysteem van de professional) maken dat SPV-en patiënten als ‘moeilijk’ ervaren. Hoewel de meeste van de 46 door de experts geïdentificeerde problemen werden herkend door SPV-en, waren er aanzienlijke verschillen in het relatieve belang dat beide groepen eraan hechtten. Drie aan de professional gerelateerde problemen (‘machtelos voelen’, ‘denken dat de patiënt zich wel anders kan maar niet anders wil gedragen’, ‘pessimisme over de verandermogelijkheden van de patiënt’) bleken erg belangrijk. Hetzelfde gold voor enkele zorggerelateerde variabelen (het aantal contacten per week en opname op een gesloten afdeling in het laatste jaar) en sociale variabelen (het aantal psychosociale problemen). Het uiteindelijke regressiemodel bevatte geen patiëntgerelateerde variabelen, maar uitsluitend professionalgerelateerde, zorggerelateerde en sociale variabelen. Dit toont aan dat ervaren moeilijkheid minder met patiëntkenmerken te maken heeft dan met complexe behandelsituaties.

In hoofdstuk 4 wordt verslag gedaan van de volgende stap: kwalitatief onderzoek onder 21 ‘moeilijke’ niet-psychotische chronische patiënten zelf. Het perspectief van patiënten die moeilijk gevonden worden is tot dusverre nog nauwelijks belicht geweest in onderzoek. Het doel was daarom om ons begrip van complexe behandelsituaties te vergroten, zoals ervaren door patiënten. In een *Grounded Theory*-studie met individuele interviews, gaven patiënten inzicht in hun eigen moeilijke gedrag en de problemen in contact met hulpverleners en het psychiatrisch zorgsysteem. Verschillende verklaringen kwamen naar voren, samen te vatten als een ervaren ‘gebrek aan erkenning’. Erkenning sloeg op het gezien worden als patiënt en persoon, niet slechts als volledig ‘ziek’ of volledig ‘gezond’. Patiënten gaven aan dat zij hun manoeuvreerruimte in contact met professionals als erg klein ervoerden, maar dat ze zelf ook weinig ruimte gaven aan professionals, daarmee het interpersoonlijke element van hun moeilijke gedrag benadrukkend. De hoofdverklaring voor zowel het ervaren gebrek aan ruimte, als het ervaren gebrek aan erkenning lijkt de afwezigheid van overeenstemming tussen patiënten en professionals te zijn over de verwachtingen van het hulpverleningscontact.

De kwalitatieve patiëntendata werd voorts gebruikt om de verwachtingen van patiënten verder te expliciteren in een voorlopige beschrijving van de interactie tussen patiënt en professional. Dit proces wordt gekenmerkt door drie fasen van contactontwikkeling en drie fasen van behandeling. Hoewel contact en een goede therapeutische relatie noodzakelijke voorwaarden zijn voor daadwerkelijke behandeling, zijn ze niet voldoende. Later in het proces wordt de inhoud van de behandeling belangrijker dan alleen de vorm of het contact. Volgens patiënten is er in elke van de zes fasen een ‘therapeutisch venster’ van optimaal professioneel gedrag, en twee grotere gebieden daaronder en daarboven die kunnen worden beschreven als ‘toxisch’. Dit model van de interactie introduceert niet alleen ‘tijd’ als een belangrijke variabele, het geeft ook de kans om mogelijke veranderingen in de reacties van professionals voor te stellen.

> *Verklaringen voor het ontstaan en voortbestaan van ‘moeilijke’ patiënten*

Op basis van de drie voorgaande studies, onder experts, professionals en patiënten, werd duidelijk dat er verschillende beschrijvingen en verklaringen naast elkaar bestaan voor het fenomeen van de ‘moeilijke’ patiënt. In hoofdstuk 5 wordt daarom een studie beschreven die als doel had om de perceptie van patiënten als moeilijk te begrijpen vanuit alle eerder genoemde perspectieven. Analyse van de resultaten van de studies in hoofdstukken 1 t/m 4, vond plaats binnen het theoretische raamwerk van het ziekterol-concept, en resulteerde in de constructie van een voorlopig, verklarend theoretisch model. Het ‘moeilijke’ patiëntlabel wordt gegeven wanneer de volgende patiëntkenmerken aanwezig zijn: (1) veel, complexe symptomen die niet eenvoudig

tot een logische diagnose leiden, (2) afwijkend hulpzoekgedrag in het bijzonder en lastig interpersoonlijk gedrag in het algemeen, (3) een veelheid aan complexe sociale problemen. Deze voorwaarden zijn noodzakelijk maar niet voldoende voor het oordeel 'moeilijk'. De causale attributie die professionals maken over de oorzaak van deze drie kenmerken, bepalen of een patiënt wel of niet als 'moeilijk' gelabeld wordt. Mogelijke attributies variëren van moreel, via psychologisch en sociaal tot neurobiologisch. De morele attributie (de patiënt is 'slecht') leidt meestal tot het 'moeilijk'-label omdat het de grootste nadruk legt op de patiënt's eigen keuzes en verantwoordelijkheden. De neurobiologische attributie (de patiënt is 'ziek') leidt daarentegen zelden tot het 'moeilijk'-label omdat het de nadruk legt op een fysiek proces dat buiten de patiënt's controle ligt. De psychologische en sociale attributies resulteren in een positie ergens tussen deze twee extremen in.

De status van 'moeilijke' patiënt wordt makkelijk bekrachtigd door gedrag van patiënten en professionals (bv. geen enkele hulp accepteren door patiënten, geen echte hulp bieden door professionals), waardoor aanvankelijk afwijkend hulpzoekgedrag verwordt tot 'moeilijk' of ineffectief chronisch ziektegedrag. Een gebrek aan middelen in zowel GGZ-instellingen (bv. effectieve methoden) als het sociale systeem van de patiënt (bv. voldoende sociale ondersteuning) beïnvloeden de patiënt-professionalinteractie negatief. Deze bevindingen illustreren dat het beloop van psychiatrische stoornissen, of in ieder geval het beloop van het contact van een patiënt met de psychiatrische zorg, niet alleen bepaald wordt door de kenmerken van de patiënt. Patiënten en professionals bepalen gezamenlijk het beloop van de zorg en de stoornis, versterkt door de invloed van het sociale en gezondheidszorgsysteem.

Bovengenoemde studie laat zien dat de aanvankelijke beoordeling van patiënten als 'moeilijk' veel te maken heeft met patiëntkenmerken en professionele attributies. Het voortbestaan van 'moeilijke' patiënten is echter van andere aard: de aanwezigheid van deze patiënten in psychiatrische zorg en het blijven labellen van deze patiënten als 'moeilijk', wordt meer bepaald door aangeleerde ineffectieve reacties op elkaar dan door het aanvankelijke patiëntengedrag. Vergelijkbaar met het ineffectieve ziektegedrag van patiënten, vertonen professionals ineffectief hulpverlenergedrag. Daarom moet een interventieprogramma zich meer focussen op ineffectief gedrag van zowel patiënten als professionals, dan op het proberen te verminderen van aanvankelijke moeilijke gedragingen van patiënten of veranderen van professionele attributies.

› *Ontwikkeling en evaluatie van een interventieprogramma ten behoeve van ‘moeilijke’ patiënten*

In hoofdstuk 6 wordt een studie beschreven over de ontwikkeling van een gestructureerd programma, met als doel het effectief gedrag van niet-psychotisch chronische patiënten en de behandelende professionals te doen toenemen. Het hierboven beschreven model (hoofdstuk 5) vormde het theoretisch fundament voor een interventieprogramma genaamd Interpersoonlijke Sociaal Psychiatrische Begeleiding (ISPB). Interventies uit *evidence based* behandelingen en huidige *best practices* werden geplaatst bovenop het theoretisch raamwerk, in samenspraak met een groep van sociaal-psychiatrische experts (verpleegkundigen, psychiaters en psychologen). Het doel van ISPB is om effectief gedrag van zowel patiënten als professionals te doen toenemen, door patiënten meer actief bij hun behandelproces te betrekken en door professionals te ondersteunen om hun behandeling te structureren. Daartoe wordt een aantal generieke (bv. structuur van de behandeling) en specifieke technieken (bv. vaststelling van zorgbehoeften en omschrijven gespreksmethoden) gebruikt.

In de laatste studie, beschreven in hoofdstuk 7, werd het interventieprogramma (ISPB) geïmplementeerd en geëvalueerd onder sociaal-psychiatrisch verpleegkundigen en ‘moeilijke’ patiënten. Door kwantitatieve en kwalitatieve onderzoeksmethoden te gebruiken, werden de toepasbaarheid, bruikbaarheid en voorlopige effectiviteit van ISPB vastgesteld. We vonden dat de kwaliteit van leven van patiënten toenam en hun onvervulde zorgbehoeften afnamen. Echter, volgens patiënten nam de kwaliteit van de therapeutische relatie af. Vergelijkbaar daarmee, vonden we bij een intensief gebruik van ISPB-elementen door professionals een hogere waardering van de sessies door professionals, maar geen verschil in waardering door patiënten. In de kwalitatieve interviews waren patiënten grotendeels positief over ISPB, hoewel de structuur en focus op de patiënt-professionalrelatie door sommigen te intensief werd gevonden. Professionals waren ook positief over de bruikbaarheid en gaven relevante suggesties ter verbetering. Concluderend lijkt ISPB een programma te zijn dat succesvol kan worden uitgevoerd door sociaal-psychiatrisch verpleegkundigen, dat over het algemeen als bruikbaar en nuttig wordt gezien door patiënten en professionals, en dat positieve effecten heeft op zowel het proces als resultaat van sociaal-psychiatrische begeleiding.

Algemene discussie

Twee grote thema's kwamen steeds opnieuw terug tijdens dit onderzoeksproject. Deze hadden zowel betrekking op de resultaten als op de onderzoeksmethoden. Het eerste thema is het gebrek aan objectieve criteria om ‘moeilijke’ patiënten te beschrijven of te

definiëren. Het tweede thema is de morele lading die het bijvoeglijk naamwoord ‘moeilijk’ heeft wanneer het gebruikt wordt om patiënten te beschrijven.

> *Het objectiveren van ‘moeilijke’ patiënten*

Met de dagelijkse praktijk van de geestelijke gezondheidszorg als aanleiding, vertrok dit project vanuit de observatie dat bepaalde patiënten als ‘moeilijk’ worden gezien door professionals. Deze patiënten worden vervolgens ook zo genoemd en in dergelijke termen besproken met collega’s. Onze brede literatuurstudie leverde een aantal gedragingen en diagnostische kenmerken van deze patiënten op, maar was nog altijd weinig precies. Om drie redenen beperkten we onze doelgroep in het verdere onderzoek tot niet-psychotische patiënten: (1) omdat er weinig behandelingen beschikbaar waren voor deze groep, (2) omdat de grootste moeilijkheden zich bij deze groep voordeden, en (3) omdat deze afbakening de precieze omschrijving van de doelgroep vereenvoudigde. Daar we ook vonden dat chroniciteit een belangrijk onderscheidend kenmerk was van ‘moeilijke’ patiënten, beperkten we doelgroep verder tot niet-psychotische *chronische* patiënten.

Een aantal van de definitieproblemen werd ondervangen door alleen patiënten met een chronische, ernstige psychiatrische stoornis, volgens de veelgebruikte omschrijving van Ruggeri et al. (2000), te includeren. Hierdoor waren diagnose, ernst en zorggebruik gedefinieerd, maar ‘moeilijkheid’ nog niet. Daarom voegden we een criterium toe waaraan patiënten moesten voldoen om deel te kunnen nemen aan de studies. Er moest in de afgelopen twee jaar minimaal één keer een gebrek aan overeenstemming zijn geweest over de vorm en inhoud van de behandeling, tussen de patiënt en minimaal twee professionals. Door dit criterium toe te voegen, werd ‘moeilijkheid’ duidelijk geoperationaliseerd als een kenmerk van de therapeutische relatie van patiënt en professional – zoals gepercipieerd door de professional. Hoewel dit criterium nog altijd niet objectief is, is het minder subjectief door de noodzaak dat minimaal twee professionals een gebrek aan overeenstemming ervaren moeten hebben gedurende een afgebakende tijdsperiode. Daardoor worden puur individuele, arbitraire en tijdelijke percepties van patiënten als ‘moeilijk’ uitgesloten.

De beschrijvende studies die we uitvoerden met en over deze doelgroep van ‘moeilijke’ niet-psychotisch chronische patiënten leverden uiteenlopende resultaten op in de drie deelnemende groepen van experts (hoofdstuk 2), professionals (hoofdstuk 3) en patiënten (hoofdstuk 4). Deze studies verduidelijkten welke kenmerken ‘moeilijke’ patiënten kunnen hebben. Zoals samengevat in hoofdstuk 5, de bepalende kenmerken van patiënten die als ‘moeilijk’ worden gezien zijn: (1) symptomen die niet eenvoudig tot

een logische en consistente diagnose leiden, (2) afwijkend hulpzoek- en interpersoonlijk gedrag, en (3) een veelheid aan complexe sociale problemen. In dit hoofdstuk wordt ook uitgelegd hoe deze kenmerken leiden tot het oordeel 'moeilijk'. De hiervoor genoemde drie kenmerken zijn op zichzelf onvoldoende, de causale attributie die de professional maakt over de oorzaak van de patiënt's gedrag of situatie, is doorslaggevend. Deze attributie bepaalt of de patiënt als 'moeilijk' of niet 'moeilijk' wordt gepercipieerd. Het is belangrijk om op te merken dat een volledig 'objectieve' of 'gedragmatige' beschrijving van 'moeilijke' patiënten dus onmogelijk is.

Gedurende dit project werd steeds meer duidelijk dat de 'moeilijke' patiënt geen natuurverschijnsel is, uitsluitend afhankelijk van de aanwezigheid van een aantal patiëntkenmerken. Er bleek geen diagnose, gedraging of probleem van patiënten te zijn die ervaren moeilijkheid volledig (of zelfs maar deels) verklaarde. Ervaren moeilijkheid is dus een samenspel van een aantal factoren gerelateerd aan de patiënt, de professional, de interactie, het sociaal systeem (van de patiënt) en het geestelijke gezondheidszorgsysteem (van de professional).

> *Morele oordelen en 'moeilijke' patiënten*

Het tweede belangrijke thema gedurende dit onderzoek was de morele dimensie die het bijvoeglijk naamwoord introduceerde in de ogenschijnlijk waarde vrije omgeving van de geestelijke gezondheidszorg en het daarmee samenhangende onderzoek. Zoals we hebben laten zien in hoofdstuk 5 kunnen de attributies die professionals maken over potentiële 'moeilijke' patiënten, meer neutraal (bv. neurobiologische attributie) of minder neutraal (bv. morele attributie) zijn. Los van het argument dat de term 'moeilijk' weinig precies is, kan deze dus ook worden gezien als veroordelend, stigmatiserend, negatief, en contra-effectief. Volgens verschillende critici van de term 'moeilijk' voor mensen met een psychiatrische stoornis (bv. Corrigan, 2006; Tyrer, 2008), zou het dan ook beter zijn deze niet langer te gebruiken in de geestelijke gezondheidszorg en wetenschappelijke publicaties. Hoe verleidelijk dit idee ook klinkt, suggererend dat het niet gebruiken van de term 'moeilijk' zal leiden tot het verdwijnen van 'moeilijke' patiënten, het lijkt toch wat in tegenspraak met onze bevindingen en de dagelijkse werkelijkheid in de zorg.

Gedurende dit project zijn verschillende meer patiëntvriendelijke alternatieve termen de revue gepasseerd, zoals bijvoorbeeld 'tegenoverdracht' (moeilijkheid als probleem van professionals), 'slechte therapeutische relatie' (moeilijkheid als een interactieprobleem), 'meervoudige probleemsituaties' (moeilijkheid als een – mogelijk – sociaal probleem), en 'gebrek aan effectieve behandelingen' (moeilijkheid als een probleem van de geestelijke

gezondheidszorg of wetenschap). Hoewel deze alternatieven niet onjuist, en zelfs accurate beschrijvingen zijn van elementen van het door ons onderzochte onderwerp, bieden allen een meer ‘technologisch’ alternatief voor de moreel beladen term ‘moeilijke’ patiënt. Wij zijn weliswaar voorstanders van het gebruik van patiëntvriendelijker termen zoals gebruikt in hoofdstuk 6 en 7 (‘ineffectief ziektegedrag’ en ‘ineffectief professioneel gedrag’) maar denken ook dat het belangrijk is om de morele dimensie van het vaak gebruikte ‘moeilijk’ niet te verdoezelen.

Deze morele dimensie wordt weinig erkend in de huidige geestelijke gezondheidszorg en het daaraan verwante onderzoek (Scheurich, 2002). Technische neutraliteit en objectief empirisme zijn noodzakelijk – al zijn deze uitgangspunten op zichzelf al niet waarde vrij – maar moeilijk vol te houden in de complexe context van de geestelijke gezondheidszorg. Hoewel we niet geloven dat het praten over patiënten als ‘moeilijk’ hen veel goed doet, zijn we ervan overtuigd dat de term een sterke aantrekkingskracht heeft op professionals in de dagelijkse praktijk en dat ze – belangrijker – een aantal niet-rationele elementen van de zorg aan het licht brengt. Deze niet-rationele elementen omvatten ineffectieve gedragingen door professionals die hun oorzaak vinden in o.a. onzekerheid, angst, schuld of woede. Ook omvatten ze heel andere zaken, zoals systematische bureaucratische procedures die hoge drempels opwerpen voor de deelname van patiënten aan bepaalde behandelingen. Het model dat beschreven is in hoofdstuk 5 brengt, zonder één of meer partijen de schuld te geven, deze elementen en de processen in beeld die ervoor zorgen dat het ‘moeilijke’-patiëntlabel kan ontstaan en voortbestaan in GGZ-instellingen.

Aangezien dit model zowel objectieve als subjectieve variabelen omvat, en aandacht besteedt aan zowel rationele als niet-rationele processen, wordt recht gedaan aan de morele dimensie zonder de ‘schuld’ alleen bij de patiënt te leggen. Daarom vinden we het hier wijs om de term ‘moeilijke’ patiënt in te ruilen voor de meer neutrale en complete term ‘ambivalente verhouding’ of ‘ambivalente behandelsituatie’. Het geïllustreerde model (hoofdstuk 5) en het geconstrueerde interventieprogramma (hoofdstuk 6) bieden een gestructureerde benadering voor analyse en behandeling. Het behandeldoel in deze situaties is steeds de toename van effectief gedrag door patiënten en professionals.

Implicaties voor de praktijk

Om verschillende redenen – o.a. een onduidelijke diagnose, lastig interpersoonlijk gedrag van de patiënt en een veelheid aan complexe sociale problemen – kunnen patiënten als te ingewikkeld, of te zwaar gezien worden voor een gestructureerd, diagnose-specifieke

evidence-based behandeling. Voor veel patiënten met een niet-psychotische chronische stoornis betekent dit dat ze geen of nauwelijks gestructureerde zorg ontvangen, van een professional met weinig ervaring in en kennis van effectieve behandelmethodes. Dit onderzoeksproject heeft laten zien dat het mogelijk is om een gestructureerd aanbod te ontwikkelen, dat niet diagnose-specifiek maar wel gebaseerd is op een algemeen theoretische model. Hieronder zullen we verder bespreken welke implicaties een dergelijke gestructureerde behandeling heeft, en welke professionals die zouden kunnen uitvoeren.

> *Gestructureerde behandeling of begeleiding*

Volgens de generieke benadering van Interpersoonlijke Sociaal Psychiatische Begeleiding (ISPB), krijgen de therapeutische relatie en het maken van een gezamenlijk overeengekomen agenda voor de behandeling, meer aandacht dan symptomen passend bij specifieke psychiatrische diagnoses. Vervolgens is deze procesmatige benadering aangevuld met inhoudelijke behandelelementen, ingezet ten behoeve van concrete problemen en doelen. Concrete problemen, geïdentificeerd als zorgbehoeften door middel van een valide vragenlijst, zijn daarbij eigenlijk nog minder belangrijk dan de doelen die patiënt en professional gezamenlijk overeen komen. Doelen en praktische problemen krijgen dus prioriteit boven symptomen, echter zonder de laatste over het hoofd te zien. Deze benadering vindt haar origine in een ander praktijk- en wetenschapsgebied (sociale psychiatrie) dan de diagnosespecifieke benadering. De sociaal-psychiatische praktijk heeft lang achtergelopen bij de ontwikkeling van *evidence based* methoden maar slaagt er langzamerhand beter in om de effectiviteit van deze benadering aan te tonen, bijvoorbeeld op het gebied van *problem solving* (Malauff et al., 2007), sociale steun (bv. Davidson et al., 2004), en *supported employment* (bv. Burns et al. 2007). Het ontwikkelen en evalueren van een generiek, niet diagnosespecifiek, gestructureerd interventieprogramma mag als een soortgelijke poging ter verbetering van de praktijk worden gezien.

Los van het onderscheid in verschillende behandelfasen en daaraan gerelateerde gespreksmethoden in ISPB, zouden gestructureerde programma's zoals ISPB maximaal gebruik moeten maken van het monitoren van proces en uitkomstvariabelen door middel van wetenschappelijk onderbouwde instrumenten. Dergelijke instrumenten kunnen ook in de behandeling zelf worden gebruikt, zoals we bijvoorbeeld hebben gedaan met de vragenlijsten over zorgbehoeften en de tevredenheid over het gesprekscontact. We mogen concluderen dat voor mensen die al een (niet-succesvolle) diagnosespecifieke behandeling hebben doorlopen, of voor mensen die niet passen in een dergelijke behandeling, een gestructureerde aanpak wél mogelijk is. Tegengesteld aan het geloof onder sommige professionals, is een gestructureerde aanpak die verschillende *evidence based*

instrumenten en methoden combineert, goed uit te voeren. De effectieve invoering van een dergelijke benadering in de dagelijkse praktijk vraagt echter om veel inzet en kennis van de betrokken professionals.

› *Professionals in de ambulante langdurige zorg voor mensen met ernstige psychiatrische problematiek*

We hebben eerder gesteld dat professionals in de langdurige zorg, over het algemeen, niet academisch geschoold zijn en onderdeel uitmaken van een professie die goed ontwikkelde en aangetoond effectieve behandelingen ontbeert (zie ook Kerr et al., 2007). Hoewel de meeste ambulante langdurige zorg in Nederland geboden wordt door psychiatrisch verpleegkundigen, bieden ook agogisch werkenden, maatschappelijk werkenden en anderen deze zorg.

Kijkend naar sociaal-psychiatrisch verpleegkundigen (SPV-en), de meest intensief bestudeerde professionals in dit project, zien we dat hun werk vaak wordt bekritiseerd vanwege een gebrek aan structuur, theoretische basis en aangetoonde effectiviteit (Couldwell et al., 2007). Tegelijkertijd heeft de SPV een belangrijke, zo niet de belangrijkste, rol in het bieden van sociaal-psychiatrische zorg aan mensen met een ernstige psychiatrische stoornis. Terwijl veel patiënten, verpleegkundigen, collega's van andere disciplines en managers menen dat SPV-en waardevol en noodzakelijk werk doen, is de hiervoor genoemde onvrede merkbaar in onze onderzoeksresultaten. Experts beschrijven de langdurige begeleiding door SPV-en als 'pappen en nathouden' (hoofdstuk 2). Patiënten, wanneer daarnaar gevraagd in individuele interviews, zeggen dat ze doorgaans een aardig contact met hun SPV hebben maar dat er niet veel inhoudelijks gebeurt in dat contact (hoofdstuk 4).

In de studies die SPV-en betroffen (hoofdstukken 2, 3, 4 en 7) vonden we steeds dat zij de therapeutische relatie met hun patiënt als het meest belangrijke onderdeel van hun zorg ervaren. Hierdoor lijkt deze relatie een doel op zich te worden, in plaats van een middel om (behandel)doelen te bereiken. Patiënten en niet-verpleegkundige professionals zijn, hoezeer ze de therapeutische relatie ook waarderen, echter kritisch over deze overheersing van proces (de relatie) over de inhoud (doelen maken en interventies uitvoeren). Dit gebrek aan aandacht voor de inhoud kan leiden tot langdurige, aangename contacten tussen patiënten en hun SPV-en zonder veel verbetering in het psychisch en sociaal functioneren van de patiënten. Bovendien is er een behoorlijk risico dat, wanneer de therapeutische relatie niet zo aangenaam verloopt – vaak het geval bij 'moeilijke' patiënten – de negatieve interpersoonlijke relatie de gehele behandeling gaat overheersen. Met andere woorden: als het contact niet aangenaam is en er geen inhoud is om op terug

te vallen, komen SPV-en makkelijk in de verleiding om patiënten de schuld te geven van deze ongemakkelijkheid en hen 'moeilijk' te noemen.

In dit project is een alternatief ontwikkeld voor de exclusieve aandacht voor de therapeutische relatie, en het daarmee verbonden risico op het 'moeilijk' noemen van patiënten in lastige situaties. Een theoretisch model dat de moeilijkheden tussen patiënt en professional beschrijft, werd geconstrueerd vanuit onderzoek in de dagelijkse GGZ-praktijk. Vervolgens is een interventieprogramma ontwikkeld dat zowel theoretisch als empirisch ondersteund werd. Ten slotte werden SPV-en getraind om dit programma effectief uit te voeren. De resultaten van de pilotstudie laten zien dat SPV-en wat minder 'zorgzaam' worden, en meer 'motiverend', ten einde patiënten te helpen om hun persoonlijke verantwoordelijkheid en kracht te benutten en te werken aan doelen in het leven buiten de geestelijke gezondheidszorg.

> *Implementatie*

Zowel voor SPV-en, implementatiedeskundigen, als onderzoekers is het een uitdaging om de via ISPB behaalde winst te behouden. Werken volgens een structuur, geconcentreerd blijven op het maximaliseren van de patiënt's potentieel voor eigen verantwoordelijkheid en groei, en niet verstrikt raken in langdurige collusies, zijn complexe vaardigheden voor SPV-en. Ook voor andere professionals zal het steeds moeilijk blijven om geen morele oordelen te gebruiken en patiënten niet 'moeilijk' te noemen. Hoewel ISPB strategieën bevat die helpen om zulke vaardigheden te verwerven en te behouden, o.a. door regelmatige supervisie en collegiale feedback, zijn verdere stappen in de ontwikkeling van het programma nodig. De deelnemende SPV-en hebben waardevolle feedback gegeven die de toepasbaarheid en effectiviteit van ISPB in de toekomst mogelijk nog kan vergroten. Een praktisch handboek, een standaardtraining en anderen strategieën zijn voorts nodig om verdere implementatie te faciliteren en mogelijk, op termijn, een gerandomiseerde trial met ISPB uit te voeren.

Voorts vraagt een succesvolle implementatie en voortzetting van ISPB om enkele veranderingen in de organisatie van de geestelijke gezondheidszorg. Ten eerste moet worden onderkend dat de centrale rol die SPV-en en soortgelijke professionals spelen in de zorg voor mensen met ernstige psychiatrische problematiek, hen onder behoorlijke druk zet. In veel gevallen bestaan er nauwelijks alternatieven voor sociaal-psychiatrische begeleiding hetgeen het risico op het 'dumpen' van chronische, complexe en potentieel 'moeilijke' patiënten bij SPV-en behoorlijk groot maakt. De aanwezigheid van alternatieven, in de 1e-lijns dan wel de 2e-lijns zorg, kan SPV-en helpen om hoopvol en gecommitteerd te blijven aan een gestructureerde methode zoals ISPB. Ten tweede, SPV-en

hebben mogelijk meer steun nodig van collega's en moeten derhalve beter gefaciliteerd worden om de last van hun individuele case-load te delen met anderen. Hoewel de volledige teambenadering van Assertive Community Treatment waarschijnlijk te veel van het goede is, zouden duale begeleiding (door twee SPV-en) en eenvoudiger toegang tot een psychiater kunnen helpen. Teambrede supervisie, zoals die werd geboden tijdens de pilotstudie in dit project, zou structureel moeten zijn. Ten derde moet worden opgemerkt dat veel van de processen die beschreven zijn in het verklarende model (hoofdstuk 5), zoals het al dan niet legitimeren van de ziekterol, niet alleen plaats vinden bij individuele hulpverleners maar in de geestelijke gezondheidszorg als geheel. Ondanks de indrukwekkende ontwikkelingen in de hulp aan ernstig psychotische patiënten, zoals bijvoorbeeld Assertive Community Treatment voor de meest kwetsbare mensen, zijn er nog steeds veel hoge drempels voor mensen met ernstige niet-psychotische problematiek. Bijna iedere behandelmodule vraagt om een duidelijke diagnose, enigszins aangenaam gedrag en een stabiele sociale situatie, waardoor precies de als 'moeilijk' ervaren patiënten worden uitgesloten.

Beperkingen en sterke punten

Het gebrek aan een volledig objectieve definitie of omschrijving van de 'moeilijke' patiënt kan gezien worden als een beperking van dit onderzoeksproject. Deze beperking is het meest opvallend in het licht van de huidige focus op gedragsmatige beschrijvingen van psychiatrische stoornissen. Het huidige classificatiesysteem (DSM-IV), haar voorgangers, en haar opvolger (DSM-V), zijn alle gebaseerd op de categorisering van waarneembare fenomenen. Hoewel de dominantie van dit paradigma betwist kan worden, maakt het wel duidelijk hoe problematisch het is om patiënten te selecteren voor onderzoek op basis van deels niet-waarneembare criteria. Ten eerste moet deze selectie altijd plaats vinden door de betrokken professionals, aangezien deze patiënten zonder hun 'moeilijk'-oordeel niet eens als zodanig zouden bestaan. Selectiebias is dan een serieus risico omdat ons 'objectieve' criterium over het hebben gehad van een gebrek aan overeenstemming, nog steeds erg uiteenlopend geïnterpreteerd kan worden door professionals. Ten tweede kan de geselecteerde groep zeer heterogeen zijn qua diagnose (er bestaan erg veel niet-psychotische stoornissen, al dan niet in combinatie met elkaar), qua gedrag en qua interactie (een gebrek aan overeenstemming kan veel verschillende vormen en bronnen hebben). Hoewel heterogeniteit niet per definitie problematisch is, kan ze dat wel zijn wanneer deze uitkomsten gegeneraliseerd zouden worden naar anders samengestelde groepen van mensen met niet-psychotische stoornissen. Het derde en mogelijk het meest belangrijke punt is dat de huidige definitie van de doelgroep, met een aanvullend door professionals bepaald criterium, impliceert dat 'moeilijkheid' niet objectief gemeten kan worden.

Deze derde beperking is, hoe problematisch het ook is om ‘moeilijke’ patiënten niet te kunnen herkennen aan alleen patiëntkenmerken, tegelijk een belangrijk sterk punt van dit onderzoek. Hoewel we het gebruik van het bijvoeglijk naamwoord ‘moeilijk’ gehandhaafd hebben gedurende het hele onderzoek, omdat dit het criterium was waarop mensen in de studie kwamen, heeft dit project juist aangetoond dat er veel verschillende oorzaken zijn voor het ontstaan en voortbestaan van ‘moeilijke’ patiënten. Deze oorzaken konden alleen worden gevonden dankzij verschillende onderzoeksmethoden en verschillende onderzoeksdeelnemers. Voor zover wij weten is dit het onderzoek het eerste dat ervaren moeilijkheid heeft onderzocht onder zowel experts, professionals, als patiënten. Bovendien is het in hoofdstuk 5 gepresenteerde model de eerste poging om verschillende databronnen en sociaalwetenschappelijke theorieën te integreren in één verklarend raamwerk.

Een andere beperking is dat de resultaten van de laatste pilotstudie (hoofdstuk 7) alleen voorzichtige indicatoren zijn van de effectiviteit van het programma. Het uitvoeren van een gecontroleerde trial viel buiten het doel van deze studie en was ook niet opportuun gezien het stadium van ontwikkeling van het interventieprogramma. De voorlopige effectiviteit en bruikbaarheid van dit programma garanderen echter nog niet dat morele oordelen nu niet meer voorkomen bij de gebruikers ervan, wel dat er mogelijk sneller naar gekeken wordt en dat er effectievere manieren van omgang mee zijn. Aanvullend onderzoek is nodig om de hierboven genoemde kwesties aan te pakken.

Verder onderzoek

Voorstellen voor verder onderzoek doen we op drie terreinen, aansluitend bij de hierboven besproken kwesties: (1) de objectieve beschrijving van ‘moeilijke’ patiënten, (2) de morele dimensie in complexe behandelsituaties, en (3) de implementatie en het gebruik van het interventieprogramma.

Tijdens dit project hebben we lang gezocht naar patiëntkenmerken die zowel noodzakelijke als voldoende voorwaarden zijn voor het universeel beschouwen van deze patiënten als ‘moeilijk’. We hebben dergelijke kenmerken echter niet gevonden en vonden juist dat het moeilijke patiëntschap niet alleen aan de patiënt kan worden toegeschreven. Daarom raden we aan om vervolgonderzoek te richten op de totale behandelsituatie, inclusief de kenmerken van patiënt, professional, interactie, sociaal systeem en gezondheidszorgsysteem. Hoewel onderzoek naar interactiekenmerken, de therapeutische relatie, vrij gebruikelijk is, vindt nauwelijks onderzoek plaats naar de professional en de sociale situatie van de patiënt. Ook onderzoek naar de organisatie van de geestelijke gezondheidszorg is beperkt. Hoewel sommige organisatie modellen (bv. Assertive

Community Treatment) beter lijken te werken dan andere modellen, is nog onbekend of de betere uitkomsten moeten worden toegeschreven aan organisatorische of andere factoren. Sociaalwetenschappelijk onderzoek naar de cultuur van GGZ-instellingen kan systematische verschillen in hun manier van reageren op bepaalde patiënten aan het licht brengen.

Ten aanzien van de morele dimensie, zoals geïntroduceerd door de term ‘moeilijk’, denken we dat meer kennis over de attributies die professionals maken op basis van het gedrag van patiënten, zeer nuttig is. In dit onderzoek hebben we weliswaar een grof onderscheid gemaakt tussen vier attributietypen maar deze hebben we niet in detail onderzocht, noch hebben we bekeken in welke mate professionals geneigd zijn deze attributie te maken. Voor de dagelijkse praktijk zou het bovendien erg nuttig zijn om te weten hoe deze attributies te veranderen zijn.

Ten slotte, is het erg belangrijk de pilotstudie te herhalen in een andere setting. Het design moet dan verbeterd worden door middel van meer deelnemers en een controlegroep. Voor dat dit kan plaats vinden moet het interventieprogramma worden verbeterd aan de hand van de feedback van de deelnemers aan de studie.

Conclusie

Mensen met een langdurige niet-psychotische stoornis en moeilijk gedrag kunnen een morele reactie (het oordeel ‘moeilijke’ patiënt) oproepen. We zijn erin geslaagd om de gevolgen van deze en andere reacties voor het contact tussen patiënt en professional te ontwarren. Een model, dat alle nu bekende variabelen bevat, is nuttig gebleken om complexe behandelsituaties te analyseren vanuit verschillende perspectieven. De resultaten van een interventieprogramma, ontwikkeld op basis van dit model, laten zien dat verbeteringen voor patiënten en professionals mogelijk zijn als een theoretisch raamwerk en aantoonbare effectieve interventies worden gecombineerd. Een generiek gestructureerde aanpak, zoals gebruikt in ISPB, kan nuttig zijn voor mensen met langdurige problematiek. De toepassing van programma's zoals ISPB zou een goed toekomstperspectief kunnen bieden aan de langdurige zorg voor mensen met een niet-psychotische chronische stoornis, omdat ze een brug slaan tussen het noodzakelijke gebruik van effectieve interventies (die schaars zijn voor deze groep) en de uitdagingen en zorgnoden die deze patiënten ons presenteren. Verder onderzoek naar het interventieprogramma, maar ook naar complexe behandelsituaties, is nodig.

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Over de auteur

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De basis van dit proefschrift ligt ergens op een gesloten afdeling nabij Utrecht, waar ik in 1996 als invalkracht met drie maanden ervaring in de psychiatrie, weekenddiensten deed. De afdeling bood plaats aan de ‘moeilijke’ patiënten uit de regio: jonge schizofrene mannen, ‘gepsychiatriseerde’ vrouwen, en (ex-) TBS’ers. Agressie van patiënten, jegens elkaar en personeel, maar meer nog jegens zichzelf, was er schering en inslag. Er waren nachten dat één, twee of drie van de ‘gepsychiatriseerde’ vrouwen naar de EHBO gingen en met tientallen hechtingen terugkwamen. In schril contrast daarmee hingen in de gangen foto’s van patiënten die in de Ardennen met rugzakken liepen of bij een kampvuur zaten. De afdeling organiseerde regelmatig buitenactiviteiten, en tijdens die activiteiten ging het vaak opvallend goed met de deelnemers – ook met de EHBO-gangers en andere ‘moeilijke’ patiënten.

De tweede aanleiding voor het doen van dit onderzoek komt voort uit de ambulante psychiatrie. Mijn team, gespecialiseerd in de behandeling van mensen met persoonlijkheidsstoornissen, besteedde wekelijks in de behandelbespreking veel tijd aan het opsommen van ingewikkelde gedragingen van bepaalde patiënten. Dit waren steeds dezelfde, ‘moeilijke’, patiënten en zelden kwamen we verder dan ach en wee-gemompel, vrijblijvende suggesties die meestal direct door de betrokken behandelaar van de hand werden gewezen als onmogelijk, en de constatering dat het weer niet gelukt was alle (andere) patiënten te bespreken. Graag wilde ik meer begrijpen van de interactie tussen professionals en patiënten die als moeilijk werden gezien en vooral weten wat daar – door verpleegkundigen – aan te veranderen viel.

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Curriculum Vitae

Bauke Koekkoek werd op 7 september 1973 te Amstelveen geboren. Na het afronden van het atheneum in Breda haalde hij zijn propedeuse in de sociale wetenschappen in Amsterdam. Een jaar werkte hij in de zorg en in het buitenland, om daarna de opleiding tot verpleegkundige te beginnen (HBO-V, diploma 1997). Hij werkte als verpleegkundige op afdelingen voor acute opname en in de psychiatrische thuiszorg, en volgde de opleiding tot sociaal-psychiatrisch verpleegkundige (post-HBO SPV, diploma 2000). Tijdens en na de opleiding tot Verpleegkundig Specialist GGZ (diploma 2005) werkte hij vooral met ambulante patiënten met ernstige en langdurige problematiek. Hij nam verschillende malen verlof op om elders (België, Frankrijk, Verenigde Staten, Australië) buitenactiviteiten te ondernemen met jeugdigen en volwassenen met psychiatrische en andersoortige problemen.

Eind 2005 verwierf hij een subsidie van ZonMw en begon in april 2006 met zijn promotietraject, daarnaast werkend als sociaal-psychiatrisch verpleegkundige. Tijdens dit traject volgde hij de EMGO-opleiding Epidemiologie en Biostatistiek (diploma 2010) en werd geregistreerd als Epidemioloog A. Sinds augustus 2010 is Bauke als senior wetenschappelijk onderzoeker werkzaam bij Proces, het onderzoeks- en opleidingscentrum van De Gelderse Roos/Pro Persona.

Bauke woont samen en heeft twee dochters van 5 en een zoon van 1 jaar oud.

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A neighbourhood on a narrow peninsula, surrounded by a national wildlife refuge and the Atlantic Ocean. Within miles of one of the world's most lively cities, and close – but not too close – to a large international airport. Far Rockaway, and its nearby neighbourhoods on the south-eastern fringe of New York City, have it all. Yet in spite of these impressive credentials, Far Rockaway is one the city's unsafer neighbourhoods, and large parts of the eastern peninsula now are urban wasteland. Although crime rates have plummeted throughout NYC since the mid-90s, Far Rockaway has seen a steady increase.

Dreaded and blamed by many New Yorkers for its high poverty and crime rates, Far Rockaway is looked at differently by historians and social scientists. For decades, official and unofficial city policies have resulted in a large influx of poor and deprived people into a small area with few housing options and even fewer facilities. When the state psychiatric hospitals were dismantled in the 1950s and 1960s, Far Rockaway became home to a disproportionate number of psychiatric patients, who were largely left to their own devices.

We may state that New York's 'difficult' cases were transported to these Queens' outskirts without any support – with disastrous effects on the area's social structure in the long run. The pictures printed in this book were all taken by the author during and around an A-train subway ride to Far Rockaway on October 11, 2010. Most pictures are taken on the peninsula, some in Queens.

Chapter 1:
subway over Queens Boulevard/Northern Boulevard intersection

Chapter 2:
trains at Sunnyside Yard from Honeywell St

Chapter 3:
public housing from the subway track across Jamaica Bay

Chapter 4:
public housing ('projects') along the A-line subway track

Chapter 5:
McDonalds add at Mott Avenue

Chapter 6:
shopping centre sign at Mott Avenue

Chapter 7:
abandoned car at Associated Supermarket

