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# How do patients come to be seen as 'difficult'?: A mixed-methods study in community mental health care

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ABSTRACT

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 between June 2006 and October 2009. 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. 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. These findings illustrate that the course of mental illness, or at least the course of patients' contact with mental health professionals and services, is determined by patient and professional and reinforced by the social and mental health care system. 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 (Hahn et al., 1996; Jackson & Kroenke, 1999; Koekkoek, van Meijel, & Hutschemaekers, 2006; Lin et al., 1991; Steinmetz & Tabenkin, 2001). In physical health care, no particular medical diagnosis is associated with perceived difficulty, but medically unexplained symptoms and a psychiatric label often are (Jackson & Kroenke, 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. O'Reilly, Gilliland, Steele, & Kelly, 2001; Pelet, Besson, Pecoud, & Favrat, 2005). Professionals working with these patients report more stress and burn-out (An et al., 2009; Stacey, Henderson, MacArthur, & Dohan, 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

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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 & Malterud, 2003), including those who care for chronic psychiatric patients (Bachrach, Talbott, & Meyerson, 1987) in spite of the limited suitability of the sick role concept with chronic illnesses (e.g. Freidson, 1970; Parsons, 1951).

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 & Malterud, 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 & Malterud, 2003) and has resulted in substantial interest in the phenomenon of medical uncertainty (e.g. Fox, 2000; 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 using 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" (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 states 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 (Barrett, 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, Garske, & Davis, 2000; Mead & Bower, 2000). Likewise, the general concept of illness behaviour has received substantial attention in physical health, but much less in mental health (e.g. Rief, Ihle, & Pilger, 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 experts', professionals', and patients' views of the patient–professional relationship.

## 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, undertaken between June 2006 and October 2009. The methods of these individual studies will be outlined briefly below. Ethical approval for these studies was obtained from the Institutional Review Board of the organisation the 1st author is affiliated with, Altrecht Mental Health Care, Den Dolder, The Netherlands.

### 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 or bipolar disorder according to DSM-IV criteria (APA, 1994), 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., 2007).

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, van Meijel, Schene, & Hutschemaekers, 2009).

#### *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 psychiatric nurses (CPNs) label non-psychotic chronic patients as 'difficult'. A questionnaire was designed and administered to 1946 CPNs, 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, van Meijel, Schene, & Hutschemaekers, 2010a).

#### *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., 2010b).

#### *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' 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 & van Tilburg, 2010; Koekkoek, Gunderson, Kaasenbrood, & Gutheil, 2008; Koekkoek, Spijker, Schaik, & van Schene, 2010c).

### 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

**Table 1**
Initial patient behaviours perceived as difficult.

| |
|---|
| 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. |

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 during training sessions and conferences, resulting in further refinement.

## Results

### *Use of the 'difficult'-label*

Apart from its presence in the literature (Koekkoek et al., 2006) and everyday mental health care (observed in formal and informal conversations), we found the 'difficult'-label to be heavily used throughout our studies. The following three quotes from group interviews with different mental health clinicians exemplify this:

> *With difficult patients, the initiative lies with us* [mental health professionals] *and actually we are told by the patient or bystanders or whoever, that we have to do something about it.* [psychiatrist1 in Delphi-study]

> *I think that most of these really difficult patients are stuck in, when I say it very disqualifying, some sort of 'pampering and dithering'-contacts.* [psychologist2 in Delphi-study]

> *We* [staff in specialized department] *get only difficult patients, we get those patients that other teams have broken their teeth on.* [psychiatric nurse3 in Delphi-study]

### *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* [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-

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

| | Definition of 'difficult patient' | Explanations | Consequences | Suggested strategy |
|---|---|---|---|---|
| Patients | A person with a strong need for help | - Lack of sensitivity in professional<br>- Professional pessimism | Unwilling and angry patient | Improvement professional skills |
| Professionals | A person with many complex problems, poor social function, and consistent failure to improve | - Lack of social support<br>- Professional pessimism | Demoralization | – |
| Experts | A person with multiple diagnoses or co-morbidity, and unusual help-seeking behaviour | - Lack of professional skills<br>- Lack of view on problems<br>- Lack of suitable and structured treatment<br>- Lack of organisational support | Undertreatment of patient | Improvement quality and quantity of treatments |

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. 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 participants' views of the relationship between patient and professional.

### *Integrating findings into a model*

The explanatory model presented here (Fig. 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 consists of five subsequent stages that show the process from a patient's entrance into treatment, through various stages, and finally into a vicious cycle of ineffective patient and professional behaviours.

#### *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,

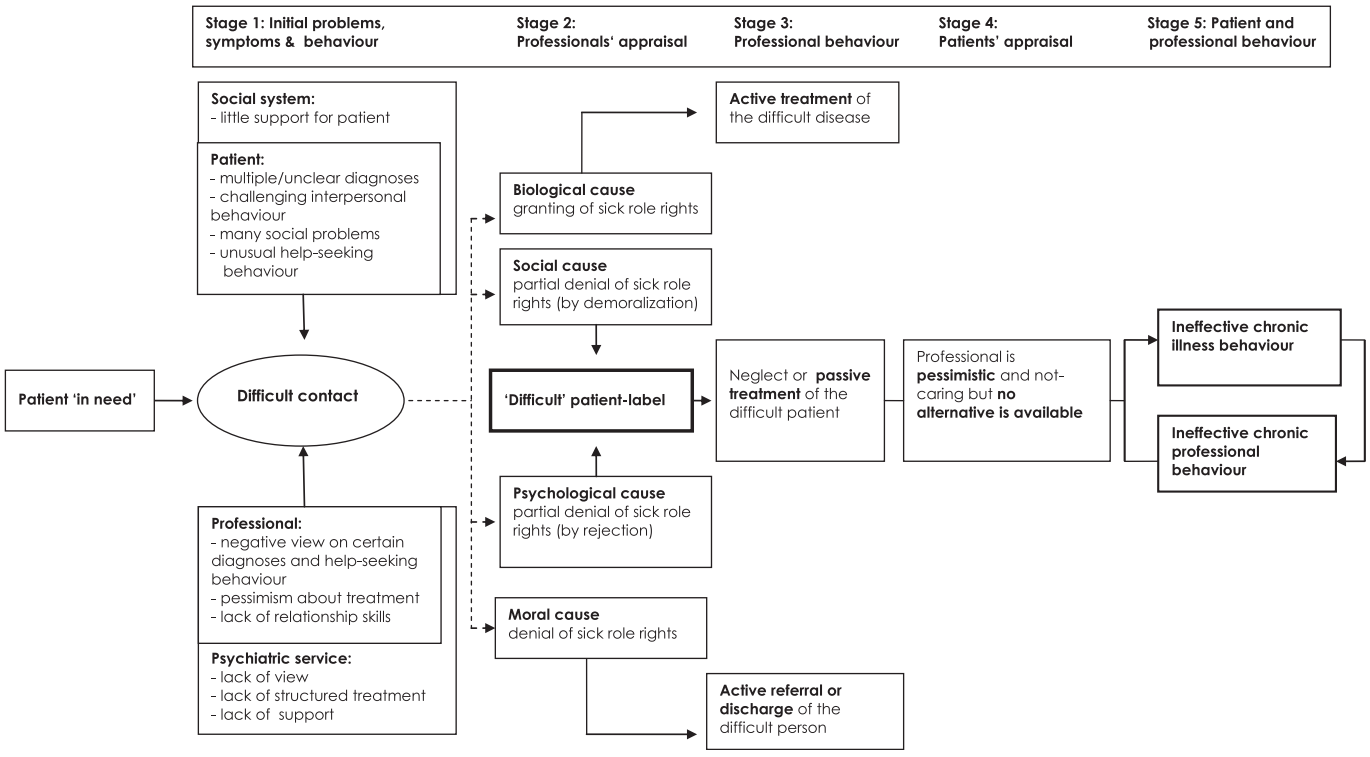


**Fig. 1.** Model of ineffective chronic illness behaviour and ineffective chronic professional behaviour.

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.

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.* [psychologist3 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…* (patient in qualitative study)

> *As far as I know these patients, they have only one support system left and that is mental health care.* [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 (Table 3), 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

**Table 3**
Ineffective behaviours by patients and professionals.

| Ineffective chronic illness behaviour | Ineffective chronic professional behaviour (either in response, or autonomous) |
|---|---|
| Claim help frantically | Deny treatment |
| Miss scheduled appointments | Ignore non-compliance |
| Call frequently between scheduled appointments | Be unreachable for the patient |
| Threat self-destructive actions | Take over all or deny any responsibility |
| Disqualify or seduce professional | Be overly kind or hostile to patient |
| Intrude in professional's privacy | Fail to set limits |
| Claim help at multiple institutions | Refer patient elsewhere |
| Conceal other treatment contacts | Argue with other professionals about patient and his/her treatment |
| Refuse to set treatment goals | Fail to set treatment goals and structure |
| Constantly bring up unsuitable themes | Be overly rigid and formalistic with patient |

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.

## 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' or ineffective chronic illness 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 Weiner, 1995 and Rhodes, 2000).

### *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 main 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 & Kirmayer, 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, Blackwell, & Winget, 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, Schwartz, & Price, 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 (Forsyth, 2007; Markham & Trower, 2003) and the lay public (e.g. Martin et al., 2000). 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, Chisholm, Burns, & Harvey, 2000; Hunter 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 & Macmillan, 1993), motivation (e.g. motivational interviewing; Miller & Rollnick, 2002), 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 (Koekkoek, van Meijel, Schene, & Hutschemaekers, 2010d).

### *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. 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, Fogarty, & Yellowlees, 1995). 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, has 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 researched 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 sick role theory and other social scientific theories, provides a better understanding of the labelling 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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