Use of Routine Outcome Monitoring data for evaluating Assertive Community Treatment

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Part I

Chapter 1 – Introduction

Preface

Vignette

Mike is 40 years old, divorced, and homeless. Over recent years he has been involved with the police several times, mostly for minor offences.

About three years ago he started to blame his mother for obstructing him in the pursuit of his life goals. He also believed that she had been spying on his 'important' projects. From that time on, he became quick to anger. Once he became so angry, threatening and pushing his mother – then 64 – that he was committed to a psychiatric hospital. Here he was diagnosed with schizophrenia and alcoholism. Unfortunately, he refused to accept any kind of treatment.

Later, Mike was referred to an outpatient program: Assertive Community Treatment (ACT). At first he wanted nothing to do with it. But after continuous offers, he finally accepted help with his housing and finances, a process that helped greatly to build a relationship based on trust. Eventually, he accepted treatment for his psychosis and alcoholism, and got back on speaking terms with his mother.

This real-life vignette reflects several key features of ACT: its patients, their difficulties in engaging with treatment, and the integrated approach to delivering ACT services. ACT helped Mike to find a safe place to stay, to organize his finances, to manage his illness, and a meaningful reconnection with his mother.

But while the example clearly shows some of the merits of ACT, these services are difficult to study empirically: Mike would have been unlikely to agree to inclusion in a research program that intended to study a treatment he had at first refused. The difficulty in determining the value of these services is highlighted by simple facts, such as the fact that patients fail to show up for research projects, even to fill in a questionnaire. Such things mean that there is a gap in our knowledge-base on these patients – especially at the start of treatment.

To overcome this research gap, gathering of empirical data on patients in contact with ACT services might be ameliorated by the addition of routinely collected outcomes data for which no informed consent is needed. In this manner outcome data can provide real-life information on outcomes, which allows us to make an adequate evaluation of the performance of mental healthcare. It is thus inspiring to learn that the collection of routine outcome data is now one of the most rapidly advancing developments within the field of mental healthcare.

Accordingly, over ten years, many mental-healthcare institutions in the Netherlands have implemented Routine Outcome Monitoring (ROM) procedures. Currently, several Dutch working groups are trying to reach a consensus on instruments for ROM procedures, and are exploring the options how to analyze these data. With regard to consensus, much has already been achieved, such as the instruments of choice – a limited set of instruments for each group of patients, such as the HoNOS, CANSAS or MANSA for patients with a severe mental illness (Mulder et al., 2010).

Although the primary goal of ROM – "to improve the quality and effectiveness of healthcare" (Slade, 2002) – still predominates, other parties beyond clinicians and patients have an interest in these data, researchers, managers and insurance companies among them. Thus, while healthcare professionals and patients may be interested in using ROM as a direct means to evaluate the outcome of treatment, managers may want to use ROM data not only to improve overall services, but also to fulfill transparency and accountability obligations towards insurance companies. Meanwhile, to empirically study the performance of mental healthcare, researchers focus on high-quality design and the use of instruments with satisfactory psychometric properties (Mulder et al., 2010).

As the proper interpretation of aggregated ROM data is thus important to this broad range of interests, it now receives a great deal of attention in the ROM working groups. By providing unique data on the long-term outcomes of psychiatric patients, ROM procedures can be used to measure the effectiveness and relevance of treatment in daily practice (Newnham & Page, 2010).

The studies described in this thesis used such data to provide practice-based evidence (Barkham & Mellor-Clark, 2003) on the ACT services for patients like Mike, who represent a group that is exceptionally difficult to engage not only in treatment, but also in research, as they require assertive outreach and are often unwilling or unable to participate in office-based treatment. We trust that our outcomes research on ACT will afford insight into real life outcomes in patients receiving ACT, and that this will lead to better decisions on mental healthcare – such as improved approaches to treatment (Trauer, 2010 b) – that will better meet the needs of these difficult-to-engage patients.

The plan of the thesis

This thesis presents data on outcomes in patients with a severe mental illness (SMI) treated in ACT-teams, and is organized into five successive parts. Part I states our underlying contention and sets out our theoretical orientation. For readability purposes, Part I starts with discussing authoritative works on Severe Mental Illness, Assertive Community Treatment, Routine Outcome Monitoring, and research paradigms, it ends by stating the aim of the thesis.

Parts II, III and IV constitute the main body of the thesis, each setting forth its findings. Part II consists of a study of the biases that may be manifest in ROM data, and their implications for outcomes research within the context of ACT. Part III consists of two studies of clinical outcome of patients in contact with ACT. Part IV presents two studies on motivation for treatment and its relation with clinical outcome.

Part V, the discussion, presents the overall findings and answers the research questions, whose relevance is tested against existing knowledge and developments in the field of mental healthcare. For this purpose, we summarize implications for treatment and service planning, and present suggestions for future research. The thesis ends with a critique of the research, whose overall strengths and weaknesses are evaluated.

Study setting

The studies were conducted at Bavo-Europoort, a public mental healthcare organization in the city of Rotterdam, the Netherlands. Bavo-Europoort is part of the Parnassia Groep, an institution for mental healthcare in the greater Rotterdam area that treats adults and elderly patients with psychiatric disorders as well as patients with traumatic brain injury. The total population in its catchment area is approximately 1,300,000. Bavo-Europoort employs a staff of some 1,200 at 23 sites (see: www.Bavo-Europoort.nl).

Treatment for adults focuses on patients with a serious and persistent psychiatric disorder and with psychosocial problems in several life domains. Inpatient and outpatient services are both provided, the latter consisting mainly of office-based community psychiatric care (Illness Management and Recovery teams) and ACT programs. From 2002 – 2011, Bavo-Europoort had seven ACT teams providing treatment for difficult-to-engage patients with a SMI, which in this context usually involved a psychotic disorder with or without a comorbid substance-abuse disorder. In 2003, ROM was introduced in all ACT teams and all available ROM data were used for the studies described in this thesis.

1.1 Severe Mental Illness

1.1.1 Severe Mental Illness

This thesis focuses on patients suffering from a Severe Mental Illness (SMI). Although this term is difficult to define, most definitions currently include criteria for diagnosis, duration and dysfunctioning (Bachrach, 1988; Kroon, Theunissen, van Bussenbach, van Raven, & Wiersma, 1998). In accordance with these expert opinions, we used a three-dimensional definition of SMI that consisted of 1) a diagnosis of a severe psychiatric disorder (mostly a psychotic disorder); 2) a history of illness or treatment for two years or more (displaying its persistence); and 3) several disabilities (Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000).

As well as their primary psychiatric DSM-IV Axis I disorder, most of these patients also suffer from complex problems such as coexisting substance-use disorders, physical symptoms or a poor medical condition, problems in organizing their daily activities, poor living conditions, few social contacts or severely disrupted relationships, financial problems and debts, and sometimes even victimization or problematic behavior leading to criminal convictions (Mulder et al., 2010). Pre-existing problems (developmental disorders) are also common.

Household of a patient treated in ACT

It should thus be clear that these patients' psychiatric illness has created great personal turmoil and emotional distress, inevitably reducing the patients' ability to function in daily life, and causing untold suffering for themselves and their families. Unfortunately, treatment outcome in these patients is usually poor (Drake & Mueser, 2000; RachBeisel, Scott, & Dixon, 1999). One factor contributing to this is a lack of motivation for treatment, as some do not seek treatment for their mental illness.

1.1.2 Motivation for treatment

Motivation for treatment is often described as "the probability that a person will enter into, continue, and adhere to a specific change strategy" (Miller & Rollnick, 1991). While it is obvious that motivation for treatment is necessary for a patient to benefit from treatment, (Rüsch & Corrigan, 2002) things are not necessarily so simple, as problems with motivation for treatment are not always synonymous with resistance to change or simply acceptance of treatment. It turns out that what we perceive as motivation for treatment actually is a rather ambiguous concept. And the concept of motivation for treatment is often defined as some sort of treatment related behavior, but it frequently is unclear to what specific behavior motivation for treatment refers (Drieschner, Lammers, & van der Staak, 2004).

Despite the fact that motivation for treatment mostly relies on internal factors (Miller, 1999) such as distress, outcome expectancy or problem recognition it is important to emphasize that it is not just a patient characteristic or attribute, rather it can be conceived as a state of being within an interpersonal context, implicating that therapist attitudes (e.g. friendly, emphatic etc.), external pressure and social support greatly influences a patients motivation for treatment (Miller, 1985).

> *"The concept of sufficient motivation and "really trying" quickly reduce to the notion of will power, and the client is left with moral culpability for treatment failure." (Miller, 1985)*

There may be several inter- and intrapersonal reasons contributing to lack of motivation for treatment: The first is avoidance of stigmatizing behaviors, which can be influenced by personality traits that affect the need for acceptance (agreeableness) (Lecomte, et al., 2008). In such cases, patients may be aware of their problems, but seek solutions outside psychiatry because they feel that contact with psychiatric services is embarrassing.

The second reason is an insecure attachment style (Lecomte et al., 2008) due to a history of childhood trauma (Mueser, Rosenberg, Godman, & Trumbetta, 2002). This could mean that a patient does not want the involvement of others, as previous traumatic experiences have led them to mistrust other people.

The third reason lies in earlier or anticipated negative treatment experiences, such as court ordered commitment, bothersome side effects of medication or other distressing experiences in treatment (e.g. drug withdrawal or exposure to traumatic memories).

Fourthly, what potentially explains poor motivation for treatment, is a patient's demoralizing belief that his or her problems are beyond help or that therapy will not provide relief and/or that other strategies may be more promising (Drieschner et al., 2004).

Finally, (perceived) problems with motivation for treatment or non-adherence with treatment may be underlain by impairments such as deficits in cognition (e.g. working memory or concentration) (Silverstein, 2010); illness insight; anhedonia or avolition (Tattan & Creed, 2001); or recovery style (sealing over) (Tait, Birchwood, & Trower, 2009). Impairments such as cognitive problems may thus mean that patients forget appointments because they are paying too much attention to internal stimuli or feel that there is no need for psychiatric treatment as there is no or little problem recognition.

These explanations for problems with motivation for treatment (e.g. entering into or continuing treatment) can be divided roughly into two types of reason: those reflecting unwillingness and those that reflect intrinsic impairments and disabilities (Staring, Mulder, van der Gaag, Selten, & Hengeveld, 2006). Besides this, it is also worth mentioning that situational factors may also be a crucial factor for not entering into or continuing treatment (Drieschner et al., 2004), as co-payment or public transport tickets are not always financially feasible, therefore patients may decide that treatment is not an option at this moment or perceive it as being too expensive. Other circumstances such as having a full-time job can make the use of health care during office hours quite difficult, but also being a single parent of young children may add to the feeling that treatment takes too much of their time.

1.1.3 Evidence-based practices for patients with a SMI

During the last decades, psychiatric services have undergone considerable development, and it is now possible to claim that there are treatments for most mental illnesses whose efficacy as well as effectiveness has been proven (Lehman, Goldman, Dixon, & Churchil, 2004). So despite these patients' severe and persistent problems, there is hope that their disabling symptoms can be overcome, and that they can escape the invalidating environments that so trouble and impair them. For, given the provision of proper pharmacologic and ongoing psychosocial interventions, most patients can be helped and treated (Drake et al., 2000). Such interventions may be especially effective if they target a patient's current and most prominent needs (Drake et al., 2000).

Several evidence-based practices (EBPs) in treatment of this complex patient group exist: 1) Assertive Community Treatment (ACT) (Marshall & Lockwood, 1998; Marshall & Lockwood, 2000); 2) Illness Management Recovery (IMR) (Mueser et al., 2002); Both programs include psycho education, learning skills to take medication effectively/ behavioral tailoring, coping skills training, and relapse prevention; 3) Cognitive behavioral therapy (Dixon et al., 2009); 4) Family Interventions (Pilling et al., 2002); 5) Individual Placement and Support (IPS) (Bond, Drake, & Becker, 2012); 6) Token economy interventions (Dixon et al., 2009); 7) Integrated Dual Disorder treatment (IDDT) (Brunette & Mueser, 2006; Drake &

Mueser, 2000); 8) Motivational Interviewing (Manthey, Blajeski, & Monroe-DeVita, 2012); 9) Cognitive remediation (McGurk, Twamley, McHugo, & Mueser, 2007); 10) and interventions for weight management (Dixon et al., 2009). Although this list of interventions is not complete, these interventions may be successful in helping patients with complex problems, particularly when they are implemented properly (McHugo, Drake, Teague, & Xie, 1999). However, we should acknowledge that while these interventions can be helpful, they are no panacea, as the introduction of guidelines, or new treatments and interventions for patients with SMI has not prevented high levels of disability (Hunter, Cameron, & Norrie, 2009) and social exclusion (Huxley & Thornicroft, 2003).

As these interventions have been demonstrated to be effective, it is surprising that little is known about the extent to which they are actually implemented and used in community mental healthcare (Lehman et al., 2004; McHugo et al., 2007; Puschner et al., 2010; Schoenwald & Hoagwood, 2001; Wells, Miranda, Bruce, Alegria, & Wallerstein, 2004) – and thus about their bearing on outcome. In the public mental health sector, this has generated an increasing demand for transparency and accountability. Therefore a key empirical question always remains whether patients who are in contact with mental health services actually get better and achieve significant health gains (Burgess, Pirkis, & Coombs, 2006).

1.2 Assertive Community Treatment (ACT) and Flexible-ACT (F-ACT)

1.2.1 Assertive Community Treatment (ACT)

Assertive Community Treatment (ACT) is an EBP consisting of an integrated, rehabilitation oriented, community-based service-delivery model for patients suffering from a SMI (Dixon, 2000). The ACT approach is greatly influenced by the work of Stein and Test (1980), who believed that it is in the community, not in the hospital, that patients need help.

> *"Finally, we believe that until we are able to prevent or cure chronic psychiatric disease we should change our treatment strategy from preparing patients for community life to maintaining patients in community life."*
>
> *(Stein & Test, 1980)*

ACT services are provided for those in need of ongoing mental healthcare and an assertive outreach approach (Wright et al., 2003). According to van Veldhuizen (2007), the ACT target group comprises about 20% of all SMI patients, a proportion that matches the proportion of patients treated in ACT teams (700-800 patients) and standard care (3200 patients) by Bavo-Europoort. As most patients in need of ACT are unwilling or unable to participate in standard community care, there is considerable emphasis on out-of-office interventions and home visits, not least because ACT also focuses on keeping these patients in contact with services (Sytema, Wunderink, Bloemers, Roorda, & Wiersma, 2007). However, when patients in ACT teams constitute a danger to themselves or others and are not motivated for treatment, clinicians can start a procedure for them to be committed to a psychiatric hospital.

Besides its key feature – assertive outreach – the delivery of ACT comprises several basic principles that can be characterized as time-unlimited and as a complete and customized approach to service delivery. More specifically, this means that ACT services provide not only pharmacotherapy, psycho-education, coping-skills training, crisis-intervention, and substance-abuse treatment; but that they also help organize proper housing, finances, and day-to-day problems in life – and sometimes family or occupational therapy (Dixon, 2000; Philips et al., 2001).

Bond, Drake, Mueser and Latimer (2001) described several critical components for ACT to be effective, including multidisciplinary staffing, shared caseloads, integrated services, low client-staff ratios, more than 75% of contacts in the community, frequent patient contact, assertive outreach, focus on symptom management, day-to-day problems in life, ready access in times of crisis (24/7) and time-unlimited services.

Since then, ACT has become one of the most investigated treatment models (Bond et al., 2001). The Cochrane Review (Marshall & Lockwood, 1998; Marshall & Lockwood, 2000) found that it was effective in keeping patients in contact with services, reducing the length of hospitalization, and improving clinical and social outcome.

The most authoritative studies to show superior results were performed some time ago in the US, and compared ACT to standard care. However, their results were not replicated in more recent European studies, possibly due to differences in the standards of community care in the US and in the European countries that had already implemented certain aspects of ACT (Burns, Fioretti, Halloway, Malm, & Rossler, 2001; Fiander, Burns, McHugo, Drake, 2003), or due to differences in model fidelity (McHugo et al., 1999; van Vught et al., 2010).

1.2.2 Recent developments: ACT now turning into F-ACT

Recently a Dutch alternative for ACT, Flexible-Assertive Community Treatment (F-ACT), has become increasingly popular in the Netherlands as a service-delivery model for patients with SMI (van Veldhuizen, 2007). In our study setting ACT programs are currently transitioning into F-ACT. F-ACT involves regular office-based case-management teams who, when necessary, can intensify their treatment on the basis of the principles of ACT (van Veldhuizen, Bähler, Polhuis, & van Os, 2008).

The appeal of F-ACT may lie in the flexibility it offers with regard to matching the intensity of services to current patient needs (Bond & Drake, 2007). This means that F-ACT delivers two types of care: 1) individual case management for patients with a SMI who are relatively stable, and 2) shared case management and assertive outreach (i.e., ACT) for patients with a SMI who are at risk of relapse and hospital readmission (van Veldhuizen, 2007).

An essential aspect of F-ACT is its flexibility in delivering ACT or case-management. Van Veldhuizen (2007) regards patients with a SMI as a relatively homogenous group in which there are considerable overlaps between patients treated in ACT and those under individual case-management.

Due both to this overlap between the two patient groups and to their changing needs, there is a considerable need for a service model that facilitates the continuity of care (Drukker et al, 2008; van Veldhuizen, 2007) and provides care economically (through stepped care: balancing between over- and under-treatment). This explains why investments in F-ACT teams are increasing in the Netherlands, even though F-ACT has not been shown to be more effective than other individual types of outpatient care (Drukker et al., 2008).

While F-ACT is described as a rehabilitation-oriented service delivery model (van Veldhuizen, 2007), Bond and Drake (2007) express their concerns that F-ACT case management may simply lead to brief contacts for patients who are not in crisis. Although van Weeghel (2008) attempted in the F-ACT handbook to specify critical EBPs that should be included in the F-ACT model (e.g. IMR, family interventions, IDDT and IPS).

Within the context of this thesis, however, we studied patients in ACT teams, as the transformation from ACT to F-ACT took place after the ROM data for this thesis had been collected.

1.3 Routine Outcome Monitoring (ROM)

1.3.1 Routine Outcome Monitoring in clinical practice

The understanding that clinicians should follow up patients to assess the results of their treatment was first proposed a century ago by Ernest Codman in his end-result idea (1924). However, at that time, the proposal received little approval (Swensen & Cortese, 2008).

> *"In the first place, what is the end-result idea? It is that every hospital should trace each patient with the object of ascertaining whether the maximum benefit has been obtained and to find out if not, why not."*
> *(Codman, 1924; Codman, 2009)*

It was after publications by Donabedian (1988) on the assessment of the quality of care and by Ellwood (1988) on outcomes management that measuring health outcomes gained momentum.

> *"There was a time, not too long ago, when this question could not have been asked. The quality of care was considered to be something of a mystery: real capable of being perceived and appreciated, but not subject to measurement."*
> *(Donabedian, 1988)*

> *"The problem is our inability to measure and understand the effects of the choices of patients, payers, and physicians on the patients aspirations for a better quality of life. The result is that we uninformed patients, skeptical payers, frustrated physicians and besieged health care executives"*
> *(Ellwood, 1988)*

Today, monitoring outcome – the routine collection of clinically relevant outcome data on patients in everyday clinical practice (de Beurs et al., 2011; Slade, 2002) – is considered important, and is increasingly becoming part of everyday clinical practice (Slade et al., 2006), mainly due to its aim of improving the effectiveness and quality of care (Harrison & Eaton, 1999; Slade, 2002).

ROM assessments quantify and record the situation of a patient at a certain point in treatment. By using repeated assessments per individual patient, the clinician can determine empirically whether the use of services brought the patient any benefit (de Beurs et al., 2011; Trauer, 2010 a). However, as service use may have preceded beneficial change but not have caused it (Trauer, 2010 a), problems of attribution remain an issue (Lakeman, 2004).

Despite this attributional problem, the process of treatment evaluation provides an opportunity to prevent potential treatment failures, as early response to treatment – or the lack of it – can be detected (Lambert, 2010). This makes it possible to detect patients who fail to progress or respond as expected (Newnham & Page, 2010). This is particularly important, as early response predicts treatment outcome (Howard, Moras, Brill, Martinovich, & Lutz, 1996), and outcomes may be improved by informing the therapist whether or not the patient is on track (Azocar et al., 2007; Lambert, 2007; Reese, Norsworthy, & Rowlands, 2009). However, it should be noted that these favorable effects of feedback were found in studies in relatively young patients whose prognosis was good, and who were assessed on an ongoing basis, not intermittently (Lambert, 2010).

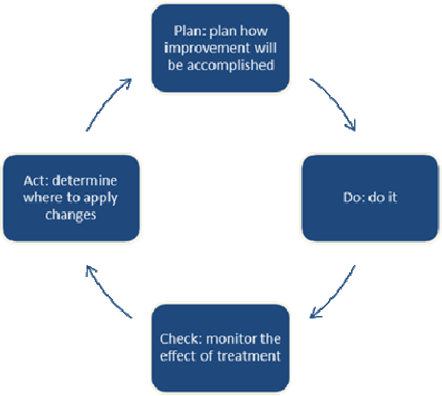
A ROM procedure in which assessments were made intermittently (e.g. each year or more frequently) maybe useful nonetheless. Although, we must admit that there is no evidence to suggest that an intermittent outcome procedure improved treatment effectiveness in patients with a SMI. Still we feel it remains promising, as it allows treatment progress to be evaluated, and is helpful in the development of individual care plans. This delivers valuable information for the treatment planning of patients with a SMI, who are often characterized by a combination of serious problems, such as a coexisting substance-use disorder, physical problems, or problems with daily activities, housing or contacts (Drukker et al., 2010). This cocktail of complex problems adds to the complexity of delivering effective psychosocial interventions. In this context, care is optimal care if the interventions target changing needs and various degrees of motivation (Essock, Drake, Frank, & McGuire, 2003).

All-in-all, if a ROM procedure includes the collection of structured and standardized clinical relevant information, it provides an accurate quantitative profile at a given period of individual patients' needs and psychiatric problems, and also of their motivation for treatment, their quality of life, and their satisfaction with services. This profile can help the clinician to create or adjust a treatment plan that represents the perspectives of patient and clinician, and that also targets the patient's current needs (Drukker et al., 2010). At the same time, we should underline that there is no (inter)national consensus on how often outcomes measures should be administered. Based on pragmatic feasibility criteria a minimum of once a year for SMI patients is proposed in the Netherlands (Stuurgroep ROM ggz, 2011). As a consequence it is left up to the clinician to decide whether or not the patient should be assessed more frequently than the minimum of once a year (prior to the treatment plan evaluation).

Despite its clinical relevance, (mandatory) outcome measurement has not been equally popular among all clinicians (Gillbody, House, & Sheldon, 2002). This may be because they feel that it does not quite capture the individual patient (Lakeman, 2004), that it takes too much time and there is no benefit in filling in what you already know, or that it is both too non-specific and too insensitive to be truly useful (Davies, 2006). In this context, Lakeman (2004) describes outcome measurement using the Health of the Nation Outcome Scales (HoNOS) as "an exercise akin to asking someone to describe a Picasso in 12 words or less". And of course it is only proper to acknowledge that the quality of a ROM procedure is only as good as the combination of the instruments that are used (Lambert, 2010).

1.3.2 Why use aggregated ROM data?

Aggregating individual outcome data may support resource allocation and service development (Meehan, McCombes, Hatzipetrou, & Catchpool, 2006), as well as helping to develop a case-mix classification system in which outcome data contributes as a predictive factor for costs of episodes of care (Eagar et al., 2004). In this manner, outcome measurement could meet the demands for accountability, which, despite its various claims and promises, has not yet taken place (Trauer, 2010 a). While understanding its attributional problems, experts still believe that ROM has the capacity to achieve best quality of care by providing information on overall treatment progress and the provision of mental healthcare for a defined regional population (Slade, 2010 b). This will make it possible to make informed choices for modifying the mental-health infrastructure (Drukker et al., 2010). In both contexts – individual and aggregated – ROM can be used for quality improvement by monitoring the performance of the health services as part of a simple and repetitive "plan, do, check and act" cycle (PDCA cycle) (Durman, Lucking, & Robertson, 2008).



ROM as part of a plan, do, check and act cycle

Furthermore aggregating outcome data may also create opportunities to compare performances of local healthcare programs. As local comparisons may set higher standards and attainable goals for treatment progress, the organizations in question will then be able to optimize treatment by modifying their service delivery. Therefore a regional benchmark can play a relevant part in this PDCA process (Axford et al., 2004), ensuring that the therapy is both effective and efficient (Enderby, Hughes, John, & Petheram, 2003).

However building a valid benchmark may not be so easy to achieve, because differences between healthcare programs in patient characteristics may be a potential source of confounding (van Os et al., 2012). Also we must be sure that the samples consist of sufficient assessments to be representative of the target population. Therefore, despite its appeal serious concerns have nonetheless been raised about whether the implementation of ROM procedures is the holy grail of quality improvement (Liptzin, 2009). In addition to the above concerns there may be other potential problems with outcome-driven benchmarks such as the risk of overlooking a group of patients in whom poor outcome does not mean poor treatment – one example being patients suffering from chronic conditions, of which the maintenance of a “stabilized” health status is a valid therapeutic goal (Trauer, 2010 b). In such cases, where follow-up assessments show little measurable change, it may be difficult to distinguish between effective and ineffective services (Mckay & MacDonald, 2010), “before and after” outcome comparisons being less appropriate for measuring the effects of psychiatric services (Trauer, 2010 b) than “with care” and “without care” ones (Trauer, 2010 b). Although it is clearly understood that it is ethically unrealistic to make a valid comparison of “with care” and “without care”, the lack of such knowledge makes it very difficult to interpret ROM data properly. An outcome-driven benchmark for patients with chronic conditions may thus be flawed, and may even create incentives to treat patients with a relatively good prognosis (Blais, Frank, Nierenberg, & Rauch, 2009). It would also neglect the quality of the services delivered, i.e., the application of best practices of care (Weisman, Grason, & Strobino, 2001), which is presumably at least as important as outcome in this context, if not more important.

1.3.3 ROM data and research

When outcome data are used for research purposes, they provide real-life information on outcomes during the course of a patient’s treatment. In this context, they can be used to empirically study the effectiveness of mental health services (Harrison & Eaton, 1999). This kind of research can be characterized as both naturalistic and observational, as it studies effectiveness using data from an existing database (ROM records) that lacks randomization and the experimental features linked to the treatment (Stroup et al., 2000). In consequence, this kind of research does not assess efficacy, as it does not measure whether the intervention has the capacity to achieve a result, but does measure effectiveness, i.e., whether the treatment works in real life under circumstances that are sometimes far from ideal (Haynes, 1999). However, it also means that there are serious methodological limitations: as strong assertions on attribution cannot be made, interpretation is very difficult. But despite its inherent design flaws, it does answer questions, such as those with respect to whether the health of patients in contact with mental health services improves significantly (Burgess et al., 2006). And to keep up with the advances and changing circumstances in contemporary mental health care, it is valuable to have an indication of what has been achieved in daily practice.

Observational research is considered appropriate under conditions where experimental research has serious drawbacks or is simply unrealistic (Rosenbaum, 2005), either due to uncooperativeness, huge dropout proportions, or complex problems, which are often the very reason for excluding patients in research protocols. To provide information on real-life settings and patients with complex problems, it is therefore clear that an observational study design has certain advantages, even though its design departs from the gold standard for research designs, which is the randomized controlled trial (RCT) (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Because RCTs have higher internal validity than observational studies (Cartwright, 2007), and because they allow dissimilarity in outcomes to be related to differences in treatment, they are seen as the most reliable method of research (Evans, 2003).

The type of evidence they provide – and particularly the meta-analysis of this type of data – are therefore dominant within the evidence-based practice (EBP) paradigm (for example the Cochrane review on ACT) (Cooper, 2003). This paradigm promotes practices that have proved to be better than other or no intervention (Essock et al., 2003). By supporting informed decisions on treatment, EBPs provide guidelines for clinical practice (Dassori, Chiles, & Swenson-Britt, 2000).

Is it is clear, then, the knowledge on which we base our treatments is based on evidence gathered in research and, it is this evidence that depends on scientific premises. So, to be able to understand our knowledge on treatments we must take into account the consequences of these premises. Therefore it is interesting to note that there is a vast amount of literature on the limitations of the RCT design (Hodgson, Bushe, & Hunter, 2007), which acknowledges that RCTs cannot address all relevant questions in healthcare (von Elm et al., 2007), especially with regard to SMI patients. In this context, long-term outcomes provide more accurate and clinical relevant information than short-term ones. Gathering evidence on long-term outcome requires long-term studies and because RCTs are much more expensive than observational studies, it can be financially difficult to complete one with long-term follow-up (Walwyn & Wessely, 2005).

Another important drawback of RCTs is their rigorous methodology, which is complicated when applied to SMI patients. When patients are excluded on a rather restrictive criterion, i.e., when selection criteria are conservative (Gilbody, Wahlbeck, & Adams, 2002), large numbers of patients suffering from SMI are excluded from an RCT, thereby compromising the extent to which the results can be generalized to the entire patient population (Walwyn & Wessely, 2005). Similarly, when experimental designs have impacted the implementation of a particular service to a level that does not necessarily correspond to the routine service delivered in clinical practice, the external validity of an RCT can be seriously compromised (Summerfelt & Meltzer, 1998) – a situation that is exacerbated when the quality of the services in the control condition has been somewhat neglected. So it can be argued that the notion of the hierarchy of research designs, which is so popular nowadays serves to conceal the reality, i.e. that the choice of research designs depends on the type of knowledge we seek (Krumholz, 2009) and potentially functions to disguise what we see in daily practice.

> *"The popular belief that only randomized, controlled trials produce trustworthy results and that all observational studies are misleading does a disservice to patient care, clinical investigation, and the education of health care professionals." (Concato, Shah, & Horwitz, 2000)*

Thus, despite the attractive internal validity of RCTs, extra evidence may be needed on external validity (Rothwell, 2005). This is in line with the expert opinion of Barkham and Mellor-Clark (2003), who conclude that no single research paradigm can deliver research that is both rigorous and relevant. It is therefore important to stress that observational study designs have strong external validity, as they closely represent "real life", meaning that their results can be generalized to the patient population, local or otherwise (Essock et al., 2003). To ensure that this is done properly, von Elm et al. (2007) provided guidelines for reporting observational studies (STROBE), and emphasizes that patient selection, exposure, outcomes used, potential confounders, biases and assessment methods should all be described in detail. Ultimately, this prevents observational data from being no more than projection material.

A persuasive example of the differences between RCTs and observational studies can be found by consulting two Dutch studies on ACT. Whereas an RCT in the north-eastern of the Netherlands with a follow-up of 1 - 2 years (Sytema et al., 2007) showed 0% drop-out in ACT, naturalistic data on ACT in the city of Rotterdam (south-west Netherlands) showed that 22% of patients left care after 1 year and another 9% after 2 years (Kortrijk & Mulder, 2011). We found that a significant proportion of these patients had not been referred to other services (Mulder & Kortrijk, 2012). These discrepant results demonstrate that the research population may be somewhat different from real-life examples found in observational research. In turn, this means that knowledge derived from RCTs is not the only point of reference from which one should navigate, and that the gap between the two paradigms demonstrates the need to integrate evidence-based practices and practice-based evidence (Page & Stritzke, 2006). This would allow us to examine the relationship between efficacy and effectiveness (Swartz, Swanson, & Hannon, 2004). While, admittedly, this turns out to be not so easy to achieve (Slade, 2010 b), it is nonetheless highly relevant.

Despite their differences, both study designs – when used in the study of the performance of healthcare – also have certain similarities. Usually, for instance, evidence found in RCTs and observational studies both reflects local evidence. Meaning that differences between study outcomes may also be due to different healthcare infrastructures

(Cooper, 2003), this may (partly) explain the differences in outcomes between the RCTs performed in Europe and the US on the efficacy of ACT (Burns et al., 2001; Fiander et al., 2003) – a major issue that needs to be considered, as it makes the interpretations of effects very difficult.

A complicating factor for patients with a SMI is the difficulty in determining what has been delivered, as psychosocial interventions tend to co-occur. As these interventions usually comprise pharmacotherapy, psychotherapy and/or coaching, it is hard to unravel their working ingredients (Trauer, 2010 a). As well as these integrated services, patients with a SMI often receive other forms of support, mostly from outside mental healthcare (Essock et al., 2003), that are thus strongly dependent on a given city's priorities and policies.

When all things are considered, we feel that, despite important methodological limitations, ROM data should be used to enrich the knowledge derived from RCTs. Then it would be possible to provide EBPs with more accurate data from the real world (Vandenberghe, 2008).

1.3.4 Routine Outcome Monitoring in this thesis

In agreement with expert opinions derived from the Dutch national remission working group, most instruments selected for patients with a SMI in our ROM procedure are short, valid, reliable, simple to use, sensitive to change, and, as well as assessing several relevant domains (Salvador-Carulla, 1999), take both the patient's and clinicians' perspectives into account (Mulder, et al., 2010). The ROM assessment includes clinician-rated instruments and self-reports on important outcome domains, including quality of life, clinical symptoms, psychosocial functioning (Juckel & Morosini, 2008), needs for care, satisfaction, and general health status (Salvador-Carulla, 1999).

The instruments used in the ROM assessments in ACT teams in Rotterdam included the Health of the Nation Outcome Scale (HoNOS; Mulder et al., 2004; Wing et al., 1998), the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS; Slade, Beck, Bindman, Thornicroft, & Wright, 1999), the Positive and Negative Syndrome Scale (PANSS; Kay, Fiszbein, Opler, 1987; Kay Opler, Lindenmayer, 1989), remission criteria items (Andreasen et al., 2005), Global Assessment of Functioning (GAF-S (symptoms) and GAF-D (disabilities); Pedersen, Hagtvedt, & Karterud, 2007), quality of life (QoL; Drukker et al., 2010, MANSA; Priebe, Huxley, Knight, & Evans, 1999), and a scale for assessing motivation for treatment (Mulder, Koopmans, & Lyons, 2005) and for assessing satisfaction with services (van Os et al., 2001). Further, data were collected on DSM IV diagnosis and several socio-demographic variables such as: gender, age, age at first contact with mental healthcare, age at first psychotic symptoms, living conditions, country of birth, education, legal status and the use of medication.

ROM data were collected by independent raters (most of them psychologists), preferably on the basis of personal interviews. Additional information was collected from patient files, electronic and paper based records. In some cases a personal interview with the patient appeared to be impossible. Instead raters then tried to organize an interview with the clinician to fill in the clinician-rated scales.

A ROM procedure using independent raters has potential benefits over the alternative (whereby clinicians rate their patients), in that (a) the clinicians are involved in the patients' treatment, which may make them biased. (b) The use of independent raters may also positively affect the reliability of the data, since they usually have more experience and training in ROM instruments. (c) The number of missing ROM data may also be lower, since the number of ROM records is higher in Bavo-Europoort under the condition of independent raters compared to the situation were clinicians rate their own patients. This favorable outcome may have occurred under the circumstances that independent raters gave ROM more priority. Despite these benefits we also identified disadvantages inherent to the use of independent raters, in that (a) more time may be needed to assess the patient, (b) some patients may be more hesitant to discuss personal information with someone they are not familiar with and (c) the ROM data may not be used by the clinician to evaluate the treatment plan (Mulder, et al., 2010). It is not known which of the two procedures is more expensive, however, it appears that there may be a trade-off between both procedures (clinical utility versus a higher number of assessments and/or more reliable assessments).

The Bavo-Europoort ACT teams administered ROM instruments once or twice annually: twice annually from February 2003 to January 2010, and once from then on. This decision was made to make sure that ROM was capable of being done for all patients in contact with Bavo-Europoort, not just those in contact with the outreaching programs. In an effort to enhance the clinical utility ROM assessments were planned to occur annually in advance of the evaluation of the treatment plan. The ROM assessments were available to the clinicians in their electronic patient files, so they could use all outcome data in their discussions of treatment progress with the patient. In these computerized records we presented the scores on the individual items and total scores of each ROM instrument, provided a graphical display of the scores over time, also including a legend to interpret scores properly (see appendix). Clinicians were also trained in the interpretation and use of the outcome scales.

1.4 Aims of the thesis

This thesis addresses three aims related to the issues specified above (part I), for which we used ROM data on a group of patients treated in ACT teams.

(1) The first aim involved the methodological issue of biases in observational research (part II). To understand this more comprehensively, we investigated: 1a) whether there were selection biases in our ROM dataset, and 1b) whether any potential biases may impact estimates of the effectiveness of ACT services.

(2) In the public mental health sector for patients with a SMI treatment outcome research is needed. Among other reasons we feel this is important because a) there is only a limited knowledge base on the actual implementation and use of interventions in clinical practice (Lehman et al., 2004; McHugo et al., 2007; Puschner et al., 2010; Schoenwald & Hoagwood, 2001; Wells et al., 2004), b) most of the relevant research on ACT was performed some time ago in the US (Burns et al., 2001; Fiander et al., 2003), and, c) new developments in treatment approaches (better and/or cheaper) are always under way. As a result, a key empirical question remains: whether patients in contact with public mental health services get better and achieve (more) health gains (Burgess et al., 2006). As our second research question therefore focused on outcomes of patients in contact with ACT (part III), we wished to determine 2a) the clinical outcomes of patients receiving ACT, 2b) the clinical outcomes of patients who had been involuntarily admitted, and 2c) which patients treated in ACT had a poor or good outcome.

(3) As problems with motivation are one of the main inclusion criteria for ACT, we wished to elaborate on this issue (part IV) by determining 3a) the extent to which problems with motivation for treatment are manifest in patients in contact with ACT services, 3b) whether patients who are not motivated for treatment at the start of ACT become motivated for treatment during ACT, but also for those patients who were involuntarily admitted during their ACT and, 3c) whether problems with motivation for treatment are related to clinical outcomes.

Part II

Chapter 2 - Outcome measurement

Duration of Assertive Community Treatment and the interpretation of routine outcome data

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Abstract

Objective: Statistical inferences based on routine outcome monitoring data are susceptible to biases. Because this process may be influenced by differences in attrition and treatment duration, we wished to gain insight into the relationship between treatment duration and clinical outcome.

Method: We enrolled 569 Assertive Community Treatment team patients. As part of a six-monthly routine outcome-monitoring (ROM) procedure, we used the GAF scale, the HoNOS, and a scale to assess their treatment motivation and satisfaction with services. Duration of ACT showed that treatment duration was short for 292 patients (≤ 3 ROM assessments; 11.6 (SD=6.1) months), medium for 191 (4-6 ROM assessments; 26.9 (SD=7.3) months), and long for 86 (≥ 7 ROM assessments; 44.06 (SD=7.1) months). Chi-square and ANOVA were used to compare patient characteristics and baseline values across different treatment-duration groups, and structural equation modeling to unravel interdependencies between the baseline and outcome variables.

Results: More patients receiving long-term Assertive Community Treatment were diagnosed with a psychotic disorder and/or substance abuse than those whose treatment was shorter. Patients whose treatment lasted longer had worse baseline GAF and HoNOS scores than those whose treatment was shorter. Structural equation modeling showed that the interdependencies between determinants and outcome variables (concerning the relationships between both identical and nonidentical variables over time) were different for each of the treatment-duration categories.

Conclusions: Patients in Assertive Community Treatment teams with different treatment durations constitute distinguishable groups with different outcomes. This should be taken into account when using outcome data for benchmarking purposes.

Introduction

Routine Outcome Monitoring (ROM) consists of evaluating psychiatric treatment by repeatedly assessing patient-level outcomes. Its primary goal is to improve efficacy and quality of care (Slade, 2002); one secondary goal is to empirically study mental health outcomes to supplement findings of randomized controlled trials (Holloway, 2002), and thus to bridge the gap between the research world and the real world (Harrison & Eaton, 1999). Although ROM is being widely implemented, several important problems are involved in basing valid statistical inferences on ROM data (Gilbody, House, & Sheldon, 2002; Young, Grusky, Jordan, & Belin, 2000).These include reporter bias, insufficient characterization of interventions, and the impact of potential confounding variables, such as treatment duration.

Differences in treatment duration may be influenced by several factors, such as patient attrition (i.e. patients who leave care in an untimely fashion). A study by Herinckx, Kinney, Clarke and Paulson (1997) showed that drop-out over time in community mental health care ranged between 32 and 57%. In the context of Assertive Community Treatment (ACT), a recent study by Mohamed, Rosenheck and Cuerdon (2010) showed that 42% of patients terminated health care after 3 years of treatment.

Attrition has been found to be related to patients' level of functioning, their motivation for treatment, and their satisfaction with services (Joe, Simpson, & Broome, 1999; Primm et al., 2000; Romney, 1988; Sue, McKinney, & Allen, 1976; Young et al., 2001). When outcomes data are used to evaluate the performance of mental healthcare services, biases caused by differences in treatment duration may lead to invalid conclusions, particularly when patients leave care because their level of functioning has changed (i.e. outcome dependent). This means that patients whose treatment duration was shorter may have been different at baseline and have different outcomes than those who remain in care (Reynolds, Frank, & Kathy, 2005). If patients leave care after relatively short treatment because their condition is worsening, this may lead the success of their treatment to be overestimated (Bond, McGrew, & Fekete, 1995). Conversely, if they leave care when they have completely or partly recovered, treatment success may be underestimated (Young et al., 2000), thereby filtering patients who remain in need of long term treatment as they have not yet recovered from their psychiatric condition. In both cases, attrition can produce selection bias, which can in turn impact benchmarking, making it important to be acknowledged.

We therefore wished to gain insight into the relationship between treatment duration and clinical outcome in the context of ACT. We did so by exploring the relationships between duration of ACT and clinical outcome variables.

Methods

Setting

The study involved patients from six ACT teams in the city of Rotterdam, the Netherlands. There were three selection criteria for treatment by an ACT team: (a) age 18 and older, (b) having a severe mental illness (usually a psychotic or bipolar disorder, with or without a comorbid substance-use-related disorder); and (c) lack of motivation for treatment at the start of ACT, which made assertive outreach necessary. The fidelity of ACT programs can be assessed using the Dartmouth Assertive Community Treatment Scale (DACTS) (Bond, Drake, Mueser, Latimer, 2001; Salyers et al., 2003; Teague, Bond, & Drake, 1998), whose fidelity score showed that our six teams had implemented ACT moderately successfully (Kortrijk, Mulder, Roosenschoon, & Wiersma, 2010).

Data collection

Data were collected as part of a ROM procedure used in clinical practice to discuss treatment course and outcome between patient and the clinician. ROM assessments, which were planned to take place on entry to the service and every six months thereafter, were performed by independent raters, most of them psychologists. The actual saturation of ROM records in our dataset showed that, on average, the ROM assessments had taken place 9 months apart (SD = 3.6). ROM data-collection was approved by the Dutch Committee for the Protection of Personal Data. Data for this study refer to the period from January 2003 to February 2009; they were used anonymously.

Instruments

We collected socio-demographic data on gender, age, and level of education, and on the diagnosis made by the ACT team psychiatrist.

Four instruments were used. The first was the Global Assessment of Functioning (GAF), (World Health Organization, 1992), which was divided into a symptom scale (GAF-S, range 1–100) rating the global symptom severity, and a functioning scale (GAF-F range 1–100) rating the level of impairment of psychosocial functioning (Pedersen, Hagtvet, & Karterud, 2007).

To assess psychosocial functioning more specifically, we used the Health of Nation Outcome Scales (HoNOS), which was originally developed as a standardized assessment tool for routine use by the mental-health services. It consists of 12 five-point clinician-rated scales, each ranging from 0 (no problem) to 4 (severe/very severe), and thus yielding a total score from 0 to 48. The psychometric properties of the English and Dutch HoNOS version have been found to be acceptable (Mulder et al., 2004; Wing et al., 1998). For the present study, we used only HoNOS total scores. The HoNOS covers the following domains: (1) overactive, aggressive, disruptive or agitated behaviour, (2) non-accidental self-harm, (3) problem drinking and drug-taking, (4) cognitive problems, (5) physical illness and disability, (6) hallucinations and delusions, (7) depressed mood, (8) other psychological symptoms, (9) relationship problems, (10) problems with activities of daily living, (11) problems with living conditions, and (12) problems with occupation and activities.

Motivation for treatment was assessed using one item adapted from the Severity of Psychiatric Illness scale (Lyons, 1998; Mulder, Koopmans, & Lyons, 2005); it was scored in five categories (score range 0-4) similar to those in the HoNOS. The motivation for treatment scale was scored on the basis of an interview with the patient and the clinician.

Finally, we assessed satisfaction with services using an item adapted from the Manchester Short Assessment of Quality of Life (MANSA) (Priebe, 1999).This item was scored on a seven-point scale similar to the MANSA scale from ‘couldn't be worse’ to ‘couldn't be better’ (scored 1-7) (van Os et al., 2001).

Statistical analyses

Assessments (including records of missed assessments) were handled using a blocked design of six-monthly assessments. On the basis of the number of assessments and time since start of ACT, duration of ACT was trichotomized into short duration (2-3 ROM assessments, with a mean treatment duration since first assessment of 11.6 (SD=6.1) months); medium duration (4-6 ROM assessments, with a mean treatment duration since first assessment of 26.9 (SD=7.3) months); and long duration (7 and more ROM assessments, with a mean treatment duration since first assessment of 44.06 (SD=7.1) months). We used ANOVA and chi-square tests to analyze differences in diagnosis and baseline characteristics between patients with different treatment durations.

To clarify the relationship between the clinical variables, Pearson product-moment correlations were calculated: this enabled us to estimate the bivariate associations of the determinants (gender, age, and level of education, and, at baseline, GAF-S and GAF-F, HoNOS total score, motivation for treatment, and satisfaction with services); and the outcome variables (GAF-S and GAF-F, HoNOS total score, motivation for treatment, and satisfaction with services at the last assessment).

To unravel the interrelationships between determinants and outcome variables, we used structural equation modeling (SEM). This statistical tool, which performs prediction analyses and solves several equations simultaneously, makes it possible to unravel interdependencies between determinants and outcome variables. It is used in clinical research to visualize the interrelationship between determinants and outcome variables, and to estimate the magnitudes of the effects of the determinants. Although there are no absolute standards concerning sample size in relation to model complexity, it is desirable to have a minimum of 10 patients for each parameter to be estimated. The modeling was based on the data of 569 patients. In the final model, the number of clinical and statistical relevant parameters to be estimated equaled 25. As a result, the patient/parameter ratio turned out to be greater than 10:1, which indicates a sufficiently large sample size.

When outcomes data are used to compare the performances of the mental health care it can be assumed that the interdependencies between the relevant parameters are all the same, even for patients with different treatment durations. That is, that they ‘behave’ identically over time. If they do not, patients with different treatment durations represent different groups, which should be assessed for their outcomes separately. To test this assumption, we examined several SEM models to identify the best performing model using different treatment-duration categories; our purpose was to establish whether it was acceptable to impose equality constraints between the categories of treatment duration for the auto-regressions or cross-regressions in the model. We started with a model in which the auto-regressions between the determinants and outcome variables (identical variables) were constrained to be equal across patients with different treatment durations. Next, we tested a model in which the cross-regressions between the determinants and outcome variables (nonidentical variables) were constrained to be equal across patients with a different treatment duration. Finally, we tested a model in which no equality constrains were imposed.

In the modeling process we started with the following determinants: gender, age, level of education and GAF-S, GAF-F, HoNOS total score, motivation for treatment, and satisfaction with services at baseline; and with the following outcome variables: GAF-S, GAF-F, HoNOS total score, motivation for treatment, and satisfaction with services at the last assessment. We used maximum likelihood estimation, as it is a statistically efficient method (Jöreskog, 1973) for fitting the statistical model to the data, and for providing estimates for the model's parameters. To allow parsimonious modeling (thereby reducing the complexity), we also determined whether it was acceptable for each path to be removed while remaining a good fit. We started at the end of the model, guiding this process by the Modification Index (Sörbom, 1989). We used standardized regression coefficients as estimates of the magnitude of the effect of the path; theoretically, these ranged from -1.00 (perfect negative association) to 1.00 (perfect positive association). For each model, we evaluated the fit by examining the individual parameter estimates, measures of overall fit, and detailed assessment of fit (fitted and standardized residuals and modification indices).

To evaluate the model fit, we used the following performance measures: 1) chi-square for model fit (low and non-significant values of the chi-square are desired); 2) chi-square/degrees of freedom-ratio (a value <2.0 was predefined as being acceptable); 3) Comparative Fit Index (CFI); 4) Tucker-Lewis Index (TLI) (CFI and TLI: values of >0.95 suggest a good fit; high values are desired, but values >1.0 indicate over-identification); 5) root-mean-square error of approximation (RMSEA; a value <0.05 indicates a close fit); and 6) standardized root mean square of residuals (SRMR; a value of <0.05 indicates a good fit).

The SPSS statistical package version 15.0 (SPSS, Inc., Chicago, IL) was used for the chi-square test, ANOVA and the calculation of correlation coefficients. M-plus version 5.2.1 (Muthén and Muthén, Los Angeles, CA) was used for SEM. Results of individual parameters were regarded as statistically significant if two-sided p was <0.05.

Results

Patients

Five hundred and sixty-nine patients were enrolled, 77% of them male. The mean time patients spent in contact with services was 21.7 months (SD = 13.4; range: 3 to 67). The mean age at the first assessment was 40.3 years (SD = 11.2; range: 18-79). The diagnosis was schizophrenia or other psychotic disorder for 71.7% of all patients; 34% were diagnosed with a coexisting substance-use-related disorder. A small proportion of patients (5.6%) were diagnosed with an affective disorder (first listed); in 4.7%, the diagnosis or condition had been deferred or was missing.

Clinical characteristics

Table 1 shows the association between patient characteristics and baseline values and treatment duration. There were statistical differences in diagnosis and other baseline patient characteristics. Fewer patients with shorter treatment duration were diagnosed with a psychotic disorder, substance-use disorder or combination of both (dual diagnosis). Patients with a longer treatment duration had lower GAF-S and GAF-F scores at baseline. The same was found for the baseline values of the HoNOS total scores, which were lower (i.e. there were fewer problems) for patients with a shorter treatment duration than for those with a long duration of ACT.

Table 1. Sociodemographic and clinical characteristics of patients treated in ACT teams

		Treatment duration[§]			
		Short (n=292)	Medium (n=191)	Long (n=86)	
Treatment duration (months) mean (sd)		11.6 (6.1)	26.9 (7.3)	44.1 (7.1)	
Males[†]		73.5%	83.2%	79.1%	χ2=3.127, df=1, P=.08
Age (years), mean (sd)[‡]		40.84 (11.17)	39.33 (10.88)	39.44 (9.31)	F= 1.334, df=2, P= .27
Education[†, ¶]	low	31.7%	35.1%	29.9%	
	middle	31.3%	38.1%	44.2%	
	high	37.0%	26.8%	26.0%	χ2=.527, df=1, P=.47
Psychotic disorder[†]		**66.3%**	**78.0%**	**75.6%**	**χ2=5.789, df=1, P=.02**
Substance use disorder[†]		**27.9%**	**40.8%**	**39.5%**	**χ2=7.517, df=1, P=.01**
Dual diagnosis[†,††]		**17.5%**	**29.8%**	**27.9%**	**χ2=7.868, df=1, P=.01**
Baseline GAF-S, mean (sd)[‡]		**37.8 (11.8)**	**42.3 (13.1)**	**37.5 (11.2)**	**F=9.132, df=2, P<.001**
Baseline GAF-F, mean (sd)[‡]		**35.2 (9.1)**	**37.2 (9.7)**	**34.2 (9.2)**	**F=4.123, df=2, P=.02**
Baseline HoNOS total score, mean (sd)[‡]		**16.4 (5.4)**	**19.3 (4.8)**	**20.8 (5.6)**	**F=4.624, df=2, P=.01**
Baseline Motivation score, mean (sd)[‡]		2.1 (1.2)	2.0 (1.3)	2.3 (1.2)	F=1.474, df=2, P=.23
Baseline Satisfaction score, mean (sd)[‡]		5.4 (1.5)	5.6 (1.6)	5.4 (1.8)	F=0.843, df=2, P=.43

[†] χ2 statistic, linear by linear association (twotailed)

[‡] ANOVA

[§] Duration: short, medium and long

[¶] Education: low = none or primary, middle:= secondary (Dutch: lbo/vbo) and high = Secondary and over (Dutch > = Mavo)

[††] Psychotic disorder and substance abuse

Interrelations of determinants and outcome variables

Table 2 presents Pearson product-moment correlation coefficients of determinants (demographic and clinical variables at baseline) and outcome variables (the last assessed clinical outcome variables). The correlations of the demographic variables with the other determinants and with the outcome variables were only small. As expected, the auto-correlations (i.e., correlations of two identical variables assessed at different moments) of all outcome variables turned out to be both substantial and significant (table 2). There were also some substantial cross-correlations (i.e., correlations between two different variables assessed at different moments).

Treatment-duration models

Table 3 shows the performance measures of the treatment-duration models subjected to SEM analysis. To ascertain whether the auto-regressions could be constrained to be equal for the three categories of treatment duration, we tested the first model that had some clinical and statistical relevant cross-regressions and auto-regressions. This model was rejected because of the significant chi-square value for model fit (χ^2= 152.17; df=55; p=0.001).

The second model was similar to the first, but now the cross-regressions were constrained to be equal for the three categories of treatment duration. This model also showed a significant chi-square for model fit (χ^2 = 76.96; df=55; p=0.03). The model fit was probably better because the auto-regressions were no longer constrained to be equal.

The third model tested was similar to the first, but now with no constraints regarding the cross- and auto-regressions between the different treatment-duration categories. This resulted in an adequate model fit, as the chi-square test for model fit turned out to be non-significant (χ^2 = 58.69; df=45; p=0.09). The third model was thus considered the best-performing model, as it showed that associations between the determinants and outcome variables were different between the three treatment-duration groups. This reflects significantly different treatment courses, each course associated with a different treatment duration, among distinguishable patient groups in ACT teams. To differentiate between the three categories of treatment duration, Figure 1 shows the standardized coefficients of model 3.

Table 2. Correlation matrix of determinants and outcome variabels§

			Determinants								Outcome variables				
			1	2	3	4	5	6	7	8	9	10	11	12	13
Determinants	GAF-S	1		0.001	0.001	0.001	0.001	0.246	0.112	0.228	0.001	0.001	0.001	0.001	0.002
	GAF-F	2	0.665		0.001	0.001	0.001	0.104	0.245	0.006	0.001	0.001	0.001	0.008	0.018
	HoNOS Total	3	-0.381	-0.457		0.001	0.116	0.024	0.655	0.001	0.001	0.001	0.001	0.011	0.571
	Motivation	4	-0.384	-0.337	0.276		0.001	0.551	0.531	0.998	0.001	0.001	0.001	0.001	0.001
	Satisfaction	5	0.16	0.178	-0.073	-0.325		0.001	0.188	0.999	0.049	0.001	0.019	0.001	0.001
	Gender	6	-0.04	0.057	-0.08	0.021	0.147		0.001	0.286	0.424	0.434	0.09	0.299	0.267
	Age	7	-0.055	-0.04	0.016	0.022	-0.061	0.166		0.999	0.046	0.202	0.222	0.949	0.953
	Education	8	0.048	0.11	-0.146	0	0	0.043	0		0.307	0.074	0.004	0.59	0.68
Outcome variables	GAF-S	9	0.589	0.366	-0.199	-0.275	0.09	-0.28	-0.069	0.041		0.001	0.001	0.001	0.001
	GAF-F	10	0.434	0.576	-0.287	-0.298	0.156	0.027	0.044	0.071	0.665		0.001	0.001	0.001
	HoNOS Total	11	-0.199	-0.209	0.522	0.2	-0.108	-0.06	0.043	-0.117	0.389	-0.441		0.001	0.001
	Motivation	12	-0.149	-0.092	0.09	0.564	-0.293	0.036	0.002	0.021	-0.284	-0.293	0.358		0.001
	Satisfaction	13	0.143	0.109	-0.026	-0.246	0.66	-0.051	0.003	-0.02	0.169	0.171	-0.181	-0.401	

§Pearson product moment correlation; lower triangle: intercorrelations; upper triangles: p-values

Table 3. Model performances of determinants variables in relation to outcome variables, distinguished by duration of treatment

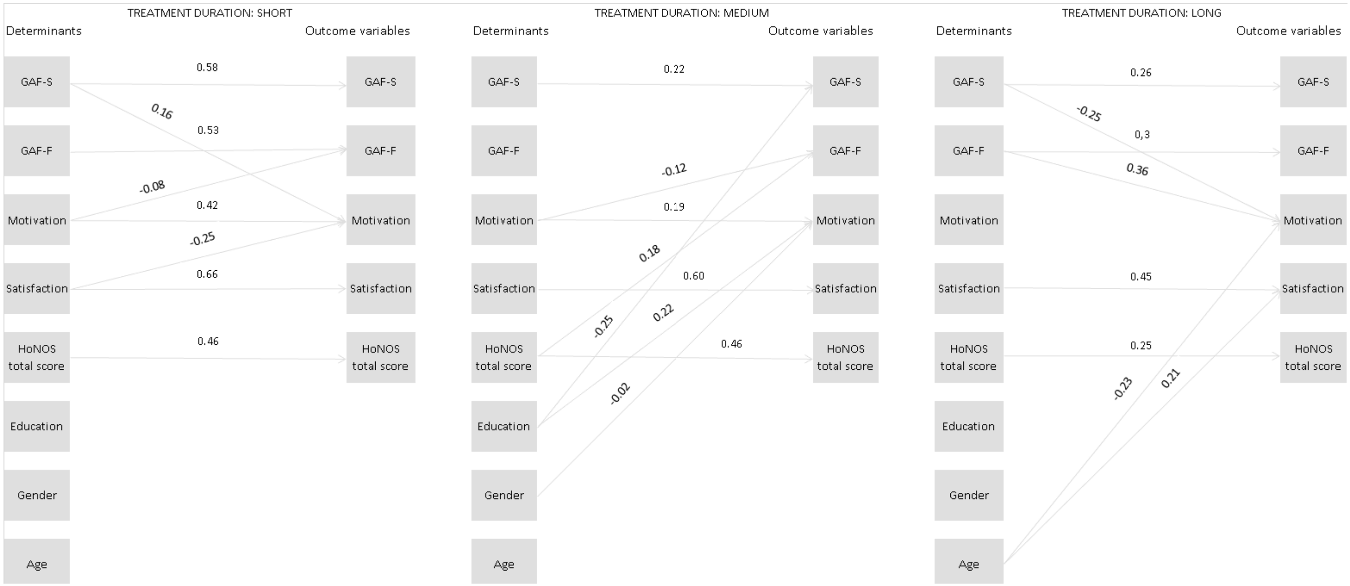
	Treatment duration§	**performance measures**†							
nr	**Models**‡	**chi^2**	**df**	**p**	**chi^2/df**	**CFI**	**TLI**	**RMSEA**	**SRMR**
1	Only autoregressions and a couple of cross-regressions, but equality constraints of autoregressions between the categories of treatment duration	152.17	55	<0.01	2.77	0.92	0.76	0.1	0.08
2	Model 1, but equality constraints of crossregressions between the categories of treatment duration	76.96	55	0.03	1.4	0.98	0.95	0.05	0.04
3	**Model 2 only autoregressions and a couple of cross-regressions no equality constrains**	**58.69**	**45**	**0.09**	**1.3**	**0.99**	**0.96**	**0.04**	**0.03**

† Chi2: test for model performance; p: level of significance; CFI: Comparative Fit Index; FLI: Tucker-Lewis Index; RMSEA: Root Mean Square Error of Approximation; SRMR: Standardized Root Mean Square Residual

‡ All models included gender, age and education

§ Duration of treatment, trichotomised into: short, medium, long

Figure 1. Visualization of the effects of the determinants and outcome variables.† Groups were defined on the basis of treatment duration



† The lines represent standardized regression coefficients (auto-regressions and cross-regressions) for each of the three categories of treatment duration

Auto-regressions and cross-regressions for the treatment-duration model

The auto-regressions of all variables for the three categories of treatment duration were dissimilar, ranging from non-significant, to small, medium and large. The cross-regressions between all variables were also dissimilar for the three categories of treatment duration. The cross-regressions in the short and medium treatment duration categories were minor. For the long treatment-duration category, most of the effects could be considered to be moderate.

Discussion

We used a large study population (569 ACT patients) to assess the impact of treatment duration on the interpretation of Routine Outcome Monitoring (ROM) data. Our results showed that diagnosis, clinical characteristics and interdependencies among baseline and outcome variables differed between patients who had undergone long-term ACT and those whose ACT services had been shorter. This indicates that ROM datasets such as those used in our study contain distinct patient sub-populations that may need to be analyzed separately for their outcomes.

Duration of ACT

Patients' first contact with the mental health services started about a decade before they entered ACT (Kortrijk, Mulder, van der Gaag, & Wiersma, 2012). Our results demonstrate a clear association between duration of ACT and patient characteristics: longer treatment was associated with higher numbers of patients with a psychotic disorder, with substance-use-related disorder, with a combination of both (dual diagnosis), and with more severe psychosocial problems at baseline.

Unlike patients without a comorbid substance-use disorder, dual-diagnosed patients usually had a poor prognosis (Green, Drake, Brunette, & Noordsy, 2007; Kortrijk et al., 2010; Mueser et al., 2000) This was due to higher risks of poor response to pharmacologic treatment, non-adherence to psychotropic medication, increased symptom severity, relapses, hospitalizations, infectious illnesses, suicide, victimization, violence, incarceration and homelessness (Abram & Teplin 1991; Bartels, Drake, & McHugo, 1992; Dixon, 1999; Swoffoord, Kasckow, Scheller-Gilkey, & Inderbitzin, 1996). It is therefore understandable that those with high levels of psychosocial problems at the start of treatment and those with poor prognosis both remain in ACT.

There are several more reasons that a particular patient would have been in either the short, medium or long-duration treatment group. The first involves the time a patient was admitted to ACT. Irrespective of his or her demographic and clinical characteristics, a patient admitted in 2008 would by definition have been treated for a shorter period (and have had fewer ROM assessments) than one admitted to ACT in 2003. Despite this, we found significant differences in patient characteristics among patient groups with different treatment durations.

The second reason is that patients could drop out of ACT for several reasons – because they no longer needed ACT and had been referred elsewhere, for example, or because the ACT team had lost contact with them for other reasons (see limitations).

As our use of Structured Equation Modeling (SEM) showed, the best-performing SEM model for treatment duration indicated that the auto- and cross-regressions were not equal across groups of different treatment duration (i.e. short, medium or long). This means that the interrelationships between the clinical outcome variables and their relation with patient characteristics varied from one category of treatment duration to another. These differences between the short, medium and long treatment duration groups are unlikely to have been caused solely by longer treatment duration: the SEM analyses showed a mix of decreasing and increasing sizes of cross-relationships and auto-relationships (i.e. different interdependencies for each treatment duration group). Having combined these findings, we argue that each of the groups – each of whose ACT was of a different duration – represents a distinct patient sub-population that should thus be regarded as a heterogeneous population. No group should be analyzed with all the others as if they all comprised a homogeneous group.

Implications

In our judgment, our results provide evidence that patient characteristics and the duration of follow-up should be taken into account when ROM data are used.

While Young et al. (2001) suggest that the problem of informative drop-out should be overcome by collecting outcome data from patients who have left care, we feel that it is not only time-consuming to correct for biases by collecting outcome data, but also inconsistent with the primary goal of ROM. As money and clinician-time are required to collect outcome assessments from patients who have left care (Walter, Krikby, & Marks, 1998), such a procedure would be unlikely to be implemented as part of a ROM system. Neither is it likely that these data will actually correct for biases, as these patients no longer receive the same treatment.

A more practical way of dealing with this problem would be to analyze the outcome data in more homogenous cohorts – on the basis, for example, of treatment duration. This would produce analyses that were more accurate and less biased. Policymakers, researchers and clinicians should note that if outcome data were analyzed over a long period, it would produce analyses of patients whose serious and chronic psychiatric condition required long-term treatment. Keeping this in mind, other more valid questions could then be formulated in the context of ROM. If account were taken of treatment duration and patient characteristics, one might thus ask not how effective 3 years of ACT is, but what the outcomes are of the patients who are treated in it.

Thus, if one does not consider baseline patient characteristics, treatment duration and drop-out scores, it is impossible to compare measures such as the HoNOS in a ROM dataset of patients in standard community care with HoNOS scores of patients in ACT, as the drop-out rates of the former may be higher than those of the latter (Sytema, Wunderink, Bloemers, Roorda, & Wiersma, 2007). When outcome data from a patient dataset – of ACT patients, for example – was analyzed over a long period of time, it would be possible to pay less attention to patients whose treatment duration was shorter. Because such patients differ from those whose treatment was longer, no data are randomly missing. In addition, if a patient's condition deteriorates and the patient therefore leaves care (because, for example, he or she was committed for a long period), patients may not all be assessed at that critical time point of leaving. In such cases, missing data in the ROM dataset would, once again, not be random (and may not even depend on the observed outcome data). This also suggests that the impact of treatment duration on the interpretation of the outcome data may be different if the outcome data includes data from less severely mentally ill patients who did not require ACT for a long period. In our opinion, outcome data would thus be analyzed more accurately if the analyses accounted for time since start of treatment. By creating more homogeneous subgroups, this would deal with one of the problematic confounders in a manner that was consistent with the primary goals of ROM.

Strengths and limitations

Our study is characterized by a number of strengths, including a large study population of difficult-to-engage patients and the use of SEM as a statistical technique for modeling complex pathways in our analysis. By unraveling the relationships between variables in a ROM dataset from patients receiving ACT, we were able to visualize complex pathways, thereby making possible biases more easily comprehensible. These insights into ROM data may provide points of departure for the formulation of research questions relevant to evaluating the performance of mental health services.

However this study has several limitations. First of all we stress that, in the classification system for treatment duration in ACT services in Rotterdam, it makes sense to post-stratify treatment duration the way we did in order to differentiate between patient groups. However, these treatment duration periods may not necessarily be identical for other services in other places. Our categorization of patient groups is therefore fairly arbitrary. Similarly, because it is unknown beforehand how long patients with a short duration of ACT will remain in treatment, heterogeneous groups may still arise.

Our research focused on treatment duration and did not include information on attrition and the reasons for it. It is important to know whether patients stopped ACT because their condition improved, or because it worsened, leading to consequences such as long-term hospitalization. To generate a more comprehensive understanding of selection biases in ROM procedures, future studies should examine attrition and its causes, and relate them to treatment duration and clinical outcome.

With regard to the modeling process, we acknowledge that the position of the variables might be debated. In our model, the demographic variables were placed adjacent to the determinants, allowing a confounding impact on the outcome variables. The alternative would be a non-confounding approach that used the demographic variables as a determinant variable for baseline measures. We should also mention that the SEM analyses were based on the manifest variable – i.e., those observed. Due to its complexity, we refrained from ideal modeling which is latent variable modeling.

We also feel that the results cannot be generalized to other, non-severely mentally ill (SMI) populations. Our SMI patients were receiving long-term treatment in the context of ACT: it is inherent to this that they lacked motivation for treatment at the start of ACT, and that they had a severe mental illness. If our outcome data had included data on patients in whom shorter treatment was more likely (such as those with depressive or anxiety disorders), treatment duration might have had a very different impact on our outcome data.

Part III

Chapter 3.1 - Outcome

Symptomatic and functional remission and its associations with quality of life in psychotic disorder patients in Assertive Community Treatment teams

Kortrijk, H.E., Mulder, C.L., van der Gaag, M., & Wiersma, D. (2012). Symptomatic and functional remission and its associations with quality of life in psychotic disorder patients in Assertive Community Treatment teams. *Comprehensive Psychiatry, Epub ahead of print.*

Abstract

Objectives: (1) to determine the proportion and characteristics of patients treated in Assertive Community Treatment (ACT) teams who achieve symptomatic remission (SR) and/or functional remission (FR), (2) to explore the association between both types of remission, and (3) their bearing on quality of life.

Methods: Data comprised assessments from 278 patients, who were repeatedly assessed using the Positive and Negative Syndrome Scale (PANSS) to assess SR, the Health of the Nation Outcome Scales (HoNOS) to assess FR and a shortened version of the Manchester Short Assessment (MANSA) to assess Quality of life (QoL). Chi-square tests and a logistic regression analysis were used to analyze the relation between patient and treatment characteristics and achieving SR or FR. A Kruskall-Wallis test, Mann-Withney U tests and a logistic regression analysis were used to analyze the relationship between remission status and quality of life.

Results: After a mean treatment duration of 2.4 years 26% met the criteria for SR and 30% for FR. Prescription of antipsychotic medication was associated with both achieving SR and FR. Approximately half of the patients who achieved SR also achieved FR. Achieving FR was associated with better QoL. Patients in SR did not have better QoL than patients not in SR.

Conclusions: Remission of symptoms in patients treated in ACT-teams was not a prerequisite for functional remission or vice versa. FR, not SR, was associated with better quality of life**.**

Introduction

Outcome in schizophrenia is a multidimensional construct, including symptom level, functioning and quality of life (Eack & Newhill, 2007; Isaac, Chand, & Murthy, 2007; Mortimer, 2007; Priebe, 2007). Symptomatic remission (SR) is often used to measure the success of treatment and can be defined as a state characterized by a fall in the severity of symptoms with a low to mild symptom threshold over a meaningful period of time (Andreasen et al., 2005; Harvey & Bellack, 2009; van Os et al., 2006). Andreasen et al. (2005) proposed criteria for SR as a low to mild symptom level (positive, negative and disorganized symptoms) for more than six months, with no impact on the individual's behavior. Outcome can also be assessed in terms of functional remission (FR) (Wunderink, Sytema, Nienhuis, & Wiersma, 2009), although to date no generally accepted definition of FR exists (Bodén, Sundström, Lindström, & Lindström, 2009; Harvey & Bellack, 2009; Lambert, de Marinis, Pfeil, Naber, & Schreiner, 2010; Liberman, Kopelowicz, Venture, & Gutkind, 2002). Defining FR may be more difficult because there is no societal norm or clear reference for the level of functioning in daily life (for instance about being employed, social role, independent living and the quality of social contacts) (Essock & Sederer, 2009; Harvey & Bellack, 2009). Some authors propose that FR in psychotic disorder patients consists of adequate functioning in a variety of important life domains including social relationships, productive activities, activities of daily living and living conditions (Harvey & Bellack, 2009). Wunderink et al. (2009) suggest that FR should reflect appropriate social role functioning in the main domains of everyday life, such as occupation, social relationships, citizenship, and partnership. Based on similarities in the descriptions of FR we propose to define FR as adequate or no more than minimal or mild disabilities in social functioning, daily-life activities and living conditions.

To date, it is unknown whether SR is a prerequisite for FR, and which one of the two is associated with quality of life (QoL). Two recent studies (Henry et al., 2010; Wunderink et al., 2009) showed that patients meeting the SR criterion did have better levels of functioning than patients not in remission. However there was no evidence that achieving SR was an essential precondition for appropriate functioning.

Results of studies on the associations between SR and/or FR and QoL are inconsistent (Dunayevich, Sethuraman, Enerson, Taylor, & Lin, 2006; Galuppi, Turola, Nanni, Mazzoni, & Grassi, 2010; Harvey & Bellack, 2009; Helldin, Kane, Karilampi, Norlander, & Archer, 2008; van Os et al., 2006; Wunderink et al., 2009). Some authors suggest that there is no clear relation between the level of functioning or symptoms and QoL (Harvey & Bellack, 2009; Wunderink et al., 2009), while others have argued that the severity of the symptoms as well as the level of social functioning is of importance for quality of life (Dunayevich et al., 2006; Galuppi et al., 2010; Helldin et al., 2008; van Os et al., 2006).

Therefore in this study we determined the proportion of patients treated in Assertive Community Treatment teams (ACT) who achieved SR and/or FR, examined which patient and treatment characteristics were associated with achieving SR and/or FR, and explored the association between both types of remission, and their bearing on quality of life.

Methods

Setting and patients

The study involved psychotic disorder patients from seven ACT teams in the city of Rotterdam, the Netherlands. Criteria for treatment by an ACT team were (1) age 18 or older, (2) having a severe mental illness, usually a psychotic disorder, with or without a comorbid substance use disorder (SUD), and (3) a lack of motivation for regular treatment at the start of ACT that made assertive outreach necessary.

Data collection

Data from this study was obtained as part of a routine outcome-monitoring (ROM) procedure. The ROM assessments included several instruments and were planned every six months. The assessments were completed by independent raters (mostly psychologists), and were used in clinical practice to discuss treatment progress with the patient. ROM data-collection was approved by the Dutch Committee for the Protection of Personal Data. Data for the present study were used anonymously. In addition to the ROM assessments, data was collected on gender, age, ethnicity (country of birth), education level, age of first contact with mental health services, DSM-IV diagnoses (as made by the psychiatrist of the ACT team), being prescribed antipsychotic medication (yes or no), and duration of treatment in ACT.

Instruments

Assessment of Symptomatic Remission

To assess SR, we used 8 items of the Positive and Negative Syndrome Scale (PANSS) proposed by the Remission in Schizophrenia Working Group (Andreasen et al., 2005). SR was defined as scores of ≤ 3 over a six-month period or more for eight items: P1 (delusions), P2 (conceptual disorganisation), P3 (hallucinatory behaviour), N1 (blunted affect), N4 (social withdrawal), N6 (lack of spontaneity), G5 (mannerisms/posturing), and G9 (unusual thought content).

Assessment of Functional Remission

We have proposed to define FR as no more than mild disabilities in social functioning, daily-life activities and living conditions. It should be emphasized that there is no generally accepted definition of FR, and thus no specific instrument to assess it. In the present study, we used three items of the Health of the Nation Outcome Scales (HoNOS) to assess FR (Mulder et al., 2004; Wing et al., 1998). The HoNOS was originally developed as a standardized assessment tool for routine use by mental health services. It consists of 12 clinician-rated scales, each using five points from 0 (no problem) to 4 (severe/very severe). The psychometric properties of the English and Dutch HoNOS scores have been found to be acceptable (Mulder et al., 2004; Wing et al., 1998). The following three items were used to assess FR: (1) everyday social functioning (item 9: relationship problems); (2) activities of daily living and complex skills (item 10: problems of daily living), such as budgeting, organising life, occupation recreation, mobility, the use of transport, and shopping; and (3) housing (item 11: problems with living conditions). Patients achieved FR if their disabilities in social functioning, daily-life activities and their living conditions were no more than minimal to mild – in other words, if these HoNOS items were scored ≤ 2 over a period of six months or more.

Assessment of Quality of Life

The cumulative needs for care monitor (CNCM) quality of life scale was used to measure subjective quality of life (Drukker et al., 2010). This instrument was based on the Manchester Short Assessment of quality of life scale (MANSA) (Priebe, Huxley, Knight, & Evans, 1999). The scale consists of six items (van Os et al., 2001) including financial situation, accommodation, relationship with others, physical health, psychological health, and life as a whole, which were rated on a 7-point scale (1="Couldn't be worse" to 7="Couldn't be better").

Analyses

SPSS version 15.0 was used for all analyses. First, we determined the proportion of patients who had been in SR and FR over the last two assessments. Using Pearson's chi-square test we compared patient characteristics: gender, age (18-30, 30-40, 40-50, >50 years), ethnicity (born in the Netherlands or elsewhere), education level (none, elementary, lower high school and over), comorbid SUD (yes or no) and treatment characteristics: prescription of antipsychotic medication (yes or no) and treatment duration (0-1, 1-2, 2-3, >3 years of ACT prior to their assessment) between patients achieving SR and/or FR versus those who did not. We also used Pearson's chi-square test to explore the relationship between patients achieving SR and FR.

After these analyses, logistic regression analyses were performed, including baseline values and all patient and treatment characteristics as predictors of SR and FR. Note that PANSS baseline values were not included, as they were not available. Logistic regression was carried out starting with a stepwise forward selection, predictors required a probability value of $P<0.25$ for entry into the model, then subsequently the predictors were removed at a probability value of $P>0.05$ using the stepwise backward elimination procedure and a log likelihood test. Next interaction terms were calculated, followed by a forward stepwise ($P>0.25$) and backward elimination ($P>0.05$) procedure of these interaction terms (Hosmer & Lemeshow, 2000).

To explore the relationship between remission (SR and FR) and their bearing on QoL, we analyzed the relationship between remission status and QoL (total score) during the last ROM assessment using a Kruskall Wallis test and Mann-Withney U-tests. Afterwards a logistic regression analysis was performed, including baseline QoL scores and remission status (SR and FR) as predictors of QoL (dichotomized via median split).

Results

Patients

Within all seven ACT teams, in total 519 patients were diagnosed with a psychotic disorder. ROM outcome data (two repeated complete HoNOS and PANSS assessments) was obtained from 278 patients, representing 54% of all ACT patients with a psychotic disorder. Based on the patient characteristics these patients appeared to be representative for all ACT patients with a psychotic disorder, as we observed that the only statistical significant difference between these patient groups was that there were more male patients in our patient selection (82% in the ROM group and 77% in the total group). We observed no other statistically significant differences with respect to age, ethnicity or education level.

Most patients were male (82.4%) and had a mean age of 41.4 years (SD=10.8). Only 44.2% was born in the Netherlands. Diagnosis for all patients included in the study was schizophrenia or other psychotic disorder. Forty-nine percent was also diagnosed with a comorbid SUD. The mean treatment duration from the start of Assertive Community Treatment (ACT) was 2.4 years (SD=1.5) and the first contact with mental health services started about a decade before entering in ACT (mean 10.4 years; SD=9.0 years). The time period between the two last consecutive ROM assessments, which constituted the remission assessment period, consisted of an average timeframe of 9.6 months (SD=4).

Proportions of symptomatic and functional remission (table 1)

SR was achieved by 72 (26%) of the 278 patients, and 84 patients (30%) met the criteria for FR; 160 patients (58%) achieved neither SR nor FR and 38 patients (14%) achieved both SR and FR.

Of the 72 patients in SR, 38 (53%) also met the criteria for FR; of the 84 patients in FR, 38 (45%) were also in SR (table 1). These data do not suggest a sequential relationship between SR or FR, indicating that SR and FR do not seem to be pre-requisites for one another in this sample. The chi-square test for the association between SR and FR ($\chi 2 = 23.457$, df=1, p<0.001) however, showed that the proportion of patients in SR who achieved FR (53%), differed from the proportion of patients who did not achieve SR but achieved FR (22%) (Odds ratio=3.887; 95% CI=2.205 – 6.854).

Table 1. Symptomatic and functional remission in 278 patients after a mean of 2.4 years (SD =1.5) of treatment in ACT teams

		FR N (%)	NFR N (%)	Total N (%)
SR	N (%)	38 (R 52.8%)	34 (R 47.2%)	72 (R 100%)
		(C 45.2%)	(C 17.5%)	(C 25.9%)
NSR	N (%)	46 (R 22.3%)	160 (R 77.7%)	206 (R 100%)
		(C 54.8%)	(C 82.5%)	(C 74.1%)
Total	N (%)	84 (R 30.2%)	194 (R 69.8%)	278 (R 100%)
		(C 100%)	(C 100%)	(C 100%)

SR = symptomatic remission; NSR = no symptomatic remission; FR = functional remission; NFR = no functional remission; N= number of patients; R= row percentage; C = column percentage.

Table 2 presents patient characteristics and their associations with SR and FR, respectively. These analyses showed that younger age, presence of a SUD and the prescription of antipsychotics were associated with achieving SR. Younger age and the prescription of antipsychotics were also associated with achieving FR. Logistic regression analyses (table 3) showed that only the prescription of antipsychotics remained as an independent predictor of achieving both SR and FR.

Remission & Quality of Life (table 4)

Patients who were in SR (irrespective of FR) had higher QoL scores than patients who were not in SR (Z=-2.338, p=.019). The same was found concerning patients in FR (irrespective of SR), also reporting a significantly higher QoL compared to those who were not in FR (Z=-4.376, p<.001). When patients were divided into the following four groups: (1) SR plus FR, (2) SR but no FR, (3) FR but no SR and (4) no SR plus no FR, they showed significant differences in QoL total scores (Kruskall-Wallis test: $\chi 2=21.203$, df=3, p<.001). Further analyses showed that patients who were both in FR as well as in SR (Group 1) had better QoL scores compared to patients who were in neither FR nor SR (Group 4) (Z=-4.107, p<.001). However there was no difference in QoL between patients who were only in SR (Group 2) versus those who were neither in SR nor FR (Group 4) (Z=-.552, p=.581). Interestingly, patients only in FR (Group 3) had better QoL than patients who were neither in FR nor SR (Group 4) (Z=-2.825, p=.005). A logistic regression analysis confirmed these findings indicating that only FR was independently associated with QoL (β=2.584, p=.011; 95% CI = 1.248 – 5.349).

Table 3. Logistic Regression Analyses for the association between demographic variables, SUD and medication use and symptomatic remission and functional remission, respectively

		95% CI for Exp(B)		
Symptomatic remission (SR)	Beta (SE)	Lower	Exp(B)	Upper
Constant	-1.745 (.327)²	-	0.175	-
Prescription of antipsychotic medication	0.884 (0.361)¹	1.192	2.42	4.912
Functional remission (FR)	Beta (SE)	Lower	Exp(B)	Upper
Constant	-.239 (.224)	-	0.778	-
Prescription of antipsychotic medication	1.069 (.37)²	1.409	2.911	6.013
Baseline FR	1.341 (.284)²	2.193	3.823	6.664

SR: R2= .036 (Nagelkerke), Hosmer & Lemeshow Goodness of Fit: χ^2 = -, p= -; FR: R2= .064 (Nagelkerke), Hosmer & Lemeshow Goodness of Fit: χ^2 = 4.556, p=.102; ¹ P<.05 ² P<.01

Table 4. Quality of life total scores in ACT patients with or without symptomatic or functional remission

QoL total score	FR	NFR
	Median (IQR)	Median (IQR)
SR	33 (31 - 37)	29 (24 - 34)
NSR	32 (28 - 35)	28 (22 - 34)

SR = symptomatic remission; NSR = no symptomatic remission; FR = functional remission; NFR = no functional remission; IQR = interquartile range.

Table 2. Characteristics of patients achieving symptomatic and functional remission

		N=278 (%)*	N (%)** in SR	N (%)** not in SR	χ^2 SR	N (%)** in FR	N (%)** not in FR	χ^2 FR
Sex								
	Male	229 (82.4%)	59 (25.8%)	170 (74.2%)	n.s.	69 (30.1%)	160 (69.9%)	n.s.
	Female	49 (17.6%)	13 (26.5%)	36 (73.5%)		15 (30.6%)	34 (69.4%)	
Age								
	18-30 years	50 (18%)	18 (36%)	32 (64%)	p <.1	21 (42%)	29 (58%)	p <.1
	30-40 years	78 (28.1%)	22 (28.2%)	56 (71.8%)		25 (32.1%)	53 (67.9%)	
	40-50 years	84 (30.2%)	23 (27.4%)	61 (72.6%)		26 (31%)	58 (69%)	
	>50 years	64 (23%)	9 (14.1%)	55 (85.9%)		12 (18.8%)	52 (81.3%)	
	Missing	2 (.7%)						
Ethnicity								
	Native	123 (44.2%)	31 (25.2%)	92 (74.8%)	n.s.	34 (27.6%)	89 (72.4%)	n.s.
	Non native	155 (55.8%)	41 (26.5%)	114 (73.5%)		50 (32.3%)	105 (67.7%)	
Level of education								
	None	26 (9.4%)	8 (30.8%)	18 (69.2%)	n.s.	6 (23.1%)	20 (76.9%)	n.s.
	Elementary	38 (13.7%)	11 (28.9%)	27 (71.1%)		12 (31.6%)	26 (68.4%)	
	Lower and over	161 (57.9%)	42 (26.1%)	119 (73.9%)		48 (29.8%)	113 (70.2%)	
	Missing	53 (19.1%)						
Substance use								
	SUD	137 (49.3%)	43 (31.4%)	94 (68.6%)	p<.05	44 (32.1%)	93 (67.9%)	n.s.
	No SUD	141 (50.7%)	29 (20.6%)	112 (79.4%)		40 (28.4%)	101 (71.6%)	
Medication use								
	Prescription of AP	202 (72.7%)	60 (29.7%)	142 (70.3%)	p <.05	73 (36.1%)	129 (63.9%)	p <.05
	No prescription of AP	74 (26.6%)	11 (14.9%)	63 (85.1%)		11 (14.9%)	63 (85.1%)	
	Missing	2 (.7%)						
Treatment duration								
	0-1year	57 (20.5%)	15 (26.3%)	42 (73.7%)	n.s.	22 (38.6%)	35 (61.4%)	n.s.
	1-2 years	70 (25.2%)	18 (25.7%)	52 (74.3%)		20 (28.6%)	50 (71.4%)	
	2-3 years	62 (22.3%)	15 (24.2%)	47 (75.8%)		16 (25.8%)	46 (74.2%)	
	>3 years	87 (31.3%)	23 (26.4%)	64 (73.6%)		26 (29.9%)	61 (70.1%)	
	Missing	2 (.7%)						

* Column percentage; ** Row percentage; SR: Symptomatic remission; FR: Functional remission; χ^2: Pearson's chi square test; SUD: Substance use related disorder; AP: antipsychotics.

Discussion

Remission frequencies

Our results showed that 26% of the patients achieved SR, and 30% achieved FR after a mean of two and a half years of ACT. Being prescribed antipsychotic medication was associated with achieving SR and FR. FR, but not SR was associated with QoL.

Symptomatic and functional remission

In our study the prescription of antipsychotic medication was related to both achieving SR and FR. It may be that the use of medication increases the chance of achieving SR and FR or that those patients accepting medication have a better prognosis, independent of the medication itself. The observational design of the present study does not allow us to determine causality.

On average SR rates in patients from our study were slightly inferior to those found by Shida et al. (2008) and Lambert et al. (2010) who found that one in three of their patients were in SR after a period of about one year. A study in first-episode patients reported 52% SR over a two-year follow-up (Wunderink et al., 2009). Other studies even reported SR rates of 60% over three to five-year periods (Eberhard, Levander, & Lindstrom, 2009; Gasquet, Haro, Tcherny-Lessenot, Chartier, & Lépine, 2008; Haro & Salvador-Carulla, 2006) and of 66% over a two-year period (Verghese et al., 1989). These discrepancies are likely to be related to the duration of follow-up, treatment history and patient characteristics. Patients in ACT often show less treatment engagement and medication adherence, possibly leading to a relatively worse outcome. Also our patient sample was older as compared the study using first episode patients. With regard to the possible impact of age several factors may negatively influence SR. Firstly, the impact of prolonged (untreated) illness and secondly higher age may reflect a filtering of chronically difficult to engage patients in an ACT team. Most patients treated in our ACT teams were in contact with mental health services for more than a decade.

Interestingly, we found approximately the same FR rates as compared to the study by Wunderink and colleagues (2009), who found FR rates of 26.4% after a two-year period in first-episode patients using the Groningen Social Disabilities Schedule (GSDS). Other studies showed different proportions of patients achieving FR. For example, one study by San and colleagues using a restrictive threshold of at least 81 points on the Global Assessment of Functioning scale (GAF) reported that social functioning was adequate in only 10.2% of all schizophrenia patients (San, Ciudad, Álvarez, Bobes, & Gilaberte, 2007). Another study using the WHO Disability Assessment Schedule showed that only 14% of schizophrenia patients had no functional disability after 15 years of follow-up (Wiersma et al., 2000). In the present study however, we allowed for some minimal disability, so the incongruence between these studies is likely to be related to the use of different scales and definitions of FR, which may have affected the remission rates (Lauronen et al., 2007). Therefore we were not able to make valid comparisons with other studies.

We found no evidence of a temporal sequence for SR following FR, since more than half of the patients who achieved SR also achieved FR, and almost half the patients who achieved FR also achieved SR. If a temporal sequence would have been the case, more patients who achieved SR would also have achieved FR or vice versa. This is only partly in line the assumptions of Weiden and Zygmunt (1997) and Priebe (2007), who suggested that the presence of more symptoms is associated with worse functioning. Based on our data however, it does not seem necessary to focus on achieving SR first in order to achieve FR.

Remission and quality of life

Patients who achieved FR, irrespective of SR, reported better QoL than patients who did not achieve FR. Achieving SR without FR, however, was not associated with a better quality of life. The association of FR with QoL suggests that FR is a desirable treatment goal for patients, family and clinicians.

These results are in partial disagreement with those of Wunderink et al. (2009), who found that neither SR nor FR were associated with QoL. This discrepancy may be due to the levels of QoL in their sample of first-episode psychosis patients, which were generally much higher than ours. While Harvey and Bellack (2009) suggest that “subjective well-being does not have a clear correlational relationship with other symptomatic and functional features of the illness”, our results indicate that FR is associated with better QoL, but that SR is not. By showing that SR tends to be of less importance for patients' well-being than FR, our results thus contrast with those of other studies (Dunayevich et al., 2006; Galuppi et al., 2010; Helldin et al., 2008; Hofer et al., 2005).

Limitations

Our results were based on 54% of all ACT patients with a psychotic disorder. Although we did not find statistical differences between both patient groups, except for gender, the generalizability of the results to all ACT patients treated in our center remains unknown. Also, our patient group differed from the patient groups in other studies, making it difficult to compare results, as stated above.

Another limitation of the work presented here is the missing data in our study. Firstly we had no data on PANSS assessments at baseline. Therefore, the true relation between patient and treatment characteristics and SR could not be properly assessed, as we were not able to adjust for baseline values of SR. Secondly the missing rate of self-reports on quality of life was high (38.8%). Although we found no evidence of a relation between the missing self-reports and socio-demographic variables, patients with missing self-reports tend to have more severe problems (FR). This means that the differences found in QoL scores between patients in FR and those not in FR may have been be underestimated.

An important conceptual limitation of our study is that we used a specific definition of FR, based on three items of the HoNOS. Therefore, we acknowledge that our assessment of FR was a rather crude measure for FR. Although this definition is in line with proposed criteria of FR (Harvey & Bellack, 2009; Wunderink et al., 2009), other studies used other scales for assessing FR. Using the HoNOS, however, has the advantage that this scale is widely used in clinical practice in many countries and easy to administer. In doing so, we feel that it is important to emphasize and underline the expert-opinion of Mausbach and colleagues who argue that we should try to use existing measures for assessing functioning that are already in routine use (Mausbach, Moore, Bowie, Cardenas, & Patterson, 2009). New instruments with the sole purpose to measure FR will increase the risk that these instruments will be used only in research but not in clinical practice. For this reason, we believe that HoNOS is an appropriate instrument to assess FR.

Apart from the question which instrument to use for measuring FR (e.g. the GAF, WHO-DAS, GSDS, HoNOS or another instrument), differences in cut-off levels are also important. We defined FR as the three relevant HoNOS items scoring ≤ 2 (mild severity). However, FR might also be operationalized more stringently, for example using a cut-off score of ≤ 1 (minimal severity). In that case only 2.3% of our patients would have achieved FR (implying no or minimal disabilities). Using those criteria would mean that FR is nearly unachievable for patients receiving ACT, and therefore these stringent criteria do not seem appropriate to assess FR.

Since we found higher FR rates than in other studies (San et al., 2007; Wiersma et al., 2000), this may suggest that our definition of FR was less stringent. In the absence of a consensus definition of FR, this remains unknown. We believe that our definition included important life domains (social functioning, daily-life activities and living conditions). It may be that when FR would be defined more stringently e.g. as having work, living independently and having an appropriate social role, the proportion of patients achieving FR might be lower. For that reason, it is likely that our results concerning FR are a product of its assessment. After all, anyone in a job will plainly be hampered by severe psychotic symptoms. Thus our outcomes concerning FR rates and its associations with SR are best understood as the result of the operationalization of FR, being: proper housing, self-care and social contacts. Following from this, it is clear that different assessment methods or cut-off criteria contribute to discrepant findings (i.e. 2.3% achieving FR and a different relation between FR and SR). However, we feel it is very difficult and complex to create specific FR norms as no absolute reference exists, and because these norms may be related to factors such as age or a downward economic situation.

Conclusions

SR was achieved by 26% of ACT patients after an average period of two and a half years and 30% reached FR. SR did not seem to be a pre-requisite for FR or vice versa. Patients who achieved FR, irrespective of SR, reported better quality of life than those who did not, supporting the choice of FR as a desirable treatment goal for patients, family and clinicians.

Chapter 3.2 - Outcome

Treatment outcome in patients receiving Assertive Community Treatment

The results of study were published as: Kortrijk, H.E., Mulder, C.L., Roosenschoon, B.J., & Wiersma, D. (2010). Treatment outcome in patients receiving Assertive Community Treatment. *Community Mental Health Journal, 46,* 330-336.

Abstract:

Introduction: In an observational study of severely mentally ill patients treated in Assertive Community Treatment (ACT) teams, we investigated how treatment outcome was associated with demographic factors, clinical factors, and motivation for treatment.

Methods: To determine psychosocial outcome, patients were routinely assessed using the Health of the Nation Outcome Scales (HoNOS). Trends over time were analyzed using a mixed model with repeated measures. The HoNOS total score was modeled as a function of treatment duration and patient-dependent covariates.

Results: Data comprised 637 assessments of 139 patients; mean duration of follow-up was 27.4 months (SD = 5.4). Substance abuse, higher age, problems with motivation, and lower educational level were associated with higher HoNOS total scores (i.e. worse outcome).

Discussion: To improve treatment outcome, we recommend better implementation of ACT, and also the implementation of additional programs targeting subgroups who seem to benefit less from ACT.

Introduction

Assertive Community Treatment (ACT) is an intensive treatment model in which multidisciplinary teams provide community care for non-motivated patients with a severe mental illness (Bond, Drake, Mueser, & Latimer, 2001). If correctly implemented, ACT is regarded as an evidence-based intervention (McHugo, Drake, Teague, & Xie, 1999). Its primary objectives are to reduce hospital admissions, keep patients in contact with services, and improve psychosocial outcome (Marshall & Lockwood, 1998).

Several studies, most of them American, have provided evidence for the effectiveness of ACT (Burns & Santos, 1995), whose main effects were to reduce admissions and to keep patients in contact with the mental health services. ACT's effects on symptoms, housing stability, and subjective quality of life were less clear (Marshall & Lockwood, 2008). However, in European studies that compared it with standard community care, ACT had no effects on psychiatric hospital use, symptoms, or quality of life (Kent & Burns, 2005; Sytema, Wunderink, Bloemers, Roorda, & Wiersma, 2007).

Despite the lack of European evidence for its beneficial clinical effects, ACT has been widely implemented in Great-Britain and other European countries (Killaspy et al., 2006), including the Netherlands. For this reason, with regard to ACT's effect on symptom-reduction, functioning and quality of life, it should be established which patients may benefit from ACT and which do not.

Several studies which defined treatment outcome as level of symptoms, level of functioning, employment and quality of life have identified the predictive factors associated with poor response to various types of treatment (including ACT). Briefly, these studies identified nine such factors: (1) male gender (Grossman, Harrow, Rosen, & Faull, 2006); (2) age (Roberts, Blow, Copeland, Barry, & van Stone., 2000); (3) low educational level (Lauronen et al., 2007); (4) concomitant substance abuse (Batel, 2000; Dixon, 1999; Drake, Bartels, Teague, Noordsy, & Clark, 1993; Greenfield et al., 2006); (5) early manifestations of symptoms (Remschmidt, Schulz, Martin, Fleischhaker, & Trott, 1994); (6) negative symptoms (Wieselgren, Lindström, & Lindström, 1996); (7) lack of awareness of symptoms (Rossi et al., 2000); (8) poor treatment compliance (Gerlach, 2002); and (9) duration of untreated psychosis (Singh, 2007).

However, to our knowledge, no studies have specifically investigated the influence of these predictive factors on psychosocial outcome in the context of ACT. Using an observational study design in patients receiving ACT over a two to three-year period, we therefore examined the influence of three of these predictors on treatment outcome, which was defined as level of symptoms and social functioning over time (HoNOS total score). We used the following predictors: substance abuse, motivation for treatment, and demographic factors (age, ethnicity, level of education, and gender).

Methods

Setting

The study involved patients from six ACT teams in the city of Rotterdam, the Netherlands. There were three criteria for treatment by an ACT team: (1) age 18 or older, (2) diagnosis with a severe mental illness (usually a psychotic or bipolar disorder, with or without a comorbid addiction disorder); and (3) lack of motivation for treatment at the start of ACT, which made assertive outreach necessary.

Data were collected as part of a routine outcome-monitoring (ROM) procedure, and were used in clinical practice to discuss treatment outcome with the patient and the clinician. The collection of routine outcome monitoring data, which was done by independent raters with a Master's degree in psychology, was approved by the Dutch Committee for the Protection of Personal Data. All data were analyzed anonymously.

Model fidelity

To assess the fidelity of the six treatment programs to ACT, we used the Dartmouth Assertive Community Treatment Scale (DACTS), which assesses fidelity on the basis of 28 items using anchored five-point scales (Bond & Salyers, 2004; Salyers et al., 2003; Teague, Bond, & Drake, 1998). Psychometric properties such as internal consistency, inter-rater reliability and sensitivity to change over time have been found to be acceptable (Bond & Salyers, 2004; Winter & Calsyn, 2000). A mean score of all items between 0 and 2.9 means that a treatment team has failed to implement ACT; a score between 3.0 and 4.1 means that ACT has been implemented to a moderate degree, and a score between 4.2 and 5 means that it has been fully implemented (Salyers et al., 2003; Teague, Bond, & Drake, 1998).

Outcome measures

Data were collected over the period from January 2003 to August 2008. At the start of the treatment and then at six-month intervals, patients were assessed using the Health of Nation Outcome Scales to determine psychosocial outcome (HoNOS; Mulder et al. 2004; Wing et al., 1998). To this we added one additional observer-rated item to assess motivation for treatment.

HoNOS was originally developed as a standardized assessment tool for routine use by the mental-health services. It consists of 12 observer-rated scales, each using five points from 0 (no problem) to 4 (severe/very severe), and thus yielding a total score from 0 to 48. The psychometric properties of the English and Dutch HoNOS total scores have been found to be acceptable (Mulder et al., 2004; Wing et al., 1998). HoNOS covers the following domains: (1) overactive, aggressive, disruptive or agitated behaviour, (2) non-accidental self-harm, (3) problem drinking and drug-taking, (4) cognitive problems, (5) physical illness and disability, (6) hallucinations and delusions, (7) depressed mood, (8) other psychological symptoms, (9) relationship problems, (10) problems with activities of daily living, (11) problems with living conditions, and (12) problems with occupation and activities.

Predictors variables

The scale for assessing motivation for treatment was adapted from the Severity of Psychiatric Illness scale (Lyons, 1998; Mulder, Koopmans, & Hengeveld, 2005), and was scored in five categories in the same way as the HoNOS scale: (0) strong motivation: significant degree of motivation for treatment; (1) clear motivation: there may be some hesitation, but this does not lead to problems with motivation; (2) some motivation: there is motivation for treatment but also ambivalence or mild passive resistance; (3) poor motivation: the individual appears not to be motivated and there is passive resistance; and (4) no motivation / resistance: the individual actively resists treatment. On the basis of an interview with the patient and the clinician, the motivation for treatment scale was scored by independent raters who were not involved in the patients' treatment.

To assess substance abuse, patients were routinely assessed on the basis of two items—alcohol use and drug use—taken from the Camberwell Assessment of Need (CAN). The ratings were based on the interviewee's perspective (as opposed to the patient's). The CAN severity ratings are 0 (no need), 1 (met need) and 2 (unmet need) (Wennström, 2008).

We collected socio-demographic and diagnostic data on gender, age, ethnicity (according to the definition of the Statistics Netherlands: i.e. parents' countries of birth), level of education, and DSM-IV-TR diagnoses as made by the psychiatrists of the ACT team.

Data analysis

SPSS version 15.0 was used for all analyses. Treatment outcome was defined as the HoNOS total score. Linear Mixed Models with repeated measures were used to assess the association of the predictors and psychosocial functioning over time.

Factors of primary interest included time (treatment duration) and psychosocial functioning (HoNOS total score). To capture a curvilinear decline which would assume a more rapid change in the early months, the model also included a square-root transformation of time.

Predictors: All covariates were selected on the basis of a theoretically or empirically documented association with treatment outcome. Demographic information included education, age and ethnicity; other covariates were problems with motivation and substance abuse at baseline.

Model: For the initial specification of the model, we included linear time, square-root time, HoNOS total score, demographics (age, level of education and ethnicity), motivation at baseline, and substance abuse at baseline. Fixed factors: To obtain the most parsimonious model, fixed effects were dropped in subsequent iterations and eliminated, since each effect was either not significantly related to the HoNOS total score, or did not appreciably alter outcome (likelihood ratio test; Fitzmaurice, 2004). Patient's identification number was used as a random factor (random intercept deviation). Random effects were modeled if they significantly contributed to the model (likelihood ratio test).

Final model: The fixed effects in the final model were intercept, time and a square-root transformation of time (which fitted the data better than a linear time slope alone); motivation at baseline; substance abuse at baseline; age; and level of education. Repeated measures were modeled on the assumption of a first-order autoregressive covariance structure (based on REML) (Fitzmaurice, 2004).

Lastly, in an effort to replicate and supplement earlier findings (Grossman, Harrow, Rosen & Faull, 2006), we performed a variation of the primary analyses for men and women separately. Because the sample included only a small number of women, we included all covariates from the model (as defined above), not just covariates that were statistically significant. Non-significant results for the smaller group were examined to ascertain whether their size (β) and direction were similar to those of the larger group. Although non-significant results might indicate that the sample size was not great enough to allow comparison between the groups, any differences in their magnitude or direction indicates that the results are not explained solely by sample size.

Results

Patients

The data included 637 assessments from a total of 139 patients. On average, assessments were 6.9 months apart (SD = 1.4). The mean treatment duration of follow-up was 27.4 months (SD = 5.4). The mean age was 38.3 years (SD = 9.5). Diagnosis was schizophrenia or other psychosis for 72.3% of the patients. The patients' characteristics are described in table 1.

Table 1. Patient characteristics

		N	%
Sex	male	115	82.7%
	female	24	17.3%
Age	<30	29	20.9%
	30 – 39	48	44.5%
	40 – 49	48	44.5%
	50 – 59	12	8.6%
	> 60	2	1.4%
Level of education			
	no education / elementary	31	22.3%
	secondary school	56	40.3%
	upper high school and over	42	30.2%
	missing	10	7.2%
Ethnicity			
	ethnic Dutch and western immigrants	65	46.7%
	non-western immigrants (parents)	71	51.1%
	missing	3	2.2%
Diagnosis			
	schizophrenia	86	61.7%
	other psychosis	15	10.6%
	affective disorders	9	7.3%
	substance abuse*	72	51.7%
	missing	23	16.5%
Previous voluntary and involuntary admissions			
	yes	76	54.7%
	no	29	20.9%
	missing	34	24.4%
HoNOS total score (baseline)			
	≤ 10	7	5.1%
	11-15	23	16.6%
	≥ 15	78	49%
	not all items available / missing**	31	22.3%
Motivation for treatment (baseline)			
	mean score (SD)	2.29 (1.12)	

*: substance abuse as a primary or secondary diagnosis; **: these patients were included in the analyses

Model fidelity

The mean of the total DACTS scores of the six ACT teams was 3.5 (range: 3.4 – 3.6), meaning that ACT had been implemented with moderate success. The lowest scores were awarded to various categories pertaining to substance abuse: substance-abuse specialist on staff (m= 2.8), individualized substance-abuse treatment (m= 2.8), dual-disorder treatment groups (m= 1.2) and dual disorders (dd) model (m=3).

Determinants of treatment outcome for the whole group

In the final model, the following predictors were significantly associated with the HoNOS total score: substance abuse at baseline (CAN score 2: serious problem on items 12 (alcohol) or 13 (drugs) versus 0: no problem or 1: intervention); motivation for treatment at baseline; education level (no education or elementary school versus lower high school and over); and age (< 30 years versus ≥ 30 years).

Analysis of changes during follow-up in the HoNOS total score revealed a significant improvement over time (table 2: linear time: F = 7.841, p= .005, square-root time: F = 14.534, p<.001). Of all predictors, substance abuse at baseline was most strongly associated with the HoNOS total score: the main effect was (β = 3.47, F = 24.414, p < .001). Because the HoNOS incorporates problematic alcohol use and drug taking it is evident that the HoNOS total score will positively correlate with substance abuse. Therefore we did 2 analyses, (1) on the relation between the HoNOS total score (including problematic alcohol use and drug taking (above analysis)) and substance abuse and (2) on the relation between the HoNOS total score (excluding problematic alcohol use and drug taking) and substance abuse. The second analysis shows that, substance abuse still remains a predictive factor (β = 1.60, F = 5.874, p = .017).

The results also showed that age was independently associated with the HoNOS total score (β = 2.26, F = 7.341, p = .007), meaning that older patients had higher overall HoNOS total scores. Problems with motivation at baseline were also associated with higher overall HoNOS total scores (β = .733, F = 6.460, p = .012). Lastly, analyses revealed that the level of education was significantly associated with HoNOS total score (β = -1.916, F = 5.028, p = .027), as patients without education or elementary school had higher overall HoNOS total scores than patients whose education level was lower high school or above.

Gender and outcome

Table 2 also shows the men and women’s respective levels of psychosocial functioning. The results showed differences in the significance and direction of the associations. In men, poorer treatment outcome was predicted by substance abuse, age (30 or older), and level of education (no education, or elementary school only). In women, the pattern of associations was different, in that only substance abuse and problems with motivation for treatment were strongly and significantly associated. In addition, there was also a non-significant association with age, in the opposite direction than that of male patients. Because the association with education was also non-significant in women, its significance was different than it was with men.

The two covariates – time and square-root transformations of time – were also different for men and women, men showing a significant decline over time, and women showing a non-significant decline.

Table 2. Prediction of HoNOS total scores among men and women

Predictors	β (total)	SE	β (men)	SE	β (women)	SE
Intercept	26.57**	3.69	29.40**	4.07	18.98*	8.99
Linear time	3.27**	1.21	3.98**	1.32	-.11	2.82
Square-root time	-14.56**	3.91	-17.23**	4.27	-1.51	9.20
Substance abuse	3.47**	.70	3.14**	.82	6.30**	1.65
Age	2.26**	.83	2.55**	.89	-2.53	2.85
Level of education	-1.92*	.85	-2.21*	.99	-.981	1.42
Motivation for treatment	.73*	.29	.65	.34	1.80**	.53

*** p< .05**

**** P< .01**

Discussion

The fidelity score of the DACTS model showed that the six teams had implemented ACT moderately successfully, but that treatment for dual disorder had been implemented relatively unsuccessfully.

Although the patients' psychosocial functioning improved significantly over time, the gains seem to have been concentrated mainly in the first months of treatment; later on, the level of functioning appeared to stabilize. Despite this early improvement, two factors indicate a need for long-term ACT: patients' level of functioning over time, and the risk that their lack of motivation for treatment will cause their situation to worsen. It should also be stated that the significant improvement in psychosocial functioning was restricted to men, although the non-significant results for women may have been a product of the sample size.

Our analysis also showed that the level of psychosocial functioning was significantly hampered by substance abuse, age over 30, low level of education (either no education, or elementary school only), and problems with motivation for treatment. In that these patient characteristics were associated with significantly more problematic functioning over time, our results confirmed earlier findings on treatment outcome in other patients with a severe mental illness (Batel, 2000; Dixon, 1999; Drake, Bartels, Teague, Noordsy, & Clark, 1993; Gerlach, 2002; Greenfield et al., 2006; Lauronen et al., 2007; Roberts, Blow, Copeland, Barry, & van

Stone, 2000). Our finding that older patients had higher HoNOS total scores may have been due to the fact that the duration of mental illness (Jenner, 2003) or of untreated psychosis was longer in these patients, each a factor that has been associated with worse prognosis (Singh, 2007).

Our study further demonstrated that the pattern with which these variables were associated with psychosocial outcome was different between men and women. The differences between the sexes' levels of psychosocial functioning—women tending to have fewer psychosocial problems over time, but also improving less—may have been due to a floor effect.

However, the fact that substance abuse had more adverse consequences for women than for men may have been because women seemed more prone to perilous activities, such as turning to prostitution as a means to earn the money they needed to support their substance use. This led to problems regarding physical health and daily living conditions, and is in line with previous research by RachBeisel, Scott and Dixon (1999), who suggested that substance abuse among women is associated with increased risks for physical health problems and sexually transmitted diseases.

The third difference between men and women, problems with motivation for treatment, also resulted in a higher risk (i.e. stronger association) for psychosocial problems in women than in men, which may be related to more disruptive behavior, and which therefore leads women to have more problems with motivation for treatment.

For men, risk factors were being aged 30 or older, low level of education, and substance abuse. This is in agreement with findings that older patients had poorer global functioning (Roberts et al., 2000), and may indicate that these patients are more at risk of neglecting their personal care than women are. These findings also supplement those of Gur, Petty and Turetsky (1996) by showing more specifically how the clinical features of patients with a severe mental illness are moderated by aging and gender.

The association with low level of education may indicate that such patients have more difficulty managing or coping with problems in their lives. Neisser et al. (1996) showed that because educational level was moderately highly correlated with intelligence, it may also reflect a patient's ability to make use of any services on offer, and to foresee the consequences of their behavior. Because a low level of education may also lead to greater isolation from the labour market (Wolbers, 2000), it may also complicate rehabilitation.

Bhugra, Leff, Mallett, Der and Corridan (1997) showed that non-western ethnicity was associated with poorer treatment outcome, a finding we were unable to replicate, due possibly to differences in outcome assessment: whereas Bhugra et al. used employment status, we defined outcome more broadly in terms of psychosocial functioning as measured by the

HoNOS. Our study therefore suggests that, in terms of psychosocial functioning over time, non-western immigrants do not differ from other patients.

Limitations of the study

We should acknowledge two limitations of the present study. The first concerns the design. Because this was a naturalistic follow-up study that used routine outcome-monitoring data, we had no information on other factors that may have co-determined the outcomes, such as negative symptoms, lack of awareness of symptoms, and duration of untreated psychosis. Neither does the design make it possible to draw any causal inferences, although Shrier et al. (2007) suggests that, like randomized controlled trials, an observational study design can also contribute to evidence-based research.

The second limitation concerns the small number of women in the analyses, which was a product of the substantial overrepresentation of male patients in the ACT teams. We therefore checked non-significant results for the female patients to see if they were similar in magnitude (β) and direction to those in the larger group. Although non-significant results may indicate that the sample size was not enough for purposes of comparing the groups, the differences in magnitude or direction we found here indicate that the results were not explained solely by sample size.

Conclusion

Since model fidelity has been shown to be associated with better outcome (Bond et al., 2004; Latimer, 1999; McGrew et al., 1994; McHugo, 1999), our results suggest that our ACT teams should improve their fidelity with the ACT model. We also conclude that special attention should be paid to patients who seem to benefit less from ACT.

Our results emphasize the importance of implementing the ACT-model fully, including substance abuse treatment programs. This can be done by implementing IDDT (Drake et al., 2001), or other substance abuse programs. McHugo, Drake, Teague and Xie (1999) showed that faithfully implemented dual-disorder programs achieved better treatment outcomes. These recommendations agreed with our DACTS findings, which also support a better implementation of ACT, especially with regard to the dual-disorder elements that achieved low DACTS scores in this study.

Because our results also indicate that treatment outcome was significantly hampered by low education (including mental retardation), we propose the implementation of programs based on behavioral therapy for mentally retarded patients. One example of such a program is token economy (Comaty, Stasio, & Advokat, 2001), which has also shown to increase adaptive behavior in schizophrenic patients (Dickerson, TenHula, & Green-Paden, 2005).

To address problems of motivation for treatment, we recommend the structural implementation of Motivational Interviewing (Martino, Carroll, O'Malley, & Rounsaville, 2000; Gerlach, 2002). The central purpose of motivational interviewing is to examine and resolve ambivalence in treatment goals. Research by Bien et al. (1993) and Brown and Miller (1993) has shown that patients who were given motivational interviewing had participated more fully in treatment, and appeared to be more motivated than those who had not received this intervention. If motivational interviewing is implemented, motivationally challenged patients may benefit more from assertive community treatment.

To meet the special needs of patients in different age categories, we also argue for the development of innovative programs such as the differentiation of ACT teams according to patients' age (i.e., young, adult and elderly). Because clinicians working in ACT teams serving a subpopulation such as the elderly, may have special skills for dealing with specific needs, such as somatic and cognitive problems. Therefore these teams may be better equipped to deal with specific problems related to age. Finally, because several important factors such as problems with recovery and substance abuse have shown to be different for men and women (Grossman, Harrow, Rosen, & Faull, 2006; Mangrum, Spence, & Steinley-Bumgarner, 2006), it may be necessary to adopt a gender-specific approach. This will mean that separate treatment programs are adapted to the specific needs of men and women.

Part IV

Chapter 4.1 - Motivation for treatment

Changes in motivation for treatment in precontemplating dually diagnosed patients receiving Assertive Community Treatment

Kortrijk, H.E., Mulder C.L., van Vliet, D. van Leeuwen, C., Jochems, E., & Staring, A.B.P. (2012). Changes in motivation for treatment in precontemplating dually diagnosed patients receiving Assertive Community Treatment. *Community Mental Health Journal, under revision.*

Abstract

In a population of dually diagnosed patients receiving Assertive Community Treatment (ACT) we used the theoretical framework of the TransTheoretical Model (TTM) to establish (a) the proportions and characteristics of patients who were not motivated for treatment for psychiatric symptoms and substance use, (b) the proportion of patients who moved towards behavioral change after about one year, and examine how this change was related with clinical outcome; and (c) the sequence of change processes. Chi-square tests and T-tests were used to compare the patient characteristics and outcomes of patients who remained in precontemplation with those who progressed. During follow-up, 47% of the patients came out of the precontemplation phase for treatment of psychiatric symptoms and 38% for substance use behavior. Those who remained in precontemplation benefited less from treatment. Of those who did move forward, most appeared to become motivated for psychiatric treatment before becoming motivated to reduce substance use.

Introduction

The TransTheoretical Model (TTM) is a stage-based theory of behavioral change in which the Stages of Change (SoC) represent a temporal framework of motivational readiness for changes in lifestyle. It identifies five stages of behavior change: precontemplation, contemplation, preparation, action and maintenance (DiClemente & Prochaska, 1998). Although movement through these stages is thought to be effectuated by three factors (processes of change, decisional balance and temptation/self-efficacy) (Prochaska & Velicer, 1997), the findings are inconclusive (Dijkstra, Tromp, & Conijn, 2003; Herzog, Abrams, Emmons, Linnan, & Shadel, 1999; Wright, Velicer, & Prochaska, 2009).

A review by Littell and Girvin (2002) concluded that although the model oversimplifies the process of change, the TTM has greatly helped to define behavioral change for substance-use behaviors and psychiatric treatment models. The TTM is used in the evidence-based practice of Integrated Dual Diagnosis Treatment (IDDT) (Drake et al., 2001), a method that provides integrated treatment for dual diagnosis (DD) patients who suffer simultaneously from a severe mental illness (SMI) and a substance-use-related disorder (SUD). A coexisting SUD is common among patients with SMI, approximately 50% are diagnosed with a SUD somewhere during their lifetime (Mueser & Noordsy, 1996; Regier et al., 1990). DD patients are often difficult to engage in treatment, and their prognosis is poor (Green, Drake, Brunette, & Noordsy, 2007; Kortrijk, Mulder, Roosenschoon, & Wiersma, 2010). IDDT provides TTM-stage-based interventions that aim specifically to enhance SoC-progress for substance use, and hopefully to improve outcome (Drake, Bartels, Teague, Noordsy, & Clark, 1993; Drake et al., 2001; Minkoff, 1998; Mueser & Noordsy, 1996; Prochaska, Diclemente, & Norcross, 1992).

The TTM can be used not only to improve our understanding of the SoC in substance-use behavior (Vilela, Jungerman, Laranjeira, & Callaghan, 2009), but also to conceptualize patients' motivation to be treated for severe mental illness (which can be manifested through their medication adherence and treatment attendance) (Corrigan, McCracken, & Holmes, 2001; Finnell & Osborne, 2006). This motivation is not necessarily congruent with their SoC for substance use (DiClemente, 1999; Heesch, Velasquez, & von Sternberg, 2005).

Although the TTM has been used in many different patient populations, it is still unclear whether it applies to patients with a dual diagnosis, and, if so, how. Bellack and DiClemente (1999) assume that substance use in patients with schizophrenia serves to reduce their psychotic symptoms and to lighten the side-effects of neuroleptics. While a patient is still undergoing the psychiatric condition and neuroleptic treatment, change in substance-use behaviors is thus likely to be more difficult. Some authors suggest that causality lies the other way around: that substance use – such as cannabis exposure – in vulnerable people increases their risk of psychosis and relapses (Hickman et al., 2009; Smit, Bolier, & Cuijpers, 2004). Evidence for both hypotheses in the literature remains inconsistent, suggesting that both pathways may lead to a dual diagnosis.

Neither is much known about transitions in the SoC in DD patients – about what differentiates changers from non-changers, and about which factors are associated with specific stage allocations. In a population of DD patients receiving Assertive Community Treatment (ACT), we therefore explored the transitions in the SoC, examining their motivation for treatment of psychiatric symptoms and for changing substance-use behavior.

We had three specific objectives. The first was to determine the proportion of patients who had come out of the precontemplation stage after one year of ACT. Here, we focused on their motivation both to be treated for their psychiatric symptoms and to change their substance-use behaviors. The second was to compare the relationship between patient characteristics and clinical outcome in patients who remained in precontemplation (either for psychiatric symptoms or substance use) with those in patients who moved forward. Our third objective was to seek information indicating which motivation for change came first: the motivation to be treated for psychiatric symptoms, or the motivation to change substance-use behaviors.

Methods

Setting

The study involved patients from seven ACT teams in the city of Rotterdam, the Netherlands. Criteria for treatment by an ACT team were (a) age 18 or older, (b) having a severe mental illness, usually a psychotic or bipolar disorder (with or without a co-morbid SUD); and (c) a lack of motivation to be treated at the start of ACT, such that assertive outreach was necessary. For this study we selected patients with a co-morbid substance use disorder. All ACT teams provided integrated treatment for both psychiatric symptoms and substance use. The model fidelity of the ACT teams was assessed using the Dartmouth Assertive Community Treatment Scale (DACTS; Teague, Bond, & Drake, 1998). The mean of the total DACTS scores of the ACT teams was 3.5 (range: 2.9 – 3.8), meaning that, on average, ACT had been implemented with moderate success. On the ‘human resources’ subscale, model fidelity was high (i.e., items that were awarded with scores 4-5). Low scores (items that were awarded with scores 1-2) were awarded to various items pertaining to the ‘nature of services’ subscale – items such as intensity of services, frequency of contact, provision of dual disorder treatment groups, and role of consumers on team.

Design

Data from this observational study were obtained as part of a routine outcome monitoring (ROM) procedure in a naturalistic setting. Assessments were performed by trained independent raters (mostly psychologists) and were planned every six months. These ROM assessments were available for clinicians so that they could be used in clinical practice to discuss treatment progress with the patient. The data-collection of ROM was approved by the Dutch Committee for the Protection of Personal Data. Data for this study refer to the period from February 2004 to October 2010 and were used anonymously.

Measurements

Data was collected on gender, age, ethnicity (country of birth), education level, and DSM-IV diagnoses (as made by the psychiatrist of the ACT team).

TransTheoretical Model - Stages of Change

Two different SoC scores were assessed, one for motivation to be treated for psychiatric symptoms (usually psychotic symptoms), and one for motivation to change substance-use behaviors. Motivational levels were assessed using the SoC as described by Prochaska and DiClemente (1983). The rating for the SoC for treatment of psychiatric symptoms was based on all the information available to the rater; it concerned either medication adherence (for patients who were prescribed psychotropic medication) or treatment attendance (for those who were not).

The TTM states that patients in the *precontemplation stage* do not recognize that they have the symptoms of a psychiatric illness and do not intend to change any time soon. This means that the patient is not taking and does not consider taking the medication prescribed by the physician; alternatively, if he or she has not been prescribed medication, the patient is not attending office based treatment sessions (e.g. psycho education, coping skills training or Cognitive Behavioral Therapy) and not considering doing so, although he or she may allow staff to keep in touch by home visits for example. Next, in the *contemplation stage*, patients are ambivalent towards change; they are considering the arguments for and against change, but have not yet planned any change in lifestyle. In the case of psychiatric treatment, this means that patients are not taking the medication (or, if no medication has been prescribed, are not attending treatment sessions), but are thinking about doing so sometime during the next six months. In the *preparation stage*, patients acknowledge the relevance of changing, and intend to make a behavior change. They now start planning to use medication as prescribed by the physician, or, if this has not been prescribed, to attend treatment sessions sometime in the next 30 days. In the *action stage*, patients are undertaking behavior change, at least in the short term. They are consistently taking the medication, or, if this has not been prescribed, attending the treatment sessions prescribed by the physician. Finally, patients in the *maintenance stage* achieve long-term change (over more than six months). They consistently use medication, or, if this has not been prescribed, have consistently attended treatment sessions for over six months (Corrigan et al., 2001; DiClemente, Bellino, & Neavins, 1999; Finnell & Osborne, 2006; Rüsch & Corrigan, 2002).

In our study, we also based the rating for the SoC for substance-use behavior on all information available to the rater. SoC were conceptualized in a manner similar to that described above, with the difference that it now concerned substance use. However DiClemente (1999) has argued that, as a concept, motivation for treatment is not equivalent to motivation for change, since a patient may be open to participating in treatment without being ready to abstain from alcohol or drugs. So, it should be noted that whereas the SoC for psychiatric symptoms is regarded as the patients' motivation to be treated for their psychiatric symptoms, the SoC for substance use is regarded as their motivation for changing substance-use behaviors. Thus, when it is applied to this field, the SoC does not describe treatment acceptance, but behavior concerned with reducing or quitting substance use. Therefore, the first stage of change for substance use (precontemplation phase) was characterized by no recognition of problematic behavior and no intention to change alcohol or drug use anytime soon, and the last stage was defined as having abstained for more than six months, although addiction could still be identified as part of the treatment (DiClemente et al., 1999; Prochaska et al., 1992).

Psychosocial functioning

Psychosocial functioning was assessed using the Health of the Nation Outcome Scales (HoNOS), which was originally developed as a standardized assessment tool for routine use by the mental-health services. It consists of 12 observer-rated scales, each using five points from 0 (no problem) to 4 (severe/very severe), and thus yielding a total score from 0 to 48. The psychometric properties of the English and Dutch HoNOS total scores have been found to be acceptable (Mulder et al., 2004; Wing et al., 1998). The HoNOS covers the following domains: (1) overactive, aggressive, disruptive or agitated behavior, (2) non-accidental self-harm, (3) problem drinking and drug-taking, (4) cognitive problems, (5) physical illness and disability, (6) hallucinations and delusions, (7) depressed mood, (8) other psychological symptoms, (9) relationship problems, (10) problems with activities of daily living, (11) problems with living conditions, and (12) problems with occupation and activities.

Treatment needs

The Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) consists of 22 items (Slade, Beck, Bindman, Thornicroft, & Wright, 1999), assesses the need for care, and is a modified version of the Camberwell Assessment of Need (CAN; Phelan et al., 1995). It assesses health and social needs across the following 22 domains: accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, childcare, basic education, telephone, transport, money, and benefits. Each item is scored 0 (no problem), 1 (met need) or 2 (unmet need). The reliability of the CANSAS is acceptable (Trauer, Tobias, & Slade, 2008).

Analyses

SPSS version 15.0 was used for all analyses. Three patient groups were constructed – some with overlap – on the basis of their TTM-stage at their first assessment. Group 1 involved patients who, at their first SoC assessment, had been in the precontemplation phase for treatment of their psychiatric symptoms; group 2 involved those who had been in the precontemplation phase for changing their substance-use behavior; and group 3 involved those who had been in the precontemplation phase both for treatment of psychiatric symptoms and for substance use.

Patient groups 1 and 2 were selected for the first and second study objectives: (1) to determine the proportion of patients who remained in or came out of the precontemplation phase after about one year, and (2) to determine differences in patient characteristics (gender, age, ethnicity, education and diagnosis) and outcome variables (change scores between first and follow-up assessment on the HoNOS total score and the number of unmet needs on the CANSAS) between those who stayed in the precontemplation phase versus those who moved forward. For these analyses we used Chi square and T-test. Using the timeframes 0-1 year, 1-2 years, and >2 years of ACT before the first SoC assessment, we also assessed whether treatment duration before the first SoC assessment was associated with progression on the SoC.

Patients in group 3 were selected for the third study objective: to seek information indicative about which change comes first, the motivation to be treated for psychiatric symptoms, or the motivation to change substance-use behaviors. For this, we calculated a cross-tabulation of the proportion of patients who remained in or came out of the precontemplation phase with regard to motivation to be treated for psychiatric symptoms or to change substance-use behaviors.

Results

Patients

The data comprised assessments of 253 DD patients who had been assessed repeatedly using the TTM for the motivations to accept treatment for psychiatric symptoms and to change substance-use behaviors. Of the patients included, 87 were in precontemplation for treatment of their psychiatric symptoms (34%; group 1), and 152 were in precontemplation concerning their substance use (60%; group 2). Ninety-three percent of the patients were male, the average age was 41 years (SD=10.2), and 44.8% had been born in the Netherlands. The mean treatment duration from the start of ACT to the first TTM assessment was less than a year (0.8 year, SD=1.0). The first contact with mental health services had started about a decade before entering ACT (11.9 years, SD=9.4). Around 74% had been diagnosed with schizophrenia or another psychotic disorder, and all had been diagnosed with a SUD.

Proportions of patients coming out of the precontemplation phase (Group 1 and 2)

During a mean follow-up period of 0.9 years (SD=0.5) we found the following results. Group 1: with regard to being treated for psychiatric symptoms, 47% of patients (46 out of 87) came out of the precontemplation phase. Group 2: with regard to their substance use, fewer patients came out of precontemplation: 38% (58 out of 152).

Patient characteristics, clinical outcome, and progress on the SoC (Group 1 and 2)

First of all, the results showed that progression through the SoC for treatment of psychiatric symptoms or motivation to change substance-use behaviors was not related to any patient characteristics or to duration of treatment in ACT before the first SoC assessment (all p-values >0.5). Neither were baseline values from the HoNOS and CANSAS scores for patients who remained in precontemplation significantly different (p>.05) than those for patients who had progressed (see table 1 and 2).

Group 1: Relative to patients who remained in precontemplation, those who had come out of it for treatment for psychiatric symptoms made greater improvement in HoNOS total scores and had more favorable changes in the total number of unmet needs on the CANSAS (p-values <.05). Group 2: Relative to patients who remained in precontemplation, those who had come out of it for substance use made greater improvement in HoNOS total scores, and had more favorable changes in the total number of unmet needs on the CANSAS (p values <.05) (see table 1 and 2).

Table 1. Characteristics of dual diagnosis patients in the precontemplation stage for treatment of psychiatric symptoms or for substance use

		Precontemplation for treatment of psychiatric symptoms			Precontemplation for change in substance-use behaviors		
		Change in motivation on the SoC			Change in motivation on the SoC[3]		
		No change	Change	statistic	No change	Change	statistic
Number of patients (%)		46 (53%)	41 (47%)		94 (62%)	58 (38%)	
Gender (% Male)		91.3%	92.5%	χ2=.041, df=1,p=.84[1]	93.4%	89.5%	χ2=.833, df=1,p=.361[1]
Age in years M (SD)		38.3 (11.9)	37.3 (10.7)	T-value =.406, df=81, p= .98[2]	36.5 (10.3)	34.2 (10.5)	T-value=.013, df=118.8, p=.99[2]
Ethnicity (% native)		47.8%	41.5%	χ2=.355, df=1,p=.551[1]	44.7%	41.4%	χ2=.159, df=1,p=.690[1]
Education	% None & primary	17.4%	17.1%	χ2=.002, df=1,p=.969[1]	21.3%	19%	χ2=.118, df=1,p=.731[1]
	% Lower and >	82.6%	82.9%		79.7%	81%	
Diagnosis (% Psychotic disorder)		67.4%	68.3%	χ2=.008, df=1,p=.928[1]	76.6%	72.4%	χ2=.335, df=1,p=.563[1]
Treatment duration before first SoC assessment							
	0-1 years of ACT	64.4%	71.8%		57.9%	67.4%	
	1-2 years of ACT	24.4%	17.9%	χ2=.303, df=1,p=.582[1]	22.8%	19.6%	χ2=1.553, df=1,p=.213[1]
	> 2 years of ACT	11.1%	10.3%		19.3%	13%	
Inpatient and outpatient commitment at baseline		15.2%	9.8%	χ2=.585, df=1,p=.444[1]	16%	12.1%	χ2=.438, df=1,p=.508[1]
HoNOS total score at baseline		16.9 (4.1)	16.6 (4.4)	T-value =-.302, df=84,	16.9 (4.4)	17.6 (5.2)	T-value =.882, df=148, p=.379[2]
Number of unmet needs at baseline		6.2 (3.0)	5.6 (3.2)	T-value =-.302, df=84, p=.38[2]	5.8 (3.3)	6.1 (3.4)	T-value =.54, df=150, p=.38[2]

[1] χ2 statistic, linear-by-linear association (two tailed)

[2] T test

[3] Change in motivation on the SoC during a mean follow-up of 0.9 years (SD=0.5)

Table 2 Differences between dual diagnosis patients who came out of the precontemplation phase versus those who did not

		SoC for Psychiatric symptoms Mean change score (SD)*	test statistics	SoC for Substance use Mean change score (SD) *	test statistics
Progress in SoC	Change in HoNOS total score	M = 2.17 (5.12)	T=-2.362, df=71.411, p=0.021	M = 2.53 (3.89)	T=-2,953, df=148, p=0.004
No progress in SoC score	Change in HoNOS total	M =-.11 (3.63)		M = .41 (4.85)	
Progress in SoC	Change in N of unmet needs	M = 1.15 (3.64)	T=-2.033, df=85, p=0.045	M = 1.81 (3.52)	T=-2.528, df= 150, p=0.013
No progress in SoC needs	Change in N of unmet	M = -.24 (2.69)		M = .33 (3.5)	

T = T test
N = Number
SoC = Stages of Change
* = Positive change indicates fewer problems

Table 3. Cross-tabulation of precontemplators of both psychiatric and substance-abuse treatment.

		SoC for Substance use		
		No change	Change	Total
SoC for Psychiatric symptoms	No change	34 (C: 69%) (R: 89%)	4 (C: 17%) (R: 11%)	38 (C: 53%) (R: 100%)
	Change	15 (C: 31%) (R: 44%)	19 (C: 83%) (R: 56%)	34 (C: 47%) (R: 100%)
	Total	49 (C; 100%) (R: 68%)	23 (C: 100%) (R: 32%)	72 (C: 100%) (R: 100%)

SoC = Stages of Change C= Column percentage R= Row percentage

Progression through SoC in patients in precontemplation for both treatment of psychiatric symptoms and substance-use behaviors (Group 3)

Table 3 shows the association between progression through the SoC regarding precontemplaters for both groups. The results showed that 19 of the 23 patients (83%) who came out of precontemplation for substance use also came out of it for psychiatric symptoms. However, only 19 of the 34 patients (56%) who came out of precontemplation for psychiatric symptoms also came out of it for substance use.

Discussion

In our sample of dual diagnosis ACT patients, 34% were in the precontemplation phase regarding their motivation for treatment of their psychiatric symptoms, and 60% were in precontemplation regarding their motivation to change substance-use behaviors. Although this data is presented as a baseline, it is difficult, if not impossible to determine the exact point in time of their treatment histories at which these assessments had been taken, considering that, before their first assessment, most had been in contact with mental health services for over a decade.

Interestingly, these proportions show that more patients were in the precontemplation phase for treatment of their substance use than for treatment of psychiatric symptoms. While this might imply that dual diagnosis patients seek treatment for their psychiatric symptoms rather than for their substance use, it may also be related to the nature of the services, whose main focus may thus be on psychiatric illness at the expense of treatment for substance use.

Coming out of precontemplation

Our finding that 47% of the patients came out of the precontemplation phase for psychiatric treatment and that 38% came out of it for treatment of substance-use behaviors suggests that, after approximately one year of ACT, most precontemplating ACT patients do not increase their motivation for behavioral change as outlined by the SoC. We realize that these findings are limited by a relatively small sample size, and also by the possibility that stage transitions (fluctuations in motivation) were not picked up due to our reliance on periodic ROM assessments and a relatively short (i.e., one-year) follow-up period. Notwithstanding these limitations, there appears to be a group of ACT patients who remain in precontemplation and who may be chronically difficult to engage in treatment for either their psychiatric symptoms or their substance use. These proportions may be somewhat discouraging, particularly in view of the potentially devastating impact of service disengagement, especially for those who require ongoing treatment (Kreyenbuhl, Nossel, & Dixon, 2009; Staring et al., 2006; Torrey

& Zdanowicz 2001). This is exacerbated by the fact that the same applies to problems related to substance use (Green et al., 2007).

To interpret these results correctly, it should be noted that motivation is typically regarded as a dynamic state within a person that fluctuates over time in response to both internal and external factors (Deci & Ryan, 1985). Patients with severe mental illnesses also have several reasons for disengaging from service. Falling into roughly two types – reasons that manifest unwillingness, and reasons that reflect disabilities (Constantino, DeGeorge, Dadlani, & Overtree, 2009; Lecomte et al., 2008; Mueser, Rosenberg, Goodman, & Trumbetta, 2002; Silverstein, 2010; Tait, Birchwood, & Trower, 2003) – these make it particularly difficult to interpret lack of motivation for treatment. Are the patients who remain in precontemplation the consequence of ineffective services (ACT) that do not properly target this therapeutic problem? Or of certain patient characteristics? Or of an interaction between the two?

Stages of change and clinical outcome

For the second study objective we compared patient characteristics and clinical outcome in those who stayed in the precontemplation phase (either for psychiatric or substance use treatment) with those of patients who moved forward. This showed that progression through the SoC model was related to better clinical outcome. Change in motivation for treatment of patients' psychiatric symptoms was positively related to more favorable outcomes as measured by the HoNOS and CANSAS. The results for substance use were similar, indicating that patients who remained in precontemplation for treatment of their psychiatric symptoms or substance-use behaviors benefited less from treatment.

Changes in motivation in patients in precontemplation for both psychiatric treatment and substance use

The third study objective was to investigate whether patients first became motivated for treatment of their psychiatric symptoms, or first became motivated for treatment of their substance use. Our results showed that 83% of the patients who came out of precontemplation for substance use also came out of precontemplation for psychiatric symptoms, against only 56% the other way round. In other words, motivation to change substance-use behaviors was, in most cases, accompanied by change in motivation for treatment of psychiatric symptoms, not vice-versa.

These results therefore provide some indirect evidence that, in most cases, patients first moved out of precontemplation for motivation for treatment of psychiatric symptoms, and then out of precontemplation for substance use. This is consistent with the insights of

Bellack and DiClemente (1999), who assumed that substance use may, in a patient's perception, help to alleviate or reduce psychotic symptoms. Meaning that substance use will be harder to change as long as the psychiatric condition and its treatment continue, we therefore share their point of view. However, we accept that other factors may also have contributed: for example, as psychiatric symptoms may cause more suffering than substance use does, patients may be more motivated to accept treatment for them. Or perhaps because change in substance-use behaviors is associated with more lifestyle changes compared to accepting treatment for their psychiatric symptoms. Finally, because IDDT was not fully implemented (for example, in some ACT teams no dual diagnosis groups were running), and because treatment of substance-use problems was therefore not optimal, the results may be due to the nature of the services delivered.

To give a better understanding of what the interventions were to improve motivation, three examples describe practices employed by clinicians in the ACT teams:

Motivating patients to change – three examples

(1) ACT staff may apply positive reinforcement to increase treatment adherence. One of the interventions that was started in the ACT teams to reinforce dually diagnosed patients to accept their medication was by paying them small amounts of money. The results of this pilot-study were very promising: all patients accepted their depot injections and only one was re-admitted (Staring, Mulder, & Priebe, 2010). Despite the ethical criticism (Marteau, Ashcroft, & Oliver, 2009), this project of 'money for medication' appeared to be a rewarding and effective intervention to move some ACT patients from precontemplation towards accepting treatment.

(2) In order to treat addiction problems clinicians used motivational interviewing techniques (Miller & Rollnick, 1991) to increase motivation to change substance use. Using these interventions, clinicians tried to raise awareness of the effects of drug use on health or lifestyle by exploring the subjective benefits as well as the negative effects of using substances. This may help patients realize that substance use has both pros and cons, and that change may be necessary to reach their personal goals.

> *(3) In case motivational strategies fail, the team may have used housing as leverage to improve treatment adherence (Monahan et al., 2005):*
>
> *"You wish to keep living in this house, but you get very agitated and confused while coping with all types of hassles, and your landlord is complaining. Medication could help in becoming less agitated and might help in keeping the house."*

Thus, although these practices were used by clinicians, a substantial number of patients did not come out of the precontemplation phase. It may be that the clinicians need to use more or other positive reinforcement strategies, have better training in motivational interviewing, or use more leverage to increase motivation. Additional research is needed to know which (combination) of these measures is effective to improve motivation.

Limitations

Although we believe that our findings on the association between SoC and clinical outcome are relevant and provide useful insights, there is considerable controversy about the methodological quality of the SoC and the TTM (Bridle et al., 2005). The debate includes (1) the effectiveness of TTM interventions to facilitate SoC progression (West, 2005), (2) the arbitrary dividing lines between the stages, (3) the fact that SoC definitions are a composite of different constructs, (4) the assumption that patients make coherent and stable plans, and (5) a focus on conscious decision-making (Bridle et al., 2005).

Given the observational nature of this research, our study design had limitations. With regard to the nature of the services, for instance, we know that many patients have contact with different services next to their ACT, making it practically impossible to provide clear data on duration and intensity of treatment (or treatments) and services. Similarly, we may have missed fluctuations in motivation, and may not have taken into account important background information such as referral source. Referral source may be an important factor to consider, as treatment adherence may be better or easer maintained for patients referred from the hospital compared to 'new' patients or those referred from outpatient programs. However, we found no differences in progress on the SoC between patients with a court ordered procedure at baseline and those without (see table 1).

Further, considering that 55% was born outside the Netherlands, various cultural issues may have (co)determined motivation for treatment. Even though it is difficult to reflect on specific cultural aspects, because they are an ethnically diverse group (20% born in

Suriname, 9% in the Dutch-Antilles, 7% in Morocco and 19% in other countries), it is important to acknowledge that different cultural backgrounds may have affected the frequency of substance use (Room, 2006) and the acceptance of psychiatric treatment (e.g. due to stigma or various explanatory models of illness), which requires flexibility in treatment strategies from the ACT staff (Archie et al., 2010). Despite these limitations, however, we feel that our results are important to evidence-based psychiatry, since they provide new insight into the motivational processes of dually diagnosed patients in outpatient treatment. Previous research on the SoC has largely neglected the population of patients with severe mental illness and co-existing substance use, and has been based on a more motivated and less severely ill patient population. Our study provides evidence that outcomes on substance use and psychiatric symptoms in the context of ACT are associated with the degree of motivation to engage in treatment.

Conclusion

While this study has provided some preliminary evidence that the SoC are helpful in understanding the motivational processes underlying treatment engagement and treatment outcome in patients with a dual diagnosis, more research is needed to understand the exact mechanisms of change (and non-change) in this complex patient population. What remains to be determined is whether transitions in the SoC are dependent on other TTM constructs (such as the processes of change, self-efficacy, and decisional balance), or on other factors such as the therapeutic alliance, neurocognitive functioning and insight into illness.

Chapter 4.2 - Motivation for treatment

Involuntary admission may support treatment outcome and motivation in patients receiving Assertive Community Treatment

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Abstract

Objective: Patients with severe mental illness who are treated in Assertive Community Treatment (ACT) teams are sometimes involuntarily admitted when they are dangerous to themselves or others, and are not motivated for treatment. However, the consequences of involuntary admission in terms of psychosocial outcome and treatment motivation are largely unknown. We hypothesized that involuntary admission would improve psychosocial outcome and not adversely affect their treatment motivation.

Methods: In the context of routine six-monthly outcome monitoring in the period January 2003 to March 2008, we used the Health of the Nation Outcome Scales (HoNOS) and a motivation-for-treatment scale to assess 260 severely mentally ill patients at risk for involuntary admission. Mixed models with repeated measures were used for data analyses.

Results: During the observation period, 77 patients (30%) were involuntarily admitted. Relative to patients who were not involuntarily admitted, these patients improved significantly in HoNOS total scores (F=17,815, df=1, p<.001) and in motivation for treatment (F=28.139, df=1, p<.001). Patients who were not involuntarily admitted had better HoNOS and motivation scores at baseline, but did not improve.

Conclusions: Involuntary admission in the context of ACT was associated with improvements in psychosocial outcome and motivation for treatment. There are no indications that involuntary admission leads to deterioration in psychosocial outcome or worsening of motivation for treatment.

Introduction

Assertive Community Treatment (ACT) is a model for treating patients with severe mental illness who are difficult to engage in treatment (Fiander, Burns, McHugo, & Drake, 2003; Priebe, Watts, Chase, & Matanov, 2005). Its two main components are assertive outreach and the provision of medical and social care (Burns, Catty, & Wright, 2006). If patients in ACT teams constitute a danger to themselves or others and are not motivated for treatment, clinicians can start a procedure for involuntary admission to a psychiatric hospital.

However, a key empirical question is whether involuntary admissions are effective (Monahan et al., 1995). Therefore the use of involuntary admissions should be vigilantly monitored (Keski-Valkama et al., 2007). We found no studies that focused on treatment outcome and motivation in patients that were involuntarily admitted during Assertive Community Treatment. Few studies investigated the effects of involuntary admission. Most studies showed that psychiatric symptoms in involuntarily admitted patients improved (Katsako & Priebe, 2006). Motivation for treatment, however, was adversely affected by involuntary admission as compared to voluntary admission in some studies, while other studies showed no differential effects (Kallert, Glöckner, & Schützwhol, 2007). Part of this discrepancy may be explained by differences in percentages of patients regarding their admission as justified and/or the treatment as beneficial, varying from 33 to 81% (Gardner et al., 1999; Kaltiala-Heino, Laippala, & Salokangas, 1997; Katsakou & Priebe, 2007; Rain et al., 2003).

This naturalistic prospective follow-up study focused on psychosocial outcome and motivation for treatment in a cohort of severely mentally ill patients who were treated in Assertive Community Treatment teams and were also at risk for involuntary admission. We hypothesized that involuntarily admission would be likely to improve their psychosocial outcome, and that it would not adversely affect their motivation for treatment.

Methods

Setting

The study involved patients from four ACT teams in the Dutch city of Rotterdam. Criteria for treatment by an ACT team were (1) having a severe mental illness, usually a psychotic or bipolar disorder, with or without a comorbid addiction disorder, (2) having problems in three or more of the following domains: physical illness, relationships, activities of daily living, housing, occupation and daily activities, and (3) a lack of motivation for treatment at the start of ACT, the combination of which made assertive outreach necessary.

No written informed consent was required, as data were collected as part of a routine outcome monitoring (ROM) procedure, and were used in clinical practice to discuss treatment outcome with the patient and the clinician. The collection of routine outcome assessment data was approved by the Dutch Committee for the Protection of Personal Data. Data for the present study were analysed anonymously.

Dutch Mental Health Act

The Dutch Mental Health Act (1994) stipulates that patients aged 12 years and older can be involuntarily admitted if they are suffering from a mental disorder that causes danger to themselves or others, and if involuntary admission is the only way to prevent this danger (the 'ultimate remedy' principle). There are three procedures for involuntary commitment.

The first is emergency admission (i.e., admission within 24 hours). To make such an admission, a patient is examined by an independent physician (usually a psychiatrist) not involved in his or her treatment, who examines and assesses the danger he or she poses to himself/herself or others. This physician then completes a medical report stating the mental disorder, and the nature of the danger he or she represents. On the basis of this information, and after consulting with the independent physician, the mayor issues an emergency admission. Within five working days, a judge must then decide whether or not to authorize a continuation of the admission (up to a total of three weeks from the date of admission).

The second procedure is court-ordered admission, in which admission usually takes place within two weeks. This can be obtained after the patient has been examined by a psychiatrist not involved in his/her treatment, who assesses the danger they pose to their own health and safety or that of others. On the basis of this information and after consultation with the psychiatrist, a judge decides whether or not to authorize the patient’s involuntary admission for a maximum period of six months. Earlier release is possible if the medical director of a psychiatric hospital considers that the patient is no longer dangerous.

The third procedure is court ordered outpatient treatment. Patients can be released from hospital on certain conditions. This involves a process similar to that described for court-ordered admission, after which a judge may decide to authorize an outpatient treatment order for a maximum of six months. During the period the court ordered outpatient treatment is in force, the patient agrees to comply with a treatment plan whereby the danger can be averted. If the patient does not comply with the treatment plan, he or she can be involuntarily admitted.

In the Netherlands however involuntary hospital admission does not involve involuntary treatment, although the majority of the patients do receive treatment. Since the treatment was not registered in the dataset, we cannot control for this.

For the present study, all patients who were involuntarily admitted using an emergency admission procedure or on the basis of a court order were included in the involuntary admission group.

Outcome measures

Data were collected from January 2003 to March 2008. At the start of the treatment and then at six-month intervals, patients were assessed using the Health of Nation Outcome Scales to determine psychosocial outcome (Mulder, et al., 2004; Wing et al., 1998), plus one additional observer-rated item to assess motivation for treatment.

The HoNOS was developed as a standardized assessment tool for routine use in mental health services. It consists of 12 observer-rated scales, each using five points from 0 (no problem) to 4 (severe/very severe), and thus yielding a total score from 0 to 48. The psychometric properties of the English and Dutch HoNOS total scores were acceptable (Mulder, et al., 2004; Wing, et al., 1998). HoNOS covers the following domains: (1) overactive, aggressive, disruptive or agitated behaviour, (2) non-accidental self-harm, (3) problem drinking and drug-taking, (4) cognitive problems, (5) physical illness and disability, (6) hallucinations and delusions, (7) depressed mood, (8) other psychological symptoms, (9) relationship problems, (10) problems with activities of daily living, (11) problems with living conditions, and (12) problems with occupation and activities.

The scale for assessing motivation for treatment was adapted from the Severity of Psychiatric Illness scale (Lyons, 1998; Mulder, Koopmans, & Hengeveld, 2005) and was scored in the same way as the HoNOS scales. The degree to which patients were motivated for treatment was expressed in five possible categories: (0) strong motivation: significant degree of motivation for treatment, (1) clear motivation: there may be some hesitation, but this does not lead to problems with motivation; (2) some motivation: there is motivation for treatment but also ambivalence or mild passive resistance; (3) poor motivation: the individual appears not to be motivated and there is passive resistance; and (4) resistance/no motivation: the individual actively resists treatment.

On the basis of an interview with the patient and the clinician, the HoNOS and the motivation for treatment scale were scored by independent raters who were not involved in the patients' treatment. It was possible for assessments to take place either in an outpatient situation or in a psychiatric hospital at the time of a scheduled routine outcome assessment.

Apart from the routine outcome monitoring data, data were collected on gender, age, ethnicity (country of birth of the parents) and DSM-IV-TR diagnoses as assessed by the psychiatrists of the ACT team.

Analyses

Patients were divided into two groups: patients who were involuntarily admitted during the observation period (group 1) and those who were not involuntarily admitted (group 2). For the first group we used data from three assessments: (a) the assessment before involuntary admission (time 1), (b) the assessment six months later (time 2), during involuntary admission, and (c) a final assessment again six months later (time 3). Group 1 was further divided into two subgroups, (1a) patients discharged at time 3, and (1b) patients still involuntarily admitted at time 3. The mean time for patients to become involuntarily admitted after the start of ACT was 8.2 months (SD=10.1). This was taken as the point of reference for group 2, whose trend over time was also analysed using three consecutive assessments, with the second assessment in the ROM dataset as a starting point. The durations of ACT for group 1 and 2 were thus levelled out.

For all analyses, SPSS version 15.0 was used. Trends over time for the HoNOS total scores and the scale for assessing motivation for treatment were analyzed using a mixed model with repeated measures. Patients' identification number were used as random factor assuming a first order autoregressive structure. Differences over time, in HoNOS total scores and motivation for treatment scores, between involuntarily admitted patients and patients that were not involuntarily admitted were analysed using involuntary admission as a covariate. Because mixed models make it possible to account for missing data, patients with incomplete data sets were not excluded from the analysis.

Results

Patients (Table 1)

ROM data were available for 260 ACT patients; the mean observation period was 12.9 months (SD=2.74). 77 (30%) Patients were involuntarily admitted during the observation period. Most of these patients had a psychotic disorder (89.4%); their mean HoNOS total score at the assessment before involuntary admission was 22.50 (SD=7.31). 32 (12%) Patients were involuntarily admitted only during time 2, whereas 26 (10%) patients were involuntarily admitted at both time 2 and time 3, meaning that their minimal admission period was six months; 19 involuntarily admitted patients (7.3%) lacked assessment three, and no information was available on the status at the relevant point in time.

183 Patients (70%) were not involuntarily admitted during the observation period; their mean HoNOS total score at the first assessment was 15.06 (SD=5.56). Of these patients 75% had a psychotic disorder.

Changes in HoNOS total scores

There were significant differences in the HoNOS total scores between involuntarily admitted patients and patients who were not involuntarily admitted during follow-up assessments (F=18.708, df=1, p<.001) as well as a time*group interaction (F=22.363, df=2, p<.001); this means that patients who were involuntarily admitted during ACT improved more than those who were not (Figure 1, Table 2).

Table 1. Characteristics of patients in ACT-teams who were involuntarily admitted (n = 77) and who were not involuntarily admitted (n = 183)

	Involuntarily admission n = 77			No involuntarily admission n = 183		
	M	(SD)	%	M	(SD)	%
Age	38.38	(12.50)		39.58	(11.98)	
Sex (male)			73%			79%
Ethnicity						
- native			46%			54%
Diagnosis :						
- Psychotic disorder*			89.4%			57.5%
Emergency admission			9.1%			0%
Court-order admission			90.9%			0%

*: significant differences between involuntarily admitted and non-involuntarily admitted patients (p<0.05)

We also found significant differences between patients discharged at time 3 and patients still admitted at time 3 (F=12.507,df 1, p=.001), i.e. patients who remained involuntarily admitted had higher total HoNOS scores on all assessments than those who were discharged ($\beta = 4.19$, p=.001); this indicated that the patients who were involuntarily admitted for a longer period had more problems. There was no interaction between time and groups (F=.355, df=2, p=.717) for these groups of patients, meaning that longer involuntarily admission was not associated with more improvement in HoNOS total scores.

Table 2. Test of fixed effects (HoNOS total score)

	F-value	df	P
Intercept	1524.193	1	<.001
Assessment	0.003	2	0.997
Admission	18.708	1	<.001
Assessment*Admission	22.363	2	<.001

Test of fixed effects showing significance of intercept, assessment (time), admission and the interaction between assessment time and admission. In this model, a significant interaction would indicate dissimilarities in the associations between involuntarily admitted patients and non involuntarily admitted patients and HoNOS total scores over time.

Table 3. Mean (M (SD)) HoNOS total scores of involuntarily admitted patients and patients that were not involuntarily admitted during ACT (higher scores indicate more severe problems)

Involuntarily admitted patients and patients without involuntary admission during follow-up*	M time 1	(SD)	M time 2	(SD)	M time 3	(SD)
Involuntarily admitted patients (n=77)	22.50	(7.31)	17.47	(5.42)	14.46	(5.44)
Admitted at time 2 (n=32)**	21.67	(7.85)	16.32	(5.59)	13.38	(5.89)
Admitted at times 2 & 3 (n=26)***	26.22	(5.39)	20.64	(4.93)	16.62	(4.19)
Non admitted patients (n=183)****	15.06	(5.56)	15.04	(4.89)	15.05	(4.94)

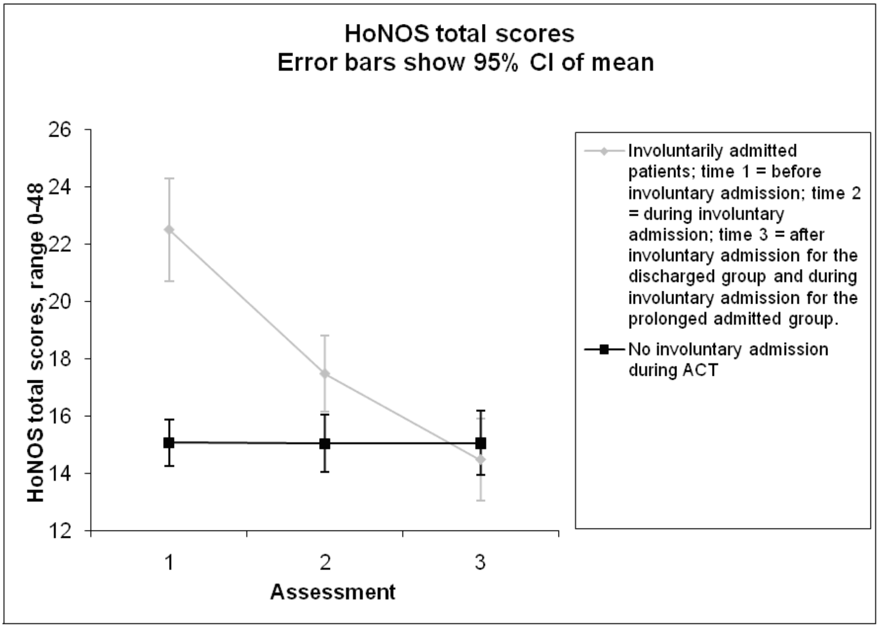
*: Time 1 = before involuntary admission; time 2 = during involuntary admission; time 3 = after involuntary admission for the discharged group and during involuntary admission for the prolonged admitted group. Assessments 1,2,and 3 were six months apart. There were 19 missings for assessment 3.

**: Involuntarily admitted at time 2 and later discharged.

***: Involuntarily admitted at time 2 and still admitted at time 3.

****: Patients not involuntarily admitted during follow up.

Figure 1 Six-monthly HoNOS total scores for involuntarily admitted patients and patients that were not involuntarily admitted during ACT



Changes in motivation for treatment

Patients who were involuntarily admitted during the observation period displayed more problems with motivation for treatment (F=25.178, df=1, p<.001) than those who were not. There was a time*group interaction (F=6.255, df=2, p=.002), meaning that patients who were involuntarily admitted showed more improvement in motivation for treatment over time than patients who were not (Figure 2, Table 4).

Patients who remained admitted at time 3 had more problems with motivation for treatment than those who were discharged at time 3 (F=9.601, df=1, p=.003). There was no interaction between time and groups (F=.551, df=2, p=.579), meaning that longer admission was not associated with less improvement in motivation for treatment.

Table 4 Test of fixed effects (Motivation for treatment score)

	F-value	df	P
Intercept	252.858	1	<.001
Time	2.141	2	0.119
Admission	25.178	1	<.001
Time*Admission	6.255	2	0.002

Test of fixed effects showing significance of intercept, assessment (time), admission and the interaction between assessment time and admission. In this model, a significant interaction would indicate dissimilarities in the associations between involuntarily admitted patients and non involuntarily admitted patients and problems with motivation scores over time.

Table 5 Mean (M (SD)) motivation for treatment scores of involuntarily admitted patients and patients that were not involuntarily admitted during ACT(higher scores indicate lower motivation)

Involuntarily admitted patients and patients without involuntary admission during follow-up*	M time 1 (SD)		M time 2 (SD)		M time 3 (SD)	
Involuntarily admitted patients (n = 77)	2.60	(1.35)	2.15	(1.33)	1.64	(1.29)
Admitted at time 2 (n=32)**	2.29	(1.46)	1.87	(1.34)	1.44	(1.42)
Admitted at times 2 & 3 (n=26)***	3.12	(.90)	2.73	(1.22)	1.96	(1.00)
Non-admitted patients (n=183)****	1.50	(1.21)	1.24	(1.26)	1.38	(1.36)

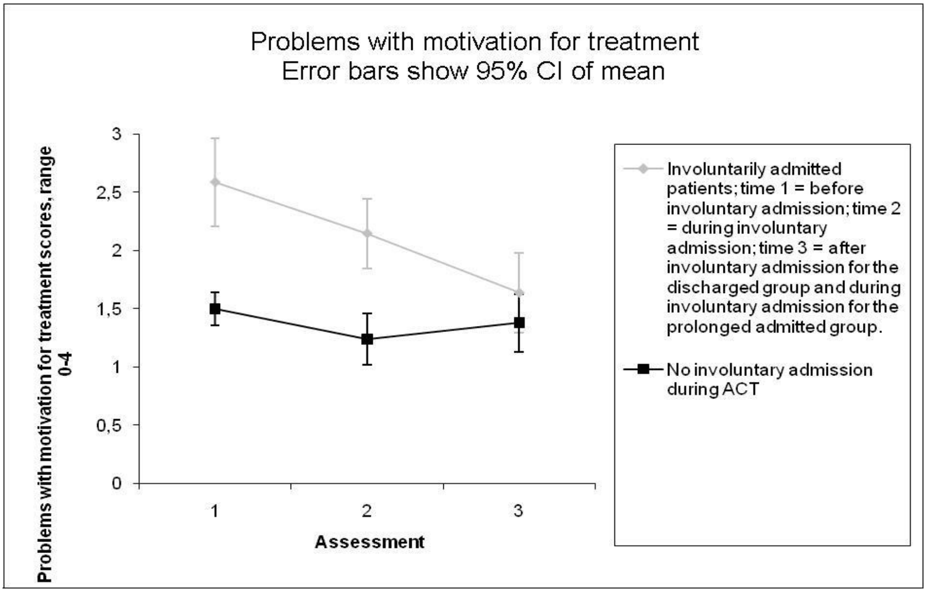
*: Time 1 = before involuntary admission; time 2 = during involuntary admission; time 3 = after involuntary admission for the discharged group and during involuntary admission for the prolonged admitted group. Assessments 1,2,and 3 were six months apart. There were 19 missings for assessment 3.

**: Involuntarily admitted at time 2 and later discharged.

***: Involuntarily admitted at time 2 and still admitted at time 3.

****: Patients not involuntarily admitted during follow up.

Figure 2 Six monthly problems with motivation for treatment scores for involuntarily admitted patients and involuntarily admitted patients that were not involuntarily admitted during ACT



Discussion

This study in patients receiving ACT showed that involuntary admission did not adversely affect psychosocial functioning and motivation for treatment. The results rather suggest that involuntary admission may be associated with improved psychosocial outcome and an increased motivation for treatment.

Psychosocial outcome

All patients, whether involuntarily admitted or not, had on average very severe psychosocial problems at baseline (i.e. their HoNOS total scores were higher than 15; Parabiaghi, Barbato, D'Avanzo, Erlicher, & Lora, 2005). The involuntary admitted patients had significantly more psychosocial problems (HoNOS total scores) at baseline compared to the patients that were not involuntarily admitted. This probably reflects the reason for the admission. Involuntarily admitted patients showed an improvement over time in psychosocial outcome. On average this was a reliable improvement in HoNOS total scores according to criteria defined by Parabiaghi et al. (2005) (i.e. a change of more than 7 points on the HoNOS total score). The reason for the improvement of the involuntarily admitted patients could be explained by two factors, namely favourable effects of treatment and/or a selection of natural fluctuations of the illness over time. The mean HoNOS total scores of patients that were not involuntarily admitted did not change.

Our results also showed that, patients who were discharged within six months of admission reached the same level of psychosocial functioning as those who had not been involuntarily admitted during ACT. While those who stayed in hospital displayed more psychosocial problems than discharged patients, they still improved during involuntary admission in the same manner.

Finally, during follow-up, the total HoNOS scores of the involuntarily admitted and the patients that were not involuntarily admitted remained severe (an approximate score of 15 for both groups). An intensive form of outpatient treatment, such as ACT, thus remained necessary in both cohorts of patients.

In line with earlier studies (Kallert et al., 2007; Kataskou & Priebe, 2007) these findings indicate that involuntary admissions are associated with improvement in psychosocial functioning in severely mentally ill and dangerous patients who are not motivated for treatment. However it should be noted that subjectively reported outcome and outcome measured by assessing change in level of functioning differs (Wallsten, Kjellin, & Lindström, 2006).

Motivation for treatment

Patients who were involuntarily admitted during the observation period showed less motivation for treatment than patients who were not admitted. Again this is what may be expected, as the criteria for involuntarily admission include resistance to therapy. This is in line with a previous study (Mulder, Koopmans, & Hengeveld, 2005) which showed that lack of motivation for treatment is a common phenomenon among severely mentally ill patients in emergency psychiatric services. Problems with motivation for treatment decreased more steeply in patients who had been involuntarily admitted than in those who had not. The results also show that patients who were discharged within six months of admission reached nearly the same level of motivation for treatment as those who were not admitted. Although patients who remained in hospital for more than six months had more motivational problems than discharged patients, they still improved in the same manner during involuntary admission.

These results contrast with findings from a cross-sectional survey of individuals with schizophrenia spectrum disorders (Swartz, Swanson, & Hannon, 2003) in which patients who were involuntarily admitted were reluctant to seek outpatient treatment due to a fear of coerced treatment. In that case, however, it was unknown whether the reluctance had increased after the involuntary admission, or whether the patients involved had already been reluctant before the involuntary admission. Our results show, paradoxically, that involuntary admission is associated with improved motivation for treatment.

The differences in motivation for treatment over time between the involuntarily admitted patients and the patients that were not involuntarily admitted during ACT may be explained by the use of medication during admission, leading to less (psychotic) symptoms and thereby probably to more illness insight, which is associated with better motivation for treatment (Mintz, Dobson, & Romney, 2003). The lack of treatment engagement and adherence among patients that were still involuntarily admitted after six months may explain the differences in psychosocial functioning (Craw & Compton, 2006) from patients that were discharged. Underlying this may be that the discharged patients experienced that their admission reduced their psychosocial problems (i.e. less psychosocial problems compared to the patients who were still admitted) and did meet their basic needs, as was found through the decrease in HoNOS' problem scores.

At the end of the follow-up, 26 patients were still involuntarily admitted. These patients had significantly more psychosocial and motivational problems, which probably made their prolonged admission necessary (Sellwood & Tarrier, 1994). Or, on the other hand, it may reflect an inability to provide more suiting alternative care for a group of more demanding patients (Lorant, Depuydt, Gillain, Guillet, & Dubois, 2007).

Limitations of the study

Since this was a naturalistic follow-up study, using routine outcome monitoring data, we did not have information on other factors that may have co-determined our outcomes, including voluntary admission, exact length of voluntary or involuntary hospital stay, or specific pharmacological treatments. As patients who are not involuntarily admitted in the Netherlands cannot be forced to take medication, but those who are involuntarily admitted can, it is likely that the these patients received more medication than patients who were not involuntarily admitted.

Patients were not randomly assigned to involuntary admission. Obviously, involuntarily admitted and non involuntarily admitted patients have various clinical differences that influence the decision on whether or not they should be involuntarily admitted. As the primary reason for involuntary admission is the dangerousness inherent to a patient's mental illness, it would be ethically problematic to conduct a randomized trial. This makes it impossible to draw causal conclusions.

Similarly, because our patients were not randomly assigned to involuntary admission, regression to the mean may have influenced the results. We nonetheless find it unlikely that this statistical artefact would have influenced our results. There are two reasons for this. First, patients were selected because they had been involuntarily admitted, not because they had extreme scores on the HoNOS. Second, we quantified the RTM effect on the basis of the method described by Hopkins, 2002 (New View of Statistics: Regression to the Mean. Retrieved from http://www.sportsci.org/resource/stats/regmean.html, 2008) and found that HoNOS total scores could regress 1.8 points towards the mean. It is therefore unlikely that our results were caused solely by an error bias. However, we cannot draw causal assumptions on the reason for improvement (i.e. favourable treatment effects or that the results are due to a selection based on natural fluctuations in illness severity). The results nevertheless show significant associations between involuntary admission and improvement on the HoNOS total score and motivation for treatment.

Our findings show that the number of patients with a psychotic disorder was much higher in the involuntarily admitted group than in the group was not involuntarily admitted. When we analyzed the data using only patients with psychotic disorders, our results did not change (results not shown). We therefore conclude that this overrepresentation of patients with psychotic disorders did not play a confounding role in our observation that involuntary admission was associated with decreases in HoNOS scores and motivation.

Motivation was assessed using only one item. Researchers conducting future studies should consider including more comprehensive instruments measuring motivation for treatment, such as the Service Engagement Scale [20] as well as new instruments for assessing patients' motivation for different treatments.

Conclusion

Our findings in severely mentally ill patients receiving ACT indicate that involuntary admission is associated with improvements in psychosocial outcome and an increase in motivation for treatment. When clinicians decide on the involuntary admission of a patient, they can take these findings into account, which suggest that patients do not need to become less motivated for treatment after involuntary admission, and also that patients may benefit psychosocially from involuntary admission. However, because individual patients may still experience negative side-effects such as a decrease in motivation for treatment, involuntary admission should only be used where no other treatment options are available. Future studies should aim to define subgroups of patients who do not benefit from involuntary admission and who become less motivated for treatment.

Part V

Chapter 5 - General discussion

5.1. Discussion

This overall discussion groups the main findings of the thesis and draws final conclusions regarding the main research questions. The thesis had a threefold objective, and posed three main research questions concerning selection biases in outcome data, treatment outcome of patients in contact with ACT, and these patients' problems with motivation for treatment.

The clinical implications are discussed for each research question and suggestions for future research are presented. We describe a clinical vignette of a person receiving ACT, that, besides being illustrative, contributes to our discussion as it accentuates the complexity of the delivery and evaluation of ACT services. The chapter ends in a discussion of the limitations and strengths of the studies.

Vignette

Sergio is fifty-three years old and has a long history of homelessness. In the past decade he stayed at shelters for the homeless and lived an isolated life without friends and family.

He was diagnosed with schizophrenia and had paranoid delusions about the government, believing they were out to get him. These feelings of imminent danger were so strong that he had paranoid outbursts and accused everyone of wrongdoing. While most people laughed it off, others avoided him or became fed up with his hostility. Following a violent incident, the shelter felt they could no longer manage him and referred him to an Assertive Community Treatment (ACT) program. Sergio disagreed with his referral, and persistently refused contact. Despite threats, complaints and demands to be left alone, he was visited every week. Most of the time these visits were very brief, as Sergio would walk out instantly or angrily demanded that they should take off right away. This, however, changed after a year or so, as he had grown accustomed to the visits and stopped protesting. Then, after more than 2.5 years, he finally accepted help with housing. This formed the basis for further cooperation between Sergio and the social workers from the ACT program.

As illustrated in the vignette above, patients referred to an ACT program are often living on the edge of society, suffer from severe psychosocial problems and may have persistent problems with motivation for treatment. In Sergio's case it is worth mentioning that it took more than two and-a-half years before he finally accepted help from the ACT team.

What this vignette shows, is that building a trusting relationship may take a lot of time, effort and patience. While such a long term-effort may be necessary for building a relationship based on trust, this also raises questions, about whether or not these services are sustainable. Since it is unknown how long, if at all, it will take for a patient to become motivated for treatment. Note that in this vignette the first years of treatment did not lead to any significant and measurable improvement in the level of psychosocial problems, which demonstrates the difficulties in demonstrating its effects.

5.2 Discussion of key findings: Biases in outcome data

Our first research question related to whether there are selection biases in ROM datasets, and, if so, which impact this may have on estimates of the effectiveness of the services delivered. This is a relevant question, as it is widely known that biases in observational research are not uncommon, and difficult to get around. Often these biases are associated with patient characteristics, treatment proficiencies or attrition rates (Grimes & Schulz, 2002).

We found that patient groups that were treated for a short, medium or a long period of time in ACT differed from each other in relation to diagnosis and outcome. Thus, patients in ACT teams with different treatment durations constitute, to some extent, distinguishable groups. It appeared that patients with relatively higher levels of psychosocial problems at the start of treatment and those with poor prognosis remain in ACT for a longer period of time. These findings are well illustrated by the vignette.

It can therefore be concluded that the interpretation of long-term outcomes of ACT is hampered by this bias – one that is best described as a filter for patients who still need long-term treatment because they have not yet recovered from their psychiatric condition. This was confirmed in another study (using assessments from the same patient population) demonstrating that most referrals were made to less intensive services (Mulder & Kortrijk, 2012). There thus appears to be a selection bias of non-responders who were selected on the basis of an undesirable condition: no treatment response (or only a marginal response) related to continued exposure to services (Aschengrau & Seage III, 2008). If such a bias is not properly acknowledged, this may lead to questionable conclusions on the performance (long term) of mental healthcare services. In our case, it is likely to underestimate the effectiveness of ACT.

Implications

When describing the outcomes of treatment of patients in ACT (and possibly of any form of long term mental health care), we have to deal with selection biases based on selective attrition. This means that duration of treatment and attrition needs to be taken into account when analyzing ROM data.

Recommendations for future research

To generate a more comprehensive understanding of selection biases in ROM data, future studies should examine attrition and the reasons for it. They should also relate these phenomena to treatment duration and clinical outcomes. We could compare attrition (rates and reasons for attrition) across different ACT-teams within and between mental health institutions, to see whether ACT teams are successful in maintaining contact with difficult to engage patients and to improve their psychosocial problems in the long run. Without information on attrition we will not be able to understand treatment outcome in the context of long-term mental health services such as ACT.

5.3 Discussion of key findings: Treatment outcome

The second research question concerned clinical outcomes of patients in contact with ACT teams and those who were involuntarily admitted during ACT. Before discussing the outcomes of these studies, we need to point out four relevant issues so that these studies and their relationships can be properly understood: (1) differences in patient samples, (2) different assessment methods, (3) service implementation and (4) the arbitrariness of starting points in long term treatment.

Ad 1. Note that the outcome studies in this thesis comprised of (slightly) different patient populations. Our first study concerned symptomatic and functional remission and involved a subset of patients with psychotic disorders who were treated in ACT teams. This differs from the second and third outcome studies which made use the HoNOS total scores over time from all ACT patients.

Ad 2. In our first study (chapter: 3.1), we investigated clinical outcome on the basis of remission criteria (Andreasen et al., 2005). To determine the proportions of patients achieving remission we used the two most recent assessments (constituting the remission assessment). This means that we presented a ‘snapshot’ of remission frequencies at a given point in time during treatment. The second and third studies (chapter: 3.2 and 4.2) used continuous outcomes – the actual sum-score of an instrument – of repeated assessments of the HoNOS over time. The advantage of using continuous scores such as the HoNOS total scores is that they may be better understood by clinicians, who know what certain total scores (such as those in the HoNOS) actually represent (Mulder, 2010). Also, the total score may be more sensitive to change and provides more specific information on the level of functioning. However, it should be kept in mind that in a large sample, small differences can be detected as statistically significant (Coe, 2002). Further, merely summing up improvements and deteriorations in total score may cancel out any change in individuals that has occurred (Trauer, 2010 a) obscuring relevant findings concerning the proportions of patients achieving a meaningful outcome. To address the research question on the clinical outcomes, both approaches (using remission criteria as well as total scores) could be used as complementary strategies, both providing relevant information about the course of the psychiatric and social problems. Importantly, as the use of the HoNOS is becoming widespread both nationally and internationally, our outcomes research offers the possibility of comparisons with other future studies (Kisely, Campbell, Cartwright, Cox, & Campbell, 2010),

Ad 3. It is of great significance to have background information about the services which were offered to have a better understanding of the outcomes in our studies. Therefore information about the degree of intervention implementation can be helpful. For this purpose the fidelity of the ACT programs was assessed using the Dartmouth Assertive Community Treatment Scale (DACTS) and revealed that the ACT teams had a moderately successful implementation of ACT, in which treatment for dual disorder had been implemented relatively unsuccessfully.

Ad 4. Another relevant aspect in these studies that needs consideration are the baseline ROM assessments, as they actually represent a rather arbitrary starting point in a patients treatment career. Most patients were in contact with mental health services for over a decade, it is thus difficult to hold on to the idea that the baseline assessments used in the studies presented in this thesis were a true starting point of psychiatric treatment.

5.3.1 Discussion of key findings: Treatment outcome **-** *Remission*

In the first study we used remission of symptoms and functioning as an outcome parameter. Remission is a relevant outcome and is frequently used in studies to evaluate treatment success in psychiatric illnesses such as schizophrenia (Andreasen et al., 2005), mood-disorders (Zimmerman, McGlinchey, Young, & Chelminsky, 2006), or anxiety disorders (Doyle & Pollack, 2003). Using remission as a desirable and achievable outcome makes it possible to compare study outcomes, and even to improve healthcare by setting goals to achieve a certain percentage of patients in remission (in line with recent developments in benchmark initiatives).

In our outcome study of symptomatic and functional remission (SR; FR) in psychotic disorder patients receiving ACT, we found after a mean treatment duration of approximately 30 months that 26% met the criteria for SR and 30% for FR. However, the comparison with remission rates of other studies is difficult. SR rates reported in other studies vary substantially, mostly higher, up to more than 60 percent (Bak et al., 2007; Eberhard, Levander, & Lindstrom, 2009; Gasquet, Haro, Tcherny-Lessenot, Chartier, & Lépine, 2008; Haro, Salvador-Carulla, 2006; Lambert, Marinis de, Pfeil, Naber, & Schreiner, 2010; Shida et al., 2008; Wunderink, Sytema, Nienhuis, & Wiersma, 2009). This may be related to duration of follow-up, study design, treatment history and patient characteristics. Regarding FR, other studies (Lauronen et al., 2007; San, Ciudad, Álvarez, Bobes, & Gilaberte, 2007; Wiersma et al., 2000; Wunderink et al., 2009) also showed different proportions of FR, of course the use of other scales and definitions of FR make valid comparisons difficult. Interestingly, however, our study demonstrated that regaining SR did not appear to be a prerequisite for FR or vice versa and, importantly, FR, not SR, was associated with better quality of life.

We should acknowledge that our assessment of FR was a rather crude measure for FR as it was defined as adequate or no more than mild disabilities in social functioning, daily-life activities and living conditions. This is not entirely in line with the Dutch national remission working group, who proposed a somewhat more comprehensive assessment of FR that also included adequate daytime activities (e.g. participating in meaningful leisure activities or work) (National Remission Working group (NRW) of the Dutch Association of Psychiatry; Wiersma et al., in preparation)). However, our criteria were easy to assess using the HoNOS, an instrument already in routine use. The results showed that FR was an achievable goal, and that it was associated with quality of life which underlined its relevance in clinical practice.

5.3.2 Discussion of key findings: Treatment outcome - psychosocial functioning

In the second outcome study we examined outcome over time in patients who had received more than 2 years of ACT. Outcome was defined as the level of symptoms and social functioning over time (total sum of the 12 individual HoNOS items). We found that the patients' psychosocial functioning improved significantly over time, although the health gains seem to have been concentrated in the first six months of treatment (2 to 3 HoNOS points). Looking at the entire ACT population at 'baseline' (N=1167), we saw that they had a mean HoNOS total score of 15.8 (SD =5.4). So the change in total score was approximately 0.5 SD, which may be indicative of an on average meaningful change and noticeable for a careful observer (Burgess, Pirkis, & Coombs, 2009; Eisen, Ranganathan, Seal, & Spiro III, 2007; Norman, Sloan, & Wyrwhich, 2003). While the HoNOS is an internationally widely used instrument, it is surprising that there is no consensus about how to determine how services are performing based on the HoNOS (Burgess, Pirkis, & Coombs, 2009). Despite this, we have reason to believe that on average patients in contact with ACT got noticeably better, at the same time admitting that the benefits were only modest. Our results also showed that the patients' level of functioning appeared to stabilize later, and that this stabilized curve does not necessarily mean that nothing changes at the individual level; the proportions of patients who improve may be more or less the same as the proportion who deteriorate.

We also found that the level of psychosocial functioning was significantly associated with four patient characteristics: co-occuring substance use, age over 30, low level of education (possibly reflecting pre-existing problems such as an intellectual disability, but it may also reflect an early manifestation of the illness), and problems with motivation for treatment. These characteristics were associated with problematic functioning over time, and confirmed earlier findings on treatment outcome in other patients with a severe mental illness (Batel, 2000; Dixon, 1999; Drake, Bartels, Teague, Noordsy, & Clarke, 1993; Gerlach, 2002; Greenfield et al., 2006; Lauronen et al., 2007; Roberts, Blow, Copeland, Barry, & van Stone, 2000).

Most of these characteristics appeared to have had a different impact on male and female patients: overall, female patients functioned better, although the impact of substance use and problems with motivation for treatment was more severe. However, it should be acknowledged that relatively few females (17%) were included in the study.

Taken together, these outcome studies demonstrate that on average significant health gains are made by patients in contact with ACT services. Overall, the improvements in problem severity were concentrated mainly in the first months of treatment. In subsequent years, the mean problem score on group level did not change. Again, this does not mean that functioning on individual level did not change (Trauer, 2010 a). Although it is still unknown whether these early gains would have been lost if ACT had been stopped, this seems likely from a clinical point of view. In addition at a given point in time (after an average of 2.4 years of ACT) we found that about a quarter of those in contact with ACT services regained remission of symptoms or functioning. This supports the statement that a substantial proportion of patients in contact with assertive outreach services might improve, and that there is hope that patients suffering from an SMI may overcome their problems.

At the same time, it also means that there is a large proportion of non-responders within the ACT patient population (i.e. of people who do not regain remission at all). These patients remain in ACT and constitute a group with severe and (until now) treatment-resistant problems.

To achieve better treatment results, it may be helpful to improve the implementation of ACT as an association has been found between DACTS fidelity scores and effectiveness of ACT (van Vught, et al. 2011). It is expected that implementation of other evidence-based practices can also lead to better outcome such as Integrated Dual Diagnosis Treatment (IDDT; Brunette & Mueser, 2006), Individual Placement and Support (IPS; Bond, Drake, & Becker, 2002), Family Interventions (Pilling et al., 2002), Illness Management Recovery (IMR; Mueser et al., 2002), Token Economy interventions (Dixon et al., 2009), Motivational Interviewing (MI; Manthey, Blajeski, & Monroe-DeVita, 2012) and other psychosocial treatments (Dixon et al., 2009). However, until victory is attained and Schizophrenia can be cured we must also recognize that we may not be able to prevent high levels of disability

(Hunter, Cameron, & Norrie, 2009) despite our efforts to improve community life of patients so that they can learn to live beyond their illness.

Our third outcome study concerned outcomes in patients who had been committed to a psychiatric hospital. While remarkably few studies have reported on the effects of such involuntary admission on psychosocial outcomes, our findings indicated that, as expected, it was associated with improvements in psychosocial outcome. This supports the claim that involuntary admission, even though it naturally remains an *ultimum remedium*, can be used to support treatment outcome.

Implications

1) Although association is not causation, our evidence supports the suggestion that ACT helps a group of patients with a SMI to get better, in the sense that ACT successfully meets (some of) their needs. However, not all patients seem able to profit from ACT (based on the ROM assessments) and the levels of psychosocial problems remain relatively stable in later years, for which they remain in need of the intensive services of an ACT-team.
2) As substance-abuse programs have been relatively poorly implemented, and as patients using substances have more psychosocial problems, we recommend ACT teams to improve treatment of substance-abuse. The same is probably true for other patients whose outcome seems to be poor (e.g. patients with a low level of education), who may also be better helped by specialized ACT programs.
3) To achieve functional remission (FR), it does not seem necessary to focus on achieving symptomatic remission (SR) first. While we realize that this advice is a product of our assessment of FR – after all, anyone in a job will plainly be hampered by severe psychotic symptoms – SR does not appear to be a *conditio sine qua non* for achieving proper housing, self-care and social contacts.
4) Our outcome studies identified several predictors of treatment outcome that may aid the development of a casemix classification system for SMI patients, i.e. ROM data can be used as an information tool and provide information related to clinical complexity. Among other predictors this could be used to predict the cost of the delivered services.
5) Involuntary admission was associated with improvements in psychosocial functioning, justifying its use in patients who meet the criteria for involuntary admission.

Recommendations for future research

1) Investigate the group of non-responders to ACT, and determine which factors (treatment, patient or environmental factors) contribute to non-response. Of course, of particular interest are the factors which we can influence in the service delivery process.

2) Define the subgroup of patients who do not benefit from involuntarily hospitalization in terms of improving of symptoms and functioning. Although the primary goal of involuntary admission is averting danger, this is potentially very important, as it could inform the clinician whether or not it is likely that a patient may profit from involuntary admission, and what kind of additional interventions may be necessary.

5.4 Discussion of key findings: Motivation for treatment

5.4.1 Discussion of key findings: Motivation for treatment in patients receiving ACT and its relation with clinical outcome

Motivation for treatment is a crucial element for treatment success since patients who are not motivated or even refuse treatment will make no effort to change, and will thus not take medication, or quit substance use. Despite the importance of motivation for treatment outcome, relatively little is known about motivation for treatment among patients receiving ACT. This is remarkable, since problems with motivation for treatment are one of the inclusion criteria for the provision of ACT services.

Our results showed that, at their first assessment, 35% of dual diagnosis patients were in pre-contemplation for treatment of their psychiatric symptoms, and 62% for treatment of their substance-use behaviors. This means that a substantial proportion of patients were not motivated for treatment at start, especially for substance use. After about one year of ACT, 47% came out of pre-contemplation phase for psychiatric symptoms and 38% for substance use. Nevertheless, most did not progress towards a behavior change after one year of ACT. Interestingly, we also found that most dual diagnosis patients seemed first to become motivated for psychiatric treatment, and later for substance use reduction. It remains unclear how this was related to the nature of the services, as the implementation of services specifically targeting substance use was relatively poor in the ACT teams.

All in all, the results show that it can take several years before a patient in ACT becomes motivated for treatment (which was illustrated in the case of Sergio at the beginning of this chapter). In case patients remain unmotivated for their psychiatric problems, a termination of ACT may be considered, for instance when no dangerousness criteria apply (such as risks of suicide or self-harm, the safety of others, or the arousal of aggression of others, but also a severe social breakdown or self-neglect). In case of Sergio long term ACT services was also justified since he was at risk of becoming aggressive. However, in our view a lifelong exposure to ACT services can only be justified in relation to the level of problems, meaning that the principles of subsidiarity, effectiveness and proportionality must be taken into account.

5.4.2 Discussion of key findings: Involuntary admission and its relation with motivation for treatment.

Patients treated in ACT are at risk of involuntarily admission when they are a danger to themselves or others and are not motivated for treatment. Surprisingly, the outcomes of involuntary admissions in terms of treatment motivation are largely unknown.

As involuntary admissions are not uncommon, and practice-based evidence may increase the knowledge-base on this topic, our study is therefore relevant. The findings showed that approximately 30% of the patients with a SMI receiving ACT were admitted involuntarily, and that this was associated with amelioration in problems with motivation for treatment (post-hoc analysis revealed that motivation for treatment deteriorates in 12% of the patients, remains stable in 38% and improves in 50%). Note that despite the involuntary initiation of treatment we did not differentiate between extrinsic and intrinsic motivation. However, importantly, we found no evidence at a group level that involuntary admission would worsen motivation for treatment. Still, this does not mean that at the individual level all patients became more motivated for treatment, as the post-hoc analysis revealed that some have become less motivated.

Further, we have to acknowledge that our assessment of motivation for treatment (HoNOS- addendum) was a rather rudimentary measure for motivation for treatment. We used a single item assessment of motivation for treatment which is potentially problematic, as it is a rather ambiguous concept (Drieschner, Lammers, & van der Staak, 2004) and may refer to different treatment related cognitive or behavioral elements which makes it difficult to interpret. Despite this limitation, it does allow for a useful and relevant insight to the degree in which a patient actively participates in the offered treatment program. Furthermore a ROM procedure makes it necessary to have a relatively short assessment of most relevant domains, therefore an extensive thorough assessments is not achievable.

Clinical implications:

1) In dually diagnosed patients receiving ACT, patients first appear to move out of pre-contemplation of treatment of psychiatric symptoms, and then out of pre-contemplation of treatment for substance abuse. This may mean that substance abuse is harder to change than psychiatric symptoms, or that patients first need to be stabilized in terms of psychiatric symptoms before substance abuse can be adequately addressed.
2) On a group level, patients who are involuntarily admitted do seem to become more motivated for treatment.

Future research:

1) To improve our understanding of the effectiveness of services for dually diagnosed patients, future research should examine the course of motivation for treatment of psychiatric symptoms as well as of substance abuse problems.

2) In our studies on motivation for treatment, we narrowed motivation down to one item which is essential in ROM procedures but does not cover the entire complexity of the motivational problem. Therefore we feel that clinical research is needed to understand the exact mechanisms of change (and non-change) in patients with a SMI. One relevant research question concerns the extent to which the stages of change depend on the processes of change, self-efficacy, and decisional balance; or on other factors, such as the therapeutic alliance, neurocognitive functioning, and insight into illness (Jochems, Mulder, van Dam, & Duivenvoorden, 2011). Also, we did not distinguish between extrinsic and intrinsic motivation. Therefore future research might explore extrinsic and intrinsic motivation for treatment of patients who were involuntarily admitted to learn which aspects of motivation can be improved.

3) Future studies should aim to define subgroups of patients who do not benefit from involuntary admissions and who become less motivated for treatment. These studies should also focus on issues such as negative and positive experiences during involuntary admission. For instance, it would be interesting to learn to what extent positive or negative experiences during involuntary admissions play a role in motivation for treatment (Baars, Wierdsma, Hengeveld, & Mulder, 2010).

5.5 General limitations and strengths

Despite increasing awareness of the importance of outcomes research, we also understand that inherently to the use of ROM data for research purposes there are serious methodological limitations.

The most important limitation is that all our studies lacked experimental elements (Stroup et al., 2000). We should therefore recognize the existence of potentially uncontrolled confounding elements that may have influenced outcome, such as unstandardized and not-allocated treatment. As we have no evidence that comparable patients who do not receive ACT do not get better (Trauer, 2010 a), neither can we rule out other possible explanations for their improvement. We should thus keep in mind that these observational data allow us to draw no causal statements on the effects of ACT.

Further, not only is our study design susceptible to biases, we should also acknowledge that there is evidence of a selection bias. First, patients are selected for treatment (new or continued) on the basis of their serious condition (Rosenbaum, 2005). Second, experience from the field tells us that the ROM procedure unintentionally may have omitted patients who refused assessments. Also, in the studies presented in this thesis, we have no empirical data on these patients. Similarly, in case of cooperation of unmotivated patients, they may not have disclosed reliable information about themselves, stressing that nothing was wrong with them and that ACT was unnecessary. Although the protocol stated that raters in these cases should try to organize an interview with the treating clinician to fill in the clinician-rated scales, they did not always succeed. And when they did succeed, the assessment was unquestionably less precise, either being incomplete or containing errors. We should therefore be aware that a significant proportion of patients (i.e., those who consistently refused every contact with ACT and ultimately were discharged) inevitably had more missing and imprecise assessments than those who adhered to treatment. Previous research shows that this may come near to 5% of the ACT patient population (Mulder & Kortrijk, 2012). This will apply particularly to self-reports on quality of life and to a lesser extent to the clinician-rated scales. As clinical experience suggested that poor treatment adherence may be a manifestation of serious psychological problems (besides many other aspects), this may be problematic. Therefore clinicians/raters should try to fill in the clinician rated outcome scales even when patients are unmotivated for treatment and do not show up for appointments.

The third evidence of selection bias is that patients who are in acute crisis may be less frequently assessed than patients not in crisis situation, not only because they refused contact or were unable to fill in the self-reports, but also because the designated clinician frequently argued that it was not the most opportune moment for an assessment, possibly feeling that one would not do them justice.

These factors represent a systematic distortion of the samples used in our studies. Together with the lack of experimental design this means that we were unable to test the effectiveness of ACT under the most ideal conditions. Each factor has a different and perhaps even counteracting effect on the estimates of treatment outcome. The first (selection bias of non-responders) may produce an underestimation of treatment success. The second (omission due to patients refusing treatment) and third (less frequent assessment of patients in acute crisis) may have had a mixed impact on outcomes, potentially overestimating treatment success (i.e., giving the false impression of few patients in acute crisis), but underestimating the overall severity of the patient group.

Another limitation is the possibility of a regression-to-the-mean phenomenon (Barnett, van der Pols, & Dobson, 2004), which is common in studies of patients with chronic health conditions. This occurs if patients are referred to treatment when they are at their worst, and so improvements in their condition may be related to natural fluctuations instead of the beneficial effect of treatment. We cannot rule out these phenomena in our outcome studies.

We must recognize that the baseline values used in our studies did not necessarily reflect the starting point of patients' treatment career. Rather it represented a point in time in which ACT services were considered appropriate. Also the inability to assess all patients during their intake phase (due to the uncertainty of whether or not ACT was appropriate or due to problems with motivation for treatment) means that we do not have a true starting point of psychiatric treatment.

In addition to the limitations mentioned above, other elements in our studies may have compromised the results. First, in some cases, repeated assessments were made by different assessors. This may be problematic even if the psychometric properties of the instruments are satisfactory, as rater drifts may produce unwanted artifacts.

Secondly, since its introduction at Bavo-Europoort, the ROM procedure has undergone several changes and improvements. In the meantime, as extra instruments have been incorporated in the original ROM procedure, some patients have baseline assessments of instrument X but not of instrument Y, while those who were recently referred to ACT had baseline assessments of both instruments. We were also faced with an ever-growing number of (in)complete assessments. As a result the number of included patients increased each time we used all available records and the studies in this thesis consist of more or less different samples.

Although we used instruments in our ROM procedure which were in agreement with the Dutch National Remission Working group (Mulder et al., 2010) our choice can be debated as, obviously, we were not able to monitor all relevant aspects of treatment. For instance, regarding the example of Sergio (vignette), most clinicians would agree that a lot of therapeutic work has been done in the past years, in particular in building a relationship with Sergio. This means that using ROM datasets such as the one in our studies missed relevant information e.g. on the therapeutic relationship, illness management or coping strategies.

Another issue concerning ROM is that to date in clinical practice few clinicians actually use the assessed outcomes for following progress of their patients. Perhaps this is because ROM is not equally popular among all clinicians. Facing the problem of low ROM rates, managers have placed great emphasis on getting ROM assessments done, i.e. making sure that most patients have a ROM assessment each year. However ROM therefore is at risk of becoming part of an administrative control (which will not contribute to its popularity). This may be exacerbated by recent developments in which insurance companies are creating financial incentives for outcome measurement. Whereas, at the same time, there is little emphasis on the use of ROM as a treatment tool, which appears to be somewhat neglected. For that reason we believe that it is important to facilitate the use of ROM in treatment. This not only requires adequate feedback systems, but also training in how ROM can be used in treatment, for instance by demonstrating how techniques of problem solving treatment can be used to discuss ROM results.

Besides these limitations there are also several methodological strengths worth noting. The main strengths of our studies include: (1) Its longitudinal character, we were able to use repeated outcome assessments in several studies. (2) The frequent follow-up assessments (in many cases even twice a year) over a long follow-up period. (3) Our studies comprised of representative samples of difficult-to-engage patients, because we were able to include assessments of patients refusing treatment, not just the treatment adherers. Furthermore, most of our studies used an adequate sample size, so these studies may be a good reflection of the ACT population. 4) We used data from a rather comprehensive ROM procedure and were therefore able to take many relevant factors into account. (5) We used outcome measures who are (inter)nationally widely used, which has the potential benefit that it may enable future effectiveness comparisons. (6) We should also underline that most instruments have satisfactory psychometric properties. (7) Additionally, the use of independent raters may have positively affected the reliability. (8) Last but not least we were able to provide information on the ACT services via DACTS scores. The actual level of implementation may also be considered reflective of contemporary ACT services in the Netherlands, because the mean level of implementation of ACT services in our studies corresponds to the mean level of implementation found in a Dutch ACT fidelity study (van Vugt et al., 2011).

All in all, when we take the limitations and strengths into account we should stress that we are unable to provide the definitive answer to the treatment-outcome question. However, because the analyses were based on a representative community sample of difficult-to-engage patients, and the studies comprised of sufficient data to provide reliable estimates of outcomes we are certain of their relevance, as they provide treatment outcomes from a “real world” healthcare setting. Although outcome evaluation of ACT using ROM data can never provide the answers to all of the relevant questions. We therefore recognize the importance of the internal validity of clinical trials as well as their ability to make more comprehensive assessments of factors such as functional remission and motivation for treatment, which our ROM procedure assessed rather crudely.

Although randomized trials remain important, we feel that outcomes research too is urgently needed, because it helps us understand what is really achieved in daily practice, needing ongoing reexamination. Therefore we argue against the popular belief that only RCT’s produce trustworthy and useful insights (Concato, Shah, & Horwitz, 2000; Krumholz, 2009). Furthermore as outcome research may improve (i.e. modify) service planning and delivery, we hope it may also lead to better outcomes.

Summary

Summary in Dutch (Samenvatting)

Author index

Words of thanks

Summary

Part 1: Introduction and aims of the thesis

Assertive Community Treatment (ACT) is the most studied service-delivery model for patients with a severe mental illness who lack motivation for treatment. Most studies demonstrating its effectiveness were performed in the US some time ago, and found that ACT was effective in keeping patients in contact with services, reducing the duration of hospitalization, and improving clinical and social outcome. However, more recently, European studies that compared ACT with standard care did not show these effects, and ACT was proved to be more effective only in keeping patients in contact with services.

This discrepancy may be due to differences in control or experimental groups: in European countries, certain aspects of ACT were already part of 'care as usual', but also differences in model fidelity may account for the discrepant findings. Importantly, however, most of these randomized controlled trials used rather short follow-up periods, and included a small number of patients. This might mean that we know little about longer-term outcomes in patients receiving ACT under real-life conditions.

To bridge this gap and to gain insight into the long-term course of illness of patients in ACT teams, we gathered routine outcome monitoring data collected over the 2002–2011 period. This gave us the opportunity to study real-life outcomes of patients in ACT teams over a relatively long period of time. To increase our insight into treatment outcome under real-life conditions, ROM data was used to study the outcomes of ACT. This thesis had three aims: (1) to investigate whether there were selection biases in our ROM dataset, and whether any potential biases might impact estimates of the effectiveness of ACT services; (2) to determine the clinical outcomes of patients receiving ACT, or those who had been admitted involuntarily during their ACT, and to identify the factors associated with outcome; and (3) to establish the proportion of patients who had problems with their motivation for treatment, and investigate the proportion of patients who did become motivated as ACT proceeded. We also investigated changes in motivation of patients who had been admitted involuntarily.

Part 2: Outcome measurement

Part 2 deals with methodological issues regarding the use of routine outcome data for research purposes. When evaluating ACT on the basis of ROM data, statistical inferences are susceptible to biases caused by patient self-selection, meaning that certain patients receive ACT longer than others. We therefore investigated whether there were selection biases in our ROM dataset, and, if so, what impact this might have had on estimates of the effectiveness of the services delivered.

We found that a higher number of patients who had received long-term ACT had been diagnosed with a psychotic disorder and/or substance use disorder than patients who had a shorter treatment duration. Patients who had a longer treatment duration also had worse baseline values as compared to those who had a shorter treatment duration. We also found that the relationships between the determinants and outcome variables were different for each of the treatment-duration categories. On the basis of these findings, we concluded that patients in ACT teams with different treatment durations constitute of distinguishable groups with different levels of functioning. If this selection of patients with a relatively poor prognosis is not properly acknowledged, this may lead to questionable conclusions on the (long term) performance of mental healthcare services. In our case, it is likely to underestimate the effectiveness of ACT. This should be taken into account when using outcome data for studying the effectiveness of ACT.

Part 3: Outcome

Part 3 contains two studies of treatment outcome in patients receiving ACT. In the first study, we determined the proportion and characteristics of patients treated in ACT teams who achieved symptomatic remission and/or functional remission. We also investigated the associations between both types of remission, and their bearing on quality of life.

Three items (relationship problems, problems of daily living and problems with living conditions) of the HoNOS (Health of the Nation Outcome Scales) were used for assessing functional remission. The Positive and Negative Syndrome Scale remission criteria items were used for assessing symptomatic remission. We found that after a mean treatment duration of 2.4 years, 26% of the 278 patients met the criteria for symptomatic remission, and 30% met those for functional remission. Prescription of antipsychotic medication was associated with achieving both symptomatic and functional remission. Remission of symptoms in patients treated in ACT teams was not a prerequisite for functional remission, or vice versa. Functional remission and not symptomatic remission was associated with better quality of life. Our results therefore showed that functional remission was an achievable goal, and that it was associated with quality of life – which thereby underlined its relevance in clinical practice.

In the second outcome study we investigated treatment outcome over time and how outcome was associated with demographic factors, clinical factors, and motivation for treatment. During a follow-up period of about 2.3 years in 139 patients we found that the patients' psychosocial functioning improved significantly over time, and that the health gains seem to have been concentrated in the first months of treatment. In subsequent years the mean HoNOS score on group level remained relatively stable and reflected serious problems for which ACT remained necessary. Substance abuse, higher age (30+), problems with motivation, and lower educational level were associated with higher HoNOS total scores over time (i.e. worse outcome). Males were over-represented and most of these characteristics appeared to have had different impacts on male and female patients

Part 4: Motivation for treatment

Focusing on the impact of motivation for treatment on clinical outcome, part 4 consists of two studies. In the first study we investigated a population of dually diagnosed patients receiving ACT, and determined the proportions and characteristics of those who were not motivated for treatment for psychiatric symptoms and substance use. We also examined the proportion of patients who became motivated for treatment after about one year, and investigated how this change was related with clinical outcome.

Of the 253 patients included, at baseline 34% were unmotivated for treatment of their psychiatric symptoms and 60% were unmotivated for treatment of their substance use; 28% were unmotivated for both. During follow-up we found that 47% of these patients became motivated for treatment of psychiatric symptoms and 38% for treatment of substance use. Those who remained unmotivated benefited less from treatment. Most patients appeared to become motivated for psychiatric treatment before becoming motivated to reduce substance use.

The second study investigated the effects of involuntarily admission in terms of psychosocial outcome and treatment motivation. We hypothesized that involuntary admission would be associated with improved psychosocial outcome and would not adversely affect their treatment motivation.

During the observation period, 77 patients (30% of the 260 ACT patients) were admitted involuntarily. Relative to those who were not admitted involuntarily, they improved significantly in HoNOS total scores and in motivation for treatment. Patients who were not admitted involuntarily had better HoNOS and motivation scores at baseline, but did not improve. We concluded that, on average, involuntary admission in the context of ACT was associated with improvements in psychosocial outcome and motivation for treatment. However, it should be noted that there may be differences between subjectively reported outcome (for example quality of life, on which we did not reported in the study) and outcome as assessed by clinicians in terms of psychosocial functioning. The results nonetheless supported the claim that involuntary admission, even though it naturally remains an *ultimum remedium*, can be used to support treatment outcome.

Part 5: General discussion

In this chapter we discussed the main findings of the studies, and concluded that, over the last decade, increasing awareness of the importance of external validity in evaluation has brought considerable momentum to outcomes research. It is therefore relevant to study whether the patients' health improves when they are treated by ACT teams. However, as we describe in Part 2, we realize that the use of ROM data for research purposes has serious methodological limitations, including a selection bias of patients requiring long term ACT.

In the outcome studies presented in Part 3, we found evidence that a substantial proportion of patients in contact with assertive outreach services improved, and that there is hope for patients suffering from a complex SMI to overcome their problems. However, on average, most of the health gains seemed to have been concentrated in the first period of ACT. The studies also showed that there was a large proportion of non-responders within the ACT patient population (i.e. of people who do not regain remission at all). These patients remain in ACT and constitute a group with severe and – as yet – treatment-resistant problems. To achieve better treatment results, we recommend the implementation of interventions targeting substance use or motivation for treatment.

We also found indirect evidence that, to achieve functional remission, it does not seem necessary first to focus on regaining symptomatic remission; this may have been a result of our operationalization of functional remission. In addition, functional remission, not symptomatic remission, was associated with better quality of life. This indicates that our assessment of functional remission using the HoNOS is relevant for clinical practice.

In our studies on motivation for treatment, we found that this factor plays an important role in treatment outcome. Our studies also showed that a substantial proportion of patients were unmotivated for treatment and that it may take several years before they finally become motivated.

Part 5 is concluded with a discussion on the strengths and limitations of the studies. We stress that no causal conclusions can be drawn on the basis of the studies described in this thesis. As our study design lacked experimental elements, we were also unable to test the effectiveness of ACT under the most ideal conditions. Several factors may therefore have influenced the treatment outcomes and had a different – perhaps even counteractive – effect on the estimates. The first factor, a selection bias of non-responders, may have produced an underestimation of treatment success. The second and third, which are related to the omission of assessments of patients in acute crisis or those refusing treatment, may overestimate treatment success (i.e., giving the false impression of few patients in acute crisis), while underestimating the overall severity of the patient group.

Besides these limitations, it is important to note that our studies comprised representative samples of difficult-to-engage patients. We were therefore able to provide reliable estimates of relevant outcomes, from a “real world” healthcare setting which helps us to understand what is achieved in daily practice. We can now value what has been achieved and judge whether the services were successful.

Samenvatting

Deel 1: Introductie en doelen van het proefschrift

Assertive Community Treatment (ACT) is het best onderzochte organisatiemodel voor de behandeling van patiënten met ernstige psychiatrische aandoeningen die niet gemotiveerd zijn voor behandeling. De eerste studies die de effecten van ACT hebben onderzocht zijn uitgevoerd in de VS. Deze studies toonden aan dat ACT, vergeleken met standaard zorg, beter was voor het in zorg houden van patiënten, en leidde tot minder opnamedagen en beter psychosociaal functioneren. Echter, recentere Europese studies lieten minder gunstige effecten zien van ACT, al toonden sommige studies wel aan dat ACT beter was dan standaard zorg ten aanzien van het in zorg houden van patiënten. Het feit dat de Europese studies, voor een belangrijk deel uitgevoerd in het Verenigd Koninkrijk, vrijwel geen verschillen lieten zien tussen ACT en standaard zorg kan mogelijk verklaard worden doordat de standaard zorg in deze studies al veel elementen van ACT bevatte, maar anderzijds mogelijk ook doordat de ACT conditie minder modelgetrouw was.

Boven bedoelde studies betroffen gerandomiseerde onderzoeken met controlegroepen (RCT's). Dit type onderzoek geldt als de gouden standaard binnen het wetenschappelijk onderzoek, omdat de effecten die in deze studies worden gevonden zijn toe te schrijven aan de interventie. Echter deze studies hadden ook beperkingen, zoals een relatief korte follow-up periode, kleine aantallen patiënten en veel patiënten die weigerden mee te werken aan het onderzoek. Daarnaast is de getrouwheid aan het ACT-model in deze RCT's vaak van een hoger niveau dan in de dagelijkse praktijk. Deze factoren zorgen voor een kloof tussen de kennis over effecten van behandeling verkregen uit RCT's en de dagelijkse praktijk. Om deze kloof te overbruggen is naast kennis uit RCT's ook kennis uit de dagelijkse praktijk nodig, waarbij de meetgegevens verkregen worden bij 'real life' patiënten. Gegevens die verzameld worden in het kader van routine outcome monitoring (ROM; periodiek meten van toestand van patiënt tijdens behandeling) kunnen hiervoor gebruikt worden. Echter, hoewel we concluderen dat kennis van beide typen onderzoek (RCT's en ROM) nuttig zijn voor het maken van een inschatting over de behandeleffecten van ACT, is het erg lastig om deze kennis aan elkaar te koppelen. Dit komt doordat er verschillen kunnen zijn tussen gegevens verzameld door middel van RCT's en ROM procedures in (a) patiënten populaties, (b) kenmerken van de setting en de behandeling, (c) duur van de follow-up en (d) uitkomst maten.

Om de behandelresultaten van ACT in de dagelijkse praktijk te onderzoeken, hebben we enkele studies gedaan die ACT evalueren aan de hand van ROM data (verkregen in de periode van 2002 tot 2011). Het doel van deze studies was drieledig: (1) onderzoeken of er sprake was van een selectie bias in de ROM data en zo ja, hoe dit de beoordeling van behandeluitkomsten van ACT kon beïnvloedden, (2) het beschrijven van behandelresultaten bij (a) patiënten in ACT teams en (b) patiënten die tijdens ACT onvrijwillig waren opgenomen; en exploreren welke factoren een bijdrage leverden aan een goede of een slechte uitkomst, (3) bepalen in hoeverre problemen met motivatie voor behandeling zich voordeden bij ACT patiënten, en of de problemen met motivatie na 1 jaar behandeling verbeterden en welke impact dat had op behandeluitkomsten.

Deel 2: Uitkomstmetingen

In het 2^{e} deel werden methodologische problemen onderzocht die zich voor kunnen doen bij het gebruik van ROM data voor onderzoeksdoeleinden. Een van de problemen is selectiebias. Uit het onderzoek kwam naar voren dat een langere behandelduur in ACT samenhing met diagnose (psychotische stoornis en/of middelengebruik) en meer psychosociale problemen op baseline. Ook toonden we aan dat er verschillen bestonden tussen groepen met een korte, middellange en lang behandelduur, in de relatie tussen baseline en uitkomst variabelen. Deze bevindingen lieten zien dat patiënten met een verschillende behandelduur van elkaar te onderscheiden groepen betreffen. Onderzoek naar lange termijn uitkomsten van ACT kan daardoor beïnvloed worden, doordat er een selectieve groep patiënten bestaat die ACT nodig blijft houden: patiënten met complexe problematiek blijven in ACT. Bij het beoordelen van de effectiviteit van ACT kan hiermee rekening gehouden worden, door de duur van de geleverde zorg als variabele mee te nemen.

Deel 3: Uitkomsten

Het 3^{e} deel bevat twee studies naar behandeluitkomsten van patiënten in ACT. In de eerste studie is bestudeerd welk deel van de patiënten in symptomatische en functionele remissie (SR; FR) kwam. Daarnaast werd onderzocht wat de relatie was tussen het bereiken van remissie en patiëntkenmerken, wat de relatie tussen SR en FR onderling was en hoe ze gerelateerd waren aan de ervaren kwaliteit van leven.

Voor de operationalisatie van FR hebben we gebruik gemaakt van 3 items van de Health of the Nation Outcome Scales (HoNOS; items huisvesting, ADL en sociale contacten).

Uit deze studie bleek dat na een gemiddelde behandelduur van 2.4 jaar 26% van de 278 patiënten met een psychotische stoornis in SR kwam en 30% in FR. Een voorspeller voor deze uitkomsten was een voorschrift van antipsychotische medicatie (proxy voor medicatiegebruik). SR bleek overigens in deze studie geen voorwaarde te zijn voor het behalen van FR (of vice versa). FR, niet SR, bleek gerelateerd aan een betere kwaliteit van leven.

In de tweede studie naar behandeluitkomsten van ACT hebben we het beloop van het psychosociaal functioneren van 139 patiënten onderzocht (72% was gediagnosticeerd met een psychotische stoornis en alle patiënten waren meer dan 2 jaar in behandeling bij ACT). Uit deze studie bleek dat het psychosociaal functioneren van de ACT patiënten verbeterde, echter de verbetering concentreerde in de eerste periode van behandeling. Daarna stabiliseerde het niveau van psychosociaal functioneren, waardoor het groepsgemiddelde nauwelijks veranderde. Middelengebruik, een leeftijd boven de 30 (proxy voor ziekteduur), problemen met motivatie voor behandeling en een laag opleidingsniveau waren factoren die samenhingen met meer psychosociale problemen. Opvallend was dat de patiënten populatie hoofdzakelijk bestond uit mannen, maar ook dat bovengenoemde factoren een verschillende impact leken te hebben voor mannen dan voor vrouwen.

Deel 4: Motivatie voor behandeling

Het 4^{e} deel van dit proefschrift richt zich hoofdzakelijk op het concept motivatie voor behandeling en bevat 2 studies. In de eerste studie hebben we onderzocht welk deel van de patiënten met een dubbele diagnose niet gemotiveerd was voor behandeling van psychiatrische en/of verslavingsproblemen. Vervolgens is na 1 jaar ACT beoordeeld welk deel van de patiënten gemotiveerd geraakt was voor behandeling en onderzocht of behandeluitkomsten gerelateerd waren aan verandering in motivatie. De resultaten laten zien dat bij aanvang 34% van de 253 patiënten ongemotiveerd was voor behandeling van psychiatrische symptomen, 60% ongemotiveerd om middelengebruik te veranderen en 28% ongemotiveerd voor beide. Na 1 jaar bleek dat 47% gemotiveerd was geraakt voor behandeling van psychiatrische symptomen en 38% voor het veranderen van middelengebruik. Patiënten die ongemotiveerd bleven hadden minder profijt van behandeling. We hebben aanwijzingen gevonden dat patiënten meestal eerst gemotiveerd raken voor psychiatrische behandeling en daarna voor het veranderen van hun middelengebruik.

In de tweede studie hebben we de effecten onderzocht van een gedwongen opname tijdens ACT op zowel het niveau van psychosociale problemen als de problemen met motivatie voor behandeling. Onze verwachting was dat een opname zowel het psychosociaal functioneren verbeterde als de motivatie voor behandeling. Tijdens de observatieperiode werden 77 (30% van de 260 ACT patiënten) opgenomen. Ten opzichte van de patiënten die niet waren opgenomen verbeterde de HoNOS totaal score (maat voor psychosociaal functioneren) en namen de problemen met motivatie voor behandeling af. Echter deze groep patiënten bleef ernstige problemen houden, net als de patiënten die niet werden opgenomen. De patiënten die niet gedwongen waren opgenomen verbeterden niet op groepsniveau.

Deel 5: Discussie

Tenslotte omvat het 5^{e} deel een algemene discussie van de bevindingen. We hebben geconstateerd dat in het afgelopen decennium er een toenemende bewustwording is voor het belang van externe validiteit van onderzoek, waardoor er meer aandacht ontstaan is voor onderzoek naar de effecten van behandelingen in dagelijkse klinische praktijk. Observationeel onderzoek kan hierin een grote rol spelen omdat dit type onderzoek helpt zicht te krijgen op datgene wat in de dagelijkse praktijk bereikt wordt. Echter dit type onderzoek kent methodologische beperkingen, waaronder een potentiële selectiebias, welke uitvoerig in deel 2 is besproken. Daarin hebben we aangetoond dat patiënten met ernstige problematiek ‘geselecteerd worden’ voor een langere behandeling binnen ACT.

Het 3e deel van dit proefschrift bestaat uit 2 onderzoeken naar behandeluitkomsten van ACT patiënten. De resultaten van deze studies laten zien dat een deel van de ACT patiënten kan profiteren van behandeling. Echter, de gezondheidswinst heeft voornamelijk plaats gevonden in de eerste periode van behandeling. Dit betekent dat er tegelijkertijd ook veel patiënten in ACT blijven die niet of weinig reageren op behandeling en geen remissie van symptomen of functioneren bereiken. Om betere uitkomsten te bereiken wordt aanbevolen om het behandelaanbod te verbeteren ten aanzien van middelengebruik en problemen met motivatie voor behandeling. Daarnaast zijn er aanwijzingen gevonden dat het niet nodig is om in de behandeling eerst SR te bereiken en dan pas FR. Echter deze bevinding is nauw verbonden aan onze assessment van FR (hooguit beperkte problemen met sociale contacten en een voldoende niveau van ADL en woonomstandigheden). Wanneer het hebben van werk ook onderdeel van FR was, zouden waarschijnlijk minder patiënten FR hebben bereikt en zal FR zich anders verhouden tot SR. Toch is onze assessment van FR relevant, aangezien FR en niet SR samenhangt met ervaren kwaliteit van leven. Daarnaast wordt de HoNOS, het instrument dat we voor FR hebben gebruikt, (inter)nationaal al routinematig afgenomen en dat maakt het gebruik van dit instrument voor de routinematige assessment van FR aantrekkelijk.

Het vierde deel omvat studies naar motivatie voor behandeling en de invloed die problemen met motivatie voor behandeling hebben op behandeluitkomsten. Deze studies laten zien dat er na 1 jaar ACT een grote groep patiënten bestaat die nog steeds niet gemotiveerd is voor behandeling. Dit betekent dat het soms meerdere jaren kan duren voordat ACT patiënten gemotiveerd raken voor behandeling. Verder hebben we aangetoond dat bij gedwongen opnames tijdens ACT zowel het psychosociaal functioneren als de motivatie voor behandeling verbeterde. Afsluitend hebben we uitdrukkelijk gesteld dat op basis van de uitgevoerde studies geen causale verbanden aangetoond kunnen worden. Dit komt doordat in de onderzoeken experimentele elementen ontbreken. Hierdoor kunnen de resultaten worden beïnvloed door storende factoren, bijvoorbeeld wanneer vooral patiënten met complexe problemen langdurig in ACT blijven. Zo kon er een selectie van patiënten ontstaan met een relatief ongunstige behandelprognose. Dit kan ertoe leiden dat het behandeleffect van ACT wordt onderschat. Daarnaast kunnen ook andere storende factoren van invloed zijn. Er zijn namelijk relatief weinig assessments afgenomen van patiënten in acute crisis en van hen die contact met hulpverleners van ACT blijvend hebben geweigerd. Dit kan onterecht het beeld wekken van behandelsuccessen en tegelijkertijd de ernst van de problematiek onderschatten.

Door deze factoren zijn we niet in staat het definitieve antwoord te geven op de vraag naar: ‘de behandeluitkomst’. Echter doordat deze studies een grote groep ACT patiënten bevatten en komen uit de alledaagse praktijk van ACT, geloven we dat deze studies eraan bijdragen om te begrijpen wat in de dagelijkse praktijk van ACT bereikt wordt. Dit is een belangrijk gegeven omdat we zo niet alleen in staat zijn om ACT beter op zijn waarde te schatten, maar ook om te beoordelen of we met onze behandelingen op de goede weg zijn.

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My concluding words turn to those who are the subject of this thesis, the people who struggle day in and day out with a chronic illness; I truly hope that they may receive the treatment they need and go on to live full and healthy lives in the community.

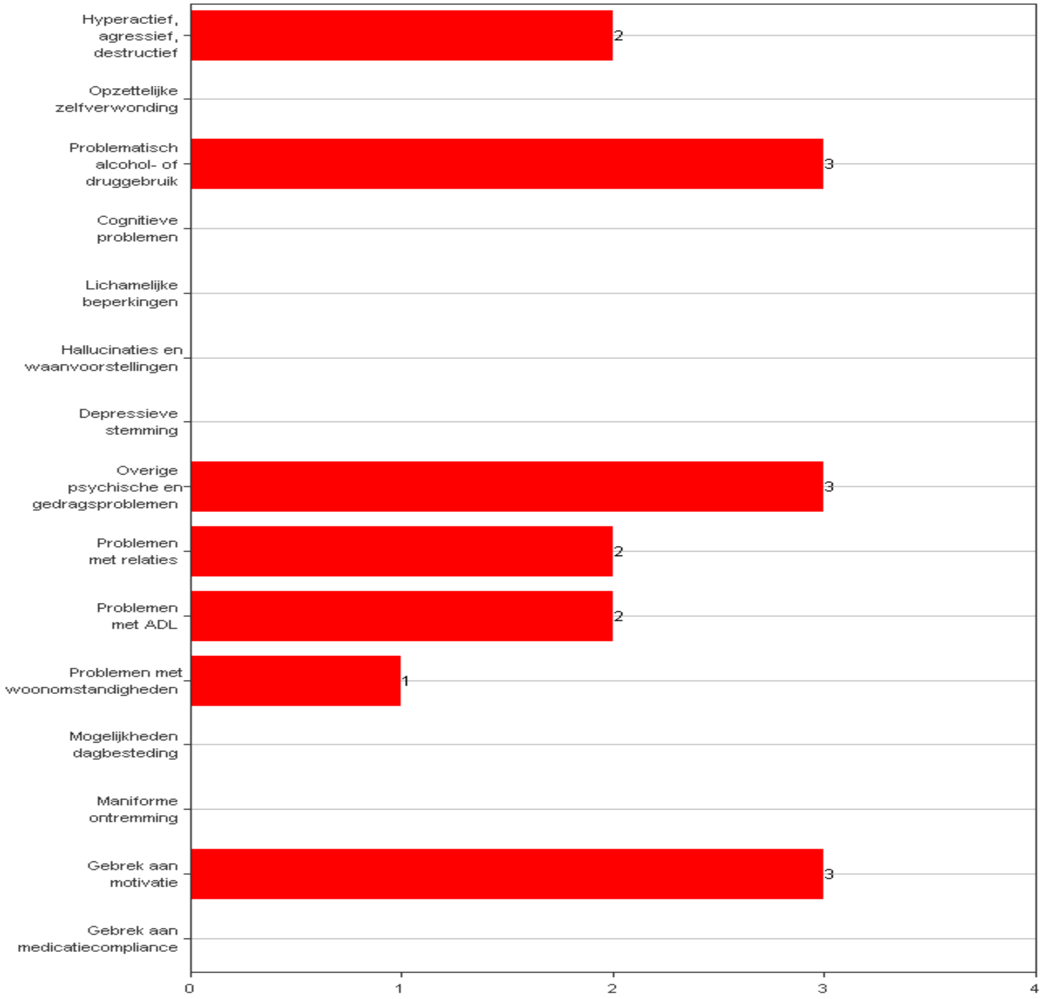
Appendix I - Example of computerized ROM record

Basisgegevens (PBG) (score van 1 meting)

Hoe zijn de gegevens verzameld?	Score	Antwoord
HoNOS	0	interview met cliënt
remissietool	0	interview met cliënt
CANSAS	0	interview met cliënt
veiligheid / geweld	0	interview met cliënt
QOL / tevredenheid met zorg	2	ontbreekt

HoNOS (Health of the National Outcome Scales): Totale bevolking (score van meting)

Meting: huidige meting (01-04-2011)



Legenda HoNOS score
0 = geen probleem 1 = ondergeschikt probleem, vereist geen actie 2 = licht probleem, maar duidelijk aanwezig 3 = matig ernstig probleem 4 = ernstig tot zeer ernstig probleem

HoNOS (Health of the National Outcome Scales) (score van huidige meting)

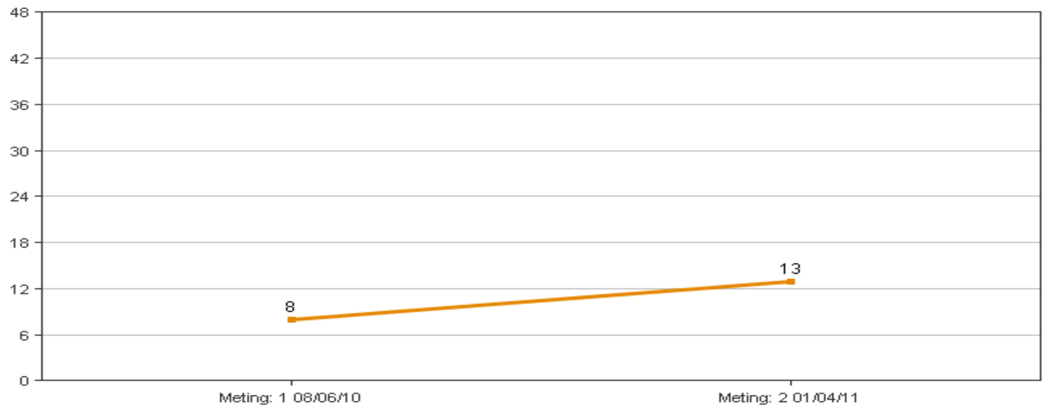
Item 8 HoNOS	Welk probleem (nr. probleem)	Welk probleem (naam probleem)
' Welk overig psych. of gedragsprobl. '	4	Gespannenheid

HoNOS (Health of the National Outcome Scales) (scores)

Schaal	Score Meting: 1 08-06-10	Score Meting: 2 01-04-11
01 Hyperactief, agressief, destructief	1	2
02 Opzettelijke zelfverwonding	0	0
03 Problematisch alcohol- of druggebruik	3	3
04 Cognitieve problemen	0	0
05 Lichamelijke beperkingen	0	0
06 Hallucinaties en waanvoorstellingen	0	0
07 Depressieve stemming	0	0
08 Overige psychische en gedragsprobl.	0	3
09 Problemen met relaties	1	2
10 Problemen met ADL	2	2
11 Problemen met woonomstandigheden	1	1
12 Mogelijkheden dagbesteding	0	0
add1 Manifiorme ontremming	0	0
add2 Gebrek aan motivatie	2	3
add3 Gebrek aan medicatiecompliance	0	0

HoNOS (Health of the National Outcome Scales)   (score verloop metingen)

HoNOS totaalscore



Remissietool (op basis van PANSS) (score verloop metingen)

Symptomatische remissie	Score Meting: 1 08-06-10	Score Meting: 2 01-04-11
Aantal items boven de 3	0	0

Legenda remissietool

De patiënt heeft geen schizofrenie of is in symptomatische remissie als het 'aantal items boven de 3' bij twee opeenvolgende metingen 0 is.

GAF schaal - Symptomen en Handicap/Belemmeringen (scoreverloop)

Schaal	Score Meting: 1 08-06-10	Score Meting: 2 01-04-11
GAF symptomen	45	41
GAF belemmering	45	41

CANSAS (Onvervulde zorgbehoeften (huidige meting))

Schaal (range)	Score	Behoefte
ADL (0-4)	0	Voorzien
GGZ (0-10)	3	Behoeftig
Rehabilitatie (0-7)	4	Zeer behoeftig
Voorzieningen (0-6)	0	Voorzien
Totaalscore (0-27)	7	Behoeftig

CANSAS (Zorgbehoeften en onvervulde zorgbehoeften)

CANSAS (score op itemniveau)

Item	Score Meting: 1 08-06-10	Score Meting: 2 01-04-11
01 Huisvesting	1	1
02 Voeding	0	0
03 Zorg voor het huishouden	0	0
04 Zelfverzorging	0	0
05 Activiteiten overdag	2	2
06 Lichamelijke gezondheid	0	0
07 Psychotische symptomen	0	0
08 Informatie over ziekte en behandeling	0	0
09 Psychisch onwelbevinden	2	2
10 Veiligheid van de persoon zelf	0	0
11 Veiligheid voor anderen	0	0

CANSAS (score op itemniveau)

Item	Score Meting: 1 08-06-10	Score Meting: 2 01-04-11
12 Alcohol	2	2
13 Drugs/medicatie	2	2
14 Gezelschap	0	2
15 Intieme relaties	0	0
16 Beleving van de sexualiteit	0	0
17 Zorgen voor de kinderen	0	0
18 Elementair onderwijs/educatie	0	0
19 Telefoon (communicatie)	0	0
20 Vervoer (mobiliteit)	0	0
21 Geld	1	1
22 Uitkering	1	1
23 Betaald werk	2	2
24 Bijwerkingen van medicatie	0	0
25 Zingeving en herstel	2	2
26 Juridisch	0	0
27 Slaap	0	0

Legenda CANSAS score

0 = geen zorgbehoefte
1 = wel zorgbehoefte, maar (structureel) bevredigend opgelost
2 = wel zorgbehoefte, maar geen of een onbevredigende oplossing

QOL en tevredenheid met zorg (score)

Hoe tevreden bent u met... (range 1-7)	Score Meting: 1 08-06-10	Score Meting: 2 01-04-11
1 Woonsituatie	4	5
2 Sociale relaties	4	5
3 Lichamelijke gezondheid	4	5
4 Psychische gezondheid	4	5
5 Financiële situatie	1	3
6 Werksituatie	1	3
7 Leven als geheel	4	5
8 Professionele hulp	4	3

About the Author

Curriculum Vitae

Hans Erik Kortrijk is geboren op 20 december 1982 te Smallingerland. Hij heeft zijn HAVO diploma behaald in 2000 aan de R.S.G. ‘t Slingerbos te Harderwijk en zijn VWO diploma heeft hij behaald in 2001 aan Landstede te Harderwijk. Daarna heeft hij zijn studie psychologie (specialisatie neuropsychologie) afgerond in 2005 aan de Universiteit van Utrecht.

Na zijn studie heeft hij in 2006 gewerkt als groepsleider bij de TBS kliniek de Kijvelanden en is vanaf eind 2006 werkzaam als psycholoog en onderzoeker bij Bavo-Europoort. Vanaf 2008 verricht hij wetenschappelijk onderzoek naar Assertive Community Treatment aan de hand van routine outcome monitoring data. Sinds 2009 is hij binnen Bavo-Europoort als psycholoog werkzaam in een polikliniek (Illness Management en Recovery team) alwaar hij zijn opleiding tot GZ-psycholoog in 2012 heeft afgerond. Ook is hij sinds 2009 tot 2012 werkzaam geweest bij Delta Psychiatrisch Centrum als onderzoeker. Naast patiëntenzorg en onderzoek is hij actief in diverse werkgroepen rondom de voortgang en vormgeving van ROM.

PhD Portfolio

Name PhD student:	Hans Kortrijk
PhD period:	2008-2012
Erasmus MC Department:	Psychiatry
Promotor:	Prof. dr. C.L. Mulder
Research School:	O3 Research Center

PhD training	**Year**
Research skills	
Repeated Measurements in Clinical Studies	2009
Presentations	
Bavo-Europoort - several feedback presentations in ACT teams	2008-2010
ACT congres - workshop: “ROM bij ACT”	2008
Bavo-Europoort - presentation: “ROM bij ACT”	2009
Delta - symposium - workshop: “ROM SMI”	2009
Delta - presentation: “ROM in Delta”	2009
GGZ-Nederland - presentation: “ROM & feedback”	2009
Nationale remissie werkgroep - presentation research	2011
Bavo-Europoort - presentation research	2011
GGZ-Nederland - presentation: expertgroep EPA	2011
GGZ Nederland - workshop: “effectmaten bij ROM”	2012

Teaching	**Year**
Training	
Training for trainers HoNOS - The Royal College of Psychiatrists	2008
HoNOS training provided at multiple sites in the Netherlands	2008-2010
Post-master training as GZ-psychologist	2009-2012
Supervision PhD	2008-2012
Workshop – “hoe geef ik een workshop”	2010
Workshop – “Get the best out of your PhD!”	2012
Training “Illness Management and Recovery”	2011

Teaching	**Year**
Training	
Training "Werken met families - gezinsinterventies bij ernstige psychiatrische stoornissen"	2012
Training "Motiverende Gespreksvoering"	2012

Other activities	**Year**
Editorial work	
Webpage psychiatrienet – ROM	2010-2012
E-learning HoNOS	2010-2011
Working Group and Intervision	
Bavo-Europoort - Working group ROM	2008 – 2012
Bavo-Europoort – Research committee	2011 – 2012
Delta – Working group ROM	2010 – 2012
Parnassia Bavo Groep - Working group ROM	2010 – 2011
Rijnmond - Working group ROM	2010 – 2012
O3 researchmeetings – intervision	2009 – 2012
GGZ-Nederland - expertgroep ROM EPA	2010 – 2012

Publications

Kessels, R.P.C., Kortrijk, H.E,, Wester, A.J., & Nys, G.M.S. (2008). Confabulation behavior and false memories in Korsakoff's syndrome: The role of source memory and executive functioning. *Psychiatry and Clinical Neurosciences, 62*, 220-225.

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