Assertive Community Treatment for Elderly Patients with Severe Mental Illness Jolanda Stobbe

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Effects, care needs, psychosocial functioning and treatment motivation of patients treated in an Assertive Community Treatment elderly team

Jolanda Stobbe

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Effects, care needs, psychosocial functioning and treatment motivation of patients treated in an Assertive Community Treatment elderly team

Assertive Community Treatment voor oudere patiënten met ernstige psychiatrische aandoeningen

Effecten, zorgbehoeften, psychosociaal functioneren en behandelmotivatie bij patiënten behandeld in een Assertive Community Treatment team voor oudere patiënten

Proefschrift

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Fearwol Brandaris! Goeie, ôde toer,

Seinpealdune, Griene Strân.

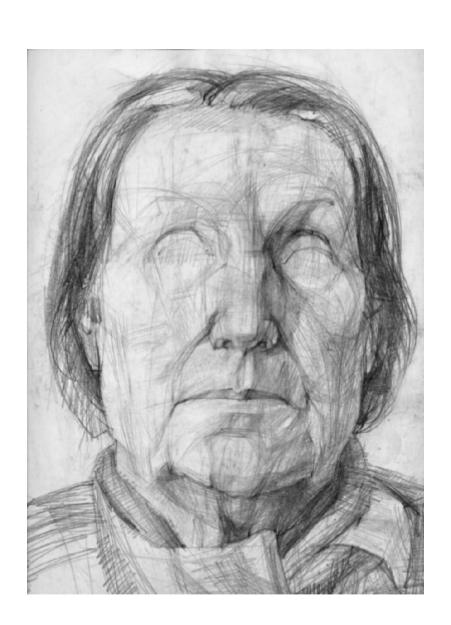
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CHAPTER 1

GENERAL INTRODUCTION

healthcare service for elderly outpatients. She lived alone, had problems with living conditions and had paranoid thoughts. She was socially isolated and difficult-to-engage in treatment. After a few contacts, the community mental-healthcare services discharged her from care, as, due to her lack of illness insight and

perceived needs, she was unwilling to accept help.

involuntary treatment, she was discharged from care again.

to a psychiatric hospital for elderly patients.'

'Mrs J was 72 years old when she was first referred to the community mental-

Two years later Mrs J was again referred for psychiatric outpatient care. The reasons were the same: paranoid thoughts, social isolation, severe problems with living conditions (such as those with basic necessities such as running water). Financial problems were also looming. Due to the waiting list at the community mental-healthcare services, a mental-healthcare worker tried to contact her six months after she had been referred. This failed: once again, Mrs J refused to come to the mental-health institution or accept home visits. There was no caregiver or relative present to talk with her about it. The multidisciplinary team concluded that the patient refused care, and as she met none of the criteria to justify

Eight months later, a court ordered her eviction: due to her paranoid thoughts, she had not paid the rent for a long time. Crisis contact was arranged with a mental-health service. But Mrs J refused contact, barricaded her front door and responded to social workers with agitation. When she became homeless, she was taken into a crisis centre on a voluntary basis — and wanted to leave again after a few hours. Due to her serious psychiatric symptoms, lack of insight, agitated behaviour, homeless situation and lack of treatment acceptance, she was committed

1.1 Preface

The vignette of Mrs J illustrates the type and complexity of problems that can be faced by elderly patients with severe mental illness (SMI) – including lack of motivation to seek help. Problems in several life domains justify the provision of care by a multidisciplinary team. This team provides integrated care, including psychiatric and addiction treatment, social services, housing assistance, help with daytime activities and finance or budgeting services. In order to reach difficult-to-engage patients, clinicians and social workers working with unmotivated SMI patients also use assertive-outreach strategies.

The Dutch consensus group on SMI (1) formulated the following definition of SMI: patients suffer from the combination of a mental illness such as schizophrenia spectrum disorder, bipolar disorder, or persistent severe depression with enduring social problems such as difficulties with practical matters in their day-to-day welfare and environment. While integrated care is needed to promote remission and community participation (1), few multidisciplinary assertive outreach teams to date have provided targeted integrated care for elderly patients with SMI who also have treatment motivation problems. There is also limited evidence of the efficacy of such integrated outreach community mental-health services (2).

Due to demographic changes and the deinstitutionalization of the mental-health services, more elderly patients with psychiatric disorders now live independently in the community (3, 4). However, many of those with SMI do not access the mental-health services (5). They face problems such as stigma, lack of motivation, or lack of insight into their illness (6-8). Often, elderly patients' psychiatric problems also remain unrecognized and untreated, sometimes because general practitioners see psychiatric problems as part of older people's life (9, 10), and sometimes because such patients may express psychiatric symptoms as somatic ones (3, 9). Therefore, elderly patients with SMI often suffer in silence and experience various forms of neglect, functional impairment and unfulfilled mental and social healthcare needs (9, 11, 12). Compared with elderly people without psychiatric disorders (13), those with SMI are more likely to end up in long-term care facilities and nursing homes (14) and to have higher mortality rates. Within this group, there is a subgroup of patients with severe psychiatric disorders – often combined with somatic and social problems – who are difficult-to-engage in treatment due to

treatment motivation problems. As population-based studies do not include this group of elderly SMI patients, the exact numbers who are difficult-to-engage is unknown. Regular outreach mental-health services may not reach them.

1.2 Difficult-to-engage and treatment motivation

Whether adult or elderly, many patients with SMI are not motivated for treatment. Due either to lack of treatment compliance or drop-out from treatment, this can lead to a worse prognosis (15, 16). Various factors have been associated with lower motivation for treatment in adult SMI patients: patient-related factors, such as more severe symptoms, more severe substance-abuse problems, lack of insight or lack of information about their illness, male gender, younger age, and lower education; relationships factors, including lower therapeutic alliance and less family support (17-20); and factors related to the service-delivery system, such as problems accessing care, and lack of information about outreach services (21).

While treatment motivation in elderly SMI patients has barely been investigated, it is known that SMI elderly patients often suffer in silence, experiencing not only various forms of neglect, but also functional impairments and unmet needs with regard to their mental-health and their physical and social functioning (9, 11, 12). Their loss of capabilities for independent living is associated not only with unmet needs regarding daily living activities, but also with problems in accepting or initiating contact with others, and with problems asking for professional and other kinds of help (12, 22, 23). Due to their lack of perceived needs and the corresponding lack of motivation for treatment, a subgroup of SMI elderly patients has been found to be difficult-to-engage in mentalhealth services (24, 25). If they do not enter the mental-health system, they may deteriorate further, sometimes causing dangerous situations such as self-neglect and social breakdown.

Relative to adults with SMI, their elderly counterparts were found to have more needs related to physical problems, medication management, self-care (26), household skills, accommodation and food (27). Elderly SMI patients thus need support across the full range of psychosocial functioning. They particularly seem to need integrated care,

including treatment of psychiatric, addiction and somatic problems, as well as help with social, housing and financial problems, and the activities of daily living.

1.3 Integrated care

In the United Kingdom, various models have been proposed to integrate health and social services for older people. Psychiatric care was also integrated into primary care, and community mental-health teams were developed specifically for older people. Whereas research showed that older non-SMI patients benefited from integrated medical and social health-care (which reduced the number of general hospital admissions, and also improved health outcome and satisfaction with the services), there is little evidence that integrated psychosocial services affect elderly patients with SMI (28).

In adult mental-healthcare, Assertive Community Treatment (ACT) was developed as an integrated model to meet the needs of difficult-to-engage SMI patients with complex problems. As well as psychiatric, addiction and somatic care, ACT provides social care in order to support patients' ability to live in the community (29). But although in the United States (US) ACT reduced hospital admissions and led to more stable housing its effects on symptoms or social functioning were no more beneficial than those of treatment as usual (TAU) (29, 30). In Europe, however, studies investigating ACT did not show any beneficial effects with regard to lower admission rates or better clinical outcomes. ACT was found to engage patients in treatment more successfully than TAU (31-33). Due to the time-unlimited services of ACT (whereby care is provided as long a patient needs it), and also to the increasing number of elderly people in the population, the number of elderly SMI patients in these teams is increasing. Despite this phenomenon, few studies have investigated the effects of integrated outreach services for elderly SMI patients.

1.4 Literature review on outpatient mental-healthcare services for difficult-to-engage SMI patients

We used Medline (via OvidSP), PsycINFO (via OvidSP), EMBASE, Web-of-Science, PubMed Publisher and Cochrane Central databases for finding studies on the effectiveness of integrated community mental-health services for difficult-to-engage SMI elderly patients.

The search was supplemented by a manual search of references from relevant literature. Search terms were ordered into four categories. The first encompassed keywords for older age (middle aged, aged, elderly, geriatrics, geriatric care, gerontology, geriatric patient, senior, late life). The second category encompassed terms for severe mental illness (e.g. bipolar disorder, psychosis, schizophren*, dual disorder, chronic* mental*, psychiatr*, depress*). The third category included terms for community mental healthcare (community mental health, community mental-health centre, integrated healthcare system, outpatient care, ambulatory care, community care, psychosocial rehabilitation, outpatient, outreach*). The last category included terms for treatment motivation (motivation, patient compliance, avoidance behaviour, alliance, unmotivat*, noncomplian*, nonadheren*, engag*, dropout*).

1.4.1 Review method

The review included randomized controlled trials (RCT) as well as observational studies. Studies were limited by language to those in English, Dutch and German. Papers were excluded if the patients did not meet our inclusion criteria, for example if the study did not focus on subjects over 50 years of age, if it focused on patients with other mental illnesses such as dementia, primary drug or alcohol problems, if it focused on special subgroups such as veterans or migrants, or if it focused on patients without persistent impairment in several areas of functioning, or on patients in institutional settings. Articles were also excluded if the intervention was purely pharmacological or if they focused on a specific non-pharmacological technique (e.g. cognitive behaviour therapy or social skills training). We described the study design, characteristics of the study population, the mental-health service, and the impact of the services on outcome.

1.4.2 Selection of trials

In total, 2389 papers were identified, 2130 of which were excluded on the basis of the criteria stated above. Two hundred fifty-nine full-text articles were assessed for inclusion. We found one publication that focused on difficult-to-engage elderly patients, which we included in this study even though it did not indicate the severity of the psychiatric illness (34) – an inclusion criterion we later dropped due to the lack of studies about difficult-to-

engage elderly SMI patients. We identified one RCT (35) and three observational studies (34, 36, 37). Due to the lack of similarity among study designs and outcome measurements, and due also to the low number of studies available, only a narrative review was carried out.

1.4.3 Results of literature review

Table 1 summarizes studies on the effectiveness of community mental-health services for elderly SMI patients. All studies were conducted in the US. Two focused on elderly patients with schizophrenia or schizoaffective disorders (35, 37), and one included mainly patients with major depression (36). The last study included mainly patients with affective disorders (34).

The studies varied with respect to type of community mental-health service and the disciplines included in the team. The intervention in the study by Kohn et al (2010) consisted of psychiatric, medical, and social interventions, including home visits to provide ongoing treatment focusing on psychopharmacological, psychotherapeutic, psychosocial, and family interventions. The multidisciplinary team consisted of a psychiatrist, a doctor of internal medicine, psychiatric social workers, a mental-health aide, a gerontologist, and medical students; as well as workers in nursing, occupational therapy, social work and public health.

The intervention in the study by Levin and Miya (2008) comprised ACT for the elderly (ACTE). ACTE had a staff-to-member ratio of 1:10. The team used shared caseloads and met every morning to discuss patients. Services were directed by a personal care plan made by the team and the client together. Services were based on a psychosocialrehabilitation philosophy, which focused on recovery and strengths rather than on illness and disability. The multidisciplinary team consisted of social workers, nurses, a psychiatrist, a substance-abuse specialist and an employment specialist.

The intervention in the study by Cummings (2010) was described as casemanagement, individual and group therapy, medication management, family treatment, crisis intervention, and day treatment. Disciplines included social workers, a psychologist, clinical nursing specialist, psychiatric consultant (psychiatrist) and case managers.

The last study was an RCT; the authors did not describe which disciplines were employed in TAU (38) or in the intervention condition (35). The intervention group in this RCT received social rehabilitation and health management components (skills classes, community practice trips and one-to-one meetings with a nurse). Patients in TAU (38) received pharmacotherapy, case management or outreach services from disciplines other than nursing.

The follow-up periods varied from 6 months up to 2.5 years. The mean follow-up period for patients included in the study by Kohn et al (34) was not reported (the second measurement took place upon discharge or at 2.5 years, the close of the study). All studies specified the number of patients lost to follow-up, which ranged between no drop-outs (34) to 43.5% dropouts (36). The outcome variables of all studies were related to functioning and symptoms of patients, except in the study of Levin & Miya, in which the only outcome parameters were the costs, the number of hospital days, and the number of contacts.

A majority of the patients participating in these studies were women; the participants' mean age lay between 60 and 80. In the one RCT, the 'social rehabilitation and integrated healthcare' intervention was, relative to TAU, associated with significant improvement in social skills, community and psychosocial functioning, negative symptoms, and self-efficacy (35). Relative to the pre-intervention periods, the multidisciplinary interventions of the non-controlled observational studies consisted of fewer hospitalizations, fewer days in hospital, and fewer depressive symptoms (36), better global assessment of functioning (GAF) scores (34), and lower costs (37).

Table 1 Description of studies that evaluated community mental-healthcare services for elderly SMI outpatients

| | Kohn et al 2002 | Levin & Miya 2008 | Cummings 2009 | Mueser et al. 2010 |
|-----------------------------|--|--|---|--|
| Study | Treatment of Homebound Mentally ill Elderly Patients | Assertive Community Treatment for older adults | Treating Older Persons with Severe Mental Illness in the Community | Randomized Trial of Social Rehabilitation and Integrated Health Care for Older People (HOPES) with Severe Mental Illness |
| Study design | Observational Pre-post assessments | Observational Pre-post assessments | Observational Pre-post assessments | RCT comparing HOPES with treatment as usual (38). |
| Patients | N = 93 | N = 42 | N = 69 | N = 183 |
| Lost to follow-up | N = 0 | N = 11 (26.2%) | N = 30 (43.5%) | N = 34 (18.6%) |
| Follow-up period | Various (up to 2.5 years) | 1 year | 6 months | 2 years |
| Setting | Single centre study | Single centre study | Single centre study | Multicentre study |
| Team included | Psychiatrist, internal medicine physician, social psychiatric workers, mental- health aide, gerontologist, students in medicine, nursing, occupational therapy, social work and public health | Social workers, nurses, psychiatrist, substance abuse specialist, employment specialist | Social workers, psychologist, clinical nurse specialist, psychiatric consultant (psychiatrist), case managers | Not described |
| Outcome Variables | Degree of being homebound Global Functioning Medical disorders Level of activities of daily living Extent and intensity of interventions | Number of hospital days Mean number of contacts Aim of the contacts Costs | Severity of Depression Life satisfaction Health Acute care utilization Service utilization | Functional Skill Performance Psychosocial functioning Self-efficacy Negative symptoms Cognitive functioning |
| Assessment | Semi-structured interview | Count of hospital admissions + days, count of number (and aim) of contacts and count of cost of care | Semi-structured interview | Semi-structured interview |
| Measurement Instruments* | Reasons for homebound (self developed) DSM III – TR, GAF, MMSE, Katz Index | None | GDS, LSS, HsSIADL, Acute care utilization Service utilization | UPSA, MCAS, SBS, ILLS,UPSA, RSES,SANS, DKEFS, CVLT-II |

^{*} DSM III-TR = Diagnostic and Statistical Manual of Mental Disorders, third revised edition; GAF = Global Assessment of functioning; MMSE = Mini-Mental State Exam; Katz Index = Katz Index of Activities of Daily Living Scale for Instrumental Activities of Daily Living; GDS = Geriatric Depression Scale; LSS = Life Satisfaction Scale; HsSIADL = Health status Scale for Instrumental Activities of Daily Living; UPSA = University of California at San Diego Performance-Based Skills Assessment; MCHA = Multnomah Community Ability Scale; SBS = Social Behavior Scale; ILSS = Independent Living Skills Survey; RSES = Revised Self- efficacy Scale; SANS = Scale for the Assessment of Negative Symptoms; DKEFS = Delis-Kaplan Executive Functioning System; CVLT-II = California Verbal Learning Test—II

Table 1 (Continued) Description of studies that evaluate community mental-healthcare services for elderly SMI

| Kohn et al 2005 | Levin & Miya 2008 | Cummings 2009 | Mueser et al 2010 |
|--|---|---|---|
| 79.7 years | 60 years | 66.5 years | HOPES (n = 76): 60.3 years TAU (n = 73): 60.1 years |
| Female: 76.3% | Female: 57% | Female: 81.2% | HOPES Female: 58.9% TAU Female: 57% |
| Mostly affective disorder and dementia: both 33.3% | Schizophrenia 57% Schizoaffective disorder: 36% | Depression: 67.2% | HOPES Schizophrenia/ Schizoaffective: 54.5% TAU Schizophrenia/ Schizoaffective: 58.1% |
| Increase in GAF score and accepting home care Less Psychiatric disability in homebound mentally ill elderly patients | ACTE reduced hospitalization and costs ACTE is promising model to meet the needs of older adults with SMI | A decrease in depressive symptoms, in psychiatric hospitalization and a increase in life satisfaction | Significant improvement for older adults assigned to HOPES compared with TAU in performance measure of social skill, psychosocial and community functioning, negative symptoms and self-efficacy |
| Lack of a control group Small number of participants Limited number of outcome measures | Lack of a control group Small number of participants No assessment of functioning | Lack of a control group Small number of participants Limited follow-up period | Two-third of the invited patients declined to participate in the study; there is no information about this group |
| | 79.7 years Female: 76.3% Mostly affective disorder and dementia: both 33.3% Increase in GAF score and accepting home care Less Psychiatric disability in homebound mentally ill elderly patients Lack of a control group Small number of participants Limited number of | 79.7 years 60 years Female: 76.3% Female: 57% Mostly affective disorder and dementia: both 33.3% Schizophrenia 57% Schizoaffective disorder: 36% Increase in GAF score and accepting home care Less Psychiatric disability in homebound mentally ill elderly patients Lack of a control group Small number of participants No assessment of functioning | 79.7 years 60 years 66.5 years Female: 76.3% Female: 57% Female: 81.2% Mostly affective disorder and dementia: both 33.3% Schizoaffective disorder: dementia: both 33.3% ACTE reduced hospitalization and costs ACTE is promising model to meet the needs of disability in homebound mentally ill elderly patients ACTE is promising model to meet the needs of older adults with SMI in psychiatric hospitalization and a increase in life satisfaction Lack of a control group Small number of participants No assessment of participants Limited number of functioning Limited follow-up |

1.4.4 Discussion of the literature

There are very few data on the effectiveness of outreach mental-health services for SMI elderly patients. Most studies did not include difficult-to-engage elderly patients with SMI. One single RCT on social rehabilitation with health-management components for such patients found positive outcomes in social skills, psychosocial and community functioning, negative symptoms and self-efficacy (35). In addition, three non-controlled observational studies suggested that their multidisciplinary community mental-healthcare services produced potential benefits (34, 36, 37). However, since these studies used no control groups, and had small numbers of participants, the results are of limited value. Neither may their findings be generalizable to other service settings or cultures: the studies were all conducted in the United States, and only the study by Mueser et al (2010) was a multicentre study. In that study, however, two-thirds of the invited patients

refused to participate, with selection bias as a possible consequence. Weak study designs and a paucity of literature mean that there is little evidence on the effectiveness of community of mental-healthcare for elderly SMI patients.

1.5 Aims of the thesis

The overall aim of this thesis was to investigate the effects of multidisciplinary and integrated treatment for elderly patients with SMI who are difficult-to-engage in treatment. We chose ACT as the model of multidisciplinary and integrated outpatient care. Our first specific objective was to compare the effectiveness of Assertive Community Treatment for elderly patients (ACTE) with that of TAU (38). For this, we used an RCT design in the setting of the outpatient care department for elderly patients at BavoEuropoort, a department of Parnassia Psychiatric Institute, a mental-healthcare centre in the Netherlands.

After a description of the study protocol of this RCT in Chapter 2, Chapter 3 describes the main results of the RCT, in which we hypothesised that, relative to TAU, ACTE would 1.) succeed in establishing contact with more patients within 3 months of their signing up for care, 2.) have fewer dropouts, 3.) have a better effects on patients' psychosocial functioning (the primary outcome variables); 4.) would meet patients' unmet needs more effectively, and 5.) would reduce mental-healthcare use (secondary outcome variables).

Chapter 4 compares less-motivated and more-motivated SMI elderly patients treated in ACTE with respect to baseline characteristics and clinical factors. In this crosssectional study we tested the hypothesis that less-motivated elderly SMI patients had greater unmet care needs than more-motivated ones, had different types of unmet need, and had more psychosocial problems.

In adult mental-healthcare, meeting patient-rated unmet needs has been shown to lead to better patient-rated treatment adherence (39). In Chapter 5 we therefore investigated in SMI patients treated in ACTE whether a decrease in unmet needs over time was associated with changes in treatment motivation during the same time period (parallel association); and whether a decrease in unmet needs would precede an increase in treatment motivation (sequential association).

As most studies of ACT have been conducted in adults, we investigated and described predictors of outcome in ACT for elderly patients (Chapter 6). We hypothesized that poor treatment outcome was associated with the following: a psychotic disorder (relative to non-psychotic disorders) (23); comorbid somatic problems (relative to patients without somatic problems) (9); a lower level of education (relative to a higher level); and a lack of treatment motivation at baseline (relative to more motivated patients) (40).

Finally, we were interested in whether our ACTE team had a specific group of patients that justified a specific ACT team for elderly people with SMI who are difficult-toengage. Taking a reference group consisting of patients aged 55 years and older who were treated by an ACT team especially for elderly SMI patients, Chapter 7 therefore describes the differences with regard to the met and unmet needs and psychosocial functioning of a similar age group who were being treated by an ACT adult (ACTA) team.

The general discussion (Chapter 8) presents our conclusions and interpretations of the studies, and this chapter ends with the summary, acknowledgements, references, PhD Portfolio and list of publications.



CHAPTER 2

Assertive Community Treatment for elderly people with severe mental illness – study protocol

ABSTRACT

Background: Adults aged 65 and older with severe mental illnesses are a growing segment of the Dutch population. Some of them have a range of serious problems and are also difficult-to-engage. While Assertive Community Treatment is a common model for treating difficult-to-engage severe mental illnesses patients, no special form of it is available for the elderly. A special Assertive Community Treatment team for the elderly is developed in Rotterdam, the Netherlands and tested for its effectiveness.

Methods: We will use a randomized controlled trial design to compare the effects of Assertive Community Treatment for the elderly with those of treatment as usual. Primary outcome measures will be the number of dropouts, the number of patients engaged in care and patient's psychiatric symptoms, somatic symptoms, and social functioning. Secondary outcome measures are the number of unmet needs, the subjective quality of life and patients' satisfaction. Other secondary outcomes include the number of crisis contacts, rates of voluntary and involuntary admission, and length of stay. Inclusion criteria are aged 65 plus, the presence of a mental disorder, a lack of motivation for treatment and at least four suspected problems with functioning (addiction, somatic problems, daily living activities, housing etc.). If patients meet the inclusion criteria, they will be randomly allocated to either Assertive Community Treatment for the elderly or treatment as usual. Trained assessors will use mainly observational instruments at the following time points: at baseline, after 9 and 18 months.

Discussion: This study will help establish whether Assertive Community Treatment for the elderly produces better results than treatment as usual in elderly people with severe mental illnesses who are difficult-to-engage. When Assertive Community Treatment for the elderly proves valuable in these respects, it can be tested and implemented more widely, and mechanisms for its effects investigated.

Background

Adults aged 65 plus are a fast-growing segment of the Dutch population. This sharp rise is leading to an increase in the number of elderly people who live on their own and who have psychiatric disorders (3, 41). Just 8%-16% of elderly people with such disorders receive treatment from a healthcare provider (7, 8, 41). This group of older psychiatric patients is not only difficult-to-engage, but often also has a range of serious problems in other aspects of their lives (3). Some of them neglect themselves and their immediate surroundings, and thus live in extreme squalor. Exact numbers of (self)-neglected elderly are not known (11, 42). But elderly in the community with depressive symptoms or cognitive impairment are at risk for development of self-neglect (43) and more than half of the elderly who are neglecting their environment has a psychiatric disorder such as dementia, paranoid disorder, addiction or depression (42). It is unknown whether mental-healthcare services to date are sufficient to help them, e.g. because these patients drop out of care due to the lack of motivation (44, 45), or whether active outreach care, such as Assertive Community Treatment (ACT), is needed.

In adult mental-healthcare, ACT is a much-examined, frequently used organizational model for treating difficult-to-engage patients with severe mental illness (SMI) (46, 47). Particularly in the United States, ACT has been proven to be effective in reducing admissions and making patients' housing status more stable. It improves patients' satisfaction and motivation for treatment (30, 48). A relatively high number of ACT patients also remain in care (49, 50). We think this last observation is very important, since drop out of care may lead to further deterioration. European studies, however, have been less unanimous about the effects of ACT and showed no difference between ACT and treatment as usual (TAU) (38) in terms of psychosocial functioning and hospital admission days (51-53). Part of this discrepancy may be explained by improvements in the quality of TAU in Western Europe (54, 55), but also by the fact that TAU contains some features of ACT (56).

Intervention studies for SMI elderly in the community are rare. Two studies showed that intensive community care given to depressive elderly people (sometimes

with delusions) caused a fall in the number of admissions to a psychiatric unit, stabilization of psychiatric symptoms, and an improvement in quality of life (57, 58) as compared to TAU. Another study showed that psychiatric symptoms and functioning improved when elderly people with psychiatric problems received outreach services rather than office-based ones (8). We found no studies that focused on the effects of ACT for patients' aged 65 and over.

Research aim

Using a randomized controlled trial (RCT) design, we will compare the effects of ACT elderly (ACTE) with those of TAU for elderly patients with SMI who are difficultto-engage in care.

Hypotheses

Our first hypothesis is that ACTE will decrease the number of patients who drop out of care (number of patients who have no registered contact with the services over a period of 3 months and/or the number of patients discharged out of care). The other primary hypotheses include that ACTE will increase the number of patients engaged in care (patients who receive care within 3 months after admission to the team) and will improve patients' psychiatric, somatic and social symptoms. Secondary hypotheses include that ACTE reduce the number of unmet needs more than TAU does. We also expect an increase in patients' subjective quality of life and in patients' satisfaction with mental-health care. Finally we hypothesize that to a greater extent than TAU, ACTE will reduce the number of crisis contacts, reduce voluntary and involuntary admission rates and reduce length of stay in a psychiatric hospital.

Methods - Design

This trial is being funded by BavoEuropoort centre for mental-healthcare, Rotterdam, the Netherlands.

Research design

This RCT will use one intervention group consisting of patients who receive treatment according to ACTE, and one control group consisting of patients who receive treatment according to TAU. We will use a pre-randomized block design, with four patients per block, whereby patients are randomized before they consent to participate, the so-called Zelen's design (59). The design and execution of this study were approved by the Dutch union of medical-ethic trial committees for mental health organizations.

Participants - setting

The study was carried out in the Netherlands by BavoEuropoort centre for mental-healthcare in the greater Rotterdam area (1.3 million residents). BavoEuropoort has 1,300 staff, who are employed at 32 sites in eleven municipalities. It provides treatment and guidance to people in whom complex psychiatric disorders are combined with problems in several life domains. It has various outpatient clinics and clinical settings for voluntary or involuntary admission. There are six ACT teams for patients who are difficult-to-engage in treatment. One of these teams focuses on elderly patients. BavoEuropoort also provides mental-healthcare services for elderly people (55+) in their third and fourth stages of life who have mental-health complaints and/or cognitive disorders. Participants are elderly outpatients (aged 65 years or older) with severe psychiatric problems, who are difficult-to-engage, and who are resident in the BavoEuropoort catchment areas.

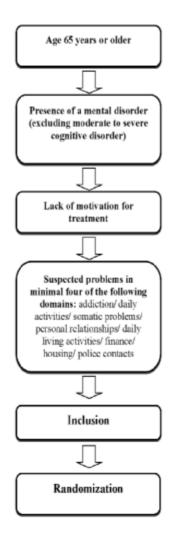
Procedure

BavoEuropoort has one ACT team for elderly people (intervention condition). In the control condition (38), participants were identified by three general community mental-health teams working for elderly people living in the community. Two of these teams focused on patients' with psychiatric disorders; the other focused mainly on patients with cognitive impairments. Community mental-healthcare professionals from these teams will use a checklist to

determine whether all new elderly service-users meet the inclusion criteria. The inclusion of patients started July 2008 and was closed on 1 August 2010. Figure 1 shows the inclusion flowchart.

Inclusion criteria are: 1.) age 65 year or older; 2.) having a severe mental illness (patients with a severe psychiatric disorder, usually psychotic or bipolar disorder or severe depression, leading to a complex combination of psychiatric and social needs); 3.) no motivation for treatment (actively or passively resisting treatment; the patient is very difficult to involve in any form of treatment, including treatment by the general practitioner); 4.) and four problems of the following domains: addiction: taking alcohol and drugs taking not in a social context, occasional minimal loss of control of drinking or drugs use or adverse consequences or incapacitated due to alcohol or drug problems; somatic problems: all kind of somatic problems, including illness or disability from any cause that limits mobility, impairs sight or hearing, or otherwise interferes with personal functioning; daily living activities: the overall level of functioning in activities of daily living: e.g., problems with basic activities of self-care such as eating, washing, dressing, toilet; also complex skills such as budgeting, recreation and use of transport, etc.; housing: the overall severity of problems regarding the quality of living conditions, accommodation and daily domestic routine, taking into account of the patient's preferences and degree of satisfaction with such circumstances. Are the basic necessities met; daytime activities: the overall level of problems regarding the quality of the daytime environment. Limited or no daytime activities, the patients problems are made worse by a lack of daytime activities; social relationships: problems associated with social relationships, as identified by the patient or apparent to carer or others. These included active or passive withdrawal from social relationships, a tendency to dominate, social relationships or non-supportive, destructive or self-damaging relationships; finances: problems associated with finance (such as debts), and problems with skills such as budgeting; police contacts: contact within police in the last year that were a product of the patients psychological situation. Examples: nuisance, public drunkenness or minor offence by psychological situation.

Figure 1 Inclusion flowchart



We exclude patients with severe cognitive problems (severely disorientated, for example consistently disorientated with regards to time to time, place, or person, or suffering memory impairment for example only fragments remain, loss of distant as well as recent information, unable to effectively learn any new information, no effective communication possible through language or inaccessible to speech.

Primary and secondary outcome variables were collected by means of an interview of patients willing to give informed consent as well as from the patients' files. A trained independent research assessor will record these primary and secondary outcome measures. This research assessor contacts after patient randomization the clinician to make an appointment to visit the patient together. In this contact with the patient the research assessor asked questions (via semi structured interview) to rate the assessment instruments. Because patients are difficult-to-engage they don't fill in questionnaires themselves. If patients refuse to answer questions, the research assessor will collect data from the patient's records or via asking the clinician about the patients' situation. Data are collected as part of the routine outcome assessments of the mental-health center. The first interview was done closely after inclusion in the study. The second interview took place 9 months after the first and the last interview after 18 months.

Intervention and treatment as usual

The intervention will be ACTE, an integrated multidisciplinary treatment model. It will have four main components: 1.) the caseload will be both small and shared (10 patients per case manager); 2.) services and assertive outreach will all be community based; 3.) all services (i.e. both medical and psychosocial) will be provided by the ACTE team; and 4.) and all services will be provided on an unlimited basis (60-62). ACTE has been described in a manual that describes the target group, the team's working method, and tasks of the various disciplines involved. It also includes various programs (modules) based on other evidence-based practices. Under ACTE, care is given with regard to various essential life domains, at whichever location the patient is (63). Professional mental-healthcare workers invest in a long time relationship with the patient, even if he or she initially continues to refuse care. To address the most common problems of the target group, the

ACTE team will represent several disciplines (Table 1), and will have ten full-time equivalents working force. The low caseload will allow for intensive contact with patients. Team members will collaborate closely on each patient, using one treatment plan. Table 1 contrasts ACTE working methods with those of TAU (60-62), the latter consisting of three teams: a psycho-geriatric team for elderly patients with cognitive problems and two gerontology psychiatric team for elderly patients with psychiatric problems. Table 1 shows that the main differences between ACTE and TAU will concern team approach including a shared caseload, contact frequency, and the location of care provision.

Because care under ACTE will be provided in the patients' living environment, there will often be intensive collaboration with a number of organizations (such as the police in cases of nuisance or homelessness, or with psychiatric hospitals upon admission). Because this group of elderly psychiatric patients is difficult-to-engage in treatment and may have bad experiences with the care provision circuit, it is very important than time and energy are devoted to establishing contact with them.

Outcomes and measurement instruments

Our primary outcome measures will be the number of dropouts (drop-out being defined as no registered contact with the services over a period of 3 months and/or the number of patients discharged out of care). The number of patients who are engaged in care (patients who receive care within 3 months after admission) and patient's psychiatric symptoms, somatic symptoms, and social functioning.

Our secondary outcomes measures will be 1.) the number of unmet needs, 2.) subjective quality of life, 3.) patients' satisfaction with mental-health care, 4.) the number of crisis contacts and (in)voluntary admissions, and the number of admission days. The admission days and crisis contacts were calculated during two periods of observation. The first period was the year before inclusion in the study. The second was the variable observation period ranging till 2 years after inclusion. In both periods, the admission data were standardized as mean number of days per month and crisis contacts as mean number.

| Table 1 Differences between ACTF and TAL |
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|--|

| Table 1 Differences between ACTE and TAU | | | | | |
|--|--|--|--|--|--|
| Intervention Group - ACTE | Gerontology psychiatry teams - TAU | Psycho geriatric team -TAU | | | |
| A shared caseload (all care providers know all the patients and work together in the treatment). | Individual care providers responsible for patient assessment and for coordination and treatment. | Individual care providers responsible for patient assessment and for coordination and treatment. | | | |
| A low caseload (a maximum of ten patients in the team per individual care provider). | A high caseload for the individual practitioner (> 20). | A high caseload for the individual practitioner (> 20). | | | |
| The care provider takes the initiative on maintaining contacts, and visits patients mainly in their own environment, wherever they are (also when they are hospitalized), the intention being to prevent dropout. | In general, whether contact takes place in the office or at home, involvement ceases (temporarily) after admission has taken place, or if the patient refuses to maintain (long-term) contact. (Normally, there is no contact when the patient is hospitalized.). If patient refuses contact or fails to show up, discharge usually follows. | In general, whether contact takes place in the office or at home, involvement ceases (temporarily) after admission has taken place, or if the patient refuses to maintain (long-term) contact. (Normally, there is no contact when the patient is hospitalized.). If patient refuses contact or fails to show up, discharge usually follows. | | | |
| Unlimited investment in terms of time (high contact frequency). | Limited contacts, frequency as low as possible. | Limited contacts, frequency as low as possible. | | | |
| All aid is offered though the ACT team (psychiatric treatment, rehabilitation, assistance with addiction, financial problems, and somatic care). | Only psychiatric care is provided. Addiction, financial problems and other problems are treated by other services. | Only psycho geriatric care is provided. Addiction, financial problems and other problems are treated by other services. | | | |
| Disciplines: Doctor of Medicine or nursing-home doctor (especially for somatic problems) or visiting geriatrist Social worker Psychiatrist Psychologist Community Mental-Health Nurse Rehabilitation worker Somatic nurse, Mental-Health nurse Homecare worker One of above discipline is specialized in addiction (or double diagnosis) | Disciplines: Doctor of Medicine or nursing home doctor Psychiatrist Psychologist, Community Mental-Health Nurse | Disciplines: Doctor of Medicine or nursing home doctor or visiting geriatrist Psychologist, Community Mental-Health Nurse | | | |
| Each morning there will be a team meeting on all patients in which any necessary appointments are made. | Patients are discussed in patient meetings once every six months. Difficult cases are discussed during weekly team meetings. | Patients are discussed in patient meetings once every six months. Difficult cases are discussed during weekly team meetings. | | | |
| Staff will receive training in the methodology. | No specific staff training. | No specific staff training. | | | |
| | | | | | |

Assessment instruments

Measurements will be made at three points of the study: at baseline, and after 9 and 18 $\,$ months. In the meantime, the patients will be treated according to the ACT model or TAU. The same instruments will be used for all three measurements. Table 2 shows an overview of all outcome measures and instruments. The following data will be obtained from the patients' electronic records: demographic and socio-economic characteristics (including gender, age, ethnicity), data concerning living situation, homelessness, employment, and education, the psychiatric diagnosis, use of medication, deaths (included suicide) and data on the number of patients who are engaged in care, the number of dropouts and the time between the start of the treatment and dropout. Also the number of crisis contacts and voluntary and involuntary admissions, and the length of stay of admission will be collected. Using assessment instruments, the following data will be collected:

- Psychosocial functioning (psychiatric, somatic and social functioning) by means of the Health of the Nations Outcome Scale for the elderly (HoNOS65+, Dutch version) (64, 65),
- Care needs by means of the abridged Camberwell Assessment of Needs Elderly (CANE, short version, Dutch version (66, 67),
- · Quality of life (QoL) by means of the quality of life, abridged version of the Manchester short assessment of quality of life (68, 69).

HoNOS65+

The purpose of the HoNOS65+ is to describe the psychological and social functioning of elderly psychiatric patients, and to provide insight into the severity of various psychosocial problems by identifying changes in relevant areas of life. The HoNOS65+ can be used to measure the effect of treatment. It consists of 12 items in four sub-scales: behavior disturbance (items 1-3), impairment (items 4-5), symptoms (items 6-8), and social problems (items 9-12). A Dutch addendum to the HoNOS65+ contains three questions: on problems resulting from manic-depressive disorder, motivation for treatment, and medication compliance. These items have not been validated (70). All items will be completed on a 5-point Likert scale from 0 (no problem), 1 (minor problem), 2 (mild problem), 3 (moderate problem), to 4 (severe problem). The Dutch version of the HoNOS65+ has been shown to be properly valid (71).

The CANE establishes whether an elderly person has problems and/or care needs in various areas of life, and, if necessary, whether adequate effective care is being given. It consists of 26 questions on items such as needing a diet, daily activities, and psychotic symptoms. Care needs are scored in the following manner: 0 (no need), 1 (met need), and 2 (unmet need).

QoL

Quality of life will be measured using the QoL scale, which has shown itself to be well suited to measuring satisfaction in the chronic psychiatric target group. Dealing with patients' subjective perceptions with respect to quality of life, the scale consists of six elements covering patients' satisfaction with their 1.) life as a whole, 2.) living situation, 3.) personal relationships 4.) physical health, 5.) mental health and 6.) financial situation. Per item, the researcher will ask the patient to award a score on a 7-point Likert scale ranging from 1 (bad or not at all satisfied) to 7 (good and very satisfied).

Satisfaction with the care-provider

The QoL scale will be extended with one question on patients' satisfaction with their treatment. This will be taken from the satisfaction questionnaire (69), and, like all answers in the QoL, be rated as a single question on a 7-point Likert scale.

Other measurement instruments

Collaboration between patient and care-provider

The level of collaboration between patient and care provider will be analyzed using the relationship scale from the working relationship questionnaire for case management (72), which consists of seven elements that are filled in by the care provider who is most familiar with the patient. The care provider responsible for the file is the one who is most familiar with the patient. In the TAU this is the patient's clinician. In the ACTE this is the clinician who gets to know the patient best after the intake procedure, and who is also the contact person for family and institutions.

Model fidelity of ACT

Research has shown that ACT has the best results when it is implemented in full according to the original ACT model (73-80). As recommended in the literature, model fidelity will be determined on the basis of both conditions (55). The fidelity of ACT and TAU will be measured twice (in 2010 and in 2011) by two independent researchers using the Dartmouth Assertive Community Treatment scale (DACTS). The DACTS consists of 28 items covering three dimensions (team structure, organizational structure, and features of service delivery). All twenty-eight items are rated on a 5-point scale range from 1 (no implementation or only a low degree of implementation) to 5 (complete implementation) (81-83).

Table 2. Overview of all outcome measures and instruments

| Variable | Instrument Assessed by | | Baseline | 9 | 18 |
|--------------------------|------------------------|--------------------------|----------|--------|-------|
| | | | | months | month |
| Socio-demographics | Patient records | Interviewer | Х | Х | X |
| Psychiatric history | Patient records | Interviewer - researcher | X | | |
| Psychiatric diagnosis | DSM-IV | Psychiatrist or doctor | Х | Х | Х |
| Drop-out | Registration system | Researcher | Х | Х | Х |
| Crisis contacts | Registration system | Researcher | х | Х | Х |
| Admission days | Registration system | Researcher | х | Х | Х |
| Psychosocial functioning | HoNOS65+ | Interviewer | х | Х | Х |
| Care needs | CANE short appraisal | Interviewer | х | Х | Х |
| Quality of Life | QoL | Interviewer | х | Х | Х |
| Satisfaction with care | One question on 7 | Interviewer | Х | Х | Х |
| | point scale | | | | |
| Collaboration patient / | Working Relationship | Interviewer | х | Х | Х |
| care-provider | Questionnaire for | | | | |
| | case-management | | | | |
| ACT model-fidelity | DACTS | Trained ACT evaluators | X | | X |

Power analysis

The sample size was determined by means of a power analysis. To detect a clinically significant impact (average effect size (Cohen's d) ≥ 0 . 6) on the primary outcome variable (number of patients remain in care with an alpha of 0.05 and a power of 0.85), we needed at least 50 patients per condition. In another ACT trial, Sytema et al (33) found 20% lose for randomization due to patients' failure to meet the inclusion criteria, and patients who refused to give informed consent for the interview (33). We therefore wanted to include 80 patients in the ACTE team and 80 patients in the TAU condition. This will be enough to prove a clinically significant effect.

Randomization

The patients were referred to BavoEuropoort by general practitioners or other institutions (such as the police or municipal health service), who filled out a form describing the patient's characteristics and current problems. To determine whether the patients fulfilled the inclusion criteria, this form was reviewed using a checklist by the researcher (JS) and clinicians. If the patient did meet the criteria, he or she was allocated a number chronologically by the service administrator. Each number was given to the researcher, who then decided on the condition (intervention or treatment as usual). This was done on the basis of a previously arranged list of numbers randomized to each of the two conditions (with help from http://www.randomizer.org). To ensure similar numbers in both conditions the pre-arranged list of numbers are based on a block design (block size of four). Inclusion and randomization of patients was done before informed consent was obtained for participation in an interview with the interviewer.

Statistical analysis

Analyses will be performed according to the intention-to-treat principle, which means that everyone who is randomized stays in the group in which they were randomized. Statistical package for the social sciences (SPSS), version 15.0 will be used to analyze the data. The primary outcome measure is the differences between ACTE and TAU regarding the number of patients who were out-of contact with mental-health services. Secondary outcome measures are improvement of psychosocial functioning (total HoNOS65+ score, total score from baseline to the final interview after 18 months), need-for-care over time (primary outcome measures), the number of crisis contacts and (in)voluntary admissions, and the number of admission days (these last 3 measures will be retrieved from administration files). The interviewer collects the other secondary outcome measures (subjective quality of life and client satisfaction). Categorical variables shall be analyzed using chi-square tests. Mixed models with repeated measurement were applied for the continuous outcomes. This model will be used because of the ability to include participants with missing data. Missing data at the second and third interview will be imputed with the last carried out interview.

Ethical considerations

Because the patients included in the study are difficult-to-engage, they will be allocated randomly over the two conditions without asking informed consent. This Zelen design [24] and the execution of this study were approved by the Dutch union of medical-ethic trial committees for mental-health organizations. Data will be processed anonymously. Confidential information and patient names will be treated according to the medical confidentiality rules. All personal details will be awarded a code to which only the research team has the key.

Research procedures & timelines

This study will proceed in four stages:

- a. Preparation for data collection (1 March 2008 to 1 July 2008)
- b. Inclusion of patients (1 July 2008 to 1 August 2010)
- c. Follow-up (1 April 2009 to 1 March 2012)
- d. Data-analysis, publication of articles, knowledge transfer, and writing of a thesis (1 March 2012 to 1 March 2013).

Discussion

The central research question in this study is whether ACTE can ensure that elderly people with SMI remain in care and whether ACTE can reduce psychosocial symptoms

and unmet needs more than TAU. Other research questions include whether the intervention can reduce the number of crisis contacts, reduce the number and duration of voluntary and involuntary admissions, and improve quality of life and client satisfaction. This study will thus provide opportunities to examine how well ACTE works in practice with this group of elderly people, and whether it has any extra value over TAU. By helping to increase overall understanding of various forms of mental-healthcare, its implementation may lead to an evidence-based intervention for this special group. If ACTE is shown to have added value, it can be implemented, and further research can follow. The study results will be prepared for national and international publication and for presentation at national and international conferences. They may also lead to the publication of a handbook on ACT for the elderly.

This study has two specific strengths and two limitations. The first strength is that we will use and RCT design to test the effectiveness of ACT for the elderly. The second is its internal validity, which is protected by the structured protocol monitoring the ACT model, as well assessing the contents of the TAU by also applying the DACTS scale. The first limitation is the fact that community mental-healthcare professionals and the independent research assessor will not be blinded for which patients are included in this study. Because the only way in which independent research assessor can reach elderly people with SMI is through collaboration with the community mental-healthcare professionals, it will not be possible to blind them both. The second limitation is that TAU exists of different kind of teams in different area, with different working methods. These working methods will be describe in the outcome of the DACTS but can negatively or positively affect the outcome results. In addition, the effects of ACTE will also depend on the TAU. When the quality of care of the TAU is high, there is less chance of demonstrating an effect of ACTE. This limitation is a problem in all studies comparing a new intervention with TAU (84). Therefore, we will describe TAU thoroughly also using the DACTS, to demonstrate in what aspects ACTE and TAU differ. The last limitation is the inclusion format. We started with the following inclusion criteria: (1) age 65 year or older; (2) having a severe mental illness, (3) no motivation for treatment, and (4) having four or more additional problems within the following domains: addiction, somatic problems, activities of daily living, housing, daytime activities, social relationships, finances, or police

contacts. Until June 2009 only 35 patients were included. Therefore we broadened our inclusion criteria by lowering the minimum age to 60 years. January 2010 only 50 patients were enrolled and we decided to limit the number of problems in several domains to 2 (was 4). Finally, in March 2010 we included only 56 patients, and then we let loose of criterion no 4. At the end of the trial by July 31 2010 we recruited 64 participants. Till August 1st 2010, fife patients died, 3 in the intervention group and 2 in the control group (no suicides). Because of the number of patients enrolled in this study (64 patients) the power of the study is a problem.



CHAPTER 3

The effectiveness of Assertive Community Treatment for elderly patients with severe mental illness: a randomized controlled trial

Stobbe J, Wierdsma AI, Kok RM, Kroon H, Roosenschoon BJ, Depla M, Mulder CL (2014):

The effectiveness of assertive community treatment for elderly patients with severe
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ABSTRACT

Background: Due to fragmented mental, somatic, and social healthcare services, it can be hard to engage into care older patients with severe mental illness. In adult mental-health care, Assertive Community Treatment is an organizational model of care for treating SMI patients who are difficult-to-engage. So far all outcome studies of Assertive Community Treatment have been conducted in adults.

Methods: In a randomized controlled trial design we compare the effectiveness of Assertive Community Treatment for elderly patients with that of treatment as usual. Sixty-two outpatients (60 years and older) with severe mental illness who were difficultto-engage in psychiatric treatment were randomly assigned to the intervention or control group (32 Assertive Community Treatment for elderly patients and 30 treatment as usual). Primary outcomes included number of patients who had a first treatment contact within 3 months, the number of dropouts (i.e. those discharged from care due to refusing care or those who unintentionally lost contact with the service over a period of at least 3 months); and patients' psychosocial functioning (HoNOS scores) during 18 months followup. Secondary outcomes included the number of unmet needs and mental-health care use. Analyses were based on intention-to-treat.

Results: Of the 62 patients who were randomized, 26 were lost to follow-up (10 patients in Assertive Community Treatment for elderly patients and 16 in treatment as usual). Relative to patients with treatment as usual, more patients' allocated to Assertive Community Treatment for elderly patients had a first contact within three months (96.9 versus 66.7%; X^2 (df=1) = 9.68, p = 0.002). Assertive Community Treatment for elderly patients also had fewer dropouts from treatment (18.8% of Assertive Community Treatment for elderly patients patients versus 50% of treatment as usual patients; X² (df=1) = 6.75, p = 0.009). There were no differences in the other primary and secondary outcome variables.

Conclusion: These findings suggest that Assertive Community Treatment for elderly patients engaged patients more successfully.

Background

Due to fragmented mental, somatic, and social healthcare services, it can be hard to engage into care older patients with severe mental illness (SMI) who have problems in multiple life domains and problems in treatment motivation (5, 9, 12, 28). Assertive community treatment (ACT) was developed as an integrated model to meet the needs of difficult-to-engage patients with complex problems (29). Critical components of ACT associated with reducing hospital admissions were shared caseload, community based services, 7x 24 hour services, a team leader who participated in patient care, full responsibility for treatment services, daily team meetings and time unlimited services (31). Although there is no agreement on which critical components of ACT are associated with psychosocial outcomes, better outcomes have both been shown to be associated with having a better team structure and with having a consumer provider in the team (31, 85, 86). Better engagement was associated with a smaller caseload in ACT than in TAU, and with a shared caseload (32).

In the United States, ACT reduced hospital admissions more than treatment as usual (TAU) (29, 30). European studies however showed mixed effects of ACT when compared with TAU, due possibly to better quality of care in the TAU control-conditions and/or inadequate implementation of key ACT-components. Reduced effectiveness of ACT in Europe could also be explained by a loss of focus on preventing admissions when ACT-teams are confronted with very strict admission criteria, or conversely, when inpatient beds are readily available (51, 73, 87, 88).

One group of patients who might benefit from ACT are elderly patients with SMI who are difficult to engage, have heterogeneous care needs, such as psychiatric as well as somatic problems, and have problems with activities of daily living, housing and social support (4, 22). Only one study has focused on ACT for the elderly (ACTE). Although results suggested that the ACT model supplemented with specific care for the elderly was suitable for this subgroup, the study presented no data on the effectiveness of this service (37).

To meet the different needs of older patients with SMI who are difficult to engage, a specialized ACTE team was started. We tested its effectiveness in a randomized controlled trial (RCT). We hypothesised that ACTE, as compared to Treatment As Usual

(TAU), more often succeeds in establishing contact with patients within 3 months of their signing up for care, has fewer drop outs, and has better effects on patients' psychosocial functioning (primary outcome variables). We also hypothesized that ACTE would meet patients' unmet needs more effectively, and would reduce mental healthcare use (secondary outcome variables) as compared to treatment as usual.

Methods

Intervention

ACT is a community-based treatment approach for outpatients whose SMI results in difficulties in daily living activities and social functioning often including problems with relationships, physical health, addiction, work, daytime activities, and living conditions. ACT was developed for patients who are high users of inpatient hospital services and who are unwilling to use mental health services (89). Unlike other community-based programs, ACT provides individualized services directly to the patients. To meet patients' various needs, a multidisciplinary team provides psychiatric, somatic and rehabilitation treatment. Team members are trained in the areas of psychiatry, social work, nursing, substance abuse, and rehabilitation (90). Key features of ACT are: assertive engagement, a small caseload (maximum of 10 patients per clinician); shared caseload (i.e. all clinicians collaborated closely on each patient using one treatment plan); and community-based and assertive services on a time-unlimited basis (29, 89). ACTE was implemented using the ACT manual developed for adults. The descriptions in this manual include the team approach and the duties of each discipline (89). The ACTE team was staffed by: a substance-abuse specialist, a rehabilitation worker, a social worker, a psychiatric nurse, a nurse specialized in somatic care, a community mental health nurse and a psychiatrist (the last two were both specialized in treating elderly people).

Treatment as usual was provided by three community mental health teams for elderly patients. Two of these teams were for patients with primary psychiatric disorders, and one was for patients with cognitive disorders. The teams provided regular mental health services, including psychiatric care on an outreach basis. Various disciplines (including community mental health nurses, a psychiatrist, and a psychologist) were individually responsible for the patients and their treatment plans (no shared caseload);

their caseload was relatively high (more than 25 patients per practitioner). All clinicians were specialized in treating elderly people.

Trial design and recruitment

The study was carried out by Parnassia Psychiatric Institute, department BavoEuropoort, a mental healthcare centre in the greater Rotterdam area in the Netherlands. BavoEuropoort provides inpatient and outpatient care in an urban population of some 1.3 million people.

The ACTE study was designed as a parallel group randomized controlled trial, with one intervention group and one control group. The study was approved by the Dutch Union of Medical-Ethical Trial Committees for mental health organizations. See Stobbe et al. (91) for a more detailed description of the study.

All elderly patients referred to the BavoEuropoort mental healthcare centre in Rotterdam (the Netherlands) between July 2008 and July 2010 were screened with regard to meeting the inclusion criteria.

General practitioners or municipal health services referred patients according to usual procedures (the person who referred the patient filled out a form describing the patient's characteristics and current problems). Inclusion and exclusion criteria were filled in and checked by the clinicians of the ACTE and the community mental health teams. The initial inclusion criteria included: 1.) age 65 years or older, 2.) presumption of a severe mental illness (for example schizophrenia spectrum disorders or major affective disorders); 3.) problems in four or more of the following areas: daily functioning, (e.g. personal hygiene, social relationships), daytime activities, addiction, financial problems, housing, somatic problems, or police contacts; and 4.) difficulties in engaging in treatment (for example patients who were unwilling to use mental health services, or those who had a history of involuntary admissions or of drop-out from mental healthcare). There was one exclusion criterion: the presumption of moderate to severe cognitive impairment (91).

Because the inclusion rate was low during the first year of inclusion (n = 35), we extended the inclusion period to a total of 24 months. Extending the inclusion period was not sufficient for recruitment, and therefore the inclusion criteria were broadened: after 1 year we broadened the inclusion criteria by lowering the minimum age to 60 years. We

also dropped problems in various domains as an inclusion criterion, since patients often received no medical or psychiatric treatment so that only limited information was available when patients were referred.

We compared patients who were recruited during the first year of the study to patients who were recruited later. Patients' level of unmet needs and psychosocial functioning at baseline did not differ between patients included during the first year of the study and patients included after we broadened the inclusion criteria. Because we lowered the minimum age after 1 year, patients included after this year were younger than patients included the first year of the study (72.1 years, standard deviation (SD) 8.7 versus 76.7 years (SD 7.2). T-test 2.24, degrees of freedom (df) = 60, p = 0.029).

Randomization

To allocate the patients to ACTE or TAU we used a randomization list generated by a computer (http://www.randomizer.org). Participants who fulfilled the inclusion criteria received a number chronologically from the ACTE service administrator. On the basis of this number, an opaque sealed envelope with the corresponding number was opened and the patient was allocated randomly.

Outcomes

The study focused on three primary outcome measures. First we computed the number of patients who had a first treatment contact with the mental healthcare worker within 3 months of being signed up for care. Second, the number of dropouts during the follow-up period was assessed where there were two categories: being discharged for refusing care and (temporary) unintentional loss of contact with the service for at least 3 months; and thirdly psychosocial problems over time.

Secondary outcome measures comprised the number of unmet needs over time, the number of in-patient psychiatric hospital admissions, duration of admission and the number of crisis contacts (91).

Outcomes were assessed at three time points: at baseline (T1), at 9 months after baseline (T2), and 18 months after baseline (T3).

Instruments

Demographic characteristics and dropout data were collected from patients' electronic files. The number of psychiatric hospital admissions, duration of admission and the number of crisis contacts were collected from the central system of registration.

The Dutch version of the Health of the Nation Outcome Scales for elderly people (HoNOS65+) was used to assess the severity of psychosocial problems (64, 92). The HoNOS65+ is divided into 12 items: overactive and aggressive behaviour, non-accidental self-injury, problem drinking or drug-taking, cognitive problems, physical illness or disability problems, hallucinations and delusions, depressed mood, other mental and behaviour problems, problems with relationships, problems with activities of daily living, problems with living conditions, and problems with occupation and activities. We used the sum score of the HoNOS65+. All items were scored on a 5-point scale, from 0 (no problem) through 1 (minor problem), to 2 (mild problem), 3 (moderate problem), and 4 (severe problem). The Dutch version of the HoNOS65+ has been shown sensitive enough to measure change (92, 93).

The short Dutch version of the Camberwell Assessment of Needs for the Elderly (CANE, staff member version) (66, 94) was used to measure care needs in twenty-four areas. Each item was scored as 0 = no need, 1 = met need (due to an intervention) or 2 = unmet need (intervention is needed, or intervention had no effect). We used the sum score of the unmet needs. The validity and reliability of the original scale were good (66) and acceptable for the Dutch version (94).

Measuring model fidelity of ACT is a method to evaluate how close ACT was implemented to the academic ideal. The model fidelity of ACTE and TAU was measured two years after the start of the ACTE team, using the Dutch version of the Dartmouth Assertive Community Treatment Scale (DACTS) (81, 82). The scale items were divided into three sections: human resources, organizational boundaries and nature of services.

Data-collection procedure

Outcome data were collected by psychology students on the basis of face-to-face contact with each patients, which was combined with information provided by the clinician and data in the patients' electronic files. If patients refused contact, data were collected only

on the basis of information provided by the clinician and of data in the patients' electronic files. Data were analysed anonymously. For practical issues, raters could not be blinded for the treatment condition. Because we were dealing with unmotivated patients, the instruments were assessed from the raters point of view.

Statistical Analyses

First, all variables were checked for outliers and missing values. Next, we compared sociodemographic and clinical characteristics at baseline. Chi-square tests were used to analyze differences between the intervention and control group in the number of patients who had a first treatment contact within three months and the number of dropouts. To test differences regarding psychosocial functioning (total score HoNOS65+), the intervention and control group were compared using regression analysis, with centred psychosocial functioning at baseline as covariate and treatment condition as factor. Finally, the Wilcoxon test was used to investigate secondary outcomes, including within-group changes in unmet needs, the number of hospital days and crisis contacts during follow-up. The statistical significance level was set at p<0.05. The Statistical Package of the Social Sciences (SPSS), version 17 for Windows, was used for all analyses.

The research question was to demonstrate differences between ACTE and TAU. In order to avoid overestimation, data were analyzed on an intention-to-treat basis. This meant that patients who did not fully adhere to the protocol or patients who received the treatment from the group they were not allocated to, were kept in their original group for the analyses (95).

Results

Model fidelity

Table 1 shows that the ACTE team had a mean DACTS score of 3.6, meaning that the ACT model was implemented to a moderate degree (81, 83). The TAU teams had lower model fidelity scores (all 3 teams had a score of 2.4). ACTE scored high on the following components of ACT: the small and shared caseload, and time-unlimited services (60, 61). While ACTE had the maximum scores for the other components of ACT (community based services and assertive outreach), almost all TAU teams also scored high on these components.

Table 1. Difference in DACTS score between ACTE and TAU

| DACTS Criteria | PG team | GP team North | GP team South | ACTE |
|--|---------|------------------|------------------|------|
| Small Caseload | 1 | 1 | 2 | 4 |
| Team Approach | 1 | 2 | 1 | 5 |
| Program Meeting | 1 | 1 | 1 | 5 |
| Practicing Team Leader | 5 | 5 | 5 | 5 |
| Continuity of Staffing | 5 | 5 | 2 | 4 |
| Staff Capacity | 5 | 5 | 2 | 5 |
| Psychiatrist on Staff | 1 | 1 | 2 | 3 |
| Nurse on Staff | 3 | 3 | 3 | 5 |
| Substance Abuse Specialist on Staff | 1 | 1 | 1 | 3 |
| Vocational Specialist on Staff | 1 | 1 | 1 | 2 |
| Program Size* | 4 | 5 | 3 | 3 |
| Team structure mean: | 2.5 | 2.7 | 2.1 | 4 |
| Explicit Admission Criteria | 4 | 4 | 5 | 4 |
| Intake Rate | 1 | 1 | 1 | 1 |
| Full Responsibility for Treatment Services | 2 | 3 | 4 | 5 |
| Responsibility for Crisis Services | 1 | 1 | 1 | 1 |
| Responsibility for Hospital Admissions | 4 | 4 | 5 | 5 |
| Responsibility for Hospital Discharge Planning | 1 | 2 | 3 | 5 |
| Time-Unlimited Services | 1 | 4 | 2 | 5 |
| Organizational boundaries mean: | 2,0 | 2,7 | 3 | 3,7 |
| In-vivo Services | 5 | 4 | 2 | 5 |
| No Drop-Out Policy | 5 | 4 | 3 | 5 |
| Assertive Engagement Mechanisms | 5 | 3 | 5 | 5 |
| Intensity of Service | 1 | 1 | 1 | 2 |
| Frequency of Contact | 1 | 1 | 1 | 1 |
| Work with Support System | 5 | 1 | 5 | 2 |
| Individualized Substance Abuse Treatment | 1 | 1 | 1 | 4 |
| Dual Disorder Treatment Groups | 1 | 1 | 1 | 1 |
| Dual Disorders Model | 1 | 1 | 1 | 3 |
| Role of Consumers on Treatment Team | 1 | 1 | 1 | 1 |
| Nature of services mean: | 2,6 | 1,9 | 2,1 | 2,9 |
| TOTAL MEAN SCORE DACTS* | 2,4 | 2,4 | 2,4 | 3,6 |

Each item is rated on a 5-point scale from 1 (not implemented) to 5 (fully implemented), the scale items of the DACTS are divided into three sections: human resources, organizational boundaries and nature of services (bold data are mean scores of these sections). * Program size is not included in score summary.

^{0-2.9:} inadequate implementation ACT model,

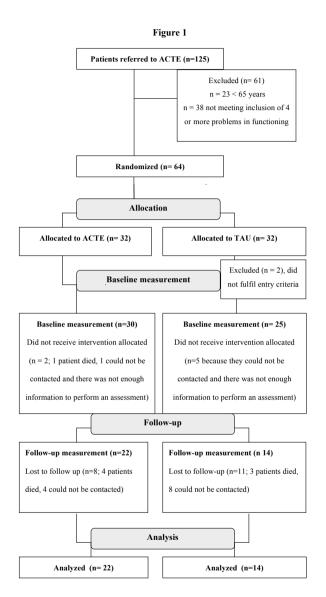
^{3.0-4.1:} moderate implementation ACT model,

^{4.2-5.0:} full implementation ACT model.

The ACTE and the TAU teams also had high scores on components such as explicit admission criteria, a team leader who participated in patient care, and responsibility for hospital admission. ACTE had low model fidelity on the following components: a vocational specialist and consumer provider in the team, the frequency of contact, the intensity of service, the intake rate, dual-disorders treatment groups, work with support system, and responsibility for crisis services.

The flowchart of the study is presented in Figure 1. Sixty-one patients of the 125 patients referred did not fulfil the inclusion criteria, and were excluded. Twenty-three patients were excluded because they were younger than 65 years and thirty-eight patients were excluded because they did not meet the narrow inclusion criteria at the start of the study, of four or more problems in daily living activities and functioning. At the end of the inclusion period we recruited 64 participants. Directly after randomization two patients, allocated to TAU, were excluded from care, these patients did not fulfil the entry criteria (incorrect entry of the patient into the trial).

Two patients who had originally been allocated to TAU received ACTE. These patients were analysed in TAU, according to the intention to treat principle. Patients were lost to follow-up because they were deceased or could not be contacted - sometimes because they were admitted to in-patient services (elderly homes) but mostly because patients didn't open the door or refused contact. At follow-up, assessments were available of 22 patients in ACTE and 14 patients in TAU (see Figure 1). The mean time between these follow-up measurements was 17.6 months for ACTE patients (SD 5.2) versus 17.8 months (SD 5.7) for patients in TAU. Due to loss to follow-up, we used only two measurements per patient. For patients with three measurements (n = 25) we used only the first and last measurement. There were 7 patients with two measurements. Thus, for these we used both measurements.



Baseline characteristics

Demographic details, service attendance, HoNOS65+ total score and, total unmet needs are shown in Table 2. At baseline, there were no differences in demographic characteristics between patients receiving ACTE or patients receiving TAU.

Table 2. Characteristics of the study population

| Characteristics of the study population | ACTE n=32 | TAU n=30 | | | | | |
|---|--------------|-------------|--|--|--|--|--|
| Mean age (SD) | 74.4 (7.0) | 75.1 (9.3) | | | | | |
| | | | | | | | |
| Mean age at first contact with mental health services | | | | | | | |
| (SD) | 61.5 (16.5) | 60.7 (21.5) | | | | | |
| | | | | | | | |
| Gender (%) | | | | | | | |
| Male | 16 (50) | 10 (33.3) | | | | | |
| Female | 16 (50) | 20 (66.7) | | | | | |
| Marital status (%) | | | | | | | |
| Unmarried | 14 (43.8) | 9 (30.0) | | | | | |
| Married | 4 (12.5) | 2 (6.7) | | | | | |
| Divorced | 7 (21.9) | 10 (33.3) | | | | | |
| Widowed | 7 (21.9) | 9 (30.0) | | | | | |
| Living situation (%) | | | | | | | |
| Independent | 27 (84.4) | 27 (90.0) | | | | | |
| Other | 5 (15.7) | 3 (10.0) | | | | | |
| Country of birth (%) | | | | | | | |
| The Netherlands | 29 (90.6) | 22 (73.3) | | | | | |
| Other | 3 (9.4) | 8 (26.7) | | | | | |
| Diagnosis Axis I (%) | | | | | | | |
| Schizophrenia spectrum disorders | 11 (34.4) | 11 (36.7) | | | | | |
| Mood disorder | 5 (15.6) | 3 (10.0) | | | | | |
| Cognitive impairment | 4 (12.5) | 7 (23.3) | | | | | |
| Other disorders | 12 (37.5) | 9 (30.0) | | | | | |
| Psychiatric admission (%) | | | | | | | |
| Yes | 10 (31.3) | 7 (23.3) | | | | | |
| No | 22 (68.8) | 23 (76.7) | | | | | |
| Total HaniOSSE+ score Moon (SD)* | 21 17 /2 07\ | 20 4 (4 59) | | | | | |
| Total HoNOS65+ score Mean (SD)* | 21.17 (3.87) | 20.4 (4.58) | | | | | |
| Total unmet needs score | | | | | | | |
| Median (range)* | 7.5 (1-15) | 6.5 (2-13) | | | | | |

First contact within 3 months and dropout patients

First contact and the dropout data are presented in Table 3. Within three months of signing up for care, patients allocated to ACTE had contact with mental healthcare workers significantly more often than those allocated to TAU. While ACTE also had significantly fewer dropouts from treatment than TAU did, within the TAU condition two patients were lost only temporarily (for 8 and 10 months).

Table 3. First contact and dropout (during follow-up) stratified by treatment programme

| | ACTE | TAU | Test of significance |
|-------------------------------|-----------|-----------|----------------------|
| | n=32 (%) | n=30 (%) | |
| First contact within 3 months | | | |
| Yes | 31 (96.9) | 20 (66.7) | $X^{2}(df=1) = 9.68$ |
| No | 1 (3.1) | 10 (33.3) | p = 0.002 |
| Drop-out | | | |
| Yes | 6 (18.8) | 15* (50) | X^2 (df=1) = 6.75 |
| No | 26 (81.3) | 15 (50) | p = 0.009 |

Chi-squared test was used

Psychosocial functioning

The mean total HoNOS65+ scores at follow-up showed an improvement in psychosocial functioning in both groups. At baseline, the mean score in the ACTE group was 20.6 (SD 4.1); at follow-up it was 16.0 (SD 5.0), t-test: t = 3.71 (df = 21), CI: 2.0-7.2, p = 0.001. The effect range lay between a 5-point increase in psychosocial problems and a 15-point decrease. The mean baseline score for TAU patients was 20.4 (SD 5.3) and at follow-up it was 16.1 (SD 6.7), t-test: t = 1.86 (df = 13), CI = -.68-9.3, p = 0.085. The effect range lay between + 9 and -19. Table 4 shows the result of the regression analysis, which indicates that no significant effect was found for treatment condition on psychosocial outcome.

^{* 2} patients dropped out temporarily (for 8 and 10 months)

Table 4. Regression analysis of a comparison of psychosocial functioning (HoNOS65+ follow-up) and random treatment condition, analysis of covariance

| Source | B (SE) | 95% CI | p-value |
|----------------------|-------------|-------------|---------|
| Intercept | 16.1 (1.54) | 12.96-19.22 | 0.000 |
| Baseline measurement | 0.08 (0.22) | 36-0.53 | 0.699 |
| Treatment condition | 0.10 (1.97) | -4.10-3.91 | 0.962 |

SE = standard error; CI = confidence interval

Unmet needs

In both conditions, the total median number of unmet needs decreased significantly over time. At baseline, the median total unmet needs score for ACTE patients was 7.5 (range 1-15); at follow-up it was 2.5 (range 0-6, Wilcoxon W test z = -3.50, p = < 0.001). At baseline, TAU patients had a median score of 8 (range 3-13) and at follow-up it was 2 (range 0-11), respectively (Wilcoxon W test z = -3.11, p = 0.002).

Hospital days and crisis contacts

Three patients were hospitalized 2 years before the start of the study (2 patients in ACTE and 1 in TAU). After the start of the study, 4 patients in both conditions were hospitalized. Seven patients in ACTE and no patients in TAU had a crisis contact before the start of the study. Two years after the start of the intervention, 5 patients who received ACTE and 4 patients in TAU had had a crisis contact. As very few patients had been admitted or had had crisis contacts, these variables were not analyzed statistically.

Discussion

The major findings of this study were that ACTE succeeded better than TAU in engaging patients into care within 3 months, and was also able to prevent dropout from treatment (18.8% dropout in ACTE patients versus 50% in the TAU condition). Our results also demonstrated that ACTE did not produce better outcomes with respect to psychosocial functioning, unmet needs or mental health care use.

By showing better engagement but no effects on psychosocial functioning, these results are in line with studies on the effects of ACT in adults (33, 96, 97). Some studies explained the lack of added value of ACT due to the high quality of TAU teams (51, 87, 98) or due to a lack of implementation of evidence based modules in ACT teams (33). In their study, Killaspy et al. explained that better engagement in ACT was associated with a smaller caseload in ACT than in TAU, and with the team approach (shared caseload) (32). These characteristics were also present in our own ACTE condition. TAU was characterized by larger caseloads and individual case management. It may be that having a large caseload as well as individual case management both limit the possibilities for trying to make contact with difficult-to-engage patients and for preventing dropout.

Although there is no agreement on which critical components of ACT are associated with psychosocial outcomes in elderly patients, better outcomes in adults have been shown to be associated both with having a better team structure (shared caseload, daily team meetings, and a team leader who participated in patient care) and with having a consumer provider in the team (31, 85, 86). Both ACTE and TAU did not have a consumer in the team whereas also in both conditions the team leader participated in care, thereby limiting the differences between ACTE and TAU.

Various reasons are possible for the lack of differences with regard to outcome in psychosocial functioning. First, given the differences in the numbers of patients who dropped out of care, it is possible that patients who dropped out of TAU had worse psychosocial outcomes, which led to a selection bias in TAU. Second, ACTE may have caused selection bias by preventing the dropout of patients who had worse prognoses than the others. Third, TAU used components of ACT, so in some critical components of ACT differences between the intervention and control group were small. Also contact frequency in ACTE was low. Lack of integrated care and degree of contacts was associated with lack of differences found in effect studies in Europe (99). Various studies have shown that ACT has the best results when it is implemented in full accordance with the original ACT model (77, 80, 100). However, other studies showed no association with model fidelity and outcome in ACT (32, 38, 96). In the present study, ACTE had moderate model fidelity: for example ACTE did not fully implement a consumer in their team and the contact frequency was low. Also ACTE did not include a psychologist in the team (38, 101). This may have limited its effectiveness. Nevertheless it could be that, as in line with

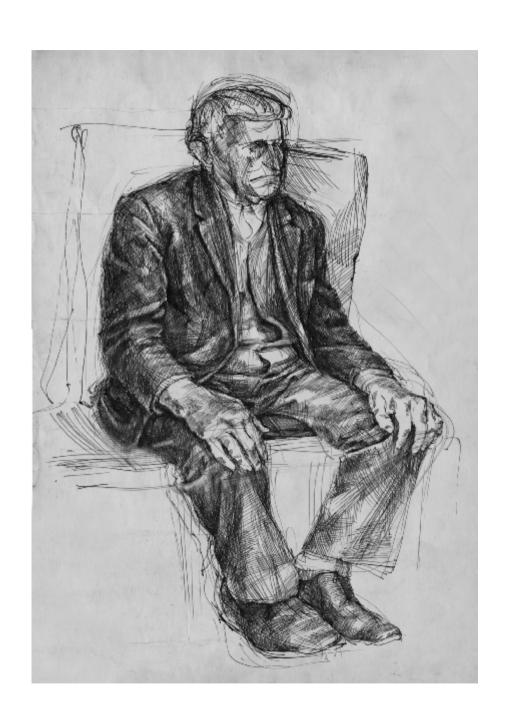
earlier mentioned studies, ACTE does not have added value in improving psychosocial outcomes (38, 96).

Strengths and limitations

The strength of this study is that we managed to include difficult-to-engage patients with SMI in an RCT. To our knowledge this study is the first RCT that investigated the effectiveness of a special ACT team for elderly patients. One limitation is the low number of patients enrolled in this study and the high number of patients lost to follow-up, which meant that the power to detect changes was low (lack of power resulting in a type 2 error). Another limitation is the selection bias; the findings do not apply to all elderly patients with SMI since data were collected in one institution in an urban setting and most patients were, at baseline, difficult to engage. Furthermore it is possible that differences in psychosocial functioning between the intervention and control group were not detected because of measurement limitations. The sum score of the HoNOS65+ has been criticized for not properly measuring change in psychosocial functioning (102). Finally not all assessments were filled out after a face-to-face contact with the patient and raters were not blind for the treatment condition.

Conclusions

In conclusion, ACTE had better results than TAU with regard to engaging patients into treatment and fewer dropouts. However, we could not demonstrate that ACTE led to better psychosocial functioning. To replicate these findings further research is needed in a larger group of patients.



CHAPTER 4

Lack of motivation for treatment associated with greater care needs and psychosocial problems

ABSTRACT

Objective: To compare the care needs and severity of psychosocial problems in older patients with severe mental illness (SMI) between those who were and were not motivated for treatment.

Methods: Cross-sectional study in which we enrolled 141 outpatients with SMI aged 55 and older. Needs were measured using the Camberwell Assessment of Needs for the Elderly, and psychosocial problems with the Health of the Nation Outcome Scale 65+. Motivation for treatment was assessed using a motivation-for-change scale. Parametric and non-parametric tests were used to analyze differences between motivated and nonmotivated patients. Explorative logistic regression analyses were used to establish which unmet needs were associated with motivation.

Results: Less-motivated patients had greater unmet care needs and more psychosocial problems than those who were motivated. Logistic regression analyses showed that lack of motivation was associated with greater unmet needs regarding daytime activities, psychotic symptoms, behavioral problems and, addiction problems.

Conclusions: Lack of treatment motivation was associated with more unmet needs and more severe psychosocial problems. Further research will be needed to identify other factors associated with motivation in older people with SMI, and to investigate whether this group of patient benefits from interventions such as assertive outreach, integrated care or treatment-adherence therapy.

Introduction

Older patients with severe mental illness (SMI) often suffer in silence, experiencing not only various forms of neglect, but also functional impairments and unmet needs with regard to their mental health, physical, and social functioning (9, 11, 12). Predictors of a greater number of unmet needs in this type of elderly population include depression, living alone, and social isolation (12, 103). These patients' loss of capabilities for independent living is associated not only with unmet needs regarding daily living activities, but also with problems in accepting or initiating contact with others, and with problems in asking for professional and other help (12, 22, 23). Due to their lack of perceived needs and an accompanying lack of motivation for treatment, a subgroup of severely mentally ill elderly patients has been found to be difficult-to-engage in mental-health services (24, 25). If they do not enter the mental-health system, they may deteriorate further, sometimes leading to dangerous situations, including self-neglect and social breakdown.

Similarly, less motivation for treatment in adults was associated with greater severity of symptoms (21), particularly for patients with psychotic symptoms and addiction problems (104-106). Unmet needs in adult mental-healthcare have been associated with poor quality of life (107, 108), a higher level of psychiatric symptoms (109), and more intense use of inpatient services (110). More unmet needs were also associated with negative perceptions of mental illness (111) and lower therapeutic alliance (39).

To our knowledge, it has not been studied how motivation in elderly patients with SMI is associated with unmet needs and level of psychosocial problems. In a cross-sectional study, we therefore tested the hypothesis that less-motivated elderly SMI patients had greater unmet care needs than more-motivated patients, had other types of unmet need, and had more psychosocial problems.

Method

This study was carried out in patients who were treated by an Assertive Community Treatment (ACT) team for elderly patients (ACTE) at BavoEuropoort, a mental-healthcare centre in the greater Rotterdam area in the Netherlands.

In the present study we enrolled patients referred to ACTE between April 2008 and August 2010; at the time of referral, they were not receiving psychiatric treatment. There were three inclusion criteria for ACTE: 1.) age 55 years or older, 2.) referral on the presumption of severe mental illness (such as schizophrenia spectrum disorders or major affective disorders); and 3.) difficulties in engaging in treatment, (being unwilling to use mental-health services, having a history of involuntary admissions, or having a history of drop-out from mental-healthcare).

In total, 154 patients were enrolled in this study. Two patients died (of natural causes) before baseline measurement, and 11 could not be contacted. One hundred and forty-one patients completed the baseline measurement and participated in this study. The baseline measurement was conducted after patients had had their first contact with healthcare workers.

The study was approved by the Dutch Union of Medical-Ethical Trial Committees for mental-health organizations. Data for research purposes were used anonymously.

Data-collection procedure

As part of the routine outcome measurement (ROM) procedure, independent assistants collected data during face-to-face contact with patients. The ROM assistants were psychology students trained in the use of the instruments. To score the measurement instruments, all the information that could be obtained was used, not only that provided by the patient and the clinician, but also that contained in the patients' electronic files. If patients refused to be contacted by the ROM assistants, the assessments were based on the information provided by the clinician and on the data in the patients' electronic files, but only if the information was specific enough to complete the dataset, and only if patients were in contact with a healthcare worker.

There were no significant differences in socio-demographic variables and HoNOS65+ scores between (1) patients who were assessed during face-to-face contact with the assistant and (2) those whose scores were based only on the information provided by the clinician and on the data in the patients' electronic files. However, patients who had been assessed face-to-face (n=51) had fewer total unmet needs

(median 6.0, range 0-15) than those not assessed face-to-face (n=90, median 7.0, range 0-19, Mann-Whitney U test, U = 1920, p = 0.020).

Measures

Socio-demographic data were collected from patients' electronic files. They consisted of information on gender, age, marital status, living situation, ethnicity, age at first psychiatric contact, admission history, and the presence of a caregiver (i.e. a relative or friend who provided the patient with emotional and social support, or helped them with activities of daily living or providing). Psychiatric diagnoses were based on a clinical interview by the team's psychiatrist according to the Diagnostic and Statistical Manual of Mental Disorders, fourth revised edition (DSM IV-TR).

Needs

Needs for care were measured using the Dutch version of the Camberwell Assessment of Needs for the Elderly (66) (CANE short appraisal), which provides information about older patients' needs for care, both met and unmet, and comprises physical, psychological, social, and environmental needs. It covers 24 areas of need: accommodation, household skills, food, self-care, caring for others, daytime activities, memory, eyesight or hearing, mobility or falls, continence, physical health, medication, psychotic symptoms, psychological distress, information (on condition and treatment), deliberate self-harm, accidental self-harm, abuse/neglect, problematic behavior, alcohol or drugs addiction, company, intimate relationships, money management, and social benefits. Each item was scored as 0 = no need, 1 = low need or met need (no intervention is needed, or need is met through an intervention); and 2 = high need or unmet need (intervention is needed, or intervention had no effect). We used the following dichotomized CANE scores: 0 = no need (including met need); or 1 = unmet need. The CANE was scored from the perspective of ROM assistants. For the analysis, we used the total number of unmet needs. The validity and reliability of the original scale were good (66), and acceptable for the Dutch version (94).

Psychosocial problems

The severity of psychosocial problems was assessed using the Dutch version of the Health of Nations Outcome Scale for elderly people (HoNOS65+) (64), which consists of twelve items and the following four subscales: behavior problems (3 items); impairment (2 items); symptoms (3 items); and social problems (4 items). All items were scored on a 5-point Likert-type scale, from 0 (no problem), 1 (minor problem), 2 (mild problem), 3 (moderate problem), to 4 (severe problem). The Dutch version of the HoNOS65+ has been shown to be sensitive enough to measure change (92, 93). For analysis, we used the total scores of all items (total score between 0-48) and the total scores of the subscales.

Motivation – Stages of Change

To establish patients' motivation for change, we used a scale based on the stages of change (SoC) in trans-theoretical theory (112). Specifically, patients' motivation to accept treatment for their psychiatric problems was scored on the following 5-point ordinal scale: 1= pre contemplation phase (the patient is not planning to accept psychiatric treatment within 6 months; while it is possible that there is contact with the healthcare professional, the patient does not recognize his/her psychiatric symptoms or unmet needs); 2= contemplation (the patient recognizes some of his/her problems and unmet needs, but has no plan to start treatment within one month. There is contact with healthcare professionals, and the psychiatric problems and unmet needs can sometimes be discussed cautiously); 3= preparation (the patient is considering starting psychiatric treatment within one month; treatment options can be discussed, and sometimes the patient accepts help for practical unmet needs); 4= action (the patient accepts psychiatric treatment and help for unmet needs); and 5= maintenance (psychiatric treatment is maintained for six months or longer; the patient tries to prevent relapse) (113). Due the skewed distribution, the SoC scores were dichotomized into more-motivated patients (n = 37 = 26.2%), who were in the preparation, action and maintenance phase; and lessmotivated patients (n = 104, 73.8%) who were in the pre-contemplation and contemplation phase.

Statistical Analyses

To analyze differences in socio-demographic characteristics and clinical factors between motivated and unmotivated elderly patients, we used independent sample t-tests for continuous variables and chi-square tests (X^2) for categorical variables. Differences in unmet needs were analyzed using the independent sample t-test and Mann-Whitney U test. To examine how unmet needs differed between the more-motivated and lessmotivated groups, we performed explorative analyses using logistic regression analyses, in which we first calculated unadjusted odds ratios (OR) with corresponding 95% confidence intervals (CI).

Multiple logistic regression analyses were performed using stepwise forward and backward procedures, with treatment motivation as the dichotomous dependent variable. The explanatory variables (unmet needs) were entered into the model if they were significant at the 0.05 levels in the explorative analysis. Other independent variables were psychosocial functioning (total score HoNOS65+), and the four socio-demographic variables (gender, age, ethnicity and diagnosis). Variable selection was based on likelihood-ratio test statistics (114). Model-fit was assessed using the pseudo R^2 , Model X^2 and the Hosmer & Lemeshow Goodness of Fit test. SPSS (version 17 for Windows) was used for all analyses.

RESULTS

Patients' characteristics

Table 1 shows demographic characteristics, admission history, the number of file measurements, and the time in weeks between the first contact with the mentalhealthcare worker and the baseline measurement. With the exception of the mean age (less motivated patients were significantly older), demographic characteristics did not differ between motivated and unmotivated patients (Table 1). There were no differences between less and more-motivated patients with respect to diagnoses, psychiatric history, file measurements, and the time between the first face-to-face contact with the healthcare worker and the baseline measurement.

Table 1. Characteristics of more-motivated and less-motivated elderly patients

| Table 1. Characteristics of more-motivated and le | Total N=141 | More motivated | Less motivated |
|--|----------------|---------------------------|----------------------------|
| Mean age* (SD) | 71.3 (8.2) | n=37 69.3 (7.9) | n=104 72.6 (8.2) |
| Mean age at first contact with mental-health services (SD) | 62.1 (17.0) | 58.3 (18.4) | 63.5 (16.3) |
| Gender (%) | | | |
| Male | 64 (45.4) | 18 (48.6) | 46 (44.2) |
| Female | 77 (54.6) | 19 (51.4) | 58 (55.8) |
| Marital status (%) | | | |
| Unmarried | 52 (36.9) | 12 (32.4) | 40 (38.5) |
| Married | 13 (9.2) | 3 (8.1) | 10 (9.6) |
| Divorced | 43 (30.5) | 13 (35.1) | 30 (28.8) |
| Widowed | 33 (23.4) | 9 (24.3) | 24 (23.1) |
| Living situation (%) | | | |
| Independent | 111 (78.7) | 26 (70.3) | 85 (81.7) |
| Sheltered housing | 14 (9.9) | 5 (13.5) | 9 (8.7) |
| Homeless | 16 (11.3) | 6 (16.2) | 10 (9.6) |
| Country of birth (%) | | | |
| The Netherlands | 108 (76.6) | 30 (81.1) | 78 (75.0) |
| Other | 33 (23.4) | 7 (18.9) | 26 (25.0) |
| Diagnosis Axis I (%) | | | |
| Schizophrenia /psychosis | 74 (52.5) | 16 (43.2) | 58 (55.8) |
| Other diagnosis | 37 (26.2) | 11 (29.7) | 26 (25.0) |
| Mood disorders | 13 (9.2) | 5 (13.5) | 8 (7.7) |
| Cognitive disorders | 17 (12.1) | 5 (13.5) | 12 (11.5) |
| Previous hospitalization (%) | | | |
| Yes | 47 (33.3) | 12 (32.4) | 35 (33.7) |
| No | 94 (66.7) | 25 (67.6) | 69 (66.3) |
| File measurement | | | |
| Yes | 51 (36.2) | 10 (27.0) | 41 (39.4) |
| No | 90 (63.8) | 27 (73.0) | 63 (60.6) |
| Baseline measurement# | | | |
| Mean in weeks (SD; range) | 4.6 (2.1; 1-8) | 4.9 (2.0; 1-8) | 4.5 (2.2; 1-8) |

Differences in total unmet needs and in psychosocial functioning

As Table 2 shows, the total score of unmet needs was significantly higher in the lessmotivated group (where the median number of unmet needs was 7) than in the motivated group (where it was 3); Mann-Whitney U test: U = 1712, p = < 0.001.

Table 2 Differences in total unmet needs and psychosocial functioning between moremotivated and less-motivated elderly patients with SMI

| | Total | More motivated | Less motivated | Test of significance |
|--------------------|------------|-------------------|----------------|---------------------------|
| | N=141 | n=37 | n=104 | |
| Total unmet needs | | | | |
| Median (range) | 6 (0-19) | 3 (0-11) | 7 (0-19) | #U=1712, p= <0.001 |
| Total HoNOS65+ | | | | |
| Mean (SD) | 19.8 (5.3) | 16.2 (5.2) | 21.1 (4.8) | *t(139)=518, p= <0.001 |
| HoNOS Subscales | | | | |
| Mean (SD) | | | | |
| Behaviour problems | 2.6 (1.9) | 1.5 (1.3) | 3.0 (1.9) | *t(139)=-4.52, p= <0.001 |
| Impairment | 2.9 (1.6) | 3.0 (1.7) | 2.9 (1.6) | *t(139)=0.386, p= 0.700 |
| Symptoms | 4.3 (2.5) | 3.8 (2.2) | 4.5 (2.5) | *t(139)=-1.555, p= 0.122 |
| Social functioning | 9.9 (3.2) | 7.9 (3.5) | 10.6 (2.8) | *t(139)=-4.773, p= <0.001 |
| | | | | |

SD= standard deviation # = Mann-Whitney U test, *= paired t test

Table 2 shows also that total mean HoNOS65+ score was significantly higher in patients who were less motivated for treatment. On the HoNOS65+ subscales, these patients had significantly more behavioural and social functioning problems, compared with patients who were more motivated for treatment.

Table 3 shows the differences in individual unmet needs between the moremotivated and less-motivated groups. Less-motivated patients were more likely than motivated patients to have unmet needs for daytime activities, medication, psychotic symptoms, information, abuse/neglect, behavior problems, addiction, and company.

Table 3. Differences in unmet needs between more-motivated and less-motivated elderly patients with SMI

| patients with SMI | | | | | |
|------------------------|----------------|-----------------|------|---------------|--------|
| Needs | More-motivated | Less- motivated | OR | 95% CI Exp(B) | P |
| | N=37 (%) | n=104 (%) | | | |
| Accommodation | 9 (24.3) | 36 (34.6) | 1.65 | 0.70-3.86 | 0.251 |
| Household skills | 8 (21.6) | 40 (38.5) | 2.27 | 0.94-5.45 | 0.068 |
| Food | 4 (10.8) | 21 (20.2) | 2.09 | 0.67-6.55 | 0.207 |
| Self-care | 6 (16.2) | 29 (27.9) | 2.00 | 0.76-5.29 | 0.164 |
| Caring for others | 1 (2.7) | 3 (2.9) | 1.07 | 0.11-10.61 | 0.954 |
| Daytime activities | 18 (48.6) | 86 (82.7) | 5.04 | 2.22-11.46 | <0.001 |
| Memory | 3 (8.1) | 21 (20.2) | 2.87 | 0.80-10.25 | 0.105 |
| Eyesight – hearing | 5 (13.5) | 15 (14.4) | 1.08 | 0.36-3.21 | 0.892 |
| Mobility – falls | 4 (10.8) | 13 (12.5) | 1.18 | 0.36-3.87 | 0.787 |
| Continence | 0 | 11 (10.6) | 1.12 | # | # |
| Physical health | 7 (18.9) | 25 (24.0) | 1.36 | 0.53-3.46 | 0.524 |
| Medication | 8 (21.6) | 51 (49.0) | 3.49 | 1.46-8.34 | 0.005 |
| Psychotic symptoms | 7 (18.9) | 55 (52.9) | 4.81 | 1.94-11.93 | 0.001 |
| Psychological distress | 7 (18.9) | 24 (23.1) | 1.29 | 0.50-3.29 | 0.601 |
| Information | 11 (29.7) | 64 (61.5) | 3.78 | 1.69-8.49 | 0.001 |
| Deliberate self-harm | 2 (5.4) | 1 (1.0) | 0.17 | 0.02-1.93 | 0.153 |
| Accidental self-harm | 0 | 18 (17.3) | 1.21 | # | # |
| Abuse /neglect | 3 (8.1) | 26 (25.0) | 3.78 | 1.07-13.33 | 0.039 |
| Behavior problems | 3 (8.1) | 39 (37.5) | 6.80 | 1.96-23.63 | 0.003 |
| Addiction | 3 (8.1) | 25 (24.0) | 3.59 | 1.01-12.69 | 0.048 |
| Company | 23 (62.2) | 83 (79.8) | 2.41 | 1.06-5.46 | 0.036 |
| Intimate relationships | 6 (16.2) | 16 (15.4) | 0.94 | 0.34-2.62 | 0.905 |
| Money – budgeting | 8 (21.6) | 27 (26.0) | 1.27 | 0.52-3.12 | 0.600 |
| Benefits | 4 (10.8) | 18 (17.3) | 1.73 | 0.54-5.48 | 0.354 |
| | | | | | |

Not calculated due to empty cells

Multivariate logistic regression analysis showed that poor treatment motivation was independently associated with unmet needs for daytime activities, psychotic symptoms, behavior problems, and addiction. No interaction effects were found (i.e. with gender, age, ethnicity, diagnosis or psychosocial functioning; see Table 4).

Table 4. Results of logistic regression analysis. The independent variables were unmet needs (individual items), total psychosocial functioning, and the socio-demographic variables (gender, age, ethnicity and diagnosis). The dependent variable was the level of motivation (more-motivated versus less-motivated)#

| | 95% CI for Exp(B) | | | | | |
|------------------------|----------------------------|-------|--------------|----------------|-------|--|
| Needs | Beta (SE) | Lower | Exp(B) | Upper | р | |
| Constant | -1.27 (0.46) | | 0.28 | | 0.006 | |
| Daytime activities | 1.31 (0.50) | 1.40 | 3.71 | 9.86 | 0.009 | |
| Psychotic symptoms | 1.73 (0.53) | 1.99 | 5.65 | 16.08 | 0.001 | |
| Abuse/neglect | 1.28 (0.70) | 0.91 | 3.60 | 14.21 | 0.067 | |
| Behavior | 1.45 (0.69) | 1.10 | 4.25 | 16.36 | 0.036 | |
| Addiction | 2.05 (0.73) | 1.88 | 7.80 | 32.30 | 0.005 | |
| Abuse/neglect Behavior | 1.28 (0.70) 1.45 (0.69) | 0.91 | 3.60 4.25 | 14.21 16.36 | 0.067 | |

Model summary: R2= .41 (Nagelkerke), Hosmer & Lemeshow Goodness of Fit = 7.45, p=.384; #: only independent variables which contributed to the model were listed in the table

Discussion

This study of elderly SMI patients showed that those who were less motivated for psychiatric treatment had greater unmet care needs than those who were more motivated, had more severe psychosocial problems, more behaviour problems, and more problems in social functioning. Explorative logistic regression analyses showed that less motivated patients had greater unmet care needs with regard to daytime activities, psychotic symptoms, behavior problems, and addiction.

Our results are consistent with those in studies in adult mental-healthcare that also found less motivation for treatment to be associated with the presence of psychotic symptoms and addiction problems (21, 104-106) - associations which may be partly explained by the lack of insight that is common in psychotic and addiction-disorder patients (15). Our finding of more behavioral problems in the less-motivated patient group may be a negative consequence of these symptoms or problems (105, 106, 115). In other studies, higher numbers of unmet needs for daytime activities were associated with a lack of social integration (116, 117) – a finding that may also apply to the less motivated patients in our study, as they had more serious problems on the HoNOS65+ subscale psychosocial functioning than the more-motivated patients did.

In both our groups, the total number of unmet needs was higher than that reported

in other studies with elderly patients (103, 118, 119). These differences may have been due to the greater severity of psychiatric problems in our study than in the studies by Houtjes et al. and Cummings et al., in which most patients had been diagnosed with depression (103, 118). Additionally, in the study by Meesters et al, not only were almost all of the patients with schizophrenia spectrum disorders motivated for treatment, symptoms were in remission in nearly 30% of them (119). In our own study, however most of our patients were not motivated for treatment and had entered the mentalhealthcare services more recently.

Clinical implications

Our results showed that lack of motivation was associated with greater unmet care needs and more severe psychosocial problems, both indicating a higher burden of disease. Given the variation in the patients' needs, the provision of outreach psychiatric services for these patients might be integrated with social services and addiction treatment, as described for Assertive Community Treatment (29, 89).

So far, only one study (37) has focused on ACT for the elderly. While this small study concluded that, supplemented with specific care for the elderly, the ACT model was suitable for this subgroup, it presented no data on the effectiveness of this service. Another study on an integrated care programme for severely mentally ill elderly people suggested that, relative to treatment as usual, integrated care provided better outcomes in social skills and psychosocial and community functioning (35). A small pilot study with seven elderly patients with SMI showed that elderly people could benefit from integrated illness management and recovery (with integrated physical care and psychiatric illness management) (120). However, the lack of evidence-based practice in (psychosocial) interventions in elderly patients with SMI (22) highlights the need for research on determining which interventions lead to a better outcome or prevent further deterioration.

Our own finding that lack of motivation was associated with higher burden of disease suggests that special attention – such as motivational interviewing techniques or treatment-adherence therapy (121, 122) - is required to tackle these patients' lack of motivation for treatment, and to get them to engage in it. However treatment motivation

is a complex concept; in elderly SMI patients it is particularly poorly understood. It might nonetheless be improved if these patients were offered some of the interventions used in younger SMI adults.

One study have shown that any improvement in the therapeutic alliance depends upon agreement between clinicians on unmet needs and the treatment plan (39). This is why a full needs assessment could be used for planning treatment in elderly patients with SMI.

Limitations

First, the use of the design did not allow us to draw causal conclusions. Second, the SoC scale has not been validated. Third, motivation problems may have been influenced by a variety of factors (including lack of insight, stigma, and poor therapeutic alliance (15), which were not assessed in this study. Fourth, because data were collected from patients who had been referred in the context of a study on ACTE in one institution in an urban setting, the results of our study sample may not be generalizable to other populations in other settings. Finally, not all of the patients had face-to-face contact with the routine outcome measurement assistant. The strength of this study is that we included difficultto-engage elderly patients with SMI: to our knowledge, it is the first study to examine how motivation in this patient group is associated with unmet needs and psychosocial problems.

Conclusion

Our results suggest that elderly patients with SMI who are less motivated for treatment have greater unmet care needs and more psychosocial problems than those who are more motivated. For identifying other factors associated with motivation in SMI elderly patients, further research should investigate whether these patients benefit from interventions such as assertive outreach, integrated care or treatment adherence therapy.



CHAPTER 5

Decrease in unmet needs helps improve motivation for treatment in elderly patients with severe mental illness

SUMMARY

Objective: To investigate the pattern of associations between changes in unmet needs and treatment motivation in elderly patients with severe mental illness.

Methods: Observational longitudinal study in 70 patients treated by an Assertive Community Treatment team for the elderly. At baseline, after 9 and after 18 months, unmet needs were measured using the Camberwell Assessment of Needs for the Elderly. Motivation for treatment was measured using the Stages of Change scale. The scores of the Stages of Change scale were dichotomized into two categories: motivated and unmotivated. Multinomial logistic regression procedures were conducted to determine whether changes in motivation parallel or precede changes in unmet needs.

Results: The number of patients who were not motivated for treatment decreased over time: at baseline, 71.4% were not motivated, at the second measurement 51.4% were not, and at 18 months 31.4% were not. Decreases in unmet needs between 0 and 9 months and 0 and 18 months were associated with remaining motivated or with a change from unmotivated to motivated during the same observational period (parallel associations). A decrease in unmet needs from 0-9 months was also associated with remaining motivated or with a change from unmotivated to motivated during the 9-18 month follow-up (sequential associations).

Conclusions: Our findings suggest that a decrease in unmet needs is associated with improvements in motivation for treatment.

Introduction

Many patients with severe mental illness (SMI) are not motivated for treatment. If they fail to comply with treatment or if they drop out of it, this may lead to a worse prognosis (15, 16). To engage such unmotivated patients in treatment, assertive outreach may be needed (33, 123), as in Assertive Community Treatment (ACT), which was developed as an integrated model to meet the needs of difficult-to-engage patients with complex problems (29).

Various factors have been found to be associated with lower motivation for treatment in adult SMI patients. They include patient-related factors (such as more severe symptoms, greater substance-abuse problems, lack of insight, male gender, younger age, and a lower educational level); relationships factors (including poorer therapeutic alliance and less family support) (17-20); and factors related to the servicedelivery system (such as problems accessing care, and lack of information about their illness) (21). Treatment motivation in elderly SMI patients has barely been investigated. In an earlier cross-sectional study in elderly patients treated by an Assertive Community Treatment team for the elderly (ACTE), we found that a higher number of unmet needs was associated with poor treatment motivation at baseline (124).

Whereas the studies referred to above used a cross-sectional design, the longitudinal associations between changes in needs and changes in motivation have barely been studied. If clinicians are to prioritize interventions intended to improve motivation for treatment, greater insight into these associations is needed.

Because treatment adherence has been shown to improve when a patient perceives his or her unmet needs to have been met (39), we investigated in SMI patients treated in ACTE whether a decrease in unmet needs over time was associated with changes in treatment motivation during the same time period (parallel association); and whether a decrease in unmet needs would precede an increase in treatment motivation (sequential association).

Method

Design

Longitudinal observational study among elderly patients diagnosed with an SMI who were treated in ACTE. This 18-month study was part of a larger study of the effectiveness of ACTE. The study design was approved by the Dutch Union of Medical-Ethical Trial Committee for mental-health organizations.

Subjects

The research population consisted of community-dwelling elderly patients with an SMI who were difficult-to-engage in treatment and who were receiving mental health care from the ACTE team at BavoEuropoort, a mental healthcare center in the greater Rotterdam area in the Netherlands. The three inclusion criteria for ACTE were age 55 and over; having an SMI (for example schizophrenia spectrum disorder or major affective disorder); and being difficult-to-engage in treatment (patients who avoided or did not respond well to usual community mental-health care). The exclusion criterion was having a severe cognitive impairment. All patients referred to ACTE between April 2008 and end of July 2010 were enrolled in this study and were assessed at three time points (baseline, and after 9 and 18 months).

Data-collection procedure

Independent raters (psychology students trained in the use of the instruments) collected all data as part of a Routine Outcome Measurement (ROM) procedure. Instruments were scored during a face-to-face meeting with each patient, and also on the basis of information from clinicians and from the patients' electronic files. If a patient declined the assessment, or if the ROM assessment failed due to no-show (after three attempts to have face-to-face contact), his or her assessment was based on the information provided by the clinician and by the data in the patient's electronic files. However, this was done only if the information was specific enough to complete the ROM assessment.

In the baseline, 9-month and 18-month assessments, the number of unmet needs and motivation for treatment did not differ between patients whose data had been collected during face-to-face contact or from electronic files and clinicians. Only patients assessed at 9 months during a face-to-face meeting were more motivated than patients whose data had been collected from electronic files (58 versus 32%, Pearson's' chi square test = 4.28 degrees of freedom (df) = 1, p = 0.039).

Socio-demographic data were collected from patients' electronic files. Psychiatric diagnoses were based on a clinical interview by the team's psychiatrist according to the Diagnostic and Statistical Manual of Mental Disorders, fourth revised edition (DSM IV-TR).

Measures

Motivation

Motivation for psychiatric treatment was assessed with a stages-of-change scale (SoC) based on the algorithm of stages of change stated in the trans-theoretical theory (112). This scale measures motivation for treatment of the psychiatric disorder. The ratings were based on the patients' behaviour and on information from clinicians and the patients' electronic records.

The SoC model includes five different stages of motivation: 1 = pre-contemplation phase (patient does not recognize his psychiatric symptoms and treatment adherence is lacking; 2 = contemplation phase (the patient recognizes some of his psychiatric problems and unmet needs, but there is no plan to start treatment within one month); 3 = preparation phase (treatment options can be discussed, and the patient is considering starting psychiatric treatment within one month); 4 = action phase (the patient accepts psychiatric treatment and help for unmet needs); and 5 = maintenance phase (psychiatric treatment has been maintained for six months or longer, the patient tries to prevent relapse, and care needs have been met) (113, 124).

Due to the skewed distribution, the motivation-for-change scores were dichotomized into an unmotivated group (pre-contemplation and contemplation phase) and a motivated group (preparation, action and maintenance phase).

Needs

Needs were assessed using the Dutch version of the Camberwell Assessment of Needs for the Elderly (66) (CANE), which covers care needs in twenty-four areas including environmental, physical, psychological and social needs. The care needs were assessed

from a raters' point of view. Environmental needs included needs with regard to accommodation, household skills, food, caring for others, money management and social benefits. Physical needs covered self-care, eyesight/hearing, mobility/falls, continence, physical health, and medication (side effects and compliance). Psychological needs included needs with regard to memory, psychotic symptoms, psychological distress, deliberate self-harm, accidental self-harm, behavior problems, and addiction problems. Finally, social needs covered daytime activities, information about illness or treatment, abuse/neglect, company, and intimate relationships.

The validity and reliability of the original scale was good, (66); for the Dutch version it was acceptable (94). Each item was scored either as 0 = no need; 1 = met need or low need (due to an intervention or to a low need that does not require an intervention); or 2 = unmet need (intervention is needed, or intervention had no effect). In the present study, only unmet needs were taken into account.

Statistical Analyses

To assess changes in motivation, we calculated the changes in the SoC from baseline to the second measurement (0-9 months); from baseline to the last measurement (0-18 months); and from the second measurement to the last measurement (9 months-18 months). For all periods (0 to 9 months, 0 to 18 months and 9 months to 18 months), patients were categorized as 0 = unmotivated from the start - no improvement in motivation over time; 1 = motivated from the start – no decrease in motivation over time; or 2 = improved motivation -unmotivated at the start, but becoming motivated for treatment over time. There were no patients who were motivated at the start but then became unmotivated.

All analyses were conducted using SPSS (version 20 for Windows). One-way analysis (ANOVA) for continuous variables and chi-square tests (X2) for categorical variables were used to analyse differences in socio-demographic characteristics and clinical factors between patients in contrasting groups of change in motivation. Multinomial logistic regression analyses were conducted to determine associations between changes in needs and motivation for treatment. First, we investigated the associations between changes in unmet needs parallel to changes in motivation during the follow-up period (0-9 months, 0-18 months, 9-18 months). Second, we investigated whether a decrease in unmet needs from 0-9 months was associated with a change in motivation during the follow-up period from 9-18 months.

Change in motivation was the dependent variable, with patients who remained unmotivated being used as a reference group. We controlled for socio-demographic variables (gender, age, having a psychotic disorder) and total unmet needs at baseline. Variable selection was based on likelihood-ratio test statistics. Model-fit was assessed using Pearson's Chi² test and the Deviance Goodness of Fit test and pseudo R² (Nagelkerke and McFadden).

Results

The original sample of this study consisted of 128 patients. Three patients had died from natural causes before the first contact took place, and 3 patients could not be traced. One hundred and twenty-two patients completed the first measurement. Fifty-two patients were eventually lost to follow-up: 7 died from natural causes, 5 moved out of the region, 17 were discharged from care as they had refusing it, 10 were hospitalized long-term, 3 were transferred to another team (for treatment of less severe patients), and 7 were discharged from care for other reasons. As we were unable to contact one patient, and as two more were excluded because they were lost to the second measurement (unable to contact), this left 70 patients who completed the set of measurement instruments.

Between patients engaged in care and those lost to follow-up there were no differences in demographic characteristics and the median number of unmet needs, except with regard to educational level: 16.7% of those lost to follow-up had only no education or elementary education, against 41.4% of those in the follow-up group (Pearson's chi-square test = 19.4, degrees of freedom (df) = 2, p = <0.001). However, much of the group that was lost to follow-up had no data on educational level (45.8%, against 11.4% in the follow-up group).

Patients' characteristics

At baseline, 71.4% of patients were not motivated for treatment; after 9 months, 51.4% were not motivated; and after 18 months, 31.4% were not motivated. Table 1 shows the

characteristics of the 3 patient groups (contrasting changes in motivation from 0-18 months). Motivated patients entered the mental-health services at a younger age (one way ANOVA: F = 4.56, df= 2, p = 0.014). Unmotivated patients were more likely to have a psychotic disorder (Pearson's chi-square test: $X^2 = 13.3$, df = 2, p = 0.001). Patients who remained motivated had had fewer unmet needs at baseline (Kruskall Wallis test: X² = 14.0, df = 2, p = 0.001).

Table 1. Baseline characteristics in groups contrasting changes in motivation for treatment (TO-T18)

| Table 1. Baseline characteristics in group | Total | Remained | Improved | Remained |
|--|-------------|-------------|-------------|-------------|
| | | Unmotivated | motivation | Motivated |
| | N=70 | n = 22 | n = 28 | n = 20 |
| Mean age (SD) | 72.1 (7.3) | 74.0 (7.1) | 71.8 (7.3) | 70.6 (7.2) |
| Range | 61-88 | 63-88 | 61-83 | 61-83 |
| Mean age 1 st contact mental-health* (SD) | 59.4 (17.8) | 64.7 (15.6) | 62.0 (16.2) | 49.9 (19.4) |
| Range | 13-87 | 28-87 | 25-86 | 13-72 |
| Gender (%) | | | | |
| Male | 31 (44.3) | 7 (31.8) | 15 (53.6) | 9 (45.0) |
| Female | 39 (55.7) | 15 (68.2) | 13 (46.4) | 11 (55.0) |
| Marital state (%) | | | | |
| Unmarried | 28 (40.0) | 9 (40.9) | 14 (50.0) | 5 (25.0) |
| Married | 6 (8.6) | 2 (9.1) | 2 (7.1) | 2 (10.0) |
| Divorced | 21 (30.0) | 7 (31.8) | 7 (25.0) | 7 (35.0) |
| Widowed | 15 (21.4) | 4 (18.2) | 5 (17.9) | 6 (30.0) |
| Level of education (%) | | | | |
| No/elementary education | 35 (50.0) | 12 (54.5) | 12 (42.9) | 11 (55.0) |
| Secondary/higher education | 27 (38.6) | 8 (36.4) | 13 (46.4) | 6 (30.0) |
| Missing | 8 (11.4) | 2 (9.1) | 3 (10.7) | 3 (15.0) |
| Living situation (%) | | | | |
| Independent | 54 (77.1) | 20 (90.9) | 19 (67.9) | 15 (75.0) |
| Homeless | 8 (11.4) | - | 4 (14.3) | 2 (10.0) |
| Protective living | 8 (11.4) | 2 (9.1) | 5 (17.9) | 3 (15.0) |
| Nation of birth (%) | | | | |
| The Netherlands | 53 (75.7) | 17 (77.3) | 21 (75) | 15 (75.0) |
| Other | 17 (24.3) | 5 (22.7) | 7 (25) | 5 (25.0) |
| Psychotic disorders (%)** | | | | |
| Yes | 42 (60.0) | 20 (90.9) | 14 (50.0) | 8 (40.0) |
| No | 28 (40.0) | 2 (9.1) | 14 (50.0) | 12 (60.0) |
| Psychiatric admission (%) | | | | |
| Yes | 15 (21.4) | 4 (18.2) | 5 (17.9) | 6 (30.0) |
| No | 55 (78.6) | 18 (81.8) | 23 (82.1) | 14 (70.0) |
| Unmet needs baseline** | | | | |
| Median | 6.0 | 6.5 | 6.0 | 2.5 |
| Range | 0-15 | 0-11 | 1-15 | 0-10 |

Continue variables were tested with one-way ANOVA, categorical variable with Pearson's chi-square test and unmet needs with Kruskall Wallis test. SD = standard deviation. *p = 0.014, **p = 0.001

Most of the respondents had unmet needs with regard to company (71.4%), daytime activities (65.7%) and information on their illness or treatment (42.9%). As Table 2 shows, the percentages of all unmet needs decreased over time. At 18 months follow-up, most patients suffered from unmet needs with regard to company (38.6%), daytime activities (31.4%) and treatment for psychotic symptoms (27.1%).

Table 2 Percentage of unmet needs at different time noints

| | Baseline | 9 months | 18 months |
|------------------------|-----------|-----------|-----------|
| Unmet Need | N =70 (%) | N=70 (%) | N =70 (%) |
| Accommodation | 26 (37.1) | 14 (20.0) | 8 (11.4) |
| Household skills | 24 (34.3) | 8 (11.4) | 7 (10.0) |
| Food | 8 (11.4) | 3 (4.3) | 3 (4.3) |
| Self-care | 17 (24.3) | 11 (15.7) | 3 (4.3) |
| Caring for others | 1 (1.4) | 2 (2.9) | 0 |
| Daytime activities | 46 (65.7) | 22 (31.4) | 15 (21.4) |
| Memory | 8 (11.4) | 7 (10.0) | 4 (5.7) |
| Eyesight – hearing | 11 (13.5) | 3 (4.3) | 4 (5.7) |
| Mobility – falls | 8 (11.4) | 3 (4.3) | 6 (8.6) |
| Continence | 4 (5.7) | 2 (2.9) | 0 |
| Physical health | 13 (18.6) | 9 (12.9) | 6 (8.6) |
| Medication | 26 (37.1) | 16 (22.9) | 14 (20.0) |
| Psychotic symptoms | 28 (40.0) | 19 (27.1) | 14 (20.0) |
| Psychological distress | 13 (18.6) | 4 (5.7) | 3 (4.3) |
| Information | 30 (42.9) | 16 (22.9) | 10 (14.3) |
| Deliberate self-harm | 2 (2.9) | 0 | 0 |
| Accidental self-harm | 7 (10.0) | 3 (4.3) | 2 (2.9) |
| Abuse /neglect | 12 (17.1) | 2 (2.9) | 1 (1.4) |
| Behavior problems | 16 (22.9) | 10 (14.3) | 4 (5.7) |
| Addiction | 15 (21.4) | 13 (18.6) | 10 (14.3) |
| Company | 50 (71.4) | 27 (38.6) | 19 (27.1) |
| Intimate relationships | 10 (14.3) | 3 (4.3) | 1 (1.4) |
| Money – budgeting | 19 (27.1) | 5 (7.1) | 4 (5.7) |
| Benefits | 11 (15.7) | 1 (1.4) | 1 (1.4) |

Unmet needs were measured with the Camberwell Assessment of Needs Elderly, short appraisal

Figure 1 shows the median number of unmet needs over time in the 3 groups classified according to change in motivation. For all groups, the decrease in median number of unmet needs (T0-T18) was significant (patients remained motivated: Wilcoxon signed rank test Z = -2.7, p = 0.008; patients remained unmotivated: Z = -2.6, p = 0.008; patients with improved motivation: Z = -4.5, p = <0.001).

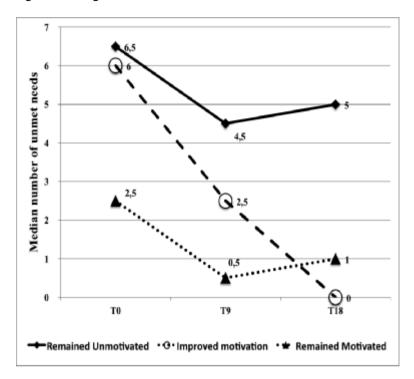


Figure 1. Change in unmet needs over 18 months

Parallel changes in needs and motivation

Multinomial logistic regression analyses showed that, unlike in the group of patients who remained unmotivated, unmet needs decreased significantly over time in patients who remained motivated and also in those whose motivation improved. This was the case both from 0-9 months (Ex (B) 1.445; 95% confidence interval (Cl) 1.04-2.0; p = 0.026) and from 0-18 months (see Table 3). There was no association between a change in unmet needs and change in motivation during the 9-18 months period.

As Table 3 shows, for each need whereby the number of unmet needs decreased over the 18-month period, patients had a 2.1 times greater chance of belonging to the group of patients who remained motivated, or a 2.5 times greater chance of belonging to the group of patients who became motivated over time.

Table 3. Decrease in unmet needs over time (T0 minus T18) associated with change in motivation for treatment (change between T0 and T18)

| Predictors | No chance - remaining unmotivated | Change – improved motivation |
|-------------|-----------------------------------|------------------------------|
| | Exp (B) 95% CI | Exp (B) 95% CI |
| | р | р |
| | | |
| Unmet needs | 2.103 | 2.495 |
| T0 -T18 | 1.32 - 3.35 | 1.60-3.91 |
| | p = 0.002 | p = <0.000 |
| | 0.347 | 0.801 |
| Unmet needs | 0.20-0.61 | 0.25-0.68 |
| baseline | p = <0.001 | p = 0.001 |

Reference category were patients remaining motivated over time

Sequential changes in needs and motivation

Multinomial logistic regression analyses (see Table 4) showed that, relative to the group of patients who remained unmotivated in 9-18 months follow-up, a decrease in unmet needs from 0-9 months was associated with patients remaining motivated or with patients whose motivation improved during the 9-18 month follow-up. For need whereby the number of unmet needs decreased over the 0-9 months period, patients had a 1.7 times greater chance of belonging to the group of patients who remained motivated, or a 1.4 times greater chance of belonging to the group of patients who became motivated over time. When socio-demographic factors (gender, age and having a psychotic disorder) were added, likelihood-ratio test statistics showed no model improvement.

⁻² Log likelihood intercept only 130.20, final model 81.38, Chi²= 48.83 (df = 4), p = < 0.001. Nagelkerke R² = 0.57, McFadden $R^2 = 0.32$

| Table 4. Decrease in unmet needs over | time (T0 minus | T9) prior to change | in motivation for |
|---------------------------------------|----------------|---------------------|-------------------|
| treatment (between T9 and T18) | | | |

| Predictors | No chance - remaining motivated Exp (B) 95% CI | Change – from unmotivated into motivated Exp (B) 95% CI |
|----------------------|--|---|
| | р | р |
| Unmet needs T0 - T9 | 1.678 | 1.471 |
| | 1.22 – 2.33 | 1.05 – 2.04 |
| | p = 0.001 | p= 0.025 |
| Unmet needs baseline | 1.721 | 1.323 |
| | -2.33 – 1.27 | 0.99 – 1.82 |
| | p = 0.001 | p = 0.093 |

Reference category were patients remaining unmotivated over time

Discussion

In this study we examined whether a decrease in unmet needs over time was associated with changes in treatment motivation, and whether a decrease in unmet needs would parallel or precede an increase in treatment motivation among 70 patients treated in ACTE. We found that, relative to the situation in patients who remained unmotivated over time, a decline in the number of in unmet needs (from baseline to 18 months) was associated not only with remaining motivation for treatment, but also with becoming motivated for it. Even during the first nine months after beginning of the treatment, a decline in the number of unmet needs was associated with an improvement in motivation. We also found that a decrease in unmet needs from baseline to 9 months was associated with an improvement in motivation for treatment during the subsequent 9 months. These findings suggest that meeting the needs of elderly patients with SMI who are difficult-to-engage in treatment may lead to a positive change in motivation for treatment. In addition, patients who remained unmotivated for treatment had more unmet needs at baseline. They were also more likely to be diagnosed with a psychotic disorder.

⁻² Log likelihood intercept only 129.67, final model 109.47, Chi² = 20.2 (df = 4), p = < 0.001. Nagelkerke R² = 0.29, McFadden $R^2 = 0.14$

Towards better motivation for treatment

Motivation for treatment is a complex concept that is influenced by many factors. This may mean that, over time, it changed in our group for other reasons than a decline in the number of unmet needs. Although we have been unable to find studies that specifically investigated the association between motivation and needs, two earlier findings are in line with our own: an association between more unmet needs and negative perceptions of mental illness (111); and an association between more unmet needs and lower therapeutic alliance (39).

Our findings showed that improvement in the level of unmet needs from 0-9 months follow-up was associated with becoming motivated for treatment during this period and during 9-18 months follow-up. This indicates that meeting a patient's need may increase motivation for treatment, and, by corollary, that an inability to address unmet needs may keep a patient unmotivated. As one way to increase this motivation, we therefore recommend clinicians working with elderly people with SMI and treatmentmotivation problems to start fulfilling their unmet needs. For example, if a patient is in need of adequate housing (125, 126), the provision of a house may motivate them to accept treatment, for example by accepting medication. Patients who experience benefit from their clinicians may be more willing to accept the treatment they offer for their psychiatric symptoms. Naturally, however, some unmet needs are not easy to address (e.g. unmet needs for intimate relationships).

It could also be, however, that clinicians try to fulfill unmet needs in all patients, motivated and unmotivated alike, but that only patients who are motivated - or are becoming motivated - due to a third factor (e.g. working alliance) are able to benefit from these interventions and thereby have more of their needs met.

Our findings should be interpreted with some caution. First, as stated above, this observational study does not allow causal inferences to be drawn on the basis of the associations we report. Second, because our data were collected in one institution in an urban setting and because most patients were difficult-to-engage at baseline, our findings do not apply to all SMI elderly patients. Finally, our results may have been affected by the high number of patients lost to follow-up.

Despite these limitations, the strength of this study is that, to the best of our knowledge, this is the first longitudinal study to examine the associations between changes in unmet needs and changes in motivation for treatment of SMI elderly patients. Further research is needed to unravel causal relationships and to determine whether interventions to improve unmet needs lead to better motivation.

Conclusion

These results in elderly SMI patients treated by an ACT-team suggest that a decrease in unmet needs is associated with improvement in motivation for treatment. While it may be possible to increase motivation for treatment by addressing unmet needs, special attention is required by subgroups of patients who remain unmotivated over time. These patients will need an intervention to improve treatment motivation.



CHAPTER 6

Predictors of the psychosocial outcome of Assertive Community Treatment in elderly patients with severe mental illness

ABSTRACT

Objective: To identify predictors for the psychosocial outcome of Assertive Community Treatment in elderly patients with severe mental illness (SMI).

Methods: Longitudinal data collection from 72 SMI outpatients aged ≥ 55 treated in a specialized Assertive Community Treatment team for elderly patients (ACTE). At baseline and 18 months, severity of psychosocial functioning was assessed using the Health of Nations Outcome Scale for elderly people (HoNOS65+). Potential predictors included level of education, being motivated for treatment, having a schizophrenia spectrum disorder and somatic disorders.

Results: Although, on average, most patients' psychosocial functioning improved over time (HoNOS65+ total score), regression analysis showed that none of the potential predictors except for the total score at baseline were related to overall psychosocial outcome. The HoNOS65+ subscales showed that patients with a psychotic disorder and those with a low educational level were more likely to have treatment-resistant psychiatric symptoms; outcome in social problems was poor in less-educated patients who also had somatic disorders.

Conclusions: Overall psychosocial functioning improved in difficult-to-engage elderly patients treated in ACTE. Treatment outcome is a complex process whereby, at a subscale level of the HoNOS65+, less-educated patients are more vulnerable to poor outcome with respect to symptoms and social functioning.

Introduction

In adult mental-health care, Assertive Community Treatment (ACT) is an organizational model of care for treating severely mentally ill (SMI) patients who are difficult-to-engage. The ACT model operates with a small, shared caseload, with 10-12 patients per fulltime worker and all clinicians collaborating closely on each patient. This community-based service draws on the skills of the team workers rather than on outside agencies. ACT is an integrated service whose activities include the provision of psychiatric, somatic and social care) (60, 62).

Relative to treatment as usual, ACT in the United Sates reduced hospital admissions, led to more stable housing, improved outcome, and had fewer dropouts (29, 30). While outcome studies in Europe did not show that ACT had any effects regarding reduced admissions or clinical outcome (31), it engaged patients in treatment more successfully than treatment as usual (33, 123). To date, all outcome studies on ACT have been conducted in adults aged \leq 55 years. Recently, we finished the first randomized controlled trial (RCT) in elderly SMI patients (aged \geq 55 year) receiving ACT. Although this showed no differences in psychosocial outcome between ACT for elderly patients (ACTE) and treatment as usual, ACTE more successfully engaged patients into treatment (123).

Treatment outcome for elderly patients in ACT is poorly understood. When one is developing interventions for elderly difficult-to-engage SMI patients, it is relevant to predict who will benefit from ACTE and who will not. Poor outcome in ACT for adults has been associated with having a longer psychiatric history, poor engagement with services and homelessness (96), and also with substance-abuse problems, a higher age, a lower educational level, and treatment-motivation problems (40). As it is unknown whether this also applies to elderly patients in ACT, we wished to determine which variables predict the outcome in psychosocial functioning at 18 months follow-up. We expected poor treatment outcome to be predicted by a psychotic disorder (relative to non-psychotic disorders) (23); by comorbid somatic problems (relative to patients without somatic problems) (9); by a low level of education (relative to a higher level); and by a lack of treatment motivation at baseline (relative to more motivated patients) (40).

Methods

We conducted an observational longitudinal study in patients treated by the ACTE team at BavoEuropoort (a department of Parnassia Psychiatric Institute), a mental-healthcare centre in the greater Rotterdam area in the Netherlands. The ACTE team treated patients aged ≥ 55 who had an SMI (defined as psychotic disorder, bipolar disorder, or persistent severe depression) and were difficult-to-engage in treatment.

We included patients who had been referred to ACTE between April 2008 and August 2010. Routine outcome data were collected at two time points: at baseline and at 18 months. The instruments were completed by psychology students on the basis of contact with the patient and of information provided by the clinician and the patients' electronic files. If patients refused contact, data were collected solely on the basis of information provided by the clinician and the patients' electronic files. In both measurements, patients' HoNOS65+ scores did not differ significantly between face-to-face assessments and assessment based on electronic files.

This study was part of a larger study into the effectiveness of ACTE with an RCT that was approved by the Dutch Union of Medical-Ethical Committees for mental health organizations.

Outcome measures

The severity of psychosocial problems was assessed using the Dutch version of the Health of Nations Outcome Scale for elderly people (HoNOS65+) (64, 65). The 12 items of the HoNOS65+ scale are divided into four subscales: a) behavioural problems (behavioural disturbance, non-accidental self-injury, problem drinking or drug use); b) impairment (cognitive problems, physical illness or disability problems); c) symptomatic problems (problems associated with hallucinations and delusions, problems with depressive symptoms, other mental and behavioural problems); and, d) social problems (problems with relationships, with activities of daily living, with living conditions, and problems with occupations and activities). The HoNOS65+ items are scored on a 5-point scale measuring the severity of problems from 0 (no problem) to 4 (very severe problem). The Dutch version of the HoNOS65+ has been shown to be sensitive enough to measure changes (92, 93).

To describe only the relevant psychosocial problems, we used the item score of 2 points of higher, as a score beginning at 2 indicates a clinically relevant problem (127). Treatment outcome was defined as the sum score of the 12 items of the HoNOS65+ at follow-up (total score between 0-48), as well as the sum score of the 4 subscales of the HoNOS65+ at follow-up.

Predictive factors

Socio-demographic and clinical predictors collected from patients' electronic files included psychiatric diagnosis (i.e. having or not having a psychotic disorder), comorbid somatic disorders, and level of education. Psychiatric diagnosis was based on a clinical interview conducted by the ACTE team psychiatrist according to the Diagnostic and Statistical Manual of Mental Disorders, fourth revised edition (DSM IV-TR). For somatic disorders, we used axis III of the DSM-IV TR (i.e. patients with and without an axis III diagnosis). Patients with no education or only with elementary education were compared with patients with secondary education or higher education. Treatment motivation was also used as a predictor and was assessed on a stages-of-change scale (SoC) based on the transactional theory (112). Motivation was scored on a 5-point scale: 1= the patient is not planning to accept psychiatric treatment, or does not recognize their psychiatric symptoms, 2= patients recognizes some of their psychiatric problems, but is not planning to start psychiatric treatment within one month, 3= the patient is considering starting psychiatric treatment within one month, 4= acceptation of psychiatric treatment, 5= psychiatric treatment is maintained (113, 124). Due the skewed distribution, the motivation scores were dichotomized into a motivated group (phase 3-5) and an unmotivated group (phase 1-2).

Statistical analysis

To analyse socio-demographic and clinical characteristics at baseline, we used paired ttests for continue variables and chi-square tests (X²) for categorical variables for the whole group of patients. Paired t-tests were used to investigate change in psychosocial functioning during the follow-up period. Multiple regression analysis (generalized linear models) was used to identify the variables that predicted the outcome in psychosocial 94

functioning. The dependent variables were the total score at follow-up of the HoNOS65+ and the scores of the four subscales of the HoNOS65+ controlled for the (centred) baseline measurements of the total and subscale scores of the HoNOS65+. We controlled for potentially confounding factors such as age and gender. Regression analyses were performed using stepwise procedures. Variable selection was based on likelihood-ratio test statistics. SPSS (version 20 for Windows) was used for all analyses.

Results

The original sample of this study consisted of 124 referred patients, 3 of whom died from natural causes before the first contact had taken place, and 3 of whom could not be traced. The first measurement was completed by 118 patients, 46 of whom were then lost to follow-up, with 7 dying from natural causes, 5 moving out of the region, 17 refusing and thus being discharged from care, 10 being hospitalized long-term, 3 being transferred to another team (teams for the treatment of less severe patients), 3 being discharged from care for other reasons, and one proving impossible to contact. Seventy-two patients thus completed the set of measurement instruments. Table 1 presents their demographic and clinical characteristics, including those of the 46 patients lost to follow-up.

Except for level of education, there were no differences in demographic characteristics between patients engaged in care and patients who were lost to follow-up (see Table 1). Neither were there any differences between patients who were and who were not lost to follow-up patients in HoNOS65+ scores (total score or subscale score; see Table 2).

Table 1. Baseline characteristics of the study population (total group, patients with follow-up measurements, and patients lost to follow-up)

| | N = 118 | n = 72 | n = 46 |
|---|------------|------------|-------------------|
| | Total | Follow-up | Lost to follow-up |
| Mean age SD | 71.8 ±8.0 | 70.8 ±7.0 | 71.9 ±9.3 |
| Mean age 1 st contact mental-health (SD) | 61.3 ±17.1 | 59.2 ±17.7 | 64.7 ±15.6 |
| Gender (%) | | | |
| Male | 56 (47.5) | 32 (44.4) | 24 (52.2) |
| Female | 62 (52.5) | 40 (55.6) | 22 (47.8) |
| Marital state (%) | | | |
| Unmarried | 46 (39.0) | 28 (38.9) | 18 (39.1) |
| Married | 11 (9.3) | 7 (9.7) | 4 (8.7) |
| Divorced | 36 (30.5) | 21 (29.2) | 15 (32.6) |
| Widowed | 25 (21.2) | 16 (22.2) | 9 (19.6) |
| Level of education (%)* | | | |
| No/elementary education | 43 (48.9) | 35 (55.6) | 8 (32.0) |
| Secondary/higher education | 45 (51.1) | 28 (44.4) | 17 (68.0) |
| Missing | 30 | 9 | 21 |
| Living situation (%) | | | |
| Independent | 90 (76.3) | 56 (77.8) | 34 (73.9) |
| Homeless | 15 (12.7) | 8 (11.1) | 7 (15.2) |
| Protective living | 13 (11.0) | 8 (11.1) | 5 (10.9) |
| Diagnosis Axis I (%) | | | |
| Schizophrenia spectrum disorders | 67 (56.8) | 43 (59.7) | 24 (52.2) |
| Abuse disorders | 11 (9.3) | 8 (11.1) | 3 (6.5) |
| Mood disorder | 10 (8.5) | 6 (8.3) | 4 (8.7) |
| Cognitive disorder | 11 (9.3) | 5 (6.9) | 6 (13.0) |
| Other disorders | 19 (16.1) | 10 (13.9) | 9 (19.6) |
| Diagnosis Axis III (%) | | | |
| Yes | 68 (58.1) | 41 (56.9) | 27 (60.0) |
| No | 47 (41.9) | 31 (43.1) | 18 (40.0) |
| History of psychiatric admission | | | |
| Yes | 41 (34.7) | 27 (37.5) | 14 (30.4) |
| No | 77 (65.3) | 45 (62.5) | 32 (69.6) |
| Motivated for treatment | | | |
| Yes | 33 (28.0) | 23 (31.9) | 10 (21.7) |
| No | 85 (72.0) | 49 (68.1) | 36 (78.3) |

SD= standard deviation, paired t test was used for continuous variables and Pearson's chi-square test for categorical variables, * X (df1) = 4.0, p = 0.046

Table 2. Psychosocial functioning at baseline (HoNOS65+ in the total group, in patients with follow-up measurements, and in patients lost to follow-up)

| measurements, and in par | N=118 | n=72 | n=46 | Test of significance |
|--------------------------|------------|------------|-------------------|-----------------------------|
| | Total | Follow-up | Lost to follow-up | |
| Total HoNOS65+ | | | | |
| Mean (SD) | 19.8 (5.4) | 19.0 (5.8) | 21.0 (4.7) | t (df=116) = 1.92 p = 0.058 |
| | | | | |
| HoNOS Subscales | | | | |
| Behaviour problems | 2.7 (1.9) | 2.7 (2.0) | 2.7 (1.7) | t (df=116) =002 p = 0.999 |
| Mean (SD) | | | | |
| | | | | |
| Impairment | 3.0 (1.6) | 2.7 (1.6) | 3.3 (1.7) | t (df=116) = 1.95 p = 0.054 |
| Mean (SD) | | | | |
| | | | | |
| Symptomatic problems | 4.4 (2.4) | 4.1 (2.4) | 4.7 (2.5) | t (df=116) = 1.40 p = 0.163 |
| Mean (SD) | | | | |
| | | | | |
| Social problems | 9.8 (3.3) | 9.6 (3.5) | 10.2 (2.9) | t (df=116) = 1.08 p = 0.283 |
| Mean (SD) | | | | |

^{*} HoNOS total score and subscale scores were analysed with the students' t-test

Problems in psychosocial functioning at baseline

Table 3 shows the percentage of patients with a score of 2 points or higher on the baseline HoNOS65+ items. Most patients had severe problems with social relationships, followed consecutively by problems with occupations and activities, problems with physical illness or disabilities, problems in activities of daily living, and other psychiatric or behavioural problems.

Table 3. Percentage of problems at baseline (HoNOS65+ items, total group, patients with follow-up measurements and patients lost to follow-up)*

| measurements and patients lost to follow-up) | N = 118 | n = 72 | n = 46 |
|--|------------|-----------|-------------------|
| | Total | Follow-up | Lost to follow-up |
| Subscale Behaviour problems | | | |
| Overactive and aggressive behavioural | 58 (48.2) | 34 (47.2) | 24 (52.2) |
| problems | | | |
| Non accidental self-injury | 9 (7.6) | 7 (9.7) | 2 (4.4) |
| Problem drinking or drugs-taken | 30 (25.4) | 19 (26.4) | 11 (23.9) |
| Subscale Impairment | | | |
| Cognitive problems | 32 (27.1) | 15 (20.8) | 17 (37.0) |
| Physical illness or disabilities | 92 (78.0) | 55 (76.4) | 37 (80.4) |
| Subscale Symptomatic problems | | | |
| Hallucinations and delusions | 66 (55.9) | 38 (52.8) | 28 (60.9) |
| Depressed mood | 22 (18.6) | 11 (15.3) | 11 (23.9) |
| Other psychiatric and behavioural problems | 79 (66.9) | 46 (63.9) | 33 (71.7) |
| Subscale Social problems | | | |
| Problems in social relationships | 113 (95.8) | 68 (94.4) | 45 (97.8) |
| Problems in activities of daily living | 88 (74.6) | 54 (75.0) | 34 (73.9) |
| Problems with living conditions | 64 (54.2) | 41 (56.9) | 23 (50.0) |
| Problems with occupation and activities | 99 (83.9) | 59 (81.9) | 40 (87.0) |

^{*}Score of 2 points or higher at the HoNOS65+ item; a score of 2 or higher requires active monitoring or intervention

Outcome in psychosocial functioning

Although the mean total HoNOS65+ score at follow-up showed a significant reduction of 5.2 points over time (see Table 4), with an effect size of 0.9 (indicating a medium large effect in improvement in psychosocial functioning), the overall distribution was wide, ranging from +13 (i.e. a 13-point increase in problems) to -20 (i.e. a 20-point decrease in psychosocial functioning). Overall, the HoNOS65+ subscales reflected significant improvements in behaviour problems, symptomatic problems and social problems, but no change in impairment (Table 4).

Table 4. Outcome (18 months) in psychosocial functioning (HoNOS65+)

| | Baseline | Follow-up | Difference |
|----------------------|-------------|-------------|---------------------------|
| | Mean (S.D) | Mean (S.D) | Mean (S.D) |
| HoNOS65+ total score | 19.0 (5.8) | 13.8 (5.3) | -5.2 (6.5) |
| Range | 8/32 | 4/26 | -20/13 |
| | | | *t (71) = -6.8, p= <0.001 |
| HoNOS65+ subscales | | | |
| Behaviour problems | 2.65 (2.00) | 1.97 (1.72) | 68 (1.8) |
| (score 0-12) | | | *t (71) = - 3.3, p= 0.002 |
| | | | |
| Impairment | 2.72 (1.60) | 2.94 (1.63) | 0.22 (1.1) |
| (score 0-8) | | | *t (71) =1.7, p= 0.103 |
| | | | |
| Symptoms | 4.03 (2.37) | 2.72 (2.18) | -1.3 (2.7) |
| (score 0-12) | | | *t (71) = -4.1, p= <0.001 |
| | | | |
| Social functioning | 9.63 (3.48) | 6.14 (3.06) | -3.5 (3.9) |
| (score 0-16) | | | *t (71) =-7.7, p= <0.001 |
| | | | |

^{*} Paired t test

Predictors of outcome in HoNOS65+ scores

Table 5 presents the final multiple regression analyses, which shows that, except for the total score at baseline, no single factor or interaction effect was associated with overall psychosocial functioning (total HoNOS65+ score) at 18 months. The HoNOS65+ subscales showed that patients with a psychotic disorder and those with a low educational level were more likely to have treatment-resistant psychiatric symptoms; outcome in social problems was poor in less-educated patients who also had somatic disorders (interaction effect).

Table 5. Predictors of outcome in psychosocial functioning (HoNOS 65+) from generalized linear models*

| Table 3. Predictors of Outcome in psychosocial functioning (nowos 63+) from generalized infeat models. | ne ini psycilosocial idio | LIUIIII (HONOS 05+) IIUII | ı generalized imear mode | . 51 | |
|--|---------------------------|---------------------------|--------------------------|-------------------------|-----------------------|
| | HoNOS total score | Behavioural problems | Impairment | Symptoms | Social functioning |
| | β (SE) p | β (SE) p | β (SE) p | β (SE) p | β (SE) p |
| Model 1 | | | | | |
| Intercept | 13.78 (0.59) | 1.97 (0.17) | 2.94 (0.13) | 2.72 (0.24) | 6.14 (0.34) |
| HoNOS65+ baseline | 0.29 (0.10) p= 0.005 | 0.48 (0.08) p= <0.001 | 0.76 (0.08) p=<0.001 | 0.27 (0.10) p= 0.008 | 0.27 (0.10) p= 0.006 |
| Intercept | | | | 2.04 (0.36) | |
| HoNOS65+ baseline | | | | 0.30 (0.11) p= 0.004 | |
| Low education | | | | 0.96 (0.49) p = 0.050 | |
| Intercept | | | | 1.35 (0.48) | |
| HoNOS65+ baseline | | | | 0.17 (0.11) p= 0.127 | |
| Psychotic disorder | | | | 1.15 (0.53) p = 0.031 | |
| Intercept | | | | | 7.33 (0.87) |
| HoNOS65+ baseline | | | | | 0.28 (0.10) p = 0.006 |
| Low education | | | | | -2.61 (1.11) p= 0.019 |
| Somatic problems | | | | | -1.76 (1.09) p= 0.105 |
| Educ*Somatic | | | | | 3.64 (1.43) p= 0.011 |
| | | | | | |

*Only independent variables which contributed to the model were listed in the table;

Deviance Model 1 Symptoms = 306.8; AIC = 314.7, Final Deviance Model = 288.3; Chi2 (df= 2) = 11.1, p = 0.004; AIC = 312.2; R² McFadden = 0.1;

Deviance Model 1 Social functioning = 602.6; AIC = 363.3, Final Deviance Model = 468.9; Chi2 (df= 4) = 12.5, p = 0.014; AIC = 317.2; R² McFadden = 0.3

Discussion

In the present study we examined the course and predictors of psychosocial problems in elderly patients with SMI, treated in a specialized elderly ACT team. We found that HoNOS65+ scores decreased over an 18-month period. Using multiple regression analyses we did not find associations between a set of predictor variables and HoNOS65+ total scores at 18 months follow-up, except for HoNOS total score at baseline. We have to keep in mind however, that we had a small sample, possibly leading to a type II error.

As compared to other studies, the mean HoNOS65+ score of our sample (mean total HoNOS65+ score of 19.0) was high as compared to an adult group of patients with SMI (schizophrenia spectrum disorders, bipolar affective disorders and recurrent depressive disorders with psychosis) in intensive case management (mean score of 10.5, measured with the HoNOS adult version) (128), a group of mainly depressed elderly patients (mean score of 11.4) (129) and a group of psychotic elderly patients (mean score of 17.3) (93). This indicates that patients in our study did have a relatively high level of psychosocial problems

Although none of our predictors were significantly associated with the total HoNOS65+ score, some specific associations were found with subscales scores of the HoNOS65+ at 18 months follow-up. Apparently, patients with psychotic disorders as compared to patients with other disorders and patients with a relatively low level of education exposed poorer outcome in level of symptoms. When low educated patients also had somatic problems, the improvement in social functioning lagged behind, suggesting that this group of patients with combined problems remained socially impaired. It is possible that the intervention period was too short to produce relevant changes in symptoms or social functioning for low educated elderly patients or that the ACTE team did not provide interventions tailored to the subgroup of low educated patients. Others have also found that a low level of education was associated with both somatic and psychiatric morbidity (130, 131).

To improve symptoms and social functioning for low educated patients (with or without somatic problems) and patients with psychotic disorders it could be necessary to extend ACTE with special interventions such as 'illness management and recovery' (IMR) (132), tailored to less educated patients. A small pilot study with 7 elderly patients with

SMI (4 of them were low educated), showed that elderly could benefit from integrated physical and psychiatric illness management (IMR). For elderly patients with psychotic disorders, cognitive behavioural social skills training improved social functioning (120). However there is a lack of evidence based practices regarding (psychosocial) interventions in elderly patients with SMI (22).

Clinical implications

Despite some limitations, our results showed that difficult-to-engage elderly patients improved in psychosocial functioning. On subscale level (HoNOS65+) having a psychotic disorder and having a low level of education were risk factors for poor outcome in symptoms. This suggests that it may be important to record educational level of patients and provide tailored interventions. In combination with awareness of possible somatic health problems, clinicians may increase their focus on initiating and implementing interventions target low educated patients in order to improve symptoms, and social functioning for this impaired group of SMI elderly patients.

However, the lack of evidence based practices regarding (psychosocial) interventions in elderly patients with SMI (22) expose the need for research to address which interventions lead to better outcome or in preventing further deterioration, especially in patients with intellectual disabilities.

This study has several limitations. The first limitation was that we only used two measurements 18 months apart. Secondly, the high number of patients lost to follow-up may have affected the results and the small sample restricts the number of predictors we could use in this study. Thirdly, we used the HoNOS65+ scale for assessment of psychosocial functioning, which is rather a broad measure, not providing detailed information on e.g. the level of psychotic symptoms (severity of hallucinations and delusions). The strength of this study is that, as far as we know, this is the first study in ACT especially for SMI elderly patients that determined which variables predict the outcome in psychosocial functioning. Also we have reached a group of patients who were difficult-to-engage in treatment. Most of the time, these patients do not take part in research.

In conclusion, the overall psychosocial outcome in SMI elderly patients treated in ACTE improved. However we were not able to identify specific predictors that were related to overall psychosocial outcome, except for level of psychosocial functioning at baseline. On a subscale level the group of patients with psychotic disorders and patients who had less education, were vulnerable for poor outcome with respect to psychiatric symptoms. When low educated patients also had somatic problems, they were at risk for poor outcome in social functioning. Our findings highlighted the needs for further research in outcome in elderly patients receiving ACT, and to further identify factors associated with treatment outcome and to identify which strategies improve treatment outcomes, especially for low educated patients.



CHAPTER 7

Do elderly patients with severe mental illness have special needs?

ABSTRACT

Objective: to examine differences in the needs and psychosocial functioning of severely mentally ill (SMI) patients (≥ 55 years) treated in an Assertive Community Treatment team for the elderly (ACTE) and in Assertive Community Treatment teams for adults (ACTA).

Method: Cross-sectional study that included 141 patients in ACTE and 168 patients in ACTA. Needs were measured using the Camberwell Assessment of Needs for the Elderly and the Camberwell Assessment of Needs (short appraisal). Psychosocial functioning was measured using the adult and elderly versions of the Health of the Nation Outcome Scale. Differences in patients' characteristics were analysed using parametric and nonparametric tests. Differences between the needs of patients in ACTE and ACTA and their severity of psychosocial functioning were examined using regression analyses.

Results: Patients in ACTE had a higher mean age than those in ACTA and were older at first contact with the mental-health services. More were female, widowed, and living independently, and more had been diagnosed with a cognitive disorder. However, regression analyses showed no differences regarding the number of needs and the severity of psychosocial problems between patients in ACTE or patients in ACTA.

Conclusions: Because the overall needs and psychosocial functioning of patients included in ACTE are not essentially different from those of patients included in ACTA, it may be possible for elderly patients with SMI to be treated by a regular ACT team for adults. However, service policies might favour implementation of specialized ACTE teams.

Introduction

Assertive Community Treatment (ACT) is a community-based mental-health service that helps improve the lives of patients diagnosed with serious and persistent mental illness. To support patients' ability to live in the community, it provides integrated care (including psychiatric, addiction, somatic and social care) (29). In the United Sates, ACT reduced hospital admissions and led to more stable housing. However, relative to treatment as usual, it had no beneficial effects on symptoms or social functioning (29, 30). In contrast, while European studies showed no reduction in admissions of ACT relative to treatment as usual (31), the ACT model engaged patients in treatment more successfully (33, 123).

Due to the time-unlimited service of ACT (whereby care is provided as long as patients need), the number of SMI elderly patients aging in ACT teams is increasing. Despite this, most studies of ACT have been conducted in groups aged approximately 35-40 years (31, 38, 40, 51). Although ACT for the elderly (ACTE) was introduced to provide specialized mental-health services for SMI elderly patients (55+), it is unknown whether older adults really need a specialized ACT team, or whether a regular ACT team might also serve this population. But, due to the complex care and specialist assistance elderly SMI patients would need, several studies have recommended that special ACTE teams should be developed (4, 8, 103). The present study aimed to compare the differences between the met needs, unmet needs and psychosocial functioning of patients aged 55 years and older in an ACTE team with those of patients of the same age in ACT adult (ACTA) teams.

Methods

This cross-sectional study compared patients from six ACTA teams and one ACTE team at a mental healthcare centre in the greater Rotterdam area in the Netherlands (BavoEuropoort, Department of Parnassia Psychiatric Institute). Patients in ACT teams were those with an SMI who were difficult-to-engage in treatment; SMI was defined as schizophrenia spectrum disorder, psychotic disorder, bipolar disorder, dual diagnosis, or persistent severe depression. ACTA teams treated patients aged 18 years and over (however, in our study only patients aged 55 years and over, were included), and the ACTE team treated patients aged 55 years and over. While ACTE used the ACT model, it

also included a community mental-health nurse specialized in elderly patients and a psychiatrist specialized in geriatric psychiatry.

We included patients from ACTE who had been referred between April 2008 and August 2010 and had had the first routine outcome monitoring (ROM) assessment. The patients included from ACTA teams were 55 years or older at the time of the first ROM assessment. The ROM instruments were completed on the basis of contact with the patient in combination with information provided by the clinician and the patients' electronic files. If patients refused contact, data were collected only on the basis of information provided by the clinician and the patients' electronic files. Instruments were rated according to the insights of the ROM assistants.

The study was part of a larger study into the effectiveness of ACTE, which had been approved by the Dutch Union of Medical-Ethical Committees for mental-health organizations.

Outcome measures

Needs

Needs for care in the ACTA teams were measured using the Dutch version of the Camberwell Assessment of Needs for adults short appraisal schedule (CANSAS) (133). In the ACTE team they were measured with the version for the Elderly (CANE) (66). The CANSAS and CANE provide information on patients' needs for care (both met and unmet), and cover physical, psychological, social, and environmental needs. The validity and reliability of both scales were acceptable (94, 133). Because the CANSAS (22 items) and CANE (24 items) cover different needs, we used only items on equivalent needs: accommodation, household skills, food, self-care, daytime activities, physical health, psychotic symptoms, psychological distress, information (on condition and treatment), self-harm, alcohol addiction, company, intimate relationships, money management, and social benefits. Each item was scored as 0 = no need, 1 = low need or met need (i.e. no intervention is needed, or need is met through an intervention); and 2 = high need or unmet need (intervention is needed, or intervention had no effect).

The nine items excluded in ACTE were needs regarding caring for others, needs regarding memory, eyesight/hearing, mobility/falls, continence, medication (side-effects, compliance), accidental self-harm, abuse/neglect relationships, and needs due to behaviour problems. The seven needs excluded in the ACTA teams were those for the safety of others, drugs, sexual expression, child-care, basic education, telephone use and transport.

Psychosocial functioning (HoNOS)

In the ACTA teams, the severity of psychosocial functioning was assessed using the Dutch version of the Health of Nations Outcome Scale for adults (HoNOS) (70, 134); in the ACTE team it was assessed using the HoNOS65+ for elderly people (64, 65). The 12 items of both HoNOS scales are divided into four subscales: behavioural problems (behavioural disturbance, non-accidental self-injury, problem drinking and drug-taking); impairment (cognitive problems, physical illness or disability problems); symptomatic problems (problems associated with hallucinations and delusions, problems with depressive symptoms and other mental or behavioural problems); and social problems (problems with relationships, problems with activities of daily living, problems with living conditions and problems with occupations and activities). Both versions of the HoNOS are scored on a 5-point scale measuring the severity of problems from 0 (no problem) to 4 (very severe problem). The Dutch version of the HoNOS adult and HoNOS elderly have been shown to be sensitive enough to measure change (70, 92, 93).

The severity of functioning in psychosocial functioning was measured on the basis of the sum scores of 11 items of the two HoNOS scales (total score between 0-44) and of the 4 subscales. We excluded item 12 (occupation and activities) of the two HoNOS scales because, unlike the adult version, the HoNOS65+ also measures the extent of the patient's collaboration (64). Although both the HoNOS and HoNOS65+ were suitable for measuring outcome in elderly patients, the HoNOS65+ glossary is more relevant for problems in elderly patients and may therefore be more sensitive for problems specific to elderly patients (135).

Statistical analyses

Differences between the total number of unmet needs and the combined totals of met and unmet needs were analysed using the Mann–Whitney *U* test. Psychosocial

functioning was analysed using the independent sample *t-test*. To analyse differences in socio-demographic characteristics and clinical factors between patients in ACTE and patients in ACTA, we used independent sample t-tests for continuous variables and Pearson's chi-square tests for categorical variables.

Regression analyses were used to examine how the total numbers of met and unmet needs and the mean of psychosocial functioning differed between patients in the ACTE team and the ACTA teams. For easier interpretation of the results, we report the normal regression models, as Poisson regression did not differ from normal linear regression analyses. Three different analyses were conducted, the independent variables being the total score of the HoNOS scales, the total number of unmet needs, and the total number of met and unmet needs together. The dichotomous independent variable was the type of ACT (ACTE or ACTA). We controlled for the following: gender, centred age, diagnosis (which had been made dichotomous, i.e. having or having not a schizophrenia spectrum disorder); and duration of treatment until measurement took place (centred duration in months). Variable selection was based on likelihood-ratio test statistics. Model-fit was assessed using the R² (McFadden), Model X² and the Goodness of Fit test. SPSS (version 20 for Windows) was used for all analyses.

Results

We included 141 patients in the ACTE team and 168 patients aged 55 years or older in the ACTA teams. Table 1 shows the differences in demographic characteristics. Table 1 shows that the patients in ACTE had a higher mean age than those in ACTA. They were also significantly older at their first contact with the mental-health services, and more of them were woman, widowed, and living independently. More of them had been diagnosed with cognitive disorder.

Differences in unmet needs (CANE and CANSAS)

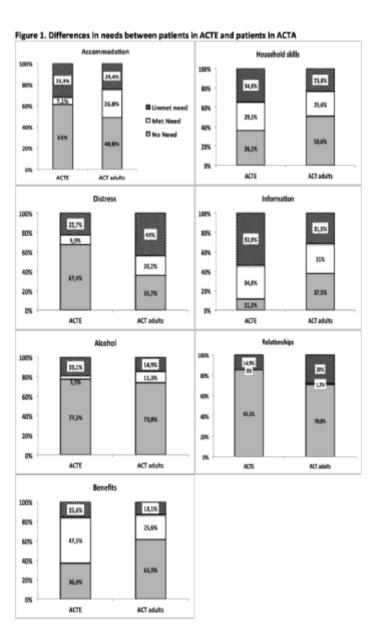
The teams did not differ with regard to the median number of *unmet needs* (median of 5, range 0-13 *unmet* needs for patients in ACTE; and median number of 4 *unmet* needs, range 0-12 for ACTA patients, Mann-Whitney U test: U = 11100, p = 0.338). Neither did they differ with regard to the total number of *met* and *unmet* needs (median score of 8).

for both teams, range 2-13 for ACTE and 1-14 for ACTA, Mann-Whitney U test: U = 11722, p = 0.875). Nor were there any differences with regard to needs between ACTE and ACTA on the following items: food, self-care, daytime activities, psychosis, self-harm, company and budgeting. Figure 1 shows the differences in needs between the two patient groups after testing with Pearson's chi-square.

Table 1. Characteristics of elderly patients in ACTE and ACTA

| | ACTE N = 141 | ACTA N =168 | р |
|--|-----------------|----------------|-----------------------------|
| Mean age (SD) | 71.8 (8.2) | 60.2 (5.2) | t=15.0 df=307 p = <0.001 |
| Mean age at first contact with mental-health services (SD) | 62.1 (17.0) | 46.3 (15.3) | t=7.6 df=247 p = <0.001 |
| Gender (%) | 64 (45.4) | 96 (57.1) | X ² =4.24 df=1 |
| Male | 77 (54.6) | 72 (42.9) | p = 0.039 |
| Female | | | |
| Marital state (%) | 52 (36.9) | 77 (51.3) | $X^2 = 21.0 df = 3$ |
| Unmarried | 13 (9.2) | 8 (5.3) | p = <0.001 |
| Married | 43 (30.5) | 56 (37.3) | |
| Divorced | 33 (23.4) | 9 (6.0) | |
| Widowed | 0 | 18 | |
| Missing | | | |
| Living situation (%) | 111 (78.7) | 66 (50.4) | X ² =40.2 df=3 |
| Independent | 14 (9.9) | 20 (15.3) | p = <0.001 |
| Sheltered living | 16 (11.3) | 17 (13.0) | |
| Homeless | 0 | 28 (21.4) | |
| Other | 0 | 37 | |
| Missing | | | |
| Country of birth (%) | 110 (78.0) | 106 (68.8) | $X^2 = 3.2 df = 1$ |
| The Netherlands | 31 (22.0) | 48 (31.2) | p = 0.075 |
| Other | 0 | 14 | |
| Missing | | | |
| Diagnosis Axis I (%) | 73 (52.1) | 96 (63.2) | X ² =18.7 df=4 |
| Schizophrenia spectrum disorders | 23 (16.4) | 35 (23.0) | p = <0.001 |
| Other disorders | 20 (14.3) | 5 (3.3) | |
| Cognitive disorders | 13 (9.3) | 13 (8.6) | |
| Mood disorders | 11 (7.9) | 3 (2.0) | |
| Addiction disorders | 1 | 16 | |
| Missing | | | |
| Previous hospitalization (%) | 48 (34.0) | 74 (44.0) | X ² =3.2 df=1 |
| Yes | 93 (66.0) | 94 (56.0) | p = 0.073 |
| No | | | |
| | | | |

SD= standard deviation, Paired t test was used for continuous variables and Pearson's chi-square test for categorical variables.



Patients in ACTA were more likely to have *no* needs for information ($X^2 = 30.0$, degrees of freedom (df) = 2, p = <0.001). They also had more *met* needs for accommodation ($X^2 = 18.5$, df = 2, p = <0.001) and alcohol ($X^2 = 6.9$, df = 2, p = 0.032). While ACTE patients had more *met* needs for social benefits ($X^2 = 19.8$, df = 2, p = <0.001), more had *no* need for intimate relationships ($X^2 = 9.7$, df = 2, p = 0.008) and for psychological distress ($X^2 = 30.8$ df = 2, p = <0.001). Regression analyses showed that the number of *unmet* need was not related to the ACT type (B = 0.28, standard error (SE) = 0.29, Wald = 0.90, p = 0.342). Neither were any interaction effects found.

Table 2 shows an interaction effect between the total number of *met* and *unmet* needs, treatment duration and gender. The shorter the treatment duration, the higher the total number of *met* and *unmet* needs. Although male patients were more likely to have more *met* and *unmet* needs at baseline, the small change in R² indicates that gender and treatment time were not relevant to the number of needs.

Table 2. Regression analysis of patients in ACTE and patients in ACTA in relation to the number of *met* and *unmet* needs

| | B (SE) | Wald | df | р |
|--|-------------|---------|----|-------|
| Model 1 | | | | |
| Intercept | 7.76 (0.20) | 1517.68 | 1 | |
| ACTE | 12 (0.29) | 0.16 | 1 | 0.693 |
| Final Model | | | | |
| Intercept | 7.20 (0.26) | 760.91 | 1 | |
| ACTE | 06 (0.29) | 0.05 | 1 | 0.825 |
| Treatment duration (centred in months) | 03 (0.01) | 6.51 | 1 | 0.011 |
| Male | 0.85 (0.29) | 8.65 | 1 | 0.003 |

Deviance Model 1 = 2060.7; AIC = 1469.2; Final Deviance Model = 1940.9; Chi2 (df= 3) = 14.5, p = 0.002; AIC = 1443.7; R^2 McFadden = 0.06

Needs excluded in ACTE and ACTA

Most patients in ACTE had *no* needs with regard to the following: caring for others (96.5%), continence (85.1%), accidental self-harm (82.3%), abuse/neglect (73%), memory (72.3%), eyesight/hearing (70.9%), mobility/falls (68.1%), and behaviour (68.1%). But most had *unmet* needs with regard to medication (41.1%). Most patients in ACTA had *no* needs with regard to childcare (95.6%), drugs use (91%), basic education (88.4%), the safety of others (88%), sexual expression (86.4%), transport (84.4%) and telephone (71.3%).

Differences in psychosocial functioning (HoNOS)

Patients in ACTE had more severe psychosocial problems than those in ACTA (mean HoNOS65+ score of 16.9, standard deviation (SD) = 4.5 versus mean HoNOS score of 14.7 (SD = 4.5); t test: t = 4.3, df = 307, p = < 0.001). At subscale level, patients in ACTE scored higher with regard to behaviour problems (mean of 2.6 (SD = 1.9) versus 1.7 (SD = 1.6), t-test: t (307)= 4.50, p = <0.001) and to social problems (mean of 7.0 (SD = 2.4) versus 6.1 (SD = 2.3), t-test: t (307)= 3.12, p = 0.002).

Figure 2 shows the differences at item level of the HoNOS (score at item level of 2 of higher). Patients in ACTE had more problems with overactive/aggressive behaviour and with physical illnesses/disabilities. ACTA patients had more severe cognitive problems.

Regression analysis revealed a team effect on the total HoNOS score, whereby patients in ACTE had more severe psychosocial problems than those in ACTA (Table 3). Time in treatment was associated with severity of psychosocial functioning (the longer the patients were in treatment, the less severe the intensity of psychosocial problems) and male patients had more severe problems with regard to psychosocial functioning. Control for these variables did not change the effect of ACT team.

Behavioural problems subscale Problem drinking/drugs-taken ■ ACT adults Non accidental self-injury **B**ACTE Overactive/aggressive behaviour 100 0 80 20 40 Impairment subscale Physical illness/ disabilities Cognitive problems 0 20 40 60 80 100 Symptoms subscale Other psychiatric/behavioural problems 21,5% Depressed mood 53,6% Hallucinations/delusions 55,3% 100 Social functioning subscale **Problems with living conditions** Problems in activities of daily 80,9% living Problems social relationships 40 60 20 80 100

Figure 2. Percentage of problems at baseline (score of 2 points or higher at the HoNOS items)

Table 3. Regression analyses with HoNOS total score as dependent variable

| B (SE) | Wald | df | Р |
|------------------|--|--|--|
| | | | |
| | | | |
| 14.66 (0.35) | 1760.99 | 1 | |
| 2.21 (0.52) | 18.17 | 1 | <0.001 |
| | | | |
| 13.82 (0.46) | 901.0 | 1 | |
| 2.28 (0.51) 1.18 | 19.7 | 1 | <0.001 |
| 1.18 (0.51) | 5.3 | 1 | 0.022 |
| 06 (0.02) | 8.2 | 1 | 0.004 |
| | 14.66 (0.35) 2.21 (0.52) 13.82 (0.46) 2.28 (0.51) 1.18 1.18 (0.51) | 14.66 (0.35) 1760.99 2.21 (0.52) 18.17 13.82 (0.46) 901.0 2.28 (0.51) 1.18 19.7 1.18 (0.51) 5.3 | 14.66 (0.35) 1760.99 1 2.21 (0.52) 18.17 1 13.82 (0.46) 901.0 1 2.28 (0.51) 1.18 19.7 1 1.18 (0.51) 5.3 1 |

Deviance Model 1 = 6336.1; AIC = 1816.3, Final Deviance Model = 6034.1; Chi2 (df= 3) = 29.6, p = <0.001; AIC = 1790.8; R^2 McFadden = 0.1.

Discussion

In this study we examined differences between the met needs, unmet needs and psychosocial functioning of patients aged 55 years or older in ACTE and ACTA. Our main results showed that patients in both teams had the same total number of needs. At item level, patients in ACTA were more likely to have no needs for information, probably as a consequence of enduring SMI illness in this group (patients have longer the change to discuss their medical conditions to improve their knowledge about their illness and treatment options). The fact that more patients in ACTA lived in sheltered housing explained why they had more met needs regarding accommodation and alcohol, and were more likely to have no need regarding household skills. More ACTE patients had no need with regard to psychological distress, conceivably a consequence of expressing psychological distress through somatic problems (3, 9). More of them also had no need for intimate relationships, as a result of the late first contact with mental-health care, ACTE patients had been married and had built up a social and family life, and therefore had fewer needs with regard to intimate relationships. It is hard to find an explanation for the fact that more of them had unmet needs with regard to social benefits.

Several studies have shown that, relative to adults, elderly SMI patients had more needs with regard to physical problems, medication management, self-care (26), household skills, accommodation and food (27). Unlike these studies, we found no specific needs to be associated with ageing problems. This is in line with the study by Pratt et al., who concluded that older and younger adults with SMI had similar problems in functioning, and had similar types of need (22). One review also showed that there was an overlap in needs between younger and older patients with schizophrenia (136).

Another finding was that while patients in ACTE had more severe problems with overactive/aggressive behaviour and with physical illness/disabilities, ACTA patients had more severe problems with cognitive problems. The more severe problems in ACTE result in more severe problems in psychosocial functioning (a score of 2 points higher on the total HoNOS score). It is interesting that there was no difference in physical needs between ACTA and ACTE. This is explained by the fact that the CANE used several items to score physical functioning (needs regarding eyesight/hearing problems, needs regarding mobility, and needs regarding physical health, only the last of which was used in this study). Because the HoNOS65+ glossary includes eyesight, hearing and mobility problems, it is plausible that the difference was due to differences in the glossaries. As Turner showed (2004), the HoNOS65+ glossary is more relevant and sensitive to problems in elderly patients (135). With this in mind, the type of team does not appear to have a bearing on the clinical severity of psychosocial functioning.

Our finding that the mean age of patients in ACTE was higher than that of patients in ACTA is a corollary of the inclusion criteria for ACTE. Similarly, two findings suggest that patients in ACTE in this sample were not just a group of ageing SMI patients. First patients in ACTE were older at their first contact with the mental-health services and second more of them lived independently. As seen in studies in the elderly, higher numbers of patients in ACTE were women (35, 118, 127). Also, more of them had been diagnosed with cognitive disorders, it is possible that they had first been allocated to ACTE for psychotic or behavioural problems, and that it became clear only later that their problems stemmed from cognitive disorders.

Elderly SMI patients and their need for a specialized ACT team

The results of this study raise the question of whether a specialized ACTE team is needed. Although there is no objective criterion to decide, based on the results presented here, whether ACTE teams are needed, in our opinion, ACTA teams may also be well suited to

treating elderly patients with SMI. ACT was developed as a time-unlimited service that could provide care for as long as a patient needed it. From a patient's point of view, it may be an advantage to age in the team in you started your treatment. This is probably why, in practice, there are only a few ACTE teams – as far as we know, only in the United States (www.telecarecorp.com).

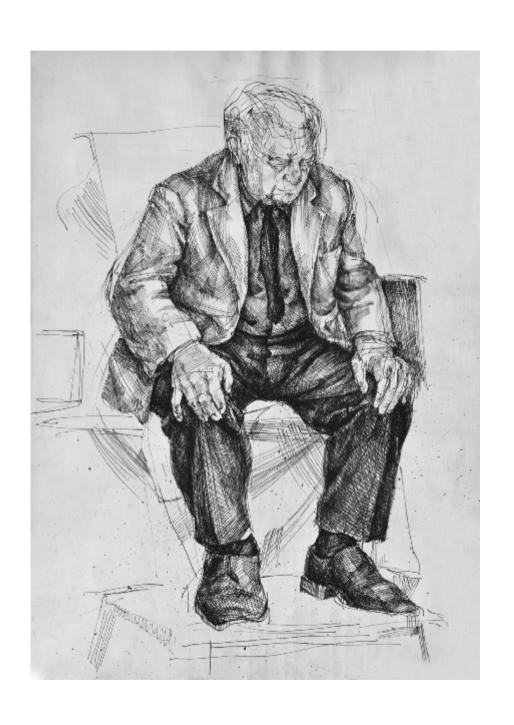
To treat SMI elderly patients in ACTA, one might devise a range of consultation options to cover special care needs for aging patients. Another option would be to add a community mental-health nurse specialized in SMI elderly patients to the ACTA team. Such nurses can handle end-of-life issues, age-related physical and mental-health needs, and collaborate on healthcare programs for elderly people in the community (e.g. rehabilitation programs for the elderly).

Within ACT, however, further research is needed that studies elderly people separately from younger groups so as to identify the differences between age categories and the kinds of intervention that are effective for the older adults in ACT. If there were differences in age categories and treatment response, it might be recommended to develop a specialized ACT team for elderly SMI patients which, by providing special treatment options, would better tackle the problems of older SMI patients. As yet, there is a lack of evidence-based practice in interventions for elderly patients with SMI (Pratt et al., 2008). However, for collaborative reasons, it might be practical to create ACTE teams, for example because many health services and mental-health services used age categories for treating young patients, adults, and elderly patients. Implementing such teams may raise costs, however. It should also be discussed which age category should be included in ACTE teams. Because the older population living in the community is becoming physically healthier and is also growing older, Orimo et al. recommend that the definition of "elderly" should be increased from 65 and older to 70 and older (137). If elderly SMI patients are also healthier, this might also be applied to the elderly people with SMI referred to ACTE. However, several studies conclude that patients aging with SMI experience more medical illnesses, cognitive problems and impairment in functioning than elderly people without SMI (4, 138, 139). In our study, most aging patients with SMI were engaged in ACTA.

The strength of this study is that, to the best of our knowledge, it is the first study to

compare older adults in different ACT teams. At the same time, the generalizability of our findings may be restricted by the following limitations. The first is the study design: our cross-sectional study cannot determine causal directions. The second is that the data were collected from one institution, making it possible that the conclusions based on the study may not be representative for the larger population of elderly people with SMI. A third limitation is that we used different, although very similar, scales to assess needs and psychosocial problems in ACTA and ACTE. On this point, however, we believe that the CANE and the CANSAS items we used are similar enough to be able to compare scores. But while the HoNOS and HoNOS65+ were suitable for measuring outcome in elderly patients, the HoNOS65+ glossary is more sensitive to the problems specific to elderly patients (135). Finally, because we did not evaluate the working methods of ACTA and ACTE, we do not know whether there were differences in interventions or intensity of the service.

In conclusion, the overall needs and psychosocial functioning of patients included in ACTE do not seem to be essentially different from those included in ACTA, possibly indicating that elderly patients with SMI could be treated by a regular ACT team for adults. While service policies could favour the implementation of specialized ACTE teams, regular ACT teams have the expertise for treating somatic and behavioural problems and to diagnose cognitive disorders, and thereby for tackling the most important specific needs of SMI elderly.



CHAPTER 8

GENERAL DISCUSSION

8.1 INTRODUCTION

The main aim of this thesis was to compare the effectiveness of Assertive Community Treatment for elderly patients (ACTE) with that of treatment as usual (38). In several parallel studies, we explored the care needs, treatment motivation problems and psychosocial functioning of difficult-to-engage elderly patients. This final chapter summarizes the research questions and results, and ends in a discussion. The strengths and limitations of the study designs will then be described. The general discussion ends with conclusions and recommendations for practice and future research.

8.2 RESEARCH QUESTIONS AND RESULTS

8.2.1 Effects of ACTE for elderly SMI patients in the RCT

Research question in Chapter 3: relative to TAU, would ACTE more often succeed in establishing contact with patients within three months of their signing up for care; does ACTE have fewer dropouts; does ACTE have better effects on patients' psychosocial functioning; would ACTE meet patients' unmet needs more effectively; and would ACTE reduce mental-healthcare use better?

In our RCT we could not demonstrate that ACTE led to better psychosocial functioning than TAU. Nonetheless, ACTE had better results with respect to engaging patients in treatment. This was also seen in European studies on the efficacy of ACT for adults (33, 96). Killaspy et al. (2009) suggested that better engagement in ACT was associated with a smaller caseload in ACT than in TAU, and with the team approach (shared caseload) (32). These characteristics were also present in our own ACTE condition. As TAU is characterized by larger caseloads and individual case management, it may be that the combination of the two limits the options for attempting contact with difficult-to-engage patients and for preventing dropout. Due to the low number of admissions and crisis contacts in our sample, we could not answer our research questions on whether ACTE was more effective than TAU in reducing the number of crisis contacts and the number and duration of psychiatric hospital admissions.

8.2.2 Treatment motivation

Chapter 4 presents the results of a study investigating whether less-motivated elderly SMI patients had more unmet care needs, other types of unmet need, and more psychosocial problems than more-motivated patients. Chapter 5 presents the results of a study investigating whether a decrease in unmet needs over time was associated with changes in treatment motivation during the same period, and whether a decrease in unmet needs preceded or paralleled an increase in treatment motivation.

In a cross-sectional study (Chapter 4), we showed that less-motivated elderly SMI patients had greater unmet care needs and more psychosocial problems than more-motivated patients. We concluded that lack of treatment motivation was associated with a higher burden of disease. These results are consistent with those of studies in adult mentalhealthcare (21, 104-106). Tackling patients' lack of motivation for treatment requires special attention, such as motivational interviewing techniques or treatment-adherence therapy. Our longitudinal study (Chapter 5) also showed that a decrease in unmet needs over time was associated with positive changes in treatment motivation. Nevertheless, motivation for treatment is a complex concept that is influenced by many different factors. As one possible way of increasing motivation for the treatment of psychiatric problems, we recommend clinicians working with SMI elderly with treatment motivation problems to start fulfilling unmet needs. This makes it necessary to assess not only their level of treatment motivation, but also their unmet needs. If a patient who is unmotivated to take medication sees that his or her needs are being addressed (through the provision of help with financial problems, for example), they may become motivated for treatment. To identify causal relationships, however, further research is needed.

8.2.3 Predictors of treatment outcome in ACTE

Research question in Chapter 6: which demographic, clinical or motivational factors assessed at baseline predict outcome in patients treated by ACTE?

The results of the longitudinal study showed that difficult-to-engage elderly patients treated in ACTE improved in overall psychosocial functioning. Although, after controlling for baseline psychosocial functioning, we were unable to identify predictors related to overall psychosocial outcome. It was shown by more detailed study of psychosocial

problems (using the subscales of the HoNOS65+), that a psychotic disorder and low educational level were associated with more psychiatric symptoms during follow-up. If these less-educated patients also had somatic problems, they also risked poor social outcome. This suggests that it may be important to record patients' educational level, and provide tailored interventions. Our findings highlighted the needs for further research on outcome in elderly patients receiving ACT that will further identify factors associated with treatment outcome, and will identify strategies for improving these outcomes.

8.2.4 Differences between patients in ACTE and ACT for adults

Research questions Chapter 7: do patients aged 55+ in an ACTE team differ from their counterparts in an ACT team for adults (ACTA) with respect to met and unmet needs and psychosocial functioning?

In Chapter 7 we investigated whether the ACTE team included a special group of patients who would justify a specific ACT team for elderly people with SMI. Our results showed that patients in ACTE had a higher mean age than those in ACTA. In addition, more of them were female, widowed, living independently and had been diagnosed with a cognitive disorder (Chapter 7). These characteristics contrasted with the characteristics of the patients usually included in studies on ACT in adults (33, 40, 101, 140, 141) and with those of patients in a study of ACTE in the United States (US) (37). While it seems that we had included a group of patients with late-onset psychiatric disorders, we found no evidence that the level of needs and psychosocial problems of patients aged 55+ in ACTE were significantly different from those of patients treated in regular ACT teams for adults.

8.3 DISCUSSION

Why did ACTE not lead to better psychosocial functioning than TAU?

The lack of differences in psychosocial outcome between ACTE and TAU may have various explanations. First, this may be due to the small number of patients included in the study. Second, ACTE was implemented with moderate model fidelity, including the lack of a psychologist and consumer-provider in the ACTE team. Third, the TAU teams were of high quality. The association between model fidelity and outcome in ACT is still a matter of controversy. Some studies have shown that ACT for adults is most effective when it is

implemented fully according to the original ACT model (76-78, 80, 85). Others, however, showed no association between model fidelity and outcome (51, 96).

Although there is no agreement on which critical components of ACT are associated with improvement in psychosocial outcomes, some studies showed that better outcomes were associated both with a better team structure (shared caseload, daily team meetings, and a team leader who participated in patient care) and with the presence of a consumer-provider in the team (31, 85, 86). While the ACTE team in this study had the first three components, it did not have a consumer provider in the team, which thereby limited the differences between ACTE and TAU. The addition of a consumer-provider to ACTE might have had a positive influence on psychosocial functioning over time and on rehabilitation and recovery (86). In literature, the effect of a consumer-provider is explained by the personal experience of the consumer-provider with burden of disease and recovery, which might have helped patients of the ACTE team to work better towards their own recovery (86). The absence of a psychologist within their ACTE teams meant that some interventions were unable to deliver (psychological interventions such as cognitive behavioural therapy) (38, 101).

ACTE's lack of advantage over TAU may also be due to the high quality of TAU teams described earlier (51, 87, 98). In our study, for example, TAU used components of the ACT model such as assertive outreach and the provision of community-based services (i.e. day-time activity centre for elderly patients or rehabilitation after hospitalization).

Other studies concluded that ACT may have less added value for patients whose hospital use is low and who are less complex and less severely ill (31, 96, 142). Because most patients in our sample were never hospitalized, no reduction in hospital beds was possible.

Finally, the RCT started 3 months after the ACTE team had been started. It may be that a new team takes longer to develop effective strategies and methods than one which has existed for longer, such as the TAU teams in our study. Similarly, whereas all the TAU staff were specialized in geriatric psychiatry, ACTE started with only one community mental-health nurse and one psychiatrist specialized in geriatric psychiatry.

Towards better motivation for treatment

Motivation for treatment is a complex concept that is affected by a wide variety of factors. In our study, this may have meant that it changed over time for reasons other than a decline in the number of unmet needs. While we have been unable to find studies that specifically investigated the association between motivation and needs, our own findings suggest that a patient's motivation for treatment may increase if his or her needs are met, and, by corollary, that an inability to address unmet needs may keep a patient unmotivated. As one way to increase this motivation, clinicians working with elderly people with SMI and treatment-motivation problems are therefore recommended to start fulfilling the patients' unmet needs, as those who experience benefit from their clinicians may thus be more willing to accept the treatment they offer for their psychiatric symptoms.

It is also possible, however, that clinicians who try to fulfill unmet needs in all patients, motivated and unmotivated alike, find that only those who are or become motivated due to a third factor (such as working alliance) can benefit from these interventions, and thereby have more needs met. Further research is needed to unravel causal relationships and to determine whether interventions to improve unmet needs lead to better motivation.

Do SMI elderly need ACTE?

As ACTE had better results than TAU with regard to engaging patients in treatment, and also had fewer dropouts, we believe that difficult-to-engage elderly patients should be able to use services such as ACT. However, the patients in this study were not high users of psychiatric services and had not often been hospitalized before they were announced to ACTE. ACTE teams in the US included patients with characteristics similar to those in our study (oral information received at the congress of the Assertive Community Treatment Association (ACTA) in Boston, US. in Mav http://www.actassociation.org). This may indicate that ACTE reached a group of patients whose mental illness occurred later in life. If so, it would be in line with our findings that age, gender and psychiatric history differed between patients in the ACTE group and those in ACT for adults. However, because we also found that patients in ACTE and ACTA had very similar care needs and psychosocial problems (Chapter 7), it is debatable whether the group of older people with SMI need a special ACTE team to solve their problems, or that a regular ACT team that includes adult SMI patients will be sufficient.

Theoretically, there are several options for serving elderly, difficult-to-engage SMI patients. One would be to add a special case-manager to TAU in elderly patients, who used assertive outreach and motivational interviewing techniques to engage patients in treatment. Another would be to complement ACT adult teams with a community mental-health nurse specialized in elderly SMI patients, who could collaborate on healthcare programs for elderly people in the community (e.g. rehabilitation programmes for the elderly). A third option would be to reorganize TAU elderly teams into Flexible Assertive Community Treatment (FACT) teams, which has been shown to be a good and cost-effective alternative to ACT (143). FACT is advisable for SMI patients who temporary need assertive outreach. It is also a good alternative to ACT when there is a small population of extra complex SMI patients, FACT (144).

Unlike ACT for adults, ACTE is not widely implemented internationally. But while the results of this thesis may provide an impetus for service development and for planning mental-health services for difficult-to-engage elderly people with SMI, it is too early to recommend the implementation of specific ACTE teams for these patients. To identify differences between age categories and the kinds of intervention that are effective for older adults in ACT, further research should study elderly people in ACTA separately from those in younger age groups. If this identifies differences between age groups and age-group-related treatment responses, a specialized ACT team for elderly SMI may be justified.

Finally, working with elderly patients requires knowledge of mental-health services for the elderly, as this facilitates collaboration. This may be a separate reason for having an ACTE team.

8.4 STRENGTHS AND LIMITATIONS

Design

The ACTE study was designed as a parallel-group randomized controlled trial, with one intervention group and one control group. The strength of the RCT was that it involved a study that included difficult-to-engage elderly SMI patients. To the best of our knowledge, it was also the first RCT to examine the effectiveness of ACT especially for elderly SMI patients. The strengths of the other studies presented in this thesis were that they were also the first studies that examined in a cross-sectional and longitudinal study design the associations between motivation problems and psychosocial functioning in a group of elderly SMI patients. However, the studies in chapter 4, 5 and 7 used an observational design, which did not allow us to draw causal conclusions.

The RCT had several limitations. First, the number of included patients was low and the dropout rate was high. Due to the lack of referred patients, we extended the inclusion period by one year, and lowered the minimum age to 60 years (from 65). The small number of participants in the RCT nonetheless resulted in a lack of power.

Similarly, the TAU condition also comprised three different teams. This is why, to understand differences in working methods between them, we used the DACTS to measure each team's model fidelity. However, all three teams had a score of 2.4, indicating that ACT was not implemented. Neither social workers in ACTE or TAU were blind for the treatment condition. So, it is possible that social workers put in extra efforts for patients randomized in TAU. Finally, as the raters who scored the outcome measures were not blind for the treatment condition, there may have been an observer bias.

Data collection

A limitation that applies to all studies in this thesis is the lack of generalizability of the results, since data were collected in one institution in an urban setting (selection bias). Neither were all assessments filled out after face-to-face contact with the patient, which may have led to the inclusion of errors or less precise information (145). Similarly, due to missing data, Chapters 3 and 6 of this thesis reflect our use of different follow-up periods.

Further limitations were our use of a non-validated motivation-for-change scale and the possibility that motivation problems were influenced by a number of factors such

as stigma, lack of insight, and poor therapeutic alliance (15), which were not assessed in this study. The number of predictors we could use was also restricted by the small sample in Chapter 6. Our results may have been affected by the high number of patients lost to follow-up (Chapters 3, 5 & 6). Finally, while we used different scales to assess needs and psychosocial problems in ACTA and ACTE in Chapter 7, we considered the CANE and the CANSAS to be similar enough to compare scores. Although the HoNOS and HoNOS65+ were both suitable for measuring outcome in elderly patients, the HoNOS65+ glossary is more sensitive for problems specific to elderly patients (135).

8.5 CONCLUSIONS

The following conclusions can be based on our studies:

- ACTE engaged patients better in treatment than TAU.
- Elderly SMI patients referred to ACTE were not high service users with multiple hospital admissions.
- It is too early to recommend the implementation of specific ACTE teams for difficult-to-engage elderly SMI patients: (1) we did not find that ACTE was better than TAU with respect to its effects on psychosocial functioning, and (2) elderly patients in ACTE had many similarities with elderly patients in ACTA.
- Lack of treatment motivation is associated with a higher burden of disease.
- It may be possible to increase motivation for treatment by addressing unmet needs. This is why a full needs assessment should be combined with an assessment of treatment motivation in planning care in elderly patients with SMI.
- No predictors of treatment outcome in ACTE were identified.
- There was no evidence that the needs and psychosocial problems of patients in ACTE differed from those of patients treated in regular ACT teams for adults.

8.6 Implications for practice

From a general point of view, the implementation of ACTE requires the team to define clear goals and objectives, to adapt to changes in patients' needs and degree of motivation, to integrate objectives and patients' needs into effective interventions, and to focus on continuity of care. These four topics interact with the practical delivery of healthcare, and also influence it.

Engaging difficult-to-engage elderly patients in treatment

This thesis has shown that ACTE engaged patients better in treatment than TAU did. Difficult-to-engage SMI elderly patients could thus benefit from assertive outreach services as it is used in ACT or FACT. However, it is still too early to recommended specialized ACTE or FACTE teams for the elderly, as it may turn out that difficult-to-engage elderly SMI patients benefit just as much from treatment in ACT for adults. For this reason, differences between younger and older adults in ACT for adults should first be identified. Neither do we know which components of ACTE (such as assertive outreach, shared caseload, and meeting practical unmet needs) lead to better engagement. However, as an association has been shown with a smaller caseload in ACT than in TAU, and also with the team approach (shared caseload) (32), further research is needed into treatment motivation in elderly difficult-to-engage SMI patients.

Effectiveness of treatment programmes for difficult-to-engage SMI elderly patients

The need to include elderly patients with SMI in ROM and research projects is highlighted by the lack of evidence-based practices for psychosocial and other interventions in these patients. Such inclusion would make it possible to assess not only the effectiveness of treatment programmes, but also patients' recovery. Assessment of the impact on patients' treatment motivation and recovery of various interventions (assertive outreach, motivational interviewing, and the fulfilment of practical unmet needs) would make it possible to develop evidence-based interventions for the difficult-to-engage members of this patient group. However, if the effectiveness of the treatment is to be reviewed, careful consideration should given to the choice of validated ROM instruments used to assess patients' treatment motivation, psychosocial functioning, needs and recovery.

Need assessment & improving motivation for treatment

This thesis has shown that less-motivated elderly patients had greater unmet care needs and more psychosocial problems than motivated patients. It has also shown that a decrease in unmet needs over time was associated with positive changes in treatment motivation. For these reasons, practitioners should use needs assessment when planning care in elderly patients with SMI, and should combine it with an assessment of patients' motivation. As treatment adherence has been shown to improve when a patient perceives that his or her unmet needs have been met (39, 146), patients should be involved in the needs assessment. To measure met and unmet needs, both versions of the CANE (the patients' version and the care-worker version) could be used.

Considerations when starting specialized ACT or FACT elderly teams

Despite the above, we do not yet recommend the implementation of specific ACTE teams for difficult-to-engage SMI elderly patients. Before a specialized ACT or FACT team is started for SMI elderly patients, it should be established whether one is actually needed. How large is the population of such patients in the region? It is also essential to decide on the specific focus a specialized team should develop. A team will be appreciated only if it is organized differently, or uses interventions other than ACT or FACT for adults, or other than regular community mental-health teams for elderly patients. If these conditions are not met, elderly SMI patients could use ACT for adults or regular services.

If it is chosen to start a specialized ACTE or FACT team, it should be considered (1) whether a consumer provider and psychologist should be included in the team, and (2) whether ACTE should be extended with evidence-based practice for SMI elderly patients. Finally, to evaluate the effects of their interventions, practitioners should assess patients' recovery consistently and often.

8.7 FUTHER DIRECTIONS FOR RESEARCH

Our thesis shows that further research is needed in the following areas: clarifying the objectives of ACTE and improving continuity of care for elderly SMI patients, assessing needs and motivation and, developing evidence-based interventions.

- Age-related differences should be investigated between younger and older SMI
 patients in ACT or FACT for adults. This would make it possible to determine not
 only the differences in the characteristics of the two groups, but also the benefits
 each group derives from ACT interventions, and the specific interventions that
 might be needed for elderly SMI patients.
- An RCT comparing ACTE or FACTE to TAU should be replicated in other settings. It should include a larger number of patients and should use high-fidelity ACT or FACT teams that use evidence based programmes.
- 3. Further research is needed to identify other factors associated with motivation in elderly people with SMI, and to investigate whether treatment motivation within this group of patients can be increased by interventions such as assertive outreach, treatment-adherence therapy or practical support.
- 4. Currently, there are, so far as we know, no evidence-based practices regarding psychosocial and other interventions in elderly patients with SMI who are difficult-to-engage. This highlights the need for research on interventions to improve outcome or prevent further deterioration, especially in patients with intellectual disabilities.



CHAPTER 8

SUMMARY

SUMMARY

Introduction

A subgroup of elderly patients with psychiatric disorders have severe mental illness (SMI) characterized by social difficulties and comorbid somatic and addiction disorders. Due to motivation problems, these patients are also difficult-to-engage in treatment. Although regular community mental-health services for the elderly offer outreach treatment through multidisciplinary teams, these usually focus on psychiatric care, whereas other institutions provide somatic, addiction and social services. We hypothesized that difficultto-engage patients might benefit from assertive outreach services (Assertive Community Treatment for elderly: ACTE) that included social services, housing assistance, daytime activities, finance or budgeting services together with psychiatric and addiction treatment.

Assertive Community Treatment for elderly patients

In adult mental-health care, Assertive Community Treatment (ACT) was originally developed as an integrated model to meet the needs of difficult-to-engage-patients with complex problems. To support patients' ability to live in the community, ACT provides psychiatric, somatic and social care. Team members have training in psychiatry, social work, nursing, substance abuse, and rehabilitation. An ACT team has a small caseload per team member (approximately 10 patients per clinician), a shared caseload (i.e. all clinicians use a single care plan, and collaborate closely on each patient), and provides community-based and assertive services on a time-unlimited basis.

In the United States, ACT reduced hospital admissions and led to more stable housing. Relative to treatment as usual (38), however, it had no beneficial effects on symptoms or social functioning. In Europe, studies showed that it had no effects in reducing admissions, and none in clinical outcome. With regard to engaging patients in treatment, however, it was more successful than TAU.

Due to the time-unlimited services of ACT (whereby care is provided as long as the patients need it, irrespective of age), the number of elderly (65+) SMI patients in ACT teams is growing. Since most studies on ACT included adults (18-65 years), it was not known whether ACT would be effective in elderly SMI patients.

Aim of the thesis

The main aim of this thesis was to study whether ACTE is more effective than TAU. To better understand the care needs and psychosocial functioning of difficult-to-engage elderly SMI patients treated in ACTE, and also to better understand factors associated with motivation for treatment, we conducted several parallel studies.

Effectiveness of ACTE

In the General introduction (**Chapter 1**) we concluded on the basis of a review of the literature that few studies have examined the effectiveness of integrated mental-health services specifically for elderly SMI patients. Weak study designs and a paucity of literature mean that there is little evidence on the effectiveness of community of mental-healthcare for elderly SMI patients. **Chapter 2** describes the study protocol of the RCT presented in this thesis and the inclusion problems we were confronted with. **Chapter 3** presents the results of the RCT: ACTE versus TAU. Independent assessors performed measurements at baseline, 9 months and 18 months follow-up. Twenty-six of the 62 patients who were randomized were lost to follow-up (10 patients in ACTE and 16 in TAU). Relative to patients with TAU, more patients allocated to ACTE had a first contact within three months (96.9 versus 66.7%; X^2 (df=1) = 9.68, p = 0.002). ACTE also had fewer dropouts from treatment (18.8% of ACTE patients versus 50% in TAU; X^2 (df=1) = 6.75, p = 0.009). However, we could not demonstrate that ACTE led to better psychosocial Functioning. We concluded that ACTE engaged patients in treatment more successfully.

Patients in ACTE: care needs, psychosocial functioning and treatment motivation

In a cross-sectional study of 141 patients (all of whom were enrolled in ACTE, including those outside the context of the RCT; **Chapter 4**), lack of motivation is shown to be associated with greater unmet needs regarding daytime activities, psychotic symptoms, behavioural problems, and addiction problems. We concluded that lack of treatment motivation was associated with more unmet needs and more psychosocial problems, both of which indicated a higher burden of disease. Our findings suggested that special strategies – such as assertive outreach and motivational interviewing – are required to tackle these patients' lack of motivation for treatment, and to engage them into

treatment. Treatment motivation in elderly SMI patients is a complex and poorly understood phenomenon. Further research will be needed to identify other factors associated with motivation in such people, and to investigate whether their treatment motivation can be increased by interventions such as assertive outreach or motivational interviewing.

In Chapter 5 we investigate whether a decrease in unmet needs precedes or parallels an increase in treatment motivation for elderly SMI patients. The results show that the number of patients who were not motivated for treatment at baseline decreased during follow-up: at baseline, 71.4% were not motivated, against 51.4% at the second measurement and 31.4% at 18 months. Three groups were defined. Patients in group 1 were motivated at baseline (based on a score on a motivation-for-treatment scale), and remained motivated during follow-up. Patients in group 2 were not motivated at baseline, but became motivated during follow-up. Patients in group 3 were not motivated at baseline, and remained unmotivated.

We found that that a reduction in unmet needs, both from 0-9 months and from 0-18 months, was associated with remaining motivated for treatment or with a change from being unmotivated to becoming motivated during the same observational period (i.e. parallel associations). We also found that a reduction in unmet needs from 0-9 months was associated with remaining motivated or with a change from unmotivated to motivated during 9-18 month follow-up (sequential associations). One possible clinical implication of our results is that treatment motivation may increase if unmet needs are addressed.

Chapter 6 used a longitudinal study design with 72 outpatients to investigate predictors of outcome in ACTE patients. We expected that poor treatment outcome could be predicted by demographic, clinical and motivational factors. The severity of psychosocial functioning (HoNOS65+) was assessed at baseline and 18 months. While the results showed that overall psychosocial outcome improved in elderly SMI patients treated in ACTE, we were unable to identify predictors that were related to overall psychosocial outcome, except for level of psychosocial functioning at baseline. On a subscale level of the HoNOS65+, we found that patients with a psychotic disorder and those with a lower educational level were more vulnerable to poor outcome with respect to psychiatric symptoms. Outcome in social functioning was poor in less-educated patients who also had somatic disorders. This suggested that it might be important to take patients' educational level into account, and to provide tailored interventions. However, the lack of evidence-based practices regarding psychosocial and other interventions in elderly patients with SMI highlights the need to determine which interventions lead to better outcomes or prevent further deterioration, especially in patients with intellectual disabilities.

In **Chapter 7** we wished to compare the specificity of the problems and needs of elderly SMI patients in ACTE with those of elderly patients treated in general ACT teams. To do so, we compared the psychosocial functioning and the met and unmet needs in patients aged 55+ who were being treated in ACT adult (ACTA) teams at BavoEuropoort with those of patients of the same age being treated in the ACTE team that was set up in the context of the present study.

This cross-sectional study included 141 patients in ACTE and 168 patients in ACTA. The results showed that the mean age of the relevant group of patients in ACTE was higher than that of patients in ACTA. These patients were also older at their first contact with the mental-health services. More of them were female, widowed, and living independently; and more had been diagnosed with a cognitive disorder. However, regression analyses showed no differences in the number of needs and the severity of psychosocial problems between patients in ACTE or patients in ACTA.

We concluded that the overall needs and psychosocial functioning of patients included in ACTE were not essentially different from those of patients included in ACTA, and that this may indicate that 55+ SMI patients could be treated as well by a regular ACT team as by a special ACTE team. To treat elderly SMI patients in ACTA, it would be possible to devise consultation options to cover the special care needs of elderly patients. Another option might be to add a community mental-health nurse specialized in elderly SMI patients to the ACTA team. This discipline can better handle end-of-life issues, agerelated physical and mental-health needs, and collaboration with healthcare programs for elderly people in the community (e.g. nursing homes and rehabilitation programs for elderly). However, further research is needed to investigate age-related differences in healthcare needs (including mental-healthcare needs) between younger and older SMI

patients, and to determine which kinds of specific intervention might be needed for elderly SMI patients. It is possible that older SMI patients react differently to psychosocial interventions intended for their adult counterparts (such as motivational interviewing), or that they need longer interventions (such as more sessions of cognitive behavioral therapy) to improve persistent symptoms.

Finally, in **Chapter 8**, the general discussion considers the findings, strengths and limitations of our study. It is too early to recommend implementation of specific ACTE teams for difficult-to-engage elderly SMI patients: relative to patients in TAU, those in ACTE did not benefit from the ACTE model in terms of better psychosocial functioning or fewer unmet needs. Neither did they have specific needs and psychosocial problems relative to patients treated in ACT for adults. However, since ACTE was better than TAU in engaging patients, it seems that using explicit assertive outreach strategies is important when dealing with difficult-to-engage elderly SMI patients.

CHAPTER 8

ABBREVEATIONS

LIST OF ABBREVIATIONS USED

ACT Assertive Community Treatment

ACTA Assertive Community Treatment for adults

ACTE Assertive Community Treatment for the elderly

CANE Camberwell Assessment of Needs Elderly

CANSAS Camberwell Assessment of Needs Short Appraisal Scale

CI Confidence Interval

DACTS Dartmouth Assertive Community Treatment Scale

df Degrees of freedom

DSM IV TR Diagnostic and Statistical Manual of Mental Disorders, 4th revised edition

GAF Global Assessment of Functioning

HoNOS Health of the Nation Outcome Scale

OR Odds Ratios

QoL Quality of Life

RCT Randomized Controlled Trial

ROM Routine Outcome Monitoring

SD Standard Deviation

SE Standard Error

SMI Severe Mental Illness

SoC Stages of Change

SPSS Statistical Package of the Social Science

TAU Treatment as Usual

US United States

SAMENVATTING

SAMENVATTING

Introductie

Binnen de groep ouderen met ernstige psychiatrische aandoeningen (EPA) is er een subgroep met gecombineerde problemen (psychiatrische- verslavings-, somatische en maatschappelijke problemen) die 'zorg mijdt' en waarvan het onzeker is in hoeverre deze groep wordt bereikt door de reguliere afdelingen ouderenpsychiatrie binnen de Geestelijke Gezondheidszorg (GGz). Deze reguliere afdelingen leveren behandeling in de thuissituatie, maar deze hulp bestaat hoofdzakelijk uit psychiatrische behandeling en de mate waarin bemoeizorg wordt toegepast om zorgmijdende patiënten te bereiken wisselt. Oudere EPA patiënten met complexe problemen zouden kunnen profiteren van teams die op een assertieve en geïntegreerde manier hulp in de thuissituatie bieden (bemoeizorg, sociale ondersteuning, ondersteuning bij het zelfstandig wonen; dagactiviteiten; omgaan met financiën, somatische zorg, psychiatrische behandeling en behandeling voor verslavingsproblemen).

Assertive Community Treatment

In de volwassenenpsychiatrie is Assertive Community Treatment (ACT) een veelvuldig onderzochte en gebruikte organisatievorm voor het aanbieden van geïntegreerde (bemoei)zorg aan EPA patiënten met complexe problemen die moeilijk in behandeling te krijgen zijn. ACT levert geïntegreerde (bemoei)zorg op zowel psychiatrisch, verslavings, somatisch en sociaal gebied aan EPA patiënten, zodat zij met ondersteuning zo goed en zelfstandig mogelijk in de maatschappij kunnen wonen en functioneren. Teamleden zijn opgeleid om op genoemde gebieden gespecialiseerde behandeling en zorg te kunnen verlenen. Hierdoor bestaat het team uit verschillende disciplines (psychiater, verpleegkundige, sociaal psychiatrisch verpleegkundige, maatschappelijk werker, verslavingsdeskundige). Medewerkers van het ACT team hebben een kleine caseload (ongeveer 10 patiënten per medewerker), delen de zorg voor alle patiënten (alle hulpverleners werken samen rond de patiënt door middel van 1 behandelplan) en de zorg wordt geleverd daar waar de patiënt zich bevindt (thuis, in het ziekenhuis, in de gevangenis et cetera). Het initiatief tot zorg ligt veelal bij de hulpverlener, zonder beperkingen omtrent de intensiviteit van de zorg (zolang en zoveel als nodig is wordt er

zorg geboden, eventueel meerdere keren per dag). De effectiviteit van ACT is met name in de Verenigde Staten (VS) (106) aangetoond. In de VS blijkt dat ACT een positieve invloed heeft op het aantal opnamedagen en het krijgen en behouden van huisvesting, in vergelijking met reguliere behandeling. Echter, ACT heeft geen meerwaarde met betrekking tot het verminderen van symptomen en sociaal functioneren. Europese studies tonen echter geen beter effect van ACT aan in het verlagen van het aantal psychiatrische opnames (of het aantal opnamedagen) of andere klinische uitkomsten. ACT krijgt het echter wel voor elkaar dat patiënten beter in zorg komen en gehouden worden, vergeleken met reguliere hulpverlening. ACT wordt aangeboden aan patiënten zolang er een zorgbehoefte is. Patiënten kunnen zolang als nodig is bij het team in behandeling blijven. Hierdoor groeit het aantal oudere patiënten (65+) in ACT. Onderzoek is echter vooral uitgevoerd bij patiënten tussen 18-65 jaar waardoor het niet duidelijk is of ACT effectief is voor oudere EPA patiënten.

Doel van het proefschrift

Het doel van deze studie was om kennis te verwerven over oudere EPA patiënten die door een ACT team voor ouderen (ACT Elderly, afgekort ACTE) behandeld werden. Het hoofddoel was om het effect van ACTE te vergelijken met effecten van de reguliere behandeling (Treatment as Usual - TAU). De effectiviteit van ACTE is getest door middel van een gerandomiseerd onderzoek (randomized controlled trial - RCT). Daarnaast hebben we verschillende analyses uitgevoerd naar zorgbehoeften, psychosociaal functioneren en behandelmotivatie bij de groep patiënten die in ACTE behandeld werden.

Effectiviteit van ACTE

In de introductie (**Hoofdstuk 1**) hebben we een literatuur onderzoek uitgevoerd en concluderen we dat er een gebrek is aan goede studies naar de effectiviteit van geïntegreerde zorg aan ouderen psychiatrische patiënten. **Hoofdstuk 2** beschrijft het studie protocol van het gerandomiseerde onderzoek en de inclusieproblemen bij de start van de studie. In **Hoofdstuk 3** beschrijven we de verschillen tussen ACTE en de regulier aangeboden zorg door de afdeling ouderenpsychiatrie van BavoEuropoort.

Onafhankelijke assistenten hebben bij patiënten drie metingen afgenomen (bij aanvang van de behandeling, na 9- en na 18 maanden). Van de 62 gerandomiseerde patiënten vielen er 26 patiënten uit het onderzoek vanwege diverse redenen (10 patiënten in ACTE en 16 in TAU). Resultaten laten zien dat, vergeleken met TAU, patiënten in ACTE vaker binnen 3 maanden contact met de hulpverleners hadden (96.9% versus 66.7%; X² (df=1) = 9.68, p = 0.002). Het lukte ACTE ook beter patiënten in zorg te houden (18.8% of ACTE patiënten vielen uit zorg versus 50% of TAU; X² (df=1) = 6.75, p = 0.009). We vonden echter niet dat ACTE meerwaarde had met betrekking tot het verbeteren van onvervulde zorgbehoeften en psychosociaal functioneren. We concludeerden daarom dat ACTE, in vergelijking met TAU, er beter in slaagde patiënten in zorg te krijgen en te houden.

Zorgbehoeften, psychosociaal functioneren en behandelmotivatie bij patiënten in ACTE

In een cross-sectionele studie met 141 patiënten (alle patiënten ingestroomd in ACTE, niet alleen patiënten uit het gerandomiseerde onderzoek, Hoofdstuk 4) werd gevonden dat gebrek aan behandelmotivatie geassocieerd was met meer onvervulde zorgbehoeften en meer problemen in het psychosociaal functioneren, vergeleken met patiënten die beter gemotiveerd waren voor behandeling. De associatie tussen motivatieproblemen en onvervulde zorgbehoeften suggereerde dat het verminderen van het aantal onvervulde zorgbehoeften en het verbeteren van psychosociaal functioneren kan leiden tot meer behandelmotivatie. Of andersom, misschien leidt het verhogen van motivatie, door middel van bijvoorbeeld 'motivational interviewing' tot verbetering in zorgbehoeften en psychosociaal functioneren.

In Hoofdstuk 5 is onderzocht of een daling in het aantal onvervulde zorgbehoeften geassocieerd was met een verbetering in de behandelmotivatie. Resultaten lieten zien dat het aantal ongemotiveerde patiënten in ACTE daalde (bij aanvang van de studie waren 71,4% van de patiënten niet gemotiveerd, na 9 maanden was dit 51.4% en na 18 maanden was dit percentage gedaald naar 31.4%). We zagen verder dat een daling van het aantal onvervulde zorgbehoeften, tussen zowel 0-9 maanden als tussen 0-18 maanden geassocieerd was met gemotiveerd blijven voor behandeling en ook met verbetering in de behandelmotivatie gedurende deze periode (parallelle associatie). Daarnaast, bestond er een associatie tussen een daling in het aantal onvervulde

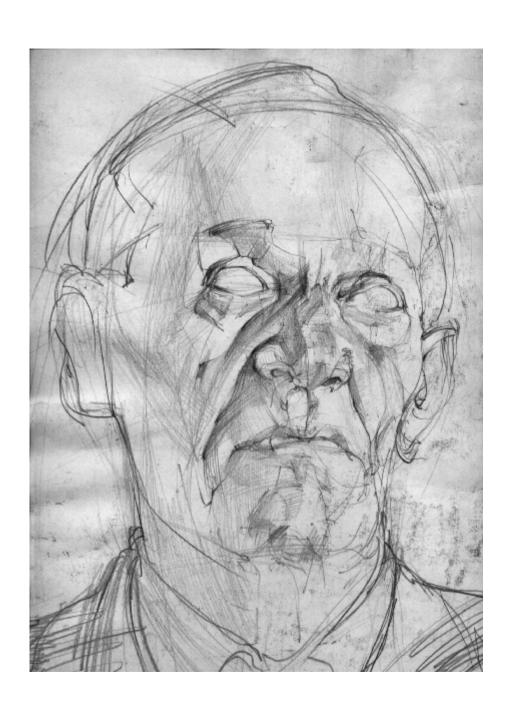
zorgbehoeften (tussen 0 en 9 maanden) en het toenemen van de motivatie in de periode erna (tussen 9 en 18 maanden, sequentiële associatie). We concludeerden dan ook dat de resultaten van de studie erop wijzen dat een daling van het aantal zorgbehoeften kan leiden tot meer behandelmotivatie. Behandelmotivatie is echter een complex concept en bij oudere patiënten met EPA nauwelijks onderzocht en begrepen.

In **Hoofdstuk 6** onderzochten we het beloop van het psychosociaal functioneren (gemeten met behulp van de HoNOS65+). We onderzochten welke predictoren geassocieerd waren met de HoNOS65+ scores in een longitudinale studie met 72 patiënten uit het ACTE team. De volgende predictoren zijn bekeken: het al dan niet hebben van een psychotische stoornis, het al dan niet hebben van een somatische ziekte, het opleidingsniveau en motivatie voor behandeling. We vonden dat de totale HoNOS65+ scores significant verbeterden tijdens de 18 maanden follow-up. Behalve de HoNOS65+ scores op baseline, vonden we met behulp van regressieanalyse geen andere predictoren voor de HoNOS65+ scores na 18 maanden. Op HoNOS65+ subschaal niveau vonden we dat patiënten met een psychotische stoornis en diegenen die laag opgeleid zijn (geen opleiding of alleen lager onderwijs), na 18 maanden vaker problemen bleven houden op de subschaal psychiatrische symptomen. Daarnaast bleven resultaten in het sociaal functioneren achter bij laag opgeleide patiënten die daarnaast ook somatische ziekten hadden. We concludeerden dat predictie van behandeluitkomsten complex is waarbij laagopgeleide patiënten een kwetsbare groep blijken wat betreft uitkomsten in psychiatrische symptomen en sociaal functioneren. Dit suggereert dat het bewust registreren van schoolopleiding belangrijk is, evenals mogelijk het ontwikkelen van specifieke interventies voor deze groep patiënten.

In **Hoofdstuk 7** onderzochten we of oudere patiënten met EPA, die behandeld werden in ACTE, specifieke psychosociale problemen en zorgbehoeften hadden in vergelijking met oudere patiënten die behandeld worden in ACT teams voor volwassenen. Dit deden we door middel van een cross-sectioneel onderzoek bij 141 patiënten van 55 jaar en ouder in ACTE en 169 patiënten van 55 jaar en ouder in ACT teams voor volwassen (ACT voor adults - ACTA). Resultaten lieten zien dat patiënten in ACTE gemiddeld ouder waren dan patiënten in ACTA. Patiënten in ACTE waren tevens ouder bij het eerste contact met de geestelijke gezondheidszorg, waren vaker vrouw, weduwe, leefden vaker

zelfstandig en werden vaker gediagnosticeerd met een cognitieve stoornis. Regressieanalyse toonde echter geen verschil aan in het aantal zorgbehoeften en in de ernst van het psychosociaal functioneren. We concluderen dan ook dat er geen grote verschillen zijn in zorgbehoeften en psychosociaal functioneren tussen 55+ patiënten in zowel ACTE als in ACTA. Dit wijst er mogelijk op dat oudere patiënten evengoed behandeld kunnen worden in de reguliere ACT teams voor volwassenen. Het is echter noodzakelijk om te onderzoeken of 55+ patiënten in ACT anders reageren op interventies dan patiënten van ≤55. Mogelijk reageren oudere patiënten anders op bepaalde interventies, zoals bijvoorbeeld therapie om motivatie voor behandeling te verhogen. Ook kan het zijn dat er meer tijd nodig is om een positief effect te krijgen van bijvoorbeeld cognitieve gedragstherapie. Als oudere patiënten in behandeling blijven bij ACT teams voor volwassenen en het blijkt uit onderzoek dat oudere patiënten anders reageren op interventies, dan kan overwogen worden om op consultatieve basis wijze gebruik te maken van een ouderenspecialist (bijvoorbeeld een sociaal psychiatrisch verpleegkundige (SPV) of psychiater gespecialiseerd in ouderen patiënten met EPA). Een andere optie is het toevoegen van een discipline (bijvoorbeeld een SPV) aan het ACT volwassen team die gespecialiseerd is in ouderen (specialistische uitbreiding van het multidisciplinaire team). Dit is mogelijk een goed alternatief bij grote aantallen oudere EPA patiënten in een ACT volwassen team. Deze discipline kan de weg vinden en samenwerken met instellingen en programma's speciaal gericht op ouderen.

Tot slot worden in **Hoofdstuk 8** de bevindingen, sterke en zwakke punten en methodologische beperkingen van de studie besproken. Vooralsnog blijkt uit ons onderzoek geen overduidelijke meerwaarde van ACTE ten opzichte van TAU en is het lastig om een advies te geven met betrekking tot het implementeren van ACT teams speciaal voor ouderen. Wel lijkt het wenselijk dat er speciale aandacht komt voor inclusie en drop-out, aangezien ACTE in dit opzicht beter was. Voordat er nieuwe vormen van zorg gestart wordt voor de groep oudere EPA patiënten met motivatieproblemen is het raadzaam onderzoek te verrichten naar verschillen in respons tussen oudere en jongere patiënten die behandeld worden in ACT teams voor volwassenen.



DANKWOORD

DANKWOORD

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PUBLICATIONS

Publications

Dutch journals and books

- Stobbe, J. 2003. Suïcidebeoordeling een vak apart. Sociale Psychiatrie, 69, 44-53.
- Stobbe, J. 2004. Het effect van Non-Suïcide Contracten op suïcidaal gedrag. Sociale Psychiatrie, 73, 43-47.
- Stobbe, J., Berends, M., Mulder, C.L. 2009. Assertive Community Treatment voor ouderen (Book section in Dutch). Assertive Community Treatment for the elderly. In: MULDER, C.L.KROON, H. Assertive Community Treatment Bemoeizorg voor patienten met complexe problemen. Amersfoort: Boom.
- Stobbe J, Wierdsma AI, van Beest RH, Mulder CL (2009): Drop-out na gedwongen opname - hoe groot is het probleem? (Article in Dutch). Drop-out from after-care following compulsory hospitalisation--how serious is the problem? Tijdschr Psychiatr, 51(11):801-812.

International journals

- Stobbe, J., Mulder, C.L., Roosenschoon, B.J., Depla, M.Kroon, H. 2010. Assertive Community Treatment for elderly people with severe mental illness. BMC Psychiatry, 10:84.
- Stobbe, J., Wierdsma, A.I., Kok, R.M., Kroon, H., Depla, M., Roosenschoon, B.J.Mulder, C.L. 2013. Lack of motivation for treatment associated with greater care needs and psychosocial problems. Aging Ment Health. 17:8. 1052-1058. http://dx.doi.org/10.1080/13607863.2013-807422
- Stobbe J, Wierdsma AI, Kok RM, Kroon H, Roosenschoon BJ, Depla M, Mulder CL (2014): The effectiveness of assertive community treatment for elderly patients with severe mental illness: a randomized controlled trial. BMC Psychiatry, 14(1):42. http://dx.doi.org/10.1186/1471-244X-14-42

PORTFOLIO

PhD Portfolio

Summary of PhD-training and teaching

| Summary of PhD-training and teaching | | | | | |
|---|-----------|-----------|--|--|--|
| Name PhD student: Jolanda Stobbe PhD period: March 2008 – August 20 | | | | | |
| Erasmus MC Department: Psychiatry Promotor(s): Prof. Dr. C.L. Mulder | | | | | |
| Research School : Epidemiological and Social Psychiatric Research Supervisor: Dr. A.I. Wierdsma | | | | | |
| institute (ESPRi) | | | | | |
| 1. PhD training | Year | Workload | | | |
| General courses | | | | | |
| - Workshop 'Hoe geef ik een workshop' | 2008 | 4 | | | |
| - Workshop EndNote | 2009 | 3 | | | |
| - Workshop 'Literatuur zoeken' | 2009 | 3 | | | |
| - Introduction to data analysis (NIHES) | 2010 | 30 | | | |
| - Regression analysis (NIHES) | 2012 | 45 | | | |
| Methodologie van patiëntgebonden onderzoek en voorbereiding van subsidie aanvragen (CPO & CQM) | 2012 | 8 | | | |
| - Beyond simple randomization (CPO & CQM) | 2012 | 5 | | | |
| - How to prepare for your future career (CPO & CQM) | 2012 | 5 | | | |
| Specific courses (e.g. Research school, Medical Training) | | | | | |
| - Training for trainers HoNOS65+ - The Royal College of Psychiatrists, London | 2008 | 10 | | | |
| Seminars and workshops | | | | | |
| - Research lunches at O3 Research Centre (current ESPRi) | 2008-2013 | 30 | | | |
| - Seminars at O3 Research Centre (current ESPRi) | 2008-2013 | 25 | | | |
| Presentations | | | | | |
| - Various presentations at research seminars and mental-health institutions | 2008-2013 | 200 | | | |
| National and international conferences | | | | | |
| Voorjaarscongres van de Nederlandse Vereniging voor Psychiatrie, Groningen (oral presentation) | 2009 | 20 | | | |
| Werken met moeilijke mensen. Nieuwe interventies en instrumenten in de openbare GGz, Poortugaal (oral presentation) | 2009 | 20 | | | |
| Assertive Community Treatment Association (90 minutes oral presentation) Washington DC, USA | 2009 | 70 | | | |
| - Zorg-coordinatie in de OGGz (oral presentation), Utrecht | 2009 | 20 | | | |
| - Trimbos Institute ACT onderzoek in Nederland en Belgie (oral presentation) | 2010 | 20 | | | |
| - European Assertive Community Treatment congress | 2011 | 30 | | | |
| Assertive Community Treatment Association (90 minutes oral presentation) Boston, USA | 2012 | 70 | | | |
| - Parnassia Psychiatric Institute department elderly congress (oral presentation) | 2012 | 20 | | | |
| Other | | | | | |
| - Supervisie PhD – werkgroep ACT ouderen | 2008-2013 | 75 | | | |
| TOTAL | | 713 Hours | | | |
| | | | | | |

REFERENCES

References

- Delespaul PH, Consensusgroep EPA (2013): Consensus over de definitie van mensen met een ernstige psychische aandoening (EPA) en hun aantal in Nederland (article in Dutch). Consensus regarding the definition of persons with severe mental illness and the number of such persons in the Netherlands. *Tijdschr Psychiatr*, 55(6):427-438.
- 2. McCrae N, Banerjee S (2011): Modernizing mental health services for older people: a case study. *Int Psychogeriatr*, 23(1):10-19.
- Boer de F, Smits C (2003): OGGZ en verwaarloosde ouderen, bereik en waardering van zorg (book in Dutch). OGGZ and neglected elderly, range and valuation of care. Utrecht: Trimbos-Instituut.
- 4. Cummings SM, Kropf NP (2011): Aging with a severe mental illness: challenges and treatments. *J Gerontol Soc Work*, 54(2):175-188.
- 5. Bartels SJ (2011): Commentary: the forgotten older adult with serious mental illness: the final challenge in achieving the promise of Olmstead? *J Aging Soc Pol*, 23(3):244-257.
- Depla MF, de Graaf R, van Weeghel J, Heeren TJ (2005): The role of stigma in the quality of life of older adults with severe mental illness. Int J Geriatr Psychiatry, 20(2):146-153.
- Pot AM, Depla M, ten Have M (2007): Monitor Geestelijke Gezondheidszorg Ouderen, Rapportage 2006 (report in Dutch) Monitor Mental Health-care for the elderly, Report 2006. Utrecht.
- Citters van AD, Bartels SJ (2004): A systematic review of the effectiveness of communitybased mental health outreach services for older adults. Psychiatr Serv, 55(11):1237-1249.
- 9. Dallaire B, McCubin M, Carpentier N, Clément M (2009): Representations of elderly with mental health problems held by psychosocial practitioners from community and institutional settings. *Social Work in Mental Health*, 7(1):139-152.
- 10. Buijssen H (2000): Psychologische hulpverlening aan ouderen (book in Dutch). Psychological care for elderly. Baarn: HB uitgevers.
- 11. Gaag van de-Haars AW (2000): Woningvervuiling bij ouderen: een onderschat en complex probleem (article in Dutch). Aged people in dirty dwellings: an underestimated and complex problem. *Ned Tijdschrift voor Geneeskunde*, 144(52):2485-2487.
- 12. Meeks S, Carstensen LL, Stafford PB, Brenner LL, Weathers F, Welch R, Oltmanns TF (1990): Mental health needs of the chronically mentally ill elderly. *Psychol Aging*, 5(2):163-171.
- Munk Laursen T, Munk-Olsen T, Nordentoft M, Mortensen PB (2007): Increased mortality among patients admitted with major psychiatric disorders: a register-based astudy comparing mortality in unipolar depressive disorder, bipolar affective disorder, schizoaffective disorder, and schizoprenia. J Clin Psychiatry, 68:899-907.
- 14. Andrews AO, Bartels SJ, Xie H, Peacock WJ (2009): Increased risk of nursing home admission among middle aged and older adults with schizophrenia. *Am J Geriatr Psychiatry*, 17(8):697-705.
- 15. Torrey EF, Zdanowicz M (2001): Outpatient Commitment: What, Why, and for Whom. *Psychiatr Serv*, 52:337-341.
- Lehner R, Dopke C, Cohen K, Edstrom K, Maslar M, Slagg N, Yohanna Y (2007): Outpatient treatment adherence and serious mental illness: A review of interventions. Am J of Rehabilitation, 10:245-274.
- 17. Frank AF, Gunderson JG (1990): The role of the therapeutic alliance in the treatment of schizophrenia. Relationship to course and outcome. *Arch Gen Psychiatry*, 47(3):228-236.
- 18. McCabe R, Priebe S (2003): Are therapeutic relationships in psychiatry explained by patients' symptoms? Factors influencing patient ratings. *Eur Psychiatry*, 18(5):220-225.
- Lysaker PH, Davis LW, Buck KD, Outcalt S, Ringer JM (2011): Negative symptoms and poor insight as predictors of the similarity between client and therapist ratings of therapeutic

- alliance in cognitive behavior therapy for patients with schizophrenia. J Nerv Ment Dis, 199(3):191-195.
- 20. Wittorf A, Jakobi U, Bechdolf A, Muller B, Sartory G, Wagner M, Wiedemann G, Wolwer W, Herrlich J, Buchkremer G, Klingberg S (2009): The influence of baseline symptoms and insight on the therapeutic alliance early in the treatment of schizophrenia. Eur Psychiatry, 24(4):259-267.
- 21. Velligan DI, Weiden PJ, Sajatovic M, Scott J, Carpenter D, Ross R, Docherty JP (2009): The expert consensus guideline series: adherence problems in patients with serious and persistent mental illness. J Clin Psychiatry, 70 Suppl 4:1-46.
- 22. Pratt SI, Citters van AD, Mueser KT, Bartels SJ (2008): Psychosocial rehabilitation in older adults with serious mental illness: A review of the reseach literature and recommendations for development of rehabilitative approaches. Am J Psychiatric Rehabilitation, 11:7-40.
- 23. Bartels SJ, Mueser KT, Miles KM (1997): Functional impairments in elderly patients with schizophrenia and major affective illness in the community: Social skills, living skills, and behavior problems. Behav Ther, 28:43-63.
- 24. Klap R, Unroe KT, Unutzer J (2003): Caring for mental illness in the United States: a focus on older adults. Am J Geriatr Psychiatry, 11(5):517-524.
- 25. Mojtabai R, Olfson M, Mechanic D (2002): Perceived need and help-seeking in adults with mood, anxiety, or substance use disorders. Arch Gen Psychiatry, 59(1):77-84.
- 26. Bedard M, Gibbons C, Dubois S (2007): The needs of rural and urban young, middle-aged and older adults with serious mental illness. Can J Rural Med, 12(3):167-175.
- 27. Abdul-Hamid W, Johnson S, Thornicroft G, Holloway F, Stansfeld S (2009): The Camberwell elderly mentally ill and their needs for services. Int J Soc Psychiatry, 55(1):82-90.
- 28. Wilberforce M, Harrington V, Brand C, Tucker S, Abendstern M, Challis D (2011): Towards integrated community mental health teams for older people in England: progress and new insights. Int J Geriatr Psych, 26(3):221-228.
- 29. Stein LI, Test MA (1980): Alternative to mental hospital treatment. Conceptual model, treatment program, and clinical evaluation. Arch Gen Psych, 37(4):392-397.
- 30. Marshall M, Lockwood A (2000): Assertive community treatment for people with severe mental disorders. Cochrane Database Syst Rev.
- 31. Burns T, Catty J, Dash M, Roberts C, Lockwood A, Marshall M (2007): Use of intensive case management to reduce time in hospital in people with severe mental illness: systematic review and meta-regression. BMJ, 335(7615):336-339.
- 32. Killaspy H, Johnson S, Pierce B, Bebbington P, Pilling S, Nolan F, King M (2009): Successful engagement: a mixed methods study of the approaches of assertive community treatment and community mental health teams in the REACT trial. Soc Psychiatry Psychiatr Epidemiol, 44(7):532-540.
- 33. Sytema S, Wunderink L, Bloemers W, Roorda L, Wiersma D (2007): Assertive community treatment in the Netherlands: a randomized controlled trial. Acta Psychiatr Scand, 116(2):105-112.
- 34. Kohn R, Goldsmith E, Sedgwick TW (2002): Treatment of homebound mentally ill elderly patients: the multidisciplinary psychiatric mobile team. Am J Geriatr Psychiatry, 10(4):469-475.
- 35. Mueser KT, Pratt SI, Bartels SJ, Swain K, Forester B, Cather C, Feldman J (2010): Randomized trial of social rehabilitation and integrated health care for older people with severe mental illness. J Consult Clin Psychol, 78(4):561-573.
- 36. Cummings SM (2009): Treating older persons with severe mental illness in the community: impact of an interdisciplinary geriatric mental health team. J Gerontol Soc Work, 52(1):17-31.

- 37. Levin S, Miya K (2008): Assertive community treatment for old adults. *Psychiatr Serv*, 59(1):113.
- 38. Brugha TS, Taub N, Smith J, Morgan Z, Hill T, Meltzer H, Wright C, Burns T, Priebe S, Evans J, Fryers T (2012): Predicting outcome of assertive outreach across England. *Soc Psychiatry Psychiatr Epidemiol*, 47(2):313-322.
- 39. Junghan UM, Leese M, Priebe S, Slade M (2007): Staff and patient perspectives on unmet need and therapeutic alliance in community mental health services. *Br J Psychiatry*, 191:543-547.
- 40. Kortrijk HE, Mulder CL, Roosenschoon BJ, Wiersma D (2009): Treatment Outcome in Patients Receiving Assertive Community Treatment. *Community Ment Health J*, 46(4):330-336.
- 41. Depla M, Pot AM, Graaf de R, Dorsselaer van S, Sonnenberg C (2005): Ontwikkeling in het gebruik van geestelijke gezondheidszorg en verslavingszorg door ouderen tot 2020 (book in Dutch). Development in the use of mental health and addiction by the elderly until 2020. Utrecht: Trimbos-Instituut.
- 42. Vaarwerk te M (1997): Zelfverwaarlozing bij ouderen (report in Dutch) Selfneglecting by older people. Utrecht.
- 43. Abrams RC, Lachs M, McAvay G, Keohane DJ, Bruce ML (2002): Predictors of self-neglect in community-dwelling elders. *Am J Psychiatry*, 159(10):1724-1730.
- 44. Depla M, Smits CHM (2003): Wonen, zorg en en welzijn. Wat willen ouderen zelf; een behoeftepeiling onder ouderen (report in Dutch) Home-care and well-being. What do elderly people want for themself; an opinion poll of needs among the elderly people. Utrecht.
- 45. NIZW: Verslag expertmeeting oudere zorgmijders in beeld (paper in Dutch) Statement expertmeeting elderly paptients difficult-to-engage in the picture. In: *Expertmeeting oudere zorgmijders in beeld*. NIZW Kenniscentrum ouderen; 2006.
- 46. Fiander M, Burns T, McHugo GJ, Drake RE (2003): Assertive community treatment across the Atlantic: comparison of model fidelity in the UK and USA. *Br J Psychiatry*, 182:248-254.
- 47. Priebe S, Watts J, Chase M, Matanov A (2005): Processes of disengagement and engagement in assertive outreach patients: qualitative study. *Br J Psychiatry*, 187:438-443.
- 48. CBO: Multidisciplinaire richtlijnen voor schizofrenie (standard in Dutch) Standard for schizophrenia. In. Utrecht: Trimbos-Instituut; 2005.
- 49. Burns BJ, Santos AB (1995): Assertive community treatment: an update of randomized trials. *Psychiatr Serv*, 46(7):669-675.
- Crawford MJ, de Jonge E, Freeman GK, Weaver T (2004): Providing continuity of care for people with severe mental illness- a narrative review. Soc Psychiatry Psychiatr Epidemiol, 39(4):265-272.
- 51. Killaspy H, Bebbington P, Blizard R, Johnson S, Nolan F, Pilling S, King M (2006): The REACT study: randomised evaluation of assertive community treatment in north London. *BMJ*, 332(7545):815-820.
- 52. Essock SM, Mueser KT, Drake RE, Covell NH, McHugo GJ, Frisman LK, Kontos NJ, Jackson CT, Townsend F, Swain K (2006): Comparison of ACT and standard case management for delivering integrated treatment for co-occurring disorders. *Psychiatr Serv*, 57(2):185-196.
- 53. Burns T, Catty J, Wright C (2006): Deconstructing home-based care for mental illness: can one identify the effective ingredients? *Acta Psychiatr Scand*, 113(s429):33-35.
- 54. Wright C, Catty J, Watt H, Burns T (2004): A systematic review of home treatment services-classification and sustainability. *Soc Psychiatry Psychiatr Epidemiol*, 39(10):789-796.
- 55. Burns T (1999): Methological problems of schizophrenia trials in community settings. In Manage or perish? The challenges of managed mental health care in Europe: Kluwer Academic/Plenum.

- 56. Burns T (2002): Exposure to case management: relationships to patient characteristics and outcome: Report from the UK700 trial. *Br J Psychiatry*, 181(3):236-241.
- 57. Hunkeler EM, Katon W, Tang L, Williams JW, Jr., Kroenke K, Lin EH, Harpole LH, Arean P, Levine S, Grypma LM, Hargreaves WA, Unutzer J (2006): Long term outcomes from the IMPACT randomised trial for depressed elderly patients in primary care. *BMJ*, 332(7536):259-263.
- 58. Klug G, Hermann G, Fuchs-Nieder B, Stipacek A, Zapotoczky HG (2008): Geriatric psychiatry home treatment (GHT): a pilot study on outcomes following hospital discharge for depressive and delusional patients. *Arch Gerontol Geriatr*, 47(1):109-120.
- 59. Torgerson DJ, Roland M (1998): What is Zelen's design? BMJ, 316(7131):606.
- 60. Bond GR, Drake RE, Mueser KT (2001): Assertive community treatment for people with severe mental illness: critical ingredients and impact on patients. *Dis Manage Health Outcomes*, 9(3):142-157.
- 61. McHugo GJ, Drake RE, Teague GB, Xie H (1999): Fidelity to assertive community treatment and client outcomes in the New Hampshire dual disorders study. *Psychiatr Serv*, 50(6):818-824.
- 62. Schaedle R, McGrew JH, Bond GR, Epstein I (2002): A comparison of experts' perspectives on assertive community treatment and intensive case management. *Psychiatr Serv*, 53(2):207-210.
- 63. Mulder CL, Kroon H (2005): Assertive Community Treatment (book in Dutch). Nijmegen: Cure & Care Publishers.
- 64. Burns A, Beevor A, Lelliott P, Wing J, Blakey A, Orrell M, Mulinga J, Hadden S (1999): Health of the Nation Outcome Scales for elderly people (HoNOS 65+). Br J Psychiatry, 174(5):424-427.
- 65. Staring T, Stobbe J, Mulder N (2003): Nederlandse vertaling van de HoNOS 65+ (Measurement instrument in Dutch). Dutch translation of the HoNOS 65+ scale.
- Reynolds T, Thornicroft G, Abas M, Woods B, Hoe J, Leese M, Orrell M (2000): Camberwell
 Assessment of Need for the Elderly (CANE). Development, validity and reliability. Br J
 Psychiatry. 176:444-452.
- 67. Drőes RM, Hout van HPJ, Ploeg van der ES (2004): Nederlandse versie Cameberwell Assessment of Need for the Elderly (Manual measurement instrument in Dutch). Dutch version of the Cameberwell Assessment of Need for the Elderly (CANE), revised version (IV).
- Priebe S, Huxley P, Knight S, Evans S (1999): Application and results of the Manchester Short Assessment of Quality of Life (MANSA). Int J Soc Psychiatry, 45(1):7-12.
- 69. Os van J, Delespaul AEG, Radstake DWS, Hilwig MM, Bak MLF, Driessen GAM (2001): Kernparameters ter evaluatie van een zorgprogramma voor psychotische patiënten (article in Dutch) Parameters in the assessment of a programme for psychotic patients. MGV, 56:952-966.
- Mulder CL, Staring ABP, Loos J, Buwalda VJA, Kuijpers D, Sytema S, Wierdsma AI (2004): De Health of the Nation Outcome Scales (HoNOS) als instrument voor 'routine outcome assessment (article in Dutch). The Health of the Nation Outcome Scales (HoNOS) in Dutch translation as an instrument for Routine Outcome Assessment *Tijdschr Psychiatr*, 46:273-284.
- 71. Broersma TW, Sytema S (2008): Implementatie van het meetinstrument HoNOS65+. Onderzoek op een afdeling voor ouderenpsychiatrie (article in Dutch) Implementation of the HoNOS65+. *Tijdschr Psychiatr*, 50(2):77-82.
- 72. Kroon H (1996): Groeiende zorg. Ontwikkelingen van casemanagement in de zorg voor chronisch psychiatrische patienten (thesis in Dutch). Growing care. Development of casemanagement among chronic psychiatric patients. NcGv-reeks, Utrecht.

- 73. Burns T, Creed F, Fahy T, Thompson S, Tyrer P, White I (1999): Intensive versus standard case management for severe psychotic illness: a randomised trial. UK 700 Group. Lancet, 353(9171):2185-2189.
- 74. Latimer EA (1999): Economic impacts of assertive community treatment: a review of the literature. Can J Psychiatry. 44(5):443-454.
- 75. Phillips ES, Barrio C, Brekke J (2001): The impact of ethnicity on prospective functional outcomes from community-based psychosocial rehabilitation for persons with schizophrenia. J Community Psychol, 29(6):657-673.
- 76. Drake RE, Goldman HH, Leff HS, Lehman AF, Dixon L, Mueser KT, Torrey WC (2001): Implementing evidence-based practices in routine mental health service settings. Psychiatr Serv, 52(2):179-182.
- 77. McGrew JH, Bond GR, Dietzen L, McKasson M, Miller LD (1995): A multisite study of client outcomes in assertive community treatment. Psychiatr Serv, 46(7):696-701.
- 78. Priebe S, Fakhoury W, White I, Watts J, Bebbington P, Billings J, Burns T, Johnson S, Muijen M, Ryrie I, Wright C, Pan-London Assertive Outreach Study G (2004): Characteristics of teams, staff and patients: associations with outcomes of patients in assertive outreach. Br J Psychiatry, 185:306-311.
- 79. Test M, Stein L (2001): A critique of the effectiveness of assertive community. Psychiatric Serv, 52:1396-1397.
- 80. Weaver T, Tyrer P, Ritchie J, Renton A (2003): Assessing the value of assertive outreach. Qualitative study of process and outcome generation in the UK700 trial. Br J Psychiatry, 183:437-445.
- 81. Teague GB, Bond GR, Drake RE (1998): Program fidelity in assertive community treatment: development and use of a measure. Am J Orthopsychiatry, 68(2):216-232.
- 82. Dijk van B, Mulder CL, Roosenschoon B (2004): Nederlandse handleiding voor de Dartmouth Assertive Community Treatment Scale (measurementscale in Dutch) Dutch manual of the Dartmouth Assertive Community Treatment Scale (DACTS). Rotterdam.
- 83. Salyers MP, Bond GR, Teague GB, Cox JF, Smith ME, Hicks ML, Koop JI (2003): Is it ACT yet? Real-world examples of evaluating the degree of implementation for assertive community treatment. J Behav Health Serv Res, 30(3):304-320.
- 84. Burns T (2009): End of the road for treatment-as-usual studies? Br J Psychiatry, 195(1):5-6.
- 85. Vugt van MD, Kroon H, Delespaul PA, Dreef FG, Nugter A, Roosenschoon BJ, Weeghel van J, Zoeteman JB, Mulder CL (2011): Assertive community treatment in the Netherlands: outcome and model fidelity. Can J Psychiatry, 56(3):154-160.
- 86. Vugt van MD, Kroon H, Delespaul PA, Mulder CL (2012): Consumer-providers in assertive community treatment programs: associations with client outcomes. Psychiatr Serv, 63(5):477-481.
- 87. Thornicroft G, Wykes T, Holloway F, Johnson S, Szmukler G (1998): From efficacy to effectiveness in community mental health services. PRiSM Psychosis Study. Br J Psychiatry, 173:423-427.
- 88. Rosen A, Killaspy H, Harvey C (2013): Specialisation and marginalisation: how the assertive community treatment debate affects individuals with complex mental health needs. Psych Bulletin, 37:345-348.
- 89. SAaMHSA: Assertive Community Treatment: Building Your Program. In. Edited by Services USDoHaH: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services; 2008.
- 90. Dixon L (2000): Assertive community treatment: twenty-five years of gold. Psychiatr Serv, 51(6):759-765.

- 91. Stobbe J, Mulder NC, Roosenschoon BJ, Depla M, Kroon H (2010): Assertive community treatment for elderly people with severe mental illness. Journal, 10:10.1186/1471-244X-10-84.
- 92. Aartsen MJ, Spitsbaard AK, van Baarsen C, Dhondt ADF, Mascini M, Nefs A, Snoeijers A, van Diest M, Wilting R (2010): Een multicenterstudie naar betrouwbaarheid, validiteit en gevoeligheid voor verandering van de HoNOS 65+ binnen de ouderenpsychiatrie (article in Dutch) A multi-centre study of the reliability, validity and sensitivity to change of the honos65+ in psychiatry for older persons. *Tijdschr Psychiatr*, 52:543-553.
- 93. Broersma TW, Sytema S (2010): De Health of the Nation Outcome Scales als effectmaat in de ouderenpsychiatrie (article in Dutch). The Health of the Nation Outcome Scales as clinical outcome indicator in elderly psychiatry. *Tijdschr Gerontol Geriatr*, 41(1):13-18.
- 94. Roest van der HG, Meiland FJ, van Hout HP, Jonker C, Droes RM (2008): Validity and reliability of the Dutch version of the Camberwell Assessment of Need for the Elderly in community-dwelling people with dementia. *Int Psychogeriatr*, 20(6):1273-1290.
- 95. Abraha I, Montedori A (2010): Modified intention to treat reporting in randomised controlled trials: systematic review. *BMJ*, 340:c2697.
- 96. Carpenter J, Luce A, Wooff D (2010): Predictors of outcomes of assertive outreach teams: a 3-year follow-up study in North East England. *Soc Psychiatry Psychiatr Epidemiol*, 46(6):463-471.
- 97. Commander M, Sashidharan S, Rana T, Ratnayake T (2005): North Birmingham assertive outreach evaluation. Patient characteristics and clinical outcomes. *Soc Psychiatry Psychiatr Epidemiol*, 40(12):988-993.
- 98. Burns T (2010): The rise and fall of assertive community treatment? *Int Rev Psychiatry*, 22(2):130-137.
- Catty J, Burns T, Knapp M, Watt H, Wright C, Henderson J, Healey A (2002): Home treatment for mental health problems: a systematic review. *Psychol Med*, 32(03):383-401.
- 100. Priebe S (2004): Characteristics of teams, staff and patients: associations with outcomes of patients in assertive outreach. *Br J Psychiatry*, 185(4):306-311.
- Killaspy H, Kingett S, Bebbington P, Blizard R, Johnson S, Nolan F, Pilling S, King M (2009): Randomised evaluation of assertive community treatment: 3-year outcomes. Br J Psychiatry, 195(1):81-82.
- 102. Veerbeek MA, Oude Voshaar RC, Pot AM (2013): Psychometric properties of the Dutch version of the Health of the Nation Outcome Scales for older adults (HoNOS 65+) in daily care. International journal of nursing studies, 50(12):1711-1719.
- 103. Cummings SM, Cassie KM (2008): Perceptions of biopsychosocial services needs among older adults with severe mental illness: met and unmet needs. Health & Soc Work, 33(2):133-143.
- 104. Perkins DO (2002): Predictors of noncompliance in patients with schizophrenia. *J Clin Psychiatry*, 63(12):1121-1128.
- 105. Nosé M, Barbui C, Tansella M (2003): How often do patients with psychosis fail to adhere to treatment programmes? A systematic review. *Psychol Med*, 33(7):1149-1160.
- 106. Sansone RA, Sansone LA (2008): Alcohol/Substance misuse and treatment nonadherence: fatal attraction. *Psychiatry*, 5(9):43-46.
- 107. Joska J, Flisher AJ (2005): The assessment of need for mental health services. *Soc Psychiatry Psychiatr Epidemiol*, 40(7):529-539.
- 108. Slade M, Leese M, Taylor R, Thornicroft G (1999): The association between needs and quality of life in an epidemiologically representative sample of people with psychosis. Acta Psychiatr Scand, 100(2):149-157.

- 110. Drukker M, van Dillen K, Bak M, Mengelers R, van Os J, Delespaul P (2008): The use of the Camberwell Assessment of Need in treatment: what unmet needs can be met? Soc Psychiatry Psychiatr Epidemiol, 43(5):410-417.
- 111. Broadbent E, Kydd R, Sanders D, Vanderpyl J (2008): Unmet needs and treatment seeking in high users of mental health services: role of illness perceptions. Aust N Z J Psychiatry, 42(2):147-153.
- 112. Prochaska JO, DiClemente CC (1983): Stages and processes of self-change of smoking: toward an integrative model of change. *J Consult Clin Psychol*, 51(3):390-395.
- 113. Corrigan PW, McCracken SG, Holmes EP (2001): Motivational interviews as goal assessment for persons with psychiatric disability. *Community Ment Health J*, 37:113-122.
- 114. Hosner DW, Lemeshow S (2000): Applied logistic regression. New York: John Wiley & Sons Inc.
- 115. Targum SD, Abbott JL (1999): Psychoses in the elderly: a spectrum of disorders. *J Clin Psychiatry*, 60 Suppl 8:4-10.
- 116. Futeran S, Draper BM (2011): An examination of the needs of older patients with chronic mental illness in public mental health services. *Aging Ment Health*:1-8.
- McCrone P, Leese M, Thornicroft G, Schene A, Knudsen HC, Vazquez-Barquero JL, Tansella M, Becker T (2001): A comparison of needs of patients with schizophrenia in five European countries: the EPSILON Study. *Acta Psychiatr Scand*, 103(5):370-379.
- 118. Houtjes W, van Meijel B, Deeg DJ, Beekman AT (2011): Unmet needs of outpatients with late-life depression; a comparison of patient, staff and carer perceptions. *J Affect Disord*, 134(1-3):242-248.
- 119. Meesters PD, Comijs HC, Droes RM, de Haan L, Smit JH, Eikelenboom P, Beekman AT, Stek ML (2012): The Care Needs of Elderly Patients With Schizophrenia Spectrum Disorders. Am J Geriatr Psychiatry.
- 120. Mueser KT, Bartels SJ, Santos M, Pratt S (2012): Integrated Illness Management and Recovery: A Program for Integrating Physical and Psychiatric Illness Self-Management in Older Persons with Severe Mental Illness. *Am J Psychiatric Rehabilitation*, 15:131-156.
- 121. Manthey TJ, Blajeski S, Monroe-DeVita M (2012): Motivational Interviewing and Assertive Community Treatment: A Case for Training ACT Teams. *International Journal of Psychosocial Rehabilitation*, 16:5-16.
- 122. Staring AB, Van der Gaag M, Koopmans GT, Selten JP, Van Beveren JM, Hengeveld MW, Loonen AJ, Mulder CL (2010): Treatment adherence therapy in people with psychotic disorders: randomised controlled trial. *Br J Psychiatry*, 197(6):448-455.
- 123. Stobbe J, Wierdsma Al, Kok RM, Kroon H, Roosenschoon BJ, Depla M, Mulder CL (2014): The effectiveness of assertive community treatment for elderly patients with severe mental illness: a randomized controlled trial. *BMC Psychiatry*, 14(1):42.
- 124. Stobbe J, Wierdsma Al, Kok RM, Kroon H, Depla M, Roosenschoon BJ, Mulder CL (2013): Lack of motivation for treatment associated with greater care needs and psychosocial problems. *Aging Ment Health*, 17(8):1052-1058.
- 125. Tsemberis S, Gulcur L, Nakae M (2004): Housing First, consumer choice, and harm reduction for homeless individuals with a dual diagnosis. *Am J Public Health*, 94(4):651-656.
- 126. Collins SE, Malone DK, Larimer ME (2012): Motivation to change and treatment attendance as predictors of alcohol-use outcomes among project-based Housing First residents. Addict Behav, 37(8):931-939.

- 127. Veerbeek M, Oude Voshaar R, Pot AM (2011): MEMO, Monitor Geestelijke Gezondheidszorg Ouderen, resultaten meetronde 2 (publication in Dutch). MEMO, Monitor Mental Health Care for the Elderly, results measurement 2. Utrecht: Trimbos-instituut.
- 128. O'Brien S, McFarland J, Kealy B, Pullela A, Saunders J, Cullen W, Meagher D (2012): A randomized-controlled trial of intensive case management emphasizing the recovery model among patients with severe and enduring mental illness. Ir J Med Sci, 181(3):301-308.
- Veerbeek M, Oude Voshaar R, Pot AM (2011): MEMO, Monitor Geestelijke 129. Gezondheidszorg Ouderen, resultaten meetronde 1 (publication in Dutch). MEMO, Monitor Mental Health Care for the Elderly, results measurement 1 Utrecht: Trimbos-instituut.
- 130. Neeleman J, Ormel J, Bijl RV (2001): The distribution of psychiatric and somatic III health: associations with personality and socioeconomic status. Psychosom Med, 63(2):239-247.
- 131. Lobo-Escolar A, Saz P, Marcos G, Quintanilla MA, Campayo A, Lobo A, Workgroup Z (2008): Somatic and psychiatric comorbidity in the general elderly population: results from the ZARADEMP Project. J Psychosom Res, 65(4):347-355.
- Mueser KT, Corrigan PW, Hilton DW, Tanzman B, Schaub A, Gingerich S, Essock SM, Tarrier 132. N, Morey B, Vogel-Scibilia S, Herz MI (2002): Illness management and recovery: a review of the research. Psychiatr Serv, 53(10):1272-1284.
- 133. Slade M, Beck A, Bindman J, Thornicroft G, Wright S (1999): Routine clinical outcome measures for patients with severe mental illness: CANSAS and HoNOS. Br J Psychiatry, 174:404-408.
- 134. Wing JK, Beevor AS, Curtis RH, Park SB, Hadden S, Burns A (1998): Health of the Nation Outcome Scales (HoNOS). Research and development. Br J Psychiatry, 172:11-18.
- 135. Turner S (2004): Are the Health of the Nation Outcome Scales (HoNOS) useful for measuring outcomes in older people's mental health services? Aging Ment Health, 8(5):387-396.
- 136. Berry K, Barrowclough C (2009): The needs of older adults with schizophrenia: implications for psychological interventions. Clin Psychol Rev, 29(1):68-76.
- Orimo H, Ito H, Suzuki T, Araki A, Hosoi T, Sawabe M (2006): Reviewing the definition of 137. "elderly". Geriatr Gerontol Int, 6(3):149-158.
- 138. Colenda CC, Mickus MA, Marcus SC, Tanielian TL, Pincus HA (2002): Comparison of adult and geriatric psychiatric practice patterns: findings from the American Psychiatric Association's Practice Research Network. Am J Geriatr Psychiatry, 10(5):609-617.
- Dickerson FB, Pater A, Origoni AE (2002): Health behaviors and health status of older 139. women with schizophrenia. Psychiatr Serv, 53(7):882-884.
- 140. Burns T, Catty J (2002): Assertive community treatment in the UK. Psychiatr Serv, 53(5):630-631.
- 141. Priebe S (2003): Assertive outreach teams in London: patient characteristics and outcomes: Pan-London Assertive Outreach Study, Part 3. The British Journal of Psychiatry, 183(2):148-154.
- 142. Wright C, Burns T, James P, Billings J, Johnson S, Muijen M, Priebe S, Ryrie I, Watts J, White I (2003): Assertive outreach teams in London: models of operation. Pan-London Assertive Outreach Study, part 1. Br J Psychiatry, 183:132-138.
- 143. Firn M, Hindhaugh K, Hubbeling D, Davies G, Jones B, White SJ (2013): A dismantling study of assertive outreach services: comparing activity and outcomes following replacement with the FACT model. Soc Psychiatry Psychiatr Epidemiol, 48(6):997-1003.
- Veldhuizen van R, Bahler M, Polhuis D, Os van J (2008): Handboek FACT. Utrecht: De 144. Tijdstroom.
- 145. Kortrijk HE (2013): Use of Routine Outcome Monitoring data for evaluation Assertive Community Treatment. Rotterdam: Erasmus University.

146. Wright N, Callaghan P, Bartlett P (2011): Mental health service users' and practitioners' experiences of engagement in assertive outreach: a qualitative study. *J Psychiatr Ment Health Nurs*, 18(9):822-832.

Wir de golven fan de Noardsee rôlj' op strân
Wir de butterblommen bloei' yn't griene lân
Nei de toer, de haven en de ôde dyk,
Nei de helmedune en de koechelwieck
Wir de kôbben krite boppen see en strân
Hear ik tuus for altyd, leit mijn Schylgerlân

(Tiny van Noord-Bos)



