Care needs of children and adolescents in psychiatry: steps towards personalized mental healthcare

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CARE NEEDS OF CHILDREN AND ADOLESCENTS IN PSYCHIATRY

steps towards personalized mental healthcare

Richard J.W. Vijverberg

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Care needs of children and adolescents in psychiatry: steps towards personalized mental healthcare

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Contents

CHAPTER 1

General introduction

Mitchell is a 13-year old boy with an above-average intelligence who, because of anxiety, has refused to go to school during the last four months. The past few weeks he has been feeling depressed. He has shifted his sleep onset time by 7 hours compared with conventional times (10–11 pm), and only leaves his bedroom during the night to eat. Mitchell's parents are desperate because they are unable to influence his behavior. They are convinced that he needs psychiatric treatment. Although Mitchell does not agree, his parents ask their general practitioner to refer him to mental healthcare. The general practitioner agrees with the parents' request and decides to refer Mitchell to an outpatient mental healthcare clinic.

Despite several attempts by the parents to motivate their son, Mitchell refuses to attend the intake appointment at the outpatient clinic. He is afraid that the mental healthcare provider will put pressure on him to go back to school. This is not an option for him, because he is afraid that teachers and classmates will ask him about the reasons for his absence. Mitchell is ashamed about his anxious and avoidant behavior. Based on information provided by the parents, the care provider at the outpatient clinic judges that psychiatric treatment is needed. However, as Mitchell is not willing to visit the outpatient clinic, the mental healthcare provider decides to refer Mitchell to a youth assertive community treatment (Youth ACT) team. The first assessment, conducted by a mental healthcare provider of the Youth ACT team, is conducted at Mitchell's home. At the beginning of the intake appointment, Mitchell refuses to leave his bedroom. He doesn't want to come to the living room to meet the healthcare provider and discuss his problems. In agreement with his parents, the care provider visits Mitchell in his bedroom, in the presence of his mother. Mitchell is hiding underneath his blanket. The mental healthcare provider introduces himself in a calm way and shows interest in Mitchell's 3-D printer. After a few minutes, Mitchell emerges. After some small talk with the care provider, Mitchell is willing to come to the living room. It seems that some trust has been gained. Once in the living room, Mitchell talks about the problems he has experienced at school. Since the start of the first year of secondary school, he has become increasingly anxious to go to school and in the end decided to stay at home. Mitchell states that he doesn't want treatment because he is convinced that the primary goal of such treatment is to get him back to school. The care provider asks Mitchell how he feels about the current situation. Mitchell says he's disappointed in himself. He thinks he has failed and does not meet his parents' expectations. The care provider asks whether Mitchell is willing to have a few conversations at home to obtain a better understanding of his current situation and his fears. Mitchell agrees to participate in these exploratory conversations.

Case vignette[1]

[1] The case vignette Mitchell is a hybrid case with a fictive name, based on multiple patients.

The vignette describes a disturbing situation in which the development of an adolescent comes to a complete standstill. Mitchell's anxiety and depressive emotions make him feel confused, and he suffers from not being able to cope with the problems. From Mitchell's point of view, school dropout and social dysfunction are due to his personal failure. The parents feel pedagogically incapable of changing their son's situation, which makes them feel desperate. At the request of his parents, Mitchell is referred to an outpatient clinic to receive mental healthcare. However, Mitchell is not willing to accept such treatment. He is too afraid that a care provider will insist that he goes back to school. While recognizing Mitchell's need for mental healthcare, the mental healthcare provider is also aware that Mitchell is difficult to reach through office-based outpatient care. Therefore, the care provider seeks a personalized solution, and decides to refer Mitchell to a more intensive form of psychiatric treatment: youth assertive community treatment (Youth ACT). Youth ACT is a low-threshold treatment modality, where patients are actively approached in their own environment, and efforts are undertaken to strengthen the patient's motivation for treatment [1, 2]. The assumption is that ACT may help to reduce severity of psychiatric symptoms, improve general functioning, and prevent psychiatric hospital admissions [3].

Introduction

During my work, first as a social worker and mental health nurse, later as a clinical nurse specialist and cognitive behavioral therapist, I frequently encountered children and adolescents whose psychiatric treatment – which was carried out according to relevant clinical guidelines – was ineffective. Not infrequently, I noticed that mental healthcare providers (including myself) felt helpless or uncomfortable because of high rates of non-compliance and drop-out of treatment. Children or adolescents seemed, at times, to have a completely different view from their parents and/or care providers regarding care they needed. This evoked the feeling, among my colleagues and myself, that these children or adolescents were difficult to reach and treat. The helplessness I felt stimulated me to contemplate whether the often one-sided focus on classification of DSM-diagnoses and evidence-based treatments may have resulted in disregard of care needs experienced by patients themselves [4-6]. My assumption was that high levels of non-adherence to treatment, or early termination of treatment may be (partly) explained by limited attention to patient's (unmet) needs for care [7].

In the past decades numerous studies have been published on childhood psychiatric disorders. Most of these studies focus on prevalence, diagnosis, aetiology, and treatment of psychiatric disorders. In the literature, the attention to children's or adolescents' preferences and experiences in different areas of functioning occupy an unduly small space [8].

This dissertation focuses on the (unmet) mental healthcare needs of children and adolescents who are receiving either office-based outpatient care or assertive outreach treatment (Youth ACT). In our studies, we include the perspectives of the children/adolescents themselves, their parents, and mental healthcare providers.
This general introduction provides an overview of the study design and outline of the studies that are part of this dissertation. Before elaborating on these studies, a brief description is provided on the epidemiology of childhood psychiatric disorders. Next, background information is provided about the pathways through child and adolescent mental healthcare. Finally, before presenting the different studies of this thesis, we take a closer look at the concept of 'care needs'.

Epidemiology of psychiatric disorders in children and adolescents

Children and adolescents constitute almost a third (2.2 billion individuals) of world's population [9]. It is estimated that, at any moment, ten to twenty percent of these children and adolescents suffer from psychiatric disorders [10-12]. There is a growing awareness that childhood onset psychiatric disorders are a major public health concern [13]. Psychiatric disorders during childhood account for a considerable proportion of the global burden of disease, and are the leading cause of disability in young people [14]. Suicide is the second leading cause of death in adolescence worldwide [15]. The most common psychiatric disorders are anxiety disorders (7%), behavioral disorders (6%), attention deficit and hyperactivity disorders (5%), mood disorders (3%), and autism spectrum disorders (1%) [12, 16, 17].
Psychiatric disorders among children and adolescents are associated with lower educational achievements, unhealthier lifestyle (e.g. more smoking and obesity), lower quality of peer relations, and crime [18]. It is estimated that over half of all psychiatric disorders in adults begin by the age of fourteen [19]. If not properly treated, childhood onset psychiatric disorders often persist during adulthood, and may also have a negative impact on future well-being and life satisfaction [12, 16, 18].

Organization and pathways through child and adolescent mental healthcare

Organization of child and adolescent psychiatry

Over the past decades, in many Western countries, a large number of changes have taken place in the organization of mental healthcare for children and adolescents [13,

20, 21]. The trends towards de-institutionalization, social inclusion movements, de-medicalization, and evidence-based practice, but also changing legislation and financing systems, have had a major impact on children and adolescent psychiatry [22-24]. At present, many Western countries have developed or initiated policies to reform mental healthcare towards community-based care [25]. Changes are found in the development of outpatient services in the community, day treatment services, community mental health centers, use of (blended) E-health, and assertive outreach services [25, 26].
At present, mental healthcare for children and adolescents includes a wide variety of services. Referring children or adolescents to the right mental health services at the right time can be challenging. To achieve the best possible treatment outcomes at reasonable costs, there are selection points integrated in the mental healthcare system (see Fig 1. [27]). These selection points function as "filters" to prevent children/adolescents from receiving a too low intensity of healthcare, but also to avoid unnecessary referrals to costly intensive treatment services (e.g. Youth ACT or inpatient care) [28].

Pathways through care in the Netherlands

In the Dutch health care system, when a psychiatric disorder is diagnosed or assumed, children and adolescents can be referred to mental healthcare by a general practitioner or municipal youth care team (see Fig 1) [29, 30]. Depending on the severity and complexity of problems, it is determined whether basic or specialized mental healthcare is appropriate, and which specific form of treatment should be provided. Most of the children and adolescents with mental health problems are referred to office-based outpatient clinics that provide evidence-based care through regular appointments [29, 30].
In clinical practice it is common to start with a relatively low intensity of mental healthcare, usually office-based outpatient mental healthcare. If mental health problems persist or deteriorate, a referral to a more intensive form of mental healthcare can be considered.
For those outpatients with severe mental health problems who are "difficult to reach", mental healthcare providers seek tailored solutions to meet the patients' needs for care, e.g. by referring them to Youth ACT [7].
Figure 1 shows the referral process within the mental healthcare system. It is possible that in this process of referral to appropriate treatment, a situation may arise in which the psychiatric treatment provided does not, or insufficiently meets the care needs of the child or adolescent patient. Such a mismatch between patient's care needs and treatment provided or proposed may hinder efficient and effective collaboration between care providers and patients [31]. The current high levels of non-compliance to treatment, non-attendance of appointments, and drop-outs in child and adolescent

psychiatry may be (partly) due to mismatches between patients' need for care and the treatment they receive [32]. Therefore, more systematic attention to patients' care needs may lead to more personalized care, improve the quality of mental healthcare provided, and ultimately lead to better treatment outcomes.
In this dissertation, we focus on children and adolescents who, within specialized mental healthcare, receive either office- based outpatient care, or Youth ACT.

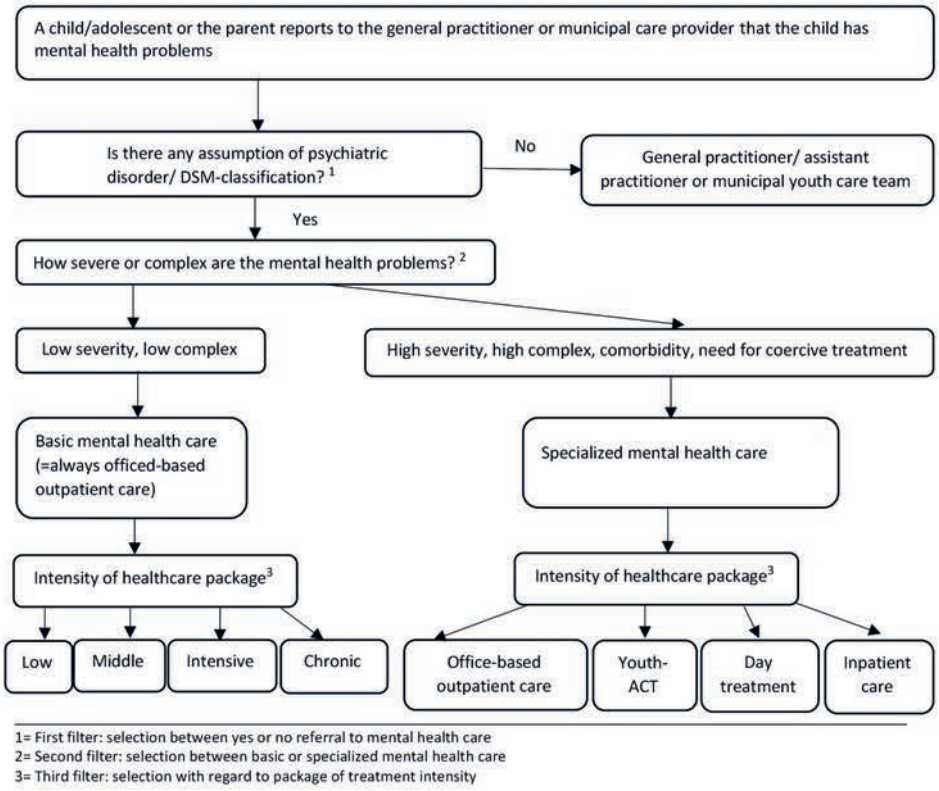

Figure 1. Organization of mental health care in the Netherlands

Care needs

The concept of "care need"

In this thesis "care need" is defined as a physical, psychological, social or environmental demand for aid, care or service intended to resolve a problem [33].

A need for care may therefore be considered as something that emerges as a consequence of a problem experienced by the patient [34]. Care needs can be subdivided into (1) met needs, i.e., difficulties in a particular domain of functioning that are adequately taken care of; and (2) unmet needs, i.e., those for which a patient is not receiving the right care or the appropriate level of care [35].

According to Bradshaw (1972), to better understand the patient's care needs, it is important to approach "care needs" from different perspectives [33]. Each perspective contributes information, and no perception is sufficient on its own [36]. The framework of Bradshaw distinguishes four conceptual approaches of care needs. The first approach concerns "felt care needs", referring to the patient's self-perceived need for treatment to resolve a problem [33]. Of course, this perspective is highly relevant as it concerns information about perspectives of patients themselves. However, providing psychiatric treatment only based on "felt needs" could be risky, given that patients may formulate their needs for treatment based on limited knowledge or a limited perspective on their mental health problems [37]. The second approach concerns "expressed care needs"; these needs are expressed by patients' use of (mental healthcare) services, or because they are on a waiting list. Expressed needs for care relate to "felt care needs" that have been turned into action.

The third approach comprises "normative care needs". Normative care needs are the patients' needs for care identified by care providers based on their professional opinion [38]. Diagnostic assessments can be used to systematically determine normative care needs. The fourth approach concerns "comparative care needs", defined as care needs of a group of individuals who are receiving (mental healthcare) services, compared to a group people of individuals with similar characteristics who are not receiving such (mental healthcare) services. The group who receives no services is considered to be "in need of care".

Bradshaw's framework illustrates that care needs can be viewed from different perspectives. It is possible that "normative care needs", do not match with the "felt care needs". If "normative care needs" identified by the care provider do not match the "felt care needs" of the patient, this may hinder efficient and effective collaboration between care providers and patients.

Care needs in child and adolescent psychiatry

There is a link between different perspectives of patients' care needs and treatment trajectories that are chosen [39]. Treatment trajectories usually start with an intake assessment during which children/adolescents and their parents are asked about the reasons for referral [40]. Next, to choose the right treatment, care providers carry out a diagnostic assessment by systematically examining the mental health problems of the patient and classifying them into DSM or ICD diagnoses [5]. Once the assessment phase is completed, children/adolescents and their parents are informed about the diagnosis and treatment options, treatment goals and specific interventions that can be delivered [41]. A drawback of this approach is that DSM/ICD diagnoses do not provide information about the care needs of individual patients [31, 39]. Another drawback is that there is no designated space in the diagnostic process to examine the patient's "felt care needs" in different areas of functioning [39]. It is clear that diagnostic processes in which there is a lack of systematic attention for the broad range of possible care needs of patients from different perspectives may result in limited understanding of existing care needs. If these care needs of patients are insufficiently understood, it is possible that treatment suggested by care providers may not match with the (unmet) care needs as perceived by the patient him- or herself.

Such a mismatch between relevant care needs and treatment provided may also negatively influence the quality of the working relationship between care providers and patients [31]. If the quality of the working relationship is poor, then it is difficult to agree on treatment goals or the treatment pathway towards achieving these goals. As a result, mental health problems may increase and functioning may deteriorate, ultimately leading to referral to a more intensive form of care [42-44].

The information about care needs presented in this paragraph shows that attention to care needs is very important. However, the current knowledge base of care needs of patients in child and adolescent psychiatry is small. There is little or no research on the extent to which children and adolescents agree or disagree with care providers on the broad range of met and unmet care needs. It is also unknown what effect the severity of psychiatric and psychosocial problems has on the care needs of patients treated in child and adolescent psychiatry. Comparison of a general outpatient settings and settings that provide a more intensive form of treatment (e.g. Youth ACT) would enable us to assess the effect of severity of psychiatric and psychosocial problems on care needs. More knowledge about the (different perspectives on) care needs of patients in child and adolescent psychiatry is important to improve treatment. Such knowledge may contribute to more personalized care in which patients may better identify themselves with the treatment provided [35]. It may help patients feel more engaged with treatment and hopefully prevent the non-adherence to treatment and drop-out [45].

Study objectives and research questions

This general introduction started with a case vignette about Mitchell. He is an example of a vulnerable adolescent with severe psychiatric problems who was referred to Youth ACT. Currently, there is little scientific literature available regarding the vulnerable population of children and adolescents with severe psychiatric problems who are receiving ACT. Who are these patients, and how effective is ACT treatment? These are the first two research questions we want to answer in this thesis.
Next, this dissertation will focus on care needs of patients in child and adolescent psychiatry. In my work as a clinical nurse specialist and cognitive behavioral therapist, I experienced that children and adolescents viewed the care they needed, at times, completely different than their parents and/or care providers. To obtain a better understanding of the care needs of patients in child and adolescent psychiatry, including possible different perspectives compared with their healthcare providers, I searched for relevant scientific literature. However, literature on this subject is scarce. It is unknown if the care needs of outpatients differ from those who are referred from outpatient care to a more intense form of treatment in the form of Youth ACT. It is also unknown to what extend the care needs felt by patients in child and adolescent psychiatry discord with the care needs viewed by their mental healthcare providers, and, if present, how such discordance may be understood. Therefore, this dissertation includes five research questions that focus on the patient's (unmet) care needs, including the perspectives of both patients and their mental healthcare providers.

The five main research questions that were addressed during the course of this thesis were:

1. What is the effect of Youth ACT treatment on: severity of psychiatric symptoms, general functioning, and psychiatric hospital admissions? **(Chapter 2)**
2. Which child, parent and family/social context factors are associated with treatment intensification from regular outpatient care to Youth ACT? **(Chapter 3)**
3. What are the unmet care needs of children and adolescents with ADHD, who are being treated in outpatient and Youth ACT settings? We chose to investigate the care needs of patients with ADHD, because this subpopulation is often referred to outpatient clinics. It is also the subpopulation whose treatment is frequently intensified from general outpatient care to Youth ACT treatment. **(Chapter 4)**
4. What are the perceptions of patients and mental healthcare providers regarding the unmet care needs of patients who are being treated in outpatient and Youth ACT settings? **(Chapter 5)**
5. Which factors are associated with the differences in perceptions between patients and providers who are being treated in outpatient and Youth ACT settings? **(Chapter 6)**

Outline

In **Chapter 2** of this thesis, we will describe the design and results of a systematic PRISMA review on Youth ACT. In this review, the results of the existing studies are summarized with respect to the effects of Youth ACT on severity of psychiatric symptoms, general functioning, and frequency and duration of psychiatric hospital admissions. In **Chapter 3**, we will describe a cross-sectional study that investigated the patient, family and contextual variables that are associated with treatment intensification from regular outpatient care to Youth ACT. In **Chapter 4**, we will zoom in on the unmet care needs in children and adolescents with ADHD, in general outpatient clinics compared with those receiving Youth ACT. In **Chapter 5**, we will examine the extent to which children and adolescents agree or disagree with care providers on the broad range of met and unmet care needs. In **Chapter 6**, we describe the factors that are associated with concordance on needs for care between patients and mental healthcare providers in child and adolescent psychiatry. Finally, **Chapter 7** provides a summary and a general discussion in which the main findings, methodological issues, and the implications for clinical practice and research are discussed.

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CHAPTER 2

The effect of youth assertive community treatment: A systematic prisma review

Published in bmc psychiatry 2017; 10: 284

Richard J.W. Vijverberg | Robert F. Ferdinand | Aartjan T.F. Beekman
Berno K.G. van Meijel

Abstract

Background

During the past decades deinstitutionalisation policies have led to a transition from inpatient towards community mental healthcare. Many European countries implement Assertive Community Treatment (ACT) as an alternative for inpatient care for "difficult to reach" children and adolescents with severe mental illness. ACT is a well-organized low-threshold treatment modality; patients are actively approached in their own environment, and efforts are undertaken to strengthen the patient's motivation for treatment. The assumption is that ACT may help to avoid psychiatric hospital admissions, enhance cost-effectiveness, stimulate social participation and support, and reduce stigma.

ACT has been extensively investigated in adults with severe mental illness and various reviews support its effectiveness in this patient group. However, to date there is no review available regarding the effectiveness of Youth ACT. It is unknown whether Youth ACT is as effective as it is in adults. This review aims to assess the effects of Youth ACT on severity of psychiatric symptoms, general functioning, and psychiatric hospital admissions.

Method

A systematic literature search was conducted in PubMed, Cochrane Library, PsychINFO and CINAHL published up to March 2017. To assess methodological quality of the included studies, the Oxford Centre of Evidence-Based Medicine grading system was used.

Results

Thirteen studies were included in this review. There are indications that Youth ACT is effective in reducing severity of psychiatric symptoms, improving general functioning, and reducing duration and frequency of psychiatric hospital admissions.

Conclusions

The current literature on Youth ACT is limited but promising. There are indications that Youth ACT is effective in reducing severity of psychiatric symptoms, improving general functioning, and reducing duration and frequency of psychiatric hospital admissions. The effect of Youth ACT may be comparable with the effect of ACT in adults. Similar as in adult ACT, the studies on Youth ACT found effects that vary from small to large. Randomized experimental research designs are needed to further corroborate effectiveness.

Introduction

In many countries, over the past decades, a transition has taken place from inpatient to community mental healthcare for individuals with a severe mental illness. Assertive Community Treatment (ACT) can be considered the result of this transition [1-3].

ACT [4], the most thoroughly studied type of psychiatric case management in adults [5], is characterized by 9 core elements [6-8]: (a) home-based treatment (obligatory), (b) small caseload (size<10), (c) patients difficult to reach, (d) transition (from clinic to home) case management, (e) early intervention, (f) psychiatric assessment in the community, (g) family support, (h) reintegration/vocational and educational therapy, (i) pharmacology. ACT teams share responsibility for patients. ACT is characterized by an active team approach which focusses on establishing a solid therapeutic alliance between patients, their relatives, and professionals. Also, efforts are undertaken to strengthen a patient's motivation for treatment and care [9].

The World Health Organization (WHO) Europe has declared assertive outreach care a necessary alternative for inpatient care. This is because treatment focuses on strengthening the patient's autonomy by enhancing skills and coping, but also by collaboration with relatives and the broader social network. Even during inpatient treatment, the ACT case manager remains involved, which enhances continuity of care [10]. In Europe, 22 out of 42 countries have policies and/or legislation requiring that individuals with severe mental disorders have access to Assertive Community Treatment or assertive outreach related services [10].

Compared to adults, children and adolescents with severe mental illness are at higher risk of being hospitalized [11-14]. Severe mental illness can be defined as a mental, behavioral, or emotional disorder, that meets the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria, and which results in serious functional impairment substantially interfering with major life activities [15]. The National Institute for health and Care Excellence (NICE) recommends assertive outreach services for children and adolescents with several severe mental illnesses (see guidelines "Psychosis and schizophrenia in children and young people" [14] and "Bipolar disorder, in adults, children and young people in primary and secondary care" [16]). Horatio, the European Association for Psychiatric Nurses [17], and the Executive Agency for Health and Consumers [18] also recommend ACT services for youths.

Because the implementation of Youth ACT is increasing, it is crucial to evaluate its benefits. ACT has been extensively investigated in adults and various reviews have published positive effects on reducing psychiatric symptoms, improving general functioning and reducing hospitalizations [19-30]. However, to date a systematic review regarding the effectiveness of Youth ACT is not available. It is unknown whether Youth ACT is effective as it is in adults [31].

The aim of the current review is to assess the effects of Youth ACT in three areas: severity of psychiatric symptoms, general functioning, and frequency and duration of psychiatric hospital admissions, since ACT has been primarily developed to positively influence these three outcomes [4].

Method

A systematic literature review in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines [32] was conducted between August 2016 and March 2017.

Inclusion criteria

This review included English language papers that focus on patients (a) between 6 to 18 years, (b) who suffer from severe mental illness (mood disorders, behavior disorders, psychotic disorders, and/or substance use disorders), and (c) who are poorly engaged with community mental health services. A treatment program was considered as Youth ACT if it contained at least 6 out of 9 core elements [6-8] and provided information about at least one of the following three possible outcomes of Youth ACT: (i) severity of psychiatric symptoms - defined as the severity of emotional problems, behavior problems, psychotic symptoms, or addiction problems [33]; (ii) general functioning - defined in the included manuscripts as general functioning, or level of school attendance, functioning in interpersonal relations and pro-social activities [34]. These constructs are important factors in general functioning and are crucial for the development of the child [35]; (iii) psychiatric hospital admission - defined as referral to a psychiatric inpatient health care facility where psychiatric patients reside overnight [36].

Assessment instruments

Psychiatric symptoms, general functioning, and frequency and duration of psychiatric hospital admissions can be measured from different perspectives [37]. Assessment instruments were classified as follows: clinician-based instruments (clinical judgements by caregivers), client-based instruments (based on opinion of patients or parents), or biometric instruments (measuring biophysical values).

Literature search

A systematic literature search was conducted in PubMed, Cochrane Library, PsychINFO and CINAHL, in close collaboration with an experienced librarian. In March 2017, the following search string was applied in PubMed:

((Assertive Community Treatment[Title/Abstract] OR Assertive outreach[Title/Abstract] OR ("Community Mental Health Services"[Mesh]) AND (Act OR assertive OR outreach*[Title/Abstract]))) AND ((("Child"[Mesh] OR child*[tiab] OR "Minors"[Mesh] OR "minors"[tiab] OR "Puberty"[Mesh] OR "puberty"[tiab] OR "Pediatrics"[Mesh] OR paediatric*[tiab] OR pediatric*[tiab] OR "Adolescent"[Mesh] OR adolescen*[tiab] OR preschool*[tiab] OR "teenager"[tiab] OR "teenagers"[tiab] OR "teen"[tiab] OR "teens"[tiab] OR youth*[tiab] OR "girlhood"[tiab] OR "girl"[tiab] OR "girls"[tiab] OR "boyhood"[tiab] OR "boy"[tiab] OR "boys"[tiab] OR "school age"[tiab] OR "school-aged"[tiab] OR schoolchild*[tiab] OR "kid"[tiab] OR "kids"[tiab] OR underage*[tiab] OR juvenile*[tiab])))

The full search strategies of the other databases are available in an Additional file.

Selection procedure

Figure 1 shows the selection procedure. English language papers focusing on the effectiveness of Youth ACT, without restrictions concerning research design, were considered for inclusion. After removal of duplicates, papers were independently screened by title and abstract by two authors (RV, RF). To verify papers selected, reference lists of included papers were checked for relevant publications. Disagreements between the reviewers were resolved through discussion. This occurred in 6% of the abstracts. All disagreements related to the decision whether the inclusion criteria were applicable. For example, the abstract did not mention the age category of the included patients. In these cases, the full text of a manuscript was read by RV, after which follow-up discussion took place with RF, until consensus was reached. Papers providing information on the effects of Youth ACT on severity of psychiatric symptoms, general functioning, or frequency and duration of psychiatric hospital admissions were included.

Data extraction

Data extraction was conducted by the first author (RV), and checked by the second author (RF). Data were extracted using a form containing the following items: author, country of origin, study design, inclusion/exclusion criteria, aim, time-period in which the study was conducted, setting of the study, patient characteristics, sample size, content of the ACT-program, duration or frequency of interventions, assessment instruments, outcomes, and conclusions. As a result, an overview was created that facilitated comparison of study designs and results.

Quality appraisal

The Oxford Centre of Evidence-Based Medicine grading system was used to assess methodological quality of the individual studies by a standardized approach [38]. The quality of studies was assessed to determine the strength of the scientific evidence of the outcomes of the different studies. The Oxford Centre of Evidence Based Medicine grading system was used because it is a widely adopted systematic hierarchy of the quality of medical research evidence. Quality was classified according to the level of evidence [38]. Studies were classified as follows. High level of evidence: 1a (=systematic review of randomized controlled trials (RCTs)), 1b (=individual RCT), 1c (=all or none RCT). Moderate level of evidence: 2a (=systematic review of cohort studies), 2b (=cohort study or low quality RCT), 2c (=outcome research or ecological studies), 3a (=systematic review of case-control studies), 3b (=case-control study). Low level of evidence: 4 (=case series). Very low level of evidence: 5 (=expert opinion) (table 1).

Clinical relevance

Although a study can be classified with a high level of evidence, statistically significant effects can still be small, and thereby in many cases of little clinical relevance [39]. To assess clinical relevance, effect sizes (ES) of significant effects were retrieved from the papers as Cohen's d. If not reported in a paper, Cohen's d was calculated by the first author (RV) if data for this calculation were provided in the manuscript [40-43].
Effect sizes were categorized as small (≥ 0.2-0.5); medium (> 0.5-0.8); or large (> 0.8) [44].

Strength of recommendation

The Oxford Centre of Evidence-Based Medicine grading system [38] was used to obtain an overall measure for the strength of a recommendation [45]. Overall conclusions with a high strength of recommendation are of more importance than those with a lower strength. The strength of a recommendation was considered high (grade A) if all studies with respect to a subject were classified with a level of evidence category 1a, 1b or 1c (categories are explained in section Quality Appraisal). The strength of a recommendation was considered moderate (grade B) if studies were classified as level of evidence category 2a, 2b, 2c, 3a or 3b. The strength of a recommendation was considered low (grade C) if studies were classified in category 4 with respect to level of evidence, and very low (grade D) in case of category 5 studies [38].

Results

The initial search strategy yielded 305 papers (figure 1). One hundred and twenty-six papers were selected based on title and abstract. After careful review, eleven studies met the inclusion criteria. Two additional studies were identified following the checking of reference lists of these eleven studies. In total thirteen studies were selected for inclusion.

All selected papers contained at least six of the nine core elements of regular ACT and are presented in table 1. Conducting a meta-analysis was not possible because of the limited number of studies and the variety of outcome variables. Therefore, the results are presented narratively.

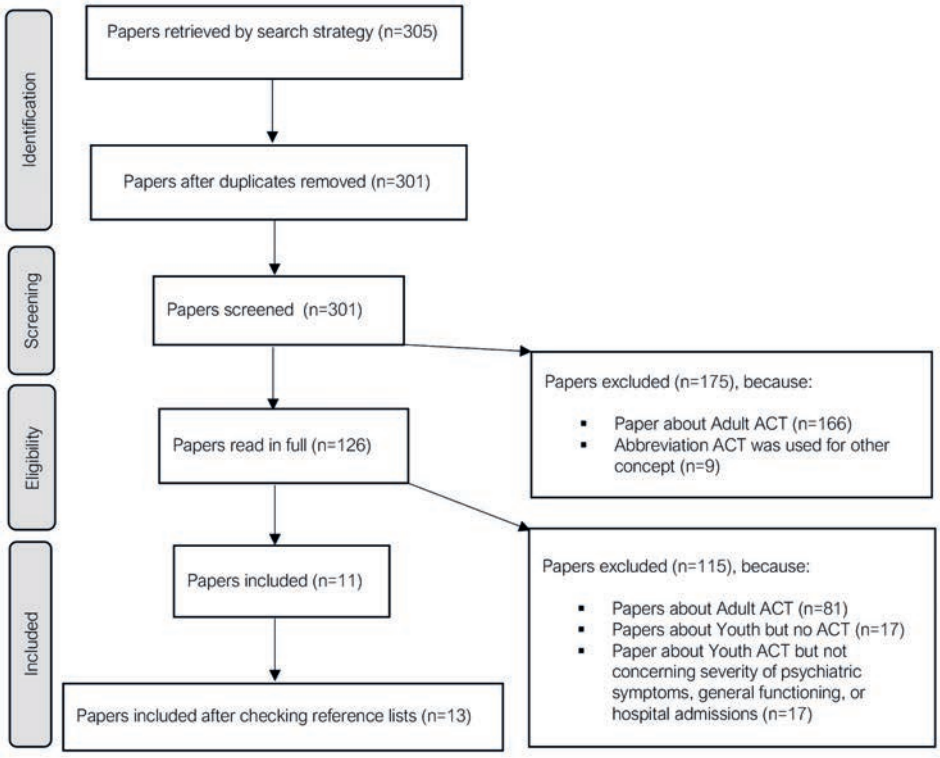

Figure 1. Flowchart of the studies included

Table 1. Overview included studies

Reference	Study design (time-frame)	Core elements of Youth ACT		Problems treated
Adrian & Smith (2014) GBR [47]	Pre-post test (2001-2011)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy[5]: Pharmacology:	Yes NR[4] Yes Yes Yes Yes Yes Yes Yes	Serious mental illness in crisis, admission is considered
Ahrens et al. (2007) USA [48]	Pre-post test (1998-2000)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy[5]: Pharmacology:	Yes NR[4] Yes Yes Yes Yes Yes Yes Yes	Long-term mental healthcare needs in transition to adulthood
Baier et al. (2013) CHE [6]	Pre-post test (2009-2010)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes Yes Yes Yes Yes Yes Yes Yes Yes	Psychiatric symptoms and avoiding outpatient care
Chai et al. (2012) AUS [49]	Pre-post test (2006-2008)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes Yes Yes Yes Yes NR Yes Yes Yes	Psychiatric symptoms and avoiding outpatient care

	N	Age	(years)	Gender	(%)	Ethnic group	(%)	Team staff	Level of evidence
	287	Range: Mean:	12-17 16	Boys: Girls:	38 62	White: Black: Asian: Other:	73 13 4 10	Psychiatrist Nurse practitioner Psychologist Support worker Administrator	2b[3]
	15	Range: Mean:	15-20 17	Boys: Girls:	80 20	White: Black:	80 20	Interdisciplinary (not specified)	2b[3]
	35	Range: Mean:	13-18 16	Boys: Girls:	43 57	NR[4]		Child psychiatrist Social workers Nurses	2b[3]
	59	Range: Mean:	11-17 15	Boys: Girls:	32 68	NR		Psychiatrist Social workers “Clinicians”	2b

Table 1. Continued

Reference	Study design (time-frame)	Core elements of Youth ACT		Problems treated
Godley et al. (2002) USA [50]	RCT (1999-2001)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes Yes Yes Yes Yes Yes Yes Yes NR	Alcohol/ drugs dependence or abuse
Godley et al. (2006) USA [51]	RCT (1999-2003)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes Yes Yes Yes Yes Yes Yes Yes NR	Alcohol/ drugs dependence or abuse
Godley et al. (2010) USA [52]	RCT (2002-2007)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes No Yes Yes Yes Yes Yes Yes NR	Alcohol /drugs dependence or abuse
Godley et al. (2015) USA [53]	RCT (2004-2008)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes NR Yes Yes Yes Yes Yes Yes NR	Alcohol/ drugs dependence or abuse

N	Age	(years)	Gender	(%)	Ethnic group	(%)	Team staff	Level of evidence
114	Range: Mean:	12-17 16	Boys: Girls:	80 20	White: Black: Other:	74 17 9	Case manager (not specified)	2b
183	Range: Mean:	12-18 16	Boys: Girls:	71 29	NR		Case manager (not specified)	2b
320	Range: Mean:	12-18 16	Boys: Girls:	76 24	White: Black: Other:	73 13 14	Case manager (not specified)	2b
305	Range: Mean:	12-18 16	Boys: Girls:	63 37	White: Black: Other:	70 12 18	Case manager (not specified)	2b

Table 1. Continued

Reference	Study design (time-frame)	Core elements of Youth ACT		Problems treated
McFarlane et al. (2014) USA [40]	Quasi-experimental (2007-2010)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes Yes Yes Yes Yes Yes Yes Yes Yes	Risk or early symptoms of psychosis
McGarvey et al. (2014) USA [41]	Pre-post test (2007-2010)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes NR Yes Yes Yes NR Yes Yes Yes	Substance use or co-occurring disorder and low income
Schley et al. (2008) AUS [42]	Pre-post test (2000-2004)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support Therapy: Pharmacology:	Yes Yes Yes Yes Yes Yes Yes Yes NR	Psychiatric symptoms, with high-risk of self-harm or harming others, avoiding outpatient care
Urben et al. (2015) CHE [8]	Pre-post test (2010-2013)	Home-based treatment: Small caseload (size<10): Hardly assessable patients: Transition case management: Early intervention: Psychiatric assessment at home: Family support: Therapy: Pharmacology:	Yes Yes Yes Yes Yes Yes Yes Yes Yes	Psychiatric symptoms and avoiding outpatient care

N	Age	(years)	Gender	(%)	Ethnic group	(%)	Team staff	Level of evidence
337	Range: Mean:	NR 17	Boys: Girls:	60 40	White: Black: Other:	62 9 19	Psychiatrist Nurse practitioner Nurse Occupational therapist Clinical counsellors	2b
147	Range: Mean:	12-18 16	Boys: Girls:	60 40	White: Black: Other:	62 9 19	Psychiatrist Nurse practitioner Nurse Occupational therapist Clinical counsellors	2b
47	Range: Mean:	12-18 16	Boys: Girls:	67 23	*City* White: Black: *County* White: Black:	 52 48 63 37	Case manager (not specified)	2b
98	Range: Mean:	NR 17	Boys: Girls:	60 40	White: Black: Other:	62 9 19	Psychiatrist Nurse practitioner Nurse Occupational therapist Clinical counsellors	2b

Table 1. Continued

Reference	Study design (time-frame)	Core elements of Youth ACT		Problems treated
Urben et al. (2016) CHE [43]	Pre-post test (NR)	Home-based treatment:	Yes	Psychiatric symptoms and avoiding outpatient care
		Small caseload (size<10):	Yes	
		Hardly assessable patients:	Yes	
		Transition case management:	Yes	
		Early intervention:	Yes	
		Psychiatric assessment at home:	Yes	
		Family support:	Yes	
		Therapy:	Yes	
		Pharmacology:	Yes	

ISO codes of representative countries (International Organization for Standardization) [46]
N: Sample size
Classification of methodological quality: 2b = RCT, low quality or cohort study (Oxford Centre for Evidence-Based Medicine) [38]
NR: Not reported
Therapy: Reintegration/ vocational therapy/ educational therapy

Study designs and level of evidence

To assess the quality of the thirteen studies, study designs are specified in table 1. Most studies had a pre-post design and lacked a control group [6, 8, 41-43, 47-49]. One study used a quasi-experimental design with a control group, but patients were not randomized [40]. Four studies were RCTs that studied a mono-disciplinary variant of Youth ACT with a limited number of sessions [50-53]. Two studies used (partly) the same patients [50, 51]. Since no systematic reviews on Youth ACT have been published to date, none of the included papers achieved high quality ratings. All studies included in this review were found to be of moderate evidence level Grade B (2b).

Sample

Sample characteristics of all included studies are presented in table 1. The included studies examined adolescents up to age 18, with a wide variety of psychiatric problems including substance abuse, psychotic, emotional, and developmental problems. Patients received Youth ACT as the only treatment [6, 8, 40, 42, 43, 47-49] or as an aftercare program [50, 51, 53]. The average ages of included patients ranged from 15 to 17 years. One study included fifteen patients, some of whom were 19 or 20 years of age [48]. However, because the majority of the included patients in this study were aged 15, 16 or 17 (mean=16.8, SD±1.4), this paper was retained [48]. None of the reviewed studies included children below age 11. Studies were conducted in the United

N	Age	(years)	Gender	(%)	Ethnic group	(%)	Team staff	Level of evidence
47	Range: Mean:	13-18 NR	Boys: Girls:	61 39	NR		Psychiatrist Psychiatric nurse Psychologist Social workers Occupational therapist	2b

States [40, 41, 48, 50-53], Switzerland [6, 8, 43], Australia [42, 49], and Great Britain [47]. Most studies investigated a Caucasian sample.

Table 1 shows that girls formed a large majority in three samples [6, 47, 49]. In the other samples, boys formed the majority [8, 40-43, 48, 50-53]. In total, 774 girls and 1217 boys were included.

Measurements

The severity of psychiatric symptoms was assessed using two clinician-based instruments, the Clinical Global Impression Scale (CGI) [54] and the Health of the Nation Outcome Scales Child and Adolescents Mental Health (HoNOSCA) [55, 56]. Client-based instruments used to measure severity of psychiatric symptoms were the Global Appraisal of Individual Needs (GAIN) [57], Structured Interview for Prodromal Syndromes (SIPS) [58], Timeline Follow Back (TLFB) [59], and the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I/CV) [60], Urine drug test or breath-analysing tests were used as biometric instruments [41, 50-53]. General functioning was measured with clinician-based instruments: the GAIN [57], Global Assessment of Functioning (GAF) [61], Children's Global Assessment Scale (CGAS) [62], and Social and Occupational Functioning Assessment Scale (SOFAS) [47] or with a subscale of HoNOSCA [55, 56]. Hospital admissions were assessed by examining medical files [47-49, 53], or by applying a client-based self-developed structured audit questionnaire [42].

Effect on severity of psychiatric symptoms

Table 2 shows that eleven studies examined the effect of Youth ACT on the severity of psychiatric symptoms [6, 8, 40-43, 47, 50-53]. Positive effects were reported in ten studies (table 2). Youth ACT may have the greatest effect on psychotic symptoms, suicidality, self-harm behavior, and emotional problems. One study reported no additional effect (ES=0.1) when Youth ACT was added to outpatient mental healthcare [52].

Psychiatric symptoms in general. Two studies reported large effect sizes of 1.2 and 1.3 respectively [6, 47] and one study a medium effect size (ES=0.6 [43]) with respect to a decrease of HoNOSCA sum-scores.

Emotional problems

Four studies (table 2) examined the effect of Youth ACT on emotional symptoms [6, 8, 42, 43]. All studies found a significant reduction of emotional problems. In two studies a medium effect size of 0.6 was found, assessed with the HoNOSCA [8, 43]. In the third study a small decrease was found in scores on the HoNOSCA-item non-organic somatic symptoms (ES=0.2), a medium decrease in self-injuries (ES=0.7), and a large decrease in mood symptoms (ES=0.8) and emotional symptoms (ES=0.8 [6]). The fourth study reported a large effect size in suicidality (ES=2.1) and deliberate self-harm behavior (ES=2.5 [42]).

Behavioral problems

One study found a small effect (ES=0.3) for the decrease in externalizing behavior assessed with the HoNOSCA [8]. Another study reported a similar small effect size for the HoNOSCA-item hyperactivity/focus problems (ES=0.3), but no significant effect size on disruptive and aggressive behaviors (ES=0.1 [6]).

Psychotic problems

Youth ACT for patients with psychotic disorders was examined in two studies [6, 40]. One study reported small effects with respect to negative symptoms (ES=0.3) and disorganized symptoms (ES=0.4) [40] assessed with the SIPS [58]. A medium effect size was reported for positive symptoms (ES=0.6) using the same instrument [40]. The second study reported a large effect size (ES=1.0) for the decrease in HoNOSCA item scores regarding hallucinations and delusions [6].

Addiction problems

Five studies reported on the effect of Youth ACT on addiction problems, using subscales of the GAIN [6, 41, 50, 51, 53]. Three studies did not find significant reduction in alcohol abuse (ES=0.1 [41, 50, 51]). Two studies found a small effect size for alcohol abuse [41, 53], however in one study this was found only for boys and not for girls [41]. Four

studies found a reduction in cannabis use [41, 50, 51, 53]. Three of these studies, reported small effect sizes for abstinence of cannabis at the one-month (ES=0.3) and the 9-month (ES=0.3) follow-up [50, 51, 53] although two studies used (partly) the same patients [50, 51]. Also, at the 3-month follow-up, a small effect size (ES=0.2) was found for diminishing use of drugs other than cannabis in one study [51]. No significant effect (ES=0.1) was found at the 9-month follow-up [51]. One study reported a reduction in days of cannabis use at 3-month follow-up, with a medium effect size for boys (ES=0.6), and a small effect size for girls (ES=0.4 [41]). This study also reported a medium effect size for reduction in days of cannabis use for boys and girls at the 6-month follow-up (ES=0.7 and 0.6 respectively), and the 12-month follow-up (ES=0.6) for both boys and girls [41].

Table 2. Effect Youth ACT on severity of psychiatric symptoms

Reference	Main results	Psychiatric disorders in sample	(%)
Adrian & Smith (2014) [47]	Youth ACT with hospital care and without hospital care was associated with reductions in severity of psychiatric symptoms. Larger effect sizes were found for psychotic symptoms, ASD and mood disorders than for self-harm, eating, and neurotic disorders	Mood: Anxiety: Psychotic: Self-harm: ASD: Eating: Other:	33 26 21 12 2 2 10
Baier et al. (2013) [6]	Youth ACT is associated with reduction of psychiatric symptoms	Psychotic: Schizophrenia: Mood: Anxiety: Conduct:	51 23 14 9 26
Godley et al. (2002) [50]	Preliminary outcomes of Godley et al. (2006). Significantly more abstinent from marijuana in Youth ACT + Usual Continuing Care (UCC) group compared to only UCC	Substance:	100
Godley et al. (2006) [51]	Significantly more long-term abstinent from marijuana in Youth ACT + Usual Continuing Care (UCC) compared to only UCC	Substance: Mood: Anxiety: PTSD: ADHD: Conduct:	100 38 38 36 57 67
Godley et al. (2010) [52]	Youth ACT had no additional effect on substance disorders compared to outpatient treatment only	Alcohol: Marijuana: Mood: Anxiety: PTSD: ADHD: Conduct:	49 75 28 8 19 34 42
Godley et al. (2015) [53]	Significantly more long-term abstinent from marijuana and alcohol in Youth ACT compared to only Usual Continuing Care (UCC)	Alcohol: Marijuana: Mood: Anxiety: PTSD: ADHD: Conduct:	58 91 32 46 33 49 65
McFarlane et al. (2014) [40]	Youth ACT was superior in reducing positive, negative, disorganized symptoms and general symptoms in adolescents compared to community care	Substance: Mood: Anxiety: PTSD: OCD: Psychosis:	8 42 8 8 7 13

Follow-up (months)	Assessment instruments	Effect size		95% CI
P-T	HoNOSCA	Reduction HoNOSCA sum-scores		
		both groups:	1.2	(1.1-1.4)
		patients that needed inpatient care during ACT treatment:	1.2	(0.9-1.5)
		patients with only ACT:	1.3	(1.1-1.5)
P-T	HoNOSCA	Reduction HoNOSCA sum-scores:	1.3	(0.8-1.8)
		Both groups: patients that needed inpatient care during ACT treatment:	1.2	(0.9-1.5)
		patients with only ACT:	1.3	(1.1-1.5)
3	GAIN TLFB Urine tests Breath-analyser Interviews	Alcohol use:	0.1	(-0.2-0.4)
		Abstinence marijuana, at 3 months follow-up:	0.4	(0.1-0.8)
3, 6, 9	GAIN TLFB Urine tests Breath-analyser Interviews	Abstinence at follow-up:		
		alcohol, 3 and 9 months:	0.1	(-0.2-0.4)
		marijuana 3 months:	0.3	(0.0-0.6)
		marijuana, 9 months:	0.3	(0.0-0.6)
		other drugs, 3 months:	0.2	(-0.1-0.5)
		other drugs, 9 months:	0.1	(-0.1-0.3)
3, 6, 9, 12	GAIN Substance problem scale Urine tests	Additional effect of Youth ACT in symptom reducing:	0.1	(-0.2-0.4)
3, 6, 9, 12	GAIN Substance problem scale Urine tests Breathalyzer	Abstinence at follow-up:		
		alcohol, 12 months:	0.3	(0.1-0.8)
		marijuana, 12 months:	0.3	(0.0-0.6)
		other drug,12 months:	0.3	(0.0-0.6)
6, 12, 24	SIPS SCID-I/CV	Symptom reduction:		
		positive symptoms:	0.6	(0.4-0.9)
		negative symptoms:	0.3	(0.0-0.5)
		disorganized behavior:	0.4	(0.2-0.7)

Table 2. Continued

Reference	Main results	Psychiatric disorders in sample	(%)
McGarvey et al. (2014) [41]	Youth ACT reduces marijuana use but does not reduce alcohol use	Substance or co-occurring disorder:	NR
Schley et al. (2008) [42]	Pre-treatment compared to post-treatment showed significant reduction in suicidality and deliberate self-harm behavior	Substance: Mood: Anxiety: Psychotic: ADHD/Disrupt: Eating: Other:	31 40 22 9 38 9 18
Urben et al. (2015) [8]	Reduction in severity of psychiatric symptoms (pre-treatment compared to post-treatment)	Internalizing: Externalizing: Mix:	36 27 37
Urben et al. (2016) [43]	Reduction in severity of psychiatric symptoms (pre-treatment compared to posttreatment)	Mood: Anxiety: Conduct disorder: Psychosis: Personality disorder:	30 19 17 11 4

Effect sizes were computed as Cohen's d rounded to the first decimal place. Positive effect sizes represents improvement. Small (≥ 0.2-0.5); medium (> 0.5-0.8); large (> 0.8) [44]. CI: Confidence interval P-T: Pre-Post measurement was conducted. NR: Not reported

Effect on psychiatric hospital admissions

All five studies reporting the effect of Youth ACT on frequency and duration of psychiatric hospital admissions found a significant effect (table 4) [42, 47-49, 53].

Frequency

Three studies examined the effect on frequency of admissions [42, 47, 49]. One study examined the frequency and duration of psychiatric hospital admissions during three-monthly intervals over a period of 12 months prior and post Youth ACT treatment [42]. This study showed that, with Youth ACT, the frequency of admissions decreased 7% at 3 month, 29.4% at 6 month, and 27.6% at 9 month follow-up. No significant effects were found at 12 months [42]. Another study found a decrease of admission rates (ES=1.0) in patients who received Youth ACT [49]. A third study reported that Youth ACT resulted in a decrease in hospital admissions [47]. For this study ES could not be calculated because required data were not reported.

Follow-up (months)	Assessment instruments	Effect size		95% CI
3, 6, 12	GAIN Drug tests	Reduction in days marijuana use at follow-up:		
		boys at 3 months:	0.6	(0.3-0.9)
		boys at 6 months:	0.7	(0.5-1.0)
		boys at 12 months:	0.6	(0.3-0.8)
		girls at 3 months:	0.4	(0.1-0.8)
		girls at 6 months:	0.7	(0.0-1.1)
		girls at 12 months:	0.6	(0.1-1.1)
		Alcohol use:		
		boys at 3 months:	0.2	(0.0-0.5)
		boys at 12 months:	0.2	(0.0-0.5)
		girls at 3 months:	0.1	(-0.4, 0.7)
		girls at 12 months:	0.1	(-0.4, 0.6)
P-T	Structured audit questionnaire developed by Youth ACT team	Suicidality:	2.1	(1.4-2.8)
		Deliberate self-harm:	2.5	(1.7, 3.3)
P-T	HoNOSCA	Reduction in HoNOSCA-scores:		
		Externalizing scale:	0.3	(-0.1-0.5)
		Emotional scale:	0.6	(-0.3-0.8)
3, 6, 9	HoNOSCA	Reduction in HoNOSCA sum-scores:	0.6	(0.0-1.2)
		Emotional scale:	0.6	(0.0-1.2)

Duration

Table 4 shows that four studies examined the effect of Youth ACT on duration of hospital admissions [42, 47, 48, 53]. Reduction in duration of hospital admission was reported in all four studies. In one study small effect sizes were found for a decrease of days in hospitals at 12-month follow-up [53]. A second study found medium effect sizes for a decrease in duration of hospital admissions (ES=0.5) and days spent in psychiatric institutions (ES=0.6 [48]). Another study found large effect sizes at 3-month (ES=1.6), 6 month (ES=1.1) follow-up, and a medium effect size at 12-month follow-up (ES=0.7) [42]. A fourth study reported that Youth ACT resulted in significantly shorter hospital admissions [47]. For this study ES could not be calculated because required data were not reported.

Effect on general functioning

Table 3 shows eight studies with information about the effect of Youth ACT on general functioning [6, 40-43, 47, 49, 53]. All studies reported significant improvements. Effect sizes ranged from small to large. Youth ACT had the largest effect on school attendance and family relations.

Five studies investigated effects on general functioning [6, 40, 43, 47, 53]: One study reported an increase in GAF-score (ES=0.3 [40]). A second study reported a large increase in CGAS-score (ES=1.5), with individuals with psychotic, mood, or autism spectrum disorders improving more than those with neurotic disorders, deliberate self-harm, or eating disorders [47]. A third study found a small effect on pro-social activities (ES=0.2 [53]). A fourth and fifth study reported large (ES=1.3) and medium (ES=0.6) effect sizes respectively, with respect to a decrease of HoNOSCA sum-scores [6, 43].

Table 3. Effect Youth ACT on general functioning

Reference	Main results
Adrian & Smith (2014) [47]	Compared to baseline 50% of the adolescents treated with Youth ACT showed improvement in general functioning according to CGAS score at discharge. Adolescents with psychotic and mood disorders improved more that patients with neurotic disorders
Baier et al. (2013) [6]	Youth ACT associated with significant improvement in social functioning measured with HoNOSCA (school attendance, and peer and family relations)
Chai et al. (2012) [49]	Significant improvement in clinician-rated levels of social functioning. Adolescents treated with Youth ACT showed increase in school attendance
Godley et al. (2015) [53]	Small significant improvement in pro-social activities. No significant differences in school attendance and family problems
McFarlane et al. (2014) [40]	Adolescents with psychotic symptoms treated with Youth ACT showed significantly higher GAF-outcomes, increased school attendance or work (21%) compared to those who received Community Care (7.0%)
McGarvey et al. (2014) [41]	Decrease in average number of days missing school (5.3 to 2.6 days) or being expelled from school (0.2 to 0.01 days) compared to baseline
Schley et al. (2008) [42]	Youth ACT decreased the frequency of violence and crime
Urben et al. (2016) [43]	Adolescents treated with Youth ACT showed significant improvements in HoNOSCA social-score which include the items family relations, peer relations and school attendance

Effect sizes were computed as Cohen's d rounded to the first decimal place. Positive effect sizes represents improvement. Small (≥ 0.2-0.5); medium (> 0.5-0.8); large (> 0.8) [44]. CI: Confidence interval. P-T: Pre-Post measurement was conducted

School attendance

Six studies examined school attendance [6, 40, 41, 43, 49, 53]. All studies found a significant effect of Youth ACT. Medium effect sizes (ES=0.6 [6]), (ES=0.7 [41]), (ES=0.7 [49]), and (ES=0.8 [43]) were reported on the HoNOSCA item school attendance, and decrease of average number of days expelled from school (ES=0.6 [41]). One study found a decrease of part-time school attendance, and non-attendance [40]. One study reported no significant effect on school attendance [53]. For these two studies ES could not be calculated because required data were not reported [40, 53].

Interpersonal relations

Two studies examined the effect of Youth ACT on interpersonal relations [6, 53]. One study used subscales of HoNOSCA [6]. Small effect sizes were found for peer relations (ES=0.4) and family relations (ES=0.5). The second study reported no significant effect on experienced family problems [53]

Follow-up (months)	Assessment instruments	Effect size		95% CI
P-T	CGAS	Baseline compared with discharge CGAS-scores:	1.3	(1.0-1.6)
		ACT combined with inpatient care: Only ACT:	1.5	(1.3-1.7)
P-T	HoNOSCA	Reduction HoNOSCA Sum-scores:	1.3	(0.8-1.8)
		Peer relations:	0.4	(0.0-0.9)
		Family relations:	0.5	(0.0-1.0)
		School attendance:	0.6	(0.1-1.1)
P-T	CGAS School attendance registration form	School attendance:	0.7	(0.4-1.1)
3, 6, 9, 12	GAIN	Pro-social activities:	0.2	(-0.2-0.4)
6, 12, 24	GAF	GAF-score:	0.3	(0.0-0.5)
3, 6, 12	GAIN	School attendance:	0.7	(0.4-1.1)
		Decrease in days expelled from school:	0.6	(0.3-0.9)
P-T	Structured self-developed questionnaire	Crime:	0.6	(0.1-1.2)
		Violence:	0.9	(0.3-1.5)
3, 6, 9	HoNOSCA	HoNOSCA Sum score:	0.6	(0.0-1.2)
		Social-score:	0.8	(0.0-1.2)
		School attendance:	0.8	(0.2-1.4)

Table 4. Effect Youth ACT on psychiatric hospital admissions

Reference	Main results	Follow-up (months)	Assessment instruments	Effect size		95% CI
Adrian & Smith (2014) [47]	Youth ACT associated with reduction in length of hospital admission	12	Medical files	NR		
Ahrens et al. (2007) [48]	Reduction in number of hospitalized days. Decrease in total number of days of inpatient psychiatric treatment, forensic treatment or incarceration	24	Medical files	Reduction admission days: Reduction in time in institutions, inpatient psychiatric treatment, and forensic treatment or incarceration:	0.5 0.6	(-0.2-1.3) (-0.3-1.4)
Chai et al. (2012) [49]	Significant reduction in rates of admission in the Youth ACT sample. Percentage of adolescents with no admissions increased from 53% prior to referral to 83% post treatment	P-T	Medical files	Reduction admissions:	1.0	(0.5-1.6)
Godley et al. (2015) [53]	Significant fewer days spent in residential treatment, juvenile detention, and hospitals over the 12 month follow-up period compared to UCC	3, 6, 9, 12	Medical files	Reduction admission days:	0.3	(0.1-0.6)
Schley et al. (2008) [42]	Comparison of psychiatric hospital admission rates and average number of days in the hospital prior to and after Youth ACT treatment showed that admission rates decreased with 17% at 3 month, 29% at 6 month, 28% at 9 month and 22% at 12 month follow-up	3, 6, 9, 12	Structured self-developed questionnaire	Reduction in hospital admissions days: 3 months: 6 months: 12 months:	 1.6 1.1 0.7	 (1.2-2.1) (0.7-1.5) (0.1-1.2)

Effect sizes were computed as Cohen's d rounded to the first decimal place. Positive effect sizes represents improvement. Small (≥ 0.2-0.5); medium (> 0.5-0.8); large (> 0.8) [44] CI = Confidence interval
NR = Not reported
P-T = Pre-Post measurement was conducted

Discussion

This review summarises the outcomes of thirteen studies examining the effects of Youth ACT on severity of psychiatric symptoms, general functioning, and frequency and duration of psychiatric hospital admissions.

Clinical implications

There are indications that Youth ACT is effective with respect to diminishing the severity of psychiatric symptoms in adolescents. Effect sizes range from small to large.
The single study that did not yield a significant effect was a RCT that found that Youth ACT had no additional effect if applied as a supplement to office-based mental healthcare [52]. This study consisted of an intervention that was limited to an average of only five to eight sessions. This low number of sessions may explain the lack of effect [39]. Because ACT in adults seems more effective in patients with severe problems [23], another explanation could be that the included patients in this study had relatively mild problems [39]. Also, it could be that ACT was compared to another intervention, in this particular case a behavioral therapeutic intervention, which was very effective with respect to substance abuse. In other words, there was no clear contrast between experimental and control group regarding therapeutic efforts.

Emotional problems

Some studies showed that Youth ACT is beneficial for adolescents with emotional problems [6, 8, 42, 43]. Studies concerning ACT in adults found effects on emotional problems that range from small (ES=0.2 [20]) to medium (ES=0.5 [28]). In youths, effects vary from small to large which could mean that ACT may be more effective in addressing emotional problems in children and adolescents.
Guidelines for emotional problems (anxiety or depression) in children and adolescents, for example the NICE guideline “Depression in children and young people” [63], do not provide recommendations with respect to Youth ACT. Children with emotional problems can be difficult to reach by outpatient care, because of avoidance (in case of anxiety) or depression (due to lack of energy, or loss of interest, for instance, in school, work or friends). Children with severe emotional problems have an increased risk of psychiatric hospitalization [64]. Youth ACT teams can actively approach these children in their own living environment, instead of leaving them at home, without offering treatment, which may result in an increase in depression and anxiety, and ultimately, self-harm behaviors, increased parental stress, and hospitalization [65]. Youth ACT might be a suitable approach for early screening, diagnosis, and treatment of care for children and adolescents with anxiety disorders or depression [65].

Behavioral problems

There is no evidence that Youth ACT is effective for disruptive and aggressive behaviors [6]. This conclusion is based on one study. If outreach treatment is needed, Multi Systemic Therapy (MST) [66, 67] or Multidimensional Family Treatment (MDFT) [68] may be more appropriate in accordance with the NICE guideline "Antisocial behavior and conduct disorders in children and young people" [69].

Psychotic problems

Two studies indicate that Youth ACT is effective in reducing psychotic symptoms [6, 40]. Effect sizes range from small to large. In adults, effects range from not significant (ES=0.1 [20]) to medium (ES=0.5 [22]). This may mean that in youth, ACT may be more effective. Children and adolescents with psychotic disorders have an increased risk of psychiatric hospitalization [70] and their long-term prognosis is often poorer than in adults [71]. Youth ACT might play a key role in limiting long-term disability by providing early diagnostics and intervention [72]. The use of assertive case management for psychotic problems in adolescents is in accordance with existing guidelines, such as the NICE guideline "Psychosis and schizophrenia in children and young people" [14] and Orygen guideline "Australian clinical guidelines for early psychosis" [73].

Addiction problems

Youth ACT appears effective in reducing cannabis use, and can be applied in case of care avoidance of children and adolescents [41, 50, 51, 53]. This conclusion is in accordance with the NICE guideline "Drug misuse in over 16s: psychosocial interventions" [74]. Unlike for adults, where effect sizes ranged from medium (ES=0.5 [25]) to large (ES=0.9 [25]; ES=1.5 [24]), a majority of the studies in youths found no evidence that Youth ACT is effective for alcohol abuse. However, it has to be noted that only a limited number of studies examined these effects. Nevertheless, and similar as in adults [75], Youth ACT is used to support care-avoiding adolescents with severe alcohol abuse who do not benefit from other intensive treatment programs [3, 76]. The NICE guideline "Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence" recommends Assertive Outreach for adolescents [77]. Based on current evidence, the question arises whether it is appropriate to apply Youth ACT in adolescents with treatment resistant alcohol abuse. More research is needed.

Youth ACT appears to improve general functioning in adolescents with severe psychiatric symptoms [6, 41-43, 47, 49, 53]. Effects seem comparable with studies investigating ACT in adults that found small (ES=0.2 [25]; ES=0.3 [21]), medium (ES=0.6 [22]) and large (ES=1.7 [24]) effects. Large significant effects on general functioning coincided with large effects on psychotic symptoms and mood disorders.

School attendance

There are indications that Youth ACT improves school attendance [6, 40, 41, 43, 47, 49]. It may be seen as encouraging that three studies with respect to school attendance found positive effects, since absenteeism is associated with an increase in severity of psychiatric symptoms, dropout from school, and unemployment [60, 78, 79].

Interpersonal relations

Youth ACT may improve interpersonal relations [6]. Effects on family relations are small, however slightly larger, these effects are comparable with adults (ES=0.3 [19]). Youth ACT programs focus on participation in the community, since adolescents with severe psychiatric symptoms often have a small social network and weak social support, which can be attributed to a high levels of impairment in social functioning [36, 80].

Hospital admissions

Youth ACT appears to reduce duration and frequency of psychiatric hospital admissions [42, 47-49, 53]. This is of interest, because children and adolescents with severe psychiatric symptoms are at a higher risk of being hospitalized than adults with similar problems [11]. Similar to adults where effects range from small (ES=0.2 [23]), medium (ES=0.4 [25]) to large (ES=1.9 [27, 81]), Youth ACT may contribute to deinstitutionalization [1, 2] and higher cost-effectiveness. In addition, fewer hospital admissions may be associated with better social functioning, since adolescents are not "removed" from their social environment [72]. This is in line with the finding that Youth ACT may help to improve interpersonal relations [6].

Strengths and limitations

This review has several strengths. First, it is the first review to date describing effectiveness of Youth ACT. Evidence has been summarized regarding current knowledge about its effects on psychiatric symptoms, general functioning, and hospital admissions. Second, studies were selected and assessed on their core elements of Youth ACT, to avoid missing relevant information.

Limitations pertain to the number and quality of studies published so far. However, despite this limitation, clear patterns are visible and unambiguous trends have been found in favour of Youth ACT.

According to the Oxford Centre of Evidence-Based Medicine grading system [38] all overall conclusions received a moderate strength of recommendation (grade B). Another drawback is that a majority of the studies were conducted in the United States which might hamper generalizability of findings to countries outside the United States [39, 82].

Recommendations

Randomized controlled trials (RCTs) in different countries are needed to obtain grade A knowledge about the effect of Youth ACT. Such studies should also include children below the age of twelve years. The focus should be on a wide range of outcomes, including psychopathology and social functioning in several areas. Future studies should report on model fidelity to obtain a better insight into specific content of the Youth ACT program. The Dartmouth Assertive Treatment Scale (DACTS) [5, 7] can be used for this purpose. Finally, although Youth ACT programs use a family approach, none of the studies provide detailed information about psychiatric and psychosocial problems of family members. Insight into these problems is needed, since such problems are likely to be present given familial aggregation of psychiatric disorders [83], and may influence treatment outcome.

Conclusion

The findings of the studies included in this literature review are promising, despite the limitations described with respect to study designs. There are indications that Youth ACT is effective in reducing severity of psychiatric symptoms, improving general functioning, and reducing duration and frequency of psychiatric hospital admissions. Implementation of Youth ACT is high on the political and mental health agenda, which stresses the need for more research on its effectiveness using rigorous research designs.

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Additional information

Search strings used to retrieve papers for the systematic PRISMA review on the effect of youth assertive community treatment.

Search string used in Cinahl

("assertive community treatment" OR (MH "Community Mental Health Services+" AND (TI "act" OR AB "act" OR TI "assertive" OR AB "assertive"))) AND (MH "Child+" OR TI child* OR AB child* OR MH "Minors(legal)" OR TI minors OR AB minors OR MH "Puberty+" OR TI puberty OR AB puberty OR MH "Pediatrics+" OR TI paediatric* OR AB paediatric* OR TI pediatric* OR AB pediatric* OR MH "Adolescence+" OR TI adolescen* OR AB adolescen* OR TI preschool* OR AB preschool* OR TI teenager* OR AB teenager* OR TI teen* OR AB teen* OR TI youth* OR AB youth* OR TI girlhood OR AB girlhood OR TI girl OR AB girl OR TI girls OR AB girls OR TI boyhood OR AB boyhood OR TI boy OR AB boy OR TI boys OR AB boys OR TI "school age" OR AB "school age" OR TI "school-aged" OR AB "school-aged" OR TI schoolchild* OR AB schoolchild* OR TI kid OR AB Kid OR TI kids OR AB kids OR TI underage* OR AB underage* OR TI Juvenile* OR AB Juvenile*)

Search string used in PsychInfo

Choose "advanced search" in Psychinfo and build the searchbuilder.

Row 1: (#1) =
(child* or Minors or Puberty or Pediatrics or Paediatrics or Adolescen* or Preschool* or Teenager or Teenager* or Teen* r Youth* or Girlhood or Girl* or Girl or boyhood or boy or Boy* or school age or schoolchild* or kid or kids or underage* or Juvenile*).ab,ti.

Row 2: (#2) = (ACT or assertive).ab,ti. and (community mental health/ r exp community mental health services/)

Row 3: (#3) = Assertive community treatment.ab,ti.

Row 4 (#4) = 2 OR 3

Row 5 (#5) = 1 AND 4

Search string used in the Cochrane Library

Step 1: Choose "advanced search" in Cochrane database

Step 2: Choose "Medical Terms (MeSH)" om MeSH termen in te voeren.

Press Lookup to go to the next field.

Step 3: Go to screen "ADD te search manager"

Row 1: (#1) = Child
Row 2: (#2) = Community Mental Health Services
Row 3: (#3) = Adolescent
Row 4 (#4) = Minors
Row 5 (#5) = Puberty
Row 6 (#6) = Pediatrics
Row 7 (#7) = assertive community treatment:ti,ab,kw
Row 8 (#8) = ACT:ti,ab,kw OR Assertive:ti,ab,k
Row 9 (#9) =
(child* or minors or puberty or Paediatric* or Pediatric* or Adolescent* or Preschool* or Teenager or Teenagers or Teen or Teens or Youth* or Girlhood or Girl or Girls or Girl or Boyhood or Boy or Boys or school age or School-aged or Schoolchild* or Kid or Kids or Underage* or Juvinile*):ti,ab,kw
Row 10 (#10) = #2 AND #8
Row 11 (#11) = #1 OR #3 OR #4 OR #5 OR #6 OR #9
Row 12 (#12) = #9 or #11
Row 13 (#13) = (#7 or #10) and #12
Please note: row 1 to 8 are mesh terms!

Step 4: MeSH term is now added to the searchbuilder.

CHAPTER 3

Factors associated with treatment intensification in child and adolescent psychiatry: A cross-sectional study

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Abstract

Background

More knowledge about characteristics of children and adolescents who need intensive levels of psychiatric treatment is important to improve treatment approaches. These characteristics were investigated in those who need youth Assertive Community Treatment (Youth ACT).

Method

A cross-sectional study among children/adolescents and their parents treated in either a regular outpatient clinic or a Youth ACT setting in a specialized mental health treatment center in the Netherlands.

Results

Child, parent and family/social context factors were associated with treatment intensification from regular outpatient care to Youth ACT. The combination of the child, parent, and family/social context factors adds substantially to the predictive power of the model (Nagelkerke R^2 increasing from 36%-45% for the three domains separately, to 61% when all domains are combined). The strongest predictors are the severity of psychiatric disorders of the child, parental stress, and domestic violence.

Conclusions

Using a wide variety of variables that are potentially associated with treatment intensification from regular outpatient clinic to Youth ACT, we constructed a regression model illustrating a relatively strong relation between the predictor variables and the outcome (Nagelkerke R^2=0.61), with three strong predictors, i.e. severity of psychiatric disorders of the child, parental stress, and domestic violence. This emphasizes the importance of a system-oriented approach with primary attention for problem solving and stress reduction within the system, in addition to the psychiatric treatment of the child, and possibly also the parents.

Introduction

Ten to twenty percent of the children and adolescents in the general population suffer from a psychiatric disorder [1-3]. With the general practitioner as the gate keeper, most of the Dutch children and adolescents with psychiatric disorders are referred to outpatient clinics [4,5]. If more intensive mental healthcare is necessary, children or adolescents can be referred by the general practitioner or via the outpatient clinic to youth Assertive Community Treatment (Youth ACT). This is an intensive home-based treatment that is provided by a multidisciplinary team of mental healthcare professionals who have small caseloads (size<15).

Existing studies (only four) mainly studied child factors (and not: variables pertaining to parents) [6, 7] , only pertained to children (and not to adolescents) [7], used small samples [8], or only studied children with autism spectrum disorder [9]. Two of the four studies were conducted more than 20 years ago [6, 7]. To increase scientific knowledge regarding the intensification of outpatient psychiatric treatment in children and adolescents we (1) studied a larger sample, and (2) examined child, parent, and family/social context factors that might predict intensification of outpatient treatment, in (3) both children and adolescents.

More knowledge about factors associated with intensifying treatment from regular outpatient care into Youth ACT is important from the perspective of prevention because it offers opportunities to determine which factors should be targeted with treatment to prevent increase in psychopathology and deterioration of functioning, ultimately leading to referral to a more intensive form of mental healthcare [6-9]. By identifying factors associated with intensifying treatment, mental healthcare professionals are encouraged to determine at an early stage whether regular outpatient care can be expected to be effective or if they should consider treatment intensification [9]. More precision in the allocation of care for those who need intensive treatment may help avoid exposure of patients to treatments that will prove to be ineffective, and lead to unnecessary delay in recovery [10, 11]. Conversely, in the vast majority of children and adolescents a more intensive form of treatment than outpatient care is not necessary, so referral to a setting such as Youth ACT would be inefficient for most patients [12-17].

The aim of this study was to investigate factors that are associated with treatment intensification from regular outpatient care into Youth ACT. We aimed to include variables on the child, parent and family/social context levels which are known from the literature to be associated with mental health of children [6-9, 18].

Our *a priori* hypotheses were that children and adolescents in whom outpatient treatment is intensified into Youth ACT have significantly more severe psychiatric disorders, more care needs, lower quality of life, and an older age [6-9]. Further, we expected that parents of children and adolescents in whom outpatient treatment is

intensified into Youth ACT have higher levels of parental psychiatric disorders, more care needs, lower quality of life, higher levels of parental stress, and a poorer parental ability to deal adequately with the psychiatric problems of the child. Studies that link functioning of parents with the utilization of inpatient care of children and adolescents support these hypotheses [7-9]. At the family/social context level, we expected that treatment intensification from regular outpatient care into Youth ACT is associated with a parent being single parent, a larger number of children in the family, more domestic violence, more financial problems, less social support, and low family socioeconomic status (SES) [7-9].

Method

Design

We conducted a cross-sectional study with children/adolescents and their parents who were treated in either a regular outpatient clinic or a Youth ACT setting.

Setting

The study was carried out between 2015 and 2017 in a specialized treatment center for psychiatric disorders in the Netherlands, GGZ Delfland. Two outpatient clinics and one Youth ACT team, who served patients in the same geographical area, were included. The two outpatient clinics carry out diagnostic assessments and treatment of children/adolescents using a multidisciplinary team. Each team consists of one child psychiatrist, six psychologists, and one nurse practitioner.

The Youth ACT team provides treatment based on the following elements and principles: (a) home-based multidisciplinary treatment, (b) intensity of treatment is scaled up or down according to the severity of current psychiatric symptoms and level of functioning of the patient, (c) small caseloads (size<15), (d) focused on patients who are difficult to reach, (e) case management, (f) early intervention, (g) family support, (h) reintegration/vocational and educational therapy, (i) medication when appropriate. The Youth ACT team consists of one child psychiatrist, five psychologists, three nurse practitioners and two psychiatric nurses.

Participants

Figure 1 presents the flowchart of the inclusion process. To be included, participants in both treatment settings had to meet the following inclusion criteria: (a) children/adolescents aged between 4 and 18 years; (b) with a DSM-IV diagnosis; and (c) had a parent who fulfilled the role of primary caregiver. Because the involvement of parents in raising a child can vary widely [19], especially when it concerns single parent families

[20], only the parent who fulfilled the role of primary caregiver was included in this study. Only children who were referred from an outpatient clinic, were included in the Youth ACT sample.
Included outpatients who were later referred to Youth ACT were excluded from the outpatient sample and included in the Youth ACT sample. Also, children were excluded when a sibling or other child living in the same household already participated in the study.

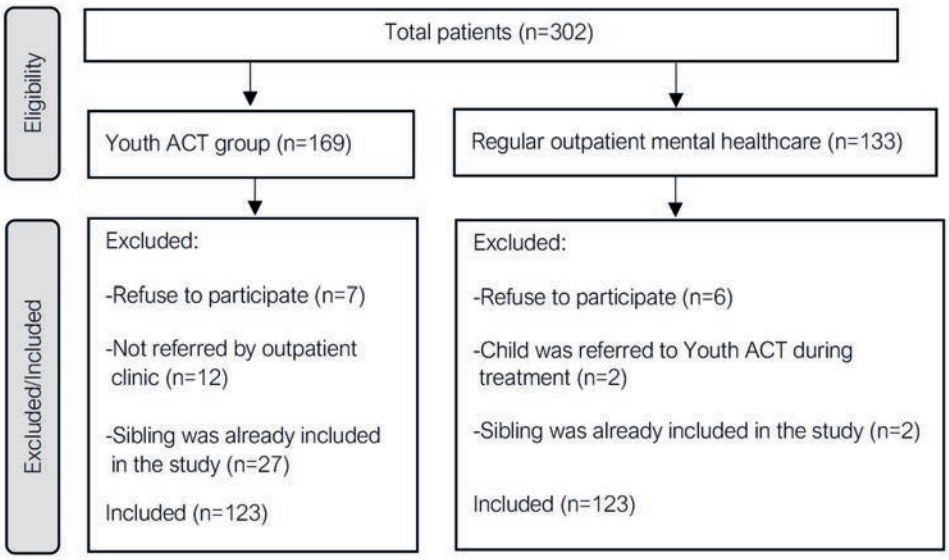

Figure 1. Participant flow diagram

Ethical approval

The study was approved by the Medical Ethics Committee on Research Involving Human Subjects of the VU University Medical Centre, Amsterdam (protocol no. 2015.245). Participants received written and oral information, separately for children and parents, about the study and were included after giving informed consent.

Measurement instruments

Child factors

For the assessment of psychiatric diagnoses, we used the Neuropsychiatric Interview for Children and Adolescent (MINI-KID), supplemented with clinical diagnoses that were not included in the MINI-KID [21].

The Health of the Nation Outcomes Scales Child and Adolescents Mental Health (HoNOSCA) was used to assess the severity of psychiatric disorders [22]. The HoNOSCA covers 15 items to be scored on a 5-point severity scale ranging from "no problems" (0) to "severe problems" (4). To calculate HoNOSCA-sum score, we used the items 1 to 13, since items 14 and 15 do not provide information about the mental health situation of the child.

The Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) was used to assess the care needs of the child [23]. The CANSAS covers 25 care need items which are scored on a nominal 3-point scale "no need" (1), "met need" (2), and "unmet need" (3). To calculate the CANSAS-sum score, the sum of met and unmet needs of the 25 items was computed.

The Kidscreen-27 was used to assess the health-related quality of life of children [24]. The Kidscreen is a self-report questionnaire that consists of 27 items to be scored on a 5-point scale ranging from "never" (0) to "always" (4). The Kidscreen sum score was calculated by adding up the scores of the 27 items.

A designated client-based standardized questionnaire (DEMOG) was used to measure the following demographic characteristics of the child: (a) age, (b) gender, and (c) country of birth [25]. This is a standardized client-based questionnaire to measure demographic characteristics.

Parental factors

The Health of the Nation Outcomes Scales (HoNOS) was used to assess the severity of psychiatric disorders of the parent [26-28]. The HoNOS covers 12 items to be scored on a 5-point severity scale ranging from "no problems" (0) to "severe problems" (4). The HoNOS sum score was calculated by adding up the scores of the 12 items.

Item 14 of the HoNOSCA was used to assess the parental knowledge about the difficulties of the child from the perception of the parent.

As with the children, the CANSAS was used by parents as a self-report scale to assess their care needs.

Parenting stress was measured using a Parenting Stress Scale. The primary caregivers rated their level of parenting stress on a scale ranging from 1 to 10.

The Manchester Short Assessment of quality of life (MANSA-16) was used to assess the health-related quality of life of the parent [29, 30]. The MANSA consists of 16 items to be scored on a 7-point scale ranging from "could not be worse" (1) to "could not be better" (7). The MANSA-16 sum score was calculated by adding up the scores of the 16 items.

DEMOG-adult was used to measure the following demographic characteristics of the parent: (a) age, (b) gender, and (c) country of birth [25].

Family/social context factors

The DEMOG-Adult was also used to assess living situation, family composition, and socio-economic status (SES; expressed in educational achievements and ethnic background).

Domestic violence was registered by a self-developed form to be scored "yes" or "no". It was assessed whether the client, parents, and siblings had used violence against other family members in the present.

Items 3 and 6 of the MANSA were used separately to assess social support and financial problems of the family, respectively.

Data-analysis

Analyses were performed using SPSS 24.0. The descriptive statistics of the outpatient sample and Youth ACT sample were calculated on item or scale level. Next, we conducted three series of univariable logistic regression analyses, with treatment setting as dependent variable, to identify candidate predictors for the multivariable regression models. The first series concerned candidate predictors at the level of the child: severity of psychiatric disorders, care needs, quality of life, and age. The second series concerned candidate predictors at the level of the parent: severity of psychiatric disorders of the parent, care needs, quality of life, parental stress, and (lack of) knowledge pertaining to difficulties of the child. The third series concerned candidate predictors at the level of family/social context: living situation, the number of children, financial problems, educational achievements and ethnic background of the primary caregiver, domestic violence, social support and financial problems.

By using this step-by-step approach, we created multivariable regression models that did not violate the statistical rule of 10 events per 1 variable and ensured the validity of the analysis [31, 32]. First, for each level (child, parent, and family/social context) we conducted three separate multivariable analyses in which we entered the predictors that were (borderline)-significant ($P<0.10$) in the univariable analyses. Finally, we conducted a stepwise multivariable analysis investigating the three levels (child, parent, and family/social context) together.

The assumptions of the logistic regression analyses (multicollinearity) were tested for indications of multicollinearity by examining the variance inflation factor (VIF) and tolerance values. No violations of limits were found (VIF range 1.00-2.00; tolerance between 0.45 and 1.00), indicating that there was no indication of multicollinearity [33]. Further, the assumptions of linearity and homoscedasticity were tested by creating a scatter plot of the standardized residuals. The distribution of the residuals was reasonably rectangular, and most of the scores were in the centre. Thus, the assumption of linearity and homoscedasticity were met in this study [33, 34]. The Hosmer and Lemeshow goodness-of-fit test was used to measure the predictive value

of the model [33]. To obtain an overall indication of how well the models performed, we used the Omnibus test [33]. The Nagelkerke R^2 was used to provide an indication of the strength of the relation between the predictor variables and the outcome variable [33]. The discrimination accuracy of the model was examined by using the area under the curve (AUC) of the receiver operating characteristic curve (ROC curve) and were categorized as fail (0.50-0.60); poor (0.60-0.70); fair (0.70-0.80); good (0.80-0.90); or excellent (0.90-1.00) [35].

Results

Characteristics of the sample

Characteristics of the study sample (n=246) are presented in table 1 and 2. The outpatient sample (n=123) comprised 56 girls (45.5%) and 67 boys (54.5%) with an average age of 11.8 years. The most frequent clinical diagnoses were attention deficit hyperactivity disorder (43.1%), anxiety disorder (31.7%), behavioral disorder (12.0%), or mood disorder (6.5%). In the outpatient sample, most primary care givers (n=123) were mothers (99.2%) with an average age of 41.0 years. The majority of mothers (66.6%) had a paid job and 73.8% of these mothers raised their children in a two-parent household.

The Youth ACT sample (n=123) comprised 52 girls (42.3%) and boys 71 (57.7%) with an average age of 13.0 years. The most frequent clinical diagnoses were attention deficit hyperactivity disorder (42.3%), anxiety disorder (41.5%), behavioral disorder (30.0%), and mood disorder (37.0%). In the Youth ACT sample 98.4% of the primary caregivers (n=123) were mothers with an average age of 43.7 years. The majority of mothers (64.2%) did not have a paid job and 57.9% of these mothers raised their children in a two-parent household.

Predictors Youth ACT

Univariable analyses

As presented in table 3, the univariable analyses shows that treatment intensification from outpatient care into Youth ACT was predicted by all variables, with the exception of educational status of the primary caregiver (P=0.210, P=0.312), social support (P=0.118), and number of children in the household (P=0.965).

At the child level, the referral to Youth ACT was predicted by the severity of the psychiatric disorders, assessed with the HoNOSCA (OR=1.29, 95% CI 1.21-1.38, P<0.001), the child's care needs (OR=1.06, 95% CI 1.00-1.12, P=0.034), quality of life (OR=0.94, 95% CI 0.92-0.97, P<0.001), and age (OR=2.24, 95% CI 1.32-3.80, P=0.003).

Table 1. Sample characteristics of the child or adolescent who received treatment

	Outpatient Child (n=123)			**Youth ACT Child (n=123)**		
Age (sd)	Total	mean	11.8 (3.2)	Total	mean	13.0 (3.2)
		range	6-17		range	4-18
	Girls	mean	13.0 (3.4)	Girls	mean	13.7 (3.0)
		range	6-17		range	4-18
	Boys	mean	11.1 (2.9)	Boys	mean	12.5 (3.3)
		range	6-17		range	6-17
Gender	Girls		45.5%	Girls		42.3%
	Boys		54.5%	Boys		57.7%
Country of birth	The Netherlands		96.7%	The Netherlands		95.1%
	Other		3.3%	Other		4.9%
Clinical diagnoses	Mood		6.5%	Mood		37.4%
	Anxiety		31.7%	Anxiety		41.5%
	Behavior		12.0%	Behavior		30.0%
	Psychotic		0.0%	Psychotic		4.0%
	ASD		11.4%	ASD		40.7%
	ADHD		43.1%	ADHD		42.3%
	Somatoform		0.8%	Somatoform		13.8%
	Drugs/alcohol		0.0%	Drugs/alcohol		3.2%
	Mental retard		3.2%	Mental retard		8.1%
	Personality		0.0%	Personality		5.7%
	Other		0.8%	Other		3.2%
GAF-score (sd)		mean	55.0 (5.4)		mean	45.7 (8.1)
		range	45-75		range	15-60
Living situation	Single parent household		26.2%	Single parent household		42.1%
	Two parent household		73.8%	Two parent household		57.9%

n: number of included patients
sd: standard deviation
ASD: Autism spectrum disorder
ADHD: Attention deficit hyperactivity disorder
GAF: General assessment of functioning

At the parent level, the severity of psychiatric disorders of the parent predicted the referral to Youth ACT (OR=1.22, 95% CI 1.15-1.30, P<0.001), as did the parents' care needs (OR=1.12, 95% CI 1.07-112, P<0.001), and the parents' quality of life (OR=0.93, 95% CI 0.91-0.96, P<0.001). Also, the parental knowledge about the difficulties of the child and the perceived parental stress were significant predictors (respectively OR=1.53 (95% CI 1.34-1.76, P<0.001) and OR=1.66 (95% CI 1.30-2.13, P<0.001)).

Table 2. Sample characteristics of the parent who fulfilled the role of primary caregiver

	Outpatient Child (n=123)			**Youth ACT Child (n=123)**		
Age (sd)	Total	mean	41.0 (6.2)	Total	mean	43.7 (7.3)
		range	27-55		range	24-70
Status	Mother		99.2%	Mother		98.4%
	Father		0.8%	Father		1.6%
Country of birth	The Netherlands		78.0%	The Netherlands		88.6%
	Other		22.0%	Other		11.4%
Education status	Basic		15.4%	Basic		25.3%
	Intermediate		22.0%	Intermediate		29.2%
	High		62.6%	High		45.5%
Employment status	Paid job		66.6%	Paid job		35.8%
	No paid job		33.4%	No paid job		64.2%

n: number of included patients
sd: standard deviation

At the family/social context level, being a single parent (OR=2.05, 95% CI 1.19-3.42, P=0.009), the presence of domestic violence (OR=12.05, 95% CI 6.20-23.42, P<0.001), having financial problems (OR=1.32, 95% CI 1.11-1.56, P=0.015), and ethnic background of the primary caregiver (OR=0.46, 95% CI 0.23-0.92, P=0.029) were significant predictors.

Multivariable analyses for each level separately

Table 3 shows that at the child level, quality of life (P=0.213), and age of the child (P=0.322) did not remain significant in the multivariable analysis. The child model showed a good fit of the data (Hosmer-Lemeshow, P=0.681) and illustrated a relatively strong relation between the predictor variables and the outcome (Nagelkerke R^2=0.43). The AUC under the ROC curve suggested that the model has a good classification ability to discriminate the referral to regular outpatient care with Youth ACT (AUC=0.84, 95% CI 0.78-0.89, P<0.001).

At the parent level, the care needs (P=0.802) and quality of life (P=0.568) did not remain significant. The model showed a good fit of the data (Hosmer-Lemeshow, P=0.912) and illustrated a relatively strong relation between the predictor variables and the outcome (Nagelkerke R^2=0.45). The model has a good classification ability to discriminate the referral to regular outpatient care with Youth ACT (AUC=0.85, 95% CI 0.80-0.89, P<0.001).

Table 3. Predictors of Youth ACT

Level of predictors	Univariable model[1]			Multivariable model[2]		
	n[3]	OR[4] (95% CI[5])	P-value[6]	n	OR (95% CI)	P-value
Child[8]				225		
HoNOSCA[7]	246	1.29 (1.21-1.38)	<.001		1.27 (1.18-1.37)	<.001
CANSAS[7]	243	1.06 (1.00-1.12)	0.034		0.93 (0.87-1.01)	0.051
Kidscreen[7]	228	0.94 (0.92-0.97)	<.001		0.97 (0.95-1.00)	0.213
Age:	246					
4-11 years old	93					
12-18 years old	153	2.24 (1.32-3.80)	0.003		1.41 (0.71-2.81)	0.322
Parent[9]				238		
HoNOS[7]	244	1.22 (1.15-1.30)	<.001		1.22 (1.10-1.35)	<.001
CANSAS[7]	246	1.12 (1.07-1.12)	<.001		0.99 (0.92-1.06)	0.802
MANSA[7]	240	0.93 (0.91-0.96)	<.001		1.01 (0.97-1.06)	0.568
Parental stress	245	1.53 (1.34-1.76)	<.001		1.42 (1.21-1.67)	0.002
Lack of knowledge pertaining to difficulties	246	1.66 (1.30-2.13)	<.001		1.60 (1.19-2.15)	0.003
Family and social context[10]				243		
Living situation:	243					
Two parents	160					
Single parent	83	2.05 (1.19-3.42)	0.009		1.30 (0.67-2.55)	0.437
Domestic violence	245	12.05 (6.20-23.42)	<.001		11.27 (5.56-22.86)	<.001
Financial problems	243	1.32 (1.11-1.56)	0.015		1.06 (0.86-1.31)	0.593
Ethnic background primary caregiver:	246					
Dutch	236					
Other	10	0.46 (0.23-0.92)	0.029		0.40 (0.18-0.91)	0.028
Social support	243	0.52 (0.23-1.18)	0.118			
Educational status:	246					
Basic	39					
Intermediate	74	1.65 (0.75-3.63)	0.210			
High	133	0.69 (0.34-1.41)	0.312			
Number of children	245	0.99 (0.76-1.30)	0.965			

[1] Univariable: binary logistic analyses of each candidate predictor preformed separately
[2] Multivariable: binary logistic regression analysis of the predictors that were significant in the univariable analysis, performed simultaneously
[3] n: number of patients
[4] OR: Odds Ratio
[5] CI: Confidence interval
[6] P-value<0.10 is considered statistically significant
[7] Sum-score
[8] Child-level: Omnibus test, Step P= 0.00, Model P=<0.00, Hosmer-Lemeshow, P=0.68, Nagelkerke R^2=0.43, AUC=0.84, 95% CI 0.78-0.89, P<0.001
[9] Parent-level: Omnibus test, Step P=0.00, Model P=<0.00, Hosmer-Lemeshow, P=0.91, Nagelkerke R^2=0.45, AUC=0.85, 95% CI 0.80-0.89, P<0.001
[10] Family-social context-level: Omnibus test, Step P=0.00, Model P=<0.00, Hosmer-Lemeshow, P=0.58, Nagelkerke R^2=0.36, AUC=0.78, 95% CI 0.72-0.84, P<0.001

At the family/social context level, being a single parent (P=0.437) and having financial problems (P=0.593) did not remain significant in the multivariable analysis. The model fitted the data (Hosmer-Lemeshow, P=0.576) and illustrated a relatively strong relation between the predictor variables and the outcome (Nagelkerke R^2=0.36). The model has a fair classification ability to
discriminate the referral to regular outpatient care with Youth ACT (AUC=0.78, 95% CI 0.72-0.84, P<0.001).

Multivariable analyses for all levels simultaneously

First, in the final logistic model, the severity of the psychiatric disorder of the child (OR=1.31, 95% CI 1.22-1.41, P<0.001) remained a significant predictor regarding referral to Youth ACT (see table 4). However, the child's care needs did not remain significant (P=0.186). Second, the significant child and parent predictors together showed that all predictors remained significant: the severity of the psychiatric disorder of the child (OR=1.21, 95% CI 1.12-1.30, P<0.001) and parent (OR=1.13, 95% CI 1.05-1.21, P<0.001), parental stress (OR=1.36, 95% CI 1.15-1.60, P<0.001) and parental knowledge about the difficulties of the child (OR=1.39, 95% CI 1.00-1.92, P=0.049). Third, when the family/social context predictors were added, the severity of the psychiatric disorder of the child (OR=1.19, 95% CI 1.11-1.29, P<0.001), parental stress (OR=1.35, 95% CI 1.13-1.62, P=0.001), and domestic violence (OR=5.19, 95% CI 2.20-12.26, P<0.001) remained significant predictors. The severity of the psychiatric disorder of the parent (P=0.085), parental knowledge about the difficulties of the child (P=0.081) and ethnic background of the primary caregiver (P=0.104) were no longer significantly associated with the dependent variable.

The model of the child, parent and family/social context predictors together showed a good fit of the data (Hosmer-Lemeshow, P=0.511), and illustrated a relatively strong relation between the predictor variables and the outcome (Nagelkerke R^2=0.61). The AUC under the ROC curve suggested that the model has an excellent classification ability to discriminate the referral to regular outpatient care with Youth ACT (AUC=0.91, 95% CI 0.87-0.95, P<0.001).

Table 4. Predictors of Youth ACT

	Child[1]		Child and parent[2]		Child, parent and family/ social context[3]	
Level of predictors	**Multivariable model[4]**		**Multivariable model**		**Multivariable model**	
	OR[5] (95% CI[6])	**P-value[7]**	**OR (95% CI)**	**P-value**	**OR (95% CI)**	**P-value**
Child						
HoNOSCA[8]	1.31 (1.22-1.41)	<.001	1.21 (1.12-1.30)	<.001	1.19 (1.11-1.29)	<.001
CANSAS[8]	0.96 (0.90-1.02)	0.186				
Parent[9]						
HoNOS[8]			1.13 (1.05-1.21)	<.001	1.07 (0.99-1.15)	0.085
Parental stress			1.36 (1.15-1.60)	<.001	1.35 (1.13-1.62)	0.001
Lack of knowledge pertaining to difficulties			1.39 (1.00-1.92)	0.049	1.34 (0.96-1.87)	0.081
Family/social context						
Domestic violence					5.19 (2.20-12.26)	<.001
Ethnic background primary caregiver: *Dutch* *Other*					0.40 (0.13-1.21)	0.104

[1] Child-level: Omnibus test, Step P= 0.00, Model P=<0.00, Hosmer-Lemeshow, P=0.26, Nagelkerke R^2=0.43, AUC=0.84, 95% CI 0.78-0.89, P<0.001
[2] Child-parent-level: Omnibus test, Step P=0.00, Model P=<0.00, Hosmer-Lemeshow, P=0.17, Nagelkerke R^2=0.56, AUC=0.89, 95% CI 0.85-0.93, P<0.001
[3] Child-parent-family/social context-level: Omnibus test, Step P=0.00, Model P=<0.00, Hosmer-Lemeshow, P=0.51, Nagelkerke R^2=0.61, AUC=0.91, 95% CI 0.87-0.95, P<0.001
[4] Multivariable: binary logistic regression analysis of all predictors entered simultaneously
[5] OR: Odds Ratio
[6] CI: Confidence interval
[7] P-value<0.10 is considered statistically significant
[8] Sum-score
[9] Parent: primary caregiver

Discussion

This cross-sectional study examined the patient, family and contextual variables that are associated with treatment intensification from regular outpatient care to a more intensive form of treatment: Youth ACT. To our knowledge, this is the first study that provides a much more detailed insight into the variables that are associated with intensifying outpatient treatment towards more intensive treatment. Through the step-by-step logical regression, a view is obtained on the hierarchy of these variables. By applying the step-by-step logistic regressions, we determined which variables are the strongest predictors of intensification of treatment. As hypothesized, we found many univariable associations between candidate predictors and intensification of

treatment (see table 3). However, not all variables that were entered as possible predictors of intensification of treatment were significant (see table 2). In contrast to our expectations, significant effects of level of social support and educational status of parents on treatment intensification were not found. Number of children in the family did not predict treatment intensification as well.

Our findings indicate that children in whom outpatient care is intensified are likely to have parents with more psychiatric problems (see table 3). A cross-sectional relation like this can be explained in three different ways: X caused Y, Y caused X or there is a third variable causing X and Y [36]. Hence, a possible explanation is that severe psychiatric problems of the child negatively affect a parent's mental health [37]. Conversely, severe psychiatric problems in parents may also negatively affect a child's mental health [37, 38]. Finally, third variables, for instance, similar genes, or living in a similar adverse environment, may influence mental health in parents and their children. We also found that parents of children in whom outpatient care is intensified display high levels of parental distress. This association may indicate that serious psychiatric symptoms in the child, that require more intense treatment, cause a high level of distress in parents, or vice versa. But, a variable influencing both psychiatric symptoms in a child, as well as parental distress, may be present as well. A relation was also found between treatment intensification and lower quality of life and more care needs in parents (see table 3). Regardless of the direction or exact nature of associations between, on one hand, treatment intensification, and on the other hand, parental mental health, parental distress, parental quality of life, and parental care needs, it is clear that all associations found possibly indicate a diminished ability of the parent to support children who are at risk for treatment intensification. In other words, several parental characteristics that were found may negatively influence treatment effects in their children [39-42].

Existing guidelines for intensive forms of treatment suggest that children who are living in families where children and parents experience many problems need a system-oriented approach [43, 44]. However, a classical system-oriented approach does not seem to be sufficient, because this approach does not specifically focus on the psychiatric problems of parents, and on their care needs and quality of life. Our findings suggest that this may be necessary, in addition to the classic system-oriented approach. When conducting multivariable analyses including all levels, three variables - severity of psychiatric disorder of the child, parental stress and domestic violence - remained significant. The logistic regression model that included these three predictors showed a strong relation between the predictor variables and the outcome illustrated by the Nagelkerke R^2 of 0.61 and has an excellent ability to discriminate (AUC=0.91, 95% CI 0.87-0.95, P<0.001), indicating a high predictive value. We may conclude that children with severe psychiatric disorders, who live in a context where parents experience high

levels of parental stress and where domestic violence takes place, are most likely to be referred from outpatient care to a more intensive form of treatment. A possible explanation is that there are negative reciprocal interactions patterns between domestic violence, parental stress and the severe psychiatric disorders in children [45]. When health care providers, together with patient and family members, are not able to break through these negative reciprocal interaction patterns when offering regular outpatient care, referral to more intensive treatment (such as Youth ACT) is needed.
The effect sizes found in relation to domestic violence and parental stress are remarkable when we consider that existing guidelines for children and adolescents do not contain recommendations regarding stopping domestic violence and reducing parental stress [46-49]. Our results show that it is important to encourage guidelines to include recommendations regarding these issues.
For clinical practice, our findings indicate that health care professionals should pay extra attention to children with severe psychiatric disorders, parents who are stressed, and families characterized by domestic violence. A first step would be to assess (all of these) problems systematically. In case of high HoNOSCA-scores, it is especially important to assess parental stress and domestic violence as well. If problems exist in these areas, it may be important to focus treatment not only on reducing psychiatric problems, but also on parental stress and domestic violence. Another, important finding (see table 4), is the prediction of treatment intensification by parental stress, and not by HONOS-scores of the parent in the final analysis. Our finding, parental stress scores being very important, is of clinical significance, because it shows that, instead of screening parents for a broad range of psychiatric disorders, which is time consuming, one single question (parental stress was assessed on a visual analogue scale in our study) regarding parental stress is sufficient to screen for children/ adolescents with a poor prognosis.
To our knowledge, regular outpatient treatment and Youth ACT programs do often not incorporate specific modules targeted at parental stress and at domestic violence [43]. The present study shows that, by adding such modules to outpatient treatment and Youth ACT programs might decrease the need for ACT. This is not to say that in the daily practice of an outpatient clinic or Youth ACT team, mental healthcare providers do not pay attention to reducing parental stress and domestic violence, but it is different to focus treatment specifically on these problems.

Strengths and limitations

This study has several strengths. First, to our knowledge, this is the first study that examined the patient, family and contextual variables that are associated with referral to regular outpatient care or Youth ACT together. Second, a methodological strength of this study is that the Youth ACT sample consisted of patients that were referred

directly from outpatient clinics in the same geographical catchment area, which assured a fair comparison of both groups. Third, the data was collected from a relatively large sample (n=246) and had limited missing values (3%). The power of the analyses was sufficient to draw relatively firm conclusions about the associations between characteristics of patients, their families and living context on the one hand, and treatment intensity on the other hand. Fourth, in order to prevent bias, the data in both samples were collected during the intake-phase of both types of treatment. A clear limitation of the study is that data were collected in one Youth ACT team and two outpatient clinics from the same mental health organization. Therefore, the results of this study cannot be generalized without reservations [36]. However, it is worthwhile to note that this study is not about a specific treatment modality, but about the phenomenon of intensification of outpatient treatment. This intensification may occur in various forms, but always involves the intensification of treatment compared to regular outpatient care. Although the Dutch situation and/or treatment facilities are specific, they are also very similar to the international guideline-based care for children and adolescents. Therefore, generalisability of our findings seems not only limited to Dutch situation, despite the variation in practice across various countries.

Recommendations

Domestic violence and parental stress are strong predictors of treatment intensification. Therefore, research is needed to determine whether the addition of special modules targeted at domestic violence and parental stress can actually prevent intensification of treatment, but also to improve effects of intensive treatment.

To date, studies examining Youth ACT mainly focussed on child-related factors, such as severity of psychiatric symptoms, general functioning, and duration and frequency of psychiatric hospital admissions [50]. In line with our research, it is important that future research regarding treatment intensification to Youth ACT includes variables at child, parent and family/social context level. The results of this study emphasize the importance of a system-oriented approach with primary attention for problem solving and stress reduction within the system, in addition to the psychiatric treatment of the child, and possibly also the parents.

Conclusion

To summarize, child, parent and family-social context factors predict treatment intensification from outpatient care to Youth ACT. Although each domain has a unique and important contribution to make, and although variables across domains are correlated, the combination of the three domains adds substantially to the predictive power of the model (increasing from Nagelkerke R^2 0.36-0.45 in the three domains

separately, to 0.61 when all domains were combined). Nagelkerke R^2 of 0.61 for treatment allocation is a high predictive power.

The strongest predictors regarding treatment intensification from outpatient care to Youth ACT are the severity of psychiatric disorders of the child, parental stress and domestic violence. From the perspective of prevention and effectiveness it is important to examine whether influencing parent and family-social context factors affects the mental health situation of the child and its need for Youth ACT.

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CHAPTER 4

Unmet needs of children with adhd

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Abstract

Background

Non-compliance to, or drop-out from treatment for childhood ADHD, result in suboptimal outcome. Non-compliance and drop-out may be due to mismatches between patients' care needs and treatments provided. This study investigated unmet care needs in ADHD patients. Unmet needs were assessed in two different treatment settings (general outpatient setting versus Youth ACT). Youth ACT treatment is an intensive outreach-oriented treatment for patients with severe psychiatric and psychosocial problems. Comparison of a general outpatient sample with a Youth ACT sample enabled us to assess the influence of severity of psychiatric and psychosocial problems on perceived care needs.

Method

Self-reported unmet care needs were assessed among 105 ADHD patients between 6 and 17 years of age in a general outpatient (n=52) and a Youth ACT setting (n=53).

Results

ADHD patients most frequently reported unmet needs regarding mental health problems, information on diagnosis/treatment, and future prospects. Outpatients differed from Youth ACT patients with respect to 30% of the unmet care needs that were investigated. Outpatients perceived more unmet needs regarding information on diagnosis/treatment (p=0.014). Youth ACT patients perceived more unmet needs concerning medication side effects (p=0.038), quality and/or quantity of food (p=0.016), self-care abilities (p=0.016), regular/suitable school or other daytime activities (p=0.013), making and/or keeping friends (p=0.049), and future prospects (p=0.045).

Conclusions

Focusing treatment of ADHD patients on unmet needs may reduce non-compliance and drop-out. In clinical practice, systematic assessment of unmet care needs in all ADHD patients may be warranted, e.g. using the CANSAS questionnaire during the screening/intake phase.

Introduction

With a worldwide prevalence rate of approximately 5%, attention-deficit/hyperactivity disorder (ADHD) is one of the most common psychiatric disorders in children and adolescents [1]. ADHD is characterized by excessive and developmentally inappropriate symptoms of inattention- disorganization, hyperactivity and impulsiveness [2]. The consequences of ADHD to well-being and daily functioning vary according to the severity of symptoms and impairments that affect daily activities such as self-care and handling money [3, 4]. They also affect participation in the community (e.g., school attendance and keeping friends) [5, 6].

If intensive psychiatric treatment is needed, children and adolescents with ADHD in the Netherlands are referred to specialized general outpatient clinics by a general practitioner [7]. Treatment generally focusses on reducing symptoms and improving psychosocial functioning [6, 8]. Common treatments include medication (e.g. stimulants); behavioral therapy and cognitive behavioral therapy; psycho-education, organization and planning-skills training; social skills training; and parental support [9, 10]. If even more intensive mental healthcare is necessary, patients can be referred to Youth Assertive Community Treatment (Youth ACT). ACT is an intensive and outreach-oriented treatment for patients with severe psychiatric and psychosocial problems. Treatment is provided by a multidisciplinary team of mental healthcare professionals [11-13].

Although effective treatments are available, many children and adolescents with psychiatric disorders remain undertreated [14-16]: in over 40% of patients, the proper delivery of psychiatric treatment interventions is hampered by non-attendance, non-compliance, or drop-out [17-22]. Several factors are associated with these problems, one of the most prominent being the mismatch between a patient's perceived care needs and the treatment that is actually provided [15, 23]. Perceived needs can be subdivided into (1) met needs, i.e., difficulties in a particular domain of functioning that are adequately taken care of; and (2) unmet needs, i.e., those for which a patient believes that he or she is not receiving the right care or the appropriate level of care [24].

At present there is little information on the perceptions of children and adolescents with ADHD regarding their met and unmet care needs. To examine these patients' care needs, previous studies have either used small samples [25, 26], or samples that also included young adults with autism spectrum disorder [27]. Other studies on ADHD patients' care needs focused on the parents' perspectives [26, 28]. But while information on the latter is important, it is not enough, especially as a parent's perspective on an adolescent patient may differ significantly from that of the patient himself or herself [24, 29, 30]. Moreover, insight into the perception of ADHD patients may help to enhance their adherence to treatment [31].

To improve our understanding of receiving treatment in specialized mental healthcare, we studied met and unmet care needs according to the categories of the International Classification of Functioning and Disability (IFC) [6, 32]. Because care needs may vary depending on the intensity of care we included patients who had been referred to an outpatient mental healthcare setting, or to a setting providing youth Assertive Community Treatment (Youth ACT) [11]. This comparison enabled us to judge the influence of severity of psychiatric and psychosocial problems on unmet care needs [13]. Further, since parents are involved differently in younger versus older children, we investigated unmet care needs in two age groups: primary school children and adolescents.

On the basis of the literature, we had two *a priori* hypotheses: (1) that ADHD patients treated in the Youth ACT setting would experience more unmet care needs than those treated in a general outpatient care setting [11, 13, 33]; and (2) that the greatest differences between patients in the two settings would involve participation in the community, with more recipients of Youth ACT perceiving that their care needs were not being met [2, 34, 35].

Method

Design

This cross-sectional study was conducted between 2015 and 2017 with patients treated in two general outpatient clinics or a Youth ACT setting, all being part of a large mental healthcare institution in the Netherlands.

Setting

Participants were recruited from two general outpatient treatment settings and one Youth ACT team.

Treatment in the general outpatient settings was provided by a multidisciplinary team consisting of one child psychiatrist, six psychologists, and one nurse practitioner.

The Youth ACT team consisted of one child psychiatrist, five psychologists, three nurse practitioners and two mental health nurses. It offered outreach-oriented (home-based) treatment to patients with more severe psychiatric and psychosocial problems who were often difficult to reach. Staff in this Youth ACT team had small shared caseloads (<15 patients) and provided intensive and outreach-oriented case management, early intervention, behavioral therapy (including cognitive behavioral therapy), family support, and pharmacological treatment. The intensity of the treatment could be scaled up or down according to the severity of current psychiatric symptoms and a patient's specific psychosocial impairments.

Participants

Participants were patients aged between 6 and 17 years, all of whom had been diagnosed with ADHD. One child per household was allowed to participate in the study. A random sample was selected from the general outpatient population. For the Youth ACT sample, we included all patients who were referred to this treatment setting during the inclusion period. These ACT-patients all had received prior general outpatient treatment. A total of 121 patients were eligible for inclusion. The final sample consisted of 105 patients: 52 in the outpatient sample and 53 in the Youth ACT sample. Fig 1 presents the flowchart for inclusion.

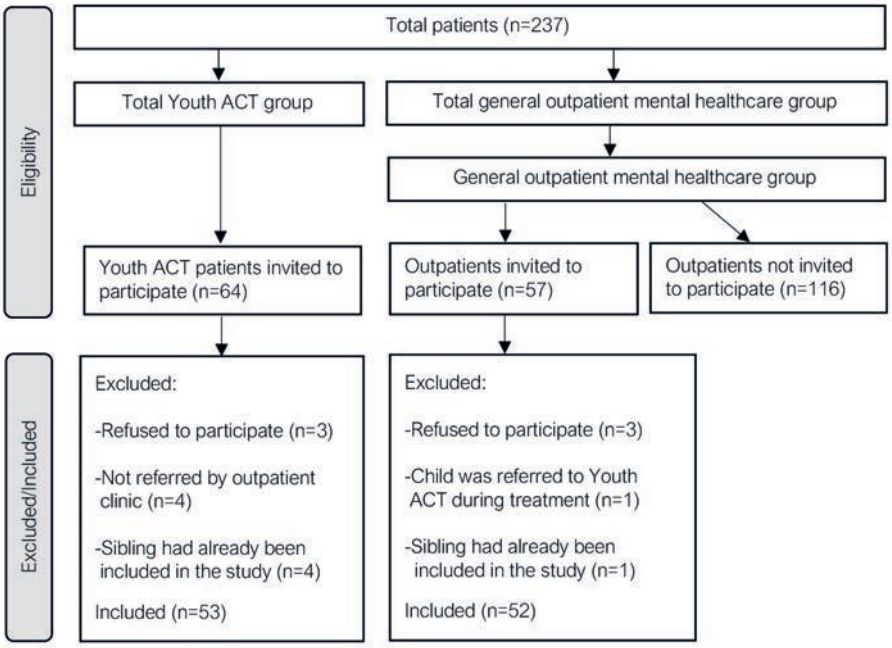

Figure 1. Participant flow diagram

Ethical approval

The study was reviewed and approved by the Medical Ethical Committee and the Scientific Committee at the EMGO+ Institute for Health and Care Research at VU University Medical Centre in Amsterdam (protocol no. 2015.245), and by the local scientific review board at the participating institution. Written and oral information on the research project was provided separately to the children or adolescent participants and their parents.

In keeping with prevailing legislation in the Netherlands, written consent from the parents and/or children/adolescents was obtained according to three age categories. Category 1: Parents were asked for consent for children younger than 12 years old. Category 2: If children were aged between 12 and 16, parents and children were both asked for consent. Category 3: Informed consent was obtained from an adolescent if he or she was aged 16 or older.

Measurement instruments

A child or adolescent's demographic characteristics were measured using the Demographic Information Questionnaire (DEMOG), a designated client-based standardized questionnaire used to measure the following demographic characteristics: (1) age, (2) gender, and (3) living situation [36].

Patients' psychiatric diagnoses were assessed using the Neuropsychiatric Interview for Children and Adolescent (MINI-KID), supplemented with clinical diagnoses based on the DSM-5 that are not included in the MINI-KID [2, 37].

Currently, there is no "gold-standard" for assessing care needs in patients with childhood ADHD. To assess unmet care needs in children and adolescents, the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) [38] has been used in previous research [27]. The CANSAS was judged as the most appropriate of the available needs assessment instruments, as it is the most widely used needs assessment tool in general mental health services [27]. The CANSAS covers 24 items, each of which distinguishes three levels of care need: (1) no need (= no problem), (2) met need (no or moderate problem because of help received), (3) and unmet need (current serious problem, regardless of any help received) [39, 40]. The CANSAS items were categorized using the following ICF (International Classification of Functioning, Disability and Health) health and health-related domains: (a) physical and mental functions, (b) performance of daily activities, (c) participation in the community [6, 32, 41]. The CANSAS was administered in a face-to-face interview with the patient during the intake procedure.

At the outpatient clinics, measurements were conducted on the day of the first appointment (intake). In the Youth ACT setting, measurements after the first (intake) or second appointment. In both settings, measurements for this study took place before patients and parents were informed about results of the clinical assessments. For children below the age of 12, the interview was carried out in the presence of the parent. The parent was encouraged to support the child in answering the question if the interviewer felt that the child's answer was unclear. Prior to the interview, parents were instructed not to answer for the child, but to clarify the questions in such a way that the child was able to answer the question from his or her own perspective.

Data-analysis

To analyse the background characteristics and the total number of self-reported unmet care needs, descriptive statistics were computed, for the overall sample and for the two subgroups separately (patients from the general outpatient setting and patients from the Youth ACT sample).

Subgroup differences were analysed using the *t*-test for continuous variables, chi-square test with Yates continuity correction (= χ^2-test), or, if the expected number in at least one of the cells was smaller than 5, with the Fisher Exact test [42]. A value below $p < 0.05$ was considered to be statistically significant.

To investigate the association between age and unmet care needs, we constructed two subgroups, i.e., primary school children (age 6-12 years) and adolescents (age 13-17 years). For the overall sample, we performed the Chi-square test with Yates continuity correction (= χ^2-test) to analyse differences between these two age groups for unmet care needs reported by at least 20% of the respondents.

All statistical procedures were performed using SPSS 24.0.

Results

Characteristics of the sample

Table 1 shows demographic characteristics of our two samples. Patients in the outpatient sample had significantly higher GAF-scores than those in the Youth ACT sample (mean = 54.7, sd = 5.5 vs. mean = 46.5, sd = 8.3). There were no significant differences between the outpatient sample and Youth ACT sample regarding age, gender, country of birth, type of ADHD diagnosis, and living situation.

The mean age in the outpatient sample (n = 52) was 11.2 years (sd = 2.8). A majority of the outpatients were boys (65.4%), most of whom were being raised in a two-parent household (69.2%). About two-thirds of outpatients (69.2%) had been diagnosed with ADHD combined type.

In the Youth ACT sample (n = 53), the patients' mean age was 12.3 years (sd = 3.2). As in the outpatient sample, a majority of Youth ACT sample consisted of boys (69.8%); and most patients (64.2%) were being raised in a two-parent household. A majority of patients in this subsample of Youth ACT patients had also been diagnosed with ADHD combined type (79.2%).

Domains of needs

Using the ICF domains, the results of this study will be first described for the overall sample, followed by the results for the two different treatment settings separately. For reasons of brevity, we only highlight unmet care needs with a frequency of 15% or more in the text of this manuscript.

Table 1. Sample characteristics of the child or adolescent who received treatment

	Outpatient Child (n=52)		Youth ACT Child (n=53)		t-test/ χ^2 -test (2-sided)/ Fisher's Exact test	*P*
Age (sd)	Total mean	11.2 (2.8)	Total mean	12.3 (3.2)	-1,76^{t}	0.08
	range	6-17	range	6-17		
	Girls mean	11.1 (3.4)	Girls mean	13.8 (1.7)		
	range	6-17	range	10-17		
	Boys mean	11.3 (2.5)	Boys mean	11.6 (3.5)		
	range	6-15	range	6-17		
Gender	Girls	34.6%	Girls	30.2%	0.08^{X2}	0.782
	Boys	65.4%	Boys	69.8%		
Country of birth	The Netherlands	100.0%	The Netherlands	94.3%		0.243^{FE}
	Other	0.0%	Other	5.7%		
ADHD diagnosis	Combined	69.2%	Combined	79.2%	0.90^{X2}	0.342
	Inattention	30.8%	Inattention	20.8%		
GAF-score (sd)	Mean	54.7 (5.5)	Mean	46.5 (8.3)	5.91^{t}	0.000
	Range	45-75	Range	15-55		
Living situation	Single parent	30.8%	Single parent	35.8%	0.12 ^{X2}	0.730
	Two parents	69.2%	Two parents	64.2%		

n: number of included patients
sd: standard deviation
GAF: general assessment of functioning
p: p-value; a value below 0.05 is considered to be statistically significant. Independent sample *t*-test was performed to compare the mean score between the outpatient and Youth ACT samples with respect to continuous variable. The χ^2 –test with a continuity correction was used to test the difference between the outpatient and Youth ACT sample with regard to a categorical variable with df=1. The Fisher's Exact test was performed because the number in at least one of the cells in the child or care provider sample was 5
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Physical and mental functions

As Table 2 shows, mental health problems were the most frequently reported unmet care need in children and adolescents with ADHD: 61% reported an unmet need in this area (outpatient sample 66.0%; Youth ACT sample 57.7%; n.s.). The second most frequently reported unmet care need – which was reported by 47.6% of all patients – concerned information on diagnosis and treatment. 60.4% of the outpatient sample vs. 34.6% of the Youth ACT sample reported this need ($p < .05$). Nearly a fifth of all ADHD patients (18.1%) perceived unmet care needs regarding medication-related side effects. This item differed significantly ($p < .05$) between the outpatient sample (9.4%) and Youth ACT sample (26.9%). Almost nine percent of all ADHD patients perceived unmet needs regarding the quality and/or quantity of food. Outpatients reported significantly fewer unmet care needs on this item than patients treated with Youth ACT (1.9% vs. 15.4%; $p < .05$).

Performance of daily activities

About 17% of all ADHD patients reported unmet care needs with respect to reading and writing skills. No significant differences were found between ACT-patients and regular outpatients. About ten percent of all ADHD-patients (10.5%) reported unmet needs pertaining to handling money, with no significant difference between the two samples. In the overall sample, about nine percent (8.6%) of the patients reported unmet care needs regarding their abilities for self-care (e.g., oral health, daily hygiene, and clothing). Patients in the Youth ACT sample reported significantly more unmet care needs on this item (15.4% vs. 1.9%; $p < .05$).

Participation in the community

Almost 29% of all ADHD patients in the overall sample perceived their future prospects (i.e., their opportunities/chances for a successful and prosperous life) as an unmet care need. Those referred for ACT-treatment reported unmet care needs in this area more frequently than those who we referred for regular treatment (38.5% vs. 18.9% respectively, $p < .05$).

More than a fifth of the ADHD patients in the overall sample (21.9%) perceived unmet needs regarding making and/or keeping friends, with a significant difference between the Youth ACT sample (30.8%) and the outpatient sample (13.2%; $p < .05$). Twenty percent of all ADHD patients reported unmet needs with respect to having regular and suitable school or other daytime activities (e.g., practicing a sport/hobby). The scores between the outpatient (9.4%) and Youth ACT samples (30.8%) differed significantly ($p < .05$).

Comparing children and adolescents

In the overall sample, no significant differences were found between primary school children (age 6-12 years) and adolescents (age 13-17 years) regarding the five most frequently reported unmet care needs: mental health problems, information on diagnosis and treatment, having regular and suitable school or other daytime activities, making and/or keeping friends, and future prospects.

Table 2. Unmet Needs overview

Unmet needs domains	Overall n (=105)	%	Youth ACT n (=53)	%	Outpatient n (=52)	%	Corrected χ^2-test (2-sided)/ Fisher's Exact test	*P*
Physical and mental functions								
Mental health problems (not psychotic)	65	61.9	30	57.7	35	66.0	0.46 (df=1)	0.497
Danger to others	10	9.5	5	9.6	5	9.4	0.00 (df=1)	1.000
Danger to themselves	7	6.7	4	7.7	3	5.7	FE	0.716
Psychotic symptoms	7	6.7	2	3.8	5	9.4	FE	0.449
Information regarding diagnosis/treatment	50	47.6	18	34.6	32	60.4	5.99 (df=1)	0.014
Physical handicap or disease	6	5.7	3	5.8	3	5.7	FE	1.000
Medication side effects	19	18.1	14	26.9	5	9.4	4.30 (df=1)	0.038
Drugs misuse/alcohol abuse	-	-	-	-	-	-	-	-
Food (qualitative or quantitative)	9	8.6	8	15.4	1	1.9	FE	0.016
Performance of daily activities								
Reading/writing skills at expected grade level	18	17.1	5	9.6	13	24.5	3.13 (df=1)	0.077
Handling money	11	10.5	5	9.6	6	11.3	0.00 (df=1)	1.000
Self-care abilities (age-related)	9	8.6	8	15.4	1	1.9	FE	0.016
Paid job (including side jobs)	7	6.7	4	7.7	3	5.7	FE	0.716
Cleaning up room (or bedroom)	5	4.8	2	3.8	3	5.7	FE	1.000
Caring for someone else (family member or pet)	1	1.0	1	1.9	-	-	FE	0.495
Participation in the community								
Regular/suitable school or other daytime activities	21	20.0	16	30.8	5	9.4	6.19 (df=1)	0.013
Making and/or keeping friends	23	21.9	16	30.8	7	13.2	3.76 (df=1)	0.049
Future prospects (opportunities/chances for a successful and prosperous life)	30	28.6	20	38.5	10	18.9	4.02 (df=1)	0.045
Access to (public) transport	5	4.8	3	5.8	2	3.8	FE	0.678
Housing	3	2.9	2	3.8	1	1.9	FE	0.618
Access to modern tools of communication	2	1.9	1	1.9	1	1.9	FE	1.000
Intimate relations	4	3.8	3	5.8	1	1.9	FE	0.363
Sexuality	1	1.0	1	1.9	-	-	FE	0.495

n: number of included patients
p: p-value; a value below 0.05 is considered to be statistically significant. The χ2 –test with a continuity correction was performed because df =1. Fisher's Exact test was performed if the number in at least one of the cells in the Youth ACT or outpatient sample was <5
FE: Fisher's Exact test
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Discussion

Non-compliance with, or drop-out from treatment, result in suboptimal results of treatment of childhood ADHD. We therefore studied unmet care needs in children and adolescents with ADHD in two treatment settings. Compared to young adults, in whom unmet care needs in various areas were found to a frequency of up to thirty percent [27], children and adolescents with ADHD reported levels of unmet needs up to sixty percent. Further, differences in frequencies of unmet needs were found between an outpatient versus a Youth ACT sample. To our knowledge, this is the first study regarding unmet care needs in children and adolescents with ADHD in such samples.

Overall sample

We found considerable variations in the frequencies with which ADHD patients reported unmet care needs. The three self-reported unmet care needs most reported by children and adolescents with ADHD lay in two domains: (1) mental health problems and information on diagnosis and/or treatment (in the domain of physical and mental functions); and (2) future prospects (in the domain of participation in the community). Given the admission of these patients to a specialized mental health treatment setting, the high number reporting these unmet care needs is what one would expect. For the same reason, however, it is striking that so many of the children and adolescents with ADHD reported no unmet care needs related to mental health problems (40%), information on diagnosis and/or treatment (50%), and future prospects (70%). Various explanations for this are possible. For example, these patients – who had already been referred to specialized mental healthcare – were aware of their problems, but considered the help they were receiving to be sufficient (meaning that their needs were being met). Alternatively, unlike their parents or mental healthcare providers, these patients had been unaware of their problems, which is why others had had to take the initiative for their treatment.

In clinical practice, such potential discrepancies in perception are significant. Our findings indicate that if a mental health problems is objectively diagnosed by a clinician, it is simultaneously important to determine whether there are differences in perceptions on the patient's (mental) health problems [43, 44]. If present, such differences may reduce the quality of any agreement between patient and mental health professionals on treatment goals and treatment options (tasks) during treatment [45]. Clarifying any possible different perceptions of care needs and exploring differing perceptions of necessary treatment may help prevent non-attendance, non-compliance and drop-out [46, 47].

No significant differences were found between primary school children and adolescents regarding the five most frequently perceived unmet care needs: mental health

problems, information on diagnosis and treatment, having regular and suitable school or other daytime activities, making and/or keeping friends, and future prospects. This is remarkable because we assumed that adolescents, due to their cognitive development and decrease of parental support, would be more aware of their problems and therefore would perceive more unmet care needs than younger children [48]. Further, the nature of unmet care needs might change across development. The lack of significant age effects may indicate that young children may be as aware of unmet care needs as adolescents. Further, in their desire for autonomy [48], adolescents may under-report unmet care needs.

Another interesting finding is that ADHD patients perceived no unmet care needs for drug misuse or alcohol abuse. This is remarkable because ADHD often co-occurs with substance abuse and dependence (e.g. cannabis misuse) [49-51]. Several factors may explain why children and adolescents expressed no unmet care needs in this area. It may be that actual use was relatively low in our sample because patients with problematic drug misuse or alcohol abuse were referred to specialized drug treatment centers. But it is also possible that patients with problematic alcohol or substance abuse did not perceive their use as a problem.

Comparing outpatient clinics with Youth ACT

Our comparison of outpatient clinics and Youth ACT revealed significant differences between settings regarding a quarter of the unmet care needs we investigated. In line with our a priori hypotheses, ADHD patients from the Youth ACT setting reported significantly more unmet care needs than those treated in the general outpatient care setting. The notable exception, in the domain of physical and mental functions, was that outpatients with ADHD were more likely than those in the Youth ACT sample to perceive unmet needs with respect to information on diagnosis and treatment.

The differences between the two settings regarding unmet needs could not be explained by age, gender, type of ADHD diagnosis, living situation or country of birth. However, comparison between the two treatment settings showed a significant difference regarding the GAF-score, indicating that ACT patients had more problems in daily functioning [2].

For the purpose of conciseness, only the results with the most clinical relevance will be highlighted now.

More frequent unmet needs in outpatient clinics

Outpatients with ADHD were more likely than those in the Youth ACT sample to perceive unmet needs with respect to information on treatment. One possible explanation for this is that patients in the Youth ACT setting had already received this information during their previous outpatient treatment, whereas many outpatients

who had recently started treatment had not. Another possible explanation is that ADHD patients in the Youth ACT setting were less interested in obtaining information on treatment because of limited engagement in treatment.
As patients' treatment adherence can be significantly improved by obtaining relevant information on treatment options and possible outcomes, we recommend that care providers investigate whether patients need such information. We also recommend that care providers investigate why a patient does not report a need for information [47]. Treatment adherence and treatment outcome may be improved by a process of shared decision-making based on shared information [52, 53].
For clinical practice, our findings suggest that many patients consider themselves uninformed about assigned diagnoses (60%) in the general outpatient group, and one third in the Youth ACT group. In both settings, clinicians should pay close attention to providing in information about diagnosis and treatment.

More frequent unmet needs in Youth ACT

In the domain of physical and mental functions, side effects of medication were perceived significantly more by Youth ACT patients than by outpatients. Given the severity of their psychiatric problems, it may be that ADHD patients in the Youth ACT setting are more likely to perceive side effects, because their treatment requires more intensive medication. It is likely that the side effects of medication they experience have a negative impact on medication compliance, and, in turn, on treatment outcome [54]. A particular recommendation for professionals in Youth ACT settings is to thoroughly identify such side effects. If necessary, action can be taken to reduce them.
With further regard to the domain of physical and mental functions, significantly more patients with ADHD in the Youth ACT setting perceived unmet needs with respect to food quality and quantity. Unmet needs in this area were reported by 15.4% of the Youth ACT sample. A possible explanation is that children treated with ACT often grow up in families with limited financial resources and more financial problems, which can lead to less healthy food patterns [11-13]. Because more than one out of ten Youth ACT patients with ADHD reported problems with food, we recommend that clinicians who treat the most vulnerable ADHD patients, in Youth ACT samples or other high-risk samples such as inpatient samples, routinely assess needs in this area. Lack of healthy food attenuates psychological and social functioning, and may influence motivation for treatment, which in turn could lead to suboptimal treatment outcome [55].
We should also draw attention to the high level of unmet care needs related to participation in the community in the Youth ACT sample. This finding is in line with our a priori hypotheses. The largest difference between patients from the two settings involved participation in the community. Recipients of Youth ACT perceived more unmet care needs in this area. As Youth ACT focuses specifically on enhancing patients'

societal functioning, this score indicates that most of these patients had been referred to the appropriate treatment setting.

A high number of Youth ACT patients in this study reported unmet needs with regard to future prospects, regular and/or suitable school or other daytime activities, and making and/or keeping friends. Problems in these areas may potentially threaten a young person's development. Hence, it is important that healthcare providers, especially those in Youth ACT settings, identify the causes underlying these problems, and subsequently initiate treatment interventions that are likely to meet the unmet care needs in question [48, 55-58]. For children and adolescents with ADHD belonging to a high-risk sample, such as those who are treated with Youth ACT, this implicates that routine assessment of school functioning, being one of the hallmarks of state-of-the-art investigation, may not be enough. Broader assessment of societal functioning, including patients' views on chances in society (future prospects), daytime activities, and abilities to make or keep friends, may be needed if regular outpatient treatment is not successful. Because patients report high frequencies of unmet needs in these areas, targeting these factors may ameliorate treatment outcome. In other words, in high-risk ADHD patients, drug treatment and other—merely—symptom focused interventions may not be sufficient.

Strengths and limitations

This is the first study to investigate the self-reported perceived care needs of children and adolescents with ADHD who had been referred to general outpatient care or Youth ACT. Our inclusion of the latter in our sample enabled us to examine the perceived unmet care needs of ADHD patients with severe psychiatric and psychosocial problems who, after failing to respond to regular interventions, had been referred to more intensive Youth ACT treatment. By comparing the perceived unmet care needs between the two samples, we were thus able to provide insight into the unmet needs of children with ADHD receiving treatment in two treatment settings characterized by different intensities of treatment. This enabled us to study the influence of severity of psychiatric and psychosocial problems on unmet care needs.

A clear limitation is the cross-sectional design of the study, which prevented us from providing causal explanations for the occurrence and persistence of unmet care needs.

Conclusions

In summary, the three most important unmet care needs perceived by ADHD patients concerned mental health problems, information on diagnosis and/or treatment, and future prospects. While outpatients perceived more unmet care needs regarding information on diagnosis/treatment, those treated within the Youth ACT setting reported more unmet needs concerning medication side effects, quality and/or quantity of food, self-care abilities, regular/suitable school or other daytime activities, making and/or keeping friends, and future prospects. Our data suggest that focusing treatment of ADHD patients on unmet needs, and not only on ADHD symptoms, may motivate patients, and may reduce non-attendance, non-compliance, and drop-out. It remains to be tested whether a needs-led approach would indeed improve treatment outcome.

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CHAPTER 5

Agreement between patients and mental healthcare providers on unmet care needs in child and adolescent psychiatry

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Abstract

Background

In mental healthcare, patients and their care providers may conceptualize the nature of the disorder and appropriate action in profoundly different ways. This may lead to drop-out and lack of compliance with the treatments being provided, in particular in young patients with more severe disorders. This study provides detailed information about patient-provider (dis)agreement regarding the care needs of children and adolescents.

Method

We used the Camberwell Assessment of Need (CANSAS) to assess the met and unmet needs of 244 patients aged between 6 and 18 years. These needs were assessed from the perspectives of both patients and their care providers. Our primary outcome measure was agreement between the patient and care provider on unmet need. By comparing a general outpatient sample (n=123) with a Youth ACT sample (n=121), we were able to assess the influence of severity of psychiatric and psychosocial problems on the extent of agreement on patient's unmet care needs.

Results

In general, patients reported unmet care needs less often than care providers did. Patients and care providers had the lowest extents of agreement on unmet needs with regard to "mental health problems" (k=0.113) and "information regarding diagnosis/ treatment" (k=0.171). Comparison of the two mental healthcare settings highlighted differences for three-quarters of the unmet care needs that were examined. Agreement was lower in the Youth ACT setting.

Conclusions

Clarification of different views on patients' unmet needs may help reduce non-attendance of appointments, non-compliance, or drop-out. Routine assessment of patients' and care providers' perceptions of patients' unmet care needs may also help provide information on areas of disagreement.

Introduction

Over 40% of the children and adolescents who use mental healthcare terminate treatment prematurely, do not comply with treatment, or do not attend appointments regularly [1, 2]. Although this is a complex issue, one important factor may be that patients and mental healthcare providers do not agree on the nature of the problems and on the unmet care needs that need to be addressed during treatment [3-5]. Such a lack of agreement may lead to disagreement on the goals to be pursued and on appropriate treatment trajectories [6]. By negatively affecting attachment between patient and care provider, it may also affect their working relationship [7-9]. If the quality of the working alliance is poor, mental health problems may increase and functioning may deteriorate, ultimately leading to referral to a more intensive form of care [10-13].

We defined a "care need" as a physical, psychological, social or environmental demand for aid, care or service intended to resolve a problem that a patient or his/her care provider perceived and expressed [14]. Care needs can be subdivided into (1) met needs, i.e., difficulties in a particular domain of functioning that are adequately taken care of; and (2) unmet needs, i.e., those for which a patient is not receiving the right care or the appropriate level of care [15].

Previous studies show that children and adolescents differ considerably from care providers with regard to the presence of psychiatric problems [16-18]. Care providers tend to report more problems than children/adolescents themselves. Higher levels of agreement were reported for externalizing problems (such as aggression and antisocial behavior) than for internalizing problems (such as sadness and anxiety) [16-18]. Although it is important during treatment to focus on psychiatric problems and related care needs, patients may also perceive care needs in other domains of functioning [19]. For this reason, a narrow focus on psychopathology-related care needs – and on possible disagreements between professionals and patients in this area – would not make it possible to fully understand patients' unmet care needs. Overall, other studies in adults that had a broad focus on care needs in different areas of functioning found that psychiatric patients scored more unmet care needs than their care providers did [20-22], but that adult patients with severe psychiatric problems and psychosocial difficulties scored fewer needs [23].

There is currently little or no research on the extent to which children and adolescents agree or disagree with care providers on the broad range of met and unmet care needs. Therefore, the aim of our study was to obtain insight into the extent of agreement on these needs between the two groups. Further, we aimed to better understand whether the extent of agreement would differ between two setting with a different treatment intensity.

We had two *a priori* hypotheses: (1) that patients in the two settings would report less unmet care needs than their care providers; and (2) that we would find more disagreements between patients and care providers on the presence of patients' unmet care needs in a Youth ACT setting – in other words, in a setting where patients had more severe psychiatric problems and psychosocial difficulties.

Method

Design

In two different mental healthcare settings characterized by different severities of psychiatric problems and psychosocial difficulties, we used a cross-sectional design to compare the extent of agreement and disagreement between patients and mental healthcare providers on reported unmet care needs.

To increase our insight into the extent of agreement regarding these needs, we first established their frequencies in a specialized mental healthcare setting, approaching them from the perspectives of children and adolescents and also from those of care providers. We then examined the extent of agreement on these needs between the two groups. To better understand how the extent of agreement on patients' unmet care needs was influenced by the severity of psychiatric problems and by psychosocial difficulties, we compared unmet care needs between two treatment settings [24]. For this purpose, we included patients from a general outpatient mental healthcare setting and from Youth ACT, an Assertive Community Treatment setting. Youth ACT is an intensive and outreaching mental healthcare service for children and adolescents with severe psychiatric and psychosocial problems [25-27].

Setting

The study was performed in a specialized treatment center for child and adolescent psychiatry in the Netherlands. Patients and care providers were included from two settings that provided care for the same catchment area.

The first was a general outpatient treatment setting (with low to moderate treatment intensity), in which treatment was provided by a multidisciplinary team consisting of one child psychiatrist, six psychologists, and one nurse practitioner, who made diagnostic assessments and provided cognitive behavioral therapy, eye-movement desensitization and reprocessing therapy (EMDR); family support; and pharmacological treatment.

The second was a Youth ACT setting (Assertive Community Treatment with high treatment intensity) consisting of one child psychiatrist, five psychologists, three nurse practitioners and two mental health nurses. This team offered home-based outreach-

oriented treatment to patients with more severe psychiatric and psychosocial problems. Care providers had small shared caseloads (<15 patients) and provided outreaching case management, early intervention, cognitive behavioral therapy, EMDR, family support, and pharmacological treatment. The intensity of ACT treatment was scaled up or down according to the severity of a patient's current psychiatric symptoms and psychosocial impairments.

Participants

Figure 1 presents the flowchart for inclusion. Participants, who were recruited between 2014 and 2016, were patients aged between 6 and 18 years. A total of 467 patients were considered for participation in the study. An initial random sample of 133 patients was selected from the general outpatient population of 298 patients. Next, ten of these outpatients had to be excluded because they already had a sibling who participated in the study (n=2), they refused to participate (n=6), or were referred to the Youth ACT setting during the inclusion period (n=2). For the Youth ACT sample, we initially selected all patients who were referred from a general outpatient setting to this ACT treatment setting during the inclusion period (n=169). Thereafter, forty-eight ACT patients had to be excluded because they did not meet the inclusion criteria: 27 patients because their sibling was already included in the study, 12 patients were not referred to the ACT setting from the outpatient setting, but by the general practitioner instead, and nine patients refused to participate. The final sample consisted of 244 patients: 123 in the outpatient sample and 121 in the Youth ACT sample.

Ethical approval

The study was reviewed and approved by the Medical Ethical Committee at VU University Medical Centre Amsterdam (protocol no. 2015.245) and by the Scientific Committee at the EMGO+ Institute for Health and Care Research Amsterdam. Approval was also provided by the local scientific review board of the participating mental health institution.

Separately, children/adolescent participants and their parents received written and oral information on the research project. In accordance with prevailing Dutch legislation, written consent from parents and/or children/adolescents was obtained as follows: (i) if children younger were aged less than 12, only parents were asked for consent for; (ii) if children were aged between 12 and 16, parents and children were both asked for consent; and (iii) if adolescents were 16 years or older, informed consent was obtained from them alone.

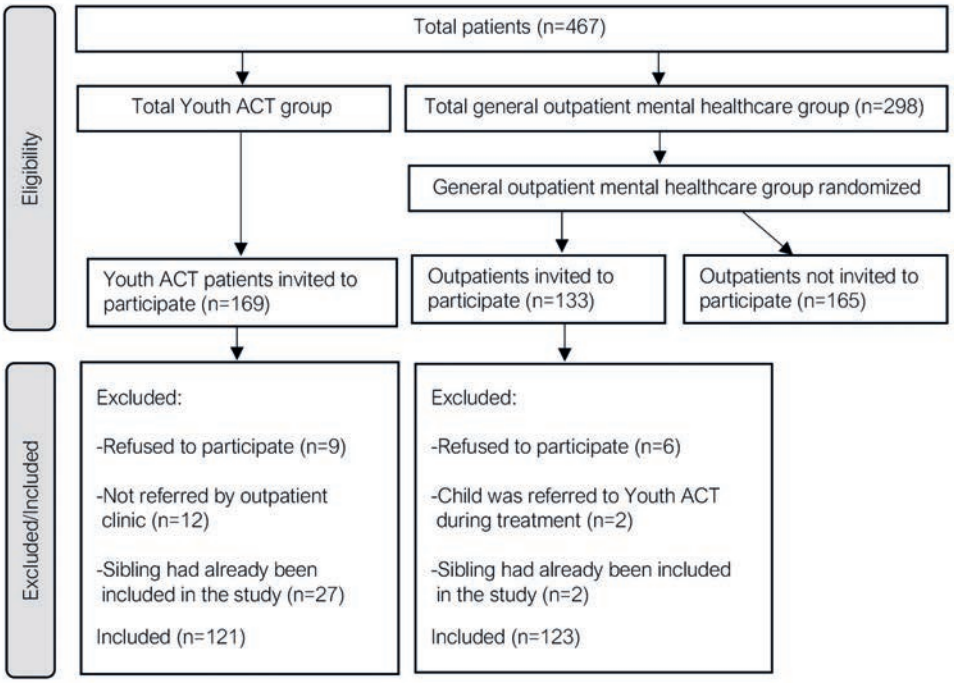

Figure 1. Participant flow diagram

Measurement instruments

The Demographic Information Questionnaire (DEMOG) was used to measure the following four demographic characteristics of each child or adolescent: (1) age, (2) gender, (3) country of birth, and (4) living in a single-parent family or a two-parent family [28].

The Neuropsychiatric Interview for Children and Adolescent (MINI-KID) was used to assess patients' psychiatric diagnoses [29], which were supplemented with clinical diagnoses that were not included in the MINI-KID [30].

The Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) was used to assess the patient's care needs as they were perceived both by the child/adolescent and by the mental healthcare provider [15]. CANSAS covers 23 items, each with three response options: (1) no need (= no problem); (2) met need (= difficulties in a particular domain of functioning that is receiving suitable assessment or intervention); (3) and unmet need (= difficulties in a particular domain of functioning that requires further assessment or is not receiving the right care or an appropriate level of care) [31]. To categorize CANSAS items (see Table 2 and Table 3), we used the following three

International Classification of Functioning, Disability and Health (ICF) health and health-related domains: (i) physical and mental functions, (ii) performance of daily activities, and (iii) participation in the community [19, 32, 33].

Data-analysis

The participants' demographics were analyzed using descriptive statistics, first for the entire sample and then separately for the two subgroups (general outpatient setting and the Youth ACT setting). Subgroup differences regarding age, gender, country of birth, general functioning, and living situation were analyzed using the *t*-test for continuous variables, or using the Chi-square test with Yates continuity correction (χ^2 -test) for categorical variables. As an alternative to the Chi-square test, Fisher's exact test was computed if the number in at least one of the cells of the categorical variable was lower than 5 [34].

To analyze the extent of agreement between patients and care providers at item level, Cohen's kappa coefficients were computed for the overall sample and then separately for the two treatment settings. On the basis of the Cohen's kappa values, the extent of agreement was categorized as follows: poor (≤ 0.20); fair (0.21 - 0.40); moderate (0.41 - 0.60); good (0.61 - 0.80); or very good (≥ 0.81 - 1.00) [35].

To determine whether patient and care provider agreed or disagreed on the presence of an unmet need, the following calculation was made for both settings at CANSAS-item level: only the patient reported an unmet care need (P > CP); patient and care provider both reported the presence or absence of an unmet care need (P = CP); or only the care provider reported an unmet care need (P < CP) (see Table 3). Frequencies of agreement or disagreement on unmet care needs between patients and care providers were calculated for the two treatment settings, and subgroup differences between these settings were analyzed using Fisher's exact test [34]. For all calculations, a value below $p < .05$ was considered to be statistically significant [35].

Results

Characteristics of the study sample

Table 1 shows the demographic characteristics of our two study samples. As would be expected, patients in the regular outpatient sample had a significantly higher score for overall functioning (GAF) than those in the Youth ACT sample (mean = 55.0, sd = 5.4 vs. mean = 45.9, sd = 8.0; $p < .05$).

In the subsample of Youth ACT patients significantly higher frequencies were found for ASD (39.7%), mood (37.2%), behavior (29.8%), somatoform (13.2%) and personality (2.9%), indicating higher levels of comorbidity in patients treated in Youth ACT.

Significantly more of those receiving ACT-treatment reported growing up in a single-parent family (42.3%) than those receiving regular outpatient treatment (26.2%; $p < .05$). There were no significant differences between the two samples regarding age, gender and country of birth.

Agreement between patients and care providers in the overall sample

Table 2 shows the kappa coefficients (k) that were calculated to determine the agreement between patients and care providers in the overall sample at CANSAS item level. In general, patients reported unmet care needs less than care providers did. Below, our results are presented using the ICF domains, but, for purpose of conciseness, we now report only the results whose frequency in at least one of the two settings (outpatient or Youth ACT) was higher than 10%.

Physical and mental functions

Agreement between patients and care providers on unmet needs for "mental health problems" – the most reported unmet care need – was poor ($k = 0.113$), with the scores between patients (63.9%) and care providers (93.5%) differing significantly ($p < .05$). Agreement on unmet care need for "information regarding diagnosis/treatment" was also poor ($k = 0.171$), with patients (54.5%) reporting unmet needs significantly less than care providers (82.4%; $p < .05$). Agreement on "danger to others" was fair ($k = 0.277$), with patients reporting significantly fewer unmet needs (7.8%) than care providers (20.0%; $p < .05$). Agreement was also fair with regard to "danger to themselves" ($k = 0.271$), with patients reporting 7.4% and providers reporting 24.9% ($p < .05$). Agreement on unmet care needs related to "psychotic symptoms" was moderate ($k = 0.438$), with no significant differences between the two groups (patients 7.8% vs. providers 10.6%). Agreement for "medication side effects" was good ($k = 0.660$; patients 10.7% vs. providers 9.4%; ns). Agreement on physical functions was moderate for unmet needs related to "physical handicap or disease" ($k = 0.570$; patients 11.1% vs. providers 14.3%; ns). Finally, agreement on "quality or quantity of food" was only fair ($k = 0.380$), with no significant differences between the two groups (patients 7.8% vs. providers 12.7%).

Performance of daily activities

Patient-provider agreement on abilities of self-care (e.g., daily hygiene and oral health) as an unmet care was fair ($k = 0.328$); the difference between patients (9%) and care providers (21.6%) was statistically significant ($p < .05$). Agreement on "cleaning up room or bedroom" was also fair ($k = 0.233$; patients 6.1% vs. providers 13.1%; $p < .05$). Agreement on "handling money" was moderate ($k = 0.411$; patients 8.6% vs. providers 12.2%), as was agreement on "paid job or side job" ($k = 0.534$; patients 9.0% vs. providers

Table 1. Sample characteristics of the child or adolescent who received treatment

	Outpatient Child (n=123)		**Youth ACT Child (n=121)**		**t-test/corrected χ^2 -test (2-sided) (df = 1)/ Fisher's exact test**	***P***
Age (sd)	Total mean	12.4 (3.2)	Total mean	13.0 (3.1)	-1,584[t]	0.439
	Range	6-17	Range	6-18		
	Girls mean	12.6 (3.4)	Girls mean	13.8 (2.8)	-0,733[t]	0.054
	Range	6-17	Range	6-18		
	Boys mean	11.1 (2.9)	Boys mean	12.5 (3.2)	-1,876[t]	0.339
	Range	6-17	Range	6-17		
Gender	Girls	45.5%	Girls	42.9%	1.001[χ2]	0.317
	Boys	54.5%	Boys	57.1%		
Country of birth	The Netherlands	96.7%	The Netherlands	95.0%		0.536[FE]
	Other	3.3%	Other	5.0%		
Clinical diagnoses	Mood	6.5%	Mood	37.2%	31.999 [χ2]	0.000
	Anxiety	31.7%	Anxiety	42.1%	2.426 [χ2]	0.119
	Behavior	12.2%	Behavior	29,8%	10.335 [χ2]	0.001
	Psychotic	0.0%	Psychotic	4.1%		0.029[FE]
	ASD	11.4%	ASD	39.7%	24.281 [χ2]	0.000
	ADHD	43.1%	ADHD	43.4%	0.000 [χ2]	1.000
	Somatoform	0.8%	Somatoform	13.2%		0.000[FE]
	Drugs/ alcohol	0.0%	Drugs/ alcohol	3.3%		0.059[FE]
	Personality	0.0%	Personality	2.9%		0.007[FE]
	Intelligence below or well below average	3.3%	Intelligence below or well below average	8.3%		0.106[FE]
	Other	0.8%	Other	3.3%		0.211[FE]
GAF-score (sd)	Mean	55.0 (5.4)	Mean	45.9 (8.0)	10.460[t]	0.000
	Range	45-75	Range	15-60		
Living situation	Single parent	26.2%	Single parent	42.3%	6.624[χ2]	0.010
	Two parents	73.8%	Two parents	57.7%		

ADHD: Attention Deficit Hyperactivity Disorder
ASD: Autism Spectrum Disorder
GAF: General Assessment of Functioning
df: degree of freedom
n: number of included patients
p: p-value; a value below 0.05 is considered to be statistically significant. An independent sample *t*-test was performed to compare the mean score between the outpatient and Youth ACT samples with respect to the continuous variable. The χ^2 –test with a continuity correction was used to test the difference between the outpatient and Youth ACT sample with regard to a categorical variable with df = 1
FE: Fisher's exact test was performed because the number in at least one of the cells in the child or care provider sample was <5
sd: standard deviation

14.7%), with no significant difference between the two groups. Agreement on unmet needs regarding "reading and writing skills at expected grade level" was good (k = 0.687), with no significant difference between patients (13.4%) and care providers (15.5%).

Participation in the community

Agreement on "future prospects" (e.g., opportunities/changes for a successful and prosperous life) – a frequently reported unmet need – was fair (k = 0.346; patients 33.6% vs. providers 65.3%, p < .05). With regard to "making and/or keeping friends" as an unmet care need, patients and care providers reported significantly differently, leading to only fair agreement (k = 0.299; 26.2% vs. 55.9%, respectively; p < .05). Agreement on unmet needs related to "regular/suitable school or other daytime activities" (e.g., practicing a hobby/sport) were moderate (k = 0.437), with significant differences between patients (23.0%) and providers (42.9%; p < .05). Patient-provider agreement for unmet care needs related to "intimate relations" was moderate (k = 0.561), with patients (7.4%) reporting significantly fewer unmet care needs related to "intimate relations" than care providers (14.7%; p < .05). Agreement on the presence of unmet needs related to "sexuality" was only poor (k = 0.181; patients 2.0% vs. providers 13.9%; p < .05).

Comparison of agreement between outpatient clinics and Youth ACT

Comparison of Youth ACT and outpatient clinics showed significant differences between the two settings for three-quarters of the unmet care needs that were investigated (see Table 3). Compared to their peers in the outpatient setting, Youth ACT patients agreed less with their care providers (P = CP) on the presence or absence of an unmet need for care. If there was disagreement, patients, unlike their care provider, did not usually report an unmet care need (P < CP). Below, for reasons of brevity, we highlight solely results of P < CP whose frequency in at least one of the two settings was higher than 10%.

Physical and mental functions

As Table 3 shows, relative to those in the outpatient setting, patients in the Youth ACT setting reported that they had no unmet needs with regard to "information regarding treatment and/or diagnosis" (P < CP 41.7%) significantly more than the care provider did (P < CP 26.0%; p < .05).

With regard to unmet care needs for "danger to others" and "danger to themselves," patients and care providers (P < CP 31.7% and P < CP 26.7%, respectively) in the Youth ACT sample disagreed significantly more than patients and their care providers (P < CP 7.3% and P < CP 3.3%, respectively; p < .05) in the outpatient sample.

With regard to "quality and/or quantity of food", there were significant differences ($p < .05$) between the two settings, with ACT patients (P < CP 14.2%) disagreements more on this item than outpatients (P < CP 2.4%).
With respect to the unmet need for "mental health problems," there were no significant differences between patient-provider disagreements in the ACT-setting (P < CP 35.0%) and those in the regular outpatient setting (P < CP 28.5%; ns).

Performance of daily activities

With regard to "abilities for self-care", patients receiving Youth ACT treatment reported unmet care needs significantly less than their care providers (P < CP 25.0%), and significantly less than outpatients (P < CP 6.5%; $p < .05$). There were also significant differences ($p < .05$) between the Youth ACT sample and outpatient sample with regard to three unmet care needs: "cleaning-up room or bedroom" (Youth ACT P < CP 19.2% vs. outpatients P < CP 1.6%); "paid job or side job" (Youth ACT P < CP 14.2% vs. outpatients, P < CP 1.6%); and "handling money" (Youth ACT P < CP 12.5% vs. outpatients P < CP 2.4%).

Participation in the community

With regard to friendship-related unmet needs, patients in the Youth ACT sample scored significantly less than their care providers did (P < CP 50.8%), and significantly less than those receiving outpatient care (P < CP 16.3%; $p < .05$). Youth ACT patients had significantly more patient-provider disagreements ($p < .05$) than outpatients with regard to unmet needs pertaining "future prospects" (Youth ACT P < CP 45.0% vs. outpatients P < CP 22.0%); "regular/suitable school or other daytime activities" (Youth ACT vs. outpatients P < CP 38.3%, P < CP 8.1%); "sexuality" (Youth ACT P < CP 20.8% vs. outpatients P < CP 3.3%); and "intimate relations" (Youth ACT P < CP 15.0% vs. outpatients P < CP 0.8).

Table 2. Unmet needs overall sample

Unmet needs domains	Child (n = 244)		Care provider (n = 245)		Level of agreement overall sample		Corrected χ^2 -test (2-sided) (df = 1) / Fisher's exact test	P
	N	%	N	%	k	95% CI		
Physical and mental functions								
Mental health problems (not psychotic)	156	63.9	229	93.5	0.113	0.023 - 0.203	61.93	0.000
Danger to others	19	7.8	49	20.0	0.277	0.126 - 0.428	14.23	0.000
Danger to themselves	18	7.4	61	24.9	0.271	0.140 - 0.400	26.43	0.000
Psychotic symptoms	19	7.8	26	10.6	0.438	0.244 - 0.632	0.85	0.355
Information regarding diagnosis/treatment	133	54.5	202	82.4	0.171	0.069 - 0.273	42.95	0.000
Physical handicap or disease	27	11.1	35	14.3	0.570	0.413 - 0.727	0.87	0.350
Medication side effects	26	10.7	23	9.4	0.660	0.499 - 0.821	0.10	0.752
Drugs misuse/alcohol abuse	5	2.0	11	4.5	0.326	-0.162 - 0.814	1.59	0.207
Food (qualitative or quantitative)	19	7.8	31	12.7	0.380	0.198 - 0.562	2.65	0.104
Performance of daily activities								
Reading/writing skills at expected grade level	34	13.4	38	15.5	0.687	0.556 - 0.818	0.13	0.716
Handling money	21	8.6	30	12.2	0.411	0.231 - 0.591	1.37	0.243
Self-care abilities (age-related)	22	9.0	53	21.6	0.328	0.183 - 0.473	14.03	0.000
Paid job (included side-jobs)	22	9.0	36	14.7	0.534	0.371 - 0.697	3.25	0.072
Cleaning up room (or bedroom)	15	6.1	32	13.1	0.233	0.056 - 0.409	5.95	0.015
Caring for someone else (family member or pet)	2	0.8	7	2.9	-0.130	-0.144 - -0.116	FE	0.176
Participation in the community								
Regular/suitable school or other daytime activities	56	23.0	105	42.9	0.437	0.331-0.543	21.04	0.000
Making and/or keeping friends	64	26.2	137	55.9	0.299	0.201-0.397	43.29	0.000
Future prospects (opportunities/chances of a successful and prosperous life)	82	33.6	160	65.3	0.364	0.274-0.454	47.88	0.000

Table 2. Continued

Unmet needs domains	Child (n = 244)		Care provider (n = 245)		Level of agreement overall sample		Corrected χ^2 -test (2-sided) (df = 1) / Fisher's exact test	P
	N	%	N	%	k	95% CI		
Participation in the community								
Access to (public) transport	13	5.3	23	9.4	0.479	0.269-0.689	2.39	0.122
Housing	11	4.5	21	8.6	0.535	0.323-0.747	2.67	0.102
Access to modern tools of communication	7	2.9	5	2.0	0.488	0.137-0.839	0.09	0.765
Intimate relations	18	7.4	36	14.7	0.561	0.398-0.724	5.94	0.015
Sexuality	5	2.0	34	13.9	0.181	0.020-0.342	21.72	0.000

n: number of included patients
N: number of reported unmet needs
k: Cohen's kappa Poor (≤ 0.20) ; fair (0.21-0.40); moderate (0.41-0.60); good (0.61-0.80); or very good (≥0.81-1.00)
p: p-value; a value below 0.05 is considered to be statistically significant. The χ^2 –test with a continuity correction was performed because df =1. Fisher's exact test was performed if the number in at least one of the cells in the child or care-provider sample was <5
FE: Fisher's exact test

Table 3. Unmet needs disagreement and agreement child – care provider

Unmet needs domains	Outpatient (n = 123)						Youth ACT (n = 120)						
	P > CP	%	P = CP	%	P < CP	%	P > CP	%	P = CP	%	P < CP	%	P (Fisher's exact test)
Physical and mental functions													
Mental health problems (not psychotic)	2	1.6	86	69.9	35	28.5	3	2.5	75	62.5	42	35.0	0.522
Danger to others	1	0.8	113	91.9	9	7.3	3	2.5	79	65.8	38	31.7	0.000
Danger to themselves	3	2.4	116	94.3	4	3.3	4	3.3	84	70.0	32	26.7	0.000
Psychotic symptoms	2	1.6	115	93.5	6	4.9	6	5.0	105	87.5	9	7.5	0.219
Information regarding diagnosis/treatment	3	2.4	88	71.5	32	26.0	10	8.3	60	50.0	50	41.7	0.001
Physical handicap or disease	1	0.8	120	97.6	2	1.6	7	5.8	100	83.3	13	10.8	0.000
Medication side effects	1	0.8	121	98.4	1	0.8	8	6.7	107	89.2	5	4.2	0.008
Drugs misuse/alcohol abuse	-	-	121	98.4	2	1.6	3	2.5	111	92.5	6	5.0	0.054
Food (qualitative or quantitative)	1	0.8	119	96.7	3	2.4	7	5.8	96	80.0	17	14.2	0.000
Performance of daily activities													
Reading/writing skills at expected grade level	3	2.4	117	95.1	3	2.4	5	4.2	107	89.2	8	6.7	0.185
Handling money	5	4.1	115	93.5	3	2.4	4	3.3	101	84.2	15	12.5	0.009
Self-care abilities (age-related)	-	-	115	93.5	8	6.5	5	4.2	85	70.8	30	25.0	0.000
Paid job (included side-jobs)	2	1.6	119	96.7	2	1.6	3	2.5.	100	84.2	17	14.2	0.000
Cleaning up room (or bedroom)	3	2.4	118	95.9	2	1.6	5	4.2	92	76.7	23	19.2	0.000
Caring for someone else (family member or pet)	-	-	122	99.2	1	0.8	2	1.7	112	93.3	6	5.0	0.026
Participation in the community													
Regular/suitable school or other daytime activities	-	-	113	91.9	10	8.1	7	5.8	67	55.8	46	38.3	0.000
Making and/or keeping friends	2	1.6	101	82.1	20	16.3	7	5.8	52	43.3	61	50.8	0.000
Future prospects (opportunities/chances of a successful and prosperous life)	2	1.6	94	76.4	27	22.0	2	1.6	64	53.3	54	45.0	0.000

Table 3. Continued

Unmet needs domains	Outpatient (n = 123)						Youth ACT (n = 120)						
	P > CP	%	P = CP	%	P < CP	%	P > CP	%	P = CP	%	P < CP	%	P (Fisher's exact test)
Participation in the community													
Access to (public) transport	1	0.8	121	98.4	1	0.8	4	3.3	105	87.5	11	9.2	0.001
Housing	-	-	121	98.4	2	1.6	2	1.7	108	90.0	10	8.3	0.008
Access to modern tools of communication	-	-	123	100	-	-	4	3.3	114	95.0	2	1.7	0.095
Intimate relations	-	-	122	99.2	1	0.8	2	1.7	100	83.3	18	15.0	0.000
Sexuality	-	-	119	96.7	4	3.3	1	0.8	94	78.3	25	20.8	0.000

n: number of included patients
P > CP: only the patient reported a unmet care need; P = CP: patient and care provider both reported the presence or absence of an unmet care need; P < CP: only the care provider reported a unmet care need
p: p-value; a value below 0.05 is considered to be statistically significant. Fisher's exact test was performed because the number in at least one of the cells in the child or care provider sample was <5

Discussion

This study is based on the assumption that agreement among patients and care providers on relevant care needs is a prerequisite not only for efficient and effective collaboration, but also for treatment adherence and treatment outcomes. Although such agreement may be even more relevant among young patients than among adults, it has not, to our knowledge, been studied systematically.

In general, care needs (met and unmet) can be studied on different levels, e.g. (i) the problems experienced by the client; (i) the interventions required to alleviate or limit these problems; (i) the services required to provide these interventions. A specific problem can be solved (and related care needs can be met) by several different interventions, which can be applied by different types of services. Since the presence of a problem may require one or more interventions to ameliorate this problem, some authors suggested that needs should not only be assessed at the problem level, but also at the intervention level [36]. In this study we have focused in the first instance on the problem level because that is where the treatment process starts, namely with the initial question: do the patient and/or practitioner think the patient has a problem for which care is needed or not?

Agreement between patients and care providers in the overall sample

In general, agreement between patients and care providers with regard to patients' unmet care needs was low (see Table 2). While 23 unmet care needs were investigated, we found poor agreement for four, fair agreement for eight, moderate agreement for nine, and good agreement for only two. The lowest level of agreement was found for "mental health problems" and "information regarding diagnosis and/or treatment." This is remarkable, as these two care needs are key topics during psychiatric treatment. Overall, in line with our first hypothesis, patients reported fewer unmet care needs than their care providers (P < CP). The first possible explanation for this is that the care provider obtained information not only from the child, but also from the parents, whose views on appropriate care needs often differ from those of their children [37-39]. A second possible explanation lies in the rather self-evident fact that while patients tend to make personal statements, care providers' statements also reflect a professional judgement [40].

Agreement in Youth ACT versus outpatient setting

Comparison of the Youth ACT setting with the general outpatient treatment setting showed significant differences with regard to three-quarters of the unmet care needs (see Table 3). In both settings, fewer patients than care providers reported unmet care needs (P < CP). The extent of disagreement was higher in the Youth ACT setting, which was in line with our second hypothesis. A possible explanation for this is that patients in the Youth ACT sample had more severe psychiatric problems [54]. Such patients are more likely to report fewer problems and needs – because they may be less aware of existing problems, are sometimes less willing to seek solutions, or believe that persisting problems cannot be resolved [23, 41, 42]. Higher frequencies of ASD (39.7%), mood (37.2%), behavior (29.8%) and somatoform (13.2%) were found in the Youth ACT sample (see Table 1). Overall, in the ACT sample more comorbidity was assessed, which supports the hypothesis that the patients in this sample had more severe psychopathology.

Another explanation why Youth ACT patients disagreed more than outpatients may be that more of these patients came from multi-problem families [27]. When a patient lives in an environment that is potentially harmful to his or her development, care providers tend to report more unmet care needs [43]. On the other hand, patients may be tempted to report unmet care needs less often when they have grown up in living situations in which they have become accustomed to the presence of problems. In contrast, care providers, who have more distance, do identify problems [44, 45].

A third explanation is that, due to the home visits ACT care providers made during the intake phase, when they observed patients in their own living environment, ACT care providers depended less than outpatient care providers on information provided by the patient to form a picture of his or her unmet care needs.

Implications for clinical practice and research

For clinical practice, the key to preventing non-compliance, non-attendance at appointments, and drop-out may be in care providers' awareness that their view of a patient's unmet care needs often differs from that of the patient. We therefore recommend care providers – particularly those in Youth ACT settings or other intensive treatment settings – to routinely assess a child's perceived care needs and compare them with their own perceptions of unmet care needs. Given the higher levels of comorbidity in the ACT sample, the examination of specific care needs related to this comorbidity should receive special attention in clinical practice. By sharing information on their perceptions of such needs, and by being explicit about the areas in which they disagree, patients and care providers can engage in a process of decision making that makes it possible to formulate goals and interventions on which they can then

collaborate. Unmet care needs on which there is no agreement can be assessed according to their urgency; it may prove possible to postpone further attention to them until a later treatment phase.

We studied unmet care needs at the problem level, and investigated agreement regarding need for care, irrespectively of the type of intervention or services needed. In the future, it may be interesting to investigate whether different informants have a common view on the interventions required, once they agree on the problems that need to be addressed during treatment. Future research could also address the impact of improving agreement between patients and care providers with regard to unmet care needs on compliance with treatment and its outcomes.

Strengths and limitations

This is the first study to provide detailed information about patient-provider (dis) agreement regarding the care needs of children and adolescents who have been referred to general outpatient care and Youth ACT. This is a strength because children and adolescents with different severity levels of psychiatric problems were studied, which supported the generalizability of findings.

A limitation of the study is its cross-sectional design, which prevented us from identifying causes of disagreements between patients and care providers on patients' unmet care needs [46].

Conclusions

We found that patients and care providers often disagreed on patients' care needs, particularly in a Youth ACT treatment setting. Clarifying different views on patient's unmet care needs may help to reduce non-attendance of appointments and early termination of treatment. Similarly, if patients and care providers systematically assessed patients' unmet care needs, useful information may be provided on areas of disagreement. Future research should show whether better treatment outcomes would be produced by an approach focused on obtaining a shared view on unmet care needs.

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CHAPTER 6

What if children with psychiatric problems disagree with their clinicians on the need for care? Factors explaining discordance and clinical directions

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Abstract

Background

Children and adolescents in mental healthcare often perceive their care needs and necessary treatment differently from their clinicians. As such discordance between young patients and clinicians may obstruct treatment adherence and compromise treatment outcomes, it is important to understand the factors associated with it. We therefore investigated the factors associated with patient-clinician discordance with regard to care needs in various areas of functioning.

Method

A cross-sectional study involving 244 children/adolescents aged 6-18 participating with their clinicians in treatment at a specialized mental healthcare center. As a previous study conducted by our research group had found the greatest patient-clinician discordance in three CANSAS care needs – "mental health problems," "information regarding diagnosis and/or treatment," and "making and/or keeping friends" – we used univariable and multivariable statistics to investigate the factors associated with discordance regarding these three care needs.

Results

Patient-clinician discordance on the three CANSAS items was associated with child, parent, and family/social-context factors. Three variables were significant in each of the three final multivariable models: dangerous behavior towards self (child level); severity of psychiatric problems of the parent (parent level); and growing up in a single-parent household (family/social-context level).

Conclusions

To deliver treatment most effectively and to prevent drop-out, it is important during diagnostic assessment and treatment planning to address the patient's care needs at all three levels: child, parent and family/social context.

Introduction

If patients and clinicians in mental healthcare are to collaborate effectively, it is crucial that they agree on the care needs that need to be addressed [1-4]. By facilitating shared decision-making on treatment goals and interventions [5, 6], such agreement opens the gates to treatment adherence and effective treatment [7, 8].

Care needs can be defined as physical, psychological, social or environmental calls for aid, care or service in solving a problem [9]. These needs can either be 'met', which implies that a patient is receiving appropriate care, or 'unmet', which means that they are not being addressed adequately [10].

Children and adolescents who receive specialized mental healthcare often disagree with clinicians about unmet care needs [11-13]. In a previous study, we used the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) to examine the extent to which children and adolescents agreed or disagreed with their clinicians on a broad range of care needs [13]; we found that they generally reported fewer unmet care needs than their clinicians. The highest discordance was found on the CANSAS items "mental health problems," "information regarding diagnosis and/or treatment," and "making and/or keeping friends."

It is likely that treatment outcomes are influenced by discordance in these clinically relevant areas [1, 3]. The presence of mental health problems is the primary reason for providing treatment. Thus, if there is a lack of agreement between patient and clinician on this presence of mental health problems, the fundamental basis for treatment seems to be absent [5].

Similarly, with respect to "information regarding diagnosis and/or treatment," if a clinician believes that a patient might benefit from information about the diagnosis and options for treatment, but the patient does not see it as important, it is possible that the patient will have little interest in the treatment approach that the clinician proposes to deliver [14]. Discordance on the need to strengthen the patient's social network shows that a clinician has observed that a patient is not functioning well in her/his social environment, but that the patient does not consider this to be a problem [14, 15].

Such discordance on care needs can undermine effective collaboration, and may also reduce treatment effects [16]. It is important to clinical practice to improve our understanding of this discordance [17], and also of the factors related to it [18]. As these factors had not yet been identified, this study was intended to fill the gap by focusing explicitly on the three CANSAS items identified above.

To categorize candidate predictors of discordance, we used the Bronfenbrenner model [19], which describes factors that influence a child's functioning at three levels: that of (i) the child itself, (ii) that of his or her parents, and (iii) that of his or her family and

social context. Given the lack of empirical research on discordance between children/adolescents and their clinicians regarding unmet care needs, we used studies that focused on factors associated with psychiatric problems and agreement on them.
With regard to the child level, existing studies suggest that children with more severe psychiatric problems in general, or with more severe internalizing and externalizing problems in particular, reported fewer mental health problems than their clinicians did [1, 3, 20, 21]. It has also been reported that dangerous behaviors towards oneself, rule-breaking behavior, and a higher age are associated with lower patient-clinician concordance on the presence of mental health problems [1, 3, 20].
With regard to the parent level, the literature shows that parents with higher levels of stress and more severe psychiatric problems report more mental health problems in their children than their children do [1, 21-23].
With regard to the level of the family/social context, the literature suggests that clinicians report more mental health problems than children or adolescents do in cases that involve lower family socio-economic status (SES), those that involve growing up in single-parent households, those that involve more problems with peers, and those that involve more problems at school [1, 24-29]. Discordance between patients and clinicians with regard to the severity of psychiatric problems was also predicted by greater child-parent discordance on the presence of mental health problems, and lower quality of the parent- child relationship [1, 3, 20, 30-32]. Given this review of literature, our *a priori* hypothesis was that discordance between clinicians and children/adolescents is predicted by predictors at all three levels, i.e., child, parent, and family/social context.

Method

Design

Factors associated with patient-clinician discordance regarding unmet care needs were investigated using a cross-sectional design.

Setting

The study was conducted at the department of child and adolescent psychiatry at a large specialized mental healthcare institution in the Netherlands. This department had two general outpatient clinics and one Youth-Assertive Community Treatment team (ACT). Diagnostic assessments and treatment (e.g., cognitive behavioral therapy, family support, and pharmacological treatment) were provided by three child psychiatrists, seventeen psychologists, five clinical nurse specialists, and two mental health nurses.

Participants

The target population consisted of all 6 to 18-year-olds who had been referred to the department between April 2015 and November 2016, and their clinicians. Only one child per household was included in the study. A total of 467 patients were eligible for inclusion. The final sample consisted of 244 patients. Figure 1 shows the flow chart of the inclusion process.

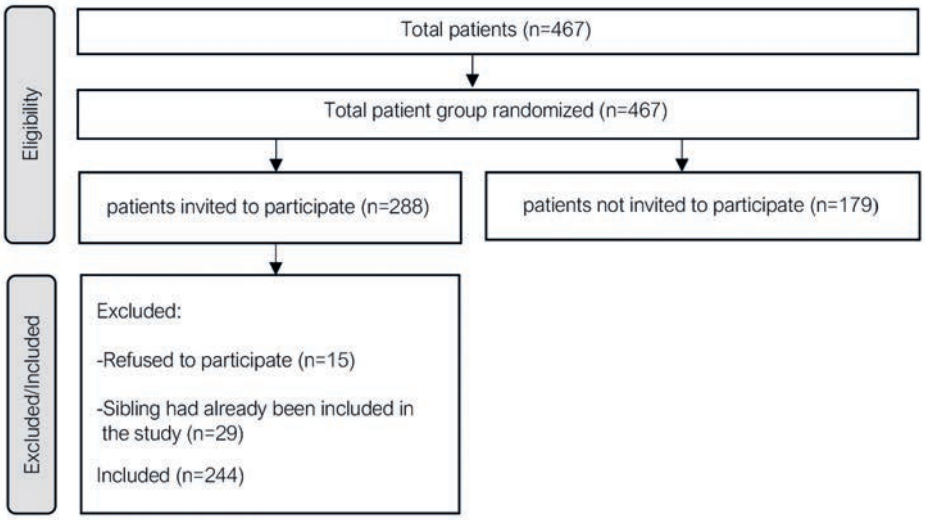

Figure 1. Participant flow diagram

Ethical approval

The study was approved by the following: the Medical Ethical Committee at VU University Medical Center Amsterdam (protocol no. 2015.245); the Scientific Committee at the Amsterdam Public Health Research Institute; and the local research committee at the participating mental health institution.

Separately, participating children/adolescents and clinicians received written and oral information on the research project. In accordance with prevailing Dutch legislation, the written consent of parents and/or children/adolescents was obtained on the following basis: (i) if children were younger than 12, only parents were asked for consent; (ii) if children were aged between 12 and 16, parents and children were both asked for consent; and (iii) if adolescents were 16 or older, informed consent was obtained only from the adolescents themselves.

Measurement instruments

Sample descriptives

The Demographic Information Questionnaire (DEMOG) child version was used to establish age, gender, and country of birth [33]. The Neuropsychiatric Interview for Children and Adolescent (MINI-KID) was used to establish the patients' psychiatric diagnoses [34]. If a child was aged 12 or above, the MINI-KID was administered. If a child was younger, the MINI-KID was administered in the presence of one of the parents. Parents were allowed to clarify questions for their child. For disorders that were not covered by the MINI-KID (personality disorders, autism spectrum disorders), clinical diagnoses were used.

Assessment of care needs

To assess a patient's unmet care needs, we used the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) [35], which covers 25 care need items that can be scored on a three-point scale. The response format is 0 = no need, 1 = met need, and 2 = unmet need. The CANSAS was used in the form of an interview. If a child was aged 12 or older, it was administered to the child alone. If the child was younger, it was administered in the presence of one of the parents. At the start of the interview, parents were instructed not to answer for the child, but to clarify the questions in such a way that the child was able to answer the question from her or his own perspective. Simultaneously, the clinician also completed the CANSAS scoring form on the basis of all the clinical information available.

Outcomes

Three dependent variables were studied: discordance between young people and their clinicians for (i) unmet care needs regarding mental health problems, (ii) unmet care needs regarding information on diagnosis and treatment, and (iii) unmet care needs regarding making and/or keeping friends.

To determine the presence or absence of patient-clinician discordance, scores for each of the three CANSAS items were recoded into 0 = no need/met need, and 1 = unmet need. Next, the item score of the clinician was subtracted from the patient's score: 0 = concordance, and 1 or -1 = discordance. As a explorative investigation, the present study did not focus on the nature of discordance i.e., on whether the clinician reported more care needs than the patient, or vice versa. Hence, all negative scores (= -1) were recoded into positive ones (= 1).

Predictors

Child factors

Candidate predictors at the child level were assessed as follows.

Severity of psychiatric problems. The Strength and Difficulty Questionnaire (SDQ, version parent) was used to assess the severity of mental health problems of the child from the parent's perspective [36]. SDQ is a questionnaire that scores 33 items on a 3-point scale, in which 0 = not true, 1 = somewhat true, and 2 = certainly true [37].
Severity of internalizing problems and externalizing problems. To measure the severity of internalizing problems and externalizing problems, we used two SDQ (parent version) subscales: "internalizing problems" and "externalizing problems" [38].
Dangerous behavior towards self. To measure whether a patient currently showed dangerous behavior towards themselves, we used the MINI-KID domain "suicidal risk" (no = 0, or yes = 1) [34].
Rule-breaking behavior. The MINI-KID domains "conduct disorder" and "oppositional deviant disorder" were used to estimate rule-breaking behavior (diagnosis absent = 0, diagnosis present = 1) [34].
Age. The age of the child/adolescent was measured using the DEMOG [33].

Parent factors

Candidate predictors at the parent level were assessed as follows:
Degree of parental stress. The Parental Stress Scale was used to measure the degree of parental stress by asking primary caregivers to indicate their degree of parenting stress on a scale ranging from 1 to 10.
Severity of psychiatric problems. The Health of the Nation Outcomes Scale (HoNOS) sum score was used to measure the severity of the parent's psychiatric problems [39]. The HoNOS consists of 12 items to be scored on a 5-point-Likert scale, ranging from 0 (no problems) to 4 (severe problems).

Family/social-context factors

Candidate predictors at the family/social-context level were assessed as follows:
Family SES. Family SES, expressed as the highest educational achieved by the parents, was measured using the DEMOG-Adult.
Growing up in a single-parent household. The DEMOG-Adult was also used to determine whether a child was growing up in single-parent or two-parent household [33].
Severity of problems with peers. The Kidscreen-27 (parent version) "friends" subscale was used to assess problems with peers as perceived by the parents. This subscale comprises spending time with friends, fun with friends, support from friends, the extent to which a child could trust his/her friends. Originally, higher item scores on Kidscreen-27 reflect better functioning, and range from 0 (= never) to 4 (= always). As we wanted to use an indicator that reflected greater severities of problems with friends as a candidate predictor, we recoded all item scores (0=4, 1=3, 2=2, 3=1, 4=0) before calculating a sum score.

Severity of problems related to school. To measure parents' view of the severity of their child's school problems, we used the parent version of the Kidscreen-27 subscale "school and learning," which taps "had a good time at school," "it went well at school," "was able to pay attention in class," and "quality of contact with teachers." A sum score was for this scale was calculated similarly as for the scale regarding "problems with peers."

Severity of child-parent discordance on mental health problems. The child and parent version of the Strength and Difficulty Questionnaire (SDQ) were used to assess the severity of child-parent discordance regarding the presence of mental health problems [36]. Higher item scores of the SQD reflect more difficulties, and range from 0 (= not true) to 2 (= certainly true). The discordance was calculated by first subtracting the parent score from the child score for each item separately, which yielded discrepancy scores for each item. We then recoded all negative scores as positive scores. Finally, we summed all discrepancy scores [37]. A higher sum score thus indicates greater discordance.

Quality of the parent-child relationship. The "parent version" of the Kidscreen-27 "family" subscale was used to assess the quality of the parent-child relationship. The "family" subscale covers 3 items: "support from parents," "treated fairly by parents," and "communication with parents." Items are scored on a 5-point-Likert scale ranging from 0 (= never) to 4 (= always). To calculate the quality of the parent-child relationship, the scores of all 3 items were summed [40].

Data analysis

To analyze background characteristics, we first calculated descriptive statistics of the sample. Next, we conducted a set of univariable binary logistic regression analyses by using (i) concordance/discordance between young patients and their clinicians for each of the three outcomes variables ("mental health problems," "information regarding diagnosis and/or treatment," and "making and/or keeping friends"; and (ii) candidate predictors at all three levels of the Bronfenbrenner model (child / parent / family, social context). A separate regression analysis was performed for each candidate predictor ($P < 0.10$) [41], and yielded information on predictors at the child, parent, and family/social-context levels that predicted discordance between patient and clinician regarding the three outcomes. Our *a priori* hypothesis was that discordance between clinicians and children/adolescents would be predicted by predictors at child level, parent level, and family/social-context level. Since predictors at different levels may correlate despite being significant in univariable analyses, we then conducted stepwise multivariable logistic regression analyses to identify predictors at each level that were independent of other predictors, either at the same level, or at other levels. Therefore, stepwise multivariable logistic regression analyses were conducted for each of the three

outcomes variables. As a first step, all child-level predictors that were significant in the set of univariable analyses were entered as possible predictors. Next, variables at parent level were entered, following by variables at family/social-context level. This step-by-step approach did not violate the statistical rule of 10 events per 1 variable [42, 43]. To test the assumptions of linearity and homoscedasticity, we generated a scatter plot of the standardized residuals [44], and tested assumptions of the logistic regression analyses for indications of multicollinearity by investigating the variance inflation factor (VIF) [41]. To measure the predictive value of models, we used the Hosmer and Lemeshow goodness-of-fit-test. Nagelkerke R^2 was used to obtain an indication of the strength of the relationship between the predictor and the outcome variable [41]. All statistical analyses were performed using SPSS version 24.

Results

Sample characteristics

Table 1 shows the characteristics of the patients in the study sample (n=244). Mean age was 12.4 years (sd = 3.3). A majority of the patients were boys (57.2%). Most patients were growing-up in a two-parent household (66.3%). The most frequent diagnoses were attention deficit hyperactivity disorder (43.4%), anxiety disorder (36.5%), autism spectrum disorder (25.4%), mood disorder (21.7%), and behavior disorder (20.9%).

Mental health problems

The univariable analyses presented in Table 2 show that discordance between patients and clinicians on unmet mental healthcare needs was associated with all but three candidate predictors: (i) severity of the child's externalizing psychiatric problems, (ii) family SES, and (iii) quality of the parent-child relationship.

Table 1. Sample characteristics of the child or adolescent who received treatment

	Patient	
	N = 244	
Age (sd)	Total mean	12.4 (3.3)
	range	6-18
	Girls mean	13.1 (3.2)
	range	6-18
	Boys mean	11.8 (3.2)
	range	6-17
Gender	Girls	42.8%
	Boys	57.2%
Country of birth	The Netherlands	95.9%
	Other	4.1%
Clinical diagnoses	ADHD	43.4%
	Anxiety	36.5%
	ASD	25.4%
	Mood	21.7%
	Behavior	20.9%
	Somatoform	6,6%
	Personality	2.9%
	Psychotic	2.0%
	Drugs/alcohol	1.6%
	Other	2.0%
GAF-score (sd)	Mean	50.5 (8.2)
	Range	15-75
Living situation	Two parent	66.3%
	Single parent	33.7%

N: number of included patients; sd: standard deviation
ADHD: attention deficit hyperactivity disorder
ASD: autism spectrum disorder
GAF: general assessment of functioning

Table 2. Factors associated with patient-clinician discordance on unmet care needs with regard to:

	Mental health problems				Information regarding diagnosis and/or treatment				Making and keeping friends			
	N	OR	95% CI	P	N	OR	95% CI	P	N	OR	95% CI	P
Child level												
Severity of psychiatric problems	244	1.077	1.034-1.123	<.001	244	1.086	1.042-1.131	<.001	244	1.113	1.065-1.164	<.001
Severity of internalizing problems	244	1.129	1.033-1.235	0.008	244	1.070	0.987-1.159	0.099	244	1.152	1.051-1.263	0.003
Severity of externalizing problems	244	1.094	0.975-1.229	0.126	244	1.182	1.046-1.337	0.007	244	1.152	1.022-1.300	0.021
Dangerous behavior												
Dangerous behavior towards self (yes/no)	244	5.268	2.980-9.312	<.001	244	4.182	2.404-7.277	<.001	244	5.582	3.156-9.871	<.001
Rule-breaking behavior (yes/no)	244	3.647	2.024-6.571	<.001	244	3.072	1.760-5.364	<.001	244	3.632	2.031-6.494	<.001
Age:	243				243				243			
6-11	90	1.823	1.033-3.219	0.038	90	1.332	0.776-2.288	0.299	90	1.978	1.122-3.486	0.018
12-18	153				153				153			
Parent level												
Degree of parental stress	244	1.525	1.316-1.768	<.001	244	1.265	1.121-1.427	<.001	244	1.407	1.229-1.609	<.001
Severity of parent's psychiatric problems	244	1.232	1.163-1.305	<.001	244	1.163	1.107-1.221	<.001	244	1.236	1.166-1.310	<.001
Family/social-context level												
Family's socioeconomic status:	244				244				244			
Basic	86			0.644	86			0.131	86			0.433
Intermediate	112	0.835	0.467-1.494	0.544	112	0.553	0.310-0.984	0.044	112	0.892	0.502-1.587	0.698
High	46	0.703	0.327-1.508	0.365	46	0.739	0.357-1.531	0.416	46	0.602	0.278-1.306	0.199
Child growing up in a single-parent household	244	4.588	2.618-8.042	<.001	244	3.110	1.813-5.335	<.001	244	3.510	2.030-6.072	<.001
Quality of the parent-child relationship	238	0.997	0.935-1.063	0.920	238	0.996	0.935-1.061	0.904	238	0.975	0.915-1.039	0.435
Degree of discordance between parent and child on the child's mental health problems	190	1.168	1.096-1.245	<.001	190	1.168	1.096-1.245	<.001	190	1.166	1.094-1.242	<.001
Severity of problems with peers	244	1.125	1.055-1.199	<.001	244	1.098	1.031-1.168	0.004	244	1.120	1.050-1.193	0.001
Severity of problems related to school	244	1.078	1.009-1.152	0.026	244	1.067	1.000-1.139	0.050	244	1.079	1.010-1.152	0.024

Univariable analysis: individual binary logistic regression analyses of each candidate factor performed separately; N: Number of patients; OR: Odds ratio; CI: Confidence interval; *P*-value<0.100 is considered statistically significant

Table 3 shows that the final step of the multivariable analysis produced two significant predictors at child level: dangerous behavior towards self, and rule-breaking behavior. Significant parent-level predictors were degree of parental stress, and severity of the parent's psychiatric problems. Predictors at family/social-context level were growing up in a single-parent household, and degree of discordance between parent and child on the severity of the child's mental health problems. The final model showed a good fit of the data (Hosmer-Lemeshow, P = 0.645), and a relatively strong relationship between predictor variables and outcome (Nagelkerke R^2 = 0.575).

Information on diagnosis and treatment

With regard to the univariable analysis, Table 2 shows that discordance regarding the need for information on diagnosis and treatment was significantly associated with all predictor variables, except for family SES, higher age of the child, and quality of the parent-child relationship.

With regard to the final step of the multivariable analyses, Table 4 shows that, at the child level, discordance on the care need "information on diagnosis and treatment" was predicted by dangerous behavior towards self. At the parent level, discordance was predicted by the presence of the parent's psychiatric problems. At family/social-context level there were two significant predictors: growing up in a single-parent household, and discordance between parent and child on the presence of mental health problems in the child. The final model fitted the data well (Hosmer-Lemeshow, P = 0.571), and showed a relatively strong relationship between predictor variables and outcome (Nagelkerke R^2 = 0.451).

Making and keeping friends

Table 2 shows that discordance on the care need "making and keeping friends" was significantly associated with all variables in the univariable analyses, except for family SES, and quality of the parent-child relationship.

With regard to the final step of the multivariable analyses, Table 5 showed two child-level predictors: severity of the child's psychiatric problems, and dangerous behavior towards self. Parent-level predictors were degree of parental stress, and severity of the parent's psychiatric problems. At the family/social-context level, discordance was predicted by growing up in a single-parent household. The model showed a good fit of the data (Hosmer-Lemeshow, P = 0.403), and a relatively strong relationship between the predictor variables and the outcome (Nagelkerke R^2 = 0.542).

Table 3. Multivariable analyses of factors associated with patient-clinician discordance on unmet care needs with regard to mental health problems

	Child multivariable model				Child and parent multivariable model				Child, parent and family/social context multivariable model			
	N	OR	95% CI	P	N	OR	95% CI	P	N	OR	95% CI	P
Child level	243				243				186			
Severity of psychiatric problems		1.072	1.011-1.137	0.020		0.992	0.938-1.048	0.769				
Severity of internalizing problems		1.041	0.905-1.199	0.572								
Dangerous behavior												
Dangerous behavior towards self (yes/no)		4.187	2.187-8.015	<.001		3.813	1.918-.7.579	<.001		3.716	1.558-8.867	0.003
Rule-breaking behavior (yes/no)		2.927	1.517-5.647	0.001		2.398	1.151-4.995	0.019		3.086	1.273-7.481	0.013
Age: *6-11* *12-18*		1.304	0.662-2.567	0.443								
Parent level												
Degree of parental stress						1.311	1.110-1.549	0.001		1.233	1.021-1.490	0.030
Severity of parent's psychiatric problems						1.180	1.104-1.261	0.001		1.137	1.054-1.227	0.001
Family/social context level												
Child growing up in a single-parent household										3.022	1.300-7.025	0.010
Degree of discordance between parent and child on the child's mental health problems										1.082	0.997-1.174	0.058
Severity of problems with peers										1.083	0.885-1.196	0.117
Problems related to school												
Severity of problems related to school										1.013	0.908-1.130	0.816

Multivariable analysis: binary regression analyses of the predictors that were significant in the univariable analysis, performed simultaneously; n: number of patients; CI: Confidence interval; P-value<0.100 is considered statistically significant
Child level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.058, Nagelkerke R2=0.295
Child-parent-level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.437, Nagelkerke R2=0.499
Child-parent-family/social-context level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.645, Nagelkerke R2=0.575

Table 4. Multivariable analyses of factors associated with patient-clinician discordance on unmet care needs with regard to information regarding diagnosis and/or treatment

	Child multivariable model				Child and parent multivariable model				Child, parent and family/social context multivariable model			
	N	**OR**	**95% CI**	**P**	**N**	**OR**	**95% CI**	**P**	**N**	**OR**	**95% CI**	**P**
Child level	243				243				186			
Severity of psychiatric problems		1.061	1.099-1.116	0.020		1.034	0.985-1.085	0.179				
Severity of internalizing problems		0.992	0.899-1.094	0.866								
Severity of externalizing problems		1.121	0.972-1293	0.118								
Dangerous behavior towards self (yes/no)		4.249	2.282-7.911	<.001		2.997	1.621-.5.540	<.001		3.334	1.478-7.517	0.004
Rule-breaking behavior (yes/no)		2.276	1.239-4.182	0.008		2.002	1.063-3.769	0.032		1.920	0.858-4.300	0.113
Parent level												
Degree of parental stress						1.069	0.929-1.229	0.352				
Severity of parent's psychiatric problems						1.107	1.047-1.170	<.001		1.125	1.054-1.200	<.001
Family/social context level												
Child growing up in a single-parent household										2.336	1.076-5.072	0.032
Degree of discordance between parent and child on the severity of the child's mental health problems										1.085	0.964-1.151	0.037
Severity of problems with peers										1.053	0.975-1.070	0.155
Problems related to school												
Severity of problems related to school										1.015	0.926-1.113	0.746

Multivariable: binary regression analyses of the predictors that were significant in the univariable analysis, performed simultaneously; n: number of patients; CI: Confidence interval; *P*-value<0.100 is considered statistically significant
Child level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.346, Nagelkerke R^2=0.261
Child-parent-level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.917, Nagelkerke R^2=0.329
Child-parent-family/social-context level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.571, Nagelkerke R^2=0.451

All three care needs

Patient-clinician discordance on all three predefined CANSAS items was associated with child, parent, and family/social-context factors. The three final multivariable models found three common significant predictors: dangerous behavior towards self (child level); severity of the parent's psychiatric problems (parent level); and growing up in a single-parent household (family/social-context level).

Discussion

This study examined associations between patient, parent, and family/social-context variables on the one hand, and patient-clinician discordance on regarding unmet need for care on the other. We investigated discordance for the following unmet needs for care: (i) mental health problems, (ii) information regarding diagnosis and/or treatment, and (iii) making and/or keeping friends. In the present sample, discordance on these three unmet care needs indicated mainly that clinicians deemed care to be necessary, whereas patients did not. As we had hypothesized, discordance between clinicians and children/adolescents was predicted by predictors at child, parent, and family/social-context levels.

Most of the variables that were analyzed univariably were associated with discordance between patient and clinician on all three care needs (see Table 2). As stated above, we conducted multivariable stepwise logistic regression analyses to identify which predictors predicted this discordance independently of other predictors, and to investigate whether variables at all three levels were needed to obtain the strongest predictive model. As this resulted in three final models (for all three outcomes) that encompassed predictors from all levels, discordance between patients and clinicians was truly predicted by information on children, parents, and the family/social context. Below, we summarize which variables predicted discordance with respect to the three care needs in the multivariable models (see Tables 3, 4 and 5). As these analyses showed which predictors were the most useful in predicting discordance, the final statistical models tended to present a prototypical picture of patients who disagreed with their clinician on their need for care, and of their parents and family/social context.

Disagreement on all three outcomes predicted by child level variables (final set of analyses)

Many patients who disagree with their clinicians on the three care needs we examined often show dangerous behavior towards themselves (e.g., suicide attempt, self-harming behavior). It seems that dangerous behavior is less a reason to seek help than a more modest demand for mental health support. This can be explained in various ways.

Suicidal thoughts or self-harm may indicate that a patient no longer sees a way out, and thus tends to think that care will not be helpful [45]. Similarly, patients who harm themselves may consider self-harm to be a better way of coping with negative emotions than treatment is [45]. In many cases they may have lost confidence in the ability of other people to help relieve their suffering. Self-harm may lead to the immediate alleviation of negative thoughts or feelings (such as tension, anxiety or anger), or may increase social support or attention [46]. It is possible that such reinforcement affects a patient's perceived need for care. In contrast, clinicians of patients who harm themselves may see opportunities for improvement, and may therefore indicate that care is needed.

Disagreement on all three outcomes predicted by parent-level variables (final set of analyses)

Children and adolescents who tended to disagree with clinicians about all three care needs had parents with psychiatric problems. Due these problems, clinicians may believe that these young people have more care needs, reasoning that the children of such parents are at greater risk, and thus require more attention. It is also the case that parents with psychiatric problems are more likely to report severer problems in their children, whatever the actual severity [47, 48]. This may lead clinicians to judge that care is needed, while the young people rate themselves as being less in need of help [1, 27]. Another possible explanation is that young people who grow up with parents with mental health problems have become accustomed to problems, and believe that they cannot be resolved [49, 50].

Disagreement on all three outcomes predicted by family/social-context level variables (final set of analyses)

We found that many young people who disagreed with their clinicians on all three of the care needs studied had grown up in a single-parent household. It is conceivable that clinicians rate care needs more highly if they feel that a child is less protected, in view of the fact that there is one parent rather than two. Alternatively, parents who run a single-parent household may report relatively high problem levels, and stress the need for care, as they are caring for their children on their own. This may cause clinicians, too, to give higher ratings to need for care.

Other significant findings

We found that the degree of a child's rule-breaking behavior (as assessed after a standardized interview with the child), predicted patient-clinician discordance on unmet need for care for mental health problems.

It is possible that young patients who break rules are less aware of their problems, or

do not see the need for change [51]. Any negative experiences with adults [52] – who make and enforce rules – may also negatively affect their motivation for collaborating with treatment intended to resolve problems. [53].

For two of the three unmet care needs we investigated – unmet care needs regarding mental health problems, and information regarding diagnosis and/or treatment – we found that the degree of discordance between parent and child also predicted discordance between patient and clinician. As proposed previously [13, 26, 48], this may mean that clinicians agree more with parents than with their children/adolescents, thus possibly indicating that clinicians take parents more seriously than they take young people.

Alternatively, children/adolescents who disagree with their parents may also tend to disagree with clinicians [47, 48]. Previous research showed that, irrespective of the actual severity, more parents with high stress levels tend to report a greater problem severity in their children [47, 48]. In theory, this might cause clinicians to give a higher rating to needs for care, and therefore to inflate patient-clinician disagreement. [1, 27]. However, we found that one specific association at least was independent of the degree of parental stress: that between child-parent disagreement and child/clinician disagreement.

Clinical implications

In the context of personalized care, care needs should be assessed from the start of the treatment trajectory [54]. They can be addressed properly only if they are examined systematically from the perspectives of the key people involved in treatment [13,54]. Our findings show that special attention should be paid to the particular perspective on care needs that applies to patients who harm themselves, exhibit suicidal behaviors, break rules, have parents with psychiatric problems, disagree with their parents on the presence of mental health problems, and grow up in a single-parent household. If patient-clinician perceptions differ, clinicians are advised to resolve the most important differences before treatment is delivered [55]. Given that positive treatment outcomes are associated with a good therapeutic relationship [4], it is important to debate differences in a way that enables the “bond” in the patient-clinician dyad to remain intact [16, 56]. However, due to the importance of factors at parent and family/context levels – such as parental psychiatric problems and growing up in a single-parent household – it is probably not effective to solve discordances solely through this dyad. It is therefore important to discuss patients’ needs for care in the triad of patient, parent, and clinician, paying specific attention to the predictive factors outlined above that significantly contribute to discordance.

Fruitful therapeutic relationships within this triad will contribute to positive treatment outcomes and the prevention of drop-out from treatment. Establishing such

Table 5. Factors associated with patient-clinician discordance on unmet care needs with regard to making and keeping friends

	Child multivariable model				Child and parent multivariable model				Child, parent and family/social context multivariable model			
	N	**OR**	**95% CI**	**P**	**N**	**OR**	**95% CI**	**P**	**N**	**OR**	**95% CI**	**P**
Child level	243				243				181			
Severity of psychiatric problems		1.114	1.049-1.247	0.002		1.049	0.993-1.109	0.088		1.079	1.006-1.156	0.032
Severity of internalizing problems		0.963	0.823-1.128	0.644								
Severity of externalizing problems		0.996	0.790-1259	0.975								
Dangerous behavior												
Dangerous behavior towards self (yes/no)		4.955	2.493-9.849	<.001		4.458	2.239-.8.875	<.001		4.691	1.918-11.476	0.001
Rule-breaking behavior (yes/no)		2.709	1.389-5.281	0.003		2.286	1.110-4.710	0.025		1.807	0.752-4.341	0.186
Age: *4-11* *12-18*	243 90 153	1.642	0.814-3.314	0.166								
Parent level												
Degree of parental stress						1.162	0.991-1.363	0.065		1.172	0.970-1.416	0.099
Psychiatric problems												
Severity of parent's psychiatric problems						1.166	1.093-1.244	<.001		1.114	1.032-1.202	0.006
Family/social-context level												
Child growing up in a single-parent household										2.782	1.182-6.546	0.019
Degree of discordance between parent and child on the severity of the child's mental health problems										1.068	0.985-1.159	0.113
Severity of problems with peers										1.043	0.945-1.145	0.382
Severity of problems related to school										1.000	0.896-1.115	0.997

Multivariable: binary regression analyses of the predictors that were significant in the univariable analysis, performed simultaneously; n: number of patients; CI: Confidence interval; *P*-value<0.100 is considered statistically significant
Child level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.657, Nagelkerke R^2=0.368
Child-parent-level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.969, Nagelkerke R^2=0.496
Child-parent-family/social-context level: Omnibus test, Step P= 0.000, Model P=<0.000, Hosmer-Lemeshow, P=0.403, Nagelkerke R^2=0.542

relationships must start with a shared view of the care that is needed. It means that patients' perspectives on care their needs should be taken seriously. It also means seeking shared goals and making decisions on interventions collaboratively – together *with* patients, not *for* them [53].

These guidelines for a care-needs-based approach provide a flexible framework that gives guidance to clinicians, while leaving them scope for appropriate action on individual and situational peculiarities. To encourage and facilitate discussion of different viewpoints on care needs, various patient-centered communication techniques can be used, including (i) motivational interviewing techniques that are characterized by bond-building, empathy, interpersonal sensitivity, and the provision of information [54]; and (ii) shared decision, which may help to establish a process for collaboratively making decisions about the care needs that will be targeted during treatment [55].

Strengths/limitations

This study has several strengths. To our knowledge, it is the first to provide insight into factors that are associated with discordance between patients and clinicians on unmet care needs [26, 55, 56]. Due to our use of more than one outcome variable for child/adolescent-clinician discordance, we were able to identify factors that predict discordance on unmet care needs. Knowledge obtained may contribute to a more personalized form of care that enables patients to better identify with the treatment provided [10]. This knowledge may help patients to feel more engaged in treatment, and to prevent non-adherence and drop-out [57]. Finally, our use of hierarchical analyses made it possible to investigate relevant predictors at child, parent, and family/social-context levels.

A limitation is that our data were collected at a single mental health organization. For this reason, our results can generalized only with reservations [58].

Conclusion

We found that discordance between young people and clinicians on unmet care needs were associated with factors at child, parent, and family/social-context levels. On this basis, we conclude that it is important to the effective delivery of treatment and the prevention of drop-out to address all three levels during diagnostic assessment and psychiatric treatment.

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CHAPTER 7

Summary and general discussion

Introduction

This dissertation had a twofold aim. The first was to generate greater knowledge about outpatients who are referred to more intensive mental healthcare in the form of Youth ACT. The second was to generate knowledge of the care needs of children and adolescents with mental health problems, such that mental healthcare could be better tailored to these needs.

The motivation for the thesis was rooted in daily clinical practice, and the rationale for the research project lay in the following: (i) indications that, due to high rates of non-compliance, non-attendance at appointments, or drop-out, many patients referred to child and adolescent psychiatry are undertreated; (ii) the assumption that such non-compliance, non-attendance, or drop-out can be explained, at least in part, by the limited attention paid to the broad range of patients' met and unmet care needs; and (iii) our identification of knowledge gaps with respect to these patients' met and unmet care needs – needs that must be addressed if patients are to receive more personalized care, if adherence to treatment is to be optimized, and, ultimately, if better treatment outcomes are to be attained. To gain a comprehensive overview of these care needs, we examined children's and adolescents' perceptions of their care needs, and also the perceptions of their mental health professionals.

This chapter begins by summarizing the main results of the studies reported in chapters 2 to 6, which are then discussed. A discussion of the scientific methods used in these studies is followed by recommendations for future research and clinical practice. The chapter ends with some general conclusions.

Summary of main findings and answer to sub-questions

What is the effect of Youth ACT on the severity of psychiatric symptoms, general functioning, and psychiatric hospital admissions?

Chapter 2 presents a systematic review of studies that examined the effect of Youth ACT on the severity of psychiatric symptoms, and on general functioning, and the frequency of psychiatric hospital admissions.

In recent decades, deinstitutionalization policies worldwide have led to a transition from inpatient mental healthcare to community mental healthcare. At present, most children and adolescents with mental health problems are referred, to office-based outpatient clinics for mental healthcare [1, 2]. Outpatients with severe mental health problems who are "difficult to reach," and who require additional treatment and care can be referred to assertive outreach teams, such as Youth ACT teams [3]. ACT (Assertive Community Treatment) is a well-organized low-threshold form of treatment that actively approaches patients in their own environment, and that tries to enhance their motivation for and commitment to treatment. The underlying assumption is that ACT may be effective by meeting their unmet care needs.

Our review included 13 studies published over the preceding 19 years. The Oxford Centre of Evidence-Based Medicine grading system was used to generate an overall measure for the strength of any recommendations we based on it. We found limited but promising evidence suggesting that Youth ACT is effective in three respects: reducing the severity of psychiatric symptoms (ES = 0.3-1.3); improving general functioning (ES = 0.2-1.5); and reducing the duration and frequency of stays in a psychiatric hospital (ES = 0.3-1.6). While the effects of Youth ACT may be comparable with those of ACT in adults, randomized experimental research designs are needed to further corroborate this.

Which child, parent and family/social contexts factors are associated with treatment intensification in child and adolescent psychiatry?

In **Chapter 3**, our aim was to investigate factors that predict an intensification of office-based outpatient treatment towards more intensive assertive outreach treatment in children and adolescents. To our knowledge, the variables associated with the intensification of outpatient treatment had never been investigated systematically. Several predictors emerged from our comparative cross-sectional study of 123 outpatients and 123 Youth ACT patients and their primary caregivers. We found that referrals from general outpatient care to Youth ACT were more likely in children with more severe psychiatric symptoms living in families with parents who experienced high levels of distress, and who are involved in, victims of, or witnesses of, domestic violence. We presume that there are negative coercive interactions patterns between

domestic violence, parental stress, and that the associated psychiatric symptoms in children lead to referral for ACT treatment. Our findings suggest that the effectiveness of outpatient treatment might be enhanced by a greater focus on parental stress and domestic violence.

What are unmet care needs in children and adolescents with ADHD who are treated in outpatient and Youth ACT settings?

Even though effective treatments are available, over 40% of patients in child and adolescent psychiatry remain undertreated because non-compliance and/or drop-out from treatment obstruct the proper delivery of treatment interventions. We assumed that non-compliance and/or drop-out may result partly from mismatches between the care needs perceived by patients on the one hand, and the treatments actually provided on the other.

In **Chapter 4,** we therefore investigated unmet care needs in two subpopulations: patients with ADHD who were receiving treatment in a regular outpatient setting, and patients with ADHD who were receiving Youth ACT. To assess care needs, we used the Camberwell Assessment of Need (CANSAS) questionnaire. We included 105 ADHD patients aged between 6 and 17, fifty-two of whom from a general outpatient sample, and 53 from a Youth ACT sample. We found that the three most important unmet care needs these patients perceived involved "mental health problems," "information on diagnosis and/or treatment," and "future prospects." Comparison of the two patient groups highlighted that outpatients differed from Youth ACT patients with respect to 30% of the unmet care needs that were investigated. While the outpatients reported more unmet care needs regarding information on diagnosis and/or treatment, the patients treated with Youth ACT perceived more unmet needs regarding the following: the side effects of medication, the quality and/or quantity of food, their self-care abilities, suitable school/daytime activities, friendships, and future prospects. Our results suggested that targeting ADHD patients' treatment on a broad range of unmet care needs, and not only on ADHD symptoms, might increase patients' motivation for treatment and their treatment adherence, and might also reduce drop-out rates. Although this remains to be tested in future experimental research, a needs-led approach might ultimately help improve treatment results.

What are the perceptions of patients and mental healthcare providers regarding the unmet care needs of patients who are being treated in outpatient and Youth ACT settings?

The purpose of **Chapter 5** was to shed more light on the extent to which patients and their clinicians in child and adolescent psychiatry agree or disagree on a broad range of unmet care needs. The study was motivated by our hypothesis that high rates of

drop out or non-compliance with treatment in child and adolescent psychiatry were related at least in part to the possibility that patients and mental healthcare providers conceptualize these care needs in profoundly different ways. If so, this would have consequences for the degree of agreement on treatment goals and interventions, and the way these are delivered.

To our knowledge, patient-care provider agreement and disagreement on a wide range of unmet care needs had never been systematically investigated. Using the CANSAS, we assessed met and unmet needs from the perspectives of patients and their mental healthcare providers. Participants in this study were 244 patients aged between 6 and 18, and 27 care providers. The primary outcome measure was patients' and care providers' agreement on unmet care needs. We also compared the treatment settings in which these patients were treated, i.e., a regular outpatient sample (n=123) and a Youth ACT sample (n=121). The inclusion of the latter sub-sample enabled us to investigate the unmet care needs of patients with severe psychiatric and psychosocial problems who, after failing to respond to regular office-based interventions, had been referred to more intensive Youth ACT treatment.

We found that patients reported fewer unmet care needs than their care providers. The lowest levels of agreement were found with regard to unmet needs related to (1) "mental health problems" ($k = 0.113$), where scores differed significantly between patients (63.9%) and care providers (93.5%; $p < .05$); (2) "information regarding diagnosis/treatment" ($k = 0.171$), where patients (54.5%) reported unmet needs significantly less than care providers (82.4%; $p < .05$); and (3) "making and/or keeping friends" ($k = 0.299$; patients 26.2% vs. care providers 55.9%; $p < .05$).

Comparison of Youth ACT and outpatient patients showed that, in both settings, for three-quarters of the care needs examined, patients reported care needs less than care providers did. Compared to their peers in the outpatient setting, Youth ACT patients agreed significantly less with their care providers about the presence or absence of an unmet care need.

Which factors are associated with differences in perceptions on the patients' unmet care needs between mental healthcare providers and patients who are being treated in outpatient and Youth ACT settings?

In **Chapter 6** we investigated the factors that may be associated with discordance on patients' unmet care needs between patients and care providers in child and adolescent psychiatry. Understanding this is important, as such discordance may obstruct shared decision-making on treatment goals and interventions. Shared decision-making opens the gates to treatment adherence and effective treatment. As Chapter 5 had found that the greatest patient-care provider discordance was found for three CANSAS care needs – "mental health problems," "information regarding diagnosis/treatment," and

"making and/or keeping friends" – Chapter 6 used univariable and multivariable statistics to investigate factors associated with discordance between patients and care providers in these three areas. To our knowledge, this had never been done before. Our cross-sectional study with 244 children/adolescents aged between 6 and 18 showed that discordance between young people and care providers were associated with factors at child, parent and family/social-context levels. Factors that predicted disagreement on in all three outcomes were dangerous behavior towards self, severity of a parent's psychiatric problems, and growing up in a single-parent household. Patient-care provider discordance was thus associated with factors at the level of the child, parent, and family/social context. To deliver treatment most effectively and to prevent drop-out, it is therefore important that assessment and treatment planning take full account of these contexts.

General discussion: toward an integration of findings

Improving adherence to treatment, and preventing dropout in patients in child and adolescent psychiatry.

How can adherence to treatment be improved and dropout in clinical practice be prevented? First and foremost, we propose a more care-needs-oriented approach that pays full attention to the three perspectives on patients' care needs: the patient's, parent's, and the care provider's [4]. Aligning these perspectives will contribute to effective collaboration during treatment, leading, we may assume, to more favorable outcomes.

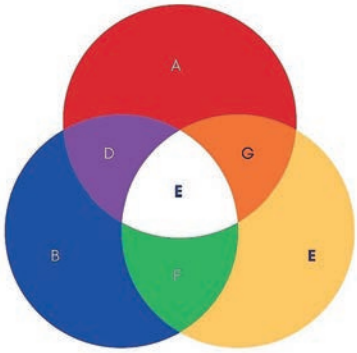

Figure. 1. Perspectives on patients' care needs.
A (red): only the patient reported an unmet care need; B (blue): only the parent reported an unmet care need; C (yellow): only the care provider reported an unmet care need; D (violet): patient and parent, but not the care provider, reported the presence or absence of an unmet care need; E (white): patient, parent, and care provider reported the presence or absence of an unmet care need; F (green): parent and care provider, but not the patient, reported the presence or absence of an unmet care need; G (Orange): patient and care provider, but not the parent reported the presence or absence of an unmet care need.

Within the triad consisting of patient, parent and care-provider, we consider the care needs a patient experiences. These are colored by a range of factors, such as age, sex, ability to reflect, distress, motives and motivation, goals, values, capabilities, limitations, fears, and moods [5]. We may also consider a patient's care needs from the perspective of his or her parents, which are themselves colored by a range of factors, including their history and background; their perception of their parental role; their views on proper education; their opinions on the child's problems; their perceptions of a meaningful life; their parenting skills; and any stress they may experience [5]. A care provider's perspective on a patient's care needs comprises factors such as professional knowledge and preferences, previous training, and personal background, such as norms, values, and personal experiences [5]. To varying extents, the three parties' perspectives on the patient's care needs are likely to overlap (see fig. 1).

Although the process of bonding, formulating goals, and choosing and delivering treatment interventions will almost certainly be positively influenced by agreement between those involved in it [6], our research (**Chapters 5 & 6**) shows that, in daily practice, perspectives on the patient's care needs often differ [7]. Since people tend to believe that their own perspective is "correct," these different perspectives may lead to varying opinions on treatment goals and the care that is needed. Further, if agreement has been reached at a certain point on patients' care needs, it cannot be assumed that this agreement will remain unchanged throughout the treatment process, as new challenges may arise [8]. Disagreement is always likely: perspectives on the patient's care needs may change over time, problems may increase or decrease, new insights may develop, and motivation for treatment may change [9]. Agreement on care needs is thus a dynamic process that requires regular and effective communication and negotiation.

If, during the course of treatment, goals and interventions continue to be sufficiently congruent with the patient's care needs, this may stimulate the patient's active involvement in treatment – to the benefit of the quality of the therapeutic alliance between patient and care provider [10]. This alliance consists of three essential components: agreement on treatment goals, agreement on interventions, and the development of a personal bond [11, 12]. Previous research among other patient groups shows that treatment outcome is predicted by the quality of the therapeutic alliance [13].

In most cases, it is not a child/adolescent but his/her parents who request the general practitioner for referral to mental healthcare [14]. Unlike the situation in adult psychiatry, where most patients arrange their own referrals, healthcare providers in child and adolescent psychiatry often encounter patients who indicate at intake that they do not see the need for mental health services [7, 15]. This is reason enough to ask ourselves how we should deal with the different perspectives on patient care needs that are encountered during the course of treatment.

Managing differences in perspectives on care needs

Diagnostic assessment of perceived problems and related care needs

From the start of a treatment trajectory, it is important to obtain information about patients', parents' and care providers' perspectives on care needs [16, 8]. If perspectives differ on the patient's core problems, those on needs for care are also likely to differ [17, 18]. It is therefore important to identify any differences of perspective regarding these problems and needs.

While the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) can be used to assess care needs in different domains [17], most assessment tools focus specifically on psychological or psychosocial needs [19]. To our knowledge, the CANSAS is the only tool that measures a broad range of care needs [19]. But as it includes a number of questions that are more appropriate for older adolescents, it could still be refined for use with children and young adolescents.

Although it is common to collect information from a range of informants, there is a risk that the collection process is neither comprehensive nor structured, and that relevant information on different perspectives is missed [5]. In clinical practice, care providers often focus on systematically identifying psychiatric symptoms and related problems before establishing a psychiatric diagnosis [20]. Although this strategy is useful because it leads to a diagnosis that provides the basis for treatment, it does not provide a comprehensive, multi-angle view on care.

The question therefore arises of where a diagnostic process should lead. Should it focus only on establishing a psychiatric diagnosis? Or should it identify a patient's broader problems and care needs – even though certain problems, such as those involving finances or housing, may require services other than those provided by the mental healthcare services? And is it always necessary to gain full insight into the extent of agreement or disagreement between the patient, his or her parents, and healthcare professionals regarding problems and care needs [21]?

Focus on differences in perspectives on problems and care needs

On the basis of our experience in current clinical practice, we therefore argue that there is a significant risk that different perspectives on problems and care needs do not receive the necessary attention. In clinical practice, it is often unclear to what extent patients' perspectives on their care needs match those of their parents and care providers. If, at the beginning of the process, any differences remain under the surface, it may be difficult to formulate goals and to choose or conduct interventions [6]. The patient may never become engaged in the treatment, or stop participating in it altogether. By identifying such differences at an early stage – i.e., from the very start of treatment – it may become clear in which areas of functioning collaboration is possible in the short-term, and in which areas the first step should be to establish

common goals [22]. In other words, it is essential to set priorities. To keep the treatment alliance with the patient intact, and to prevent dropout, the healthcare professional will, in certain cases, have to postpone treatment interventions that he/she may regard as the first priority. The question is thus which priorities should be set at first, and which may become important later.

Schematic representations

Debate on perspectives on a patient's care needs might be facilitated by having those involved collaborate on creating a schematic representation not only of the problems identified, but also of the interrelationships between them, the factors that provoke and sustain them, and care needs related to them [23]. This may be a useful technique for structuring the debate on problems and care needs [24, 25], and may also be useful for setting priorities [26, 27].

Schematic representations are widely used in cognitive behavioral therapy; if problems are complex, they help to create clarity and to gain a clearer view of reciprocal interactions, and of the relation between problems and care needs [28]. They can be presented in different forms, ranging from a simple flowchart or conceptual map to an intricate matrix using textual information and symbols [29]. In a youth-assertive community setting, it is particularly important that these representations include problems in the family and social contexts; this is due to the possible presence of common problems such as parents' psychiatric issues, parental stress, children's problems with peers, domestic violence, and financial problems) [30]. By providing deeper insight not only into the patterns in which problems co-occur, but also into the relationships – hierarchical and otherwise – between problems, these representations can be used to establish priorities [31]. The schematic representation of a patient's problems may thus establish the basis for a discussion that results in agreement on problems, care needs, treatment goals, and interventions. Care providers can add value to such discussions by playing an analytical role in which they interpret the information gained from the representation, and by non-judgmentally juxtaposing patients', parents', and care providers' views of the core problems on which treatment should focus [32].

High in the hierarchy of problems, it is useful to position those that have a strong negative impact on the patient's overall functioning, and those problems that result in many other problems. For example, if the core problem is "being cognitively overloaded at school," the following problems may stem from it: depression, being easily irritated, dropping out of school, and conflict with parents about school problems. Problems that have little impact on daily functioning, or are a derivative of core problems, may deserve little or no attention in the discussion, as they are lower in the hierarchy. It is particularly relevant to reach agreement on core problems, as these are the ones on

which the patient, parents, and care providers need to collaborate during treatment. Identifying these core problems effectively is highly likely to achieve the greatest change with regard to relieving suffering and promoting recovery.

Using patient-centered communication to discuss the different perspectives on core problems

In child and adolescent psychiatry, there is a unique triadic relationship between patients, parents, and care providers. If those involved have different views on the patient's core problems and related care needs, it is important to communicate on these differences in a way that maintains the bond between the triad's members.

In this debate, there should therefore be full, non-judgmental recognition of patients', parents' and care providers' perspectives. This requires skill on the part of the care providers, who must be able to maneuver between the different interests of those involved. To better understand the patients' and parents' perspectives, and to respond to them well, care providers need to recognize their own feelings, preferences and partialities [33]. To be able to create the space necessary to engaging in a non-directive and nonjudgmental dialogue, and to communicate empathetically and genuinely with patients and their parents, it is essential that care providers are aware of, and can reflect on, their own feelings and preferences [34]. For a productive discussion, many patients and parents need to feel both that their care provider understands them, and can be a source of support [35]. Nonjudgmental acceptance and a sensitive attitude on the part of the care provider may support patient and parents in being open to new information and in developing trust toward the care provider [34].

Several forms of patient-centered communication technique may encourage and facilitate the discussion on different viewpoints on core problems and care needs. One of these forms is the transtheoretical model of intentional behavior change, which provides a framework that can be used to understand different perspectives on a patient's problems and care needs [36]. The model holds that problems are resolved through five stages: precontemplation (not yet considering change); contemplation (i.e., considering); preparation (planning and committing to change); action (making behavior change); and maintenance (maintaining and sustaining long-term change) [36].

To communicate effectively, the care provider, patient, and parents should connect with each other in whichever stage they are happen to be. For example, the patient may be in the precontemplation stage, the parent in the preparation stage, and the care provider in the action stage. All three parties should analyze how they can understand the different perspectives on the patient's core problems, and how they can identify the change phase in those involved [22]. As people's willingness and readiness to change may vary per problem area, an overall view is needed of the other parties' willingness and readiness to change; and narrower views are needed of specific

problems and care needs. The willingness to change may be less necessary in a person who plays a smaller role in treatment [37].

Different viewpoints regarding core problems and related needs can also be discussed using motivational interviewing techniques [9]. Motivational interviewing (MI) is a person-centered communication style in which a care provider supports a patient in clarifying discrepancies between the actual and preferred situations, and in recognizing and resolving ambivalence toward behavior change. In this regard, the patient is encouraged to take individual and joint responsibility for treatment choices. The essence of MI is that motivation to change comes from within the patient, and is not imposed by the care provider or parents [38]. To support change, the care provider shows appreciation and understanding of the patient's point of view, and ensures that old and new behaviors as well as advantages and disadvantages are discussed in a collaborative atmosphere [39].

To establish a process for making joint decisions on care needs, goals, and treatment interventions, it is also possible to use shared decision making (SDM) [40], which has been shown to have a positive impact not only on the degree of patients' active involvement in treatment, but also on their treatment satisfaction, adherence, and outcomes [41, 42]. SDM is a collaborative approach in which patient, parents, and care provider share their perspectives on treatment options [37]. Conducted on the basis of equality, this discussion involves patients' and parents' experiential knowledge, values and wishes; and also scientific knowledge and the care provider's expertise [41]. The SDM method comprises five steps: 1) introducing choice(s), eliciting goals, and exploring the roles of patients and their parents; 2) giving meaning to available information sources; 3) exploring options; 4) weighing options; and 5) making a shared decision [43]. Effective decision-making depends on active participation by all parties, i.e., patient, parents, and care provider [44]. To achieve a certain degree of consensus in the triad of patient, parents and care provider, the care provider needs to alternate between multiple roles, such as initiating the discussion, offering space for the preferences of all involved in the decision-making process, advocating his/her own perspective, and assuming the role of co-decision maker [45].

People are not always rational beings

To avoid frustration, it is important for care providers to realize that people – including patients, parents, and care providers themselves – are not simply rational beings [46]. People are guided not only by the rational mind, but also by emotional, motivational and moral factors [47, 48]. Choices are not simply made rationally on the basis of effectiveness and efficiency and – in this case – the desire to benefit from treatment. Other factors also play a role, such as trust in the care provider, self-confidence, self-efficacy, emotions (e.g., mood, and fears), personal interests, and epistemic trust – i.e., being open to learning from new information [49, 50]. The options for optimizing

treatment trajectories through plannable rational processes are thus limited by human irrationality [51]. Does this mean that healthcare providers or researchers should stop trying to optimize treatment processes? By no means! Even though we must recognize our limitations with regard to optimizing treatment processes, any attempt to improve healthcare for children and adolescents with mental illness is welcome.

Implications for practice

Disseminating information

To encourage the use of an approach oriented towards care needs, it is important that key information on this approach is disseminated in mental health settings. This can be achieved through presentations at conferences and publications in peer-reviewed journal articles [52]. Influential experts and peers can also use their networks to spread information on the approach and to demonstrate its value [53, 54]. A care-needs-oriented approach can also be promoted by sharing information through social media [55].

Practice guidelines

If the recommendations incorporated in clinical guidelines are not sufficiently aligned with patients' views of the care they need, their overly rigid application can impair the therapeutic alliance [56]. This is especially the case with patients whose treatment expectations are not in line with clinical guidelines. If key information on a care-needs-oriented approach is integrated into existing guidelines, care providers may gain tools for bridging the gap between the scientific knowledge described in existing guidelines; the experiences, values and wishes of patients and their parents; and the expertise of care providers [53]. Incorporating a menu of interventions (e.g., assessment tools, MI, SDM) into existing clinical guidelines may help providers to adopt a care needs-based approach in practice, and also to bridge the gap between evidence-based guidelines, clinical practice and patients' preferences [33, 57].

Development of competencies

A care-needs-oriented approach does not require more time, but rather a shift in viewpoint and priorities [33]. Its application by the care provider requires professional knowledge, skill development, and self-assessment [58], which should focus on the following: (i) the need to start not from a fixed idea – from the professional's perspective – of the care patients should receive, but from the desire to find a shared view of what is needed; (ii) the need to take patients' and parents' perspectives seriously, and to seek to understand them; (iii) the need to seek, *with* patients, not *for* them, solutions and joint decisions on the goals to be achieved and the interventions to be planned; (iv) the need to support patients and parents in finding their own ways – sometimes within a limited window of opportunities – of dealing adequately with their problems; and, (v)

the need to encourage the highest possible degree of personal responsibility [59].

These criteria for a needs-oriented approach to care are not rigid rules, but a code of clinical practice to which a care provider can refer in order to provide guidance, while simultaneously providing the scope he or she needs to respond appropriately to individual and situational particularities [37]. Care providers need to be able to integrate the perspectives of all three parties on problems, care needs and required treatment. They must be able to move easily within their personal and professional realities, but must also be attentive to patients' and parents' perceptions and experiences. A care-needs approach thus requires more than unilateral inputs of expertise by the care provider. Instead, it requires an unconditionally positive regard for the diversity of perspectives on care needs [60]. By supporting a discussion on a range of perspectives that includes explicit inputs from patients and parents on the treatment process, care providers must be wholly open to their own perceptions and professionals' practices – including their limitations. To better understand their patients' and parents' input in the treatment process, and to respond appropriately, care providers must clearly recognize their own feelings, preferences, habits and partialities.
In short, everyone involved in treatment, including the care provider, has a stake in reaching agreement on the care that is needed [61]. Through the provision of opportunities for continuing education and supervision, care providers can be supported in further developing their knowledge, and the practical and reflective skills they need to be able to apply a care-needs-oriented approach [62]. Those who have been trained to apply this approach can then be helped by mental health organizations to disseminate their knowledge and skills to their fellow care providers [63].

Assessment tools

The process of assessing care needs is an important part of optimizing patient care [10]. This process should not be seen merely as a matter of data collection, but also as a method of (i) obtaining a comprehensive picture of a patient's care needs, (ii) assessing different perspectives on the patient's care needs, (iii) planning and evaluating service delivery, (iv) and assessing treatment outcomes [64]. Information obtained from a care-needs assessment thus provides the basis for organizing and managing personalized care. Ideally, a needs assessment will cover several domains, which means that behavioral, social, medical and psychological functions should be considered, together with the social and physical context [64]. In some cases — such as those involving patients with few care needs and no discrepancies between stakeholders — a brief assessment process may suffice [64]. If patients have many problems with complex mutual interactions, the CANSAS can be used for comprehensive assessment of the patients' care needs that covers different domains of functioning, and also the patients' and parents' preferences [64].

As patients' care needs change over time, it is important that evaluations take place throughout the treatment trajectory [65]. Validated assessment tools such as CANSAS are important instruments for obtaining information in a systematic and standardized way on a patient's care needs from those involved in the treatment.

Implications for education

As the training of mental health professionals is becoming more patient-centered [66, 67], teaching a care-needs-oriented approach to students of child and adolescent psychiatry – undergraduate nurses, social workers, psychologists, or psychiatrists – should be consistent with the steps already taken towards shaping the educational curriculum to the provision of patient-centered care [58]. It thus seems appropriate to teach students patient-centered communication techniques such as SDM and MI [33], and to familiarize them with the transtheoretical model of intentional behavior change [32].

Developing competencies

To work in a way that is person centered and care-needs based, mental health students must develop the knowledge and the reflective and practical skills that will enable them to identify, assess, and discuss patients' care needs not only from patients' and parents' perspectives, but also from their own [68]. As undergraduate students have their first interactions with patients and parents during their internships [60], they may not know what to expect from any of these parties – including themselves – in practice [68, 69]. Role-playing exercises in practical teaching sessions can provide a safe learning environment in which students can develop the competencies (i.e., knowledge, skills, and attitudes) they need to apply a patient-centered and needs-based approach in clinical practice [69]. Interaction through role-play can improve their skills in establishing both therapeutic relationships and communication based on a care-needs-oriented approach [70].

A prerequisite for students' ability to engage effectively in discussions with patients and parents in care-needs-based practice is that they are trained to develop the reflective capacity they need with regard to their own behavior and attitudes [71]. In such discussions, it is critical to strengthening and sustaining the interactive process that a healthcare provider can establish a collaborative relationship with patients and parents without the remotest sense of his or her own professional superiority, [60]. Students must learn to regard their own perspectives on a patient's care needs as one of many components of a shared view of these needs, and that these perspectives have to be integrated with those of patients and their parents. Students need courage to apply care-needs-based skills in practical training sessions, as they may later encounter barriers during their internships when interdisciplinary teams or mental health organizations are not familiar with such an approach [68].

The role of teachers

By adopting a needs-oriented and person-centered approach – in this case partly an education one – teachers may themselves serve as role models; in many ways, they could thus mirror the philosophy of a care-needs-oriented approach to mental healthcare [69]. Such teachers need to be receptive to students' perceptions of their own educational needs, and, to meet their students' unmet educational needs through an educational process, engage in a working relationship that is both active and collaborative [72]. By taking a needs-oriented approach to their own education, students gain experience through the teacher-student relationships that is transferable to the type or relationship between care provider and patients they must fulfill in clinical practice [69]. In training on a needs-oriented approach, teachers and students alike need to identify and discuss differences of perspective, both on the educational goals to be achieved, and on the training programs to be taken – all in a way that does justice to the students' personal interests and is free of reciprocal judgment. Such discussions enhance awareness and reflection, and stimulate students and teachers to develop skills they need to attain a shared view on educational needs [73]. By practicing this experiential process in education, students will develop the competencies they require to apply a care-needs-oriented approach in clinical practice [68, 74].

Implications for future research

All in all, the studies in this dissertation show that the care needs of patients in child and adolescent psychiatry merit more attention. By studying these needs in this population, we hope to have made a start on this process.

Future research could focus on obtaining a deeper understanding of the specific mechanisms behind the different views on patients' care needs – including the care providers' views [75, 76]. Mixed-methods designs would allow researchers working with patients, parents, and care providers to explore all these parties' perceptions of a patient's care needs, along with the different types of behavior they exhibit in the process of reaching agreement, and what is needed to improve agreement [77, 78]. Similarly, longitudinal studies could examine changes in patient's care needs over time as seen from different perspectives (patients', parents' and care providers'); and could determine which needs are the most salient at which points in time [77]. Further, randomized controlled trials (RCTs) could investigate whether a care-needs-oriented approach will indeed lead to fewer unmet care needs, better treatment adherence, less dropout, better treatment outcomes, and less treatment intensification [78, 79]. With regard to interventions RCTs might examine, it may be relevant to find ways of reaching agreement on care needs involving core problems that require collaboration during treatment [77].

Concluding remarks

Focusing on the care needs of children and adolescents in psychiatry, this dissertation provides proposes directions in which mental healthcare for children and adolescents might be optimized.

First, it indicates that Youth ACT is effective in three respects: reducing the severity of psychiatric symptoms, improving general functioning, and reducing the duration and frequency of psychiatric hospitalizations. These effects range from small to considerable, and appear to be comparable with effects of ACT in adults. To further corroborate their effectiveness, however, randomized experimental research designs are needed.

Second, the young people most likely to be referred from outpatient care to a more intensive form of treatment are children with severe psychiatric disorders, those with parents who experience high levels of distress, and those who are involved in, victims of, or witnesses of, domestic violence.

Third, with regard to all patients, including those with ADHD, it is possible that targeting unmet needs and not just symptoms would motivate them to engage in psychiatric and psychosocial treatment, which might reduce non-compliance and drop-out rates.

Fourth, patients and care providers often disagree on patients' care needs, particularly in a Youth ACT treatment setting. The greatest discordance between patients and care providers was found for three CANSAS care needs: "mental health problems," "information regarding diagnosis/treatment," and "making and/or keeping friends." Non-attendance of appointments and early termination of treatment may both be reduced by clarifying divergent views on patient's unmet care needs.

Fifth, several factors concerning the child, parent, and family/social context were associated with discordance between patients and care providers on the three predefined CANSAS care needs. To be able to deliver treatment most effectively and to prevent drop-out from treatment, these factors should all be addressed during assessment and treatment planning.

Future research is needed (i) to obtain greater in-depth understanding of specific mechanisms underlying divergent views on a patient's care needs, (ii) to better understand changes in patient's care needs over time as they are perceived from the perspectives of those involved in the treatment process, (iii) and to determine whether better treatment outcomes would be produced by a care-needs-oriented approach that is focused on obtaining a shared view on unmet care needs.

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APPENDICES

DUTCH SUMMARY | NEDERLANDSE SAMENVATTING

Achtergrond

Tijdens mijn werk, eerst als sociaal-pedagogisch hulpverlener en verpleegkundige in de geestelijke gezondheidszorg, later als verpleegkundig specialist GGZ en cognitief gedragstherapeut, kwam ik regelmatig kinderen en adolescenten tegen van wie de psychiatrische behandeling - die werd uitgevoerd volgens de relevante klinische richtlijnen - niet effectief was. Niet zelden merkte ik dat hulpverleners in de geestelijke gezondheidszorg (inclusief ikzelf) zich hulpeloos of ongemakkelijk voelden vanwege de hoge percentages therapieontrouw en vroegtijdige beëindiging van de behandeling. Kinderen of adolescenten leken soms een heel andere opvatting te hebben dan hun ouders en/of zorgverleners over de zorg die zij nodig hadden. Dit riep bij mijn collega's en mijzelf het gevoel op dat deze kinderen of adolescenten moeilijk te bereiken en te behandelen waren. De hulpeloosheid die ik voelde stimuleerde mij om na te denken over de vraag of de vaak eenzijdige focus op classificatie van DSM-diagnoses en evidence-based behandelingen kan hebben geleid tot het negeren van de door de patiënten zelf ervaren zorgbehoeften. Mijn veronderstelling was dat hoge mate van therapieontrouw, of vroegtijdige beëindiging van behandeling (deels) verklaard kon worden door de beperkte aandacht voor de (onvervulde) zorgbehoeften van patiënten.
In de afgelopen decennia zijn talrijke studies gepubliceerd over psychiatrische stoornissen bij kinderen. De meeste van deze studies richten zich op prevalentie, diagnose, etiologie en behandeling van psychiatrische stoornissen. In de literatuur neemt de aandacht voor de voorkeuren en ervaringen van kinderen of adolescenten op verschillende gebieden van het functioneren een te kleine plaats in.
Dit proefschrift richt zich op de (onvervulde) zorgbehoeften van kinderen en adolescenten die ofwel poliklinische geestelijke gezondheidszorg ofwel assertieve outreachende behandeling (Jeugd ACT) ontvangen. In onze studies betrekken we de perspectieven van de kinderen/adolescenten zelf, hun ouders en de hulpverleners.

Samenvatting van de belangrijkste bevindingen en antwoord op de vijf onderzoeksvragen

Wat is het effect van Jeugd ACT op de ernst van psychiatrische symptomen, algemeen functioneren, en psychiatrische ziekenhuisopnames?

Hoofdstuk 2 presenteert een systematische review van studies die het effect van Youth ACT op de ernst van psychiatrische symptomen, op algemeen functioneren, en op de frequentie van psychiatrische ziekenhuisopnames hebben onderzocht.
In de afgelopen decennia heeft deïnstitutionaliseringsbeleid wereldwijd geleid tot een transitie van intramurale geestelijke gezondheidszorg naar ambulante geestelijke gezondheidszorg. Op dit moment worden de meeste kinderen en adolescenten met geestelijke gezondheidsproblemen verwezen naar poliklinieken voor geestelijke gezondheidszorg. Poliklinische patiënten met ernstige psychische problemen die "moeilijk te bereiken" zijn en extra behandeling en zorg nodig hebben, kunnen worden doorverwezen naar assertieve outreach teams, zoals Jeugd ACT-teams. ACT (Assertive Community Treatment) is een goed georganiseerde laagdrempelige vorm van behandeling waarbij patiënten actief worden benaderd in hun eigen omgeving, en waarbij geprobeerd wordt hun motivatie voor en betrokkenheid bij de behandeling te vergroten. De onderliggende aanname is dat ACT effectief kan zijn door tegemoet te komen aan de onvervulde zorgbehoeften van deze patiënten.
Ons onderzoek omvatte 13 studies die in de afgelopen 19 jaar zijn gepubliceerd. Het beoordelingssysteem van het Oxford Centre of Evidence-Based Medicine werd gebruikt om een algemene maatstaf te genereren voor de sterkte van de aanbevelingen die we erop baseerden. We vonden beperkt maar veelbelovend bewijs dat suggereert dat ACT voor jongeren effectief is in drie opzichten: vermindering van de ernst van psychiatrische symptomen (ES = 0,3-1,3); verbetering van het algemeen functioneren (ES = 0,2-1,5); en vermindering van de duur en frequentie van verblijf in een psychiatrisch ziekenhuis (ES = 0,3-1,6). Hoewel de effecten van ACT bij jongeren vergelijkbaar kunnen zijn met die van ACT bij volwassenen, zijn gerandomiseerde experimentele onderzoeksopzetten nodig om dit verder te staven.

Welke kind, ouder en gezin/sociale context factoren zijn geassocieerd met intensivering van de behandeling in de kinder- en jeugdpsychiatrie?

In **hoofdstuk 3** wilden we de factoren onderzoeken die een intensivering van poliklinische behandeling naar een intensievere assertieve ambulante behandeling bij kinderen en adolescenten voorspellen. Voor zover wij weten zijn de variabelen die

samenhangen met de intensivering van poliklinische behandeling nog nooit systematisch onderzocht. Verschillende voorspellers kwamen naar voren uit onze vergelijkende cross-sectionele studie van 123 poliklinische patiënten en 123 Jeugd ACT patiënten en hun primaire verzorgers. We ontdekten dat kinderen met ernstigere psychiatrische symptomen die in gezinnen wonen met ouders die veel problemen ervaren, en die betrokken zijn bij, slachtoffer zijn van, of getuige zijn van, huiselijk geweld, een grotere kans hebben om verwijzen te worden van algemene poliklinisch GGZ-zorg naar Jeugd ACT. We veronderstellen dat er negatieve en elkaar versterkende interactiepatronen bestaan tussen ouderlijke stress en huiselijk geweld, en dat de daarmee gepaard gaande psychiatrische symptomen bij kinderen leiden tot doorverwijzing voor ACT-behandeling. Onze bevindingen suggereren dat de effectiviteit van poliklinische GGZ-behandeling zou kunnen worden vergroot door meer aandacht te besteden aan ouderlijke stress en huiselijk geweld.

Wat zijn de onvervulde zorgbehoeften bij kinderen en adolescenten met ADHD die poliklinische en in ACT-settings voor jongeren worden behandeld?

Hoewel effectieve behandelingen beschikbaar zijn, blijft meer dan 40% van de patiënten in de kinder- en jeugdpsychiatrie onderbehandeld, omdat therapieontrouw en/of therapie-uitval de juiste levering van behandelingsinterventies belemmeren. We veronderstelden dat therapie-ontrouw en/of therapie-uitval deels het gevolg kunnen zijn van mismatches tussen de door patiënten ervaren zorgbehoeften enerzijds, en de daadwerkelijk geleverde behandelingen anderzijds.

In **Hoofdstuk 4** onderzochten we daarom onvervulde zorgbehoeften in twee subpopulaties: patiënten met ADHD die in een reguliere poliklinische setting werden behandeld, en patiënten met ADHD die een ACT-behandeling bij de jeugd kregen. Om de zorgbehoeften te peilen gebruikten we de Camberwell Assessment of Need (CANSAS) vragenlijst. We includeerden 105 ADHD-patiënten tussen 6 en 17 jaar, van wie 52 uit een algemene poliklinische steekproef en 53 uit een Jeugd ACT-steekproef. We ontdekten dat de drie belangrijkste onvervulde zorgbehoeften van deze patiënten betrekking hadden op “geestelijke gezondheidsproblemen”, “informatie over diagnose en/of behandeling” en “toekomstperspectieven”. Vergelijking van de twee patiëntengroepen toonde aan dat poliklinische patiënten verschilden van jongeren met ACT met betrekking tot 30% van de onvervulde zorgbehoeften die werden onderzocht. Terwijl de poliklinische patiënten meer onvervulde zorgbehoeften rapporteerden met betrekking tot informatie over diagnose en/of behandeling, zagen de patiënten die met Jeugd ACT werden behandeld meer onvervulde zorgbehoeften met betrekking tot: de bijwerkingen van medicatie, de kwaliteit en/of kwantiteit van

voedsel, hun zelfzorgvaardigheden, geschikte school/dagactiviteiten, vriendschappen, en toekomstperspectieven. Onze resultaten suggereerden dat het richten van de behandeling van ADHD-patiënten op een breed scala van onvervulde zorgbehoeften,

Wat zijn de percepties van patiënten en zorgverleners in de geestelijke gezondheidszorg met betrekking tot de onvervulde zorgbehoeften van patiënten die worden behandeld in een poliklinische en Jeugd ACT setting?

Het doel van **Hoofdstuk 5** was om meer licht te werpen op de mate waarin patiënten en hun behandelaars in de kinder- en jeugdpsychiatrie het eens of oneens zijn over een breed scala van onvervulde zorgbehoeften. Het onderzoek werd gemotiveerd door onze hypothese dat hoge percentages drop-outs of het niet therapietrouw zijn in de kinder- en jeugdpsychiatrie tenminste gedeeltelijk samenhangen met de mogelijkheid dat patiënten en behandelaars deze zorgbehoeften op wezenlijk verschillende manieren conceptualiseren. Als dat zo is, zou dat gevolgen hebben voor de mate van overeenstemming over behandeldoelen en interventies, en de manier waarop deze worden geleverd.
Voor zover wij weten, is de overeenstemming en onenigheid tussen patiënten en zorgverleners over een breed scala van onvervulde zorgbehoeften nog nooit systematisch onderzocht. Met behulp van de CANSAS onderzochten wij de vervulde en onvervulde zorgbehoeften vanuit het perspectief van patiënten en hun zorgverleners. Deelnemers aan deze studie waren 244 patiënten tussen de 6 en 18 jaar, en 27 zorgverleners. De primaire uitkomstmaat was de overeenstemming tussen patiënten en zorgverleners over onvervulde zorgbehoeften. We vergeleken ook de behandelsettings waarin deze patiënten werden behandeld, d.w.z. een reguliere poliklinische steekproef (n=123) en een Jeugd ACT steekproef (n=121). De inclusie van deze laatste steekproef stelde ons in staat de onvervulde zorgbehoeften te onderzoeken van patiënten met ernstige psychiatrische en psychosociale problemen die, nadat ze niet hadden gereageerd op reguliere poliklinische interventies, waren doorverwezen naar een intensievere ACT-behandeling voor jongeren.
We ontdekten dat patiënten minder onvervulde zorgbehoeften rapporteerden dan hun zorgverleners. De laagste niveaus van overeenstemming werden gevonden met betrekking tot onbevredigde behoeften met betrekking tot (1) “geestelijke gezondheidsproblemen” ($k = 0{,}113$), waarbij de scores significant verschilden tussen patiënten (63,9%) en zorgverleners (93,5%; $p < .05$); (2) “informatie over diagnose/behandeling” ($k = 0{,}171$), waarbij patiënten (54,5%) significant minder onvervulde behoeften rapporteerden dan zorgverleners (82,4%; $p < .05$); en (3) “vrienden maken en/of houden” ($k = 0{,}299$; patiënten 26,2% vs. zorgverleners 55,9%; $p < .05$).

Vergelijking van patiënten in de ACT en de poliklinische setting toonde aan dat, in beide settings, voor driekwart van de onderzochte zorgbehoeften, patiënten minder zorgbehoeften rapporteerden dan zorgverleners deden. In vergelijking met hun leeftijdsgenoten in de ambulante setting waren jongeren met ACT het significant minder eens met hun zorgverleners over de aan- of afwezigheid van een onvervulde zorgbehoefte.

Welke factoren zijn geassocieerd met verschillen in percepties over de onvervulde zorgbehoeften van patiënten tussen zorgverleners in de geestelijke gezondheidszorg en patiënten die worden behandeld in een poliklinische setting en in een Jeugd ACT setting?

In **Hoofdstuk 6** onderzochten we de factoren die geassocieerd kunnen zijn met discordantie over de onvervulde zorgbehoeften van patiënten tussen patiënten en zorgverleners in de kinder- en jeugdpsychiatrie. Inzicht hierin is belangrijk, omdat een dergelijke discordantie een belemmering kan vormen voor gedeelde besluitvorming over behandeldoelen en interventies. Gedeelde besluitvorming opent de poort naar therapietrouw en effectiviteit. Omdat in hoofdstuk 5 was gevonden dat de grootste discordantie tussen patiënt en zorgverlener werd gevonden voor drie CANSAS zorgbehoeften - “geestelijke gezondheidsproblemen,” “informatie over diagnose/behandeling,” en “vrienden maken en/of houden” - gebruikte hoofdstuk 6 uni- en multivariabele statistieken om factoren te onderzoeken die samenhangen met discordantie tussen patiënten en zorgverleners op deze drie gebieden. Voor zover wij weten, was dit nog nooit eerder gedaan.
Onze cross-sectionele studie met 244 kinderen/adolescenten in de leeftijd van 6 tot 18 jaar toonde aan dat discordantie op alle drie de gebieden werd voorspeld door de volgende factoren: gevaarlijk gedrag naar zichzelf, ernst van de psychiatrische problemen van een ouder, en opgroeien in een eenoudergezin. Discordantie tussen patiënt en zorgverlener was dus geassocieerd met factoren op het niveau van het kind, de ouder, en het gezin/sociale context. Om de behandeling zo effectief mogelijk uit te voeren en uitval te voorkomen, is het daarom belangrijk dat bij de beoordeling en planning van de behandeling ten volle rekening wordt gehouden met deze contexten.

Conclusies

Gericht op de zorgbehoeften van kinderen en adolescenten in de psychiatrie, geeft dit proefschrift voorstellen voor richtingen waarin de geestelijke gezondheidszorg voor kinderen en adolescenten geoptimaliseerd zou kunnen worden.

Ten eerste geeft het aan dat Jeugd ACT effectief is in drie opzichten: vermindering van de ernst van psychiatrische symptomen, verbetering van het algemeen functioneren, en vermindering van de duur en frequentie van psychiatrische ziekenhuisopnames. Deze effecten variëren van klein tot aanzienlijk, en lijken vergelijkbaar te zijn met de effecten van ACT bij volwassenen. Om hun effectiviteit verder te bevestigen, zijn echter gerandomiseerde experimentele onderzoekdesigns nodig.

Ten tweede zijn de jeugdigen die het meeste risico lopen van poliklinische GGZ-zorg door verwezen te worden naar een intensievere vorm van behandeling kinderen met ernstige psychiatrische stoornissen, kinderen met ouders die veel problemen ervaren, en kinderen die betrokken zijn bij, slachtoffer zijn van of getuige zijn van huiselijk geweld.

Ten derde is het mogelijk dat alle patiënten, ook die met ADHD, door behandeling te richten op onvervulde behoeften en niet alleen op symptomen, gemotiveerd worden om deel te nemen aan psychiatrische en psychosociale behandeling, waardoor het aantal patiënten die therapieontrouw is en vroegtijdig uitvalt kan worden verminderd.

Ten vierde zijn patiënten en zorgverleners het vaak oneens over de zorgbehoeften van patiënten, vooral in een ACT-behandelingssetting voor jongeren. De grootste onenigheid tussen patiënten en zorgverleners werd gevonden voor drie CANSAS-zorgbehoeften: “geestelijke gezondheidsproblemen,” “informatie over diagnose/behandeling,” en “vrienden maken en/of houden.” Het niet komen opdagen voor afspraken en het vroegtijdig afbreken van de behandeling kunnen beide verminderd worden door het verhelderen van uiteenlopende opvattingen over de onvervulde zorgbehoeften van de patiënt.

Ten vijfde werden verschillende factoren met betrekking tot het kind, de ouder, en de familie/sociale context geassocieerd met onenigheid tussen patiënten en zorgverleners over de drie vooraf gedefinieerde CANSAS-zorgbehoeften. Om de behandeling zo effectief mogelijk te kunnen uitvoeren en om vroegtijdige beëindiging van de behandeling te voorkomen, zouden deze factoren geadresseerd moeten worden tijdens de beoordeling en de planning van de behandeling.

Toekomstig onderzoek is nodig om (i) meer inzicht te krijgen in specifieke mechanismen die ten grondslag liggen aan uiteenlopende opvattingen over de zorgbehoeften van een patiënt, (ii) meer inzicht te krijgen in veranderingen in de zorgbehoeften van patiënten in de loop van de tijd zoals die worden waargenomen vanuit het perspectief van degenen die betrokken zijn bij het behandelproces, (iii) en om te bepalen of betere behandeluitkomsten zouden worden bereikt met een zorgbehoeften georiënteerde benadering die gericht is op het verkrijgen van een gedeelde visie op onvervulde zorgbehoeften.

LIST OF ABBREVIATIONS

ARTICLE 1

ACT:	Assertive Community Treatment
AUS:	Australia
CGAS:	Children's Global Assessment Scale
CHE:	Switzerland
CGI:	Clinical Global Impression Scale
DACTS:	Dartmouth Assertive Treatment Scale
DSM:	Diagnostic Systematic Manual of Mental disorders
EAHC:	Executive Agency for Health and Consumers
ES:	Effect size
GAF:	Global Assessment of Functioning
GAIN:	Global Appraisal of Individual Needs
GBR:	Great Britain
HoNOSCA:	Health of the Nation Outcome Scales Child and Adolescents Mental Health
ISO:	International Organization for Standardization
MDFT:	Multidimensional Family Treatment
MST:	Multi Systemic Therapy
NICE:	The National Institute for health and Care Excellence
RCT:	randomized controlled trial
SCID-I:	Structured Clinical Interview for DSM-IV Axis I Disorders
SD:	Standard deviation
SIPS:	Structured Interview for Prodromal Syndromes
SOFAS:	Social and Occupational Functioning Assessment Scale
TLFB:	Timeline Follow Back
USA:	United States of America
UCC:	Usual Continuing Care
WHO:	World Health Organization

ARTICLE 2

ACT:	Assertive Community Treatment
ADHD:	Attention Deficit Hyperactivity Disorder
ASD:	Autism Spectrum Disorder
AUC:	area under the curve
CANSAS:	Camberwell Assessment of Need Short Appraisal Schedule
CI:	Confidence Interval

Fig.: Figure
GAF: Global Assessment of Functioning
HoNOS: Health of the Nation Outcome Scales
HoNOSCA: Health of the Nation Outcome Scales Child and Adolescents Mental Health
MANSA: Manchester Short Assessment of quality of life
MINI-KID: MINI International Neuropsychiatric Interview for Children and Adolescents
OR: Odds Ratio
SD: Standard Deviation
SPSS: Statistical Package for the Social Sciences

ARTICLE 3

ACT: Assertive Community Treatment
ADHD: Attention Deficit Hyperactivity Disorder
ASD: Autism Spectrum Disorder
CANSAS: Camberwell Assessment of Need Short Appraisal Schedule
df: degrees of freedom
FE: Fisher's Exact test
ICF: International Classification of Functioning and Disability
MINI-KID: MINI International Neuropsychiatric Interview for Children and Adolescents
SD: Standard Deviation
SPSS: Statistical Package for the Social Sciences
χ^2-test**:** Chi-square test

ARTICLE 4

ACT: Assertive Community Treatment
CANSAS: Camberwell Assessment of Need Short Appraisal Schedule
Df: Degrees of freedom
CP: Care provider
EMDR: Eye-movement desensitization and reprocessing therapy
FE: Fisher's exact test
GAF score: Global Assessment of Functioning score
ICF: International Classification of Functioning and Disability
K: Cohen's kappa coefficient
MINI-KID: MINI International Neuropsychiatric Interview for Children and Adolescents

ns:	Not significant
P:	Patient
SD:	Standard deviation
SPSS:	Statistical Package for the Social Sciences
$\chi 2$ test:	Chi-square test

ARTICLE 5

ASD:	Autism spectrum disorder
ADHD:	Attention Deficit Hyperactivity Disorder
CANSAS:	Camberwell Assessment of Need Short Appraisal Schedule
CI:	Confidence interval
GAF-score:	Global Assessment of Functioning score
HoNOS:	health of the nation outcomes scale
MINI-KID:	MINI International Neuropsychiatric Interview for Children and Adolescents
N:	number of patients
OR:	odds ratio
SD:	Standard Deviation
SDQ:	strength and difficulty questionnaire
SES:	social economic status
SPSS:	Statistical Package for the Social Sciences

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"Zou jij niet willen promoveren?", vroeg hogeschooldocent drs. Joke Polet halverwege het eerste studiejaar (2013) van mijn MANP-opleiding. Deze éne vraag was feitelijk de start van mijn promotietraject want ik zei direct enthousiast "Ja", maar de gevolgen van dit antwoord overzag ik niet. Joke bracht mij in contact met Berno van Meijel die op het punt stond bijzonder hoogleraar GGZ-verpleegkunde te worden. Joke, wat ben ik enorm dankbaar voor hetgeen "je mij hebt aangedaan" de afgelopen jaren. Met het promotietraject bleek ik een vriend erbij te hebben gekregen. Deze vriend hielp me om mijzelf zowel wetenschappelijk als behandelinhoudelijk verder te ontwikkelen. Maar vrienden kunnen soms onenigheid hebben, bijvoorbeeld wanneer een concept-manuscript voor de zoveelste maal moest worden aangepast of wanneer een editor van een internationaal tijdschrift een ingediend manuscript (waaraan hard was gewerkt) met een standaard e-mailtje afwees. Het promotietraject was tevens een vriend waarmee ik feest vierde wanneer een publicatie geaccepteerd werd. Een vriend die ook meeging naar verjaardagen, uitjes, en vakanties. Voor een vriend wil je knokken, dus bij tegenslagen was de enige optie om harder te werken en te blijven doorzetten. Maar het allerbelangrijkste is dat deze vriend me geholpen heeft om antwoorden te vinden op enkele vragen die ik de afgelopen twintig jaar als sociaal-pedagogisch hulpverlener en verpleegkundige, en later als verpleegkundig specialist en cognitief gedragstherapeut regelmatig aan mijzelf stelde, namelijk: hoe komt het dat kinderen vaak afwezig zijn op afspraken, of vroegtijdig stoppen met behandeling? Welke zorgbehoeften hebben kinderen en adolescenten in de kinder- en jeugdpsychiatrie? En welke type gezinnen worden doorverwezen van de polikliniek naar Jeugd ACT, en hoe effectief is deze Jeugd ACT behandeling eigenlijk?

Als eerste wil ik alle kinderen en ouders bedanken, want jullie bereidheid om deel te nemen aan dit wetenschappelijk onderzoek is essentieel geweest om inzicht te krijgen in de verschillen tussen kinderen die op een polikliniek worden aangemeld en degene die van de polikliniek worden doorverwezen naar Jeugd ACT.

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CURRICULUM VITAE

Richard Vijverberg, geboren in Nederland op 28 april 1974. Hij studeerde Sociaal Pedagogische Hulpverlening (1998), Verpleegkunde (2004), en advance nursing practice (2014, Cum Laude). Maar ook is hij geschoold in epidemiologie & biostatistiek (2017) en cognitieve gedragstherapie (2019, VGCt®). Daarnaast heeft Richard diverse psychotherapeutische cursussen gevolgd zoals: dialectische gedragstherapie, interpersoonlijke psychotherapie, EMDR kind en jeugd (VEN®), schematherapie, en acceptance and commitment therapy. Tussen 1998-2010 werkte hij op de afdeling psychiatrie van het Erasmus Medisch Centrum Rotterdam (EMCR), waar hij verschillende functies bekleedde en CGT-protocollen ontwikkelde. Sinds 2010 werkt Richard bij GGZ Delfland. Hij werd benoemd tot lid van het lectoraat GGZ-verpleegkunde van de Hogeschool Inholland (2011) en adviseur van de V&VN denktank geestelijke gezondheidszorg (2016). In 2014 is hij met steun van GGZ Delfland, Hogeschool Inholland en VU Medisch Centrum gestart met een promotietraject naar de zorgbehoeften van kinderen en adolescenten in de kinder- en jeugdpsychiatrie. Tussen 2016-2017 was hij docent aan de opleiding master advanced nursing practice aan de Hogeschool Utrecht en in de periode 2018-2021 gastdocent aan de master physician assistent aan de Hogeschool Inholland. De afgelopen 20 jaar nam hij deel aan verschillende symposia waar hij sprak over kinder- en jeugdpsychiatrie gerelateerde onderwerpen. Richard werd in 2017 benoemd tot lid van de wetenschappelijke onderzoekscommissie van GGZ Delfland. In 2021 werd Richard binnen GGZ Delfland benoemd tot plaatsvervangend praktijkopleider voor verpleegkundig specialisten. Richard Vijverberg voelt zich bevoorrecht zijn leven te delen met zijn vrouw Saskia Verrips en is de trotse vader van twee kinderen: Stefan en Lieke.

CURRICULUM VITAE IN ENGLISH

Richard Vijverberg, was born in the Netherlands on April 28, 1974. He studied Social Work (1998) and Nursing (2004), and Advance Nursing Practice (2014, Cum Laude). He is also educated in Epidemiology & Biostatistics (2017), and Cognitive Behavioral Therapy (2019, VGCt®). In addition, Richard attended many psychiatry and psychology related courses (e.g. DGT, IPT, and EMDR). Between 1998-2010 he worked at the Erasmus Medical Center Rotterdam (EMCR) department of psychiatry, where he held several positions and developed CBT-protocols. Since 2010 Richard works at GGZ Delfland. He was appointed as a member of the Centre of Expertise in Mental Health Nursing of the Inholland University of Applied Sciences (2011), and as a member of the V&VN Thinktank Mental healthcare (2016). 2015 he started his PhD supported by GGZ Delfland, Inholland University of Applied Sciences and VU Medical Center. Between 2016-2017 he held the position of lecturer at the Master Advance Nursing Practice at the Utrecht University of Applied Sciences and participated in several symposia where he spoke about child and adolescent psychiatry-related topics. Richard was appointed as a member of the Scientific Research Committee of GGZ Delfland in 2017, and in 2021 he was also appointed deputy practice leader for nurse specialists at this mental health organization. Richard feels fortunate to be married with Saskia Verrips, and he is proud to be the father of two children: Stefan and Lieke.

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PhD PORTFOLIO

PhD training	Year	Workload (ECTS)
Courses		
Introduction SPSS, EpidM, VUmc, Amsterdam	2015	0.57
Epidemiological research: development and interpretation, EpidM, VUmc, Amsterdam	2015	1.43
Principles of epidemiological data-analysis, EpidM, VUmc, Amsterdam	2015	1.29
Regression techniques, EpidM, VUmc, Amsterdam	2015	1.50
Cognitive behavioral therapy (basic)	2015	6.07
Cognitive behavioral therapy (advanced)	2016	6.07
Clinimetrics: assessing measurement properties of heath measurement instruments, EpidM, VUmc, Amsterdam	2016	0.79
Missing data: consequences and solutions, EpidM, VUmc, Amsterdam	2016	0.43
Longitudinale data-analyses EpidM, VUmc, Amsterdam	2016	1.07
Qualitative research in practice of healthcare, EpidM, VUmc, Amsterdam	2016	0.64
Multilevel analysis, EpidM, VUmc, Amsterdam	2016	0.64
Scientific writing, VU talen-centrum, Amsterdam	2017	3.00
Eye movement desensitization and reprocessing	2018	1.43
Good Clinical Practice, GCP Central, Amsterdam	2019	0.36
	Subtotal:	**25.29**
Congresses – International		
4th European Conference on Integrated Care & Assertive Outreach in Mental Disorders, oral presentation, Hamburg, Germany	2017	2.00
10th ICN NP/APN Conference 2018 “Advanced nurses/ nurse practitioners bridging the GAP”, oral presentation, Rotterdam	2018	2.00
13th International conference on ADHD, Berlin, Germany	2019	2.00
	Subtotal:	**6.00**

Congresses – national

Nationaal congress GGZ-Verpleegkunde, Poster presentation, Ede	2016	0.30
CaRe Days 2018, Netherlands school of public health and care research, Den Bosch	2018	1.00
CaRe Days 2019, Netherlands school of public health and care research, Eindhoven	2019	1.00
	Subtotal:	**2.30**

Other

Supervision MSc students 11x	2016-now	1.00
Member scientific research committee GGZ Delfland, Delft	2017-now	2.00
	Subtotal:	**3.00**
	Total ECTS:	**36.59**

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