



Cohort Profile

Cohort Profile: Tracing Achievements, Key processes and Efforts in professional care for Children and Adolescents REsearch; TAKECARE

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Abstract

TAKECARE is a prospective cohort study designed in The Netherlands to obtain evidence on the care chain for children and adolescents with psychosocial problems, and its long-term outcomes. Little is known about the content of care as offered and on whether the care is adequate. The cohort consists of children and adolescents entering care for psychosocial problems (care sample, $n = 1382$) and a random sample of the general population (community sample, $n = 666$). Children were eligible for participation if they were aged 4–18 years (inclusive) and had estimated IQs of 70 and over. The care sample covers the fields of Preventive Child Healthcare (PCH), Child and Adolescent Social Care (CASC) and Child and Adolescent Mental Healthcare (CAMH). Children, parents or guardians and involved practitioners completed five questionnaires (baseline, and at 3, 12, 24 and 36 months thereafter). The main categories of data concern the sociodemographic characteristics of children and their parents or guardians, the characteristics of entry into care and care content, and intermediate and final treatment outcomes. Information about data access can be requested by e-mail: c4youth@umcg.nl.

Key Messages

- About 20% of all children and adolescents received care for psychosocial problems. The severity of the problems of children in the CASC and CAMH groups was similar. The severity of the problems in the PCH group was lesser, but still much higher than for children and adolescents who received no care.
- Enrolment of children and adolescents in psychosocial care was associated with factors in the children's social environment, such as low family social support and poor parenting skills.
- A substantial proportion of the interventions made in the psychosocial care of children and adolescents had similar content, largely limiting the number of unique interventions within and between care organizations.
- Regarding care for adolescents with psychosocial problems, parents and adolescents rated affective communication as the most important factor in client-practitioner interaction.

Why was the cohort set up?

Psychosocial problems in children and adolescents—behavioural, emotional and social problems—are highly prevalent and can have severe and lasting consequences for children, their families and society.¹ These problems can have important consequences for education,^{2,3} relationships⁴ and socioeconomic achievements in later life.⁵ Worldwide, 10–20% of children and adolescents are affected by psychosocial problems.^{6,7} Only a minority of the children and adolescents with these problems actually receive professional care^{8,9} and, when offered, the care is frequently regarded as a ‘black box’.^{10,11} This reflects that little is known about the content of the care as offered and even less about the short and long-term outcomes. Furthermore, it is unclear whether the care offered is adequate to address these problems.^{12,13} This gap calls for more evidence on the functioning of the entire care chain for children and adolescents and on its long-term outcomes. The TAKECARE longitudinal prospective cohort study was initiated to better understand the processes and outcomes of care for children and adolescents with psychosocial problems.

The cohort covers care provided in the fields of Preventive Child Healthcare (PCH), Child and Adolescent Social Care (CASC) and Child and Adolescent Mental Healthcare (CAMH). Use of care is the result of various care-seeking processes,^{14,15} which are affected by the severity of the problems and the types of care provided by the various care providers.^{16,17} Traditionally, it can be expected that PCH handles the less severe problems, CAMH focuses on psychopathology, especially regarding behaviour or emotion regulation, and CASC aims at supporting the social and economic context of children and adolescents.¹⁶ However, over time the various types of care have gradually overlapped and included parts of each other’s approach. This could be because deprived social and economic circumstances lead to psychosocial problems and vice versa. Therefore, TAKECARE was designed to cover the entire spectrum of care for children and adolescents with psychosocial problems. In this respect, three aims were addressed in particular, to:

- i. obtain insight into the processes that lead to entry into psychosocial care, its use and outcomes for children and adolescents;
- ii. develop, test and apply a taxonomy of care for classifying the most salient aspects of the care provided to children and adolescents with psychosocial problems;
- iii. unravel the effects of client-practitioner communication on the outcomes of care for children and adolescents with psychosocial problems.

The added value of TAKECARE is its focus on long-term outcomes and on the full range of care provided to

children and adolescents with psychosocial problems and their parents or guardians (henceforth ‘parents’).

Who is in the study sample?

The cohort consisted of children who were either entering care—PCH, CASC or CAMH—for psychosocial problems (care sample), or were part of the general population in the same region (community sample). The children from the two groups were eligible for participation if they were aged 4–18 years (inclusive), had estimated IQs of 70 and over, their parent and/or the child was reasonably able to understand Dutch and they lived in the north-east of The Netherlands. Participants were included if the parent or the child provided informed consent and completed the first questionnaire. For the children in the care sample, receiving some kind of psychosocial care was a prerequisite for eligibility. The study design was assessed by the local medical ethical committee and approved without the need for full assessment.

From the north-east of The Netherlands, 3632 participants were potentially eligible (Figure 1). This number was corrected for the exclusions that were expected among those who declined the study invitation, based on the exclusion rate among those participants that were eligible. Of the potentially eligible participants, 632 refused to receive further information about the study by completing the opt-out form that was attached to the written introduction. Of the 3000 remaining eligible participants, 243 were excluded after telephone contact with research assistants, resulting in 2757 confirmed eligible participants. Of the confirmed eligible participants, 2048 were included in the study. Response rates were calculated by dividing the number of included participants by the potentially eligible participants minus the exclusions. For the care sample and the community sample the resulting response rates were 56.6% and 70.3%, respectively (Figure 1).

Participants in the care sample were recruited at four different care organizations in order to obtain a representative sample of care participants with various care profiles in terms of problem severity, duration and type. The four collaborating care organizations were the largest providers of PCH and CASC and the two largest providers of CAMH, covering the entire region. Participants in the community sample were randomly selected through primary, secondary and intermediate vocational education schools. All potentially eligible participants received oral and written information about the study, in the care sample through practitioners and in the community sample through presentations by researchers at schools. Research assistants then invited parents and children to participate in the study by telephone.

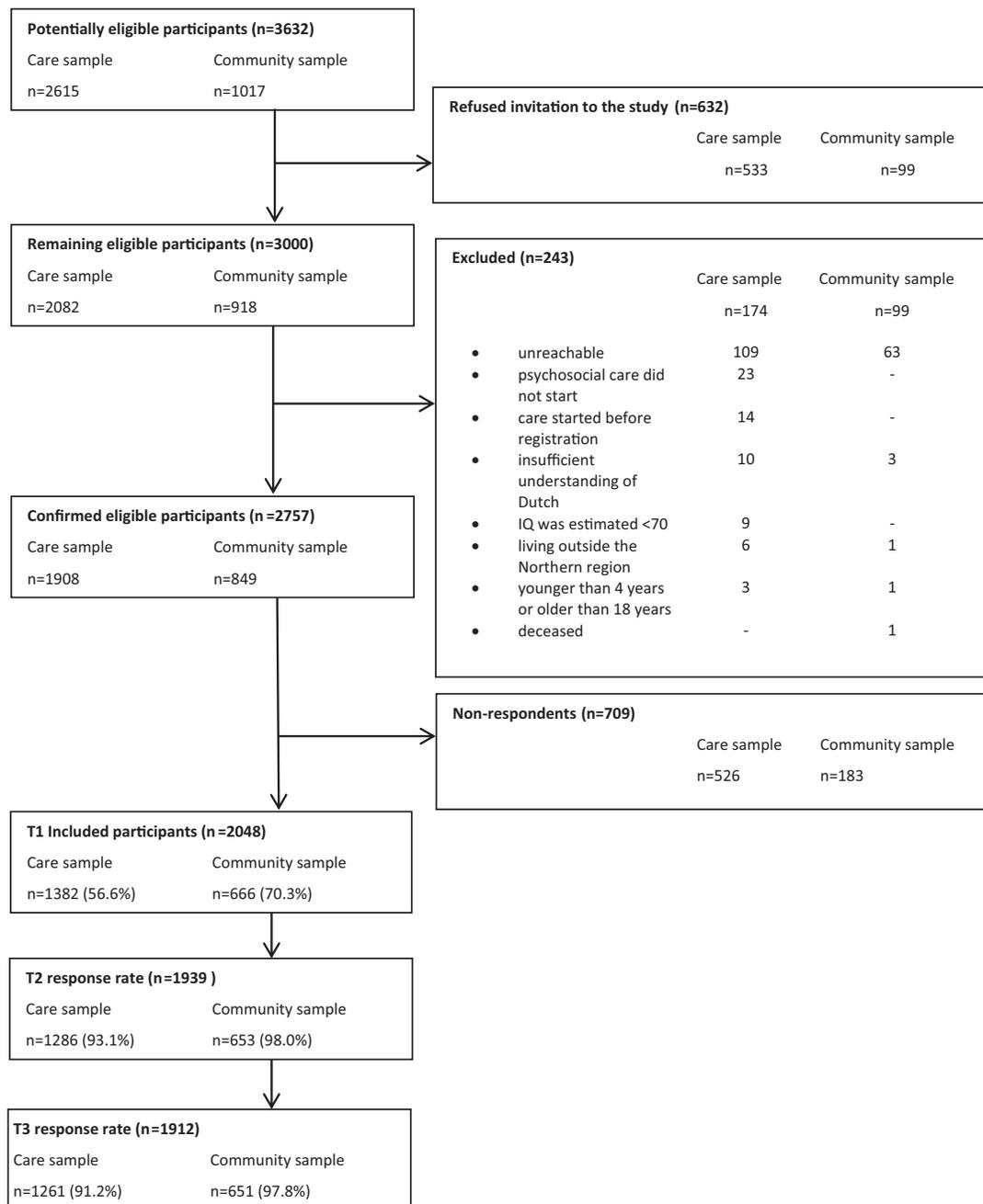


Figure 1. Flow diagram TAKECARE.

For non-respondents, contact was concluded with a request for some baseline characteristics and a question about the severity of emotional and behavioural difficulties. At baseline, differences between respondents and non-respondents in age, gender, rural/urban area and difficulties experienced were small or trivial, with maximum effects sizes of 0.12 (Table 1).

As expected, when compared with those in the community sample, the children in the care sample experienced more psychosocial problems and were more likely to have non-Dutch ethnicity and a mother with a low level of

education, and were more likely to live in low-income households and without both biological parents.^{18,19}

The effect sizes of the differences between the care and community sample were small or trivial for the demographic characteristics, and medium to high for the social characteristics and the total difficulties scores (Table 2).

How often have they been followed up?

Parents and children aged 12 years and over received the first questionnaire (T1) directly after inclusion.

Table 1. Characteristics of respondents vs non-respondents in the care and community samples

	Respondents			Non-respondents			Effect size (ES) ^a	P-value
	(n/N)	%	95% CI	(n/N)	%	95% CI		
Care sample								
12–18 years old ^b	(541/1382)	39.1	(36.6–41.7)	(200/526)	38.0	(33.9–42.2)	0.01	0.653
Girls	(645/1382)	46.7	(44.0–49.3)	(226/503)	44.9	(40.6–49.3)	0.02	0.502
Living in a rural area	(1154/1377)	83.8	(81.8–85.7)	(237/323)	73.4	(68.4–78.0)	0.11	<0.001
Definite to severe difficulties ^c	(730/1337)	54.6	(51.9–57.3)	(138/302)	45.7	(40.1–51.3)	0.07	0.005
Community sample								
12–18 years old ^b	(294/666)	44.1	(40.4–47.9)	(94/183)	51.4	(44.1–58.6)	0.06	0.082
Girls	(374/666)	56.2	(52.4–59.9)	(89/183)	48.6	(41.4–55.9)	0.06	0.070
Living in a rural area	(621/666)	93.2	(91.2–95.0)	(128/130)	98.5	(95.3–99.7)	0.08	0.021
Definite to severe difficulties ^c	(62/648)	9.6	(7.5–12.0)	(11/101)	10.9	(5.8–17.9)	0.02	0.677

^aThe measurement used to calculate the effect size was Cohen's W ($ES = \sqrt{(\chi^2/N)}$).

^bThe age of children and adolescents is categorized in two groups; 4–11 years and 12–18 years.

^cMeasured in the parents' questionnaire by asking: 'Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people (no/minor-definite/severe)?'

Table 2. Baseline characteristics of the TAKECARE cohort per sample

	Care sample			Community sample			Effect size (ES)	P-value
	(n/N)	%	95% CI	(n/N)	%	95% CI		
Demographic characteristics^a								
12–18 years old	(541/1382)	39.1	(36.6–41.7)	(294/666)	44.1	(40.4–47.9)	0.05	0.031
Girls	(645/1382)	46.7	(44.0–49.3)	(374/666)	56.2	(52.4–59.9)	0.09	<0.001
Living in a rural area	(1154/1377)	83.8	(81.8–85.7)	(621/666)	93.2	(91.2–95.5)	0.13	<0.001
Non-Dutch ethnicity child	(200/1298)	15.4	(13.5–17.4)	(55/633)	8.7	(6.7–11.0)	0.09	<0.001
Social characteristics^a								
Low educational level of mother	(592/1298)	45.6	(42.9–48.3)	(182/639)	28.5	(25.1–32.1)	0.16	<0.001
Not living with both biological parents (family structure)	(723/1375)	52.6	(49.9–55.2)	(195/665)	29.3	(25.9–32.9)	0.22	<0.001
Low household income (below social minimum)	(372/1041)	35.7	(32.9–38.7)	(55/498)	11.0	(8.5–14.0)	0.26	<0.001
Total difficulties score child (TDS)^b								
Parent/guardian report	M	(SD)	95% CI	M	(SD)	95% CI	Effect size (ES)	P-value
Parent/guardian report	15.7	(6.6)	(15.4–16.1)	7.2	(5.4)	(6.7–7.6)	1.60	<0.001
Self-report child	14.5	(5.9)	(13.9–15.0)	9.7	(4.8)	(9.1–10.2)	1.00	<0.001
Care organization/school								
	(n/N)	%		(n/N)	%			
Preventive Child Healthcare (PCH)	(309/1382)	22.3						
Child and Adolescent Social Care (CASC)	(248/1382)	18.0						
Child and Adolescent Mental Healthcare (CAMH)	(825/1382)	59.7						
Primary school				(392/666)	58.9			
Secondary school				(230/666)	34.5			
Intermediate vocational education school				(44/666)	6.6			

^aThe measurement used to calculate the effect size was Cohen's W ($ES = \sqrt{(\chi^2/N)}$).

^bThe measurement used to calculate the effect size was Cohen's D ($ES = (\mu_1 - \mu_2)/\sigma$).

Baseline measurements were taken from May 2011 until April 2013. The second (T2), third (T3), fourth (T4) and fifth (T5) questionnaires were sent 3, 12, 24 and 36 months after the first questionnaire, respectively.

The questionnaires were sent by e-mail or by surface mail, according to the participants' preference, with a reminder after 1 and 2 weeks. To prevent attrition, follow-up assessments were supported by telephone and face-to-face

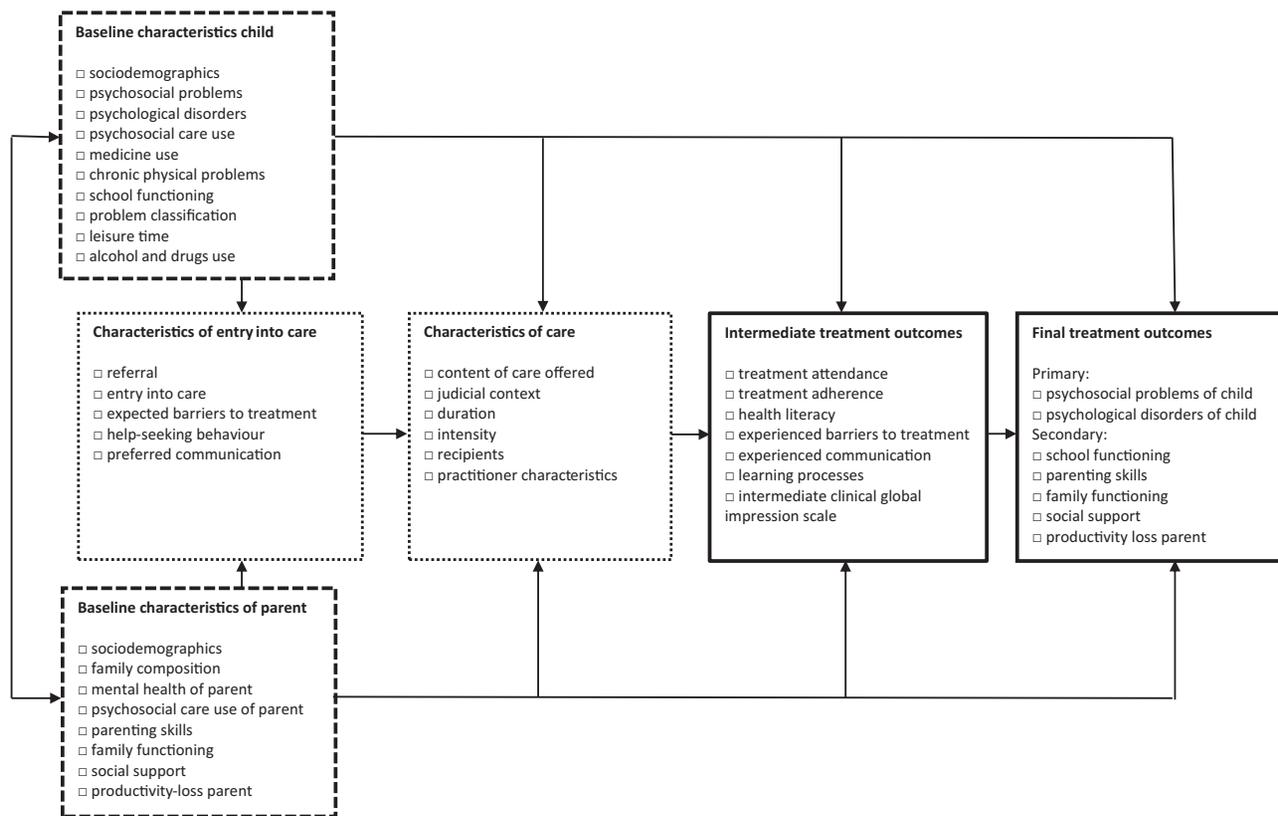


Figure 2. Model depicting the main measures in the TAKECARE study.

contact if needed, and parents and children were rewarded with a gift token after every completed questionnaire. Involved practitioners received questionnaires for as long as the participant in the care sample received psychosocial care from one of the four collaborating organizations.

The loss to follow-up at the second and third waves was 6.9% and 8.8% for the care sample and 2.0% and 2.2% for the community sample. Attrition at follow-up was higher for children with a non-Dutch ethnicity and for children who lived in a low-income household and without both biological parents. However, respondents and non-respondents did not differ in emotional and behavioural problems. It is expected that attrition will increase further at T4 and T5, though data are not yet available.

What has been measured?

Figure 2 presents a model depicting the main factors and variables of the TAKECARE study. The figure describes the baseline characteristics of the children and parents, the characteristics of (entry into) care, and intermediate and final treatment outcomes (e.g. the child's psychosocial problems and disorders). Modifiable baseline

characteristics (e.g. psychosocial problems, social support and school functioning) were also measured at T2 to T5, as well as the characteristics of care and the intermediate and treatment outcomes. Table 3 specifies the measures used during the five waves in the parent, child and practitioner questionnaires.

Preliminary results

TAKECARE has been designed to cover three specific themes, in addition to measuring the outcomes of care at four successive moments (T2–T5). These concern entry into care, a classification of the provision of care and the communication in care between practitioner and client. The main results to date regarding the three themes are summarized below.

Enrolment in psychosocial care was determined by factors such as low family social support and poor parenting skills, in particular because these were associated with more frequent psychosocial problems for the children and adolescents.²⁰ The severity of the problems of children in the CASC and CAMH groups as measured by the Strength and Difficulties Questionnaire (SDQ) were similar. The severity of the problems in the PCH group was lower, but still much higher than for children and adolescents who received no care.²¹

Table 3. Measures in questionnaires for parent, child and practitioner

Measure	Informant/wave														
	Parent					Child					Practitioner				
	1st	2nd	3rd	4th	5th	1st	2nd	3rd	4th	5th	1st	2nd	3rd	4th	5th
Child characteristics															
Sociodemographic characteristics of child	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
Psychosocial problems	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
<i>Strengths and Difficulties Questionnaire (SDQ)</i>															
Change in psychosocial problems (follow-up SDQ)	-	✓	✓	✓	✓	-	✓	✓	✓	✓	-	-	-	-	-
Psychological disorders (age of child >9 years)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
<i>Screening instrument for psychological disorders (Spsy)</i>															
Psychosocial care use	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
<i>Modified version of the questionnaire for costs associated with psychiatric illness (Tic-p)</i>															
Medicine use	✓	✓	✓	✓	✓	-	-	-	-	-	-	-	-	-	-
Chronic physical problems	✓	-	-	-	-	✓	-	-	-	-	-	-	-	-	-
School functioning	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
<i>Pediatric Quality of Life Inventory (PedsQL)</i>															
Problem classification	-	-	-	-	-	-	-	-	-	-	✓	✓	✓	✓	✓
<i>Cap-J (PCH and CASC)</i>															
<i>DSM-IV (CAMH)</i>															
Leisure time ^a	-	✓	✓	✓	✓	-	✓	✓	✓	✓	-	-	-	-	-
Alcohol and drugs use (age of child >9)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
<i>Screening instrument for psychological disorders (Spsy)</i>															
Family characteristics															
Sociodemographic characteristics	✓	✓	✓	✓	✓	-	-	-	-	-	-	-	-	-	-
Family composition	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
Mental health parent/guardian	✓	✓	✓	✓	✓	-	-	-	-	-	-	-	-	-	-
<i>General Health Questionnaire-12 (GHQ)</i>															
Psychosocial care use	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
<i>Questionnaire for costs associated with psychiatric illness (Tic-p)</i>															
Parenting skills	✓	✓	✓	✓	✓	-	-	-	-	-	-	-	-	-	-
<i>Alabama Parenting Questionnaire-9 (APQ)</i>															
Family functioning	✓	✓	✓	✓	✓	-	-	-	-	-	-	-	-	-	-
<i>McMaster Family Assessment Device (FAD)</i>															
Social support	✓	✓	✓	✓	✓	-	-	-	-	-	-	-	-	-	-
<i>Family Questionnaire (FQ)</i>															
Productivity loss of parent (i.e. sick leave or reduced productivity during paid work or unpaid work such as household activities) due to psychosocial problems of child	-	-	-	✓	✓	-	-	-	-	-	-	-	-	-	-
Characteristics of entry into care															
Referral ^b	✓	-	-	-	-	-	-	-	-	-	✓	✓	✓	✓	✓
Entry into care ^b	✓	-	-	-	-	-	-	-	-	-	✓	-	-	-	-
Expected barriers to treatment	✓	-	-	-	-	✓	-	-	-	-	-	-	-	-	-
<i>Barriers To Treatment Participation Scale-Expectancies (BTPS-exp)</i>															
Help-seeking behaviour ^b	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Characteristics of care															
Care content/interventions offered ^b	-	-	-	-	-	-	-	-	-	-	-	✓	✓	✓	✓
Judicial context ^b	-	-	-	-	-	-	-	-	-	-	-	✓	✓	✓	✓
Duration ^b	-	-	-	-	-	-	-	-	-	-	-	✓	✓	✓	✓
Intensity ^b	-	-	-	-	-	-	-	-	-	-	-	✓	✓	✓	✓
Recipients ^b	-	-	-	-	-	-	-	-	-	-	-	✓	✓	✓	✓
Practitioner characteristics ^b	-	-	-	-	-	-	-	-	-	-	✓	-	-	-	-

(Continued)

Table 3. Continued

Measure	Informant/wave														
	Parent					Child					Practitioner				
	1st	2nd	3rd	4th	5th	1st	2nd	3rd	4th	5th	1st	2nd	3rd	4th	5th
Intermediate outcomes															
Treatment attendance ^b	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓
Treatment adherence ^b	-	✓	✓	✓	✓	-	✓	✓	✓	✓	-	✓	✓	✓	✓
Health literacy (how information is managed)	-	✓	✓	✓	✓	-	✓	✓	✓	✓	-	-	-	-	-
Experienced barriers to treatment ^b	-	✓	✓	✓	✓	-	✓	✓	✓	✓	-	-	-	-	-
<i>Barriers To Treatment Participation Scale (BTPS)</i>															
Preferred and experienced communication ^b :															
Affective communication	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓
Information provision	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓
Shared decision making	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓
Inter-practitioner communication	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
Motivation and support	-	✓	✓	✓	✓	-	✓	✓	✓	✓	-	✓	✓	✓	✓
Learning processes	-	✓	✓	✓	✓	-	✓	✓	✓	✓	-	✓	✓	✓	✓
Clinical Global Impression Scale (CGI) ^b	-	-	-	-	-	-	-	-	-	-	-	✓	✓	✓	✓

✓, measured; -, not measured.

^aOnly in community sample.

^bOnly in care sample.

Using a new tool specifically developed for this study, the Taxonomy of Care for Youth (TOCFY),²² similarities and differences in care (in the interventions provided) were assessed within and across participating care organizations.²³ Initial findings show that a substantial number of differently labelled interventions within the same care organization were quite similar concerning their content; and that this also applied to interventions from different organizations.²⁴

Regarding communication, parents and adolescents rated affective communication as the most important factor in the care for adolescents with psychosocial problems. The clients' educational levels, previous care experiences, current expectations and specific problem types were associated with client priorities in communication.²⁵ Discrepancies between attributed relevance and experiences regarding communication negatively affected the adolescents' treatment adherence and learning processes.²⁶

What are the main strengths and weaknesses of the study?

TAKECARE collects information about psychosocial care use and the care pathways of individual clients in a structured way. This provides opportunities to collect evidence of the pivotal aspects of the entire care chain for children and adolescents and on its intermediate and long-term outcomes.

The main strengths of TAKECARE are the concurrent care and community samples, the relatively long follow-up period, a retention rate of more than 90% up to T3 and the wide range of measures regarding the content, processes and outcomes of care at an individual client level. The multi-informant approach reduced the possibility of information bias caused by the respondents' lack of insight, social desirability and defensiveness.^{27,28} Furthermore, the collected data enable international comparison analysis, since they cover a wide range of measures, measured with well-validated and widely used instruments.

The main weakness is the relatively low response rate in the care sample. It showed that children and adolescents with psychosocial problems and their families are a hard-to-reach target group, which indicates that potential selection bias due to systematic non-response is of concern. However, only small differences were found when comparing the respondents and non-respondents by response status, which decreases the likelihood of this type of selection bias. Another weakness which needs to be considered is related to the study design. As TAKECARE is an observational study, it cannot provide conclusive evidence of the effectiveness of different types of psychosocial care. However, it can provide evidence of prognosis in daily practice and generate indications of effectiveness which can help to prioritize the aims of clinical trials, especially when using propensity scores.²⁹⁻³³

Can I get hold of the data? Where can I find out more?

The TAKECARE consortium especially welcomes initiatives for cross-validation of findings from epidemiological analyses of similar cohort studies in different countries on the TAKECARE database. Further information can be requested by email to: [c4youth@umcg.nl].

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