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Title: Individual Unmet Needs for Care: are they sensitive as outcome criterion for the effectiveness of mental health services interventions?

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Keywords: need for care; schizophrenia; routine outcome assessment; community mental health care

Corresponding Author: Prof. Durk Wiersma, PhD

Corresponding Author's Institution: University Medical Center Groningen; University of Groningen

First Author: Durk Wiersma, PhD

Order of Authors: Durk Wiersma, PhD; Rob van den Brink, PhD; Kerstin Wolters, MSc; Rosemarie McCabe; Jens Bullenkamp; Lars Hansson; Christoph Lauber; Rafael Martinez-Leal; Wulf Rössler; Hans Salize; Bengt Svensson; Francisco Torres-Gonzales; Donna J Wright; Stefan Priebe

Abstract: Background: Mental health interventions should demonstrate an effect on patients' functioning as well as his/her needs, in particular on unmet needs whose assessment depends on the perspective of either the patient or the clinician. However, individual met and unmet needs appear to change over time, qualitatively and quantitatively, raising questions about their sensitivity to change and about the association between level of needs and treatment.

Methods: Data on baseline and follow-up need assessment in community mental health services in four European countries in the context of a cluster randomised trial on a novel mental health service intervention were used, which involved 102 clinicians with key worker roles and 320 patients with schizophrenia or related psychotic disorders. Need assessment was performed with the Camberwell Assessment of Needs Short Appraisal Schedule (CANSAS) among patients as

well as clinicians. Focus is the sensitivity to change in unmet needs over time as well as the concordance between patient and clinician ratings and their relationship with treatment condition. Results: At follow-up 294 patients (92%) had a full need assessment, while clinician rated needs were available for 302 patients (94%). Generally, the total number of met needs remained quite stable, but unmet needs decreased significantly over time, according to patients as well as to clinicians. Sensitivity to change of unmet needs is quite high: about two third of all unmet needs made a transition to no or met need, and more than half of all unmet needs at follow-up were new. Agreement between patient and clinician on unmet needs at baseline as well as follow-up was rather low, without any indication of a specific treatment effect. Conclusions: Individual unmet needs appear to be quite sensitive to change over time but as yet less suitable as outcome criterion of treatment or specific interventions.

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Individual Unmet Needs for Care: are they sensitive as outcome criterion for the effectiveness of mental health services interventions?

Short title: Unmet Needs for Care as outcome criterion

Durk Wiersma¹, Rob van den Brink¹, Kerstin Wolters¹, Rosemarie McCabe², Jens Bullenkamp⁵, Lars Hansson⁴, Christoph Lauber⁶, Rafael Martinez-Leal³, Wulf Rössler⁶, Hans Salize⁵, Bengt Svensson⁴, Francisco Torres-Gonzales³, Donna J. Wright², Stefan Priebe²

From the ¹University Psychiatric Centre, University Medical Center Groningen, University of Groningen, The Netherlands; the ²Unit for Social and Community Psychiatry, Queen Mary University of London, UK; the ³Department of Psychiatry, University of Granada, Granada, Spain; ⁴University of Lund, Lund, Sweden; ⁵Central Institute for Mental Health, Mannheim, Germany; the ⁶Psychiatric University Hospital, Liverpool, UK

Correspondence to Dr. D.Wiersma at the University Psychiatric Centre, University Medical Center Groningen, P.O.Box 30.001, 9700 RB Groningen, The Netherlands

Tel +31 50 361 3839

Fax +31 50 361 9722

durk.wiersma@med.umcg.nl

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4 **Abstract**
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8 functioning as well as his/her needs, in particular on unmet needs whose assessment
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14 questions about their sensitivity to change and about the association between level of needs
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16 and treatment.
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52 treatment effect.
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56 *Conclusions:* Individual unmet needs appear to be quite sensitive to change over time but
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Keywords: need for care, schizophrenia, routine outcome assessment, community mental health care

Introduction

Generally, patients in community care have on average four to eight needs for care – as measured with the Camberwell Assessment of Need (CAN) or the Needs for Care Assessment (NCA) -, a number which appears to be rather unrelated to gender, age or education but does appear to be related to number of symptoms, diagnosis (e.g. higher in schizophrenia), and treatment setting (higher in inpatient care or among homeless people; [30,31]). Prevalence on total number of needs, met as well as unmet, appears to be quite stable on the population level, while any change (i.e. mostly a slight decrease at follow-up) seems hardly linked to number or kind of interventions [6,8,15,23,29]; although with some exception, see Salize et al [24]. One out of two to four needs appears to be unmet, in particular in the areas of psychological distress, daytime activities, social contacts, and psychotic symptoms. Prevalence of unmet needs seems to be related to the system of mental health care and to socioeconomic circumstances as well: the less integrated and continuous the care and the poorer the life situation, the more unmet needs. Many needs are also unmet in community-oriented settings with links to primary care, affecting at least 25-50% of the patient population. Unmet needs are a strong predictor of quality of life [26]. Recently, it was demonstrated that high levels of (met) need also predict (changes in) care consumption, in particular more inpatient care [2], while unmet needs seem to be unrelated to subsequent care.

It can be argued that mental health interventions should demonstrate an effect on patients' functioning as well as on their needs, in particular on unmet needs. Some studies have suggested that standardised needs assessment might improve outcome in terms of less unmet needs and ameliorization of symptoms and functioning [10,17] while recently Priebe et al [22] demonstrated such an effect more conclusively in an RCT on a novel mental

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4 health service intervention. However, methodological issues have to be taken into account.
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6 For example, the perspective of the beholder is important, as discrepancies between the
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8 patient and professional are substantial in terms of the number as well as the type of need
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10 [5,9,27,28]; also this study]. Further, most authors compare summary scores of total
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12 number of met and unmet needs, while Wennström and Wiesel [29] argue that this might
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14 be misleading by concealing changes on an individual need level. They demonstrate that
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16 while no change over a period of six years occurred in summary scores of the Camberwell
17
18 Assessment of Needs (CAN), significant changes in need status on nearly all items were
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20 found and mostly in the favorable direction: remaining needs were more often met than not
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22 and many patients in need of care or support in 1997 appeared to be managing on their own
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24 without problems in 2003. The same phenomenon was found in a Dutch study [15] among
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26 109 schizophrenia patients with a follow-up of 18 months. The persistence or stability of
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28 unmet needs seemed rather low; most (patient rated) unmet needs disappeared, while only
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30 those relating to daytime activities, psychological distress, and company were relatively
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32 stable in about 50% of the cases.
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38 This raises the question of whether unmet needs could be used as an outcome criterion of
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40 the effectiveness of interventions in mental health care. We seek an answer to this question
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42 by investigating in detail the persistence or sensitivity to change of individual unmet needs
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44 over a one-year period, the incidence of new unmet needs at follow-up, and the
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46 concordance between patient rated needs and clinician rated needs, in the context of a novel
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48 mental health service intervention.
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54 **Settings and design**

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56 The present study was part of the DIALOG study, a cluster randomised controlled trial of a
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58 new intervention to improve communication between patient and clinician which was
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4 conducted in community psychiatric services in Granada (Spain), Groningen (The
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6 Netherlands), London (United Kingdom), Lund (Sweden), Mannheim (Germany), and
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8 Zurich (Switzerland) covering urban and mixed urban-rural areas. This novel intervention
9
10 structures communication between patients and clinicians in routine meetings by means of
11
12 a regular, two-monthly assessment of needs in 8 areas (mental health, physical health, job
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14 situation, accommodation, leisure activities, friendships, relationship with family/partner,
15
16 and personal safety) with the support of a computer mediated technology (the so-called
17
18 DIALOG intervention; [22]). The intervention had a small, but positive significant effect on
19
20 the prevalence of self-reported unmet needs (effect size .22), on subjective quality of life
21
22 (effect size .20), and on treatment satisfaction of the patients (effect size .28).
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27 In this paper we focus on data from community mental health care teams in four centres
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29 only (Groningen, Lund, Mannheim, and Zurich) because of the availability of a need
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31 assessment by the patient as well as by the clinician. In all centres multidisciplinary teams
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33 provided comprehensive care programmes for people with severe and enduring mental
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35 illnesses. They operated a key worker system in which every patient had a designated
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37 clinician working within a team but with lead responsibility for care co-ordination and
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39 delivery.
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43 Eligibility criteria for participating clinicians were a professional qualification in mental
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45 health and/or a minimum of one-year professional experience in an outpatient setting and
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47 an active caseload as key worker. Inclusion criteria for patients were: living in the
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49 community (not 24 hour supported accommodation); treatment by a community mental
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51 health care teams at least three months; capable of giving informed consent; having
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53 sufficient knowledge of the language of the host country; having a primary diagnosis of
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55 schizophrenia or related psychotic disorder (ICD-10 = F20-F29); having an age between 18
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57 and 65 years; having at least one meeting with their key worker every two months with the
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4 expectation that they would continue with the service for the next 12 months; and having
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6 no severe organic psychiatric illness or primary substance abuse.
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10 **Measurement**

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12 Needs for care were measured on the Camberwell Assessment of Need Short Appraisal
13 Schedule (CANSAS, [25]), which assesses health and social needs across 22 domains. For
14
15 each domain it distinguishes between ‘no need’, ‘met need’, and ‘unmet need’. Research
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17 assistants interviewed both the patient and his/her key worker for self reported needs and
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19 clinician rated needs in four centres (Groningen, Lund, Mannheim, and Zurich). Socio-
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21 demographic and clinical characteristics of patients were collected at baseline. The
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23 psychiatric diagnosis was obtained through a standardised and computer-based method
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25 using operationalised criteria (OPCRIT, [14]) and psychopathology was measured by
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27 means of the Positive and Negative Syndrome Scale (PANSS, [7]). Measures of patients’
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29 quality of life (MANSA, Priebe [21]), treatment satisfaction (CSQ, [16]) and clinicians’ job
30
31 satisfaction [19] were also used. Researchers received training in all rating procedures and
32
33 achieved good inter-rater reliability using videotaped interviews for PANSS (Cohen’s
34
35 kappa = 0.71) and case vignettes for CANSAS (Cohen’s kappa = 0.90).
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45 **Statistical analysis**

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47 Descriptive statistics are presented with frequency and percentage distributions for
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49 categorical data and means and standard deviations for continuous data. Correlation
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51 between baseline and follow-up was calculated by means of Rho for sumscores and the
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53 agreement between patient and clinician ratings on individual need items by means of
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55 Cohen’s kappa (unweighted). Change in individual unmet needs was tested by means of
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57 chi-square in 2x2 tables. All data were analysed using SPSS-14.0 for Windows.
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4 **Results**
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9 The four centres included 102 clinicians (49 in the DIALOG condition and 53 in the Care
10 as Usual condition) with a key worker role and a total of 320 patients (174 in DIALOG and
11 146 in Cau). At follow-up 294 patients (92%) had baseline as well as follow-up ratings on
12 needs for care, while clinician rated needs were available for 302 patients (94%) at both
13 occasions. Baseline characteristics, both socio-demographic and clinical, of patients and
14 clinicians are shown in Table 1.
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24 Insert Table 1 here (baseline characteristics)
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29 Most patients were male (67%) and single (70%), while nearly half (43%) had paid or
30 sheltered work. The duration of illness was about 18 years with nearly seven admissions.
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32 Patients were mixed to mostly satisfied with their life and with their treatment. Patients
33 were treated by slightly older and mostly female clinicians (67% of them were psychiatric
34 nurses or social workers), who had an average caseload of about 20 patients) were quite
35 satisfied with their job.
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45 *Prevalence of needs (sum indices)*
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47 Patient rated needs remained quite stable over time but unmet needs decreased significantly
48 from 2.0 to 1.6, and the proportion of patients without unmet needs increased from 34.0%
49 to 39.1%. The clinician rated needs also remained stable on a slightly higher level (on
50 average 8.0) with a significant decrease of unmet needs over time from 2.3 to 1.7, as well
51 as an increase of the proportion of patients without unmet needs (from 31.3% to 39.3).
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53 Thus, unmet needs generally decreased, in absolute as well as relative numbers, both for
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4 patient rated as well as clinician rated needs. Correlation between baseline and follow-up
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6 need ratings was modest (all below .60) suggesting quite some variability in numbers per
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8 patient.
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13 Insert table 2 (prevalence of needs) about here
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17 By far (>90%), the most prevalent need was related to psychotic symptoms (mostly met),
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19 followed in about 40% of the cases by needs in the area of accommodation, looking after
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21 home, daytime activities, physical health, information, distress, company, intimate
22
23 relationships, and money. The highest prevalence of unmet needs was for intimate
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25 relationships, company, psychological distress, daytime activities, and physical health (15-
26
27 28%); the relative difference between patient and clinician rated needs in this aspect was
28
29 relatively small (data on individual need items not shown in table).
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36 *Sensitivity to change of individual unmet needs at follow-up*

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38 Of all patient rated baseline unmet needs (N=584; see table 3) 37.0% persisted after one
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40 year; in particular in the domains of psychotic symptoms, company, intimate relations, and
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42 transport (around 50%). This was the case for 34.9% of clinician rated unmet needs
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44 (N=680); in particular in the domains daytime activities, psychotic symptoms, alcohol,
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46 drugs, intimate relations, sexual expression, and money (also around 40-50%). Thus, most
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48 unmet needs, according to both perspectives, made a transition to no need or met need.
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54 Table 3 about here
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4 Looking back retrospectively, more than half of the unmet needs at follow-up were new
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6 (54.5% for patient rated and 51.9% for clinician rated needs). Substantial proportions
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8 (30.1% and 23.1% respectively) were rated as no need at baseline. Generally, unmet needs
9
10 in the domains of intimate relationships, sexual expression, company, day-time activities,
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12 physical health, and psychological distress were rated by boths rather frequently as new.
13
14 Also, substantial proportions of patients *without* an unmet need at baseline had at least one
15
16 unmet need at follow-up (31% according to patients and 38% according to clinicians). The
17
18 same applies to patients *with* at least one unmet need at baseline and none one year later
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20 (24% according to patients and 29% according to clinicians). Change in these proportions
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22 was not related to the treatment condition.
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29 Table 4 about here
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33 Agreement (Cohen's Kappa) between the patient and clinician on individual needs at
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35 baseline was on average .27, which raised to .30 at follow-up. This actually did not reflect a
36
37 better agreement on unmet needs; on the contrary, the average proportion of agreement of
38
39 patients with their clinicians on all unmet needs dropped from 40% to 30%, and the same
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41 occurred with the agreement of the clinicians with the patients on unmet needs (33% at
42
43 baseline to 29% at follow-up). One could argue whether agreement between patient and
44
45 clinician on unmet needs at baseline would increase the chance on a met or no need later
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47 on, and whether the treatment condition would made a difference (the DIALOG condition
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49 would be expected to do better). However, it appeared that in those cases in which patient
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51 and clinician agreed on unmet need status at baseline (on average 16%, range from 0% to
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53 40%, in particular more frequently with respect to daytime activities, physical health,
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55 psychotic symptoms, psychological distress, company, intimate relationships, and sexual
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4 expression), no association with a met need status at follow-up showed up, and without a
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6 differential effect of treatment condition.
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10 Table 5 about here
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15 **Discussion**

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20 This one-year follow-up study of prevalence of patient rated as well as clinician rated
21 individual needs for care among 320 patients and their 98 key workers in community health
22 centers in four countries showed a rather stable number of met needs but a statistically
23 significantly decreasing number of unmet needs and an increasing number of patients
24 without any unmet need. Most unmet needs, nearly two thirds, according to both patients
25 and clinicians, were met or had disappeared at the time of follow-up: only four patient rated
26 unmet needs of psychotic symptoms, company, intimate relations, and transport were
27 relatively persistent (around 50%), while for clinician rated unmet needs this was the case
28 for daytime activities, psychotic symptoms, alcohol, drugs, intimate relations, sexual
29 expression, and money (40-50%). The incidence of unmet needs over one year was
30 relatively high considering the chronic illness duration of about 18 years and the existence
31 of multiple problems: 52-55% of the follow-up unmet needs were new. Finally, the
32 concordance between met and unmet needs at baseline and follow-up and the agreement
33 between patients and their clinicians at both occasions were low and virtually absent. There
34 was no indication that treatment condition (usual care with or without the novel
35 intervention DIALOG) had a discernible influence on the reduction or prevention of
36 individual unmet needs. Latter outcome seems somewhat discrepant with the result of the
37 reported overall effect of the DIALOG intervention on the reduction of unmet needs which
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4 –using the sum index- is indeed not statistically significant anymore ($P=.07$), probably due
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6 to the reduced power (from $N=502$ to 320) with the exclusion of two centres with the
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8 greatest effect sizes (Granada and London). However, the focus of this paper is more on
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10 individual needs.
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15 The strength of this study is a high inclusion rate of people with long term problems in
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17 community mental health care settings with a low number lost to follow-up (6-8%) and
18
19 only a few changes of clinicians affecting a low number of patients [22]. One limitation is
20
21 the use of exclusion criteria for the sake of the clinical trial regarding diagnosis (only
22
23 schizophrenia or related psychotic disorders), physical handicaps or organic illness, age, or
24
25 insufficient contact with care coordinator, which might restrict generalization to the whole
26
27 patient population in community care. The post hoc nature of the present analysis allows
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29 for tentative conclusions only.
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35 The agreement between patient and clinician was rather small, although both were
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37 interviewed by the same investigators who were properly trained and monitored. The inter-
38
39 rater reliability of CAN is well established [4,13,18]; this study on case vignettes: Kappa
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41 .90) and found to be good to excellent, at least on the level of summary measures with a
42
43 slight fall-off for unmet needs, while the test-retest and the inter-rater reliability with regard
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45 to individual items of needs appeared to be much less. The agreement between patient and
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47 staff ratings of needs generally is quite moderate and particularly insufficient as to
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49 individual items of unmet needs [28] (also this study: proportion between 29 and 40%;
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51 Kappa between .14 - .30). An observation is that the follow-up ratings of needs have been
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53 made by the investigators without explicitly taking into account the baseline measurement.
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58 The assessment of the status of unmet needs could therefore be strengthened by additional
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4 probing and checking of the reasons why that status has changed over time in the eye of the
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6 beholder. Another consideration, based on the study of Drukker et al [2], is to assess needs
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8 not by an independent researcher but by both parties involved together; this may yield
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10 ratings which better reflect the clinical relevance of a problem and the validity of its need
11
12 status (met or unmet) over time (see also Macpherson et al [11]). It is possibly a limitation
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14 in our study that the need assessment was research oriented and not used as a clinical tool
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16 to guide the intervention.
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22 The prevalence rate of met and unmet needs in our study is in line with earlier research
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24 including the (significant) tendency towards lower numbers at follow-up [8,30]. Overall
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26 these findings are more or less consistent with the CAN literature. However, our data
27
28 suggest an overall high sensitivity to change and a high incidence of individual unmet
29
30 needs among patients with chronic psychiatric and social problems, no matter whether
31
32 these were rated by the patient or the clinician. This is rather surprising and possibly an
33
34 underestimated phenomenon. Wennström and Wiesel [29] observed over a period of six
35
36 years that the mean number of (unmet) needs did not change much (about 6.3 for total and
37
38 1.5 for unmet needs), most (82%) needs in 1997 were (still) met or had disappeared in 2003
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40 and more than 70% of needs occurring after baseline were met at follow-up. They see this
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42 as an indication of effective care that successfully meets the health needs of the patients
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44 and argued that summary indices of needs are not a valid outcome measure in routine
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46 mental health care because they conceal important changes over time on the individual
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48 level of needs. The same variability of self-perceived unmet needs was also found in a
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50 Dutch study [15] among 109 schizophrenia patients with a follow-up of 18 months; most
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52 unmet needs disappeared, while only those relating to day-time activities, psychological
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54 distress, and company were relatively stable (about 50% of the cases). Transitions from
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4 unmet need to no or met need maybe due to various sources, such as general or specific
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6 interventions from mental health services, psychological adjustment processes, life
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8 changes, time effect, etc.
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11 Do our findings (and of others) provide indications that usual care includes such an
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13 effective rehabilitative effort that unmet needs are likely to disappear? Can it be argued that
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15 community mental health care in western industrialised countries is so advanced that we
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17 could expect such changes in unmet needs over time? On the one hand, Fakhoury & Priebe
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19 [3] criticised community mental health care and urged toward establishing better practice to
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21 support continuity of care and guided sheltered living. On the other hand Kovess-Masfétý
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23 et al [8] demonstrated in their follow-up study (with another instrument, the Needs for Care
24
25 Assessment, [1]) among 391 in-, out-, and day-patients with schizophrenia in six European
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27 centres that the number of proposed interventions was not related to need status but that the
28
29 availability of community based treatment (outpatient and rehabilitation services) seems
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31 indeed to be related to (less) unmet needs. And Kallert and Leisse [6] showed a trend
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33 towards rating unmet needs (e.g. communication, slowness, and underactivity) as not
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35 meetable over time. This option of rating a need as no meetable is not available in the
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37 CANSAS.
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43 Thus so far much evidence of the effectiveness of regular community mental health care is
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45 still lacking and the concept of unmet needs as a firm outcome criterion is probably
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47 premature. There remains a discrepancy between a stable chronic patient population with
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49 relatively high numbers of unmet needs - which not unexpectedly are difficult to meet on
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51 the one hand and the disappearance of most unmet needs in a relatively very short time on
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53 the other. Could it be partly ascribed to conceptual issues? Priebe *et al.* [20] argue that the
54
55 concept of need inappropriately simplifies the actual process of clinical decision making.
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57 They propose a way-out by clearly identifying problems, specifying goals, and choosing
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interventions of which the outcomes should be regularly be monitored. This might, for example, be better guaranteed by a more complex instrument like the Needs of Care Assessment [1,12], which may partly solve these conceptual issues but carries with it other problems of training, implementation, rating, and the perspective of one beholder (the clinician).

Our retrospective secondary analysis should be followed by prospective quantitative investigations using repeated measures to study the association between intervention and consequent impact on need status in specific domains, to assess whether the CAN is indeed sensitive to change, a true change or due to measurement error. Also more qualitative domain-specific assessment of change is worthwhile in order to better understand what it means when an unmet need changes or emerges, and to establish the domains which change due to health service intervention compared with the domains which change for other reasons.

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APPENDIX

The Mediating Community Care Group includes the following: Granada: Marta Ribes Leyva, Maria F Soriano Peña, Beatriz Arroyo de Domingo. Groningen: Kerstin Wolters, Aukelien Mulder, Jappie Tiersma. London: Rakhee Haque. Lund: Tommy Björkman. Mannheim: Marita Reichenbacher, Anette Axt. Zurich: Patric Meyer, Minka Burgi.

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Table 1. Baseline Sociodemographic Characteristics of Patients and their Clinicians,
means (SD) and proportions (%).

Patients (N=320)	
Mean age (yr)	42.8 (10.8)
Male	67.2 %
Marital status (single)	70.3 %
Employed (incl. Sheltered work)	42.5 %
Unemployed	27.5 %
Other	30.0 %
Diagnosis	
Undifferentiated schizophrenia	39.1 %
Paranoid schizophrenia	24.1 %
Other (schizo-affective, delusional)	17.4 %
Other non-organic psychosis	19.4 %
Mean length of illness (yr)	17.8 (9.8)
Mean number hospital admissions	6.7 (8.5)
Quality of Life	4.8 (0.9)
Satisfaction with treatment	25.4 (4.0)
Symptomatology (PANSS)	
Positive subscale	14.7 (5.8)
Negative subscale	16.6 (6.7)
General subscale	32.6 (9.6)
Clinicians (N=98)	
Mean age (yr)	45.0 (8.9)
Male	37.3 %
Profession	
Psychiatric nurse	45.9 %
Social worker	21.4 %
Psychiatrist	10.2 %
Psychologist	5.1 %
Other	17.3 %
Mean length of service (yr)	14.3 (8.7)
Average caseload	21.3 (13.3)
Job satisfaction [N=71]	75.0 (6.9)

Table 2. Prevalence of patient rated and clinician rated needs for care (sum indices) at baseline and 1-year follow-up, means and standard deviations (SD).

Patient rated needs (N=294)	Baseline (SD)	Follow-up (SD)	P (t-test/chi-square)	Correlation (P)	Difference (SD)
Total Needs	6.8 (3.1)	6.6 (2.9)	.41	.44 (.000)	.15 (3.2)
Met Needs	4.8 (2.7)	5.0 (2.8)	.22	.37 (.000)	-.22 (3.1)
Unmet Needs	2.0 (2.8)	1.6 (1.9)	.001	.59 (.000)	.37 (1.9)
Proportion of patients without unmet needs	34.0%	39.1%	.000		

Clinician rated needs (N=302)	Baseline (SD)	Follow-up (SD)	P (t-test/chi-square)	Correlation (P)	Difference (SD)
Total Needs	8.3 (3.7)	8.0 (3.7)	.06	.59 (.000)	.37 (3.4)
Met Needs	6.0 (3.2)	6.3 (3.4)	.16	.49 (.000)	-.27 (3.3)
Unmet Needs	2.3 (2.6)	1.7 (2.1)	.000	.46 (.000)	.63 (2.5)
Proportion of patients without unmet needs	31.3%	39.3%	.000		

Table 3. Sensitivity to change of baseline Individual Unmet Needs at 1-yr follow-up

Status of Individual Needs at 1 yr follow-up

Unmet Needs at baseline:	No Need	Met Need	Unmet Need	Total
Patient rated	209 (35.8%)	159 (27.2%)	216 (37.0%)	584 (100%)
Clinician rated	199 (29.3%)	244 (35.9%)	237 (34.9%)	680 (100%)

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Table 4. Baseline Status of Individual Unmet Needs at 1-year follow-up

Need Status at baseline:	Patient rated Unmet Needs at follow-up	Clinician rated Unmet Needs at follow-up
No need	143 (30.1%)	114 (23.1%)
Met need	116 (24.4%)	143 (28.9%)
Unmet need	216 (45.5%)	237 (48.0%)
Total	475 (100%)	494 (100%)

Table 5. Agreement between Patient rated and Clinician rated Needs, at baseline and 1 year follow-up (Spearman correlation and Cohen's Kappa)

	Correlation
Baseline (N=317)	
Sum index of Total Needs	.36
Sum index of Unmet Needs	.46
Average over Individual Unmet Needs (3 categories)	.34 (Rho) or .27 (Kappa)
Follow-up (N=289)	
Sum index of Total Needs	.46
Sum index of Unmet Needs	.34
Average over Individual Unmet Needs (3 categories)	.34 (Rho) or .30 (Kappa)
Baseline: Mean proportion agreement on individual needs of	
patient with clinician	40%
clinician with patient	33%
Follow-up: Mean proportion agreement on individual needs of	
patient with clinician	30%
clinician with patient	29%

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4 7 August 2008 resubmitted to Social Psychiatry and Psychiatric Epidemiology
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16 **Individual Unmet Needs for Care: are they sensitive as outcome criterion for the**
17 **effectiveness of mental health services interventions?**
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21 **Short title: Unmet Needs for Care as outcome criterion**
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26 Durk Wiersma¹, Rob van den Brink¹, Kerstin Wolters¹, Rosemarie McCabe², Jens
27 Bullenkamp⁵, Lars Hansson⁴, Christoph Lauber⁶, Rafael Martinez-Leal³, Wulf Rössler⁶,
28 Hans Salize⁵, Bengt Svensson⁴, Francisco Torres-Gonzales³, Donna J. Wright², Stefan
29 Priebe²
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34 From the ¹University Medical Center Groningen, Department of Psychiatry, University of
35 Groningen, The Netherlands; the ²Unit for Social and Community Psychiatry, Queen Mary
36 University of London, UK; the ³Department of Psychiatry, University of Granada,
37 Granada, Spain; ⁴University of Lund, Lund, Sweden; ⁵Central Institute for Mental Health,
38 Mannheim, Germany; the ⁶Psychiatric University Hospital, Liverpool, UK
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41 Correspondence to Dr. D.Wiersma at the University Medical Center Groningen,
42 Department of Psychiatry, University of Groningen, P.O.Box 30.001, 9700 RB Groningen,
43 The Netherlands
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45 Tel +31 50 361 3839
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47 Fax +31 50 361 9722
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49 durk.wiersma@med.umcg.nl
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57 Commission within the Framework Programme 5 (QLG5-CT-2002-01938).
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4 **Abstract**
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6 *Background:* Mental health interventions should demonstrate an effect on patients'
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8 functioning as well as his/her needs, in particular on unmet needs whose assessment
9
10 depends on the perspective of either the patient or the clinician. However, individual met
11
12 and unmet needs appear to change over time, qualitatively and quantitatively, raising
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14 questions about their sensitivity to change and about the association between level of needs
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16 and treatment.
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20 *Methods:* Data on baseline and follow-up need assessment in community mental health
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22 services in four European countries in the context of a cluster randomised trial on a novel
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24 mental health service intervention were used, which involved 102 clinicians with key
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26 worker roles and 320 patients with schizophrenia or related psychotic disorders. Need
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28 assessment was performed with the Camberwell Assessment of Needs Short Appraisal
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30 Schedule (CANSAS) among patients as well as clinicians. Focus is the sensitivity to
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32 change in unmet needs over time as well as the concordance between patient and clinician
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34 ratings and their relationship with treatment condition.
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38 *Results:* At follow-up 294 patients (92%) had a full need assessment, while clinician rated
39
40 needs were available for 302 patients (94%). Generally, the total number of met needs
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42 remained quite stable, but unmet needs decreased significantly over time, according to
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44 patients as well as to clinicians. Sensitivity to change of unmet needs is quite high: about
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46 two third of all unmet needs made a transition to no or met need, and more than half of all
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48 unmet needs at follow-up were new. Agreement between patient and clinician on unmet
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50 needs at baseline as well as follow-up was rather low, without any indication of a specific
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52 treatment effect.
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56 *Conclusions:* Individual unmet needs appear to be quite sensitive to change over time but
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58 as yet less suitable as outcome criterion of treatment or specific interventions.
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Keywords: need for care, schizophrenia, routine outcome assessment, community mental health care

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4 **Introduction**
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6 Generally, patients in community care have on average four to eight needs for care – as
7 measured with the Camberwell Assessment of Need (CAN) or the Needs for Care
8 Assessment (NCA) - , a number which appears to be rather unrelated to gender, age or
9 education but does appear to be related to number of symptoms, diagnosis (e.g. higher in
10 schizophrenia), and treatment setting (higher in inpatient care or among homeless people;
11 [34,35]. Prevalence on total number of needs, met as well as unmet, appears to be quite
12 stable on the population level, while any change (i.e. mostly a slight decrease at follow-up)
13 seems hardly linked to number or kind of interventions [10,12,19,27,33]; although with
14 some exception, see Salize et al [28]. One out of two to four needs appears to be unmet, in
15 particular in the areas of psychological distress, daytime activities, social contacts, and
16 psychotic symptoms. Prevalence of unmet needs seems to be related to the system of
17 mental health care and to socioeconomic circumstances as well: the less integrated and
18 continuous the care and the poorer the life situation, the more unmet needs. Many needs are
19 also unmet in community oriented settings with links to primary care, affecting at least 25-
20 50% of the patient population. Unmet needs are a strong predictor of quality of life [9,30].
21 Recently, it was demonstrated that high levels of (met) need also predict (changes in) care
22 consumption, in particular more inpatient care [4], while unmet needs seem to be unrelated
23 to subsequent care.
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47 It can be argued that mental health interventions should demonstrate an effect on patients'
48 functioning as well as on their needs, in particular on unmet needs. Some studies have
49 suggested that standardised needs assessment might improve outcome in terms of less
50 unmet needs and ameliorization of symptoms and functioning [14,21] while recently Priebe
51 et al [26] demonstrated such an effect more conclusively in an RCT on a novel mental
52 health service intervention. However, methodological issues have to be taken into account.
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4 For example, the perspective of the beholder is important, as discrepancies between the
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6 patient and professional are substantial in terms of the number as well as the type of need
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8 [8,13,31,32]; also this study]. Further, most authors compare summary scores of total
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10 number of met and unmet needs, while Wennström and Wiesel [33] argue that this might
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12 be misleading by concealing changes on an individual need level. They demonstrate that
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14 while no change over a period of six years occurred in summary scores of the Camberwell
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16 Assessment of Needs (CAN), significant changes in need status on nearly all items were
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18 found and mostly in the favorable direction: remaining needs were more often met than not
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20 and many patients in need of care or support in 1997 appeared to be managing on their own
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22 without problems in 2003. The same phenomenon was found in a Dutch study [19] among
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24 109 schizophrenia patients with a follow-up of 18 months. The persistence or stability of
25
26 unmet needs seemed rather low; most (patient rated) unmet needs disappeared, while only
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28 those relating to daytime activities, psychological distress, and company were relatively
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30 stable in about 50% of the cases.
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36 This raises the question of whether unmet needs could be used as an outcome criterion of
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38 the effectiveness of interventions in mental health care. We seek an answer to this question
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40 by investigating in detail the persistence or sensitivity to change of individual unmet needs
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42 over a one-year period, the incidence of new unmet needs at follow-up, and the
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44 concordance between patient rated needs and clinician rated needs, in the context of a novel
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46 mental health service intervention.
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52 **Settings and design**

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54 The present study was part of the DIALOG study, a cluster randomised controlled trial of a
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56 new intervention to improve communication between patient and clinician which was
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58 conducted in community psychiatric services in Granada (Spain), Groningen (The
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4 Netherlands), London (United Kingdom), Lund (Sweden), Mannheim (Germany), and
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6 Zurich (Switzerland) covering urban and mixed urban-rural areas. This novel intervention
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8 structures communication between patients and clinicians in routine meetings by means of
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10 a regular, two-monthly assessment of needs in 8 areas (mental health, physical health, job
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12 situation, accommodation, leisure activities, friendships,, relationship with family/partner,
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14 and personal safety) with the support of a computer mediated technology (the so-called
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16 DIALOG intervention; [26]. The intervention had a small, but positive significant effect on
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18 the prevalence of self-reported unmet needs (effect size .22), on subjective quality of life
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20 (effect size .20), and on treatment satisfaction of the patients (effect size .28).
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24 In this paper we focus on data from community mental health care teams in four centres
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26 only (Groningen, Lund, Mannheim, and Zurich) because of the availability of a need
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28 assessment by the patient as well as by the clinician. Logistical reasons and lack of research
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30 resources prevented such an assessment in Granada and London. In all centres
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32 multidisciplinary teams provided comprehensive care programmes for people with severe
33
34 and enduring mental illnesses. They operated a key worker system in which every patient
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36 had a designated clinician working within a team but with lead responsibility for care co-
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38 ordination and delivery.
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42 Eligibility criteria for participating clinicians were a professional qualification in mental
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44 health and/or a minimum of one-year professional experience in an outpatient setting and
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46 an active caseload as key worker. Inclusion criteria for patients were: living in the
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48 community (not 24 hour supported accommodation); treatment by a community mental
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50 health care teams at least three months; capable of giving informed consent; having
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52 sufficient knowledge of the language of the host country; having a primary diagnosis of
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54 schizophrenia or related psychotic disorder (ICD-10 = F20-F29); having an age between 18
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56 and 65 years; having at least one meeting with their key worker every two months with the
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4 expectation that they would continue with the service for the next 12 months; and having
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6 no severe organic psychiatric illness or primary substance abuse.
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10 **Measurement**

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12 Needs for care were measured on the Camberwell Assessment of Need Short Appraisal
13 Schedule (CANSAS, [29]), which assesses health and social needs across 22 domains. For
14
15 each domain it distinguishes between ‘no need’, ‘met need’, and ‘unmet need’. Research
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17 assistants interviewed both the patient and his/her key worker for self reported needs and
18
19 clinician rated needs in four centres (Groningen, Lund, Mannheim, and Zurich). Socio-
20
21 demographic and clinical characteristics of patients were collected at baseline. The
22
23 psychiatric diagnosis was obtained through a standardised and computer-based method
24
25 using operationalised criteria (OPCRIT, [18]) and psychopathology was measured by
26
27 means of the Positive and Negative Syndrome Scale (PANSS, [11]). Measures of patients’
28
29 quality of life (MANSA, [25]), treatment satisfaction (CSQ, [20]) and clinicians’ job
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31 satisfaction [23] were also used. Researchers received training in all rating procedures and
32
33 achieved good inter-rater reliability using videotaped interviews for PANSS (Cohen’s
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35 kappa = 0.71) and case vignettes for CANSAS (Cohen’s kappa = 0.90).
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45 **Statistical analysis**

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47 Descriptive statistics are presented with frequency and percentage distributions for
48
49 categorical data and means and standard deviations for continuous data. Correlation
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51 between baseline and follow-up was calculated by means of Rho for sumscores and the
52
53 agreement between patient and clinician ratings on individual need items by means of
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55 Cohen’s kappa (unweighted). Change in individual unmet needs was tested by means of
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57 chi-square in 2x2 tables. All data were analysed using SPSS-14.0 for Windows.
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6 **Results**
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9 The four centres included 102 clinicians (49 in the DIALOG condition and 53 in the Care
10 as Usual condition) with a key worker role and a total of 320 patients (174 in DIALOG and
11 146 in Cau). At follow-up 294 patients (92%) had baseline as well as follow-up ratings on
12 needs for care, while clinician rated needs were available for 302 patients (94%) at both
13 occasions. Baseline characteristics, both socio-demographic and clinical, of patients and
14 clinicians are shown in Table 1.
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24 Insert Table 1 here (baseline characteristics)
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29 Most patients were male (67%) and single (70%), while nearly half (43%) had paid or
30 sheltered work. The duration of illness was about 18 years with nearly seven admissions.
31
32 Patients were mixed to mostly satisfied with their life and with their treatment. Patients
33 were treated by slightly older and mostly female clinicians (67% of them were psychiatric
34 nurses or social workers), who had an average caseload of about 20 patients) were quite
35 satisfied with their job.
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45 *Prevalence of needs (sum indices)*
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47 Patient rated needs remained quite stable over time but unmet needs decreased significantly
48 from 2.0 to 1.6, and the proportion of patients without unmet needs increased from 34.0%
49 to 39.1%. The clinician rated needs also remained stable on a slightly higher level (on
50 average 8.0) with a significant decrease of unmet needs over time from 2.3 to 1.7, as well
51 as an increase of the proportion of patients without unmet needs (from 31.3% to 39.3).
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58 Thus, unmet needs generally decreased, in absolute as well as relative numbers, both for
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patient rated as well as clinician rated needs. Correlation between baseline and follow-up need ratings was modest (all below .60) suggesting quite some variability in numbers per patient.

Insert table 2 (prevalence of needs) about here

By far (>90%), the most prevalent need was related to psychotic symptoms (mostly met), followed in about 40% of the cases by needs in the area of accommodation, looking after home, daytime activities, physical health, information, distress, company, intimate relationships, and money. The highest prevalence of unmet needs was for intimate relationships, company, psychological distress, daytime activities, and physical health (15-28%); the relative difference between patient and clinician rated needs in this aspect was relatively small (data on individual need items not shown in table).

Sensitivity to change of individual unmet needs at follow-up

Of all patient rated baseline unmet needs (N=584; see table 3) 37.0% persisted after one year; in particular in the domains of psychotic symptoms, company, intimate relations, and transport (around 50%). This was the case for 34.9% of clinician rated unmet needs (N=680); in particular in the domains daytime activities, psychotic symptoms, alcohol, drugs, intimate relations, sexual expression, and money (also around 40-50%). Thus, most unmet needs, according to both perspectives, made a transition to no need or met need.

Table 3 about here

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4 Looking back retrospectively, more than half of the unmet needs at follow-up were new
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6 (54.5% for patient rated and 51.9% for clinician rated needs). Substantial proportions
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8 (30.1% and 23.1% respectively) were rated as no need at baseline. Generally, unmet needs
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10 in the domains of intimate relationships, sexual expression, company, day-time activities,
11
12 physical health, and psychological distress were rated by boths rather frequently as new.
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14 Also, substantial proportions of patients *without* an unmet need at baseline had at least one
15
16 unmet need at follow-up (31% according to patients and 38% according to clinicians). The
17
18 same applies to patients *with* at least one unmet need at baseline and none one year later
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20 (24% according to patients and 29% according to clinicians). Change in these proportions
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22 was not related to the treatment condition.
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29 Table 4 about here
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33 Agreement (Cohen's Kappa) between the patient and clinician on individual needs at
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35 baseline was on average .27, which raised to .30 at follow-up. This actually did not reflect a
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37 better agreement on unmet needs; on the contrary, the average proportion of agreement of
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39 patients with their clinicians on all unmet needs dropped from 40% to 30%, and the same
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41 occurred with the agreement of the clinicians with the patients on unmet needs (33% at
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43 baseline to 29% at follow-up). One could argue whether agreement between patient and
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45 clinician on unmet needs at baseline would increase the chance on a met or no need later
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47 on, and whether the treatment condition would made a difference (the DIALOG condition
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49 would be expected to do better). However, it appeared that in those cases in which patient
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51 and clinician agreed on unmet need status at baseline (on average 16%, range from 0% to
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53 40%, in particular more frequently with respect to daytime activities, physical health,
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55 psychotic symptoms, psychological distress, copmpany, intimate relationships, and sexual
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4 expression), no association with a met need status at follow-up showed up, and without a
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6 differential effect of treatment condition.
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10 Table 5 about here
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15 **Discussion**

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17 This one-year follow-up study of prevalence of patient rated as well as clinician rated
18 individual needs for care among 320 patients and their 98 key workers in community health
19 centers in four countries showed a rather stable number of met needs but a statistically
20 significantly decreasing number of unmet needs and an increasing number of patients
21 without any unmet need. This occurred in all four centres. Most unmet needs, nearly two
22 thirds, according to both patients and clinicians, were met or had disappeared at the time of
23 follow-up: only four patient rated unmet needs of psychotic symptoms, company, intimate
24 relations, and transport were relatively persistent (around 50%), while for clinician rated
25 unmet needs this was the case for daytime activities, psychotic symptoms, alcohol, drugs,
26 intimate relations, sexual expression, and money (40-50%). The incidence of unmet needs
27 over one year was relatively high considering the chronic illness duration of about 18 years
28 and the existence of multiple problems: 52-55% of the follow-up unmet needs were new.
29 Finally, the concordance between met and unmet needs at baseline and follow-up and the
30 agreement between patients and their clinicians at both occasions were low and virtually
31 absent. There was no indication that treatment condition (usual care with or without the
32 novel intervention DIALOG) had a discernable influence on the reduction or prevention of
33 individual unmet needs. Latter outcome seems somewhat discrepant with the result of the
34 reported overall effect of the DIALOG intervention on the reduction of unmet needs which
35 –using the sum index- is indeed not statistically significant anymore ($P=.07$), probably due
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4 to the reduced power (from N=502 to 320) with the exclusion of two centres with the
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6 greatest effect sizes (Granada and London). However, the focus of this paper is more on
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8 individual needs.
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12 The strength of this study is a high inclusion rate of people with long term problems in
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14 community mental health care settings with a low number lost to follow-up (6-8%) and
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16 only a few changes of clinicians affecting a low number of patients [26]. One limitation is
17
18 the use of exclusion criteria for the sake of the clinical trial regarding diagnosis (only
19
20 schizophrenia or related psychotic disorders), physical handicaps or organic illness, age, or
21
22 insufficient contact with care coordinator, which might restrict generalization to the whole
23
24 patient population in community care. The post hoc nature of the present analysis allows
25
26 for tentative conclusions only.
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33 The agreement between patient and clinician was rather small, although both were
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35 interviewed by the same investigators who were properly trained and monitored. The inter-
36
37 rater reliability of CAN is well established [7,17,22]; this study on case vignettes: Kappa
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39 .90) and found to be good to excellent, at least on the level of summary measures with a
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41 slight fall-off for unmet needs, while the test-retest and the inter-rater reliability with regard
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43 to individual items of needs appeared to be much less. The agreement between patient and
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45 staff ratings of needs generally is quite moderate and particularly insufficient as to
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47 individual items of unmet needs [32] (also this study: proportion between 29 and 40%;
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49 Kappa between .14 - .30). This applies also to the agreement between patient and his/her
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51 carer [3]. An observation is that the follow-up ratings of needs have been made by the
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53 investigators without explicitly taking into account the baseline measurement. The
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55 assessment of the status of unmet needs could therefore be strengthened by additional
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4 probing and checking of the reasons why that status has changed over time in the eye of the
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6 beholder. Another consideration, based on the study of Drukker et al [4], is to assess needs
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8 not by an independent researcher but by both parties involved together; this may yield
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10 ratings which better reflect the clinical relevance of a problem and the validity of its need
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12 status (met or unmet) over time (see also Macpherson et al [15]). It is possibly a limitation
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14 in our study that the need assessment was research oriented and not used as a clinical tool
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16 to guide the intervention.
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22 The prevalence rate of met and unmet needs in our study is in line with earlier research
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24 including the (significant) tendency towards lower numbers at follow-up [12,34], although
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26 after longer periods this may be reversed (see [1] on the 10 year follow-up in Sweden).
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29 Overall these findings are more or less consistent with the CAN literature. However, our
30
31 data suggest an overall high sensitivity to change and a high incidence of new individual
32
33 unmet needs among patients with chronic psychiatric and social problems, no matter
34
35 whether these were rated by the patient or the clinician. The same variability of self-
36
37 perceived unmet needs was found in a Dutch study [19] among 109 schizophrenia patients
38
39 with a follow-up of 18 months; most unmet needs disappeared, while only those relating to
40
41 day-time activities, psychological distress, and company were relatively stable (about 50%
42
43 of the cases).
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47 Nevertheless this is rather surprising and possibly an underestimated phenomenon.
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49 Wennström and Wiesel [33] observed over a period of six years that the mean number of
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51 (unmet) needs did not change much (about 6.3 for total and 1.5 for unmet needs), most
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53 (82%) needs in 1997 were (still) met or had disappeared in 2003 and more than 70% of
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55 needs occurring after baseline were met at follow-up. They see this as an indication of
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57 effective care that successfully meets the health needs of the patients and argued that
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4 summary indices of needs are not a valid outcome measure in routine mental health care
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6 because they conceal important changes over time on the individual level of needs.
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8 Drukker et al [5] also found that specific unmet needs in the area of accommodation,
9
10 household, self care, alcohol or drugs were more likely met after about 19 months than
11
12 unmet needs in the realm of psychopathology and daytime activities.
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17 Such transitions from unmet need to no or met need maybe due to various sources, such as
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19 general or specific interventions from mental health services, psychological adjustment
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21 processes, life changes, time effect, etc. Do our findings (and of others) provide indications
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23 that usual care includes such an effective rehabilitative effort that unmet needs are likely to
24
25 disappear? Can it be argued that community mental health care in western industrialised
26
27 countries is so advanced that we could expect such changes in unmet needs over time? On
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29 the one hand, Fakhoury & Priebe [6] criticised community mental health care and urged
30
31 toward establishing better practice to support continuity of care and guided sheltered living.
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33 On the other hand Kovess-Masf ty et al [12] demonstrated in their follow-up study (with
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35 another instrument, the Needs for Care Assessment, [2]) among 391 in-, out-, and day-
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37 patients with schizophrenia in six European centres that the number of proposed
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39 interventions was not related to need status but that the availability of community based
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41 treatment (outpatient and rehabilitation services) seems indeed to be related to (less) unmet
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43 needs. And Kallert and Leisse [10] showed a trend towards rating unmet needs (e.g.
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45 communication, slowness, and underactivity) as not meetable over time. This option of
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47 rating a need as no meetable is not available in the CANSAS.
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54 Thus so far much evidence of the effectiveness of regular community mental health care is
55
56 still lacking and the concept of unmet needs as a firm outcome criterion is probably
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58 premature. Need is a rather subjective concept and perfect agreement between the patient
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4 and his/her clinician or carer may not be expected but some consistency over time in needs
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6 is necessary for making sense in clinical practice. Some lack of agreement between patient
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8 and his/her clinician or even the carer is not surprising but in case of such an overwhelming
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10 lack, even more so at a second time of measurement is worrismatic. It is then difficult to
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12 give one perspective priority above the other. The more so because of the disappearance of
13
14 most - patient as well as clinician rated - unmet needs in a relatively very short time in a
15
16 stable chronic patient population without much relationship to the novel intervention which
17
18 was particularly designed to meet specific needs. This could have been a kind of validation
19
20 of the transition of unmet needs to met needs. Could it then be partly ascribed to conceptual
21
22 issues? Priebe *et al.* [24] argue that the concept of need inappropriately simplifies the actual
23
24 process of clinical decision making. They propose a way-out by clearly identifying
25
26 problems, specifying goals, and choosing interventions of which the outcomes should be
27
28 regularly be monitored. This might, for example, be better guaranteed by a more complex
29
30 instrument like the Needs of Care Assessment [2,16], which may partly solve these
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32 conceptual issues but carries with it other problems of training, implementation, rating, and
33
34 the perspective of one beholder (the clinician).
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40 Our retrospective secondary analysis should be followed by prospective quantitative
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42 investigations using repeated measures to study the association between intervention and
43
44 consequent impact on need status in specific domains, to assess whether the CAN is indeed
45
46 sensitive to change, a true change or due to measurement error. Also more qualitative
47
48 domain-specific assessment of change is worthwhile in order to better understand what it
49
50 means when an unmet need changes or emerges, and to establish the domains which
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52 change due to health service intervention compared with the domains which change for
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54 other reasons.
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APPENDIX

The Mediating Community Care Group includes the following: Granada: Marta Ribes Leyva, Maria F Soriano Peña, Beatriz Arroyo de Domingo. Groningen: Kerstin Wolters, Aukelien Mulder, Jappie Tiersma. London: Rakhee Haque. Lund: Tommy Björkman. Mannheim: Marita Reichenbacher, Anette Axt. Zurich: Patric Meyer, Minka Burgi.

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Table 1. Baseline Sociodemographic Characteristics of Patients and their Clinicians,
means (SD) and proportions (%).

Patients (N=320)	
Mean age (yr)	42.8 (10.8)
Male	67.2 %
Marital status (single)	70.3 %
Employed (incl. Sheltered work)	42.5 %
Unemployed	27.5 %
Other	30.0 %
Diagnosis	
Undifferentiated schizophrenia	39.1 %
Paranoid schizophrenia	24.1 %
Other (schizo-affective, delusional)	17.4 %
Other non-organic psychosis	19.4 %
Mean length of illness (yr)	17.8 (9.8)
Mean number hospital admissions	6.7 (8.5)
Quality of Life	4.8 (0.9)
Satisfaction with treatment	25.4 (4.0)
Symptomatology (PANSS)	
Positive subscale	14.7 (5.8)
Negative subscale	16.6 (6.7)
General subscale	32.6 (9.6)
Clinicians (N=98)	
Mean age (yr)	45.0 (8.9)
Male	37.3 %
Profession	
Psychiatric nurse	45.9 %
Social worker	21.4 %
Psychiatrist	10.2 %
Psychologist	5.1 %
Other	17.3 %
Mean length of service (yr)	14.3 (8.7)
Average caseload	21.3 (13.3)

Table 2. Prevalence of patient rated and clinician rated needs for care (sum indices) at baseline and 1-year follow-up, means and standard deviations (SD).

Patient rated needs (N=294)	Baseline (SD)	Follow-up (SD)	<i>P</i> (t-test/chi-square)	Correlation (<i>P</i>)	Difference (SD)
Total Needs	6.8 (3.1)	6.6 (2.9)	.41	.44 (.000)	.15 (3.2)
Met Needs	4.8 (2.7)	5.0 (2.8)	.22	.37 (.000)	-.22 (3.1)
Unmet Needs	2.0 (2.8)	1.6 (1.9)	.001	.59 (.000)	.37 (1.9)
Proportion of patients without unmet needs	34.0%	39.1%	.000		

Clinician rated needs (N=302)	Baseline (SD)	Follow-up (SD)	<i>P</i> (t-test/chi-square)	Correlation (<i>P</i>)	Difference (SD)
Total Needs	8.3 (3.7)	8.0 (3.7)	.06	.59 (.000)	.37 (3.4)
Met Needs	6.0 (3.2)	6.3 (3.4)	.16	.49 (.000)	-.27 (3.3)
Unmet Needs	2.3 (2.6)	1.7 (2.1)	.000	.46 (.000)	.63 (2.5)
Proportion of patients without unmet needs	31.3%	39.3%	.000		

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Table 3. Sensitivity to change of baseline Individual Unmet Needs at 1-yr follow-up

Status of Individual Needs at 1 yr follow-up

Unmet Needs at baseline:	No Need	Met Need	Unmet Need	Total
Patient rated	209 (35.8%)	159 (27.2%)	216 (37.0%)	584 (100%)
Clinician rated	199 (29.3%)	244 (35.9%)	237 (34.9%)	680 (100%)

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Table 4. Baseline Status of Individual Unmet Needs at 1-year follow-up

Need Status at baseline:	Patient rated Unmet Needs at follow-up	Clinician rated Unmet Needs at follow-up
No need	143 (30.1%)	114 (23.1%)
Met need	116 (24.4%)	143 (28.9%)
Unmet need	216 (45.5%)	237 (48.0%)
Total	475 (100%)	494 (100%)

Table 5. Agreement between Patient rated and Clinician rated Needs, at baseline and 1 year follow-up (Spearman correlation and Cohen's Kappa)

	Correlation
Baseline (N=317)	
Sum index of Total Needs	.36
Sum index of Unmet Needs	.46
Average over Individual Unmet Needs (3 categories)	.34 (Rho) or .27 (Kappa)
Follow-up (N=289)	
Sum index of Total Needs	.46
Sum index of Unmet Needs	.34
Average over Individual Unmet Needs (3 categories)	.34 (Rho) or .30 (Kappa)
Baseline: Mean proportion agreement on individual needs of	
patient with clinician	40%
clinician with patient	33%
Follow-up: Mean proportion agreement on individual needs of	
patient with clinician	30%
clinician with patient	29%

Paul Bebbington
Editor-in-Chief
Social Psychiatry and Psychiatric Epidemiology

August 7, 2008

Dear Paul,

Thanks for having me resubmit our paper on unmet needs for care. As suggested I have reviewed last couple of years of SPPE on relevant publications and as you will see I have added four (recent and interesting) papers (Arvidson 2008, Drukker 2008, Clearly 2006 and Joska 2005). Of course, this produced changes in the list of references in the text.

I will go through the reviewers comments (7) and indicate the textual changes and modifications by page.

Frontpage 1: wordcount and affiliation updated

Page 13 /14: I added some lines on the new literature (1 and 5) and moved a bit with the text, just to improve the line of reasoning.

1) include a table which lists all the need domains and the change over the year.

Of course, I have all the data on individual needs at baseline and at follow-up, including the changes in need status of the baseline unmet needs (persistency) and the new unmet needs (incidence), for both patient and keyworker rated needs. IN an earlier version of the manuscript I used two extra tables to illustrate on individual need level what is summarized in table 3 and 4 in the submitted paper. I am inclined not to do this because the reader gets a bit lost in all the details (22 needs x 6 columns of figures). I have tried to highlight the main findings. Would it not be better to have these tables just 'available on request'?

2) comment more on the limited agreement and emphasize that need is a subjective concept and that different perceptions are to be expected.

The point is well taken, I have mentioned this in the discussion, see page 15 inserted '*Need is a rather subjective concept and perfect agreement between the patient and his/her clinician or carer may not be expected but some consistency over time in needs is necessary for making sense in clinical practice*'

3) More attention needs to be given to the fact this was a multicentre study, more information is needed re any significant differences in the services and results from the different sites.

In a multicentre study there are always differences between sites. This is also the case with number of needs and also unmet needs. The trend of decreasing number of (unmet) needs occurred in all four centres (I added this to the discussion see page 11 inserted '*This occurred in all four centres*'). The difference also applies to the services (availability of staff, kind and number of therapeutic activities, number of contacts, hospitalizations, duration of care, etc). It is difficult to explain these

differences. One has to accept that countries differ in these respects and that each centre might not even be representative for the whole country. There are two papers from this European study in submission one about utilization of care and one about therapeutic activities. A conclusion is that differences between the (six) centres of contact duration and frequency in mental health services have little impact on patient outcome (e.g. unmet needs, quality of life). So, it deserves nearly a separate paper to elaborate this point properly and probably without substantial influence on the message of the current paper. I hesitate to dwell on this subject too much. I hope you can agree with me on this point.

4) Table 1 - I am not sure why clinician job satisfaction is included as it does not seem relevant to anything else in the paper

Right, I removed it from the table, not relevant here.

5) It is not clear why data are reported from 4 of the 6 study sites and not 6 (excluding the larger centres)

Simply, two centres, Granada and London, decided for logistical reasons and lack of research resources not to interview the patient on needs for care. It was clear from the beginning that they would not do it, also it was not essential for the main research question. Is acknowledged in the text see page 6 inserted '*Logistical reasons and lack of research resources prevented such an assessment in Granada and London*'.

6) A key finding is that although the numbers of unmet needs rated by staff and by patient is similar, the types of needs rated are rather different - but this is far from new and studies by Slade et al and by Ruggeri et al have previously reported this.

OK, it is acknowledged in the paper, also added that there are the same disagreements between patient and carer (Clearly et al 2006), see page 12/13 inserted '*This applies also to the agreement between patient and his/her carer [3]*'

7) The conclusion that CANSAS is less suitable for treatment outcome measurement is not fully justified as the authors argue this on the basis of patient-staff divergence of views. Rather the authors might address whether one source or the other might be given salience or how to make sense and interpret these differing views- and how to validate this finding. Indeed it might be argued that using only staff rated outcomes might not represent patient rated aspects of treatment impact.

Correct, but the main point is that for both raters and perspectives the finding is that in case of a chronic patient population with schizophrenia unmet needs come and go within a short period of time (1 year) without (a) much persistency, without (b) much relationship to a mental health intervention or specific therapeutic interventions and without (c) much agreement between keyworker and patient, although the latter might be related to methodological frailty. I am not surprised that there is some lack of agreement but that the lack is so overwhelming and even more at a second time of measurement. These three aspects worry me. Taken into account differing perspectives is essential in a therapeutic relationship but there must be a coordinating person who brings them together. And I was concerned that that has not happened yet in community mental health care in the various European countries while the DIALOG intervention was particularly designed to meet individual unmet needs.

I have tried to accommodate this comment in the discussion. See page 15 inserted
'Some lack of agreement between patient and his/her clinician or even the carer is not surprising but in case of such an overwhelming lack, even more so at a second time of measurement is worrison. It is then difficult to give one perspective priority above the other. The more so because of the disappearance of most - patient as well as clinician rated - unmet needs in a relatively very short time in a stable chronic patient population without much relationship to the novel intervention which was particularly designed to meet specific needs. This could have been a kind of validation of the transition of unmet needs to met needs'.

Looking forward to hear from you.
On behalf of all the authors

Kind regards

Durk Wiersma