

## ORIGINAL PAPER

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## Individual unmet needs for care: are they sensitive as outcome criterion for the effectiveness of mental health services interventions?

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**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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### 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; [34, 35]. 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 [10, 12, 19, 27, 33]; although with some exception, see Salize et al. [28]. 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 [9, 30]. Recently, it was demonstrated that high levels of (met) need also predict (changes in) care consumption, in particular more inpatient care [4], 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 [14, 21] while recently Priebe et al. [26] demonstrated such an effect more conclusively in an RCT on a novel mental health service intervention. However, methodological issues have to be taken into account. For example, the perspective of the beholder is important, as discrepancies between the patient and professional are substantial in terms of the number as well as the type of need [8, 13, 31, 32]; also this study]. Further, most authors compare summary scores of total number of met and unmet needs, while Wenström and Wiesel [33] argue that this might be misleading by concealing changes on an individual need level. They demonstrate that while no change over a period of six years occurred in summary scores of the Camberwell assessment of needs (CAN), significant changes in need status on nearly all items were found and mostly in the favorable direction: remaining needs were more often met than not and many patients in need of care or support in 1997 appeared to be managing on their own without problems in 2003. The same phenomenon was found in a Dutch study [19] among 109 schizophrenia patients with a follow-up of 18 months. The persistence or stability of unmet needs seemed rather low; most (patient rated) unmet needs disappeared, while only those relating to daytime activities, psychological distress, and company were relatively stable in about 50% of the cases.

This raises the question of whether unmet needs could be used as an outcome criterion of the effec-

tiveness of interventions in mental health care. We seek an answer to this question by investigating in detail the persistence or sensitivity to change of individual unmet needs over a one-year period, the incidence of new unmet needs at follow-up, and the concordance between patient rated needs and clinician rated needs, in the context of a novel mental health service intervention.

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## Settings and design

The present study was part of the DIALOG study, a cluster randomised controlled trial of a new intervention to improve communication between patient and clinician which was conducted in community psychiatric services in Granada (Spain), Groningen (The Netherlands), London (United Kingdom), Lund (Sweden), Mannheim (Germany), and Zurich (Switzerland) covering urban and mixed urban-rural areas. This novel intervention structures communication between patients and clinicians in routine meetings by means of a regular, two-monthly assessment of needs in 8 areas (mental health, physical health, job situation, accommodation, leisure activities, friendships, relationship with family/partner, and personal safety) with the support of a computer mediated technology (the so-called DIALOG intervention; [26]. The intervention had a small, but positive significant effect on the prevalence of self-reported unmet needs (effect size 0.22), on subjective quality of life (effect size 0.20), and on treatment satisfaction of the patients (effect size 0.28).

In this paper we focus on data from community mental health care teams in four centres only (Groningen, Lund, Mannheim, and Zurich) because of the availability of a need assessment by the patient as well as by the clinician. Logistical reasons and lack of research resources prevented such an assessment in Granada and London. In all centres multidisciplinary teams provided comprehensive care programmes for people with severe and enduring mental illnesses. They operated a key worker system in which every patient had a designated clinician working within a team but with lead responsibility for care co-ordination and delivery.

Eligibility criteria for participating clinicians were a professional qualification in mental health and/or a minimum of one-year professional experience in an outpatient setting and an active caseload as key worker. Inclusion criteria for patients were: living in the community (not 24 h supported accommodation); treatment by a community mental health care teams at least three months; capable of giving informed consent; having sufficient knowledge of the language of the host country; having a primary diagnosis of schizophrenia or related psychotic disorder (ICD-10 = F20–F29); having an age between 18 and 65 years; having at least one meeting with their key

worker every two months with the expectation that they would continue with the service for the next 12 months; and having no severe organic psychiatric illness or primary substance abuse.

## Measurement

Needs for care were measured on the Camberwell assessment of need short appraisal schedule (CAN-SAS, [29]), which assesses health and social needs across 22 domains. For each domain it distinguishes between 'no need', 'met need', and 'unmet need'. Research assistants interviewed both the patient and his/her key worker for self reported needs and clinician rated needs in four centres (Groningen, Lund, Mannheim, and Zurich). Socio-demographic and clinical characteristics of patients were collected at baseline. The psychiatric diagnosis was obtained through a standardised and computer-based method using operationalised criteria (OPCRIT, [18]) and psychopathology was measured by means of the Positive and Negative Syndrome Scale (PANSS, [11]). Measures of patients' quality of life (MANSA, [25]), treatment satisfaction (CSQ, [20]) and clinicians' job satisfaction [23] were also used. Researchers received training in all rating procedures and achieved good inter-rater reliability using videotaped interviews for PANSS (Cohen's kappa = 0.71) and case vignettes for CANSAS (Cohen's kappa = 0.90).

## Statistical analysis

Descriptive statistics are presented with frequency and percentage distributions for categorical data and means and standard deviations for continuous data. Correlation between baseline and follow-up was calculated by means of Rho for sumscores and the agreement between patient and clinician ratings on individual need items by means of Cohen's kappa (unweighted). Change in individual unmet needs was tested by means of chi-square in  $2 \times 2$  tables. All data were analysed using SPSS-14.0 for Windows.

## Results

The four centres included 102 clinicians (49 in the DIALOG condition and 53 in the Care as Usual condition) with a key worker role and a total of 320 patients (174 in DIALOG and 146 in Cau). At follow-up 294 patients (92%) had baseline as well as follow-up ratings on needs for care, while clinician rated needs were available for 302 patients (94%) at both occasions. Baseline characteristics, both socio-demographic and clinical, of patients and clinicians are shown in Table 1.

**Table 1** Baseline sociodemographic characteristics of patients and their clinicians, means (SD) and proportions (%)

Patients ( <i>N</i> = 320)	
Mean age (years)	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 (years)	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 ( <i>N</i> = 98)	
Mean age (years)	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 (years)	14.3 (8.7)
Average caseload	21.3 (13.3)

Most patients were male (67%) and single (70%), while nearly half (43%) had paid or sheltered work. The duration of illness was about 18 years with nearly seven admissions. Patients were mixed to mostly satisfied with their life and with their treatment. Patients were treated by slightly older and mostly female clinicians (67% of them were psychiatric nurses or social workers), who had an average caseload of about 20 patients) were quite satisfied with their job.

### ■ Prevalence of needs (sum indices)

Patient rated needs remained quite stable over time but unmet needs decreased significantly from 2.0 to 1.6, and the proportion of patients without unmet needs increased from 34.0 to 39.1%. The clinician rated needs also remained stable on a slightly higher level (on average 8.0) with a significant decrease of unmet needs over time from 2.3 to 1.7, as well as an increase of the proportion of patients without unmet needs (from 31.3 to 39.3%). Thus, unmet needs generally decreased, in absolute as well as relative numbers, both for patient rated as well as clinician rated needs. Correlation between baseline and follow-up need ratings was modest (all below 0.60) suggesting quite some variability in numbers per patient.

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 2).

### ■ 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 1 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.

Looking back retrospectively, more than half of the unmet needs at follow-up were new (54.5% for patient rated and 51.9% for clinician rated needs). Substantial proportions (30.1 and 23.1% respectively) were rated as no need at baseline. Generally, unmet needs in the domains of intimate relationships, sexual expression, company, day-time activities, physical health, and psychological distress were rated by boths rather frequently as new. Also, substantial proportions of patients *without* an unmet need at baseline had at least one unmet need at follow-up (31% according to patients and 38% according to clinicians). The same

applies to patients *with* at least one unmet need at baseline and none one year later (24% according to patients and 29% according to clinicians). Change in these proportions was not related to the treatment condition. Table 4 and Table 5.

Agreement (Cohen's Kappa) between the patient and clinician on individual needs at baseline was on average 0.27, which raised to 0.30 at follow-up. This actually did not reflect a better agreement on unmet needs; on the contrary, the average proportion of agreement of patients with their clinicians on all unmet needs dropped from 40 to 30%, and the same occurred with the agreement of the clinicians with the patients on unmet needs (33% at baseline to 29% at follow-up). One could argue whether agreement between patient and clinician on unmet needs at baseline would increase the chance on a met or no need later on, and whether the treatment condition would made a difference (the DIALOG condition would be expected to do better). However, it appeared that in those cases in which patient and clinician agreed on unmet need status at baseline (on average 16%, range from 0 to 40%, in particular more frequently with respect to daytime activities, physical health, psychotic symptoms, psychological distress, company, intimate relationships, and sexual expression), no association with a met need status at follow-up showed up, and without a differential effect of treatment condition.

## Discussion

This one-year follow-up study of prevalence of patient rated as well as clinician rated individual needs for care among 320 patients and their 98 key workers in

**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)	0.41	0.44 (0.000)	0.15 (3.2)
Met needs	4.8 (2.7)	5.0 (2.8)	0.22	0.37 (0.000)	-0.22 (3.1)
Unmet needs	2.0 (2.8)	1.6 (1.9)	0.001	0.59 (0.000)	0.37 (1.9)
Proportion of patients without unmet needs	34.0%	39.1%	0.000		
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)	0.06	0.59 (0.000)	0.37 (3.4)
Met needs	6.0 (3.2)	6.3 (3.4)	0.16	0.49 (0.000)	-0.27 (3.3)
Unmet needs	2.3 (2.6)	1.7 (2.1)	0.000	0.46 (0.000)	0.63 (2.5)
Proportion of patients without unmet needs	31.3%	39.3%	0.000		

**Table 3** Sensitivity to change of baseline individual unmet needs at 1-year follow-up

	Status of individual needs at 1 year follow-up			
	No need	Met need	Unmet need	Total
Unmet needs at baseline				
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%)

**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	0.36
Sum index of unmet needs	0.46
Average over individual unmet needs (3 categories)	0.34 (Rho) or 0.27 (Kappa)
Follow-up (N = 289)	
Sum index of total needs	0.46
Sum index of unmet needs	0.34
Average over individual unmet needs (3 categories)	0.34 (Rho) or 0.30 (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%

community health centers in four countries showed a rather stable number of met needs but a statistically significantly decreasing number of unmet needs and an increasing number of patients without any unmet need. This occurred in all four centres. Most unmet needs, nearly two thirds, according to both patients and clinicians, were met or had disappeared at the time of follow-up: only four patient rated unmet needs of psychotic symptoms, company, intimate relations, and transport were relatively persistent (around 50%), while for clinician rated unmet needs this was the case for daytime activities, psychotic symptoms, alcohol, drugs, intimate relations, sexual expression, and money (40–50%). The incidence of unmet needs over one year was relatively high considering the chronic illness duration of about 18 years and the existence of multiple problems: 52–55% of the follow-up unmet needs were new. Finally, the concordance between met and unmet needs at baseline and follow-up and the agreement between patients and their clinicians at both occasions were low and virtually absent. There was no indication that treatment condition (usual care with or without the novel intervention DIALOG) had a discernable influence on the reduction or prevention of individual unmet needs. Latter outcome seems somewhat discrepant with the result of the reported overall effect of the DIALOG intervention on the reduction of unmet needs which –using the sum index– is indeed not

statistically significant anymore ( $P = 0.07$ ), probably due to the reduced power (from  $N = 502$  to 320) with the exclusion of two centres with the greatest effect sizes (Granada and London). However, the focus of this paper is more on individual needs.

The strength of this study is a high inclusion rate of people with long term problems in community mental health care settings with a low number lost to follow-up (6–8%) and only a few changes of clinicians affecting a low number of patients [26]. One limitation is the use of exclusion criteria for the sake of the clinical trial regarding diagnosis (only schizophrenia or related psychotic disorders), physical handicaps or organic illness, age, or insufficient contact with care coordinator, which might restrict generalization to the whole patient population in community care. The post hoc nature of the present analysis allows for tentative conclusions only.

The agreement between patient and clinician was rather small, although both were interviewed by the same investigators who were properly trained and monitored. The inter-rater reliability of CAN is well established [7, 17, 22]; this study on case vignettes: Kappa 0.90) and found to be good to excellent, at least on the level of summary measures with a slight fall-off for unmet needs, while the test-retest and the inter-rater reliability with regard to individual items of needs appeared to be much less. The agreement between patient and staff ratings of needs generally is quite moderate and particularly insufficient as to individual items of unmet needs [32] (also this study: proportion between 29 and 40%; Kappa between 0.14 and 0.30). This applies also to the agreement between patient and his/her carer [3]. An observation is that the follow-up ratings of needs have been made by the investigators without explicitly taking into account the baseline measurement. The assessment of the status of unmet needs could therefore be strengthened by additional probing and checking of the reasons why that status has changed over time in the eye of the beholder. Another consideration, based on the study of Drukker et al. [4], is to assess needs not by an independent researcher but by both parties involved together; this may yield ratings which better reflect the clinical relevance of a problem and the validity of its need status (met or unmet) over time (see also Macpherson et al. [15]). It is possibly a limitation in our study that the need assessment was research oriented and not used as a clinical tool to guide the intervention.

The prevalence rate of met and unmet needs in our study is in line with earlier research including the (significant) tendency towards lower numbers at follow-up [12, 34], although after longer periods this may be reversed (see [1] on the 10 year follow-up in Sweden). Overall these findings are more or less consistent with the CAN literature. However, our data suggest an overall high sensitivity to change and a high incidence of new individual unmet needs among

patients with chronic psychiatric and social problems, no matter whether these were rated by the patient or the clinician. The same variability of self-perceived unmet needs was found in a Dutch study [19] among 109 schizophrenia patients with a follow-up of 18 months; most unmet needs disappeared, while only those relating to day-time activities, psychological distress, and company were relatively stable (about 50% of the cases).

Nevertheless this is rather surprising and possibly an underestimated phenomenon. Wennström and Wiesel [33] observed over a period of six years that the mean number of (unmet) needs did not change much (about 6.3 for total and 1.5 for unmet needs), most (82%) needs in 1997 were (still) met or had disappeared in 2003 and more than 70% of needs occurring after baseline were met at follow-up. They see this as an indication of effective care that successfully meets the health needs of the patients and argued that summary indices of needs are not a valid outcome measure in routine mental health care because they conceal important changes over time on the individual level of needs. Drukker et al. [5] also found that specific unmet needs in the area of accommodation, household, self care, alcohol or drugs were more likely met after about 19 months than unmet needs in the realm of psychopathology and daytime activities.

Such transitions from unmet need to no or met need maybe due to various sources, such as general or specific interventions from mental health services, psychological adjustment processes, life changes, time effect, etc. Do our findings (and of others) provide indications that usual care includes such an effective rehabilitative effort that unmet needs are likely to disappear? Can it be argued that community mental health care in western industrialised countries is so advanced that we could expect such changes in unmet needs over time? On the one hand, Fakhoury and Priebe [6] criticised community mental health care and urged toward establishing better practice to support continuity of care and guided sheltered living. On the other hand Kovess-Masféty et al. [12] demonstrated in their follow-up study (with another instrument, the Needs for Care Assessment, [2]) among 391 in-, out-, and day-patients with schizophrenia in six European centres that the number of proposed interventions was not related to need status but that the availability of community based treatment (outpatient and rehabilitation services) seems indeed to be related to (less) unmet needs. And Kallert and Leisse [10] showed a trend towards rating unmet needs (e.g. communication, slowness, and underactivity) as not meetable over time. This option of rating a need as no meetable is not available in the CANSAS.

Thus so far much evidence of the effectiveness of regular community mental health care is still lacking and the concept of unmet needs as a firm outcome criterion is probably premature. 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. 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 worrisome. 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. Could it then be partly ascribed to conceptual issues? Priebe et al. [24] argue that the concept of need inappropriately simplifies the actual process of clinical decision making. They propose a way-out by clearly identifying problems, specifying goals, and choosing 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 [2, 16], 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. We are indebted to the clinicians and patients who took part in the

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