2-COM: an instrument to facilitate patient–professional communication in routine clinical practice

Objective: A simple patient-completed self-report instrument may facilitate patient–professional carer communication.
Method: A 19-item self-report needs schedule was used in a sample of 243 out-patients with non-affective psychosis. Patients and professional carers commented on the usefulness of the instrument. In a subgroup of 95 patient–carer dyads, the professional carer was asked to rate the needs in addition to the patient.
Results: Patients scored their needs reliably and lower than the professionals (OR = 0.9, 95% CI: 0.9, 0.97). Concordance between patients and professional carers on individual needs was very low. More than 50% of the professional carers and more than 80% of the patients found 2-COM useful. The higher the number of needs indicated by the patient, the greater the discrepancy between patients and professional carers with regard to the usefulness of the schedule.
Conclusion: 2-COM is a useful instrument to expose, and subsequently bridge, patient–professional carer discordance on patient needs.

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Introduction

The symptoms and disabilities associated with psychotic disorder give rise to need for care. For example, lack of appropriate housing indicates a need for a targeted intervention involving, for example, social work, whereas experience of stressful hallucinations may indicate the need for a medical intervention in the form of antipsychotic medication. Accurate assessment of need for care in patients with a diagnosis of psychotic disorder is a prerequisite for the planning of treatment, both at the individual level (1) and at the level of service delivery (2–4). There is evidence, however, that needs are often assessed quite differently by clients and mental health professionals (5, 6). Although clients and mental health professionals may agree on the number of met needs (a need for which sufficient interventions have been provided) associated with a specific service intervention, they may disagree not only on the number of unmet needs (a need for which no or insufficient interventions have been provided) (7), but also on the area of need (2, 8). Disagreement in the area of unmet needs is especially important, as unmet needs have strong associations with quality of life (2, 9) but at the same time are most resistant to changes in service delivery (3).

In view of the fact that unmet needs have a major impact on subjective patient outcomes such

as quality of life, and the fact that patients and mental health professionals tend to have divergent views on them, it can be easily envisaged that miscommunication on unmet needs may arise and have adverse consequences on patient outcomes. In order to avoid such miscommunication, it would be helpful if two-way interactions between professional carers and patients on common areas of unmet needs could be facilitated in routine clinical practice. Previous work in in-patients has shown that the systematic use of a patient-completed self-report instrument on symptoms and problems in treatment planning resulted in improved patient engagement in treatment and patient satisfaction as regards hospital care and quality of interaction with staff (10). In another study, a self-report instrument on symptoms and side-effects of medication was found to reveal, in a substantial proportion of cases, problems that the professional was unaware of (11). In the present study, we wished to develop and test a self-report instrument on problems and symptoms for out-patients with psychotic illness in a European setting, to be used as a discussion document aiding communication in ambulatory treatment settings.

Aims of the study

  (i) To examine whether patients would be able to report on their needs reliably.
 (ii) To investigate whether clinicians would be frequently unaware of reported needs, justifying the introduction of the instrument.
(iii) To test whether both patients and clinicians would find such an instrument useful for improving communication, and to test whether discordance with regard to usefulness would be associated with greater patient level of needs.

Material and methods

Theoretical foundation of 2-COM

2-COM was developed in several stages and tested in an initial pilot survey including 126 patients, after which some minor changes were made, producing a revised version that was used in a fresh sample as described below. First, the most frequent needs, assessed according to the patient's view with the Camberwell Assessment of Need (CAN) (12), were identified from a database pertaining to a large sample of 707 patients with mental illness, comparable to the target population for 2-COM, who had had an interview with the CAN three times over 2 years (baseline, year 1 and

year 2) (13, 14). Unmet needs with at least a 5% frequency at all three measurement occasions were accommodation and looking after the home, self-care, daytime activities, physical health including medication side-effects, psychotic symptoms, information about treatment, psychological distress, company, intimate relationships, sexual expression, transport, money and benefits. Items covering these potential problem areas were added to a simple questionnaire (www.2COMS.homestead.com) that did not exceed, by *a priori* decision, 20 items so as not to disadvantage patients with cognitive impairments. Items were phrased simply and in such a way that questions were sensitive rather than specific, so that patients could indicate potential problems with the lowest possible threshold. The items used were: Accomodation: *are you having problems with where you live?*; Daytime activities: *do you have problems findings things to do?* and: *do you feel your life is boring?*; Treatment and medication side-effects: *are you having problems with your medication?* and: *aside from medication, are you satisfied with your treatment?*; Psychotic symptoms: *do you have thoughts or experiences that bother you?* and: *do you find it difficult to get going or be energetic?*; Information about treatment: *do you want more information about your illness and treatment?*; Company: *are you having problems getting on with your family or other people?*; Intimate relationships: *do you feel lonely?*; Sexual expression: *is the sexual part of your life satisfactory?*; Transport: *is going out or getting about a problem?*; Money and benefits: *do you have enough money for the things that you need?* Psychological distress was covered by a number of items, including subtle treatment side-effects affecting cognition and emotion that may be too subtle to be detected by objective examination, but can be reported by patients (15, 16). The psychological distress items were: *do you have difficulties sleeping?*, *do you often forget things?*, *do you often feel tired?*, *do you no longer enjoy the things you used to?*, *are you feeling tense?*, *are you easily upset?* In order not to exceed the maximum number of items, problems of self-care and aspects of physical health other than medication side-effects were not mentioned specifically but could be included under the final item: *if you have any other problems, what are they?*

Questions on a particular need came in two parts: in the first part, patients were asked whether the item was a problem for them ('is this a problem for you?') which they could tick either yes or no. The second question on the need item was 'would you like to talk about it?', which could also be ticked 'yes' or 'no'.

2-COM scoring

A need was considered present if a patient had either ticked that the problem was present, ticked that he/she wanted to talk about it, or both. This was carried out in order to ensure that the full 'burden' of problems in individual patients 'detected' by 2-COM was taken into account, including the ones that the patient did not prioritize for discussion with the professional carer. There were only a few occasions ($< 6\%$ of all possible occasions) where patients had ticked that they only wanted to discuss an issue, without ticking that it was a problem. These were included in the definition of needs, as they probably represent a simple error in filling in the instrument. Similar to previous work in the area of needs from the patient point of view (13, 14), a total needs score was constructed by adding the scores on the different items. In order to estimate the reliability in measuring this unobserved factor 'need', Cronbach's alpha was calculated using the 19 need ratings of each patient. Cronbach's alpha measures how well a set of items (or variables) measures a single unidimensional latent construct (in this case the construct of 'need'). When data have a multidimensional structure, Cronbach's alpha will usually be low.

Global scales

Global patient wellbeing outcomes in three areas were measured by visual analogue scales going from 'very well' to 'not at all well'. The three items were (i) 'overall, how are you feeling today?', (ii) 'overall, how is your medication suiting you at the moment?' and (iii) 'overall, how are you coping with everyday living at the moment?' Answers were ticked on the scale so that distance on the scale (0–100 mm) could be measured and analysed.

2-COM procedure

The procedure for using 2-COM in the clinic was as follows. Patients filled in the needs list and the three global wellbeing measures in the waiting room before seeing the clinician. They were instructed that there were no right or wrong answers for any of the questions in 2-COM. During the interview, 2-COM items ticked by the patient were discussed and after the interview both patient and mental health professional answered questions on (i) whether they thought 2-COM was useful in promoting communication between patient and professional carer (from not at all, a little, quite a bit and very much), (ii) whether they thought the doctor knew more about the patient's problems after the session (from not at all, a little, quite a bit and very much), (iii) whether 2-COM revealed any problems that the professional carer had previously not been aware of (yes/no), (iv) whether patient and professional carer thought 2-COM helped discuss the treatment plan (yes/no) and (v) whether the discussion of 2-COM items would lead to a change in the treatment plan (yes/no). Professional carers indicated how much extra time they estimated was involved in carrying out the 2-COM procedure.

Sample

In order to obtain a suitable sample for a pragmatic study, 243 patients with a clinical diagnosis of nonaffective disorder, and their professional carers, were selected from a variety of representative outpatient settings in eight Western European centres (Spain, France, Italy, the Netherlands, UK, Germany, Denmark and Austria).

Patient–professional carer concordance and test–retest

In a subgroup of 95 patient–professional carer combinations, professional carers were asked to rate the patient's needs as they thought their patients would rate them. In addition, they were also asked to rate the patient's answer on the desire to receive more information regarding treatment, and the visual analogue scales of the three overall wellbeing scales. In a subsample of 33 patients, 2-COM was administered twice within 1 week and the intraclass correlation coefficient (see below) between the total scores calculated.

Analyses

Analyses were conducted with STATA, version 7 (17). Three datasets were used. In the first, patient and professional carer-rated variables formed part of the same observation (wide format), allowing for the calculation of kappa's (a measure of chance-corrected concordance for dichotomous variables) and intraclass correlations (a measure of concordance between different raters for continuous variables) between the variables. In the second, patients and professional carers formed separate observations (long format with two observations for each pair of patients and carers), and a variable 'case'(0 = professional carer, 1 = patient) was constructed to differentiate between the patient and the professional carer observations, allowing for a standard case–control study logistic regression

analytical approach (18). In the third, an 'overall' kappa between patients and professionals was calculated for all the problem items at the same time. This was carried out by making a separate file for professionals and patients, with one observation for each problem item in each individual (long format file with 19 observations per individual) and calculating the kappa between a single patient and a single professional 'problem' variable. Similarly, an overall kappa was calculated for the test–retest procedure.

The association between needs reported by the patient compared with reports on the same needs by the professional carers was expressed as the kappa statistic; total number of needs reported by patients and professional carers were compared using the intraclass correlation coefficient for paired data. Associations between total number of needs and measures of global outcome were assessed with multiple regression analysis yielding regression coefficients (B), adjusting for possible confounding by centre.

Associations between patient/professional carer status and measures of helpfulness and usefulness of 2-COM were analysed in the long format file by logistic regression yielding odds ratio (OR) and their 95% confidence intervals (CI). A 95% CI that does not include unity denotes statistical significance at conventional alpha of 5%. In the logistic regression, the 'case' variable was the dependent variable, and the variables on helpfulness and usefulness were the explanatory variables. As in the logistic regression equation observations were clustered within pairs of patients and professional carers, compromising statistical independence of the observations, the CLUSTER and ROBUST options were used in the STATA logistic regression analyses. The CLUSTER option combined with the ROBUST option allows for the use of observations that are not independent within clusters (in this case: within pairs) and obtains the Huber/White/Sandwich estimator of variance instead of the traditional variance estimator. These procedures result in standard errors that are adjusted for clustering within persons. Interactions with possible effect modifiers were fitted by Wald test.

Results

Sample and test–retest

The sample consisted of 243 patients and their professional carers. Of the patients, 36% were women. The mean age of the patients was 38.1 years [SD = 12.2, inter quartile range (IQR): 29–46 years]. Around 80% of the sessions in which 2-COM was used had been with psychiatrists, the rest with other mental health professionals (mainly nurses and psychologists). The mean number of needs according to the patients was 9.3 (SD = 4.3, IQR: 6–12). Patient age and sex were not associated with total need score ($P = 0.34$ and $P = 0.94$, respectively). The intraclass correlation coefficient between the 2-COM total problem score in the sample of 33 who filled in the instrument twice was 0.74. The overall kappa, in the long format file, for all the items between the first and the second measurement occasion was 0.63. Cronbach's alpha was high at 0.89. Professional carers indicated that the 2-COM procedure on average added 13.1 extra minutes (SD = 5.7) to the out-patient visit.

Associations between global outcomes and total number of needs

The domains of global outcome were significantly associated with each other, but none explained more than 50% of the variance of another, suggesting that they tap into different outcome domains (Table 1). Regressing the total number of needs separately on each of the three measures of global outcome, adjusting for centre, revealed strong negative associations with each of the three domains (overall feeling: $B = -0.051$, $P < 0.001$; overall medication: $B = -0.025$, $P = 0.013$; overall coping: $B = -0.046$, $P < 0.001$). However, when all three global measures were entered jointly in the model, only the effect of overall feeling remained large and significant ($B = -0.04$, $P = 0.010$), whereas the other effects of the other two were reduced and non-significant (overall medication: $B = -0.002$, $P = 0.87$; overall coping: $B = -0.018$, $P = 0.20$).

Patients and professional carer concordance on usefulness of 2-COM

Of 230 patients who had answered the five questions on the usefulness of 2-COM, 189 (82%) had scored 'yes' or 'quite a bit/very much' on at least

Table 1. Pearson correlation coefficients between the three global outcome domains

	Overall feeling	Overall medication	Overall coping
Overall feeling	1		
Overall medication	0.50*	1	
Overall coping	0.68*	0.33*	1

* $P < 0.001$.

Table 2. Patient and professional carer concordance on usefulness of 2-COM

	Knowing patient better		Communicating better	
	Patients (%)	Professional carers (%)	Patients (%)	Professional carers(%)
Not at all	28 (12.4)	52 (25.7)	45 (19.7)	48 (23.7)
A bit	94 (41.8)	105 (52.0)	105 (45.9)	109 (53.7)
Quite a bit	68 (30.2)	38 (18.8)	54 (23.6)	41 (20.2)
Very much	35 (15.6)	7 (3.5)	25 (10.9)	5 (2.5)
Adjusted OR linear trend[1]	2.5 (1.9, 3.2)*		1.5 (1.2, 1.8)*	

[1] Summary increase in likelihood of being a patient with each higher level of 'knowing' or 'communicating'; adjusted for centre and for clustering of patients and professional carers in pairs.
*$P < 0.001$.

Table 3. Patient and professional carer concordance on usefulness of 2-COM

		Patients (%)	Professional carers	Adjusted OR
Revealed new things?	Yes	136 (62.7)	56 (28.4)	4.6 (3.1, 7.0)*
	No	81 (37.3)	141 (71.6)	
Helped discuss treatment?	Yes	133 (59.9)	79 (38.7)	2.5 (1.7, 3.7)*
	No	89 (40.1)	125 (61.3)	
Change in treatment?	Yes	91 (41.6)	43 (21.2)	2.7 (1.8, 4.1)*
	No	128 (58.4)	160 (78.8)	

*$P < 0.001$; OR adjusted for centre and for clustering of patients and professional carers in pairs.

one of the items, and 24 (10%) had indicated they found 2-COM useful on all five aspects. For the professional carers, these figures were 204 and 107, or 52%, on at least one of the items, and 11 (5%) on all five items. Comparisons on the individual items of usefulness revealed that a substantial proportion of patients and professional carers found 2-COM useful. For each of the items, however, patients were around two to four times more likely to find 2-COM useful than the professional carers (Tables 2 and 3).

Comparison of patient and professional carer-scored needs and outcomes

In the group of 95 patient–professional carer pairs where professionals had rated the patient needs, professionals rated a mean number of needs of 10.3 (3.5) and patients of 9.2 (4.1). This difference in total score discriminated significantly between cases and professional carers in the logistic regression procedure (OR adjusted for centre: 0.9, 95% CI: 0.9, 0.97, $P = 0.006$), indicating that patients scored themselves as having less needs than the professional carers. Similarly, patients assigned themselves higher scores on the global outcomes than the professional carers. Thus, the values for overall feeling, overall medication and overall coping were 64.3, 69.6 and 63.6 in the patients, and 61.2, 68.4 and 56.5 in the professional carers. The ORs for these differences were, respectively: OR = 1.01 (0.99, 1.02), OR = 1.00 (0.99, 1.02) and OR = 1.02 (1.002, 1.03).

The patient–professional carer inter-rater reliability of the total problem score was very low (intraclass correlation coefficient: 0.36), indicating that in individual patients total number of needs were scored rather differently by patients and professional carers. At the level of the individual 19 needs, correspondence between patients and professional carers was also low: the mean kappa was 0.25 (range 0.08–0.47). The overall kappa, in the long format file, was 0.29.

The intraclass correlation coefficients between patient and professional carer-scored measures of global wellbeing was somewhat higher than that for needs, but still low by psychometric standards (overall feeling: 0.50; overall medication: 0.52; overall coping: 0.40).

Determinants of patient–professional carer concordance

In the group of 95 patient–professional carer pairs where both professionals and patients had rated the patient needs, we tested, using logistic regression in the long format file, whether the discrepancies in measures of usefulness varied as a function of total problem score rated by patients and professional carers by fitting 'total problems' × 'usefulness measures' interactions. This revealed significant or suggestive positive interactions with four of the five usefulness measures: 'leads to change in treatment' (OR = 1.2, 95% CI: 1.0, 1.4, $P = 0.022$), 'revealed new problems' (OR = 1.2, 95% CI: 1.0, 1.4, $P = 0.047$), 'communicating quite a lot/very much better' (OR = 1.2,

95% CI: 1.0, 1.5, $P = 0.023$) and 'knowing the patient quite a lot ⁄ very much better' (OR = 1.2, 95% CI: 0.98, 1.4, $P = 0.071$). The positive interaction indicated that the higher the number of problems rated by patients and professional carers, the greater the difference between patients and professional carers as to whether they thought the instrument would lead to a change in treatment, reveal new problems or improve communications or increase knowledge.

Discussion

Asymmetry in patient–doctor communication is a well-known problem in clinical medicine (19). 2-COM exposed, as hypothesized, a great degree of discordance between patients and professional carers with regard to the type and number of patient needs. This already suggests that 2-COM is a useful and simple tool for routine use in clinical practice. Arguably the only way to remedy miscommunication on patient needs in clinical practice is to expose discordance in views, so that they may be discussed and bridged where necessary. 2-COM was strongly associated with global outcomes, suggesting that the needs rated by patients are important determinants of wellbeing and coping, and therefore relevant to elicit and discuss when the patient visits the professional carer.

The intra-patient reliability (kappa of 0.63) at different time points was considerably higher than the patient–professional reliability (kappa of 0.29) at the same point in time. A kappa of 0.63 for intrapatient reliability may not be very satisfactory from the psychometric point of view, but one would, however, expect a fairly large degree of variation of state measures such as problems in daily life over the period of 1 week.

Although 2-COM increased the length of the visit by the patient by around 13 min on average, more than half of the professional carers and more than four-fifths of patients found 2-COM useful in at least one aspect. These findings are encouraging and suggest that the experience was of value for patient–professional carer interaction in the majority of cases. Interestingly, however, patients were much more likely to find the instrument useful, and more likely to feel that new problems had been revealed and that treatment would be changed. One reason for this discrepancy is that professional carers may be rating usefulness 'objectively', for example obtaining a piece of clinically relevant information that they did not have before, whereas patients may equate use of 2-COM with feeling more 'vocal' and that they

have been given an opportunity to engage more in the treatment process. Thus, the discrepancy in usefulness may indirectly quantify the potential of 2-COM to engage patients in the treatment process. The fact that this discrepancy between patients and professional carers in usefulness ratings was greatest in those with the highest level of needs according to both patients and doctors, suggests that 2-COM may actually work best in those who need it most. It could be argued that the discordance between patients and professional carers is simply because of patients, but not professionals, being pleased with the increase in duration of the visit of around 13 min. However, when we fitted, post hoc, 'increase in visit duration' × 'usefulness measures' interactions in the logistic regression models as described above, no significant interactions were apparent.

Validity of 2-COM and its scoring was suggested by (i) high internal consistency, justifying our use of a construct of total number of needs, (ii) strong association with global wellbeing scales and (iii) high face validity in the sense that questions were simple, sensitive and based on previously used scales in the field. Arguably the strongest argument for validity, however, was the fact that the great majority of patients found 2-COM useful.

The results should be seen in the light of several limitations. First, it could be argued that the findings are based on self-report, which introduces an unwanted element of subjectivity to the data. However, in order to have an impression of needs according to the patient, a subjective view is necessary in order to obtain valid data (20–22). Thus, even if it were argued that the number of needs rated by patients may be reflective of a tendency to complain in general rather than the objective number of needs, the subjective rating will still count clinically, as this is what drives patient satisfaction and experience of being heard and understood by the professional carer. Furthermore, the test–retest exercise suggested that, inspite of the subjectivity of the data, 2-COM was nevertheless reliable. Secondly, the sample selected was an opportunity sample with no efforts to obtain a sample that was representative for the selected centres. However, although this may affect the generalizability of the findings (23), it will not affect their validity. Furthermore, the absence of associations between total need score and age and sex suggests that 2-COM may be useful across the whole age range of patients including, for example, first-episode patients. Finally, although both professional carers and patients thought that the instrument was useful, no data are available that suggest that 2-COM actually resulted in a change

of treatment. It could even be argued that 2-COM may provoke false expectations in the patient by allowing him or her to raise issues that the professional cannot do anything about. The purpose of 2-COM, however, is to give the patient the opportunity to be more vocal, and even if problems are raised that are not amenable to change, better understanding of the issues and clearer communication about the possibility of change results in an improved patient–carer relationship and better patient outcomes in all areas of medicine (24–26). Future studies of 2-COM should focus on its possible effect on change in treatment and outcomes among patients with severe mental illness.

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