

**FULL TITLE**

**Using Needs Assessments to Understand Continuing Disability in Patients with Enduring Mental Illness. Implications for Considerations of Service Development.**

**SHORT TITLE**

**Continuing Disability in Enduring Mental Illness**

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## **ABSTRACT**

Particular strengths of the MRC Needs for Care Assessment Schedule have been used to investigate the treatment status of patients with persistent psychiatric disability in ways that other needs assessment tools are unable to. 179 such patients from 3 settings; a private sector psychiatric hospital, two public sector day hospitals situated in the same town and a high security hospital, were found to have a high level of need. Although there were differences between settings, overall these needs were well met in all three. The high level of persistent disability found amongst these patients could not be attributed to failure on the part of those treating them to use the best available methods, or to failures to comply or engage with treatment on the patient's part. In some two thirds of instances persistent disability was best explained by the fact that even the most suitable available treatments have to be considered only partially effective.

## **INTRODUCTION**

Persistent disability amongst that small section of the population described as suffering from "enduring mental illness" (chronic psychosis or treatment unresponsive and disabling neurotic disorder) and managed in the community remains a source of suspicion and stigma to many and a challenge to those responsible for generating mental health services policy. Failure to resolve psychological or behavioural problems may be because treatments are not being offered or complied with, in which case intensified community care could improve outcome. On the other hand it might be because available treatments are, sadly, not that effective, in which case intensified community care *per se* is unlikely to make an impact upon these difficulties. This is an important contemporary issue. Health Service policy includes a commitment to Assertive Outreach closely modelled upon Assertive Community Treatment (ACT) (Stein and Test 1980,

Department of Health 1999), even though there is doubt in some circles that it will improve outcomes beyond those already achieved in British NHS settings (Tyrer 2000). This doubt stems in large part from the results of two relevant UK trials.

The first was the PRiSM Study. This was a comparison between patients treated in a catchment area served by a standard community mental health team (Standard Sector) and patients treated in a catchment area served by two teams with extended opening hours; a psychiatric acute care and emergency team and a psychiatric assertive continuing care team (Intensive Sector). The main findings were that both groups of patients fared well and achieved outcomes that were comparable if not better than a hospital based service but that there were very limited additional advantages and some disadvantages associated with management in the Intensive Sector (Thornicroft et al 1998a). The main criticisms of this have been that it was not a formally conducted randomised controlled clinical trial, and because the intensified treatment it investigated was not sufficiently “faithful” to the ACT model (Marshall et al 1999).

The first of these criticisms was met by the UK 700 trial (Burns et al 1999). This also failed to find differences in bed occupancy, social or clinical functioning between patients managed as part of a small (10-15) case load and those managed as part of a standard (30-35) case load, despite clear evidence of an enhanced rate of patient contact amongst the experimental group (Burns et al 2000). It would seem fairly clear that improving outcome in this context is going to require more than simply increasing the intensity of provision.

The interventions defined as ACT and investigated in both of the UK studies are defined exclusively in terms of service organisation; case load, the availability of a psychiatrist, in-vivo

treatment settings, frequency of contact and other factors (Teague et al 1998, Thornicroft et al 1998b, Burns et al 1999). Although appropriate enough for a study investigating service management issues, this approach does not address the nature or choice of interventions that might be provided under the framework in question. Issues of team management and organisation are an important background to the way in which care is delivered but effectiveness can only be judged if measure is also made of what that care comprises. The PRiSM study found a dilution effect in that the outcome after intensive community care in realistic settings was not as good as that obtained in more experimental settings. Was this because care was organised less intensively than in the experimental settings, (Marshall et al 1999), or because it contained fewer “therapeutic ingredients”? Such a question can only be answered by a methodology that not only investigates the intensity of care but also its content.

Investigating the content of a care package is a challenging prospect and there are few instruments that have been developed that even attempt this. One is the MRC Needs for Care Assessment Schedule; NFCAS (Brewin et al 1987). Another is the Camberwell Assessment of Need; CAN (Phelan et al 1995). This establishes whether or not provision is being made for identified problems or needs but unlike the NFCAS it does not inquire in any structured way into the nature of that provision.

The NFCAS specifies a number of potentially appropriate and clearly defined interventions for each of nine areas of symptoms and behaviour problems and eleven areas of skills and abilities. These interventions or items of care were defined in the course of a consensus exercise involving psychiatrists, clinical psychologists, nurses, occupational therapists and other professional groups (Brewin et al 1987). Where a problem in the form of current, recent or threatened symptoms or

behaviour problems are noted to be present, or there is evidence of a failure or threatened failure to exercise one of the specified skills and activities of daily living, enquiries are then made about the provision of each of the specified items of care. A rating is made for each item of care that reflects whether or not it would be appropriate. If an item of care is considered appropriate in any particular instance enquiries are then made to determine whether or not it is being provided. If it is being provided further enquiries establish whether it is deemed to be wholly effective or potentially so, or only partly effective but worth continuing. If an item of care is considered appropriate but it is not being provided, a judgement is made that reflects whether or not this is thought to be because it has been offered but refused or not engaged with, tried in the past and found to be ineffective, or contra-indicated for recognised reasons. Thus the NFCAS provides a structured review of the nature and propriety of service provision and its efficacy in any one of the twenty classes of disability where an intervention might be helpful. Distinctions can be drawn between circumstances in which the problems are present because treatments that might be effective have yet to be tried, circumstances in which all appropriate treatments are only partially effective, or circumstances in which the use of treatments that might be effective is being hindered for some reasons.

The NFCAS has been used to investigate patients' needs in a variety of contexts (Bebbington et al 1996, Bebbington et al 1997, Bebbington et al 1999, Brewin et al 1987, Brewin et al 1988, Brugha et al 1988, Lesage et al 1991, Middleton et al 1996). These differing uses have confirmed the instrument's validity and reliability and explored the fulfillment of needs for care in a variety of groups of patients in a variety of settings. This paper reports further analysis of such needs assessments. The instrument's potential to structure judgements about the propriety,

provision and engagement with specified treatments has been used in a hitherto unexplored manner. In particular the question has been addressed; “Is the presence of continuing disability due to the failure to provide treatments of known efficacy, because the use of such treatments is being hindered in some way or because treatments that are available are of only limited efficacy?”. This addresses the question of whether or not disability could be reduced by more intensive input. If continuing disability is associated with inadequate treatment or poor compliance then more intensive input or more skilled engagement might improve outcome. If on the other hand continuing disability is associated with only partially effective treatments then no improvement in outcome can be expected until more effective treatments are devised, however assiduously those currently available are being provided.

## **SUBJECTS**

### **Needs Assessments**

These were carried out upon three groups of patients from differing settings that have in common a high level of persistent psychiatric disability. One group was from a large and well-established psychiatric hospital in the private sector (Private Sector Inpatients). Another was from a pair of day centres in the same town (Public Sector Day Patients). The third was a sample of patients detained in high secure care (High Security Hospital Inpatients). In each case needs assessments were commissioned as an audit by the host organisation and were carried out upon a purposively selected representative sample of 60 patients.

### **Private Sector Inpatients**

These were selected from general adult psychiatry patients accommodated in two admission wards, one long-term care ward and one open rehabilitation ward. They were men and women who had been inpatients in one or other of those settings for a minimum of 6 months. The selected sixty were chosen by reference to an alphabetical list of names. These were thirty five men and twenty five women. The overall age range was 19 – 59 with a mean of 33.4 (sd 9.4).

### **Public Sector Day Patients**

These were chosen using a random selection generator applied to the databases listing the names of those attending each of two day centres situated in the same town. One was run by Social Services and included a ‘pool’ of seventy six people, the other was run by the NHS and included a ‘pool’ of fifty six. Thirty patients were selected from those attending each of the two facilities. The sample comprised thirty eight males with a mean age of 41.5 (sd 9.6) and twenty two women with a mean age of 51.6 (sd 11.6). All were attending their day centre at least twice a week and had been doing so for at least 6 months.

### **High Security Hospital Patients**

These were selected with the intention of balancing across the two important dimensions of gender and legal classification. Thus there were 15 men legally classified as suffering from mental illness, 15 men legally classified as suffering from psychopathic disorder, 15 women legally classified as suffering from mental illness and 14 women legally classified as suffering from psychopathic disorder. One intended female subject subsequently refused to be interviewed

and could not be replaced. The 30 men had a mean age of 34.2 (sd 6.1) and the 29 women had a mean age of 32.2 (sd 7.5). All had been an inpatient in that high security hospital for at least 6 months.

Local Research Ethics Committee agreement was obtained for each of the three sites.

## **METHODS**

The method used was the same in all three sites and followed the specifications of other uses of the NFCAS (see Brewin et al., 1987, 1988). A research worker was recruited who sampled and identified patients, and collected detailed information concerning their clinical status and treatment history. Formal ratings were then made by a research team consisting of the research worker, a psychiatrist, and a clinical psychologist all trained in the use of the instrument. The team first rated the existence of current, recent and threatened problems in nine areas of Symptoms and Behaviour Problems and 11 areas of Skills and Abilities (see Tables 3 and 4 for details of these areas). In each area the NFCAS specifies a number of items of care, and these were rated by the team according to whether each was provided, whether it was appropriate and (wholly or partly) effective, or whether it had been refused. An algorithm is then used to derive ratings of Primary Need Status or No Need, Met Need, Unmet Need (for Assessment or Treatment), and No Meetable Need (i.e. there is a significant problem but no item of care of even partial effectiveness) from these. Within the primary category of “No Need” patients are secondarily rated as having a “Possible Need” if there is a lack of performance of skills and abilities despite their possessing the necessary competence.



In addition to these conventional assessments of needs status the assessments were further analysed to address the core research question; “Is the presence of continuing disability due to the failure to provide treatments of known efficacy, because patients do not comply with treatments that are provided or because treatments that are available are of only limited efficacy?”. This was achieved by an analysis of Current Significant Problems rated as Met Need. The identification of a Current Significant Problem reflects the presence of explicit symptomatology or a behavioural problem, or the failure to be self-sufficient in one of the eleven activities of daily living. A rating of Met Need reflects the fact that the presence of such a problem has led to the provision of at least one appropriate item of care. The items of care being provided might or might not include one or more deemed to be potentially wholly effective and amongst the available and appropriate items of care there may be one or more that could be productive but are not being provided because they have been refused or prematurely turned down. Thus, for each Current Significant Problem that has been rated as a Met Need it has been possible to clarify whether or not this is one for which a potentially wholly effective item of care is being provided, and therefore the current significant problem can be expected to respond to a treatment that is available and is being provided, one for which only partially effective items of care are being provided and there exist potentially more effective items of care but their use is being hindered in some way, or one for which only partially effective items of care are available.

In all three cases the psychiatrist was HM. The clinical psychologist differed in the three sites; for the Private Sector In-patients it was CRB, for the Public Sector Day Patients it was NH and for the High Secure Hospital patients it was CB. This procedure allowed the raters to be blind to

the gender and ward of origin of the Private Sector In-patient group, the gender and day centre of the Public Sector Day Patients and the gender and legal classification of the High Security Hospital In-patients. It did not, however, allow raters to be blind to the setting. Once ratings had been completed and collated they were entered into SPSS for tabulation and statistical analysis, which employed non-parametric methods.

## **RESULTS**

### **Distribution of Problems and Needs**

The mean number of Symptoms and Behaviour problems was significantly higher (Kruskal-Wallis one-way ANOVA adjusted for ties followed by post-hoc Mann-Whitney U test comparisons) amongst the Private Sector Inpatients, although the data on needs status reveal that their problems were dealt with very effectively, with high levels of Met Need and low levels of Unmet Need. In contrast, Public Sector Day Patients had proportionately fewer Met Needs, and higher levels of Unmet and Unmeetable Needs. High Security Hospital Inpatients had high levels of Met Need and a level of Unmet Need for Treatment that was similar to the Public Sector Day Patients. These comparisons are outlined in Table 1.

There were significantly more problems with Skills and Abilities amongst the Public Sector Day Patients than among the other two samples (Kruskal-Wallis one-way ANOVA adjusted for ties followed by post-hoc Mann-Whitney U test comparisons). Needs in these areas were more frequently met amongst the Private Sector Inpatients than amongst either of the other two groups and there was a significantly higher rate of Unmet Need for Assessment amongst the Public Sector Day Patients. Both Public Sector Day Patients and High Security Hospital Inpatients had

much higher levels of Possible Need than the Private Sector Inpatients. These comparisons are outlined in Table 2.

### **Analysis of Current Significant Problems Rated as Met Needs**

There were 633 instances of a Current Significant Problem across the three groups. Of these 30 were rated as Unmet Needs for Treatment, 9 as Unmet Needs for Assessment, 57 as Unmeetable Needs and 58 as Possible Need. Thus 76% (479) instances of a Current Significant Problem were rated as Met Need. Kruskal-Wallis one-way ANOVA with post-hoc Mann-Whitney U tests indicated that there were significantly fewer Current Significant Problems rated as Met Need amongst the High Security Inpatients (mean 2.1) than amongst the Public Sector Day Patients and the Private Sector Inpatients, who did not differ from each other (mean in both cases was 2.9).

Tables 3 & 4 present details of the treatment status of these Current Significant Problems rated as Met Needs. Across the three groups it is evident that in a small minority of cases effective treatment is being precluded by patients refusing or prematurely terminating interventions that have been offered. There are more instances where potentially wholly effective interventions are being offered, but it is striking that in the majority of instances only partially effective items of care are available. These figures are shown in the right hand column of Tables 3 & 4. Across the nine areas of symptoms and behaviour problems this column accounts for 169 of 281 instances of persistent disability (60%), and across the eleven areas of skills and abilities 136 of 198 instances (69%).

The only exception amongst Symptoms and Behaviour problems is for Neurotic Symptoms. Here

there were a total of 43 patients suffering from a Current Significant Problem that was being addressed in an appropriate manner. More than half (25) were receiving at least one item of care that was felt to be potentially wholly effective, and only 14 were receiving treatment that was acknowledged as less than wholly effective and unlikely to become more so. In the area of Skills and Abilities Education provided a similar exception, but the number of patients involved was very small.

## **DISCUSSION**

As previously reported by Brewin et al. (1988), it appears that the MRC Needs for Care Assessment Schedule is capable of detecting meaningful differences between the needs of patients in different settings. This investigation has used such data to further investigate the background of instances of disability that persist despite provision of an apparently appropriate intervention.

There are some methodological reservations. Although the process of assessment and rating was the same across the three sites it was clearly unrealistic to arrange for the raters to be blind to the site from which patients had been drawn, and the identities of the research assistant and clinical psychologist involved in carrying out the ratings differed from site to site. Nevertheless there are a number of differences between the three groups of patients that carry face validity and support the view that the assessments accurately reflect the nature of clinical problems and related treatments in each of the three sites.

The Private Sector Inpatients were largely people with complex mental health needs who were

being treated in an institution which has an established and well deserved reputation for managing people with resistant and persistent mental health problems and behavioural difficulties. It is well resourced and staffed and as a result it is hardly surprising that in comparison with the other groups of patients these have a higher rate of Significant Problems and a lower rate of Unmet Needs for treatment. The Public Sector Day Patients are less intensively supervised and so it is not surprising that these had a lower rate of Met Needs and higher rates of Needs for Assessment and Unmeetable Needs. Furthermore they were older than the other two groups and might therefore be expected to have more complex difficulties. Finally, it is perhaps not surprising that the High Security Hospital Inpatients had the lowest mean number of Current Significant Problems. These patients are accommodated where they are not so much because of the complexity of their mental health problems, but because of the dangers they have presented in the past or are considered to continue to present.

### **Analysis of Current Significant Problems Rated as Met Needs**

These differences in needs status between sites notwithstanding the main purpose of this investigation was to use the NFCAS to explore the background to persistent disability despite appropriate treatment wherever it was present. Not surprisingly, reflecting the sources of these assessments, there was a high rate of such instances. Nearly half the Private Sector Inpatients had a Current Significant Problem with Positive Psychotic Symptoms that was rated as a Met Need; there was a high rate of such problems with Physical Symptoms amongst both the Public Sector

Day Patients and the High Security Hospital Inpatients and there was a high rate for Dangerous or

Destructive Behaviour amongst both the Private Sector Inpatients and the High Security Hospital Inpatients.

The NFCAS provides insight into why it is that patients continue to suffer such disabilities despite the provision of appropriate treatment. In some it will be because the treatment has not yet had time to work: instances where at least one potentially wholly effective item of care is being provided and the expectation is that it will become effective in due course. A wide range of different types of treatment for psychiatric disorder take a long time to become effective and the guideline raters used was that a treatment should only be regarded as partially effective if it had undergone an appropriate trial for a period of at least three months and disability continued. Thus, particularly when new treatments such as a change to a different or atypical anti-psychotic agent, or the beginning of a psychological treatment had only recently been instituted, the situation was viewed with optimism. In other cases continuing disability will be because only partially effective items of care are being accepted and matters could be better if an otherwise non-compliant patient were to accept further items of care believed to be more effective than those that are being accepted. A third possibility is that only partially effective items of care are available or thought to be appropriate. Tables 3 and 4 indicate how continuing problems that are being met appropriately across the range of Symptoms and Behaviour Problems, and the range of Skills and Abilities respectively can be understood in these different ways. This allows the NFCAS to address the question: "Is the fact that patients suffer continuing disability due to the fact that services are inefficient and fail to provide treatments that could be effective (Unmet Need), that services are in some way unsatisfactory because patients are being allowed to get away with not making the best use of treatments that are available, or that the treatments that are

available are only partly effective if at all?”.

Although any instance of Unmet Need is unsatisfactory and should not arise, those that did were few in number, amounting to combined ratings of “Unmet Need for Treatment” and “Unmet Need for Assessment” in under 5% of rated problems. In contrast the proportion of Current Significant Problems rated as Met Need was considerably higher (75%). Across the range of Symptoms and Behaviour Problems 34% of these Met Needs were receiving potentially effective interventions whereas 60% were instances in which all items of care that were considered appropriate were rated as only partially effective. Similarly across the range of Skills and Abilities 29% of Met Needs were receiving potentially effective interventions whereas fully 68% were instances in which only partially effective treatments were available.

Although these are not surprising findings they draw attention to an important issue. The conventional definitions of ACT include relatively low client to staff ratios, extended hours service, arrangements to supervise the delivery of medication in community settings, treatment at home and other descriptors of the organisation of the service. Broadly speaking these identify an approach that is characterised by relatively intense staff/client contact and Policy developments in this area are driven by the assumption that intensifying contact in this way will improve clinical outcome.

Although this is quite possibly true in areas where more can clearly equate to better, such as the supervision of medication or carers' respite, it is not automatically the case that more necessarily equals better under all circumstances. There is growing evidence for the value of specific therapeutic interventions that are appropriate for different types of patient and problem over and above the value of merely providing a greater quantity of "eclectic" treatment. Examples include the use of a systemic approach to understand and influence domestic and other relationships that can play a part in maintaining abnormal or unnecessary illness behaviour (Kuipers, 1993), specific cognitive/behavioural approaches to psychotic (Tarrier et al 1993) and neurotic symptoms (Clark et al 1999) and continuing critical review of any psychopharmacological strategies that might be available (Sharma and Kerwin 1996). Our review of needs assessment data suggests that outcomes for those with persistent psychiatric disability are more likely to be improved by attention to genuine therapeutic advances in these areas than by simply providing current interventions more intensively. Such conclusions suggest the need for a somewhat different approach to service improvement than is currently being advocated by service planners.

Finally it is salutary to contrast the findings from the closely supported in-patients and day patients reported upon here with the community sample recently described by Bebbington et al (1999) using the same assessment methodology. In the case of the former it would seem that needs are being met if not perfectly, certainly very adequately. Continuing disability reflects the imperfections of available treatments rather than imperfections in the organisation of the services providing them. On the other hand those in the latter sample who were regarded as suffering from "neurotic" conditions rather than those suffering a chronic psychosis were much less well catered for. As we have emphasised, for those with chronic psychosis it may be that further



improvement in outcome has to await genuine therapeutic advance, or the incorporation of specific therapeutic skills such as specific, relevant psycho-social interventions into the repertoire of those treating them. In contrast the treatment of patients broadly described as “neurotic” does suggest room for improvement in response to organisational changes that could sharpen case detection, improve compliance and engagement, and widen the use of treatments already established to be effective. Perhaps this is where the injection of additional resources might actually reap greater rewards. Unfortunately these patients tend to be less conspicuous than their chronically psychotic but unfortunately frequently less treatable counterparts.

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Table 1

| <b>Needs status: Symptoms and behaviour problems</b> |                           |                            |                                   |
|--|---------------------------|----------------------------|-----------------------------------|
|  | Private Sector Inpatients | Public Sector Day Patients | High Security Hospital Inpatients |
| Mean number of Significant Problems                  | 3.65*                     | 3.18                       | 2.91                              |
| Percentage Met Need                                  | 94.9                      | 80.8*                      | 91.6                              |
| Percentage Unmet Need for Assessment                 | 0                         | 3.7*                       | 1.8                               |
| Percentage Unmet Need for Treatment                  | 2.8*                      | 6.4                        | 5.5                               |
| Percentage Unmettable Need                           | 2.3                       | 9.1*                       | 1.1                               |

Asterisk values differ significantly ( $p < 0.05$ ) Post hoc Mann-Whitney U test.

Table 2

| <b>Needs Status: Skills and abilities</b>              |                           |                            |                                   |
|--|---------------------------|----------------------------|-----------------------------------|
|  | Private Sector Inpatients | Public Sector Day Patients | High Security Hospital Inpatients |
| Mean Number of Significant Problems and Possible Needs | 1.25                      | 2.67*                      | 1.61                              |
| Percentage Met Need                                    | 86.5*                     | 66.2                       | 63.8                              |
| Percentage Unmet Need for Assessment                   | 0                         | 3.3*                       | 1.5                               |
| Percentage Unmet Need for Treatment                    | 0                         | 4.9                        | 6.0                               |
| Percentage Unmeetable Needs                            | 12.5                      | 10.9                       | 14.4                              |
| Percentage Possible Need                               | 1.5*                      | 14.7                       | 14.3                              |

Asterisked values differ significantly ( $p < 0.05$ ) Post hoc Mann-Whitney u test.



Table 3

| <b>Analysis of current significant problems rated as met needs: Symptoms and Behaviour Problems</b> |   |   |   |
|---|---|---|---|
|   | Number (%) where at least one potentially wholly effective item of care is being provided | Number (%) where at least one partially effective item of care is being provided but at least one potentially more effective item of care has been refused or prematurely turned down | Number (%) where only partially effective items of care are available |
| Positive psychotic symptoms   | 14(25)  | 4(7)  | 37(67)  |
| Slowness and under-activity   | --  | 3(14)   | 19(86)  |
| Tardive dyskinesia and other side-effects   | 10(36)  | --  | 18(64)  |
| Neurotic symptoms   | 25(58)  | 4(9)  | 14(33)  |
| Dementia or organic psychosis   | --  | --  | 4(100)  |
| Physical symptoms or disease  | 16(36)  | 2(5)  | 26(59)  |
| Dangerous or destructive behaviour  | 15(38)  | --  | 24(62)  |
| Socially embarrassing behaviour   | 11(39)  | 4(14)   | 13(47)  |
| Distress  | 4(22)   | --  | 14(78)  |
| <b>Total</b>  | <b>95(34)</b>   | <b>17(36)</b>   | <b>169(60)</b>  |

Table 4

| Analysis of current significant problems rated as met needs: Skills and abilities |   |   |   |
|---|---|---|---|
|   | Number (%) where at least one potentially wholly effective item of care is being provided | Number where one at least partially effective item of care is being provided but at least one potentially more effective item of care has been refused or prematurely turned down | Number (%) where only partially effective items of care are available |
| Personal Hygiene  | 9(35)   | --  | 17(65)  |
| Household Shopping  | 4(22)   | --  | 14(78)  |
| Get Meals   | 3(33)   | --  | 6(67)   |
| Household Chores  | 7(24)   | --  | 22(76)  |
| Use of Public Transport   | 4(25)   | 1(6)  | 11(69)  |
| Use of Public Amenities   | 2(18)   | --  | 9(82)   |
| Education   | 5(83)   | --  | 1(17)   |
| Occupation  | 1(14)   | 1(14)   | 5(72)   |
| Communication Skills  | 2(40)   | --  | 3(60)   |
| Manage a Weekly Budget  | 14(32)  | 1(2)  | 29(66)  |
| Manage Own Affairs  | 7(26)   | 1(4)  | 19(70)  |
| <b>Total</b>  | <b>58(29)</b>   | <b>4(2)</b>   | <b>136(69)</b>  |



