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Assessing perceived need for mental health care in a community survey: development of the Perceived Need for Care Questionnaire (PNCQ)

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Abstract Background: The Perceived Need for Care Questionnaire (PNCQ) was designed for the Australian National Survey of Mental Health and Wellbeing. The PNCQ complemented collection of data on diagnosis and disability with the survey participants’ perceptions of their needs for mental health care and the meeting of those needs. The four-stage design of the PNCQ mimics a conversational exploration of the topic of perceived needs. Five categories of perceived need are each assigned to one of four levels of perceived need (no need, unmet need, partially met need and met need). For unmet need and partially met need, information on barriers to care is collected. Methods: Inter-rater reliabilities of perceived needs assessed by the PNCQ were examined in a study of 145 anxiety clinic attenders. Construct validity of these items was tested, using a multi-trait multi-method approach and hypotheses regarding extreme groups, in a study with a sample of 51 general practice and community psychiatric service patients. Results: The instrument is brief to administer and has proved feasible for use in various settings. Inter-rater reliabilities for major categories, measured by the kappa statistic, exceeded 0.60 in most cases; for the summary category of all perceived needs, inter-rater reliability was 0.62. The multi-trait multi-method approach lent support to the construct validity of the instrument, as did findings in extreme groups. Conclusions: The PNCQ shows acceptable feasibility, reliability and validity, adding to the range of assessment tools available for epidemiological and health services research.

Introduction

The Australian National Survey of Mental Health and Wellbeing

The Federal Government of Australia commissioned the Australian National Survey of Mental Health and Wellbeing to provide better information to support strategic planning of mental health services (Australian Health Ministers 1992, 1998; National Mental Health Strategy Evaluation Steering Committee 1997; Whiteford 1993). The survey included studies of four catchment areas using key informant methodologies to ascertain prevalence estimates for the psychoses (Jablensky et al. 2000), and a household survey targeting high-prevalence disorders such as depression and anxiety (Australian Bureau of Statistics 1998; Henderson et al. 2000). This latter survey is here referred to as the National Survey of Mental Health and Wellbeing (NSMHWB). Population sampling and administration of the field questionnaire were conducted by the Australian Bureau of Statistics (ABS), with guidance from reference groups of mental health researchers. An instrument and survey design was chosen to be similar to the Epidemiologic Catchment Area studies (Klerman 1986; Regier et al. 1984) and the National Comorbidity Survey (Kessler et al. 1994) from the United States. The NSMHWB data collection was carried out during July and August of 1997. The interviewers were recruited, employed and trained by the ABS, with support in training and supervision from clinicians and researchers involved in development of the Field Questionnaire for the survey.

Inclusion of perceived need in the NSMHWB Field Questionnaire

Instruments to assess diagnosis, disability, and service utilisation were obvious inclusions in the Field Questionnaire. In consideration of the role of the survey in
estimating need, we reviewed various questionnaires described as needs assessment instruments in mental health. Need is difficult to define and is closely interrelated with concepts of want, supply and demand (Stevens and Gabbay 1991). Hence, various definitions of need are applied. An important dimension in the assessment of need to have emerged is that of the perceptions of the consumer or potential consumer. Such inquiry was limited in early needs assessment instruments, such as the MRC Needs for Care Assessment (Brewin et al. 1987). However, in response to commentators from various viewpoints having argued for inclusion of a consumer perspective (Carter et al. 1995; Hogg and Marshall 1992; Marshall 1994; Morgan 1994; Slade 1994; Stevens and Gabbay 1991), this perspective is explicitly included in the more recent generation of instruments (Marshall et al. 1995; Phelan et al. 1995). For example, the Camberwell Assessment of Need (Phelan et al. 1995) includes consumer ratings as complementary to those of clinicians, while the Cardinal Needs Schedule (Marshall et al. 1995) includes this area of inquiry within its assessment of the ‘cooperation’ criterion.

There is precedent for the inclusion of perceived need as a subject of inquiry in major epidemiological surveys. The National Comorbidity Survey, the Ontario Supplement to the Ontario Mental Health Survey and the Christchurch Psychiatric Epidemiology Study are examples of surveys that included one or two questions of this type (Hornblow et al. 1990; Katz et al. 1997). In the NSMHWB, some two minutes of interview time were made available.

Choice of instruments for assessing perceived need

Existing instruments in this area were unsuitable to the task set for the NSMHWB Field Questionnaire design team. Instruments devised for clinical populations are too long, and not easily adapted to this community survey setting with administration by lay interviewers, while the questions used in other epidemiological surveys are very brief, and limited in scope (Hornblow et al. 1990; Katz et al. 1997). For these reasons, the Perceived Need for Care Questionnaire (PNCQ) was developed. This paper presents its design history and describes the reliability and validity testing of aspects of the PNCQ.

The design of the Perceived Need for Care Questionnaire (PNCQ)

A multi-stage design

The four-stage design of the PNCQ mimics a conversational exploration of the topic of perceived needs. The first stage is a structured enquiry into services received over the previous 12 months. This service utilisation element of the questionnaire was elaborated by another team in Australia (Carter 1997). It includes questions about all in-patient care and consultations with various types of generalist and specialist mental health care providers, then asks how many of such contacts were described by the subjects as having been for a mental health problem. For those who report service use related to a mental health problem, the second stage of the PNCQ asks about what types of intervention for mental health problems they have received, with choices offered from a series of categories described below. The third stage is conditional on previous responses, and probes for whether the provision of each type of intervention received is perceived as adequate or not. In the fourth and final stage, where interventions are viewed as inadequate, respondents are asked to identify the main reason from a series of possible barriers to care.

If the first stage identifies that respondents are not service recipients, the second stage is that they are prompted with a restatement of symptoms elicited earlier in the Field Questionnaire using the Composite International Diagnostic Interview (CIDI; World Health Organisation 1994). Following this prompt, these people are then asked whether they needed any of the same types of interventions for these symptoms as those asked of people who reported service use. The third stage outlined above is not relevant here, since these subjects have already stated they have not received any mental health care, so this is skipped and in an equivalent of the fourth stage above, the subjects are asked about barriers to care.

Categories of perceived need

The categories of perceived need included in the PNCQ were determined by the design team. This included a consumer and mental health professionals from various disciplines, who together reviewed the literature (e.g. Bebbington et al. 1996; Lesage et al. 1991; Phelan et al. 1995; Rogers et al. 1993; Ruggeri 1994; Thornicroft et al. 1993). Details of the content and construction of the instrument and an example of its use have been reported elsewhere (Meadows et al. 2000).

The number of categories was severely constrained by a 2-min time limitation for stages 2–4 of the PNCQ. The stem categories for stage 2 of the questionnaire are:

1. Drugs: medicine or tablets
2. Information: information about mental illness, its treatments, and available services
3. Psychotherapy: discussion about causes that stem from your past
4. Cognitive behaviour therapy: learning how to change your thoughts, behaviours and emotions
5. Counselling: help to talk through your problems
6. Social intervention: help to sort out housing or money problems
7. Help to improve your ability to work, or to use your time in other ways