Self-rated assessment of needs for mental health care: a qualitative analysis

Title: **Self-rated assessment of needs for mental health care: a qualitative analysis**

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INTRODUCTION

The Perceived Need for Care Questionnaire (PNCQ) is a self-rated needs assessment tool developed for a general population survey, the 1997 Australian National Survey of Mental Health and Well Being (NSMHWB) (Meadows, Burgess, Fossey, & Harvey, 2000; Meadows, Harvey, Fossey, & Burgess, 2000), and used since in the 2007 NSMHWB (Meadows & Burgess, 2009) and other surveys internationally (Fassaert et al., 2009; Sareen, Cox, Afifi, Clara, & Yu, 2005; Sareen et al., 2007). This paper reports a qualitative content analysis of the meanings of perceived needs for mental health care, as characterised when

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the PNCQ is completed, for the purpose of extending current understanding of the nature of self-reported needs for mental health care.

Assessing need for mental health care

Considerable international work has been undertaken to determine the mental health needs of communities using various approaches. Prevalence estimates of mental disorder and disability and service utilisation rates have been used to provide indicators of need, yet diagnosis and need for service are different (Whiteford & Groves, 2009) and service use may reflect demand or availability of services (Joska & Flisher, 2005). An alternative is direct assessment of need for specific interventions or services, for which several tools exist.

One of the first developed was the Needs For Care Assessment Schedule (NFCAS) (Brewin, Wing, Mangen, Brugha, & MacCarthy, 1987), an expert-rated assessment of the needs for care of people with persistent mental illnesses in 21 areas of clinical and social functioning. A shortened version that provides an account of the views of consumers and carers has since been developed (Marshall, Hogg, Gath, & Lockwood, 1995), as has a community version for use with primary care and general populations (Bebbington, Brewin, Marsden, & Lesage, 1996; Bebbington, Marsden, & Brewin, 1997; Boardman, Henshaw, & Willmott, 2004). Also developed in the United Kingdom (UK), the Camberwell Assessment of Need (CAN) (Phelan et al., 1995) assesses level of need and formal or informal help received in 22 areas and the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) covers these same domains, using a simpler scale of met need, unmet need, no need, or not known need, designed for rating by staff and consumers (CANSAS-S and CANSAS-P) (Macpherson, Varah, Summerfield, Foy, & Slade, 2003; Trauer, Tobias, & Slade, 2008). The CAN and CANSAS have been widely used to explore differences in consumers' and carers' perceived needs; to investigate relationships between meeting needs and improved quality of life or adequacy of care; and to measure service outcomes (Cleary, Freeman, Hunt, & Walter, 2006; Fleury, Grenier, Caron, & Lesage, 2008; Joska & Flisher, 2005; Slade, Leese, Cahill, Thornicroft, & Kuipers, 2005; Trauer et al., 2008). Other less widely known tools also gather needs profiles from consumer and staff perspectives (Crane-Ross, Roth, & Lauber, 2000).

In comparison, several international epidemiologic surveys have approached the assessment of perceived needs by asking respondents one or two explicit questions about whether they had any mental health need during the previous year and whether they received the appropriate help (Katz et al., 1997; Ojeda & Bergstresser, 2008; Urbanoski, Cairney, Bassani, & Rush, 2008). Neither the needs assessment tools for people with persistent mental illnesses nor the latter approach is suitable to explore both perceived mental health needs and barriers to care provision within an epidemiologic survey. The PNCQ was developed for this purpose.

Perceived Need for Care Questionnaire (PNCQ)

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This brief structured interview tool has good reliability and validity (Meadows, Harvey et al., 2000). It enables individuals to rate their mental health-related needs and service provision over the last twelve months by identifying whether they had any of five categories of need for care; whether they received sufficient help from services in relation to these needs; and the nature of the barriers when needs were perceived as not fully met (Meadows & Burgess, 2009). The five categories of need are: medication for a mental health problem; information about mental illness, its treatments and available services; counselling and verbal therapies; social interventions (need for practical help to sort out housing or money problems); and skills development (need for help to improve one's ability to work, to care for oneself or one's home, or to use time in other ways). For each type of intervention, a forced choice response allows the level of perceived need to be categorised as met need, partially met need, unmet need, or no need. For needs identified as unmet, or partially met, seven barriers to care response options are offered: self reliance; unawareness; lack of access; stigma; finance; non response; and alternate provision.

The PNCQ's development and administration are reported in detail elsewhere (Meadows, Harvey et al., 2000). Its use in the Australian epidemiologic surveys allowed investigation of the extent to which differing types of self-rated mental health needs in the adult population are being met, the role of primary care in meeting these needs, and the differing influences of demographic characteristics, diagnosis and disability on need (Meadows et al., 2002; Meadows, Burgess, Fossey, & Harvey, 2000; Meadows, Liaw, Burgess, Bobevski, & Fossey, 2001; Meadows & Burgess, 2009). For example, the recent NSMHWB found 14% of the adult population perceived needs for mental health care, of which almost half (45%) was rated as met and proportionally needs for medication were the most likely to be met (Meadows & Burgess, 2009). Additionally, international surveys have used PNCQ to investigate patterns of perceived mental health needs and the extent to which these are met among Canadian military personnel (Sareen et al., 2007) and migrants in the Netherlands (Fassaert et al., 2009). However, if policy and resource priorities are to be effectively identified, the first-person perspective is also important to understanding why people perceive needs for mental health care, and then either do or do not seek help (Whiteford & Groves, 2009). Therefore, this study aimed to explore what self-rated needs for mental health care mean from the viewpoint of people attending general practices and outpatient mental health services.

METHOD

The PNCQ validation study (Meadows, Harvey et al., 2000) used a two-phase validation design with mixed methods to quantitatively measure perceived needs for care using the PNCQ, and qualitatively explore participants' views of their mental health needs and barriers to receiving care. For the qualitative component reported here, a directed approach to qualitative content analysis was chosen since the intended purpose was to extend existing knowledge of the nature of self-reported needs for mental health care (Hsieh & Shannon, 2005). Thus, instead of deriving themes inductively from participants' perspectives, the a priori framework of

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the PNCQ directed the data collection and analytical approach (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005).

Setting and participants

Potential participants were recruited from general practice and specialist community mental health service settings primarily to test hypotheses about differing levels of perceived need in the quantitative validation of PNCQ. This also served to increase the possibility that wide-ranging views on the research issue were obtained, which is important in qualitative sampling to enhance the completeness of information gathered and to guard against privileging one perspective over others (Fossey et al., 2002; Graneheim & Lundman, 2004).

Fifty-one people participated: twenty-eight from a general practice and twenty-three from an area mental health service (AMHS) in Melbourne. General practice participants responded to notices distributed by reception staff seeking prospective participants for the PNCQ validation study, who did not necessarily have mental health problems, whereas AMHS participants were approached when attending community clinic appointments. Ethical approval was obtained from the appropriate ethics committee and all gave written informed consent.

Table 1 presents demographic information and self-identified mental health problems reported in participant interviews. Of the general practice participants, the majority (75%) identified current or past mental health needs and among those recruited through the AMHS, eleven reported receiving or being in the process of transfer to shared care involving GPs and specialist services (Meadows, Harvey, Joubert, Barton, & Bedi, 2007). Thus, participants had diverse experiences of service delivery spanning primary care, shared care, and specialist community mental health care.

< Table 1 about here >

Data collection

For the PNCQ validation study (Meadows, Harvey et al., 2000), each participant completed the brief, highly structured PNCQ and a semi-structured qualitative interview. An interview guide of open-ended questions directed towards exploring perceived need across the domains covered in PNCQ was used to facilitate the interview. Therefore, the qualitative interviews involved first asking participants to describe their experiences of mental health over the past year and any service provision to address their needs, followed by exploration of specific areas of need addressed by PNCQ. This began with exploring needs for information about mental illness, treatment options and how to get help, followed by participants' views about needs for medication and counselling or talking-related therapies, including their views about the issues for which they needed help, and lastly enquiring about needs for practical help and skills development.

These interviews were generally conducted in participants' homes, and otherwise at their GP practice or community mental health clinic, 5-10 days after completion of the PNCQ rating and by an interviewer blind to the PNCQ ratings. Interviewers took extensive written notes to document participants' descriptions as

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closely to their words as possible, and recorded an interview summary for verbatim transcription following each interview. Both the interviewer's recorded summary and written notes were used as material for analysis.

Data analysis

Qualitative content analysis typically aims to summarise and classify textual data through assigning labels, or codes, and grouping them according to like meaning (Graneheim & Ludman, 2004; Hsieh & Shannon, 2005). Applying a directed approach to content analysis (Hsieh & Shannon, 2005), each summary transcript was initially read and the content coded according to the five categories of needs determined by the PNCQ, using the qualitative data management software, NUD*IST (QSR International, 2002). Supplementary information from written notes made during the interviews was coded in the same manner. Sorting the data in this way facilitated the subsequent stages of analysis: assigning meaning labels to data about each category of need so as to code the ideas contained therein; and then sorting and searching the coded data across interviews so as to explore commonalities and differences among the ideas and identify their thematic content in relation to each category of need. The first author undertook this content analysis independent of the interviewers, whose written notes served to clarify understanding of the interview summaries and check coding decisions.

FINDINGS

Of the 51 participants in this study, all 23 people recruited from the AMHS and 14 (50%) of those recruited in general practice self-identified current needs for mental health care. Table 2 summarises the types of perceived needs for mental health care identified by them. As shown, multiple categories of needs for mental health care were typically identified, with the AMHS clients commonly reporting a wider range of needs. The qualitative meanings of these perceived needs are presented for each PNCQ need category with excerpts from the interviewers' notes and summaries, in which participants' words were paraphrased. Names of participants, places and services were changed to protect identities.

< Table 2 about here >

Perceived need for medication

Most participants with any perceived need for mental health care described a need for medication, so as to stay well; keep going with living; manage life's problems; control moods; or maintain some degree of quality of life. Typically, need for medication was described as fully met when participants perceived that taking medication meant their illness was well-controlled, or they described learning that "*coming off was the wrong thing to do*" [Ian] from prior experiences of worsening symptoms, hospitalisation, or being "*very up-and-down over the years*" [Adrian]. Further, some participants reported fully met need for medication having adjusted their expectations and learned to cope with symptoms, such as voices, whilst not perceiving the medication as fully effective. Yet, others found it difficult to define whether they had 'real' needs for

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medication, or whether this ‘need’ was more their doctor’s perspective than theirs; they also spoke of trying to comply with this view and wishing for more discussion and negotiation around medication issues.

In comparison, needs for medication were viewed as partially met when participants identified the medications or their medication regimes as unsatisfactory, particularly those seen as blunting emotions, blurring thinking, and producing other unpleasant effects. Other participants expressed concerns about how their medications were administered; their medications being seemingly ineffective in addressing the problem for which it was taken; or about becoming overly dependent on medications. As a consequence, these participants described perceived needs for a different type of medication, an altered dose, or for alternative treatments. From participants’ viewpoints then, perceived need for medication may co-exist with dissatisfaction with taking medication, its effectiveness or its perceived effects, and with the desire to “come off” medication, as the excerpts in Table 3 highlight.

< Table 3 about here >

Perceived barriers to medication needs being met

Information and communication-related issues were commonly reported barriers to medication needs being more fully met. As also illustrated in Table 3, participants reported not feeling able to discuss their concerns with doctors; medication options not being discussed with them; and alternatives to medication not being offered by doctors. Participants also identified not knowing what else might work, or where else to seek help, as barriers.

Perceived need for information

As shown in Table 2, information-related needs were identified by most participants with any self-reported needs. These needs were wide-ranging for information about mental illness and treatment options, physical health, lifestyle and daily occupations. Those participants whose perceived needs for information were adequately met over the past twelve months described being given information by their doctors (GPs or psychiatrists) without asking, or having opportunities to discuss their questions and options. However, when doctors and mental health professionals directly involved in their care did not address these needs, some participants described partially meeting their information needs through other sources, such as libraries and support groups (see Table 4).

In comparison, participants with diagnosed mental illness and unmet information needs typically commented that they had been given little or confusing information about their diagnosis by doctors. These participants described wanting information to better understand the nature of their illness, specific episodes of illness and related events, as well as what to expect about its course, treatment options or feedback about their progress. Identified needs in this group for information about physical health, lifestyle and occupation-related issues were also typically described as unmet.

< Table 4 about here >

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Perceived barriers to information needs being met

As with perceived needs for medication, communication issues with doctors and mental health professionals were the main barriers to participants' identified needs for information being more adequately met. Thus, some participants questioned the current state of knowledge about mental illness and its treatments, doubting whether the knowledge that they sought about their illness, prognosis or treatment was available or expressing the view that professionals would provide more information if they knew the answers. Nevertheless, other participants described it as "*extremely frustrating at times*" [Andrea] that health professionals offered little information or they expressed fear that doctors might intentionally withhold information. Additionally, participants reported feeling too pressured by the limited time in consultations, lacking confidence to ask questions of professionals, or sometimes having difficulty remembering or understanding information provided, as further barriers. Excerpts from interviews with Barry, Beth and Ian in Table 4 illustrate these points and their views that professionals should share information more frequently, and in understandable language.

Perceived need for talking-related therapies

Most participants with any identified needs for care reported needs to talk to someone supportive, or for specific types of counselling, whether met or not (see Table 2). As participants' viewpoints in Table 5 show, these included needs for a professional, with whom to talk through problems and cope with mental illness, so as to "*think straight about things*" and "*stay grounded*" [Alex & Rita]. Some participants also identified needs for counselling to gain an understanding of their illness, other stressors, or relationship difficulties, based on wishing for help beyond solely relying on medication. When described as adequately addressed, needs to be listened to, and for supportive counselling were either met by general practitioners and case managers or by multiple sources of formal help, such as doctors, social workers, and supportive social networks, with whom to talk through complex personal, relationship, or family issues.

< Table 5 about here >

In comparison, amongst those identifying unmet needs for talking-related interventions, some participants described specifically wanting professional assistance beyond the informal supports available to them. This was partly a matter of professional expertise, but also due to experiencing a lack of understanding within the wider community, as also illustrated in Table 5. Some participants also identified unmet needs for a self help/peer support group, with whom to talk about and share experiences with others "like me", who know what they have been through.

Perceived barriers to needs for talking-related therapies being met

Inadequately addressed needs for talking-related therapies were described in two ways: either service provision was too narrowly focused and did not address the issues for which help was needed (e.g. medication

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issues were addressed, but counselling opportunities were too illness-focused); or service providers were perceived as lacking interest or sufficient expertise to provide counselling. Furthermore, those with prior experience of counselling seemed to have the clearest ideas about the type of talking-related therapies that they needed, whereas others expressed uncertainty about whether their needs might be attributable to “normal living stresses” or “everyday life problems” and described lacking knowledge about where to go for help or their options being limited by financial constraints. Additionally, some participants also described being afraid to ask for a different kind of help for fear of implying criticism of their present service providers, for fear of losing current services, or because they perceived their families would disapprove (see Table 5). Hence, a range of attitudinal, information and cost-related barriers to meeting needs for talking-related therapies were identified.

Perceived need for social intervention (practical help)

Needs for practical help were more frequently identified by participants from AMHS than general practice attendees (see Table 2), and typically concerned financial, housing, or care-giving related issues. These needs were seen as fluctuating, being greater when unwell, and predominantly met with family assistance. Thus, perceived needs for practical help with financial planning to manage on limited incomes, debt management and home maintenance costs were seen as related to difficulties managing one’s affairs when unwell, or the ongoing worry of living on limited disability-related allowances. Participants also generally described preferring either to “*tough it out*” [Alan] or seek family assistance, and did not necessarily consider financial issues a mental health-related need, as shown in Table 6.

< Table 6 about here >

Participants’ identified needs for practical help with housing issues and taking care of their homes also varied. They related to improving one’s housing conditions, protecting one’s home during acute episodes of illness, and moving to alternative accommodation, but also to practically taking care of one’s home in the contexts of parenting or care-giving, ageing, physical ill-health, and fluctuating mental health. Family, church communities and social workers were identified as addressing these needs, while from participants’ viewpoints receiving help with shopping and household chores from visiting family or church communities did not necessarily equate with a perceived need for assistance.

Perceived barriers to needs for practical help being met

Several barriers to getting adequate help with financial planning and debt management were noted, including difficulties articulating needs when unwell and finding appropriate services because of “*not really knowing exactly how to get the service she requires*” [Angela]. Other unmet needs for practical help were closely linked to financial difficulties. Furthermore, family seemingly intervened when services failed to provide practical help, but embarrassment about asking for practical help from services was also raised (see Table 6

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for illustrations). In keeping with this, some participants noted preferring to seek practical assistance to develop skills, so as to manage for themselves.

Perceived need for skills training and development

All AMHS participants identified needs for assistance with skills to participate in activities of home life, work, and leisure (see Table 2). Overall, when assisted with these needs, participants typically described the involvement of professionals or services with specific foci on these issues (occupational therapists, psychologists and programs offering employment support, social and recreational activities). More commonly these needs were described as unmet, or at best partially met.

Participants who reported being unemployed and lacking any kind of occupation outside the home, described spending time sleeping, becoming bored and preoccupied with worries: *“you can feel very destructive just sitting around at home”* [Angela]; and feeling *“very apart from the world and from other people”* [Maureen]. Conversely, using time productively and keeping active were seen as important in facilitating one’s own recovery. Hence, as illustrated in Table 7, these participants identified unmet needs for assistance with time use, leisure pursuits, and *“getting out of the house”* [Angela] to counter inactivity and isolation. In comparison, for participants identifying needs for employment-related assistance, some needs were at least partially met by computer access, job-seeking assistance or contact with other unemployed job seekers, whereas needs for interview skills, specific job training and ongoing job-related support were unmet.

< Table 6 about here >

Perceived barriers to skills-related needs being met

Identified barriers to meeting of skills-related needs varied, but reflected inadequate information provision by services about sources of help, as well as attitudinal, financial and symptom-related barriers to help-seeking. Examples were wide-ranging, as illustrated in Table 7, including: not knowing that services might provide assistance or where to access help; thinking that professionals do not recognise or know how to respond to these types of needs; believing that one should be able to cope or get one’s own act together; and not knowing how to pursue finding activities and company in the face of obstacles like financial costs and discrimination.

DISCUSSION

Several tools are available to assess mental health care needs but, to our knowledge, this is the first qualitative exploration of the meanings of perceived needs for mental health care as characterised when one such tool, the PNCQ, is completed. Participants from both primary care and community mental health service settings reported perceived needs for mental health care, unsurprisingly as participants self-selected into the study. However, one quarter of Australian adults with mental disorders in a 12 month period are estimated to consult general practitioners for mental health care, often as the only provider consulted (Burgess et al. 2009). Participants’ perceived needs for medication and information were seemingly closely interconnected with

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each other, and with how they viewed the quality of communication and relationships with health professionals. Likewise, participants from both settings articulated perceived needs to talk through their situations, learn ways of coping, and emphasized valuing formal and informal support for this purpose. As might be expected, AMHS participants identified the greater range of needs, but some primary care participants also identified mental health-related needs for social interventions and skills development that may be less readily addressed in this setting. By also qualitatively exploring barriers to accessing help when needs are perceived as not fully met, this study highlights that people view and understand their various needs for care distinctly, and that they identify differing barriers related to specific categories of perceived need. This demonstrates the usefulness of needs assessment tools attending to specific perceived needs for care, together with the barriers to these needs being met.

Perceived needs for medication and information are interconnected

Participants typically described receiving prescribed medication as needed. While suggesting medication was accessible as also indicated by NSMHWB findings that medication needs are the most likely to be met (Meadows et al., 2000; Meadows & Burgess, 2009), participants in this study were neither necessarily satisfied with taking medication nor with its effectiveness. In relation to medication, it appears rating need as 'met' may co-exist with dissatisfaction, indicating that perceived needs for medication are complex and ambiguous. This finding seems to support the observation that "using medication is an active process that involves complex-decision-making and a chance to work through decisional conflicts" (Deegan & Drake, 2006, p.1638), in which the subjective experience and meaning of medication-taking, as well as the doctor-patient relationship, play parts (Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009). Indeed, inadequate information and insufficient communication about medication options were identified by participants as barriers to addressing medication needs and as important areas of unmet need.

It seems likely that if medication and information needs are both met, then consumers may be more satisfied with their medication-related treatment. This concurs with qualitative research by Happell and colleagues (2004), in which consumers reported dissatisfaction with information provision about medications and their lack of opportunities to participate in medication-related decision-making, but also suggested that being well-informed about medications meant being better prepared for the experience of taking medication. Further, participants in the current study also reported not feeling able to share their medication concerns with doctors and insufficient discussion of alternative treatments, in keeping with previous reports of consumers struggling to have their medication-related concerns taken seriously (Happell et al., 2004; Roe et al., 2009). Taken together, these findings support taking actions to foster better information-sharing and shared decision-making in treatment planning (Deegan & Drake, 2006; Roe et al., 2009; Schauer, Everett, del Vecchio, & Anderson, 2007; Torrey & Drake, 2010). This could be achieved by the implementation of recommendations regarding self-management of disease (e.g., Institute of Medicine, 2006) that emphasize the need to support

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patients in becoming “well informed about their disease, how it affects them, what the treatments are, etc., and who is actively involved in its management” (Tyreman, 2005, p.150).

Perceived needs for information in the current study were also commonly related to illness (diagnosis, explanation of nature of illness, specific episodes, progress), treatment options and access to services, and often unmet. This is consistent with Australian and US studies finding that consumers want and actively seek to know about their illnesses and treatment options (Happell et al., 2004; Tanenbaum, 2008), as well as with an earlier UK survey of consumers receiving rehabilitation services reporting low patient satisfaction with knowledge of illness and treatment (Macpherson et al., 1998). Further, needs for information about physical health, lifestyle issues, and community resources (e.g., for social contact, leisure pursuits) were expressed by fewer participants, but they are important since consumers’ physical health and associated lifestyle issues are known to be poorly addressed by mental health services (Bick, Knoesen, & Castle, 2007) and needs for information about community resources may be overlooked in primary care (O’Day, Killeen, Sutton, & Iezzoni, 2005). Thus, consumers may identify needs for varying types or amounts of information but, unless their views are actively sought, routine information provision is unlikely to meet their needs. Such active exploration of consumers’ views would also help to identify those for whom information may be anxiety-provoking or not desired.

Reported barriers to information provision in the current study suggest opportunities for ongoing communication with mental health and primary care professionals are needed to more effectively address consumers’ information needs. Some participants, like US consumers in Tanenbaum’s (2008) study, were resourceful in consulting alternative sources of information such as books, libraries or self help groups, but these sources were not viewed as substituting for discussions with health professionals in either study. This further emphasizes that collaborative approaches are necessary to better meet medically-focused information needs and enhance illness-related understanding. Yet, professionals may continue to underestimate the need for ongoing dialogue and information-sharing with consumers, so that greater use of shared decision-making aids to support consumers to weigh up information and preferences may be useful in the promotion of ongoing information-sharing (Adams & Drake, 2006).

Access to psychological interventions is constrained

Access to psychological interventions in Australia may have improved with the introduction of publically-funded psychological services, although financial barriers to meeting these needs are likely to still exist where practitioners charge co-payments (Meadows & Burgess, 2009). Thus, participants’ expressed unmet needs for talking-related therapies reflect the relative unavailability of psychological interventions in mental health services previously reported (Killackey et al., 2008). Further, these perceived needs highlight a desire for alternatives to medication and for assistance to develop self-management strategies for improved coping with emotional, relationship and stress-related difficulties.

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Other identified barriers included the perceived narrow focus of their service providers and difficulties asking for help. If, as suggested elsewhere (Herrman & Harvey, 2005; Shera, Aviram, Healy, & Ramon, 2002), illness management has tended to take precedence in community mental health services over psychosocial interventions, this may inhibit discussion with consumers about psychological interventions, as well as limiting service provision. Our findings also indicate that opportunities for sharing experiences with others in similar situations are important to some consumers, yet peer support and counselling were not seen as substituting for each other. Thus, by making psychological interventions and peer support available to consumers, services could provide more choice in meeting these needs.

Perceived needs for social interventions and skills development are diverse

These types of perceived needs were proportionally the least likely to be met in the Australian general adult population (Meadows et al., 2000; Meadows & Burgess, 2009). In this study, these needs were commonly expressed by AMHS than primary care participants; they also each encompassed more diverse areas of need than the other PNCQ domains. Identified needs for social interventions included practical help with finances, housing, domestic chores, parenting and care-giving and skills development needs related to employment, social and home life, while provision of assistance and barriers to accessing help varied among these areas of need. This finding supports greater differentiation of the need categories within these two PNCQ domains, as implemented in the 2007 NSMHWB (Meadows & Burgess, 2009).

Furthermore, participants described their needs for social interventions as fluctuating with course of illness and other life circumstances and typically met by family, in keeping with their preferences for relying on self or family. Together with the embarrassment or reluctance to ask for help expressed by some participants, this finding suggests the potential for over-burdening relatives. Ongoing collaborative review of needs for practical help that is inclusive of the perspectives of consumers and their immediate supporters may help to ensure these needs are not overlooked (Cleary et al., 2006; Drapalski et al., 2008; Fleury et al., 2008).

In comparison, perceived skills-related needs were connected with experiences of loneliness, isolation, unemployment, and lack of meaningful occupation and frequently unmet. In an Australian study using the CANSAS, Cleary et al. (2006) also found a high percentage of consumers reporting unmet needs for company, daytime activities, and intimate relationships. These findings are consistent with limited availability of psychosocial interventions (Jablensky et al., 2000; Killackey et al., 2008), but also the difficulties that restricted access to social and material resources place on participation (Harvey, Fossey, Jackson, & Shimitras, 2006; Thornicroft, 2006). Participants' reported lack of knowledge about where to access help themselves and perception that professionals are also not knowledgeable about how to assist with these needs appear to compound these difficulties. Improvement in the quality and availability of practical information about community resources is therefore recommended, as well as for carer and consumer support groups to foster sharing of such information (Cleary et al., 2006; O'Day et al., 2005). It also seems likely that better coordination of mental health care with primary care services, housing, education and employment

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agencies, as well as a greater focus on addressing issues of participation and social inclusion will be necessary to meet more effectively these needs (Harvey, Jeffreys, McNaught, Blizzard, & King, 2007).

Limitations of the study

Qualitative content analysis may be approached in several ways, the directed approach being most appropriate where an a priori framework, like the PNCQ-defined perceived need categories, is used to extend or refine knowledge (Hsieh & Shannon, 2005). This means the data was also approached with an evident bias (Hsieh & Shannon, 2005), which may have limited identification of the range of contextual features that influence perceived mental health needs and barriers to care. Written note-taking allowed the interviewers to review notes with participants during interviews to ensure their accuracy, and both these notes and the interviewers' recorded summaries were analysed to enhance understanding of the data. Nevertheless, some meanings may have been lost or obscured through handling the data in this manner. While neither audio-recording and transcription of interviews nor re-contacting participants after data analysis were practically possible in this study, it is acknowledged that these procedures respectively allow for closer representation of participants' views in their words and checking the authenticity of the findings, so as to enhance the rigour of qualitative research (Fossey, Harvey, McDermott, & Davidson, 2002).

CONCLUSION

This qualitative study contributes to understanding the meanings of perceived needs for mental health care, as characterised when using the PNCQ. It highlights the importance to this understanding of not only differentiating domains of need and the extent to which these are met, but also simultaneously unpacking the connections between perceived needs and service barriers. Further, the findings indicate that fostering collaborative therapeutic relationships, taking actions to identify and respond to consumers' information needs and shared decision-making could improve the extent to which consumers' perceived needs are addressed. The PNCQ may be helpful for screening such needs in primary care and mental health settings, but further differentiation of perceived needs for social interventions and skills development may be especially important to strengthen its usefulness in mental health services.

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Conflict of interest

The authors declare that there are no known conflicts of interest.

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Table 1. Demographic variables and self-identified mental health problems (n = 51)

Gender	
Male	20
Female	31
Age group	
20s	10
30s	13
40s	9
50s	9
60s	6
over 70	4
Family of origin *	
Australian	33
European	17
Living situation	
with family	34
with friends	6
with other tenants	1
alone	10
Self-described diagnosis *	
No mental health problem	19
schizophrenia	12
depression	7
bipolar affective disorder	6
anxiety	3
obsessive compulsive disorder	1
progressive health condition	2

**n=1 missing data*

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Table 2. Specific types of need for mental health care identified within each subgroup

	General practice attendees (n=28)		AMHS clients (n=23)
Any perceived need	Current need	Previous need	Current need
	14	7	23
Specific types of needs			
Medication	9		23
Information	12	1	19
Counselling	12	6	20
Social interventions:	1		
<i>Financial</i>	-		7
<i>Housing</i>	2		4
<i>Home assistance</i>	5		7
<i>Caregiving</i>	5		2
Skills training:			
<i>Work skills</i>	5		8
<i>Domestic skills</i>	-		4
<i>Leisure time use</i>	2		15
<i>Social contact / friendships</i>	3		15

Table 3. Perceived need for medication and barriers to these needs being met: illustrative excerpts from interview summaries

Perceived need for medication – ambiguity and complexity	<p><i>Faye says she feels that she needs medication. She is frustrated however that her medication doesn't seem to stop her from feeling depressed. Faye identifies a need to talk to professionals about how she's doing and how she's feeling. She is particularly interested in talking about alternatives to the medication she has received so far.</i></p> <p><i>Beth says that she accepts now that she needs medication... however she feels that she is on too much medication... she is not wholly happy with her medication regime but feels unable to discuss this with the doctor. She feels that she is taking too many medications and would like them to be reduced. She says one of the reasons she is unhappy about her injections is because the GP is very rough with her [whereas] the nurse at [clinic] had more expertise when it came down to giving the medication without causing bruising or pain.</i></p>
Perceived barriers to medication needs being met – information and communication	<p><i>Gill says that she feels her needs haven't been met as far as her medication is concerned because she hasn't been forceful enough in asking for a change of medication or for her medication to be reviewed.</i></p> <p><i>Gill says another barrier is that her doctor has not been clear about other alternatives that might be available to her... [and] she has felt anxious about what the doctors would think of her if she asked too many questions of them.</i></p>

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Table 4. Perceived needs for information and barriers to these needs being met: illustrative excerpts from interview summaries

<p>Perceived need for information – diverse types and access through varied sources</p>	<p><i>Ian says he has often gone to look up information in medical journals at the library and elsewhere as a way of trying to find some answers to his questions. And, in addition to reading material, he noted, you can pick up a lot of answers to questions through sharing information with other patients.</i></p> <p><i>Frank says he keeps a diary and likes to monitor any unusual thoughts or feelings he may have and he's become quite vigilant about whether he's getting some early warning signs that things are going wrong. Frank says he picked up the idea of keeping an early warning signs chart from attending [bipolar support group]... he believes [this] group organised by [clinic] has done a good job to provide him with education about [diagnosis].</i></p> <p><i>Angela says she needs a lot more information from professionals... information about medication and about side effects as well as clarification about her diagnosis. She says she needs information to help her accept that she has [diagnosis] ... that she understands from the doctors that she has a chemical imbalance and may have [diagnosis] for the rest of her life. She says she also needs to know from doctors that she's not a garbage tip, or a doormat, and that [diagnosis] is not her fault.</i></p>
<p>Perceived barriers to information needs being met – obtaining, understanding and remembering information</p>	<p><i>George says that he has received an inadequate response from professionals, even though he has asked them for more information... As a result, he has gone to the library, bought books and sought out information for himself. He reflects that the main barrier may be that professionals simply may not have the answers, and therefore it is hard to expect them to give him more information.</i></p> <p><i>I wonder if the doctors have something to hide and don't want me to get anxious. Maybe the doctors want to avoid being technical and keep things simple, but then it feels like they are keeping things from me. [Barry]</i></p> <p><i>Beth says she has received inadequate information from her GP over the past twelve months about her tablets, why she's taking them and also about her diagnosis. Beth at the same time acknowledges that she doesn't like to ask the doctor any questions... She worries about what professionals would think if she asks questions... [and] is too frightened to share her symptoms with her doctor or ask him for advice and information.</i></p> <p><i>Beth was unclear if in the past she has been told something about her diagnosis and given information about her medications... She says she easily forgets things and has poor concentration.</i></p> <p><i>Medication puts the buffer on things and medication initially is like putting a curtain over your forehead. So he wonders whether sometimes it's the medication that actually gets in the way of articulating your needs for information [Ian].</i></p>

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Table 5. Perceived needs for talking-related therapies and barriers to these needs being met: illustrative excerpts from interview summaries

<p>Perceived need for talking-related therapies – listening, reassurance and support from professionals and others</p>	<p><i>Rita explains it's a sounding board so things are not all inside you and also you can ask if it's OK that I am stressed, am I over-reacting to something? They can give you reassurance. I like to find it's OK to feel bad about things, it's a sort of reality check that what one is feeling is normal.</i></p> <p><i>Sarah says it's mainly the need just to talk to somebody... Sarah feels that talking to someone helps her with decision-making and provides support. Sarah says she has found her case manager the most helpful of all the professionals involved over the years in her care... It's the counselling that has really kept her going.</i></p> <p><i>Tom says that he hasn't received the therapy that he would have liked... he needs to talk to someone as he worries a lot about his [diagnosis] and he worries a lot about little things. He tends to make a mountain out of a mole hill... [and] if he has something to say, he can tell them (i.e. professionals)... he can't tell a neighbour.</i></p> <p><i>Alex says he would like a professional to listen because he feels that professional would understand what he has been through over the years. He has felt very rejected and very distressed by comments that others have made in the community about him when he has tried to talk to them about his troubles.</i></p> <p><i>Faye says she would like to have a link into a support group... she believes if she could talk to others who know what she has been through that this would give her added support.</i></p>
<p>Perceived barriers to needs for talking-related therapies being met – service focus, professional expertise, and consumer knowledge, fears and costs</p>	<p><i>George says he doesn't wish to be critical of individuals as he feels they have been very patient... he doesn't like to ask for [cognitive-behavioural] therapy specifically as he is afraid this may be seen as criticism.</i></p> <p><i>Beth says she would like to link in with a support group or at least have the opportunity to meet others who have a problem similar to her own... [but] she thinks her husband and her parents-in-law would be against her having contact with others, who have similar mental health problems, in case this makes her worse rather than better.</i></p> <p><i>Adrian says he doesn't know much about different kinds of therapy and can't really describe it. He just wants someone to talk to... he just wants someone to offer ideas as to how to tackle his problems and wants a listener.</i></p> <p><i>Louise says she likes to see herself as being a coper and that asking a professional for assistance in any area feels like a failing to her. Louise also comments that people don't want to go to a psychiatrist and because of the labelling effect might prefer to see a therapist or a social worker or another health professional... [but] a disadvantage of approaching other health professionals is the cost... so she believed that the main barrieris financial considerations.</i></p>

Table 6. Perceived needs for social intervention (practical help) and barriers to these needs being met: illustrative excerpts from interview summaries

<p>Perceived need for social intervention (practical help) – fluctuating and mostly met by family</p>	<p><i>Dan says that sometimes he gets into debt, but he doesn't really feel he needs to look towards professionals to help him with these problems. Usually he borrows money from his family, then pays them back and tries to sort out these problems on his own.</i></p> <p><i>Dan says his sister helps to clean up the flat from time to time.... he was waiting for his sister to come over and help him with the cleaning and to sort out his chaos [and] as his sister and family help, on the whole he prefers it that way.</i></p> <p><i>Sarah says when she is depressed... she needs a break from the children and needs foster care services or other agencies to come in and assist her with parenting and looking after the children.</i></p>
<p>Perceived barriers to needs for social intervention (practical help) being met – costs, embarrassment, trying to manage for oneself</p>	<p><i>Alan's needs were not fully met in addressing housing problems... his house is damp and he lives in squalor and poverty much of the time. Currently, his washing machine has broken down and he has no resources to repair it... he would have liked more help with relocation [last year]... costs of moving, house setting-up, repairs... Family in the end plugged this gap and helped him out.</i></p> <p><i>Alan feels embarrassed to ask for help [and] lack of contact with his case manager in his home makes it more difficult. Alan also feels he should show more independence this way but says when he's ill, it is impossible to do so.</i></p>

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Table 7. Perceived needs for skills development and barriers to these needs being met: illustrative excerpts from interview summaries

<p>Perceived need for skills development – productive use of time, especially outside the home, and access to jobs</p>	<p><i>Karen says that she feels that she has done a lot for herself over the years to assist her recovery. She says that she has managed to help others as a volunteer, as well as help herself through keeping active and having a number of interests over the years... [and] this has made a big difference to her need for professional help.</i></p> <p><i>Beth says she needs some assistance with her leisure time... she doesn't have much leisure... She feels a need to get out of the house and to find something else in her life. She says that she tries to go walking and tries to think of ways to keep active other than doing housework...or keeping herself busy cooking at home.</i></p> <p><i>Dan says he needs some assistance with helping him to think about ways he could use his time or his leisure time more productively. He often finds he stays in bed all day and is aware that he needs more variety of activities and help here.</i></p> <p><i>Dan mentions that he requires interview skills and that these need to be improved...he doesn't say enough at interviews.</i></p> <p><i>Dan also says he received some indirect assistance through [an employment support agency] helping linking him into [a work skills program], which focuses on job-related issues.</i></p> <p><i>Adrian feels frustrated at times [that] he can't hold down a job, or obtain a job. He feels he needs assistance with interview skills, self confidence ... [and ongoing] support from [an employment support agency] to maintain morale so that he can continue to look for work.</i></p>
<p>Perceived barriers to needs for skills development being met – knowing who to ask, not knowing of appropriate, affordable and timely help</p>	<p><i>Faye feels that her leisure needs have not been met because she has never really raised this issue with professionals because she just hasn't thought about it... [and] she wasn't clear that she could ask professionals about this kind of assistance.</i></p> <p><i>Alan says the service tried to help him (e.g. build in routine and structure to his life) when he is unwell, and he was not receptive to that help...[but] if he is well, then he's seen to be "too well" to need help... and financial constraints got in the way of him making the most of courses and opportunities offered to him.</i></p> <p><i>Angela feels that the professionals have done as much as they can with encouraging her to take on board new leisure activities... she sees the rest as down to her... to get her act together.</i></p> <p><i>Alex has had a little bit of help with [meeting people] in the past but this has never really been very adequate or successful. So he has come to the conclusion that professionals do not really know where there are suitable places, or don't know how to link individuals into these services.... He himself has lacked knowledge as to where to go for further assistance, and is coming to the conclusion that it is down to him to seek out company and to join clubs but doesn't quite know how to go about it... [as] he feels he has been quite rejected over the years by people and this has knocked his confidence.</i></p>