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Patient and carer perceptions of need and associations with care-giving burden in an integrated adult mental health service

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■ **Abstract** *Objective* To identify patients' and carers' perceptions of need in inpatient and community settings and investigate the relationship between need and caregiver burden. *Method* The study was conducted across a metropolitan mental health service in Sydney, Australia. Patients ($n = 407$) and carers ($n = 50$) completed the Camberwell Assessment of Need Short Appraisal Schedule. Carers also completed a shortened version of the Involvement Evaluation Questionnaire to assess caregiver burden. *Results* When completing the assessment tools, patients and carers in hospital settings were asked to consider the 4 weeks preceding hospitalisation; in the community, patients and carers were asked to consider the previous 4 weeks. These data show a high percentage of patients in hospital and community settings have unmet needs for company, daytime activities and intimate relationships. Inpatients had more unmet needs than community based patients. Agreement between patients' and carers ratings' of need ranged from 'poor' to 'moderate'. There

was a strong relationship between unmet need and burden from the carer's perspective. Patients with and without carers had similar numbers of needs. Carers of patients recently admitted to hospital reported a significantly higher burden. *Conclusions* Carers of inpatients experienced significantly more burden than carers of outpatients. Opportunities to access support, information and education should be readily available and not contingent upon demonstrating a close familial relationship to the patient. We found that unmet need was significantly related to burden, suggesting that meeting patient needs could reduce carer burden.

■ **Key words** burden – carer – mental health services – needs assessment – integrated care

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Introduction

The increasing emphasis on community mental health care and treatment over the past 30 years has resulted in patient's family and friends becoming increasingly responsible for providing support [1, 2]. However, sometimes hospitalisation is still necessary either to protect the safety of the individual and the community or review existing treatment plans. Although many consumers and health professionals recognise when a hospital admission might be necessary, to date there has been no clear articulation of the level and types of need that differentiate patients managed in the community from those requiring an admission. More information about this area would enable inpatient services to be better targeted and may open the way for empirical evaluation of their efficacy.

A 'needs-led' approach to planning is recommended as multiple perspectives can be taken into account, helping to ensure that the supply of services will be more closely aligned with what is needed [3, 4]. Whilst a number of previous studies have compared patient and staff perceptions of needs using the

Camberwell Assessment of Need [5–9] instrument, to our knowledge only one recent study has compared perception of needs between mental health consumers and their carers [10]. Previous research suggests community based patients rate fewer needs than their carers [11] or emphasise different needs [3, 10, 12]. Given the greater involvement many carers now have in consumers' care, improving understanding of these differences in both hospital and community settings has important implications for service planning.

The emotional, psychological and financial consequences of caring upon family and friends are mediated by the actual demands of caring, coping skills and the support available [13]. Thus, carers might experience fewer burdens when their friend or relative is in hospital as he or she is receiving an intensive level of support, reducing the practical demands placed upon them. An understanding of how contextual characteristics are associated with carer burden is important, not only so that support can be provided to enhance carers' well-being [14] but also because carer burden can impact on the patient's illness and functioning [2, 15]. It is also important to explore whether carers' perceptions of the patient's needs are related to carer burden as this would provide a clinical incentive for services to provide more information to carers and invest in collaborative treatment planning. Despite the importance of understanding patient and carer perceptions, there has been negligible research in community and hospital settings assessing needs and burden from both perspectives.

The aims of the study were to compare levels of met and unmet need between inpatient and community patients, to compare perceptions of need between patients and carers, to compare levels of care-giving burden among current inpatients and community patients, and to compare the associations between levels of need and carer burden.

Method

The Health Service comprises inpatient and community public mental health facilities within a culturally diverse inner-city area and has a catchment population of approximately 500,000 people. In order to obtain a representative sample of patients, (a) all patients being discharged from acute inpatient services over a three-month period (Feb–April 2004) were assessed for eligibility, and; (b) each of the six community mental health centres in the Area were visited at least eight times over a two month period (April–May 2004); all patients visiting the centres on those days were assessed for eligibility.

Exclusion criteria applicable to both inpatient and community settings were: patients aged ≤ 17 years or ≥ 65 years, non-English speaking patients, and patients with early dementia, cognitive deficit, eating disorder or primary substance abuse. Specific exclusion criteria for inpatient settings were a stay of less than 5 days or more than 6 months and patients living out of area or with no fixed abode. Exclusion criteria specific to community settings were their initial appointment at the community centre or admission to inpatient services during the inpatient data collection period. This ensured that the patients were not interviewed more than once.

All patient interviews were conducted face-to-face by the same researchers. Similar surveys were used in both inpatient and community settings with some slight adjustments to account for contextual differences. Additional questions about information needs and satisfaction with health care services were asked and reported separately [16]. At the conclusion of the interview, patients were asked to nominate a carer i.e., a parent, partner, relative or friend who, in their opinion, had provided support to them during the previous three months. If the carer was able to read, write and understand English, the patient was asked about their relationship to this person, their living arrangements and whether a questionnaire could be sent to them. With their consent, patients were asked to address an envelope and stamps were provided for the survey's return. The carer surveys were matched by number so that responses could be compared whilst protecting the respondent's identity.

When completing the assessment tools, patients and carers in hospital settings were asked to consider the 4 weeks preceding hospitalisation; in the community, patients and carers were asked to consider the previous 4 weeks.

■ Camberwell Assessment of Need Short Appraisal Schedule (CANSAS)

All patients and carers who participated in the study completed the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS). This tool was chosen because of its good psychometric properties with demonstrated reliability and validity [5], its increasing use in Australia [4, 7, 17], and its sensitivity to the subjective nature of need. The assessment can be completed by patients, service providers or carers, with no perception deemed more valid than another [18]. Indeed, Slade et al. [8] assert that patient ratings of need may be more reliable than those provided by staff, with the general consensus being that, where possible, multiple perspectives should be assessed.

The CANSAS was developed to assess need in 22 areas: accommodation, food, self-care, looking after the home, daytime activities, physical health, psychotic symptoms, information about condition and treatment, psychological distress, safety to self and others, alcohol and illicit drug use, company, intimate relationships, sexual expression, child care, access to a telephone, education, transport, budgeting and benefits. In this study, the item 'sexual expression' was excluded because it was deemed too personal in nature for carers to assess. For each of the 21 areas, the rater assessed whether or not there was a need and, if there was, whether or not it was being met (0 = 'no need', 1 = 'no/moderate problem because of continuing intervention, met need' and 2 = 'current serious problem', unmet need). For the purpose of analysis, ratings of "0" and "9" (not known) were combined according to Slade et al. [6].

■ Involvement Evaluation Questionnaire (IEQ)

All carers were sent a shortened version of the Involvement Evaluation Questionnaire (IEQ), which is easy to complete and based upon a variety of previous measures covering a range of caregiving consequences [19, 20]. The IEQ contains 27 core items that can be divided into four subscales: tension (nine items), supervision (six items), worrying (six items) and urging (eight items) [two items appear in more than one sub-scale]. For brevity in the present study, we did not include two items from the tension subscale and one item from the urging subscale. The items were scored on a 0–4 point Likert scale (never, sometimes, regularly, often and always) and a 24-item sumscore was computed.

■ Statistical analysis

Descriptive data are presented as response rates, percentages and means. Comparisons were made between hospital and community patients and patient and carer ratings of need. Categorical variables were analysed using the Pearson chi-square test for independence

Table 1 Met and unmet needs amongst inpatient and community based patients

CAN Item	Met needs		Unmet needs	
	Inpatient, <i>n</i> (%)	Community, <i>n</i> (%)	Inpatient, <i>n</i> (%)	Community, <i>n</i> (%)
1. Accommodation*	22 (11)	25 (13)	26 (13)	5 (3)
2. Food*	55 (27)	60 (30)	30 (15)	6 (3)
3. Looking after the home	54 (26)	53 (27)	27 (13)	12 (6)
4. Self-care	39 (19)	51 (26)	12 (6)	5 (3)
5. Daytime activities	9 (4)	29 (15)	70 (34)	53 (27)
6. Physical health	44 (21)	46 (23)	34 (16)	24 (12)
7. Psychotic symptoms*	60 (29)	133 (67)	78 (38)	22 (11)
8. Info on condition and treatment	11 (5)	3 (2)	34 (16)	32 (16)
9. Psychological distress***	29 (14)	79 (40)	113 (55)	32 (16)
10. Self-harm**	11 (5)	26 (13)	78 (38)	11 (6)
11. Safety to others**	15 (7)	7 (4)	43 (21)	14 (7)
12. Alcohol*	2 (1)	3 (2)	35 (17)	9 (5)
13. Illicit drugs*	4 (2)	4 (2)	28 (14)	8 (4)
14. Company	5 (2)	30 (15)	94 (45)	81 (41)
15. Intimate relationships	13 (6)	5 (3)	85 (41)	85 (43)
16. Child-care	24 (12)	15 (8)	1 (0.5)	1 (0.5)
17. Basic education	20 (10)	29 (15)	8 (4)	6 (3)
18. Telephone access	8 (4)	7 (4)	23 (11)	11 (6)
19. Transport	99 (48)	136 (68)	12 (6)	5 (3)
20. Money	44 (21)	42 (21)	43 (21)	39 (20)
21. Benefits	42 (20)	47 (24)	16 (8)	7 (4)
22. Sexual expression – not asked				

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$, Chi-square test

and group differences for continuous variables were analysed using one-way analysis of variance (ANOVA). The Kappa co-efficient was used to examine the level of agreement between patient and carer ratings of need and the relationship between need and IEQ subscales was explored using Pearson Product moment correlations corrected for family-wise errors using Bonferroni's method.

Results

A total of 407 hospital ($n = 207$) and community based ($n = 200$) patients were interviewed. Across inpatient and community settings, 67% ($n = 274$) of patients identified a carer; 65% ($n = 177$) of these were sent a survey and the response rate was 28% ($n = 50$). This area-wide sample can be considered representative of all patients receiving care from our mental health service. The consumer demographics for both inpatient and community settings were similar. The mean (SD) age for inpatients was 38.5 (11.8) years and the mean age for community patients was 40.5 (11.2) years. Sixty-four percent were male with the mean age being 39.5 years. Almost three-quarters (71%) were born in Australia and the majority (69%) had never been married. With regard to accommodation, approximately the same number of consumers lived in the family home (27%), privately rented or owned their home (34%), or resided in other types of accommodation, including Department of Housing (39%). Thirty-five percent had been admitted to hospital more than five times, 45% 1–5 times, and 20% had no previous admissions. There were no significant differences in age or other demographics between inpatients and community

patients with the exception of the number of previous admissions.

Demographics of inpatient ($n = 26$) and community ($n = 24$) based carer respondents were very similar except for gender. Twenty-six percent were male with a mean age of 50 years. The mean (SD) age of inpatient carers was 47 (14.0) years and the mean age for community carers was 54 (13.3) years. With regard to the relationship of the carer to the patient, half the carers were a parent, 32% were a spouse, partner or other relative (sibling, aunt, uncle, grandparent) and 16% were a girlfriend, boyfriend or friend. Forty-two percent of patients indicated that they lived with their carer. Nearly half (42%) were born overseas and the majority (44%) were married or living as married. With regard to employment status, 62% were not working and over half (56%) had been providing care for more than 5 years. All carers had been in contact with their relative or friend by telephone or face-to-face during the last 4 weeks. Of the 50 carer respondents, 44% indicated that they had no social life or a significantly reduced one as a consequence of caring, 30% did not take vacations and 22% were working less or had quit their job.

■ CANSAS

The mean (SD) number of needs identified by patients was 6.84 (3.32) with 3.52 (2.45) met and 3.32 (2.92) unmet. The prevalence and severity of needs for inpatient and community patients are shown in Table 1. The number of met needs identified by inpatients was 2.39 (2.38; $F = 25.51$, $df 1, 405$, $P = 0.001$)

Table 2 Met and unmet need for the 50 matched pairs of patients and carers

CAN item	Patient ratings (n = 50)		Carer ratings (n = 50)		Kappa
	Met need n (%)	Unmet n (%)	Met need n (%)	Unmet n (%)	
1. Accommodation	2 (4)	4 (8)	4 (8)	3 (6)	0.32**
2. Food	14 (28)	8 (16)	10 (20)	8 (16)	0.29**
3. Looking after home	13 (26)	7 (14)	11 (22)	5 (10)	0.31**
4. Self-care	13 (26)	2 (4)	6 (12)	6 (12)	0.26*
5. Daytime activities	1 (2)	17 (34)	3 (6)	22 (44)	0.24*
6. Physical health	9 (18)	6 (12)	8 (16)	9 (18)	0.34**
7. Psychotic symptoms	23 (46)	14 (28)	21 (42)	14 (28)	0.23*
8. Info on treatment	1 (2)	10 (20)	11 (22)	3 (6)	-0.04
9. Psych. distress	13 (26)	21 (42)	17 (34)	19 (38)	0.40***
10. Self-harm	6 (12)	15 (30)	9 (18)	22 (44)	0.39***
11. Safety to others	1 (2)	7 (14)	6 (12)	8 (16)	0.08
12. Alcohol	1 (2)	8 (16)	5 (10)	3 (6)	0.27**
13. Illicit drugs	2 (4)	9 (18)	3 (6)	11 (22)	0.45***
14. Company	2 (4)	21 (42)	5 (10)	28 (56)	0.27*
15. Int. relationships	3 (6)	16 (32)	4 (8)	25 (50)	0.41***
16. Child-care	10 (20)	0 (0)	6 (12)	1 (2)	†
17. Basic education	9 (18)	2 (4)	3 (6)	3 (6)	0.20*
18. Telephone access	3 (6)	2 (4)	2 (4)	3 (6)	0.35**
19. Transport	24 (48)	13 (26)	10 (20)	4 (8)	0.23*
20. Money	9 (18)	11 (22)	11 (22)	17 (34)	0.39***
21. Benefits	10 (20)	2 (4)	5 (10)	10 (20)	0.09
22. Sexual expression – not asked					
Total number of needs (SD)	3.36 (2.24)	3.68 (3.13)	3.16 (2.59)	4.48 (3.55)	

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$

†Kappa co-efficient could not be calculated

and the mean (SD) number of met needs identified by community patients was 4.13 (2.38). The mean (SD) number of unmet needs identified by inpatients was 4.28 (3.12) and the mean number of unmet needs identified by community based patients was 2.34 (2.32; $F = 50.70$, $df 1, 405$, $P = 0.001$). The areas in which these differences were statistically significant were: accommodation, food, psychotic symptoms, psychological distress, self-harm, safety to others, drug and alcohol use.

■ Patients with and without carers

There were no significant differences in the number of patient-rated met or unmet needs between patients with or without carers in either setting. The mean number of needs identified by patients with a carer was 6.91, with 3.48 met and 3.43 unmet. For patients with no carer, the mean number of needs was 6.70, 3.59 met needs and 3.11 unmet needs. Moreover, the profile of patients whose carers returned their survey (mean number of needs 7.04, 3.36 met needs and 3.68 unmet needs) did not significantly differ from those whose carers did not return their survey (mean number of needs 6.98, 3.14 met needs and 3.84 unmet needs).

■ Patient and carer perceptions of need

Table 2 compares the number of met and unmet needs identified by pairs of patients and their carers.

Overall, there were no significant differences in the number of needs identified by these two groups ($Paired-t = 1.04$, $df 49$, $P = 0.30$), but ratings did differ significantly regarding the types of need. The average Kappa co-efficient for patient and carer ratings of need was 0.26 and according to Landis and Koch's kappa interpretation scale [21], agreement ranged from 'poor' to 'moderate' with none of the patient-carer pairs showing 'substantial' or 'almost perfect' agreement.

■ IEQ

There were no significant differences between carer burden of male patients compared to female patients on any of the IEQ ratings. The findings presented in Table 3 show that carers of patients recently admitted to hospital were significantly more burdened in the tension and worry subscales of the IEQ, resulting in a higher sumscore than carers of patients attending community health centres.

The IEQ subscales 'tension' and 'worry' and the IEQ sumscore were also strongly related to carers' ratings of unmet need as measured by the CANSAS ($r = 0.59$, $P < 0.01$). There were no significant associations between patients' ratings of need and the IEQ subscales. Figure 1 shows a strong relationship between carer rated unmet need and IEQ sumscore for carers of inpatients ($r = 0.55$, $P = 0.005$) and community based patients ($r = 0.46$, $P = 0.026$).

Table 3 Involvement evaluation questionnaire – carers of patients in inpatient and community settings

Sub-scale	Inpatient, <i>n</i> = 25		Community, <i>n</i> = 24		Total <i>n</i> = 49	
	Mean	SD	Mean	SD	Mean	SD
Tension	10.2***	5.1	5.2	4.0	7.7	5.2
Supervision	8.7	6.6	5.5	5.3	7.1	6.2
Worrying	14.9*	5.3	10.4	6.5	12.7	6.3
Urging	12.0	5.2	9.3	6.6	10.7	6.0
Sumscore	42.0**	16.4	28.7	17.6	35.5	18.1

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$ ANOVA ($df = 1,47$)

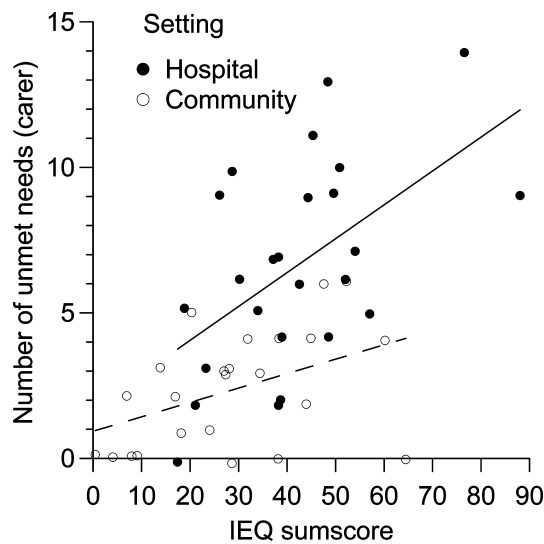


Fig. 1 Unmet needs (carer rated) and IEQ sumscores for carers of hospital and community based patients. The solid line indicates the line of best fit for inpatients and the broken line indicates the line of best fit for community patients

Discussion

These data show a high percentage of patients in hospital and community settings have unmet needs for company, daytime activities and intimate relationships. These results resonate with those reported in other studies [7, 17, 22]. Inpatients had more unmet needs than patients living in the community in the areas of accommodation, food, psychotic symptoms, psychological distress, self-harm, safety to others, and use of drugs and alcohol. This may be attributable to inpatients rating their needs in the 4 weeks prior to hospitalisation, which is a particularly challenging time. Unmet needs are associated with poor quality of life [23, 24] and using them as a way of targeting service provision can function as a guide to improve the quality of services.

Having a carer was not associated with differences in the number of needs expressed by patients. This could be because the help provided by friends and relatives reduces the demand placed upon mental health services rather than adding to the net amount of support received by patients. Contrary to the re-

sults presented by Reynolds et al. [11], patients and carers rated similar numbers of met and unmet needs but perceptions of the areas of need in which help was required differed between the two groups. Patients and carers in our study had moderate agreement regarding the need for help with drugs, intimate relationships and psychological distress, but agreement was poorer regarding the need for help with information on the condition and treatment, safety to others and benefits. This low level of agreement between patients' and carers' perceptions of need has previously been reported [10, 25].

Modest agreement about needs could be attributable to carers feeling that their relative or friend has impaired judgement in these areas [26]. This may be because of confusion about the definition of need or because patients and carers have different value judgements about the support required [25]. For example, patients place less emphasis on reducing symptoms and more emphasis on daytime activities, accommodation and social relationships [12]. Moreover, Noble and Douglas [3] report that relatives want more intensive support, while patients have a preference for supports that allow them to maintain their independence. This disagreement between patient and carer perceptions is of interest as it is indicative of disagreement about the types of care needed and whether patients' needs have been met [3].

In the current study, there were no significant differences on any of the IEQ ratings between carers of male and female patients as previously reported [27]. However, carers of patients in hospital reported a significantly higher burden of care than carers of community based patients. Evidently, the 4 weeks prior to hospitalisation is a particularly stressful time for carers who may need additional support and resources at this time. Research suggests that carer distress is related to patient symptoms which would certainly be more severe amongst the inpatient population [19, 28]. However, Boye et al. [1] state that the relatives whose family member had good cognitive functioning and fewer symptoms, reported higher levels of distress, possibly because they have higher expectations of their relative and therefore found the impact of their illness all the more distressing.

It is also feasible that the higher levels of unmet need amongst hospitalised patients contribute to the

higher levels of burden reported by carers of this group. As previously reported [2], there were no significant correlations between *patient* ratings of unmet need and carer burden. However, we found significant relationships between *carer* ratings of unmet need and burden of care on two subscales of the IEQ, tension and worrying. Clearly, need is a subjective entity and it appears that in attempting to address carer distress, carer perceptions of whether or not a need is met might be more important than the patient's opinion.

Addressing unmet need is an important goal from both patient and carer perspectives. When patients perceive that their needs are met, improvements in quality of life may result [23, 24], but carer burden may remain high unless carers also perceive that the support their relative or friend is receiving is adequate. Reducing carer burden will not only improve carers' well-being but may in turn improve patient outcomes as carer burden has been found to impact upon the patient's illness and the family in general [14, 15, 29–31].

■ Strengths and limitations

The study has several strengths. First, it describes a representative group of patients in an integrated health service during a period of standard clinical practice. Second, the same two research staff conducted all patient interviews reducing inter-rating bias. Third, by not using staff who provide direct care to the patient, the data collected were more likely to reflect patients' actual perceptions. Fourth, instruments used were reviewed and endorsed by patients sampled by the Area Mental Health Service. Finally, carer opinions were canvassed using the same instrument as that used for patients, thus allowing comparison.

The study is not without limitations. Access to carers was dependent upon patient consent and their ability to recall their carer's contact details. The fidelity of the results may have been compromised by patients' and carers' ability to accurately recall information about the care received. Shortly before discharge, inpatients were asked about their needs during the month prior to admission, whereas community patients were asked about their needs in the last month. There may have been recall bias between the groups of patients and carers. Information was not collected regarding diagnosis and external supports, which are known to have an influence upon burden. It was not possible to determine whether unmet need leads to increased burden or vice versa due to the cross-sectional nature of the study. Although the sampling method used in the community aimed to provide a representative sample, it is possible that frequent attendees were over represented. Similarly, some people excluded from the study would have been among the most needy, especially those with no fixed

abode. The carer response rate was disappointing and may reflect the reliance on a mail reply; however, low response rates and small sample sizes are not unusual in studies involving carers [31–33]. Finally, these results are from an Australian (Sydney) inner-city catchment area and the level of carer availability and support may vary in settings with different cultural and socio-economic characteristics.

Conclusions

This study surveyed a representative sample of consumers and carers in inpatient and community services across an Australian Area Mental Health Service. It provides a snapshot of needs from a consumer and carer perspective and explores the association between need and carer burden. Findings indicate that the hospital and community based patients have different need profiles and that the key difference between patients' and carers' perceptions of need relate to type rather than quantity. Carers of inpatients experienced significantly more burden than carers of outpatients and therefore opportunities to access support, information and education should be readily available and not contingent upon demonstrating a close familial relationship to the patient. We found that unmet need was related to burden and, because there was a high percentage of patients who have unmet needs for company and intimate relationships, interventions targeting these needs could be of benefit to both patients and carers. By encapsulating both hospital and community sectors, this study has system-wide relevance and has implications for the development of more integrated and sensitive services for people living with mental health problems and their carers.

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