Factors Related to Perceived Needs of Primary Caregivers of Patients with Schizophrenia

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Background/Purpose: Schizophrenia is a chronic mental illness, and sufferers are usually dependent on family, primary caregivers in particular. The present study was designed to assess the perceived needs of caregivers so that adequate services can be provided for them in the community.

Methods: A total of 177 primary caregivers were interviewed with the structured burden-and-need schedules to determine their perceived needs, and the related clinical and demographic factors. Fourteen perceived needs were identified and classified into different need clusters using the generalized association plots. A multiple regression of logistic model was adopted to explore the relationships between the related factors and perceived needs.

Results: Four clusters of perceived needs were identified, which included assistant patient care (77.6%), access to relevant information (66.1%), societal support (68.2%), and burden release (27.2%). These needs were significantly related to number of admissions, duration of illness, relationship between caregiver and patient, and education level of the caregiver.

Conclusion: Four clusters of caregivers' perceived needs were identified and found to be related to psychopathologic and demographic factors. These data are of value in designing appropriate community psychiatric programs to improve the quality of care and enhance the capacity of primary caregivers to care for patients.

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Schizophrenia is a devastating disease with a chronic course,[1,2] and results in marked impairment of social functions[3–6] in the majority of patients. Over 90% of patients with schizophrenia in Taiwan live with family;[7] therefore, families play a critical role in the daily life and care of patients. In general, psychiatric rehabilitation programs in Taiwanese communities have been inadequate,[8–10] which has left caregivers with the burden of patient care. The issue of the burden on caregivers and their families has also been emphasized in research into the cost of schizophrenia.[11,12] Because of the shortage of supply of adequate psychiatric aid in the public sector, the caring potential and innate strength of caregivers should be fostered in a society with limited resources.

The field of mental healthcare research usually adopts instruments of needs assessment, such as the Medical Research Council Needs for Care Assessment Schedule (MRC NCA) and the Camberwell Assessment of Need (CAN), to determine needs status and whether the provided services meet these needs.[13] As these instruments

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do not explore the perceived needs of primary caregivers, research findings using these instruments cannot reflect the support modalities or the potential of caregivers to care for patients. A few studies[14–17] have detected factors related to needs status (i.e. needs met or unmet) but provided no insight into the target characteristics of subjects for allocating more resources. If we could identify specific patient and caregiver characteristics from the perspective of the primary caregivers in order to distribute more mental healthcare resources, we would be able to achieve the goals of enhancing efficiency of resource allocation and fostering the innate strengths of caregivers.

Thus, the aim of this research was to explore the perceived needs of primary caregivers and to determine the related factors. Perceived needs are hypothesized to be related to patients' clinical course, and the demographic and family/social variables of the primary caregivers. This research was also designed to identify specific characteristics of patients and caregivers that have the propensity for perceiving their needs.

Methods

Samples

This study recruited patients who fulfilled the DSM-IV criteria for schizophrenia,[1] who were consecutively admitted to the acute psychiatric wards of the Department of Psychiatry, National Taiwan University, university-affiliated hospital of the Taoyuan Psychiatric Center, and Taipei City Psychiatric Center. All patients in this study underwent psychiatric treatment following the American Psychiatric Association practice guidelines for comprehensive psychosocial management and medication.[18] All subjects were also participating in the multidimensional psychopathological group research project (MPGRP)[19] sponsored by the National Health Research Institute in Taiwan, a prospective follow-up psychopathologic study of schizophrenia. The recruitment details have been given in a previous report.[20] However, this investigation focused on the perceived needs of the primary caregivers.

The inclusion criteria for the primary caregivers enrolled in this study were as follows: (1) cohabitation with the patient; (2) responsibility for patient care; (3) primary decision-maker in treatment; and (4) communication capability and availability to participate. Written informed consent was obtained from both patients and primary caregivers for recruitment as study subjects. A well-trained research assistant interviewed primary caregivers face-to-face using the *Family Caregiver Burden and Need Schedule* (FBNS).[19] Some caregivers were not able to provide information for all the research interests, and unavoidably, there was a proportion of primary caregivers who had missing data for some variables.

Data collection

The FBNS consists of 382 items: 19 involved quantitative data and were shown to have satisfactory interrater reliability (all intraclass correlation coefficients [ICC] >0.8); 156 items were rated in ranking scale, with satisfactory interrater reliability (Spearman's rank correlation coefficients >0.8) for 154, while the remaining two were acceptable in this regard (0.7–0.8); and 207 items involved categorical data, with interrater reliability of $\kappa > 0.80$ for 204, and $\kappa = 0.6–0.79$ for the remaining three items. In general, the interrater reliability of the FBNS is very satisfactory.[19] The data of the FBNS were collected during the hospitalization period of index admission.

Information with respect to the patients' clinical course and status, including basic demographic data, psychiatric and treatment history, and social function, were assessed by the attending psychiatrists, using structured clinical data schedules (CDSs)[21] with satisfactory reliability. Interrater reliability was found to be satisfactory for 140 of the 153 CDS items. The 13 remaining items with lower interrater reliability were revised appropriately, and special instructions were provided for the researchers who conducted the interviews. The CDS data were collected at discharge of the index admission.

Analyzed variables

The 14 perceived needs obtained in the FBNS were: (1) comforting the aggravating patient; (2) assisting with the aggravating patient's care; (3) transport of the aggravating patient to the service setting; (4) financial aid; (5) general psychological and practical support; (6) coping with medical teams; (7) understanding diagnosis and treatment; (8) identifying early signs of relapse; (9) understanding mental health laws; (10) general social acceptance; (11) occupational therapy; (12) sheltered work facilities; (13) advice on intimate relationships for the patient; and (14) lifelong custodial care of the patient. The interviewee provided a yes/no response with respect to these perceived needs (score, 1/0). All FNBS items had satisfactory interrater reliability ($\kappa > 0.80$).

The clinical variables used in this analysis were: (1) with/without marked negative symptoms; (2) age at onset; (3) duration of illness; and (4) first/multiple admission/s. The presence of negative symptoms was assessed with the positive and negative symptom scale (PANSS),[22] and analyzed using the generalized association plots method.[20,23,24] As for interrater reliability coefficients, ICC values of 22/33 PANSS items were > 0.80, eight were 0.7–0.8, and three were 0.5–0.7. The other clinical variables were assessed by the CDS.

The family and social variables for the primary caregivers were: (1) relationship between caregiver and patient; (2) education level; (3) job status; and (4) family size. The relationship between the caregiver and patient was categorized as follows: (1) parent; (2) spouse; and (3) other (including sibling or child).

Data analysis

The point prevalence of the 14 perceived needs was determined. The 14 perceived needs of the primary caregivers of schizophrenia patients were analyzed using the generalized association plots (GAPs)[20,23,24] to define the related proximity clusters of different dimensions. The random error coefficients[25] between any two perceived needs variables were used for the GAP analysis.

A multiple regression of logistic model[26] was used to examine the independent factors related to perceived needs, which were dependent variables. The related factors of the perceived needs were divided into two groups of clinical and sociodemographic variables of the patients and the primary caregivers, respectively. SAS software[27] was used for statistical analysis. The between 14 perceived needs paired absolute random error (ARE) coefficients ($0 \le r \le 1$) matrix was computed as the input proximity matrix for the GAP analysis. The Figure illustrates the ARE coefficients matrix for the 14 perceived needs permuted by the GAP divisive hierarchical clustering tree.[23] Each gray square in the matrix map represents a between perceived needs ARE coefficient. A darker (lighter) square stands for a larger (or smaller) ARE coefficient. The GAP divisive hierarchical clustering tree algorithm automatically sorts similar perceived needs variables at closer positions along the main diagonal of the ARE coefficients matrix. Groups of darker squares along the main diagonal identify potential clusters of perceived needs. Gray squares, which occur only for the very last two columns and rows that correspond to the need cluster for burden release, including two need items concerning advice on intimate relationships and lifelong custodial care for patients, represent negative ARE coefficients. The hierarchical clustering tree (dendrogram) structure also reveals the clear grouping pattern of the 14 perceived needs.

Results

A total of 177 patients with schizophrenia (86 male, 91 female) were recruited for this study. In terms of age distribution, 52.5%, 39.2% and 8.3% of the patients were aged > 30, 21–30 and < 20 years old, respectively. Seventy-two (44.2%) of the 163 cases with available PANSS data had marked negative symptoms on admission. It was the first admission for 66 (42.6%) patients. The interval from onset of severe psychotic symptoms until index admission was less or more than

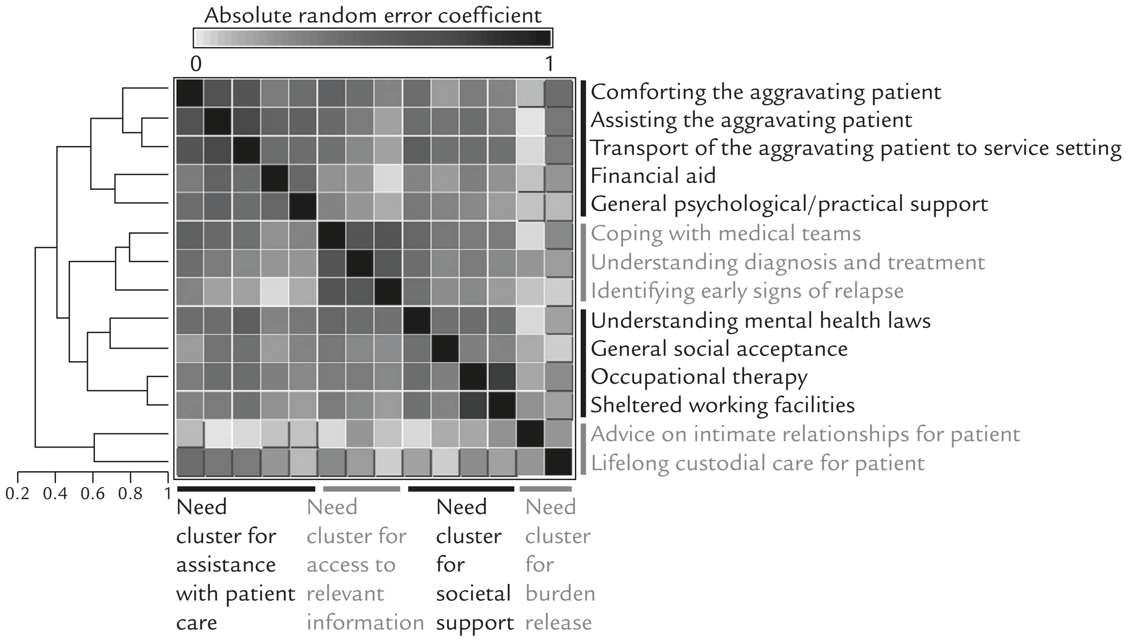

Figure. Generalized association plots for clustering the 14 perceived needs of the primary caregivers of patients with schizophrenia.

2 years in 81 (45.8%) and 96 (54.2%) subjects, respectively.

A total of 177 primary caregivers (92 male, 85 female) were also recruited for the study. The majority were aged 31–60 years (64.6%), with 29.8% and 5.6% > 60 and < 30 years, respectively. Most of the primary caregivers were parents of the patient (70.1%), with spouses or children/siblings (category other) making up 11.3% and 18.6% of the sample, respectively. Sixty percent of the families consisted of four individuals or less.

The 14 perceived needs were grouped into four proximity clusters in the following order (upper left to lower right corner along the diagonal line of the resultant proximity matrix) based on GAP analysis: (1) need cluster for assistance with patient care (5 items); (2) need cluster for accessing relevant information (3 items); (3) need cluster for societal support (4 items); and (4) need cluster for burden release (2 items) (Figure). Two out of the 14 perceived needs from the need cluster for burden release had zero and/or negative correlations with the remaining 12 (Figure).

The prevalence of the perceived needs ordered by the GAP results is presented in Table 1. Except for lifelong custodial care (11.7%), the prevalence of perceived needs was generally high (42.7–87.2%). Mean prevalence of the three principal need clusters for assistance with patient care, societal support, and access to relevant information was 77.6%, 66.1% and 68.2%, respectively, while the prevalence of burden release was relatively low (27.2%).

The results for factors related to specific clusters of perceived needs from the multiple regression of logistic model are presented in Tables 2–5. Clinical variables significantly associated with various need clusters were: (1) single/multiple admission; and (2) duration of illness. Sociodemographic variables significantly associated with need clusters were: (1) relationship between primary caregiver and patient; and (2) education level of primary caregiver.

The results reveal that, in contrast to multiple admissions, for the first admission, the caregivers had a propensity to the perceived need to comfort the aggravating patient (Table 2), to understand diagnosis and treatment (Table 3), to identify early signs of relapse (Table 3), and the need for occupational therapy (Table 4). Comparing duration of illness (≤ 2 or > 2 years), caregivers were more likely to report the need to understand mental

Table 1. Perceived needs of primary caregivers of patients with schizophrenia by prevalence and sample size

Need cluster	Prevalence of perceived needs	
	N	*n* (%)
I. Need cluster for assistance with patient care		
1. Comforting the aggravating patient	168	133 (79.2)
2. Assisting the aggravating patient	172	150 (87.2)
3. Transport of the aggravating patient to service setting	170	135 (79.4)
4. Financial aid	168	129 (76.8)
5. General psychological/practical support	171	112 (65.5)
II. Need cluster for access to relevant information		
1. Coping with medical teams	171	128 (74.9)
2. Understanding diagnosis and treatment	173	113 (65.3)
3. Identifying early signs of relapse	172	100 (58.1)
III. Need cluster for societal support		
1. Understanding mental health laws	167	117 (70.1)
2. General social acceptance	169	106 (62.7)
3. Occupational therapy	162	135 (83.3)
4. Sheltered work facilities	169	96 (56.8)
IV. Need cluster for burden release		
1. Advice on intimate relationships for patient	157	67 (42.7)
2. Lifelong custodial care for patient	154	18 (11.7)

Table 2. Factors related to the cluster of perceived needs for assistance with patient care

Perceived needs	Related factors	Comparison groups	OR	95% CI
1. Comforting the aggravating patient	Number of admissions	Multiple admissions *vs.* first admission	1:3.279	1.133–9.524*
2. Assisting the aggravating patient's care	–			
3. Transport of the aggravating patient to service setting	–			
4. Financial aid	–			
5. General psychological/practical support	Relationship with patient	Parents *vs.* spouse/others[†]	1:2.320	1.047–5.128*

**$p < 0.05$; [†]siblings and children. OR = odds ratio; CI = confidence interval.*

Table 3. Factors related to the cluster of perceived needs for accessing relevant information

Perceived needs	Related factors	Comparison groups	OR	95% CI
1. Coping with medical teams	Relationship with patient	Parents *vs.* spouse/others*	1:2.519	1.020–6.211[†]
2. Understanding diagnosis and treatment	Number of admissions	Multiple admissions *vs.* first admission	1:3.344	1.422–7.874[‡]
3. Identifying early signs of relapse	Number of admissions	Multiple admissions *vs.* first admission	1:3.534	1.639–7.634[§]
	Relationship with patient	Spouse/parents *vs.* others*	1:3.117	1.066–9.113[†]

**Siblings and children; [†]$p < 0.05$; [‡]$p < 0.01$; [§]$p < 0.005$. OR = odds ratio; CI = confidence interval.*

Table 4. Factors related to the cluster of perceived needs for societal support

Perceived needs	Related factors	Comparison groups	OR	95% CI
1. Understanding mental health laws	Duration of illness	≤ 2 yr *vs.* > 2 yr	1:5.056	2.003–12.759†
2. General social acceptance	Relationship with patient	Spouse/parent *vs.* others*	1:3.137	1.105–8.905‡
3. Occupational therapy	Relationship with patient	Spouse *vs.* parents/others*	1:10.858	3.074–38.348†
	Number of admissions	Multiple admissions *vs.* first admission	1:5.556	1.355–22.727‡
4. Sheltered work facility	Education level of caregiver	Primary school *vs.* junior high school and above	1:1.950	1.001–3.798‡

**Siblings and children; $^\dagger p < 0.001$; $^\ddagger p < 0.05$. OR = odds ratio; CI = confidence interval.*

Table 5. Factors related to the cluster of needs for burden release

Perceived needs	Related factors	Comparison groups	OR	95% CI
1. Advice on intimate relationships for patient	Relationship with patient	Spouse *vs.* parents/others*	1:8.603	1.833–40.371†
	Education level of caregiver	High school and above *vs.* primary/junior high school	1:2.299	1.196–4.959†
	Duration of illness	≤ 2 yr *vs.* > 2 yr	1:2.216	1.082–4.539†
2. Lifelong custodial care	–			

**Siblings and children; $^\dagger p < 0.05$. OR = odds ratio; CI = confidence interval.*

health laws (Table 4) and advice on intimate relationships (Table 5) in patients with illness lasting longer than 2 years.

In contrast to caregivers who were parents, those who were spouses, siblings and children were more likely to report the perceived needs of general psychological and practical support (Table 2) and coping with medical teams (Table 3). In contrast, when the primary caregiver was a sibling or a child rather than a spouse or parent, the propensity was towards the perceived need to identify early signs of relapse (Table 2), and general social acceptance (Table 4). The primary caregivers who were parents, siblings and children, rather than spouses, had a propensity towards the perceived need for occupational therapy (Table 4), and advice on intimate relationships for the patient (Table 5). Comparing education level, caregivers who had junior high school education and above had a greater propensity to the perceived need for sheltered work facilities (Table 4). Caregivers with primary/junior high school education were more likely to state the perceived need for advice on intimate relationships for the patient (Table 5).

Discussion

This study reveals that the perceived needs of primary caregivers can be grouped into four clusters, assistance with patient care, access to relevant information, societal support and burden release. Except for two items in the need cluster for burden release, all 12 other need items had high prevalence, ranging from 58.1% to 87.2%. The clinical and demographic factors related to perceived needs are first/multiple admission/s, duration of illness (≤ 2 or > 2 years), relationship between caregiver and patient, and caregiver education level. The structure of the clusters of perceived needs as explored by GAP analysis was similar to that reported by Gall et al.[28] The dimensions of social support and information with respect to patient care have also been found by

Smith[29] and Winefield and Harvey.[30] Wennström et al[31] identified three dimensions in the CAN, such as functional disability, social loneliness and emotional loneliness. Two of the clusters of perceived needs in the present study, assistance with patient care and societal support, are similar to those derived from the study of functional disability and social loneliness by Wennström et al.[31] However, the need items were not exactly the same cross-culturally, and comparison of prevalence was not practical.

The need cluster for accessing relevant information consists of the perceived need to cope with medical teams, understand diagnosis and treatment, and identify early signs of relapse, which also had high prevalence (58.1–74.9%, Table 1). Main et al[32] also found that adult sibling caregivers considered that medical information provided by mental health professionals was inadequate and confusing. This finding justifies the assertion that psychological education for the primary caregiver has to emphasize this sort of psychiatric knowledge. Furthermore, the need to continuously campaign against the stigma of schizophrenia is highlighted by these research results, as demonstrated by the high prevalence of the perceived need to understand mental health laws (70.1%) and the need for widespread acceptance in society (62.7%). As the results pointed out, there is a high prevalence of perceived need for occupational therapy and sheltered workshop facilities (56.8% and 83.3%, respectively). We suggest that providing sufficient community psychiatric rehabilitation services is indispensable.

It is interesting that the prevalence of perceived needs making up the burden release need cluster was relatively low (11.7–42.7%). Furthermore, it is quite remarkable that the prevalence of lifelong custodial care was only 11.7%, a finding which confirms the analogous studies conducted in Southern Taiwan by Shen and Chang[10] and Tsui et al.[33] This consistently low prevalence is probably a reflection of cultural values. In Taiwan, parents, who represent the majority of caregivers (70.1%), are obliged to take responsibility for care of their children with schizophrenia without hesitation. Traditionally, the siblings of these patients assume this obligation of familial care when the parents die. Most parents worry about who will care for their children after their death. Therefore, parents who are primary caregivers hope that their children might develop intimate relationships, as their spouse would then assume the caregiver role after their death. Modernization in Taiwan will also have an impact on the integrity of the traditional family structure, which is expected to increase the need for long-term custodial care in the near future. We emphasize the need for preemptive strategies in mental healthcare to deal with the issue in advance, in order to reduce the inevitable social costs associated with dramatic increases in the demand for custodial care.

The results of the present study indicate that both caregiver demographics and patient clinical variables are related to the perceived needs of primary caregivers, which provides valuable information in the design of adaptive community psychiatric programs. Caregivers of first-admission patients obviously have less experience and knowledge with respect to the care of their charges, and a greater propensity towards the perceived need to comfort the aggravating patient, to understand diagnosis and treatment, to identify early signs of relapse, and the need for occupational therapy. Our results also reveal that caregivers were initially eager for their schizophrenic family member to be cured and eventually live independently through rehabilitation programs. In contrast, family caregivers of patients with an illness duration exceeding 2 years were more likely to report the perceived needs for understanding of mental health laws and for advice on intimate relationships for the patient. These more experienced caregivers had a less optimistic attitude toward schizophrenia as they had experienced the reality of caring for an affected family member. We ought to create two separate support programs or services for caregivers, one that targets the first admission, and the other for families whose charges have endured illness of longer duration with multiple admissions.

Young caregivers have a greater likelihood of full-time employment and an active social life, and have limited available time; therefore, they are more likely to require general psychological or practical support. Furthermore, sibling and offspring caregivers had a greater propensity towards perceived needs involving access to relevant information: identifying early signs of relapse, attaining widespread acceptance in society, occupational therapy, and advice on intimate relationships for the patient.

Caregivers with higher levels of education had a propensity towards the perceived need for sheltered work facilities, while their less-educated counterparts were more concerned with advice on intimate relationships for the patient. The former group appeared to have a more aggressive and/or active attitude towards patient care, while the latter were apparently more conservative. The psychiatric medical service team must be sensitive to caregiver characteristics, so that they can provide appropriate psychological education and services.

Lauber et al[34] reported that if the perceived needs of caregivers are met, it may prevent them from complete physical and emotional exhaustion, and increase the likelihood that they will continue to care for their charges. The perceived needs assessment could establish effective psychiatric service programs, and also offer an orientation towards setting clear goals for mental health policy. Devoting limited resources to patients and caregivers with specific characteristics is efficient in terms of managing societal resources. This research approach could monitor the efficiency of mental healthcare systems and facilitate redirection of limited resources towards those in need.

Exploration of the perceived needs for services from the perspective of the primary caregiver provides valuable information for the reform of mental healthcare systems. Identifying specific clinical and demographic characteristics of patients and caregivers through the analysis of factors related to perceived needs could reallocate limited resources in an efficient way, to establish satisfactory mental health service programs. It is strongly recommended that factors related to the perceived needs of caregivers, such as the number of admissions, duration of illness, education level of the caregivers, and their relationship with the patient, must be considered in the design of psychiatric services.

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