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ORIGINAL PAPER

Needs and Demands for Community Psychiatric Rehabilitation Programs from the Perspectives of Patients and Caregivers

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Abstract This study interviewed 182 pairs of patients and caregivers to explore the needs and demands for community programs for patients with chronic mental illness and to detect the factors associated with them. The most needed and demanded programs were structured day services (69.2 vs. 78.6%), club house (71.4 vs. 74.2%), and caregiver support (72.5 vs. 74.7%). The needs and demands perceived by both patients and caregivers ranged from 3.3 to 31.9%, while those perceived by either patients or caregivers ranged from 25.8 to 72.5%. Needs and demands for individual programs were higher in caregivers (67, 65.9%) than in patients (41.2, 42.9%) and the proportion of demand (42.3–78.6%) for the eight programs was greater than the need (25.8–72.5%) for programs. The results showed that married and younger caregivers needed and demanded active community programs and the patients with a higher level of education favored a club house with high autonomy.

Keywords Community psychiatric rehabilitation · Need · Demand · Chronic mental illness · Caregiver

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Introduction

Community psychiatric rehabilitation has been advocated as an important and integral part of psychiatric care for people with chronic mental illness (American Psychiatric Association 2004), and diverse community psychiatric rehabilitation programs have been established in different countries. These include assertive community treatment (ACT) programs and clubhouses in the United States (Baronet and Gerber 1998; Macias et al. 2001), integrated psychological therapy (IPT) in Switzerland (Roder et al. 2001), care program approach (CPA) in the United Kingdom (Holloway et al. 2002), ACT and supported employment in Canada (Latimer 2005). However, there are still substantial barriers for people with mental illness to access community psychiatric services, which is reflected in the magnitude of the unmet needs and shortage of resources (Anderson and Lyon 2001; Higgins et al. 2007; Lemaire and Mallik 2005). Considering that the needs and demands for psychiatric community rehabilitation have been dominated by unilateral professional psychiatric opinions (Anderson and Lyon 2001; Higgins et al. 2007; Lecomte et al. 2005) without inputs from patient's perspective, there might be overt mismatch between needs and demands; patients may need community programs but may not demand them; they may not use

programs they need; and they may use services they don't need. Unfortunately, most past studies on community psychiatric rehabilitation have focused solely on the need for skills training (e.g., vocational rehabilitation, shopping, paying bills) (Anderson and Lyon 2001; Kersten et al. 2000; Lecomte et al. 2005; Nieves 2002; Pinkney et al. 1991) and few studies have examined the needs for community psychiatric rehabilitation programs. Exploring the needs and demands for community programs should provide a comprehensive framework for constructing psychiatric care systems.

Needs and demands data provided by patients themselves may be misleading as they might not be able to adequately express these needs and demands. Since patients often depend heavily on caregivers for activities of daily living, caregivers should be important participants and opinion providers in health care planning. In this regard, research addressing the needs and demands issue from the perspectives of both patients and caregivers could prove informative in providing a balanced view. This will be especially important for planning community programs, since in Taiwan near 90% of people with chronic mental illness live with their families (Hwu et al. 1995) and community psychiatric rehabilitation programs are still highly needed (Department of Health 2006). Considering that different community rehabilitation programs vary in their service population, goals of rehabilitation, and allocated resources and operations, diverse psychiatric rehabilitation programs such as drop-in services, accommodations, club houses, home care, respite services and caregiver support, are needed to meet individualized and multi-level needs. Currently, only structured day service and residential rehabilitation are available and covered by the National Health Insurance in Taiwan and they have to serve multipurpose functions and might not fit the needs of individual patients.

The purpose of this study was hence to explore the needs and demands for these different community psychiatric rehabilitation programs in Taiwan, from both patients' and caregivers' perspectives. Besides currently available programs, the survey covered all possible modalities of community rehabilitation. Since socio-demographic, clinical characteristics of patients and caregivers might influence the needs and demands for individual community program, multivariate statistics were used to explore the extent of impacts of these individual characteristic on needs and demands for each community treatment modality. The scopes of the study included the following: (1) to assess and describe the needs and demands for these community psychiatric rehabilitation programs; (2) to explore the factors related to needs and demands for individual community programs in terms of the characteristics of patients and caregivers.

Methods

Study Design

The current study was conducted in seven psychiatric hospitals in Taiwan between October 15, 2007 and February 15, 2008. The seven participating psychiatric hospitals were the core mental hospitals responsible for their respective regional mental health care networks and were selected after balancing the geographic distribution.

Subjects were screened and recruited from those attending outpatient clinics in the seven psychiatric hospitals when they met the following inclusion criteria: (1) an ICD9-CM diagnosis of either schizophrenia (295) or affective disorder (296); (2) a duration of illness over 2 years; (3) age less than 50 years old; (4) regular visits to psychiatric clinics; (5) unemployed; (6) never used community psychiatric rehabilitation or having used it for less than 1 month. Those who fulfilled the inclusion criteria were assumed to be in need of community psychiatric rehabilitation. After a complete description of the study, written informed consent was obtained. In-person interviews with patients and their caregivers were conducted by four trained graduate research assistants, using the structured questionnaire of the Inventory of Needs and Demands for Community Psychiatric Rehabilitation (INDCPR). The protocol and questionnaires were approved by the institutional research boards of all seven participating hospitals.

In addition to demographic and clinical information about patients and caregivers, the INDCPR assesses the needs and demands for the eight community psychiatric rehabilitation programs: structured day service, drop-in service, residential rehabilitation, accommodation, club house, home care, respite service and caregiver support. Briefly, the structured day service provides a daily schedule of activities directed by professionals, and all consumers receive aggressive rehabilitation activities in order to improve their daily living, social and vocational skills. The drop-in service provides unstructured day services with less active interventions and users are free to participate or not. The residential rehabilitation program emphasizes proactive interventions for improving daily living, social and vocational skills, and independent living in the community, whereas accommodation offers only residential service. The main function of a club house is a meeting place, and all activities are initiated and organized by members of the club house. Home care operates by professionals delivering psychiatric rehabilitation or nursing care in consumer's home. In contrast to the preceding programs which provide services for patients, respite service and caregiver support target the caregivers of patients with chronic mentally illness.

The content of individual community program was described in detail to the interviewees, and interviewer made sure that the interviewee understood the content of the programs, before inquiring whether a specific program was needed or not. When interviewers inquired about the needs and demands for these community programs, they had to remind the interviewees that not all the eight programs were currently operating in Taiwan and they could respond by solely following what they perceived to be a need or not. No matter the patients and caregivers felt they were in need of a certain community program or not, the interviewers inquired further as to whether or not the interviewees would use the program if it existed in the healthcare system. The ratings of the need/demand were: 1 need/demand; 2 no need/demand; and 3 unknown.

The validity and inter-rater reliability of the INDCPR was assessed before the field work. Six senior psychiatric professionals were invited to examine the content validity, including two psychiatrists, one psychiatric nurse, two occupation therapists, and one psychiatric social worker. Two graduate level research assistants interviewed 15 pairs of patients and caregivers to collect data for inter-rater reliability. The kappa statistics and inter-class coefficient (ICC) reliability were calculated. 325 (92.3%) of a total of 352 items in the questionnaire for patients had a kappa or ICC greater than 0.9. Only seven items (2.0%) ranged from 0.5 to 0.6. The rest of the items ranged from 0.7 to 0.8. In the questionnaire for caregivers, 311 (89.4%) of a total of 348 items had a kappa or ICC greater than 0.9. Only nine items (2.6%) ranged from 0.5 to 0.6. The other items ranged from 0.7 to 0.8.

The characteristics assessed in the study included gender, marriage (single, married and living with spouse, married and living without spouse), education level ($\leq$9, 10–12, $\geq$13 years), religion (belief, no belief), and age of patients and caregivers, duration of illness, diagnosis, and kinship of caregiver with patients. The job status of caregivers was categorized as unemployed, full-time job, part-time job, or retirement.

The need for a certain community rehabilitation program was coded as present when the patient and/or caregiver perceived that such program was needed. If the

Table 1 The variable information in multiple logistic regression analysis

Variables	Variables in patient group	Variables in caregiver group	Categories	b/a[#]
Dependent variable				
Need status	Yes	Yes	No need or need	
Demand status	Yes	Yes	No demand or demand	
Independent variables				
Gender	Yes	Yes	Male	a
			Female	b
Marriage	Yes	Yes	Single	a
			Living with spouse	b
			Living without spouse	b
Education level	Yes	Yes	$\leq$9 Years	a
			10–12 Years	b
			$\geq$13 Years	b
Religion	Yes	Yes	Belief	a
			No belief	b
Job status	No	Yes	Unemployed	a
			Full-time job	b
			Part-time job	b
			Retirement	b
	Yes	Yes	Age	c[+]
	Yes	No	Duration of illness	c[+]
Diagnosis	Yes	No	Schizophrenia	a
			Affective disorder	b
Kinship with patients	No	Yes	Parents	a
			Children	b
			Spouses	b
			Siblings	b
			Others	b

[#] b/a: a as reference category to examine the effect of the categories of the independent variable on dependent variable in contrast to the category b of this specific variable

[+] Represents continuous variables in multiple logistic regression analysis

patient and/or caregiver stated that they wanted to use such a program, it was further defined as a demand for that program. The needs and demands of patients and caregivers were further classified into 4 subcategories: need/demand of patient only, need/demand of caregiver only, need/demand of both patients and caregivers, and no need/demand. Further in regression analysis, the four subcategories of need/demand status were changed into a binary variable (need vs. no need; demand vs. no demand) by collapsing the three subcategories of need/demand of patient only, caregiver only, and both of patients and caregivers into a single category.

Data Analysis

Descriptive statistics were used to delineate the needs and demands for the eight community psychiatric rehabilitation programs. The factors associated with the need and demand for a specific individual program were explored by multiple logistic regression analysis, in which the status of need (need vs. no need) and demand (demand vs. no demand) was the dependent variable and the independent variables included gender, marital status, education level, religion, and age of patients and caregivers, duration of illness, diagnosis, kinship of caregiver with patients, and job status of caregivers. Since some of the categorical independent variables were with more than two categories, they were transformed into dummy variables. For example, since the variable of "marital status" had three categories, it was substituted by three binary dummy variables (present or not present) that represented each of the three categories. And the first category in these variables is set as the reference category. All variable information is demonstrated in Table 1, such as dependent variables, independent variables, categories in each independent variable, and the reference category in categorical variables. The odds ratio of an event in logistic regression is defined as the ratio of the probability that an event occurs to the probability that it fails to occur. For example, the odds ratio (OR) is 10.93 in the category of married and living without spouse of caregiver's marital status, which means the probability of caregivers married and living without spouse need a certain service are 10.93 times of the probability in the reference category of single caregivers, controlling the other independent variables. Statistical analyses were performed with SPSS 12.0 (SPSS Inc. 2000). Significance for all procedures was determined at the 0.05 probability level (two-tail test).

Results

A total of 182 pairs of patients and caregivers participated in the study. The patients with chronic mental illness were more likely to be males (51.1%) and single (73.6%), while the caregivers were more likely to be females (57.1%), married and living with spouse (71.1%), and employed (60.0%). The mean ages of patients and caregivers were 36.2 (SD 7.7) and 55.2 (SD 13.5), respectively. The majority of patients (83.0%) were diagnosed as schizophrenia. The mean duration of illness was 13.0 (SD 8.9) years. Among the patients, 27.4, 48.4, and 24.2% had years of education less than 10, 10–12, and more than 12, respectively. The majority of the caregivers were parents of the patients (67.1%), and 60.3% of them had less than 10 years of education (Table 2).

Table 3 shows the three most needed community programs by either patient or caregiver to be caregiver support (72.5%), club house (71.4%) and structured day services

Table 2 Characteristics of patients with chronic mental illness and caregivers

	Patient		Caregiver	
	N	%	*N*	%
Gender				
Male	93	51.1	78	42.9
Female	89	48.9	104	57.1
Marriage				
Single	134	73.6	15	8.2
Married and living with spouse	31	17.0	128	71.1
Married and living without spouse	17	9.4	37	20.6
Education level				
≤9 Years	50	27.4	109	60.3
10–12 Years	88	48.4	52	28.7
≥13 Years	44	24.2	20	11.0
Religion				
Belief	65	35.7	61	33.7
No belief	117	64.3	120	66.3
Job status				
Unemployed			72	40.0
Full-time job			62	34.4
Part-time job			21	11.7
Retirement			25	13.9
Age (Mean, SD)	36.2	7.7	55.2	13.5
Duration of illness (Mean, SD)	13.0	8.9		
Diagnosis				
Schizophrenia	151	83.0		
Affective disorder	31	17.0		
Kinship with patients				
Parents			122	67.1
Children			4	2.2
Spouses			22	12.1
Siblings			25	13.7
Others			9	4.9

Table 3 Needs and demands for community psychiatric rehabilitation programs from the perspectives of patients and caregivers

	Need/demand								No need/demand	
	Patient only		Caregiver only		Patient and caregiver		Total[a]			
	N	%	*N*	%	*N*	%	*N*	%	*N*	%
Need										
Structured day service	12	6.6	79	43.4	35	19.2	126	69.2	56	30.8
Drop-in service	16	8.8	68	37.4	27	14.8	111	61.0	71	39.0
Residential rehabilitation	15	8.2	42	23.1	12	6.6	69	37.9	113	62.1
Accommodation	12	6.6	29	15.9	6	3.3	47	25.8	135	74.2
Club house	23	12.6	58	31.9	49	26.9	130	71.4	52	28.6
Home care	23	12.6	29	15.9	26	14.3	78	42.9	104	57.1
Respite service	17	9.3	44	24.2	8	4.4	69	37.9	113	62.1
Caregiver support	28	15.4	46	25.3	58	31.9	132	72.5	50	27.5
Any of above	75	41.2	122	67.0	100	54.9				
Demand										
Structured day service	18	9.9	72	39.6	53	29.1	143	78.6	39	21.4
Drop-in service	18	9.9	66	36.3	36	19.8	120	65.9	62	34.1
Residential rehabilitation	17	9.3	54	29.7	28	15.4	99	54.4	83	45.6
Accommodation	13	7.1	44	24.2	20	11.0	77	42.3	105	57.7
Club house	25	13.7	58	31.9	52	28.6	135	74.2	47	25.8
Home care	29	15.9	35	19.2	33	18.1	97	53.3	85	46.7
Respite service	21	11.5	57	31.3	21	11.5	99	54.4	83	45.6
Caregiver support	29	15.9	47	25.8	60	33.0	136	74.7	46	25.3
Any of above	78	42.9	120	65.9	108	59.3				

[a] Denoted the need/demand perceived by either patients or caregivers

(69.2%), while those needs shared by both patients and caregivers were caregiver support (31.9%), club house (26.9%) and structured day services (19.2%). In general, the proportions of needs for specific community programs were higher in caregivers than in patients. The proportions in need of any one of the community programs in the subcategories of patient only, caregiver only, and patient and caregiver were 41.2, 67.0, and 54.9%, respectively.

The three most demanded community programs by either patient or caregiver were structured day services (78.6%), caregiver support (74.7%), and club house (74.2%). The community programs most demanded by patients and caregivers were caregiver support (33.0%), structured day services (29.1%) and club house (28.6%). The proportions of demands for any one of eight community programs in the subcategories of patient only, caregiver only, and patient and caregiver were 42.9, 65.9, and 59.3%, respectively. In general, the proportions of demands for the eight community programs were higher than those of needs for community programs.

After multiple logistic regressions analysis, independent variables achieving statistical significance in any of community psychiatric rehabilitation programs are illustrated in Tables 4 and 5. The study results shows that caregivers who were married and lived without spouses (OR 10.93), had 10–12 years of education (OR 3.4), were younger (OR 0.92), and were parents of patients (OR 0.09) had higher probabilities of being in need of structured day service than those who were single, had $\leq$9 years of education, were older, and were sibling of patients. Caregivers as parents of patients had a higher probability of being in need of drop-in services than did caregivers as sibling of patients. The major factors associated with a need for residential rehabilitation and accommodation were the marital status of patients (single patients had a higher probability than patients who were married and living with a spouse). Patients with 10–12 years of education (OR 3.14) and caregivers with religious beliefs (OR 2.96) had a higher probability of being in need for a club house than patients with less than 10 years' education and caregivers with no religious belief (Table 4).

Caregivers who were younger (OR 0.92) and married (living with/without a spouse) (OR 16.83, 30.28) had a higher probability of demanding structured day services than did caregivers who were older and single. Patients who were single (OR 0.15) and with 10–12 years of education (OR 3.13)had a higher probability of demanding a club house than were patients who were married and living

Table 4 Factors related to needs for each specific community psychiatric rehabilitation program

	Structured day service		Drop-in service		Residential rehabilitation		Accommodation		Club house		Home care	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Patients												
Marriage (ref: single)												
Living with spouse		NS		NS	0.10	(0.01, 0.75)	0.05	(0.00, 0.74)		NS		NS
Living without spouse		NS		NS		NS		NS		NS		NS
Education level (ref: ≤ 9)												
10–12 Years		NS		NS		NS		NS	3.14	(1.24, 7.97)		NS
≥13 Years		NS		NS		NS		NS		NS		NS
Age		NS		NS	1.10	(1.02, 1.20)		NS		NS	1.11	(1.02, 1.21)
Caregivers												
Marriage (ref: single)												
Living with spouse		NS		NS		NS		NS		NS		NS
Living without spouse	10.93	(1.14, 104.95)		NS		NS		NS		NS		NS
Education level (ref: ≤9)												
10–12 Years	3.40	(1.10, 10.58)		NS		NS		NS		NS		NS
≥13 Years		NS		NS		NS		NS		NS		NS
Religion (ref: no)		NS		NS		NS		NS	2.96	(1.15, 7.65)		NS
Age	0.92	(0.86, 0.99)		NS		NS		NS		NS	0.92	(0.86, 0.98)
Kinship (ref: parents)												
Children		NS		NS		NS		NS		NS		NS
Spouses		NS		NS		NS		NS		NS		NS
Siblings	0.09	(0.01, 0.76)	0.11	(0.02, 0.77)		NS		NS		NS	0.09	(0.01, 0.70)
Others		NS		NS		NS		NS		NS	0.04	(0.00, 0.56)

OR odds ratio, *CI* confidence interval, *ref* reference category, *NS* not significant

Table 5 Factors related to demands for each specific community psychiatric rehabilitation program

	Structured day service		Drop-in service		Club house		Home care		Respite service	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Patients										
Marriage (ref: single)										
Living with spouse		NS		NS	0.15	(0.03, 0.91)		NS		NS
Living without spouse		NS		NS		NS		NS		NS
Education level (ref: ≤9)										
10–12 Years		NS		NS	3.13	(1.20, 8.18)		NS		NS
≥13 Years		NS		NS		NS		NS		NS
Duration of illness		NS		NS		NS		NS	1.09	(1.03, 1.16)
Caregivers										
Marriage (ref: single)										
Living with spouse	16.83	(1.56, 181.95)	10.54	(1.46, 76.24)		NS		NS		NS
Living without spouse	30.28	(1.87, 490.53)	19.47	(1.92, 197.89)		NS		NS		NS
Age	0.92	(0.86, 0.99)		NS		NS	0.92	(0.87, 0.98)		NS
Kinship (ref: parents)										
Children		NS		NS		NS	0.01	(0.00, 0.66)		NS
Spouses		NS		NS		NS		NS	11.92	(1.22, 116.45)
Siblings		NS		NS		NS	0.11	(0.02, 0.81)		NS
Others	0.10	(0.01, 0.74)		NS		NS	0.03	(0.00, 0.36)		NS

OR odds ratio, *CI* confidence interval, *ref* reference category, *NS* not significant

with a spouse, and had ≤9 years of education. Caregivers who were older (OR 0.92) and were parents of patients had a higher probability of demanding home care, whereas patients with a longer duration of illness (OR 1.09) and caregivers as spouses (OR 11.92) had a higher probability of demanding respite services (Table 5).

Discussion

This study assesses the needs and demands for community psychiatric rehabilitation programs from the perspectives of patients and caregivers and provides important information for a developing community mental healthcare system. Based on the quantity of healthcare resources, the care planners could adopt the needs perceived by both patients and caregivers or choose the needs perceived by either patients or caregivers. The research results suggest that the needs and demands perceived by both patients and caregivers range from 3.3 to 31.9% and those perceived by either patients or caregivers range from 25.8 to 72.5% for the eight community programs. The demands for community programs are greater than the needs for corresponding programs, implying that those who will use services (demand) in the future might not now feel themselves in need of those services (need). Offering needed services is a high priority in healthcare policy and the care systems ought to avoid providing services for in which there is no need. The psychiatric care system should develop an educational campaign to balance the needs and demands for community psychiatric rehabilitation services and to provide services for those who perceive the need.

Based on health statistics (Department of Health 2006, 2007), the proportion of patients using the two existing community programs (structured day services and residential rehabilitation) are only 3.1 and 3.6%, respectively. The current study points out the extreme shortage of these two programs. For those six community programs that do not exist in Taiwan, over 25% of study subjects needed or demanded them, indicating that these facilities serve specific functions that are not covered by current programs. It is notable that the club house is among the most needed and demanded programs. This suggests that from the patients' perspective, autonomy might be one important factor determining their choice of programs, since club house is distinct in that professional supervision is absent and activities are initiated by members. The high need and demand for caregiver support might have reflected the great burden upon caregivers under the current mental healthcare system. Accordingly, providing more programs for caregiver support is likely to diminish the needs and demands for psychiatric services, through fostering the care potential of caregivers and their families.

The results of multivariate analyses reflect the individuality of programs and the target populations they are supposed to serve an important reference for care planners

in improving the efficiency of community programs. The results indicate that caregivers' factors dominated over all related factors of needs and demands for these community programs, implying that the advocates of community psychiatric rehabilitation must emphasize the importance of communications with caregivers. For example, married and younger caregivers might favor structured day services because they have little time to care for the patients, and they might more easily accept modern community programs. Single patients were in need of residential rehabilitation and accommodation. In the Oriental culture of Taiwan, parents represent the majority of caregivers (70.1%) (Hwu et al. 1995) and are usually devoted to taking care of their children with schizophrenia (Yeh et al. 2008). It is plausible that, once their parents pass away, single patients who have no spouse to take care of them will be anxious about the possibility of being homeless, hence their need for residential rehabilitation and accommodation. In this regard, it is important to offer assistance to parents and spouses in order to enhance their capacity as caregivers. This might, in turn, decrease the need for residential rehabilitation and accommodation services. Although club house is not available in Taiwan, patients with a higher level of education and caregivers having religious faith were keen to have this kind of service and it turned out to be the most needed and demanded of the community programs. This finding might reflect a concern for autonomy in the better educated patients and might be further incorporated into the current psychiatric healthcare system.

It should be cautioned that the need and demand for individual community programs may be overestimated in the current study, since patients and caregivers could have multiple options among the eight programs of community psychiatric rehabilitation. Although they may choose multiple community programs according to their needs and demands, in reality, they could not receive all these services at the same time. However, data exploring the needs and demands for community programs are especially informative for those countries with a shortage of community psychiatric care resources. Finally, considering that, for individual patients, the course of disease and family support will change over time, patients should be provided with various services to meet their needs across disease stages and life cycles. In this regard, the patients need and demand for more than one community program. Another statistical issue might be reminded, that more independent variables in multiple logistic regression analysis might cause more OR's tests achieving statistical significance. Since this potential error, the implication of the research results of the multivariate analyses might be taken conservatively.

From the policy-making perspective, information about the needs and demands for service programs supports recommendations for changes in the design of community psychiatric healthcare systems. The multi-level needs and demands for community programs require that policy makers oversee the development of community care systems step by step.

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