

Variables related to psychosocial needs among people with severe mental illness using community services and their informal caregivers

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Abstract

Objectives: To assess the needs of people with severe mental illness who live in the community and the needs of their informal caregivers, and to identify the variables associated with needs.

Method: Two related samples were evaluated: outpatients with mental illness (N=95) and their informal caregivers (N=53).

Results: The most frequently needs perceived by people with mental illness involved symptoms, information, companionship and daytime activities; the quantity of needs were related to age, educational level, professional activity, not living with family, living in community residences, global functioning, disability, and health. The most frequently needs perceived by informal caregivers involved individual counseling and support for family, economical assistance, family associations, and respite care; the quantity of needs were related to coping and utilization of services, as well as the quantity of needs and disabilities of the relative with mental illness.

Conclusions: People with mental illness and their informal caregivers have various types of needs, despite the support provided by their formal and informal networks.

Key words: Needs assessment - Mental illness - Caregivers

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INTRODUCTION AND DESCRIPTION OF THIS STUDY

It is evident that the care for people with severe and prolonged mental disorders has experienced profound transformations over the past few decades. The community mental healthcare model aims to help these people with their psychiatric and psychosocial problems within their own social and community environment in order to strengthen their maintenance and integration in the family and social context in the most normal way possible (Desviat, 2010; Gisbert, 2002; Guinea, 2007). Within this model, families represent one of the main pillars for support and care (Cañamares et al., 2001; De la Hoz et al., 1997; Touriño, Inglott, Baena and Fernández, 2010). Awareness of the needs of people with mental illness and those of their family members is critical when planning and providing adequate community care (Bebbington and Rees, 2001; Jones, 2009; Sobrino and Rodríguez, 2007).

In the field of mental health, the question of need usually arises when there is a health deficiency and, more precisely, when there is a deficit that can be addressed because a remedy for it exists (Torres, Rosales, Moreno and Jiménez, 2000). Some authors define need as the presence of a problem that interferes in a person's evolution, rehabilitation or social integration, thus necessitating a specific type of re-

sponse, care or solution (Brewin, Wing, Mangen, Brugha and MacCarthy, 1987). In relation to community healthcare, needs have been defined as the conditions that allow individuals to uphold, maintain or recover an acceptable level of social independence or quality of life (Department of Health Social Services Inspectorate, 1991).

The needs have been broadly evaluated through the use of different instruments such as the Needs for Care Assessment (NCA) (Brewin et al., 1987) and the Camberwell Assessment of Need (CAN) (Phelan et al., 1995), the latter of which has been widely used over the last few years. A review of the studies that have utilized the CAN indicates that the most frequent needs are related to everyday activities, company, psychiatric symptoms and anguish (e.g., Kulhara et al., 2010; Lasalvia, Ruggeri, Mazzi and Dall'Agnola, 2000; McCrone et al., 2001; Ochoa et al., 2003; Ochoa et al., 2005; Popescu and Micutlia, 2009; Rosales, Torres, Luna, Baca and Martínez, 2002; Slade, Phelan and Thornicroft, 1998; Thornicroft et al., 2002). The total number of needs described in the different studies is heterogeneous, ranging from 3.34 needs obtained in the study by Lasalvia et al. (2000), in which 247 users of mental healthcare community services in Verona were evaluated, and 8.64 needs obtained in the study by Phelan et al. (1995), who analyzed a sample of 60 people receiving mental healthcare services in London.

In terms of needs of the informal caregivers, there are some differences, given that these individuals do not have an illness or disability for which there is no treatment. Some authors use the term "need" to describe the lack of wellbeing among informal caregivers (Brewin, 1992). More recent definitions allude to circumstances in which the family members would like to receive assistance from service

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professionals (Osse, Vernooij-Dassen, de Vree, Schadé and Grol, 2000). In the sociocultural context of Spain, the consensus document coordinated by Guinea (2007) points out the principal needs perceived by the family members of those with mental illness: information, material and economic assistance, periods of rest or respite, emotional support, technical support, and being considered when decisions are made that could have repercussions on the family.

The number of studies which assess the needs of the informal caregivers is much lower than the quantity of those focused on people with mental illness. Nonetheless, there are many studies that have used standardized and validated tools for assessment, such as the Cardinal Needs Schedule (RCNS) (Barrowclough, Marshall, Lockwood, Quinn and Sellwood, 1998), the Involvement Evaluation Questionnaire (Schene and van Wijngaarden, 1992) and the Caregivers' Need for Support Scale (Stengard, 2002). Along with the traditional objective of identifying the educational and informational needs of family members (Marshall and Solomon, 2000; Mueser, Bellack, Wade, Sayers and Rosenthal, 1992; Stengard and Salokangas, 1997), there has been growing interest in evaluating additional areas of need as well as the degree of importance of each of these areas for family members and the degree to which these needs are met. In this regard, several studies have been done to evaluate how useful family members perceive the resources designed for them, the availability of these resources and their use (Graap et al., 2008; Pearce, McGovern and Barrowclough, 2006; Samele and Manning, 2000; Yeh, Liu and Hwu, 2010).

Based on the data found in literature on the needs of people with mental illness and their family members, this study was designed to provide updated data that are representative of Spain's social and cultural context.

OBJECTIVES

This study has the following objectives: 1) To describe the needs of people with severe and prolonged mental illness, along with the needs of their informal caregivers; 2) To analyze how the total number of needs experienced by people with mental illness is related to potentially associated variables: sociodemographic characteristics, global functioning, disability and the type of facility (centers for psychosocial rehabilitation, job rehabilitation centers, day centers or small residences); 3) To analyze how the total number of needs experienced by their informal caregivers is related to potential associated variables of both the caregiver (sociodemographic characteristics, health, family burden of the caregiving tasks and coping) as well as those of the person with the mental illness (sociodemographic characteristics, global functioning, disability and the type of facility point of origin).

METHOD

Participants

The sample of people with mental illness was comprised of 95 people selected at random from the 12 centers of the Network of Social Services for people with severe and prolonged mental illness in the Community of Madrid: centers for psychosocial rehabilitation (n=37), job rehabilitation centers (n=32), day centers (n=8) and small residences (n=18). All the participants were receiving care at mental healthcare centers. The average age was 39 (DT= 10.02); 57% were age 18-40 and 43% were between the ages of 41 and 65. Most of the participants were men (73.7%), single (83.2%) and had completed high school (75.8%); they did not have any professional activity (56.8%) and lived with family members (66.2%). A total of 55.2% of the participants had been diagnosed with schizophrenia, 11.5% with depression, 8.3% with bipolar disorder and 7.3% with personality disorders, while 3.1% had received other diagnoses. A total of 14.6% did not know their diagnosis or did not respond to the question.

The sample of informal caregivers was comprised of 53 people. The average age of caregivers was 60 (DT=12.65) and 19.2% were over the age of 70. The majority of the caregivers were women (77%), married (69.8%) and did not work outside the home (75.5%). In terms of their relationship with those they were caring for, in 61.5% of the cases, they were the mothers of the person with mental illness; 13.5% were the fathers and another 13.5% were the sisters. Other family relations appeared, though to a less extent: brothers (5.8%), wives (3.8%) and daughters (1.9%). Approximately 70% of those interviewed stated that they had been caring for their family member for more than ten years.

All the people participated in the study voluntarily after being informed of the study's objectives and giving their written consent.

DESIGN

For this study, a cross-sectional survey design was used with two samples of related peers (the sample of people with mental illness and the sample of their informal caregivers). Two independent evaluators were responsible for gathering the data in each sample. The evaluation of each participant was done during a single meeting by applying a series of standardized instruments during an interview with the participant.

INSTRUMENTS

People with mental illness

Sociodemographic questionnaire (designed by the authors)

Camberwell Assessment of Need questionnaire (CAN) (Phelan et al., 1995), Spanish language version by Jiménez, Moreno, Rodríguez and Torres (1995). The CAN assessed whether need was present in 22 areas. For each identified need, the degree of assistance that the person receives from friends and family members was assessed, along with the degree of assistance received from public services and the degree of assistance the person needs (interrater reliability=0.99; test-retest reliability=0.78; Kappa = 0.18).

The Short Disability Assessment Schedule of the World Health Organisation (WHO-DAS-II) (Üstün, 1999), Spanish language version by Vázquez-Barquero et al. (2000). This instrument has 12 items which allows the researcher to gauge the severity and duration of the disability which is assessed based on an individual's state of health (intraclass correlation coefficients=0.40-0.74).

Global Assessment of Functioning (GAF) (American Association of Psychiatry, 2007). The GAF is an instrument employed in Axis 5 of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) for the evaluation of general activity. It consists of a 100 point scale in which the professional must evaluate both the severity of the symptoms the person is experiencing as well as the degree of deterioration in one's school, job or social activities (intraclass correlation coefficient=0.57).

Informal caregivers

Sociodemographic questionnaire (designed by the authors)

Questionnaire of the needs of the informal caregiver (designed by the authors). Based on the Caregivers' Need for Support Scale developed by Stengard (2002), family members are read a list of the different services for the informal caregivers of people with mental illness. For each of the services, the family member must indicate: a) to what degree he/she considers each of these services necessary for the family on a scale of 0 (not necessary) to 10 (highly necessary); and b) if during the last year, he/she has received any of these services. The Cronbach's alpha has been calculated for this scale at 0.80. The questionnaire also includes an item taken from the European Study on the Needs of Family Members of People with Mental Illness (Spanish Federation of People with Mental Illness and their Families, 1994), which asks the family member whether he/she needs more guidance or information on different subjects of interest.

Caregiver Burden Interview (CBI) (Zarit, Reever and Bach-Peterson, 1980), Spanish adaptation by Martín et al. (1996). This assesses the main caregiver's subjective experience of burden. It includes 22 items on a scale of 1 (never) to 5 (almost always). The Cronbach's alpha obtained in this study was 0.91.

Questionnaire on coping styles (COPE) (Carver, Scheier and Weintraub, 1989), Spanish language adaptation by Crespo and Cruzado (1997). The short version was employed for this study and includes 28 items that describe different ways of coping. The scale goes from 1 (I have not been doing this at all) to 4 (I've been doing this a lot). The Cronbach's alpha obtained in this study was 0.85.

PROCEDURE

A multicenter-multiservice sampling was done at the facilities of the network of social services for people with mental illness in the Community of Madrid. At each of the participating centers, users were randomly selected and data was then gathered among the sample of people with mental illness. After identifying the main informal caregivers and requesting authorization to contact them, the next step involved gathering data among the sample of caregivers. Eleven of the caregivers refused to participate in the study. Other circumstances that led the caregiver not to participate included the following: the person with the illness indicated that he/she had no family (7 people); the person did not grant authorization for the researchers to contact their family member (15 people), or the caregiver could not be located (9 people). The only difference between the people with mental illness whose informal caregiver participated in the study and those who did not was that the latter group included a greater percentage of people without any professional activity ($\chi^2(2,95) = 9.532, p < 0.01$).

The statistical analyses consisted in descriptive analyses for each of the samples and in an analysis of correlations to determine the relation and degree of association in terms of the quantity of needs and possible variables (Pearson correlation coefficients for the quantitative variables with Gaussian distribution; Spearman correlation coefficients for the quantitative variables with non-Gaussian distribution and the Pearson chi-squared test for categorical variables). All the statistical analyses were done using the Statistical Package for the Social Sciences Version 12.0 (SPSS 12.0S for Windows, 2003).

RESULTS

People with mental illness

The average number of needs was 7.65 needs per person (DT=2.72). Specifically, the mean of met needs was 6.21 (DT=2.42) and the mean of unmet needs was 1.44 (DT=1.51). Table I shows that the most frequent needs (that is, the sum of the met and unmet needs) corresponded to the areas of psychiatric symptoms (present in 94.5% of the sample), information on illness and treatment (87.1%), company (68.4%) and daily activities (66.3%).

Table 1: Percentage of people with mental illness with met or unmet needs in each area of the CAN (N= 95).

	Met Need % (N)	Unmet Need % (N)
Accommodations	57.9 (55)	3.2 (3)
Food	54.7 (52)	0
Daily activities	60.0 (57)	6.3 (6)
Home care	30.5 (29)	1.1 (1)
Personal care	14.9 (14)	0
Childcare	4.2 (4)	3.2 (3)
Basic education	27.7 (26)	4.3 (4)
Money	51.6 (49)	2.1 (2)
Company	42.1 (40)	26.3 (25)
Relationship with a partner	4.3 (4)	33.0 (31)
Sexuality	3.9 (3)	16.9 (13)
Psychiatric symptoms	93.4 (88)	1.1 (1)
Physical health	31.9 (30)	4.3 (4)
Anguish (Distress)	30.9 (29)	4.3 (4)
Risk to oneself	9.6 (9)	5.3 (5)
Risk to others	1.1 (1)	1.1 (1)
Alcohol	3.2 (3)	0
Drugs	0	0
Information on one's state and treatment	63.4 (59)	23.7 (22)
Transportation	35.5 (33)	3.2 (3)
Telephone	0	1.1 (1)
Social benefits	5.3 (5)	8.4 (8)

As can be seen on Table I, most of the needs were met. However, in some cases, the need was unmet and the problem persisted, especially in the areas of relationships with a partner (33.0%), company (26.3%), information (23.7%) and sexuality (16.9%).

Table 2 shows the percentage of people with met needs who were receiving assistance, be it informal (that is, help from family members, friends, etc.) or formal (from professionals, public services, institutions, etc.) On average, 55% of the people with met needs were receiving informal assistance while 60% received formal assistance.

The results of the analysis of correlations between the number of needs in the total sample of people with mental illness (N=95) and the different variables of interest shows that a greater quantity of needs is associated with:

- Increased age ($r = .234, p < 0.05$).
- Higher disability ($r = .326, p < 0.01$).
- Lower level of global functioning ($r = -.440, p < 0.01$).
- A worse assessment of their general state of health ($r = .265, p < 0.01$) and higher interference of these health issues ($r = .214, p < 0.05$).
- Only finishing elementary school ($\chi^2(3.95) = 9.263, p < 0.05$).
- Not having any professional or preprofessional activity ($\chi^2(2.93) = 6.107, p < 0.05$).
- Not living with family members ($\chi^2(3.95) = 10.368, p < 0.05$).
- The type of facility point of origin, specifically, living in a

small residence was associated with more needs, while being at a job rehabilitation center was associated with fewer needs ($\chi^2(3.95) = 21.022, p < 0.001$).

No significant correlations were found between the number of needs and other variables of the person with mental illness except those referred to above.

Informal Caregivers

A total of 58.5% of the caregivers experienced burden associated with the care of their family member and in 41.5% of the cases, this burden was intense. The majority of the caretakers considered the different services available for family members of people with mental illness as highly necessary (see Table 3), especially the support and individualized advisory services for the family (94.2%); economic assistance (87.5%); family school programs (80.8%), and substitute caregiver services (80.4%). However, the use of services during the past year had only been limited, with percentages ranging from 40.5% in the case of family schools to 14.6% for information hotlines.

With respect to the principle needs for information, 94.3% of the caregivers expressed a need for more information and guidance on the future of their family member; 77.4% wanted more social, economic and job information, and 75.5% desired more information on available services. Other subjects

Table 2: People with mental illness with met needs who receive formal and informal assistance.

	People with met need (n)	People who receive in- formal assistance % (n)	People who receive for- mal assistance % (n)
Accommodations	55	67.3 (37)	47.3 (26)
Food	52	61.5 (32)	65.4 (34)
Daily activities	57	52.6 (30)	100 (57)
Home care	29	37.9 (11)	48.3 (14)
Personal care	14	42.9 (6)	50.0 (7)
Childcare	4	100 (4)	25.0 (1)
Basic education	26	65.4 (17)	53.8 (14)
Money	49	79.6 (39)	35.4 (17)
Company	40	87.5 (35)	85.0 (34)
Relationship with a partner	4	100 (4)	50.0 (2)
Sexuality	3	33.3 (1)	33.3 (1)
Psychiatric symptoms	85	48.2 (41)	96.5 (83)
Physical health	30	40.0 (12)	93.3 (28)
Anguish (Distress)	29	69.0 (20)	100 (29)
Risk to oneself	9	55.6 (5)	66.7 (6)
Risk to others	1	0	0
Alcohol	3	66.7 (2)	66.7 (2)
Drugs	0	0	0
Information on one's state and treatment	59	23.7 (14)	89.8 (53)
Transportation	33	27.3 (9)	75.8 (25)
Telephone	0	0	0
Social benefits	5	40.0 (2)	20.0 (1)

of interest for the caregivers included information on tutelary foundations (67.9%), legal information (67.9%), information on their rights as family members (64.2%), information about the genetic/hereditary aspect of the illness (62.3%) and information about how to care for the person (60.4%).

A greater quantity of needs among caregivers was associated with the following variables of the caregiver and the person with mental illness:

A greater use of certain coping strategies by the caregiver, specifically, the use of alcohol and other substances ($r = .356$, $p < 0.01$) and a reduced use of humor as a coping strategy ($r = -.324$, $p < 0.05$)

Not receiving or utilizing diverse services for family members during the past year: individualized support ($\chi^2(1.52)=17.093$, $p < 0.0001$), economic assistance ($\chi^2(1.51)=10.218$, $p < 0.001$), substitute caregiver services ($\chi^2(1.52)=9.329$, $p < 0.01$), telephone hotlines ($\chi^2(1.53)=6.675$, $p < 0.01$), family member associations ($\chi^2(1.50)=7.232$, $p < 0.05$), family schools ($\chi^2(1.53)=7.715$, $p < 0.05$).

Greater disability of the person with mental illness in everyday activities ($r = .95$, $p < 0.01$).

A lower quantity of needs of the person with the mental illness ($r = -.399$, $p < 0.01$).

Table 3: Degree of need for different types of services on the part of caregivers and the use of these services over the past year (N=53).

	Not necessary % (n)	Moderately necessary % (n)	Highly neces- sary % (n)	Use % (n)
Schools for families	7.7 (4)	11.5 (6)	80.8 (42)	40.5 (17)
Individualized support and assistance	1.9 (1)	3.8 (2)	94.2 (49)	38.8 (19)
Information and help hotlines	7.7 (4)	13.5 (7)	78.8 (41)	14.6 (6)
Family associations	0	20.8 (10)	79.2 (38)	23.7 (9)
Economic assistance	6.3 (3)	6.3 (3)	87.5 (42)	21.4 (9)
Caregiver substitute services	11.8 (6)	7.8 (4)	80.4 (41)	19.5 (8)

No significant correlations were found between the quantity of needs and the other variables related to the caregiver or the person with the illness.

DISCUSSION

The mean of needs of people with mental illness in this study was 7.65, which is similar to the findings of previous studies though somewhat higher than the average of 6.42 needs calculated in the studies that have applied the CAN among the Spanish population (McCrone et al., 2001; Ochoa et al., 2005; Rosales et al., 2002). This minor difference does not seem to be owed to a higher presence of needs that are unmet (whose mean was 1.44 in our study, which was lower than the mean of 2.11 needs calculated for the aforementioned studies), but to a higher number of met needs (the mean in this study is 6.21, which is quite higher than the mean of 4.28 needs calculated based on those studies). The results suggest that participants experience needs in diverse areas of functioning, but that these needs are met thanks to assistance provided by the family and/or services. In this regard, it is important to consider the type of participants, that is, whether they are people who use the public network of services for people with mental illness and are thus receiving support from the services, albeit to varying degrees.

The main areas of need detected are those of psychiatric symptoms, information about the illness and the treatment, daily activities, company, relationship with a partner and sexuality. These results are similar to the data obtained from other studies, especially in terms of the frequent presence of needs in the areas of company, psychiatric assistance and daily activities (e.g., Foldemo, Ek and Bogren, 2004; Hansson et al., 2001; Kovess et al., 2000; Moreno, Jiménez, Godoy and Torres, 2003; Rosales et al., 2002)

Certain authors such as McCrone et al. (2001) recommend being precautious about interpreting needs, as the provision of services can “create” needs that are met. In other words, the person can assume that if he/she is receiving a specific service, it has a corresponding need. In contrast, if the specific services are not provided, then it can lead the person to assume that no need exists in this area, thus leading actual unmet needs to be concealed.

The results indicate that the increase in the quantity of needs of people with mental illness is associated with certain healthcare and functioning variables (lower global functioning, higher disability and poorer state of perceived health) and sociodemographic (older, not have any professional or preprofessional activity, lower level of education, not living with family members and residential facilities as the point of origin). In this respect, the decisive influence of psychosocial functioning on the quantity of needs concurs with the results of previous studies. In the work by Middelboe et al. (2001),

the level of functioning was a significant predictor of the total quantity of needs, and in the study by McCrone et al. (2001), it was the best predictive variable of the quantity of unmet needs. The influence of the level of disability also reflects studies that have included measurements of this variable (Isakidis and Teesson, 1999). Given that our study focused on variables associated with the total quantity of needs, it would be interesting to specifically analyze the different types of needs and their relation to diverse variables in future studies.

In terms of the study of the informal caregivers, it is important to note that caregiving tasks are generally handled by women, who represent 77% of the sample. The predominant profile is that of a woman around the age of 60, married, generally the mother of the person with the mental illness and someone who does not work outside the home.

When interpreting the results of the needs of caregivers, it is important to bear in mind that our study is limited to the evaluation of the needs for resources and services for caretakers, but not other types of personal needs related to coping with the illness. Caregivers consider that the diverse services which target the family members of people with mental illness are essential, but the percentage of use during the past year was only moderate. This study offers a general panorama of the needs perceived by family members, but its objectives and the design of the research do not allow us to determine which factors explain the limited use of the services. Authors such as Inglott, Touriño, Baena and Fernández (2004) have suggested that even though the family members of people with mental illness frequently express a need for support, they do not always have the availability or opportunity—and are not always willing—to utilize the services. According to González-Blanch and Carra (2001), this phenomenon could be related to the physical, psychological and economic costs of the intervention for families, but was also associated with variables related to the services themselves.

The results show that a great quantity of the needs of the informal caregivers are associated with some of their psychological and social characteristics, and more specifically, with the use of certain coping strategies and a lower use of support resources. This concurs, at least partially, with a study by Stengard (2002), which classified the informal caregivers in five conglomerates based on the style of coping and the different dimensions of care. The conglomerate referred to as “coping” grouped caregivers who handled the situation effectively, with low levels of psychological discomfort, a low level of burden and minimal needs for support and information. Unlike Stengard, however, we found no relation between burden and the needs of the caregiver.

The results also revealed that a greater quantity of caregiver needs is associated with certain variables related to the person with the mental illness: a higher level of disability and a lower quantity of needs. This final result is interesting, but in

the literature on the needs of caregivers, we have not found any study which examines the relationship between these variables in order to help explain this finding. One possible interpretation is that the support provided by the family contributes to reducing the needs of the person with the mental illness but at the same time can lead to a greater number of support needs among family members who provide this coverage in a prolonged way over time. In this regard, the literature on the informal care of people with mental illness reveals that caregivers frequently give themselves over to the task of caregiving while their needs take second place (Aznar and Berlanga, 2006; De la Huerta, Corona and Méndez, 2006; Losada, Montorio, Izal and Márquez, 2006; Navaie-Waliser et al., 2002).

CONCLUSIONS

The needs of the people with mental illness and their informal caregivers are complex, multidimensional phenomena. The correlations with other studies by Spanish researchers show that the psychosocial needs of these people are quite similar in different locations within our sociocultural context, which suggests that the results of this work could be generalized and applied to other autonomous communities with comparable healthcare and social services. Given that there are unmet needs among people with mental illness and their family members in spite of the assistance received from support networks, it would be interesting to investigate the main obstacles to receiving assistance and meeting needs on the part of the people with mental illness, their family members, and the services themselves.

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