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Needs assessment of informal primary caregivers of patients with borderline personality disorder: psychometrics, characterization, and intervention proposal

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ABSTRACT

Introduction. Informal Primary Caregivers (IPC) of people with borderline personality disorder (BPD) experience a significant burden, making it important to determine their specific needs. **Objectives.** Cross-sectional study aimed at adapting and establishing the reliability of the Questionnaire on the Needs of Family Members of People with Severe Mental Disorders to identify felt and unfelt needs that may or may not have been met in IPCs of patients with BPD and suggest intervention strategies to effectively address them. **Method.** The adapted version of the instrument was completed by 80 IPCs of patients with confirmed BPD diagnosis. **Results.** Cronbach's alpha coefficients for different groups of needs evaluated through the instrument were: Knowledge/information = .77, Instrumental support = .78, Participation = .63, and Personal support = .74; and for the total score = .86. The most important unmet felt needs were: 1. having information on interventions for patients and caregivers, legal and administrative aspects, and available support services; 2. having coping skills to deal with crises and manage patients' risk behaviors; 3. receiving professional care to reduce stress; and 4. being listened by health professionals, express their personal opinions, and need for rest. **Conclusions.** The adapted instrument showed satisfactory internal consistency in IPCs of patients with BPD. The results highlight the urgent need for interventions for this population, focusing on psychoeducation, assertiveness training, stress management, and problem solving.

Keywords: Assessment, informal primary caregivers, family, care needs, borderline personality disorder, questionnaire.

RESUMEN

Introducción. Los cuidadores primarios informales (CPI) de pacientes con trastorno límite de personalidad (TLP) soportan una pesada carga, por lo que es importante conocer sus necesidades específicas. **Objetivos.** Estudio transversal dirigido a adaptar y determinar la confiabilidad del Cuestionario de Necesidades de Familiares de Personas con Trastornos Mentales Graves a fin de identificar las necesidades sentidas y no sentidas que han sido satisfechas o no en los CPI de pacientes con TLP y sugerir estrategias de intervención para que reciban una atención efectiva. **Método.** Ochenta CPI de pacientes con diagnósticos confirmado de TLP completaron la versión adaptada del instrumento. **Resultados.** Los coeficientes *alpha* de Cronbach para los cuatro grupos de necesidades evaluadas mediante el instrumento fueron: Conocimientos/información = .77, Apoyo instrumental = .78, Participación = .63, y Apoyo personal = .74; y para el total de la escala = .86. Las necesidades sentidas y no satisfechas que destacaron fueron: 1. tener información de intervenciones para el paciente y los cuidadores, aspectos legales y administrativos, y servicios disponibles para apoyarse; 2. contar con herramientas para afrontar crisis y manejar conductas de riesgo de los pacientes; 3. ser atendidos profesionalmente para reducir el estrés; y 4. ser escuchados por los profesionales de salud y tomados en cuenta en relación con sus opiniones personales y necesidad de descanso. **Conclusiones.** El instrumento adaptado mostró una consistencia interna satisfactoria en CPI de pacientes con TLP. Los resultados resaltan la necesidad urgente de intervenciones para esta población, enfocadas en psicoeducación, entrenamiento asertivo, manejo del estrés ansiedad y solución de problemas.

Palabras clave: Evaluación, cuidadores primarios informales, familia, necesidades de atención, trastorno límite de la personalidad, cuestionario.

INTRODUCTION

Relatives of people with borderline personality disorder (BPD) experience a considerable objective and subjective burden. This is the particular case of Informal Primary Caregivers (IPC), who experience half a standard deviation above the mean burden of caregivers of inpatients with other severe mental disorders (Fruzzetti, Santisteban, & Hoffman, 2007). This has been related to the presence of interpersonal problems with the BPD relative due to a lack of knowledge of the disorder, its prognosis, and treatment, as well as limited or non-existent assertiveness skills (Morgan et al., 2010).

The satisfaction of IPCs' needs—whether for information, training in specific social skills, and/or control of negative emotions—is important *per se*, and because the evolution and prognosis of relatives with BPD depends largely on the family's interaction and collaboration (Giffin, 2008). However, although there are interventions with proven effectiveness for family members who care for patients with other severe mental disorders (SMD), such as schizophrenia and bipolar disorder (Del Pino, Palomino, & Frias, 2015), scientific literature has highlighted the absence of effective standardized programs for IPCs of people with BPD (Rapaport, Bellringer, Pinfold, & Huxley, 2006), (McFarlane, Link, Duchay, Marchal, & Crilly, 1995).

This may be due in part to the lack of routine evaluations of these IPCs' needs (which does not occur in the case of relatives of people with schizophrenia, bipolar disorder, neurological disorders, and terminal diseases) (Tennakoon et al., 2000). In this respect, the objective of the present study was to adapt and evaluate the reliability (internal consistency) of the Questionnaire on Needs of Family Members of People with SMD (QNF-SMD) to detect the needs of the IPCs of patients with BPD, characterize these care needs, and propose evidence-based intervention strategies capable of meeting them in a timely and effective way.

The QNF-SMD was developed in Spain by Gómez et al., (2012) to identify felt and unfelt needs as well as those which have been met or not in caregivers of patients with SMD. It is a self-administered instrument with 27 items grouped into four areas: 1. Knowledge/information: items 1 to 9 refer to the amount of psychoeducational information on the disorder the family member has or needs; 2. Instrumental support: items 10 to 15 concern knowledge of the tools available; 3. Participation: items 16 to 20 are related to the need to participate in decision-making concerning the treatment of their relative; and 4. Personal support: items 21 to 27 explore the need for professional and social support for themselves.

The response options to each item are: "I have felt this need and it has been met", "I have felt this need, but it has not been met", and "I have not felt this need." For comparative purposes, the percentages of needs that have been met, unmet, and not felt are calculated for each area.

The QNF-SMD has been applied to relatives of patients diagnosed with a SMD in two psychosocial rehabilitation centers in Madrid, Spain, showing a satisfactory level of internal consistency. There are more met needs in Knowledge/information (63%), together with an absence of needs in the areas of Personal support and Participation (81% and 84%, respectively), with the highest proportion of felt and unmet needs being observed in Instrumental support (30%) (Gómez et al., 2012).

METHOD

Adaptation of the instrument

First, an adaptation into Mexican Spanish of the QNF-SMD to assess the specific needs of IPC in patients with BPD (vs. a SMD in general) was undertaken through the evaluation and suggestions of four experts in the clinical care of patients with BPD (three psychologists and one psychiatrist specialized in one form of psychotherapy specifically design for BPD patients [Dialectic Behavioral Therapy, for example] and with at least 10 years of experience treating patients with BPD along 10 or more hours per week).

Reliability and detection of needs

A descriptive, cross-sectional study was conducted on a sample of IPCs of patients with a confirmed diagnosis of BPD attending a public psychiatric clinic in Mexico City, Mexico.

Subjects

A convenience sample was obtained from 80 family members of patients diagnosed with BPD, all literate and over the age of 18, who considered themselves as the IPC, and agreed to participate in the study. According to Nunnally's (1991) recommendations, the minimal sample size needed to evaluate the internal consistency of each subscale of the instrument was calculated by multiplying the number of items in the area of Knowledge/information, which is the subscale with the most items (nine) by five participants. It can therefore be assumed that the sample size was suitable for psychometric purposes since it included at least 45 participants.

Procedure

The Ethics Review Board of the psychiatric institution where the study was conducted approved the protocol and all the research materials, including the informed consent form. After IPC participants had signed it, the adapted instrument was applied to obtain internal consistency and identify and describe their care needs.

All participants were invited to participate during the psychiatric follow-up consultation and after a psychiatrist confirmed their family member's diagnosis of BPD through the application of the structured interview SCID-II (First, Spitzer, Gibbon, & Williams, 1995).

BPD patients were asked to attend with the family member who supported them the most in their everyday lives and were told that, if they wished to participate in the study, they only had to answer a self-report questionnaire lasting approximately 20 minutes.

A psychiatrist/psychologist administered the questionnaires at the clinic. When patients finished the questionnaire, the psychiatrist/psychologist who administered it checked if all questions were completed and, when necessary, asked patients to do so in order to avoid missing

data. Recruitment and data collection took 24 months (2016 and 2017).

Statistical analysis

The description of the sample was made using means, standard deviations, and ranges for the continuous variables, and frequencies and percentages for the categorical variables. The internal consistency of each subscale was evaluated by calculating Cronbach's alpha coefficients. To this end, the answers were recorded in the questionnaire to group them into three categories, in which a higher score implies a greater need: 1 = unfelt need, 2 = need felt but met, and 3 = need felt but unmet.

Table 1
Development of the QNF- BDP: Changes of items of the QNF-SMD

Original item	Modified item	Modified item in Spanish
2. "How to react to the unreasonable behavior of my sick family member" (delusions, hallucinations, abandonment, negligence).	"How to react to the unreasonable behavior of my relative diagnosed with borderline personality disorder" (for example, due to emotional instability, feelings of emptiness, instability in interpersonal relationships).	"Cómo reaccionar ante las conductas poco razonables de mi familiar diagnosticado con trastorno límite de la personalidad" (debidas, por ejemplo, a inestabilidad emocional, sentimientos de vacío, inestabilidad interpersonal).
7. "To know what psychotherapy is and what it is for".	"Knowledge of what psychotherapy is and what it is when applied to patients with borderline personality disorder".	"Saber qué es la psicoterapia y para qué sirve cuando se aplica a pacientes con trastorno límite de la personalidad".
9. "What will the life of my sick family member be in the future" (whether she/he will be able to lead an independent life, whether she/he can form or maintain a family of their own).	"What will the life of my family member with borderline personality disorder be like in the future" (whether she/he will be able to lead an independent life, form or maintain a family of his/her own).	"Cómo será la vida de mi familiar con trastorno límite de la personalidad en el futuro" (si podrá llevar una vida independiente, si podrá formar o mantener una familia propia).
10. "To be informed of legal, juridical, and administrative aspects related to the illness of my family member". (such as criminal liability, civil capacity, custody and/or visits children, hospital admission).	"To be informed of legal, juridical, and administrative aspects related to borderline personality disorder" (such as criminal liability, civil capacity, custody, and/or visits children, hospital admission).	"Estar informado de aspectos legales, jurídicos y administrativos relacionados con el trastorno límite de la personalidad" (como responsabilidad penal, capacidad jurídica, custodia de infantes, admisión hospitalaria).
16. "To receive information about the associative movement and services provided by caregivers".	"To receive information about NGOs and services available to caregivers of patients with borderline personality disorder".	"Recibir información sobre las organizaciones no gubernamentales y servicios disponibles para los cuidadores de pacientes con trastorno límite de la personalidad".
19. "To have professionals listen to me and have my opinion when I warn about the 'warning' symptoms".	"To be heard by health professionals and consider my opinion when I notice the symptoms of alarm or prior to the crisis of my family member".	"Que los profesionales de la salud me escuchen y que consideren mi opinión cuando advierto sobre los "síntomas de alarma" o antes de una crisis de mi familiar".
23. "To get help to replace me in caring for my sick family member when I can't do it".	"To receive help to find alternative solutions to replace me in the care of my relative with borderline personality disorder when I can't do it".	"Recibir ayuda para encontrar soluciones alternativas para sustituirme cuando no puedo encargarme del cuidado de mi familiar con trastorno límite de la personalidad".
25. "Need to have the company of other people who have the same problem as I did".	"Need to have the company of other people who have the same problem as me (for example, other family members of patients with borderline personality disorder)".	"Necesidad de estar acompañado de otras personas que tengan el mismo problema que yo (por ejemplo, de otros familiares de pacientes con trastorno límite de la personalidad)".
26. "Need to feel the solidarity of people, whom I respect, who support me and who understand my situation."	"Need to feel the support of people (health professionals, friends, family, etc.), who respect me and understand my situation".	"Necesidad de sentir el apoyo de la gente (profesionales de la salud, amigos, familia, etc.) que me respeten y que comprendan mi situación".

Note: QNF-BDP = Questionnaire on Needs of Family Members of People Borderline Personality Disorder; QNF-SMD = Questionnaire on Needs of Family Members of People with Severe Mental Disorders.

RESULTS

Adaptation of the instrument

The four expert judges agreed to modify the syntax of the answer options. The original options “I have felt this need and I have been satisfied,” “I have felt this need but it has not been met,” and “I have not felt the need,” were replaced with: “I have felt this need and it has been met,” “I have felt this need but it has not been met,” and “I have not felt this need.”

Table 1 presents additional changes to the items agreed by the expert judges. As can be seen, the instrument underwent very few changes, mostly in expressions, adding examples to specify situations in keeping with Mexican Spanish or according to the conditions of family members of patients with BPD (vs. a SMD in general).

Detection of needs and internal consistency

The total sample in this part of the study consisted of 80 IPCs of persons with BPD. We ended up with this sample after the invitation to participate in the study to 95 IPCs of persons with BPD; one of them refused to participate explaining that he did not need any help or service as IPCs, and 14 accepted to participate and initiated the questionnaire, but decided to withdraw from the study arguing that they did not have enough time to complete the questionnaire.

Table 2 presents the demographics of caregivers, showing that a high percentage are parents (70%) and take care of their family member with BPD on a daily basis (68.8%); while only 11.3% receive psychological support.

Cronbach's alpha coefficients of the adapted questionnaire were: for the total score = .86; for the Knowledge/information subscale = .77; for the Instrumental support subscale = .78; for the Participation subscale = .63; and for the Personal support subscale = .74.

Table 3 shows the frequencies of the responses of the different needs for Knowledge/information in the total sample. There is a predominance of unmet needs concerning Knowledge/information about: what the life of the family member with BPD will be like in the future (72.5%); how to react to the unreasonable behavior of the family member (60%); what to do to stop them from abandoning their medication (58.8%) and how to react if this happens (58.8%); what psychotherapy is and how it works when applied to patients with BPD (58.8%), what rehabilitation is and what is it for (58.8%), and how to deal with the crisis of the family member (48.8%). The main met needs were knowledge of: medication and its effects (52.5%) and the cause, symptoms, and prognosis of BPD (48.6%).

Table 4 presents the results of the section on Instrumental support. The most frequent unmet needs were knowing about: how to cover expenses related to the care of the family member with BPD (67.5%); services available to

Table 2
Description of a sample of caregivers of patients with BDP

Variables	Descriptive measures	
	n, (%)	Mean \pm SD (range)
Sex		
Male	32, (40)	
Female	48, (60)	
Age (years)		49.23 \pm 13.49 (15-77)
Marital status		
Partnered	43, (53.75)	
Unpartnered	37, (46.25)	
Average schooling		13.23 \pm 3.62 (6-21)
Occupation		
Unemployed	8, (10)	
Housewife	23, (28.8)	
Student	4, (5)	
Technical work	27, (33.8)	
Professional work	18, (22.5)	
IPC's relationship to the patient		
Offspring	1, (1.3)	
Partner	17, (21.3)	
Father or mother	56, (70)	
Sibling	4, (5)	
Other	2, (2.5)	
Time living with the patient (years)		19.86 \pm 10.67 (0-43)
Frequency of care		
Every day	55, (68.8)	
Almost every day	17, (21.3)	
Once a week	5, (6.3)	
Less than once a week	3, (3.8)	
Receives help from others		
Yes	52, (65)	
No	28, (35)	
Receives psychological support		
Yes	9, (11.3)	
No	71, (88.8)	

Note: BPD = Borderline Personality Disorder; SD = standard deviation.

caregivers when they were not at home (62.5%), or when their relatives had to be admitted urgently against his/her will (55%), as well as regarding legal and administrative aspects related to the treatment of the illness (50%). Unmet needs included: being informed about how and where to file a complaint in the event of discrimination or harassment against the family member with BPD (51.3%) or if the IPC was dissatisfied with the treatment of his/her relative with BPD (48.8%).

Table 5 shows the results about Participation and personal needs. Regarding Participation, the most frequent unmet needs included: receiving information about support groups and services for caregivers (55%); being listened to

Table 3
Knowledge and information needs of IPCs of patients with BPD

	<i>I have not felt the need</i> <i>n (%)</i>	<i>I have felt the need and it has been met</i> <i>n (%)</i>	<i>I have felt the need and it has not been met</i> <i>n (%)</i>
How to deal with the crisis caused by the disorder	4 (5.0)	19 (23.8)	39 (48.8)
How to react to the unreasonable behavior of my family member	2 (2.5)	12 (15.0)	48 (60.0)
To know the causes, diagnosis, symptoms, and prognosis	1 (1.3)	39 (48.8)	38 (47.5)
To know whether the disorder afflicting my family member is hereditary	15 (18.8)	28 (35.0)	36 (45.0)
To know what the medication is for and what its effects are	1 (1.3)	42 (52.5)	35 (43.8)
To know what to do to avoid prescription abandonment and how to react if it happens	14 (17.5)	18 (22.5)	47 (58.8)
To know what psychotherapy is and what it is when applied to patients with BPD	3 (3.88)	29 (36.3)	47 (58.8)
To know what rehabilitation is and what it is for	8 (10.0)	23 (28.8)	47 (58.8)
What will the life of my family member with BPD be like in the future?	5 (6.3)	17 (21.3)	58 (72.5)

by health professionals to give their opinions as caregivers during the evaluation of the family member with BPD (51.3%); and consulting with a professional (psychiatrist, psychologist) because of the stress of taking care of a relative with BPD (46.3%).

Finally, concerning the Personal needs of the IPC, the most frequent unmet need was for rest and a reduction of the feeling of responsibility in caring for a relative with BPD (47.5%), whereas the met needs were that professionals used words they could understand (58.8%) and to feel people's support (45%). Needs that were not felt include: for professionals to consider the right of the IPC not to assume certain responsibilities regarding the treatment of BPD patients (52.5%); to receive help in finding an alternative solution for the care of the family member with BPD

when the IPC is unable to do so (51.3%); and the need to have the company of other people who have the same problem (48.8%).

DISCUSSION AND CONCLUSIONS

The version of the Questionnaire on the Needs of Family Members of People with Severe Mental Disorders (QNF-SMD) (Gómez et al., 2012), adapted to Mexican Spanish to assess the care needs of IPC of patients with BPD (QNF-BDP), demonstrated satisfactory internal consistency coefficients for the total score and for all its subscales, which were similar to those reported for the original version, with a total Cronbach's alpha = .80 (Gómez et al., 2012), sug-

Table 4
Instrumental support needs of IPCs of patients with BPD

	<i>I have not felt the need</i> <i>n (%)</i>	<i>I have felt the need and it has been met</i> <i>n (%)</i>	<i>I have felt the need and it has not been met</i> <i>n (%)</i>
Be informed of legal and administrative aspects related to the illness	31 (38.8)	9 (11.3)	40 (50.0)
Be informed of the services available to help me as a caregiver if my family member has to be admitted urgently and against his/her will	13 (16.3)	23 (28.8)	44 (55.0)
To have information about the services available to help me as a caregiver and when my family is at home	12 (15.0)	18 (22.5)	50 (62.5)
To know how to cover the expenses related to care	20 (25.0)	6 (7.5)	54 (67.5)
To be informed of how and where to file a complaint if I do not agree with the treatment of my family member	39 (48.8)	16 (20.0)	25 (31.3)
To be informed of how and where to file a complaint in the event of discrimination and harassment against my family member	41 (51.3)	10 (12.5)	29 (36.3)

Table 5
Participation and personal support needs of IPCs of patients with BPD

	<i>I have not felt the need n (%)</i>	<i>I have felt the need and it has been met n (%)</i>	<i>I have felt the need and it has not been met n (%)</i>
<i>Participation needs</i>			
Receive information about civil associations and services for caregivers	29 (36.3)	7 (8.8)	44 (55.0)
Consult with a professional (psychiatrist, psychologist) because of the stress it causes me to take care of my family member.	23 (28.0)	19 (23.8)	37 (46.3)
Be heard by health professionals and have my opinion considered in the evaluation of my family member with BPD	10 (12.5)	29 (36.3)	41 (51.3)
For professionals to listen to me and consider my opinion when I warn about the symptoms prior to my family member's crises	19 (23.8)	29 (36.3)	32 (40.0)
For professionals to listen to me and consider my opinion in planning the treatment and rehabilitation of my family member.	23 (28.0)	22 (27.5)	33 (41.3)
<i>Personal support needs</i>			
For professionals to speak to me with words I can understand	16 (20.0)	47 (58.8)	17 (21.3)
For professionals to consider the right of the family not to assume responsibilities that do not correspond to them	42 (52.5)	23 (28.8)	15 (18.8)
To receive help in finding alternative solutions to replace me in the care of my relative with borderline personality disorder when I am unable to do so	41 (51.3)	8 (10.0)	31 (38.8)
To receive specialized attention, especially family intervention programs	23 (28.8)	20 (25.0)	37 (46.3)
The need to have the company of other people who have the same problem as me	39 (48.8)	11 (13.8)	30 (37.5)
The need to feel the support of people (who respect, support, and understand me)	19 (23.89)	36 (45.0)	25 (31.3)
The need to rest and reduce the feeling of responsibility for caring for my family member	24 (30)	18 (22.5)	38 (47.5)

gesting that this measure is reliable for clinical and/or research purposes in our population.

In our sample of IPCs of people diagnosed with BPD, the results in the area of Knowledge/information needs suggest the relevance of including, as part of the interventions for family members, information on the prognosis and likely outcomes of people with BPD; on how psychotherapy and rehabilitation works in these patients; as well as training in assertive, emotional self-regulation, and problem-solving strategies, which might allow IPCs to react more appropriately to the probable abandonment of medication and/or the unreasonable behavior of their relatives with BPD.

At the same time, the results regarding the needs of Instrumental support highlighted the importance of informing relatives of patients with BPD about financial aid programs and the means for obtaining them (for example, to reduce spending on medication through government health insurance that provides it free of charge – such as the “Seguro Popular” [Mexico’s People’s Insurance Scheme], which covers, among other things, the pharmacological treatment of depression, a very frequent comorbid diagnosis in BPD patients). This need has also frequently been

detected in other samples of IPCs of patients with a SMD (Guillen, 2011). The care of a patient with BPD not only involves several costs in addition to medication, medical consultations, and recurrent hospitalizations, but also everyday expenses that may be significant in the case of patients with a high dysfunction level.

Finally, the Personal needs for rest and reduction of the sense of responsibility of the ICP is frequently expressed, which means the probable usefulness of incorporating a set of specific strategies to increase the professional and social support into interventions for family members, such as stress reduction, depression treatment, coping skills, problem solving, anxiety reduction, and adaptive emotional management (Hoffman et al., 2005). Along these same lines, Segurana & Bartel (2016) concluded that the care for patients diagnosed with BPD cannot be dealt with separately from the care for their caregivers. Providing adequate guidance and support based on specific needs prevents overload and other health problems, making it necessary to establish specialized intervention plans focused on the problems experienced by these primary caregivers.

One limitation of this study, which should be addressed in future research, is to evaluate other psychometric prop-

erties of the QNF-BPD, including its temporal stability (though a test-retest of the instrument, which could not be performed in this study since the participants were not available for a certain period of time). This would provide a more reliable evaluation of the positive changes that might occur with interventions designed to meet the needs of IPCs of patients with BPD in our context.

Additionally, the generalizability of the results should be taken with caution, given that the sample of the IPCs of people diagnosed with BPD included in the study comes from a specialized urban care center, where both IPCs and patients with BPD receive attention, and so could have less felt needs that have not been met. In other words, although it is highlighting the need for a comprehensive intervention for IPCs, the present picture may be better than the one which most caregivers face in contexts like ours.

Thus, the data obtained through the present study constitute a first step towards meeting the specific needs felt yet unmet by most IPCs of patients with BPD, including more specific psychoeducation objectives and therapeutic strategies for the development of emotional and cognitive skills.

The adapted version of the Questionnaire on the Needs of Family Members of People with Severe Mental Disorders (QNF-SMD) (Gómez et al., 2012), to identify felt and unmet needs that may have been met or not by IPCs of patients with BPD (vs. a SMD in general) –the Questionnaire on the Needs of Family Members of People with Borderline Personality Disorder (QNF-BPD)–, is characterized by a satisfactory internal consistency and allows the opportunity to explore the particular needs of this population, including psychoeducation about BPD and its treatment, assertiveness training, stress management, and problem-solving.

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Conflicts of interest

The authors declare having no conflicts of interest.

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