Original Article

Identification of the support needs of individuals with severe mental illness using the Supports Intensity Scale[1]

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Objective: to characterize the intensity of the support needs of individuals with severe mental illness. Methods: quantitative and descriptive study that applied the Supports Intensity Scale to a sample comprising 182 individuals. Results: the supports intensity profile identifies groups, individuals, and areas with different needs of support relative to the domains of home living, health, community living, learning, employment, and social living. As a whole, the intensity level of support needs found was low, and the domains with greater needs were employment and social. Conclusions: identification of the intensity of support needs is helpful in planning integral care and detecting professional training needs. The support provision-centered approach, associated with the person-related outcomes perspective, has been sparsely applied to individuals with mental illness, and this represents the main contribution of the present study. In addition, this study introduces novel approaches to assessment that are both concordant and an innovation in nursing because they might provide a tool for understanding other disabilities.

Descriptors: Dependency (Psychology); Social Support; Desabled Persons; Mentally Ill Persons.

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Introduction

Severe mental illness presupposes a health condition characterized by physical and structural deficits, limitations in activity, and restriction in participation within a context defined by personal and environmental factors that contribute to the production of disability.

The current notion of disability involves a shift in paradigm relative to the notion of incapacity because the latter points to the limitations of an individual's functioning within a patently disadvantageous social context[1-3]. That assumption is reflected in the definition of intellectual disability[4] and in the International Classification of Functioning, Disability and Health (ICF) [5]. In both instances, functioning operates as an umbrella term encompassing body functions and structures, personal activities, and fields of participation.

The abovementioned definitions might be extended to severe mental illness, and they also afford novel approaches to assessment that are both concordant with and innovations in nursing because they might be used as a tool for the understanding of other disabilities beyond the traditional assessment of disease.

The latest approach to support provision within the realm of disability bears direct correlation with the incorporation of the Person-Centered Planning (PCP) and person-related outcomes perspectives. Related terms allude to the promotion of competence and training, the strengthening of self-control over one's life by individuals with disability, and the enhancement of self-determination to succeed in their integration into the community[6].

This is particularly difficult in the collective case of individuals with mental illness because the reliability of the information supplied by the affected individuals is put into question more often compared with other fields[7]. For that reason, the required information is preferentially collected from relatives and key informants[8] and tends to focus on the identification of the signs and symptoms of the mental illness while putting aside the assessment of the individual's needs in other domains of life.

Some studies have investigated the health-related quality of life (HRQOL) or the global quality of life[9-10] and thus applied instruments such as the Drug Attitude Inventory (DAI), Global Assessment of Functioning (GAF) [11], SF-36 questionnaire, and Lancashire Quality of Life Profile in addition to ad hoc wide-scoped instruments[12].

Most of these instruments exhibit a common problem: the need to translate assessment into plans of assistance by transforming the data on the quality of life into interventions.

In addition, such plans must include the opinions of the individuals with mental illness as well as the opinions of the healthcare professionals and of the support primary group to promote joint work and assess more precisely the support and services needed by individuals with mental illness[13].

Among the scales available to assess support needs, the Spanish adaptation of the Supports Intensity Scale (SIS) stands out[14] because its rationale fully agrees with the assumptions we have just described. In addition, it has been widely used in groups of people with intellectual disability and somewhat less in individuals with mental illness.

The possible application of SIS to individuals with mental illness and its preliminary adaptation to the Mexican context have recently been analyzed with success[15]. As a consequence, we have used the SIS together with a series of interviews in the analysis of support needs in a larger sample of individuals to answer the following question: What is the intensity of the support needs of individuals with mental illness?

Objective

To characterize the intensity of the support needs of individuals with severe mental illness using the adapted Supports Intensity Scale (SIS).

Methods

This study was approved by the pertinent authority of the institution where it was conducted and complied with the General Health Law of Mexico relative to research in the field of health, Fifth Section, Single Chapter, Articles 100 and 102[16] as well as with the principles of beneficence and non-maleficence.

Convenience sampling was performed based on the clinical records of individuals assisted at a public psychiatric hospital in Mexico. Individuals with confirmed diagnoses of schizophrenia, bipolar disorder, or major depression for three years or more were selected. Data were collected in interviews jointly conducted with the patients and their primary caregivers following the signature of an informed consent form.

Data collection was performed from December 2008 to October 2009 and included the application of the 2007 Spanish adaptations of the original version of the SIS[14] and the GAF, which corresponds to the fifth axis of the Diagnostic and Statistical Manual of Mental

Disorders (DSM) system[17-20]. Application of both scales lasted an average of 45 minutes per individual.

The data corresponding to the patients' sociodemographic and certain clinical variables were collected using a structured questionnaire that included the following items: age, gender, educational level, employment, and type of illness, as well as its progression and assistance received.

The SIS was applied following the collection of the sociodemographic and clinical data. The SIS comprises three sections: the Support Needs Scale, the Supplemental Protection and Advocacy Scale, and the Exceptional Medical and Behavioral Support Needs. An initial section is devoted to the sociodemographic data of the patient and other informants[14] who might be patients' relatives or healthcare professionals.

Section 1, the Support Needs Scale, consists of 49 life activities that are grouped into six domains: 1) home living; 2) community living; 3) lifelong learning; 4) employment; 5) health and safety; and 6) social activities. Section 2, the Supplemental Protection and Advocacy Scale, measures eight items that assess the exercise of legal rights and duties, decision-making, and management of financial resources. Section 3, the Exceptional Medical and Behavioral Support Needs investigates four medical and four behavioral fields of care: 1) respiratory care; 2) feeding assistance; 3) skin care; 4) other exceptional medical care; 5) externally directed destructiveness; 6) self-directed destructiveness; 7) sexual; and 8) other.

The support intensity corresponding to the first two sections is assessed according to three dimensions, namely, the frequency, time, and type of support needed on a scale ranging from 0 to 4. The pattern of measurement is different in section 3; the abovementioned parameters are replaced by a Likert-type scale as follows: 0=no support needed, 1=some support needed and 2=extensive support needed.

Next, the GAF scale was applied to contrast the information collected using the SIS. The GAF corresponds to the fifth axis of the DSM system and seeks to provide a global measure of the severity of disease, focusing on the patient's social, psychological, and occupational functioning[17].

The GAF scale measures the individual's functioning within a hypothetical health-disease continuum scored from 0 to 100 at 10-point intervals. A score of 100 represents optimal social, psychological, and occupational functioning, whereas the more restrictive cases with scores lower than 50 denote significant severity of symptoms and remarkable impairment of functioning and social competence. Limitations due to physical or environment-related difficulties should not be taken into account in the application of the GAF[18].

The resulting database was analyzed using the SPSS version 18 software by means of descriptive and correlation analysis. For that purpose, we performed the following steps:
-we calculated the score of each item (the sum of the scores corresponded to the frequency, intensity and duration of each item);
-we calculated the total raw score of each subscale; and
-we transformed the raw results in standard scores and percentiles using the tables provided for our sample of Spanish adults.

Following the aforementioned procedures, we analyzed the internal consistency of the items and obtained Cronbach's α of 0.97. Given that the level of consistency was satisfactory even for the subscales with the lowest α values (health and safety and home living=0.83), we might infer that, as a whole, all of the SIS subscales exhibited high sensitivity in the identification of the support needs of the investigated sample, thus reinforcing its reliability[15,20].

Results

The sociodemographic data corresponding to the sample (n=182) indicated that it comprised mostly males (58.8%) and single individuals (67%) with an average age of 39.1 years old (standard deviation [SD]=12.04 years). In regard to employment, 62.23% of the sample was in a vulnerable situation because they were unemployed. Analysis of the remainder of the occupations showed that a further 13.74% was in a similar condition because they were homemakers who performed unpaid work. Only 1.1% of the sample worked in trade or specialized jobs in the service sector, while 14.29% performed unspecialized work that was mostly related to agriculture.

In regard to educational level, the largest fraction (26.9%) had attended but not finished secondary school, and the average number of years of schooling of the entire sample was 7.6 years (SD=3.8 years). Finally, only 12.09% of the sample had attended college for at least one year.

The clinical data showed that 85.17% of the sample had been diagnosed with chronic paranoid schizophrenia, and the average GAF score was 60.24 (ranging from 30 to 90) (SD=10.04). The illness had lasted 14.15 years

on average (DS=10.71 years). The participants had been admitted to hospitals 3.14 times on average (ranging from 1 to 7 admissions) (SD=2.0), while 25.8% of patients had never been hospitalized. The time elapsed since the last hospital admission was 2 to 5 years in 17% of the sample and 1 to 6 months in 14.3% of the sample. The most frequently reported length of hospitalization was 3 to 4 weeks, corresponding to 36.3% of the sample.

Regarding the SIS results, the total score corresponding to the support needs index showed that the global level of support needs of the investigated sample was low because it was located between the 26th and 38th percentiles according to the tables provided by the SIS. The subscales corresponding to employment and social activities exhibited the greatest intensity of support needs (Figure 1).
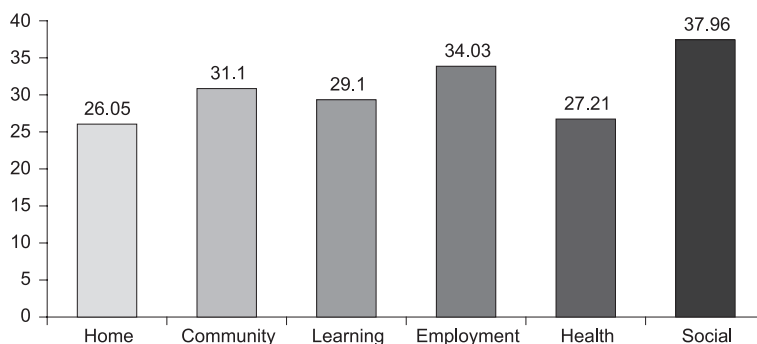

Figure 1 - Raw scores for each Supports Intensity Scale (SIS) subscale of individuals with severe mental illness at a public psychiatric hospital. Mexico, 2008-2009

As a whole, the home living subscale exhibited the lowest average raw score (26.05 points), which according to the SIS tables corresponds to a standard score of 8. The social activities subscale exhibited the highest score (37.96 points), corresponding to a standard score of 9 and denoting a relative greater need for assistance. These results were confirmed when the standard scores were placed in their respective percentile ranges, whereby the domain home living corresponded to the 26th percentile, and the domain social activities corresponded to the 38th percentile.

Finally, the total score of the support needs index showed that the global average level of support needs of the present sample corresponded to Level I (84 or less points). The dispersion of the values indicates that the studied population was distributed across Level I and Level III, corresponding to SIS scores between 100 and 115 and indicating a support intensity variation from low to high.

It is worth noting that the employment subscale exhibited the widest standard deviation (3.34), i.e., the widest variation between the minimum and maximum scores. This finding reflects the diversity of the supports intensity levels of the assessed individuals.

It must be stressed that the figure above represents the global profile of the sample, which allows us to identify the domains particularly affected in individuals

with severe mental illness and thus also affords a first approach to their support needs. Nevertheless, as shown in Table 1, regrouping the global results indicates that the participants exhibited different levels of support needs.

Table 1 - Distribution according to support need levels according to the global score in the Supports Intensity Scale (SIS) in individuals with severe mental illness at a public psychiatric hospital in Mexico, 2008-2009

Level of support needs	N	%	Cumulative %
Level I	111	60.99	60.99
Level II	64	35.16	96.15
Level III	7	3.85	100.00
Total	182	100	

Although in global terms the largest fraction of the participants exhibited a low level of support needs (60.99%), there were also groups with medium and high levels of support need. Therefore, we might elaborate a global profile for each subgroup, which would enable us to identify the needs common to their members.

Further ungrouping of the global results not only pointed to the domains exhibiting the greatest needs intensity but also to the concrete activities of each subscale that ought to be included in group planning as

a function of their relevance (see Figure 2). Identification of such concrete activities has paramount importance due to their usefulness in individual planning and in the quest for independence in life.

Subscale	Item	Activity
Home Living	5	Housekeeping and cleaning
Community Living	5	Shopping and purchasing goods and services
Lifelong Learning	8	Learning self-determination skills
Employment	1	Accessing/receiving job/task accommodations
Health and Safety Activities	8	Maintaining emotional wellbeing
Social Activities	8	Engaging in volunteer work

Figure 2 - Activities requiring greater support intensity in individuals with severe mental illness at a public psychiatric hospital. Mexico, 2008-2009

The analysis of the correlation between the scores in the six subscales and specific variables of interest is described in Table 2. The results showed significant associations of various subscales with disease progression and the participants' age. As a consequence, the longer the duration of disease and the older the individual, the greater the support needs. It is worth noting that those two variables exhibited a high degree of correlation (r_{xy}=0.75); thus, the variables age and duration of disease share 56% of the variance.

Table 2 - Correlation between percentile scores on the Supports Intensity Scale (SIS) and variables of interest in individuals with severe mental illness at a public psychiatric hospital. Mexico, 2008-2009

Subscale	Percentile score	Progression	Age	Sex	Global functioning
Home Living	26			0.166*	-0.517[†]
Community Living	31				-0.486[†]
Learning	29	0.232[†]	0.228[†]		-0.535[†]
Employment	34	0.221[†]	0.199[†]		-0.596[†]
Health and Safety	27	0.166*	0.163*		-0.559[†]
Social Activities	37				-0.544[†]
Needs global index	80.68	0.184*	0.185*		-0.617[†]

*Significant correlation with p<0.05 (bilateral)
[†]Significant correlation with p<0.01 (bilateral)

Discussion

If the results of a case-by-case analysis could be shown, we would realize that, indeed, there are coincidences between the groups that would provide us a basis for further elaboration. Nevertheless, each of the assessed subjects requires planning on an individual basis because the specific features of each one's environment and context conspire to create a wide scope of needs as a function of the different times, types and frequencies of the supports required. This circumstance has paramount importance because the main aim of the SIS is to provide a measure of the individual's support needs and thus supplies a useful tool for such planning.

Nevertheless, the impact of the individual factors cannot be passed over, nor can the factors related with the presence and progression of disease be overlooked, as analysis of their correlation shows (see Table 2). That analysis detected the presence of an association of selected sociodemographic and clinical variables with specific SIS subscales. To begin with, there is a correlation between the variable gender, which is not usually associated with the support needs scores, and the subscale measuring the activities corresponding to home living.

That significant positive correlation (noting that in our data matrix, women are represented by code 1 and men by code 2) suggests that greater needs for home living support are associated with belonging with the male gender.

In this regard, analysis of possible differences in the patients' global functioning (as measured by the GAF) as a function of gender did not find significant results (F=0.889; df=1.180; p=0.347), allowing

attribution of those differences to that variable, i.e., to cultural factors. More to the point, one might speculate that the men of the present sample require more support in the performance of home-related tasks for the simple fact of being male, which agrees with the gender role characteristic of the investigated social context. As a consequence, the greater support needs manifested by the men would not only be related to the individual progression of disease, which by itself is a cause of deterioration and of difficulties in assuming responsibility for self-care, but also to the different roles attributed to males and females in the investigated society that are determinant of the respective activities and attitudes.

A significant negative correlation between global functioning and the SIS subscales and support needs index was patently evident. This finding might be explained by the fact that the GAF assesses social, psychological, and occupational functionality; thus, the greater an individual's impairment, the greater that individual's support needs.

That correlation became even more evident when we ungrouped the GAF scores as a function of three cutoff points relative to the levels of impairment and correlated them with the support need levels. As Figure 3 shows, the group of individuals who scored 70 or higher in GAF exhibited the lowest support needs index. That correlation was statistically significant (chi-squared=48.725, df=4; p=0.000).
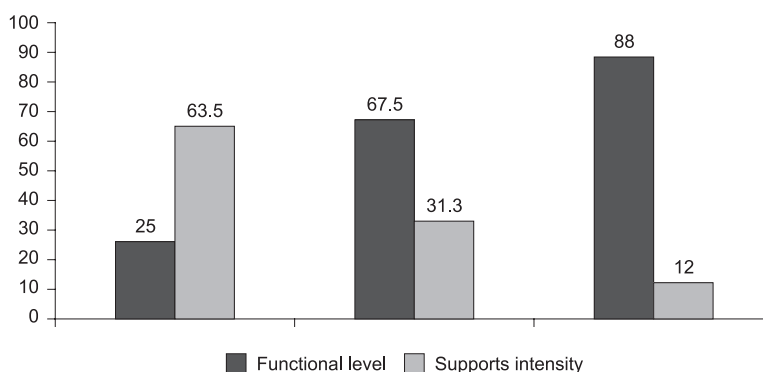

Figure 3 - Comparison of the scores on the Global Assessment of Functioning scale (GAF) and levels in the Supports Intensity Scale (SIS) of individuals with severe mental illness at a public psychiatric hospital. Mexico, 2008-2009

Conclusions

Firstly, the percentile scores of the various subscales of SIS ranged from the 26th to the 38th percentile, corresponding to the domains of home living and social activities, respectively. In addition, the scores' dispersion denoted remarkable heterogeneity in the support needs of the investigated population.

The global profile of the investigated sample was characterized by a low level of support needs. However, regrouping the participants according to their individual average scores allowed for the identification of three well-defined groups exhibiting low, medium, and high levels of support needs. The domains associated with the greatest support needs were employment and social activities.

The individual factors that exhibited correlations with greater support needs were time since the onset of disease, age, and functioning level (as measured by

the GAF). In addition, the gender variable exhibited a correlation with the support needs intensity relative to the domain of home living, which might be related to cultural factors.

The inverse correlation between the scores on the GAF scale and SIS is of particular interest because they are assessed by different types of examiners. The data relative to the SIS were provided by the patients and/ or their primary caregivers, whereas the GAF scores were attributed by healthcare professionals based on their clinical judgment of the participants and previous knowledge of their social, personal, and occupational functioning.

Based on the poor availability of formal support systems that aim to promote self-determination and the inclusion of individuals with mental illness, as well as the few opportunities for them to participate in activities common to adults, including activities related to work, leisure, and learning, we expected the support

needs index exhibited by the investigated population to be high. However, the level proved to be low. The reason for this finding might not attributed to problems inherent to the scale used but rather to characteristics determinant of the cultural context that allow the lack of opportunities for participation by individuals with mental illness to be understood as natural. The demonstration of this hypothesis, however, requires complementary qualitative studies.

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