Evaluation of social disablement, psychiatric symptoms and autonomy in long-stay psychiatric patients

Avaliação do comportamento social, sintomas psiquiátricos e autonomia em pacientes psiquiátricos de longa permanência

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Abstract

Background: Data on prevalence of social disablement, psychiatric symptoms and independent living skills in long-stay psychiatric patients are scarce in Brazil. Therefore, a cross-sectional study was carried out on a population of 881 long-stay psychiatric patients. Method: Data were collected from all the patients living in the Municipal Mental Health Institute from Rio de Janeiro city, using 3 instruments: Social Behaviour Schedule (SBS-BR), Brief Psychiatric Rating Scale (BPRS), and Independent Living Skills Survey (ILSS-BR). Results: 75% of total patients presented poor independent living skills, and high rates of social disablement, specially in the items: poor self care (50,9%), little spontaneous communication (46,2%) and underactivity (37,5%). 15.1% of schizophrenic patients showed severe symptoms of hallucinations, delusions and conceptual disorganization.11.5% did not present psychiatric symptoms in the last month, and 16% showed no social disablement Conclusion: 50% of patients are older than 65 years and have been living in the institution for more than 38 years. They present high rates of problem behaviours and poor autonomy. Our data should suggest the adoption of treatment programs or interventions for those patients. Also, there is a group without psychiatric symptoms, good autonomy degree and no social disablement that could live in therapeutic residences in the community.

Key-words: Social disablement, psychiatric symptoms, autonomy.

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Resumo

Introdução: No Brasil ainda são escassos os dados sobre limitações no comportamento social, sintomas psiquiátricos e habilidades de vida independente. Nesse sentido foi realizado um estudo seccional em uma população de 881 pacientes psiquiátricos de longa permanência. Metodologia: Foram coletados dados de todos os pacientes residentes no Instituto Municipal Juliano Moreira, utilizando três instrumentos: Avaliação das Limitações no Comportamento Social (SBS-BR), Brief Psychiatric Rating Scale (BPRS) e o Inventário de Habilidades de Vida Independente para Pacientes Psiquiátricos – (ILSS-BR). Resultados: Do total de pacientes, 75% apresentaram pouca habilidade de vida independente, *score* < 2, e limitações no comportamento social, especialmente nos itens: cuidados pessoais (50,9%), comunicação espontânea (46,2%) e retardo psico-motor (hipoatividade) (37,5%); 15.1% dos pacientes com esquizofrenia apresentaram sintomas graves de alucinações, delírios e desorganização conceitual; 11.5% dos pacientes esquizofrênicos não apresentaram sintomatologia psiquiátrica, no último mês, e 16% não apresentaram limitações no comportamento social. Conclusão: 50% dos pacientes têm mais de 65 anos e vivem na Instituição por mais de 38 anos. Apresentam altas taxas de problemas no comportamento e pouca autonomia. Os dados sugerem a importância de programas específicos para estes pacientes. Além disso, existe um grupo de pacientes sem sintomas psiquiátricos, com bom grau de autonomia e sem limitações no comportamento social que poderia viver em residências terapêuticas na comunidade.

Palavras chave: Limitações sociais, sintomas psiquiátricos, autonomia.

Introduction

In the last 30 years, the arising of new mental health care services reached an important international reward. Nowadays, there is a consensual knowledge that we need to replace the treatment provided in hospital by other facilities in the community. One of the main problems is how to manage chronic patients in the community (Arnhoff, 1975; Bandeira, 1991). As they have greater difficulties to look for care by themselves, many times they get no access to minimal subsistence conditions. Most of them finished neglected in mental health centres (Wing, 1990). It is necessary to create other facilities where they can have a distinguished care so that their difficulties can be solved (Hafner e Heiden, 1989; Garcia e Vasquez-Barquero, 1999).

Brazilian psychiatric reform needs to have its goals evaluated. Despite the efforts to transfer hospital care to community facilities, this community network is not well established.

In 1941 the rate bed/1000 inhabitants was 0.58 in Brazil, rising to 0.88 in 1984. Nowadays there are 63,660 psychiatric beds (0.36/1000). The main problem is that 21% of these beds are located in hospitals with more than 400 beds. In these hospitals most of the patients have been in-patients for more than 1 year (long-stay psychiatric patients) (DATASUS, 2004). Most of them spent their lives and got old in these macro-hospitals. This population has peculiarities, mainly according to poorer daily living skills, and must have specific health programs.

A comprehensive evaluation of long-stay psychiatric patients is very useful for policy-makers and mental health professionals who are involved in the delivery of community-based care. However, there are few studies of this issue in Brazil (Gonçalves *et al.*, 2001). Therefore, this study aimed to estimate the prevalence rates of social disablement, psychiatric symptoms and independent living skills in a population of Brazilian long-stay psychiatric patients. In the context of hospital closure, it is important to provide appropriate community care for these patients (Thornicroft e Bebbington, 1989; Trieman *et al.*, 1996). For developing alternatives of care, it is necessary to know their psychiatric characteristics, limitations in social behaviour and daily living skills (Talbott, 1979; Trieman *et al.*, 1998).

Method

Setting

The research was conducted at the Municipal Institute Juliano Moreira (IMASJM). It is an old style asylum devised to lodge adult psychiatric patients (n=881), located in the west of Rio de Janeiro metropolitan area. It was established in 1924, and municipal authorities run it now. IMASJM has five different settings inside the institution, and one outside, which are as follows: 1- *Núcleo Franco da Rocha* (NFR) and *Núcleo Ulisses Viana* (NUV) resemble "a ward in home", each one comprising 3 purpose-built houses (*welcome houses* - each house had 10 rooms with 20 patients) and 3 wards that have been reformed. These units lodge 167 women (NFR) and 167 men (NUV) separately. The staff:patient ratio (ratio of fulltime equivalent staff to patients) were 1:1.25, and 1:2, respectively; 2- *Núcleo Teixeira Brandão* (NTB) and *Pavilhão Agrícola* (PA) are conventional psychiatric wards lodging 335 women (NTB) and 62 men (PA) separately. The staff:patient ratio were 1:2.2, 1:1.8, respectively; 3- *Núcleo Rodrigues Caldas* (NRC) is a typical hospital hostel, having 97 male residents.; there are no locked doors and patients can come and go freely. The staff:patient ratio was 1:1.7 ; 4- *Centro de Reabilitação e Integração Social* (CRIS) comprises 8 community integrated living arrangement residences, close to a busy neighbourhood, lodging 31 women and 22 men separately. These patients live alone, receiving

staff-group visits regularly. The total staff:patient ratio was 1:4.4

Apart from NRC and CRIS settings, the others facilities are restrictive in their mental health care. The health staffs are minimal and are made up of general practitioners, psychiatrists, nurses, psychologists, occupational therapists and social workers. The main concern is to provide some follow up to those already in the asylum. A few patients follow a program of psychosocial rehabilitation. In general, this program is not available for all of the patients. It has been applied neither equitably nor consistently. In the TAPS Project 44 study, the staff:patient ratio (ratio of fulltime equivalent staff to patients) in the studied four facilities ranged from 1.7:1 to 1:1 (Trieman *et al.*, 1999).

Study Population

It was a cross-sectional study. All 881 patients lodged in the IMASJM at the time of data collection were included in this study. The social-demographic characteristics and psychiatric diagnosis (CID 10) were obtained from the IMASJM records and case notes.

Instruments

Social Behavioral Schedule

The Social Behaviour Schedule (SBS) covers 21 areas of behavioural difficulties exhibited or experienced by patients with chronic mental illness. These items range from day to day activities like hygiene and social mixing to behavioural signs of psychiatric illness such as depression, over activity and restlessness. They are rated on a five-point scale after discussing the severity and frequency of each of these difficulties with a key informant who was able to observe the client's behaviour in the month prior to the interview. The items are rated 0 if the informant suggests that patient behaviour regarding this item is acceptable and there is no problem in the previous month. A score of 4 is given to any reported as having a serious problem according to the coding (Wykes e Sturt, 1996; Lima *et al.*, 2003b). The BSM scoring method was used in this study to assess the presence and the absence of social behaviour problems. This method scores the problem as present (1) when the item score is 2, 3 or 4 and absent (0) when the score is 0 or 1.

Independent Living Skills Survey (ILSS)

This schedule gives us a detailed overview of the independent living skills of psychiatric patients. The Brazilian version has 86 items distributed in 9 areas, and these sub-items evaluate several aspects of daily life such as: eating, grooming, domestic activities, food preparation and storage, health, money management, transportation, leisure and job seeking (Wallace, 1986; Bandeira *et al.*, 2003; Lima *et al.*, 2003a). The interviewer administers the questionnaire to someone who knows better the patient and can give us information about the patient's greater or lesser ability to look after themselves and their interests.

Psychiatric symptoms

The severity and type of psychopathology were rated using the Brief Psychiatric Rating Scale (BPRS), Bech *et al.* (1986) version. This version has 18 items that evaluates main symptoms present in schizophrenic patients. It follows the Hamilton Depression Scale model that reduced the levels of severity to 5 levels. The items are scored in a severity degree ranging from 0 (absent) to 4 (severe) and have anchor points for all five steps of the scale for each item. This scale has been translated and adapted to Portuguese by Zuardi *et al.* (2000). The interviewers administered it to the patients using a structured interview guide.

Procedures of assessments

Data were collected from 881 patients using all instruments, from August 2000 to July 2001. Ten psychologists, who had been trained in the SBS-BR, BPRS and ILSS-BR, performed all interviews. Before beginning it, each informant was given an explanation of the study aim and asked to collaborate by giving his/her informed consent.

Data analysis

Mean prevalence rates and proportions were calculated, including subgroups. To compare one value with another the following statistical tests were used: the One-Way Analyses of Variance, independent samples T-Test, and non-parametric test Mann-Whitney U. A given difference was considered statistically significant when the p-value was equal or lower than 0.05. The Statistical Data Analysis SPSS 10.1 was used for data entry and analysis.

Results

Socio-demographic characteristics

The great majority of the study population were women (59%), illiterates (61%), unemployed (98%), but 44% had a regular income – a retirement pension or an allowance from the Municipal Government. The mean length of stay was 37.3 years (SD=11.5), and 90% of the patients have been living in IMASJM for more than 25 years. 72% had no visits in the last 6 months. The age of the patients ranged from 24 to 98 years with a mean of 65.8 years (SD = 11). 55% had more than 65 years. Regarding psychiatric diagnosis, they were based on medical records according to new ICD-10 edition: 63% were assessed as having schizophrenia, schizotypal and delusional disorders (table 1).

The distribution of these data were very similar among all settings, except CRIS which presented the lowest mean age (53.26; SD = 13.14), having the

Table 1. Socio-demographic characteristics of IMASJM patients, Rio de Janeiro, 2001.

Variables	n	%
Gender		
Female	520	59
Male	361	41
Education level		
Illiterate	537	61
Primary school	132	15
Secondary school	18	2.0
No information	194	22
Employment		
Unemployed	863	98
Employed	18	2.0
Income		
Regular	396	45
Irregular	26	3.0
None	423	48
No information	36	4.0
Number of visits in the last 6 months		
None	634	72
1 to 10	185	21
11 to 20	27	3.0
No information	35	4.0
Psychiatric diagnosis Schizophrenia, schizotypal and delusional disorders	555	63
Mental retardation	167	19
Epilepsy	53	6.0
Abuse/depence of psychoactive substance	20	2.3
Organic, including symptomatic, mental disorders	18	2.0
Mood [affective] disorders	14	1.6
Unspecified mental disorder	54	6.1

Table 2. Prevalence of social disablement in IMASJM patients (n = 881).

Item	n	%
1- Little spontaneous communication	405	46.2
2- Incoherence of speech	221	25.5
3- Odd or inappropriate conversation	107	12.4
4- Inaproppriate social mixing	210	24.1
5- Hostility	91	10.4
6- Demanding attention	82	9.3
7- Suicide ideas or behaviour	6	0.7
8- Panic attacks and phobias	60	6.8
9- Overactivity and restlessness	181	20.6
10- Laughing or talking to self	203	23.2
11- Acting out bizarre ideas	28	3.2
12- Posturing and mannerisms	132	15
13- Socially and unacceptable habits or manners	159	18.1
14- Violence or threats	21	2.4
15- Depression	55	6.3
16- Inappopriate sexual behaviour	34	3.9
17- Poor self care	446	50.9
18- Slowness	152	17.4
19- Underactivity	327	37.5
20- Poor attention span	326	41.5
21- Other behaviour	174	20.2

Table 3. Prevalence of problems on social behavior (SBS-BR) in IMASJM patients (n = 881).

Problems SBS-BR	N	%
Without problems	145	16.5
1-2 Problems	199	22.6
3-5 Problems	307	34.8
> 5 Problems	230	26.1
Total	881	100

lowest mean length of stay (27.17; SD = 14.89) and a different diagnosis distribution: schizophrenia, schizotypal and delusional disorders (40.5%), mental retardation (11%), epilepsy (11.5%), neurotic, stress-related and somatoform disorders (9.6%), of adult personality and behaviour of adult personality and behaviour (5.8%) mood [affective] disorders (3.8%), mental and behavioural disorders due to psychoactive substance use (5.7%) and unspecified mental disorder others (12.1%).

Social behaviour problems

The social behaviour problems are presented in table 1. Out of 21 isolated behavioural problems, the more frequent were as follows: 50.6% poor self-care, 46% little spontaneous communication, 41.1 % poor attention span, 37.1% under-activity, and 25.5% incoherence of speech. The overall mean score of SBS items was 3.9 (SD = 3.1). Of the population, 16% showed no behaviour problems, and 60.9% had more than 3 SBS problems (table 2 and 3)

Independent Living Skills

The great majority of the patients presented the worst scores in the following sub-items: job-seeking (94%), leisure (74.2%), money management (73.3%), food preparation and storage (56.6%), and domestic activities (53.5%). They had the best scores in the sub-item eating. The mean score of the population is 1.4 (SD=0.8). Most of population showed low autonomy and need specific intervention programs (Table 4).

Relations between independent living skills and gender

Men showed statistically significant higher rates in ILSS-BR total scores (1.50 vs. 1.37; Z = -2.21; p=0.03): money management (0.84 vs. 0.67; Z= -1.52; p=0.01), transportation (1.23 vs. 0.76; Z= -6.03; p<0.001), leisure (0.78 vs. 0.58; Z= -4.57; p<0.001), and job-seeking (0.42 vs. 0.17; Z= -5.93; p<0.001) than women, except grooming (2.10 vs. 2.30; Z= -2.38; p=0.02).

Relations between independent living skills and age group

Clients of the six different units of IMASJM were compared one-way analyses of variance in the ILSS-BR total

Table 4. IMASJM patients (n = 881) performance in 9 Sub-Items of independent living skills.

Sub-items	None/little		Reasonable		Good/excelent		Total	
	N	%	N	%	N	%	N	%
Eating	144	16.3	195	22,2	542	61.5	881	100
Grooming	401	45.5	179	20,4	301	34.1	881	100
Domestic activities	576	65.4	121	13.7	184	20.9	881	100
Food preparation and storage	627	71.2	97	11,0	157	17.8	881	100
Health	559	63.5	183	20,7	139	15.8	881	100
Money management	744	84.5	78	8,8	59	6.7	881	100
Transportation	736	83.5	72	8.2	73	8.3	881	100
Leisure	851	96.6	30	3,4	–	–	881	100
Job-seeking	855	97.0	8	1.0	18	2.0	881	100

score. Levels of significance were set at $p < 0,05$ (dunnett C adjustment). Patients under 60 years showed significantly higher total ILSS-BR scores than those over 65.

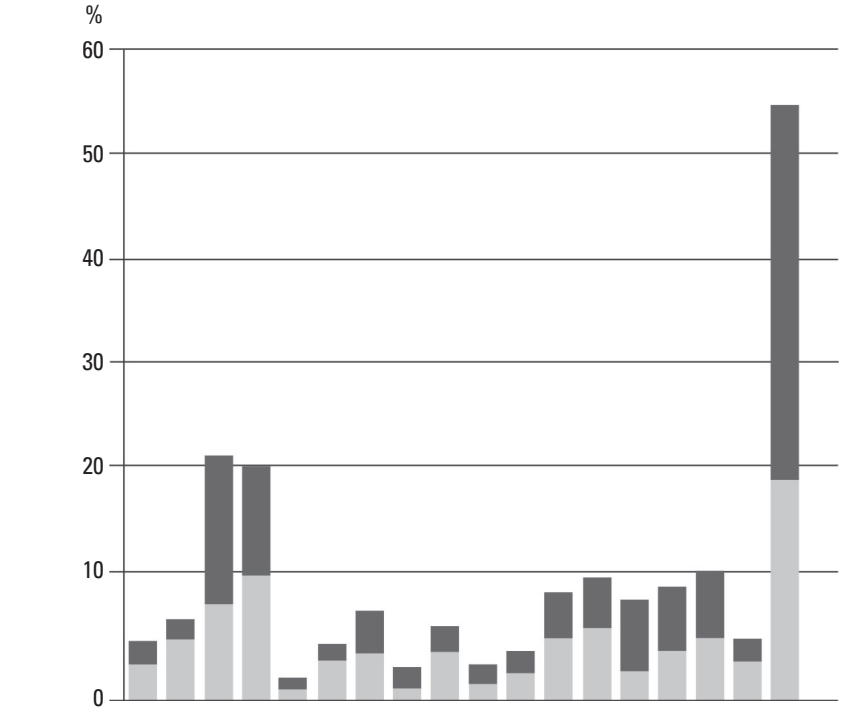
Psychiatric symptoms

All the 471 patients (53.5%) with schizophrenia diagnosis (F20) were interviewed. Psychiatric symptoms were not found (score = 0) in 54 patients (11.5%). At least one of the following symptoms (Figure 1): hallucinations, delusions and conceptual disorganization were found in 64 patients (13.1%) in severe scores (score>=3). Most of these patients (60%) presented severe scores in one of the symptoms: flattening of affect, conceptual disorganization and disorientation and confusion.

Results

Socio-demographic characteristics

Most of of the study population were more than 59 years old (59%). They have been living inside the institution for a long time. Most of them (75%) had been inpatients



	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Escore ≥ 3	2.3	1.9	14	10	1.1	1.5	4	1.9	2.6	2	2.3	4.3	4.9	7	6.2	6.4	2.3	36
Escore 2	3.6	6	9.4	12	1.3	4	4.7	1.3	4.7	1.7	2.6	6.2	7	2.8	4.9	6.2	3.8	21

1. Somatic worries
2. Psychotic anxiety
3. Flattening of affect
4. Conceptual disorganization
5. Poor self-esteem and guilty
6. Somatic anxiety
7. Specific motors disturbances
8. Increased self-esteem
9. Depression
10. Hostility
11. Suspiciousness
12. Hallucinations
13. Psychomotor retardation
14. Uncooperativeness
15. Delusions
16. Incongruity of affect
17. Overactivity and restlessness
18. Disorientation and confusion

Figure 1. Mental state findings in IMASJM patients (n = 471) with a broad diagnosis of schizophrenia.

for more then 33 years. Younger patients were living in Therapeutic Residences, coordinated by CRIS.

More than half had no friends or minimal social contact in the community. These people were not engaged in daily activities. They have some difficulties to change habits and no money to spend in leisure activities. The highest rates of unemployment have been reported in schizophrenic patients. Since they were out of working age, sheltered employment can be an alternative for these patients (Harvey, 1996).

Prevalence of social disablement

The main finding related to SBS was that 60.9% of the psychiatric population showed 3 or more social problems. The most frequent problem behaviours found were: poor self-care, little spontaneous communication, poor attention span, under-activity and incoherence of speech. These patients showed more social problems with hygiene, impoverished social networks, reduced levels of occupation, history of long psychiatric hospital admissions, and unemployment (Lima *et al.*, 2003b). Similarly results were founded in a large Brazilian psychiatric hospital, in Porto Alegre, RGS (Dias *et al.*, 2002).

Other behaviour problems found in high prevalence were: incoherence of speech, inappropriate social mixing and laughing and talking to self. Patients with high scores in these items have fewer social opportunities at their place of residence (Wykes *et al.*, 1998). Furthermore, we found low prevalence of social disablement that could result in risk to patients living in the community, such as violence, inappropriate sexual behaviour and suicidal thoughs or behaviour. In addition, a low prevalence of hostility was found, which could be a predictor of deinstitutionalization success (O'Driscoll *et al.*, 1993; Rudd *et al.*, 1998).

Although inpatients have fewer social opportunities than those living in community, it is important to know their social behaviour characteristics to be able to evaluate changes when they get out to other facilities and to determine the level of protection they will need.

Harvey (1996) and Wykes *et al.* (1998) interviewed a representative sample of people with psychosis living in the community. Regarding social disablement, their results were broadly similar. However, comparing their data with ours, we found that our population were more disabled in the great majority of items, especially little spontaneous communication, poor self-care and under activity. These symptoms did not change significantly when long-stay patients were discharged from psychiatric hospitals to live in the community (Trieman e Leff, 2002).

These symptoms were more prevalent in studies carried out in long-stay psychiatric in-patients than other ones conducted in the community (Leff *et al.*, 1996; Holloway *et al.*, 1999; Leff e Trieman, 2000). Comparing with Wykes & Sturt (1996), the following items were found significantly more prevalent in our study than theirs: little spontaneous communication, poor attention span, under-activity and incoherence of speech. Our population was also more disabled than the homeless people who were evaluated using SBS (Hamid *et al.*, 1995; Lovisi *et al.*, 2002). In sum, our sample presented more social behaviour problems than all of the samples studied. The precarious conditions of the institution, where the patients have been living for decades, and unmet individual care, may have contributed to exacerbate their social disablement.

Prevalence of independent living skills

The great majority of the patients did not present independent living skills. These results are expected in an elderly long-stay population. Most of them have no autonomy in job-seeking, leisure, money management and transportation needing specific social interventions to be drift. These areas were worst in women. In the sub-items domestic activities and food preparation and storage, the score of the population ranged from little to reasonable. Patients had no opportunities to develop these areas, since cleaning and cooking are employees' tasks. In spite of the long years of institutionalisation, the patients reached a regular score in the sub-items eating and grooming. The staff has carefully supervised these areas. The lowest scores in the sub-scales self-care and domestic activities were found in long stay patients living in the community, probably because these patients had more opportunities to practice their autonomy (Sood *et al.*, 1996; Trieman *et al.*, 1999; Wallace *et al.*, 2000).

Men presented higher level of education than women, which could explain gender differences in autonomy. The lowest age group showed statistically significant higher autonomy than older ones.

Prevalence of psychiatric symptoms

The Brief Psychiatric Rating Scale is actually used to evaluate changes in schizophrenic psychiatric patients who go from hospital to community settings. (Inch *et al.*, 1997; Curson *et al.*, 1999).

Most of the sample patients with schizophrenia did not present high proportion of severe symptoms, except disorientation and confusion, and 11.5% did not presented psychiatric symptoms in the last month. It is unsurprising to find these results in chronic patients who stay a long period of time in psychiatric hospital. However, those schizophrenic patients (15.1%) with severe symptoms such as hallucinations, delusions and conceptual disorganization were in need of intensive treatment services.

The majority of patients presented highest scores in negative factors. Therefore, our findings could suggest that negative symptoms exhibited by patients could be related to their length of stay in the institution.

The patients of CRIS had significantly higher scores in anxiety and depression symptoms than the patients who live in other units, probably because of the contact with external life stress.

Asymptomatic schizophrenic patients showed statistically significant higher rates in ILSS-BR total scores than symptomatic ones (0.90 vs. 1.42; Z = -5,02; p=0.000).

Conclusion

The lack of adequate alternative housing for mentally ill is a national problem and an important issue for the success of psychiatric deinstitutionalization (Lamb, 1979).

Analysing socio-demographic characteristics of IMASJM population, we can suppose that a large percentage of the population living in Brazilian macro-hospitals is composed of elderly patients. The incidence and prevalence of dementia disturbances grows with aging and cognitive impairments produce important deteriorations. (Langley 2000). The needs of this population, especially those disabilities related to aging, must be the principal concerns in the planning of health and rehabilitations programs.

When demographic, social disablement, living skills and psychiatric symptoms data are analysed together, it becomes clear that IMASJM lodge predominantly elderly long-stay psychiatric patients with negative symptoms and poor autonomy.

Since other macro-hospitals probably have the same profile, it is important to know the characteristic of their population for mental health police planning. Most of the studied population have no family to go back to, so they need specific kinds of facilities, with different levels of protection to leave the hospital.

Our data should suggest specific programmes and treatment interventions for these patients. An example might be relocating them to specialised community facilities linked to standard care (Wing, 1990; O'Driscoll *et al.*, 1993; Ruud *et al.*, 1998).

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