

A survey to investigate the preferred terms describing people with mental disorders – recipients' and providers' opinions

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Summary

Aim. To analyse the recipients' and staff opinions from the mental health and social care services on preferred terms describing people with mental disorders.

Method. In 2008 and 2010, 634 recipients and 397 providers from Warsaw mental health and social care services, answered survey on preferred terms describing people with mental disorders anonymously.

Results. The term "patient" was the most preferred one, as well as by the recipients (76.2%), as the providers (87.7%) of the services. The second choice among the recipients of the services, however much less preferred, was the term "person using mental health services" (25.1%), among the providers "person with mental disorders" (25.9%). With similar frequency the recipients indicated the term "person receiving psychiatric treatment" (22.4%) and "person with mental disorders" (22.1%); the staff "person with mental problems" (23.2%). The terms: "user" (3.9% recipients, 2.0% providers), "beneficiary" (respectively 5.2%, 2.0%), "client" (7.4%, 6.8%) were the less preferred ones.

The recipients from out-patient clinics and community based facilities as well as from the nursing home, occupational therapy workshop and home care services also favoured the term "patient" (71.1%, 77.8%, 63.9%, 68.3% respectively). In spite of staff profession and number of years spent working in mental health or social care services the term "patient" was the most preferred one. The providers from nursing home preferred the term "person mentally ill" (nearly 61%) and "person with mental disorders" (57%).

Conclusions. The term "patient" was the most preferred one in the group of recipients and service providers. The form of services provided did not differentiate the recipients' opinion in regards preferred terms. Profession and number of years spent working in mental health or social care services did not differentiate the providers' opinion in regards preferred terms. The providers from nursing home indicated the term "person mentally ill" and "person with mental disorders" the most frequently. Further dialogue on the preferred terms is needed, since they might empower or stigmatise.

Terms for recipients of mental health services / quality of care

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INTRODUCTION

Language matters in psychiatry [1, 2, 3]. It is claimed to have the potential to contribute either to stigma and social exclusion or to empowerment of people using mental health services [4, 5].

A variety of terms are used by health and social care professionals and by service user groups to refer to people with mental disorders.

The terms used include “patients”, “clients”, “service users”, “people affected by mental illness” [6]. Also accepted are: “recipients” [6, 7] and “attendees” [8]. Health service user groups advocate the terms: “ex-patient”, “psychiatric in-mate”, “survivor” [9] or “user” [10].

The authors’ arguments in favour of one of the terms depends on the etymology or the power relations and rights that they imply. One of the psychiatrists [11] criticises the terms “client”, “service users” in mental health services as being controversial: (...) *What are the connotations of the word client? (...) Prostitutes and lawyers have clients. The emphasis is on the freedom of the client to take or leave the service they have paid for. Most psychiatric practice is not like this. (...) What then of the term service user? People who use others are users and many of the people I meet have had experiences of being used. To become a service user after being used is deeply problematic. (...) On the contrary Neuberger and Tallis [10] argues: (...) Thus, the strongest argument against the use of patient to describe a user of health services is that word indicates immediately the unequal nature of the relationship and “objectifies” the person who is the user. (...) The user becomes passive; the provider becomes all knowing, all healing, all powerful. (...)*

Although quite numerous studies have been carried out, which sought the answer what are the patients’ and professionals’ preferences with respect to the terminology denoting people with mental disorders the consistent – satisfying solution is not found so far. However, a clear tendency emerges from the literature. A systematic review of the empirical studies about the terms used to refer to people who use mental health services revealed that the terms “patient” or “client” were indicated most often by respondents as preferable ones, with “patient” being the most popular in the UK and “client” being regarded as the best option in the US [4].

METHOD

The aim of the present study was to explore the opinions of providers and recipients of mental health and social care services with regard to the preferred terms describing people with mental disorders.

At the first stage of the study, the survey questionnaire (with separate versions for recipients

and providers) was developed by a team of researchers with various professional background (three psychiatrists, a psychologist, a sociologist, a pedagogue and a nurse) with active input from people receiving psychiatric treatment, using a *focus group* strategy. At the second stage the questionnaire was piloted among the mental health service users and staff and adjusted in accordance to the respondents’ comments. Its final version, which has already been used in our previous report [12] included fourteen terms referring to people with mental disorders and an open category “other – please let us know”. The participants were instructed to indicate as many preferred terms as they wished. A brief socio-demographic data sheet was also attached.

The study was conducted anonymously in years 2008 and 2010, in Warsaw, in various mental health facilities (in-patient wards, out-patient clinics and community teams) and social care services (a nursing home *Dom Pomocy Społecznej*, a occupational therapy workshop *warsztaty terapii zajęciowej*, a home care services *specjalistyczne usługi opiekuńcze*).

All the potential participants have been informed about the aim of the study and the anonymity and confidentiality rules during the therapeutic community meetings or in face to face contact with the staff and all have been provided with the questionnaires. They put the filled in questionnaires into special boxes, available in the services all the time.

RESULTS

Overall, 634 recipients and 397 providers from Warsaw mental health and social care services completed the survey. The socio-demographic characteristics of the respondents are summarised in Tab. 1 – *next page*.

In the recipients group gender distribution was nearly the same, among the providers women were in the majority. In both groups educated persons – on the secondary (high) school or university level were in majority. The age range in the recipients group was higher than among the staff.

In the recipients group the majority of the respondents was from the in-patient wards, the second numerous group was from the out-patient settings. Eighty percent of the providers’ group worked in the in-patient settings.

Table 1. Socio-demographic characteristics of the participants

Characteristic	Recipient n=634		Provider n=397	
	n	%	n	%
Gender:				
female	317	50.0	286	72.0
male	306	48.3	85	21.4
missing data	11	1.7	26	6.6
Age:				
range (years)	18 – 85		20 – 65	
Highest obtained education level:				
primary school	54	8.6	8	2.0
technical training	99	15.6	55	13.9
secondary school	297	46.8	178	44.8
academic degree	175	27.6	137	34.5
missing data	9	1.4	19	4.8
Type of services currently used:				
in-patient ward	411	64.8	318	80.1
out-patient clinic	92	14.5	25	6.3
community team	54	8.5	12	3.0
nursing home	36	5.7	28	7.1
occupational therapy workshop	41	6.5	14	3.5
home care services				

Tab. 2 depicts the occupational characteristics of the providers in the study. The most prominent groups were – nurses (nearly 40%) and hos-

pital orderlies (nearly 20%). The providers with over ten years experience in mental health services were in majority (56.4%).

Table 2. Providers' occupational characteristics.

Providers (n=397)	n	%
Number of years in mental health:		
≤ 1 ≤ 10	150	37.8
> 10	224	56.4
missing data	23	5.8
Profession:		
nurse	157	39.5
doctor	54	13.6
psychologist	32	8.1
hospital orderly	79	19.9
occupational therapist	10	2.5
social worker	8	2.0
attendant	13	3.3
other	14	3.5
missing data	30	7.6

As can be seen from Tab. 3, the term “patient” was definitely the most preferred one,

both by the service recipients (76.2%) and providers (87.7%). The second most frequent choice

Tabel 3. Respondents' preferred terms describing people with mental disorders

Terms	Recipient n=634		Provider n=397	
	n	%	n	%
Patient (<i>pacjent</i>)	483	76.2	332	83.6
Client (<i>klient</i>)	47	7.4	27	6.8
Mentally ill (<i>chory psychicznie</i>)	73	11.5	41	10.3
Person with mental illness (<i>osoba chorująca psychicznie</i>)	92	14.5	82	20.7
Person mentally ill (<i>osoba chora psychicznie</i>)	98	15.5	55	13.9
Person with mental disorders (<i>osoba z zaburzeniami psychicznymi</i>)	140	22.1	103	25.9
Person receiving psychiatric treatment (<i>osoba lecząca się psychiatrycznie</i>)	142	22.4	70	17.6
Person using mental health services (<i>osoba korzystająca z psychiatrycznej opieki zdrowotnej</i>)	159	25.1	74	18.6
Beneficiary (<i>beneficjent</i>)	33	5.2	8	2.0
User (<i>użytkownik</i>)	25	3.9	8	2.0
Attendee (<i>podopieczny</i>)	83	13.1	53	13.4
Person with the experience of mental illness (<i>osoba z doświadczeniem choroby psychicznej</i>)	96	15.1	41	10.3
Person with mental problems (<i>osoba z problemami psychicznymi</i>)	122	19.2	92	23.2
Person with the experience of mental crisis (<i>osoba z doświadczeniem kryzysu psychicznego</i>)	121	19.1	46	11.6
Other (<i>inne</i>)	24	3.8	26	6.5

Note: respondents were given the opportunity to indicate as many options as they wished, therefore the numbers do not total to 634 or 397 and the percentages do not sum to 100.

among the recipients of the services, however much less preferred, was the term “person using mental health services” (25.1%), whereas among the providers it was “person with mental disorders” (25.9%). With similar frequency the service recipients indicated the terms “person receiving psychiatric treatment” (22.4%) and “person with mental disorders” (22.1%) and a comparable proportion of the staff choice “person with mental problems” (23.2%). The terms: “user” (indicated by 3.9% of the recipients and 2.0% of the

providers), “beneficiary” (5.2% and 2.0% respectively), “client” (7.4% and 6.8%) were the least preferred ones.

It should be noticed that nearly four percent of the service recipients selected an open category option, suggesting the following terms: “person with emotional disturbances”, “suffering person”, “person affected by hard trauma”, “depressed person”, “person affected by neurosis”, “master, guru, your eminence”, “very important person”, “madman”, “nuts”, “loony”,

“freak”, “idiot”, “resident”, “boarder”, “participant”.

Slightly more, six and half percent of the providers chose an open category option. The following terms were proposed: “ill”, “person suffering because of mental disorders”, “person with psychotic episodes experience”, “stakeholder”, “resident”, “visitor”, “participant”.

The analysis of the respondents’ preferences with regard to the type of services they were currently using or providing revealed that the term “patient” was the most frequently chosen by all subgroups, with just one exception – the providers from nursing home preferred the term “person mentally ill” (nearly 61%) and “person with mental disorders” (57%), the term “patient” was indicated less frequently (39%), equally to the term “person using mental health services”.

Although the providers’ preferences evaluated with regard to their profession in all cases were consistent – the term “patient” was the most frequently chosen – nurses 89.1%, medical doctors 85.1%, hospital orderlies 92.4%, occupational therapists 90.0% – the certain tendency is observed: only 75.0% psychologists, only 75.0% social workers and only 53.9% attendants (professionals working in the nursing home) indicated this term.

The certain tendency in the preferences is also observed when comparing the providers’ groups dichotomised with respect to the years of experience in mental health or social services: however both of them indicated the term “patient” as the most preferable one – in the less experienced group (≤ 10 years spent working in mental health or social care services) it was 75.3%, in the more experienced one (> 10 years) – 89.7%.

DISCUSSION

In this study we explored the preferences of providers and recipients of mental health and social care services with regard to the most appropriate terms used to describe people with mental disorders. Our results are consistent with the findings of the majority of previous studies regarding this issue [4].

We can speculate that such a result might indicate that for our participants the term “patient” notifies all these values that people are looking

for when seeking medical or social help: to be protected, cared for, treated with vocation and compassion – traditional values which are deeply rooted in Polish culture – instead of being recipient of services provided, which might imply that the process of treatment and recovery is managed by the commercial rules. In our study both the recipients and the providers indicated the term “client” with nearly the same, very low frequency – 7.4% and 6.8% respectively.

The terms promoted in other countries [10] are not implemented in our cultural context so far: the term “user” was indicated with the frequency of 3.9% among the recipients group and with the 2.0% among the providers group. Others like “ex-patient”, “psychiatric inmate”, “survivor” [9] didn’t pass the threshold when working out and piloting the first version of the questionnaire.

It is worth to point out that in our survey there is high consistency among the recipients and providers regarding the preferable term. We have found it slightly astonishing that the persons using the deinstitutionalised forms of mental health services as well as the responders from social services favoured the term “patient”. In these forms of care one can expect that they feel more like “clients” or “users” than “patients”. Moreover our results are in opposition with the formally acknowledged terminology which is “user”, “client” and “attendee” for the recipients from occupational therapy workshop, social and home services respectively. It may mean that among our respondents the terminology rooted in tradition is stronger than the new one and that for them it has not negative associations with stigmatisation and disempowerment.

Among the respondents the differences raised in „open” category: the recipients’ suggestions are focusing on personhood or terms with pejorative meaning: “madman”, “nuts”, “loony”, “freak”, “idiot” or those related to the significance and knowledge: “master, guru, your eminence”, “very important person”. The respondents from social services omit the medical meaning and suggest the terms adequate to the place of the services provided like: “resident”, “boarder”, “participant”, “stakeholder”, “visitor”.

In this respect our study may suggest that some of the recipients use the defensive strat-

egy called reappropriation of stigmatising labels [13]. They suggest pejorative, discriminating terms. This way the stigmatised group becomes used to them and “immunised” itself for social exclusion. Corrigan [13] points out that such a strategy is a contradictory to the linguistic one which tries to find out the more neutral terms instead of these stigmatising ones. The author also indicates the potential advantages of reappropriation of stigmatising labels strategy: it suggests that “peculiarity” doesn’t mean inappropriateness; it increases stigmatised peoples’ self-esteem and finally makes the discriminating term useless.

Study limitation

It is difficult to generalise our findings since we have only the opinions of those who wanted to and answered our survey. The number of the respondents from the out-patient clinics, community care and social services was rather low. The study was carried out only in one urban area, without the service users associations’ participation. To get to know all involved parties’ preferences it seems necessary to replicate such a survey accordingly.

Finally, it needs to be emphasised that we did not analysed in detail the associations of the linguistic preferences of our respondents with their socio-demographic or clinical characteristics and our results can provide only very preliminary insights into this issue.

CONCLUSIONS

In our survey the term “patient” was the most preferred one in the group of recipients and service providers.

The form of services provided did not differentiate the patients’ opinion in regards preferred terms.

Profession and number of years spent working in mental health or social care services did not differentiate the providers’ opinion in regards preferred terms.

The providers from nursing home pointed to the term “person mentally ill” and “person with mental disorders” the most frequently.

Further dialogue on the preferred terms is needed, since they might empower or stigmatise.

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