Letter to the Editor

Accessibility of psychiatric vocabulary: An international study about schizophrenia essential features

For the new version of the International Classification of Diseases (ICD-11), the World Health Organization (WHO) decided to involve users of mental health services and carers in the reading of the new classification. The arguments were that communication contributes to clinical utility and that communicating implies sharing a common language (Keshavan et al., 2021; Reed, 2010). In this context, we have to ensure that medical vocabulary is understood by all stakeholders, independently of official language and culture, especially when vocabulary concerns stigmatizing diagnoses such as schizophrenia (see, e.g., Howe et al., 2014; Thornicroft et al., 2009).

The first objective was to assess how many features of schizophrenia were reported as understood, to examine whether overall understanding was related to sampling factors (survey country and status as user or carer) and/or sample characteristics, and to test potential mediations. The second objective was to analyze the understandability of each feature and to identify what prevented it from being understood.

The French WHO Collaborative Center for mental health (WHO CC) coordinated an international study, from August 2016 to March 2018. The overall sample was composed of 494 participants, half users and half carers, coming from 13 countries: Algeria, France, Greece, Hungary, India, Italy, Lebanon, Lithuania, Madagascar, Mauritania, Mexico, Morocco, and Spain (for the psycho-social and socio-demographic profile of the sample, see Roelandt et al., 2020).

The study was based on face-to-face interviews. The questionnaires for users and carers were structured in the same manner. A first section asked for background information, comprising of socio-demographic characteristics (gender, age, and educational level) and contextual psychosocial data (marital status; parenthood, occupation, and family background). The second section was composed of similar questions related to each of the 7 essential features of schizophrenia: persistent delusions; persistent hallucinations; disorganized thinking; experience of influence, passivity or control; negative symptoms; grossly disorganized behavior; psychomotor disturbance. One question concerned understandability, that is whether participants reported understanding phrases.

> "*Do you understand the phrase? Yes/No*
> *If no, why not? (single answer): None of these words are understandable/ All the words are understandable but not the phrase/Some words are understandable, some not. Which ones are not understood?*"

Overall understanding was dichotomized as low ($\leq$5) vs. high ($\geq$6) revealed effects of both sampling factors. The percentage of participants having a high overall score had the highest values ($\geq$70%) in Algeria, Greece and Madagascar, and the lowest ones (<25%) in India, Mexico and Morocco. Users scored lower than carers. Moreover, childless and unemployed people scored lower than people with children and those employed. Despite correlations between sampling and psychosocial factors, the role of the first factors was not mediated by the second.

Analyses focused on features first showed that percentage of people reporting understanding was generally higher than two-thirds, except for "Experience of influence, passivity or control" (45%). The most often rated as understood were "Grossly disorganized behavior" and "Disorganized thinking" (77%, each), followed by "Persistent delusions" and "Persistent hallucinations" (72%, each), "Negative symptoms" (69%) and "Psychomotor disturbances" (67%).

Not understanding was most often reported as being a matter of words (Table 1).

This was the case for about 80% of participants for "Persistent delusions", "Persistent hallucinations" and "Psychomotor disturbances", and for about half of them for the other features.

Finally, when not understanding was reported to be due to some words, the most frequently mentioned were "delusions", "hallucinations", "psychomotor", "disorganized" (for 2 features), and "passivity and/or control". The difficulty raised by "psychomotor" was also observed in a focus-group based study (Hackmann et al., 2019) and for "psychomotor agitation or retardation" as an essential feature of Depressive Episode (Roelandt et al., 2018).

The major limitation concerns the sample sizes. Some sites encountered difficulties to include participants to conduct the study. Moreover, all users had to be aware of their diagnosis although it is known that some professionals are reluctant to give the diagnosis, because they prefer to focus on symptoms and/or because the diagnosis is very stigmatizing.

Notwithstanding these limitations, this study highlights the importance of language in understanding medical vocabulary, and the challenges behind specific terms. It is confirmed by the fact that some sites faced specific language and translation problems and that people sometimes use local languages rather than official ones (Roelandt et al., 2018). Official psychiatric vocabulary may be misleading and call for a discussion on the international and transcultural dimension of the ICD.

Furthermore, the clinical utility of a diagnosis implies that all stakeholders share a common language to communicate efficiently. While several countries have already changed the name of the diagnosis or initiated major debates about it (for a review, see, e.g. Lasalvia et al., 2015; Mesholam-Gately et al., 2021), these findings further highlight the necessity to rename the key features. According to the WHO suggestion and based on previous changes in the names of diagnoses, the subsequent renaming of essential features should consider the participation of all stakeholders, including users and carers, and pay particular attention to countries whose language is not an official language of the WHO, where people are not familiar with it, and/or where the concept of schizophrenia is not yet familiar to everyone.

Accepted 2 March 2022

Table 1
Proportion (in %) of participants reporting that not understanding was a matter of words.

	No word is understandable	Some words are not understandable	Total
Persistent delusions (n = 138; 29%)	44.2	36.2	80.4
Persistent hallucinations (n = 112; 29%)	46.4	33.1	79.5
Disorganized thinking (n = 114; 24%)	28.1	30.7	58.8
Experience of influence, passivity or control (n = 264; 51%)	26.2	31.8	58
Negative symptoms (n = 147; 31%)	34	11.6	45.6
Grossly disorganized behavior (n = 121; 24%)	26.4	27.3	57.7
Psychomotor disturbances (n = 157; 34%)	26.7	52.9	79.6

Note. In brackets: number and percentage of participants reporting that they don't understand the phrase.

Funding

The study received financial support from the French Ministry of Health for all the necessary on-site travels and international coordination, and the participation of the WHO's Offices in Madagascar and in Mauritania.

Data availability

Data are available upon reasonable request to the EPSM Lille-Métropole.

Declaration of competing interest

None to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.schres.2022.03.001.

References

Hackmann et al., 2019 C Hackmann Balhara YPS K Clayman PB Nemec C Notley K Pike G.M. Reed P. Sharan M.S. Rana Silver Jody M. Swarbrick J. Wislon H. Zeilg T. Shakespeare 2019.

Howe, L., Tickle, A., Brown, I., 2014. "Schizophrenia is a dirty word": service users' experiences of receiving a diagnosis of schizophrenia. Psychiatr. Bull. 38, 154–158. https://doi.org/10.1192/pb.bp.113.045179.

Keshavan, M.S., Davis, B., Friedman-Yakoobian, M., Mesholam-Gately, R.I., 2021. What is my diagnosis, Doc?: Discussing psychosis diagnosis with patients and families. Schizophr. Res. 239, 92–94. https://doi.org/10.1016/j.schres.2021.10.009. Epub ahead of print.

Lasalvia, A., Penta, E., Sartorius, N., Henderson, S., 2015. Is it time to consign the label of schizophrenia to history? An invited commentary. Schizophr. Res. 162, 276–284. https://doi.org/10.1016/j.schres.2015.01.031.

Mesholam-Gately, R.I., Varca, N., Spitzer, C., Parrish, E.M., Hogan, V., Behnke, S.H., Larson, L., Rosa-Baez, C., Schwirian, N., Williams, M.J., Saks, E.R., Keshavan, M.S., Stromeyer 4th, C., 2021. Are we ready for a name change for schizophrenia? A survey of multiple stakeholders. Schizophr Res. 238, 152–160. https://doi.org/10.1016/j.schres.2021.08.034. Epub 2021 Oct 20.

Reed, G.M., 2010. Toward ICD-11: improving the clinical utility of WHO's international classification of mental disorders. Prof. Psychol. Res. Pract. 41 (6), 457–464. https://doi.org/10.1037/a0021701.

Roelandt, J.-L., Askevis-Leherpeux, F., Baleige, A., Fontaine, A., Guernut, M., 2018. Participation of users and carers in a reading of the international classification of diseases for mental and behavioral disorders (ICD-11), princeps research on two disorders: depressive episode and schizophrenia, progress report. Available from: http://www.ccomssantementalelillefrance.org/?q=participation-users.

Roelandt, J.L., Baleige, A., Koenig, M., Demassiet, V., Agoub, M., Barikova, V., Benmessaoud, D., Brunet, F., Carta, M.G., Castelpietra, G., Crepaz-Keay, D., Daumerie, N., Fontaine, A., Grigutyte, N., Kishore, J., Kiss, M., Laporta, M., Layoussif, E., Limane, Y., Lopez, M., Mura, G., Pelletier, J.F., Raharinivo, M., Richa, S., Robles-Garcia, R., Stona, A.C., Skourteli, M., Thévenon, C., Triantafyllou, M., Vasilopoulos, F., Wooley, S., Reed, G., Guernut, M., Saxena, S., Askevis-Leherpeux, F., 2020. How service users and carers understand, perceive, rephrase, and communicate about the diagnoses of "depressive episode" and "schizophrenia": an international participatory research. Soc. Psychiatry Psychiatr. Epidemiol. https://doi.org/10.1007/s00127-020-01836-6.

Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., Leese, M., 2009. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. Lancet 373 (9661), 408–415. https://doi.org/10.1016/S0140-6736(08)61817-6. Available from:

Françoise Askevis-Leherpeux[a,b,c,*], Jean-Baptiste Hazo[a,b,c], Mohamed Agoub[d], Antoine Baleige[a,b], Victoria Barikova[e], Dalila Benmessaoud[f], Floriane Brunet[a,b], Mauro-Giovanni Carta[g], Giulio Castelpietra[h], David Crepaz-Keay[i], Nicolas Daumerie[a,b], Vincent Demassiet[a,b,j], Audrey Fontaine[a,b], Neringa Grigutyte[k], Mathilde Guernut[a,b], Jugal Kishore[l], Marta Kiss[m], Marie Koenig[a,b], Marc Laporta[n], Elkhansaa Layoussif[e], Youssouf Limane[o], Marcelino Lopez[p], Gioia Mura[g], Jean-François Pelletier[q], Mbolatiana Raharinivo[r], Geoffrey Reed[s], Sami Richa[t], Rebecca Robles-Garcia[u], Shekhar Saxena[s], Marina Skourteli[v], Fabio Tassi[w], Anne-Claire Stona[a,b], Catherine Thévenon[a], Michel Triantafyllou[e], Fotis Vasilopoulos[v], Stéphanie Wooley[x], Jean-Luc Roelandt[a,b,c]

[a] *EPSM Lille-Métropole, French WHO CC, Armentières, France*
[b] *French WHO CC, Lille-Hellemes, France*
[c] *Equipe Inserm-Eceve (UMR 1123), Paris, France*
[d] *Centre Psychiatrique Universitaire Ibn Rochd, Casablanca, Morocco*
[e] *Centre d'Accueil et de Soins Hospitaliers, Nanterre, France*
[f] *Etablissement HospitaloUniversitaire Spécialisé de Psychiatrie Mahfoud BOUCEBCI, Chéraga, Algeria*
[g] *Centro di Psichiatria e Psicosomatica Azienda Ospedaliero, Universitaria di Cagliari, Italy*
[h] *Primary Care Services Area, Central Health Directorate, Trieste, Regione Friuli Venezia Giulia, Italy*
[i] *Mental Health Foundation, London, United Kingdom*
[j] *French Hearing Voices Network, France*
[k] *Vilnius University, Vilnius, Lithuania*
[l] *Safdarjung Hospital, New-Delhi, India*
[m] *Community Psychiatry Centre of Semmelweis University, Awakenings Foundation, Budapest, Hungary*
[n] *Department of Psychiatry, McGill University, WHO CC, Montreal, Canada*
[o] *Ministère de la Santé, Nouakchott, Mauritania*
[p] *Fundación Pública Andaluza para la Integración Social de Personas con Enfermedad Mental (FAISEM), Svilla, Spain*
[q] *Centre de Recherche de l'Institut Universitaire en Santé Mentale de Montréal, Montréal, Canada*
[r] *Ministère de la Santé Publique, Tananarive, Madagascar*
[s] *World Health Organization, Department of Mental Health and Substance Abuse, Genève, Switzerland*
[t] *Hôpital Hôtel de Dieu de France, Beyrouth, Lebanon*
[u] *Instituto National Nacional de Psiquiatría "Ramón de la Fuente Muñiz", Mexico City, Mexico*
[v] *Association for Regional Development and Mental Health (EPAPSY), Athens, Greece*
[w] *University of Udine, Mental Health Department of Trieste, Italy*
[x] *Mental Health Europe, Bruxelles, Belgium*

[*] Corresponding author at: EPSM Lille-Métropole, French WHO CC, Armentières, France.
E-mail address: fleherpeux@epsm-lille-metropole.fr (F. Askevis-Leherpeux).