

Contribution of Service Users to the Revision of the WHO International Classification of Diseases: Should Recovery also Apply to General Practice?

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Abstract

The purpose of this study was to contribute to the revision of the International Classification of Diseases (ICD-10) by exploring how mental health service users and their relatives conceive the influence of the contextual factors, as described in Chap. 21 of the ICD-10, on a) the onset of a mental or behavioral disorder; b) the resurgence of such a disorder; and c) the recovery process. In individual and group interviews, the 18 main categories of contextual factors proposed by the ICD-11 (beta draft) were discussed through the Contextual Factors Questionnaire (CFQ). Participants in individual interviews (N=28) completed the CFQ. Among the three dimensions, it was for the recovery process that the contextual factors were considered to be the most influential, followed by their influence on the resurgence of a mental or behavioral disorder and then by the influence on the onset of that disorder. The most influential factor for a single dimension was that of 'interventions' on the recovery process, whereas the 'social or cultural factors' are the most influential ones for all dimensions combined, closely followed, at par, by 'risk factors' and 'interpersonal relations'. As recovery is also dependent upon health services and interventions globally, this paper suggests that these could be more effective if they were recovery-oriented and with recovery as a common overarching goal for mental as well as for physical healthcare provision and thus for global recovery. However, further work is needed to validate its reliability for enhanced mental and physical health parity in general practice.

Keywords Global recovery; Social determinants; Contextual factors questionnaire; International classification of diseases

Introduction

Psychiatric patients are socio-environmentally embedded individuals [1] with high medical needs [2]. For optimal effectiveness of scientifically-based general practice, it is important to well understand the socio-economic and psycho-social determinants within which a patient evolves, and their complex interactions. The acknowledgement of these factors is necessary so that the concerned individuals and the system as a whole can eventually have a better grasp of such determinants and influence them. This project aimed at understanding the importance of the taking into account of the contextual factors that influence health status and contact with health services, according to health service users and their relatives who support and accompany them through these services and throughout their recovery journey.

The International Classification of Diseases (ICD) of the World Health Organization [3] is the standard diagnostic tool for epidemiology, health management, and clinical purposes. This includes the analysis of the general health situation of population groups. It is used to monitor the incidence and prevalence of diseases and other health problems, providing a picture of the general health situation of countries and populations.

The diagnoses of Mental and behavioral disorders are described in Chapter V of the ICD-10th version, categories F00 to F99. This project consisted of asking patients with a diagnosis of the F category (and their relatives) to focus on the Factors influencing health status and contact with health services; these are the Z categories of Chapter XXI.

Categories Z00-Z99 is provided for occasions when circumstances other than a disease, injury, or external cause classifiable to categories A00-Y89 are recorded as "diagnoses" or "problems". As defined by the WHO, this can arise in two main ways:

a) When a person who may or may not be sick encounters the health services for some specific purpose, such as to receive limited care or service for a current condition, to donate an organ or tissue, to receive prophylactic vaccination, or to discuss a problem which is in itself not a disease or injury.

b) When some circumstance or problem is present which influences the person's health status but is not in itself a current illness or injury. Such factors may be elicited during population surveys, when the person may or may not be currently sick, or be recorded as an additional factor to be borne in mind when the person is receiving care for some illness or injury.

In effect, most of the people who would clinically be in need of care regarding mental health problems, do not consult for these reasons. It is frequent, however, that they want to consult about socio-economic or psycho-social conditions that they associate to disorders related to the use of psychoactive substances (F10 to F19 categories of the ICD-10), to mood or affective disorders (F30 to F39), to neurotic disorders, to disorders in relation to stress factors, or to somatoform disorders (F40 to F48). In fact, fewer than half of the individuals suffering from a mental illness consult for a mental illness [4].

These persons can rather seek health services in general for other reasons, for example to discuss a problem which, in their view, does not necessarily represent per se a diagnosable disease. The Z00 to Z99 categories of Chapter XXI are designed for the recording of the motives of recourse to health services, other than illness. According to

the WHO, such factors should be recorded as additional factors to be taken into account when the subject receives care and treatment for a diagnosed disease, for instance a mental or behavioral disorder (F categories).

The beta draft of the ICD-11 has been made public by the WHO. The potential users of the future ICD-11, that is, doctors and other care providers, researchers, clinical and administrative managers, political leaders, service users, and relatives are invited to comment on the descriptors of the different illnesses and on the contextual factors. In collaboration with two WHO Collaborating Centers for Research and Training in Mental Health from Canada and France, a study has been proposed to allow mental health service users and their relatives to contribute to the revision of the ICD.

Materials and Methods

A Community-based participatory research (CBPR) design was used to determine how mental health service users and their relatives conceive the influence of the contextual factors on: a) the onset of a mental health problem; b) the resurgence of a mental health problem; and c) the recovery process. CBPR is an approach to research in which persons who typically are subjects of research studies have an active role in the conceptualization, implementation, and analysis of studies. CBPR allows non-academic members of the research team to immediately benefit from the research findings and to become directly involved in the knowledge translation process. Involving underserved populations as full research partners is a fundamental tenant of CBPR, and co-learning, building on strengths and acknowledgement of privilege and power are additional characteristics [5].

In that respect, a preliminary consultation process was necessary to verify if, and how service users and relatives would be interested in contributing to the WHO ICD revision. Thus, after a first series of 5 meetings between an association of Canadian mental health service users and the Montreal WHO Collaborating Centre, followed by a larger meeting with the Lille WHO Collaborating Centre in France, consulted service users in both places expressed their interest in contributing to the revision of the ICD and chose to revise Chapter XXI on the influence of contextual factors among any other category. Our CBPR approach was also to hire and train, for all elements of the study, a group of peers (persons with lived experience of mental illness) as members of the 'University of Recovery' [6,7]. For this particular project, a qualitative method was chosen to document the intricacy of the contextual factors through the narratives of persons about their experience of living with a mental or behavioral disorder, be they service users themselves or their relatives.

Participants

Ten service users from each of the three mental health university institutes of the province of Quebec, Canada, were recruited to take part in individual interviews (N=15) or in group interviews (N=15) conducted by a peer research assistant. Similarly, 10 relatives of service users (e.g. parents, friends, siblings) were each time recruited to participate in individual interviews (N=15) or in group interviews (N=15). In individual interviews, participants talked about the impact of the contextual factors on themselves, that is, with a first-person stance, whereas in group interviews, they shared their understanding of the impact of the contextual factors in general by commenting on the results to individual interviews. Although it is possible that some of the relatives were those of the participating service users, such a

matching was not sought in this study, even if it could have been interesting to compare the understanding of the service users to that of their relatives in precise cases.

Inclusion criteria

The inclusion criteria were as follows: to be at least 18 years old and be either a) a patient with a diagnosis of a serious mental illness (e.g. schizophrenia) or with a diagnosis of a common mental disorder (e.g. depression or anxiety); b) a close relative of such a person. To ensure that study participants had sufficient perspective to contribute to this study, participants who received their diagnosis fewer than 5 years prior to the study were excluded, which was also the case for patients who might have been in a psychiatric crisis during the study period (or a relative of such a person).

Data collection and analysis

The individual and group interviews have been transcribed verbatim for a subsequent in-depth qualitative analysis. What this paper reports are the preliminary results for the participants who were met in individual interviews and who completed the Contextual Factors Questionnaire (CFQ) in preparation for the individual interviews (N=28, no missing data). The CFQ is an 18-item questionnaire, each time with 3 sub-questions: for each of the main ICD-11 categories of contextual factors (beta draft), participants were invited to say, on a 6-point Likert scale (1=no influence at all, 6=very influential), how influential these factors were, either for themselves (service users) or according to their relatives.

Results and Discussion

As shown in Table 1, according to study participants who completed the CFQ, the most influential factor associated with the onset of a mental or behavioral disorder are the 'risk factors', which include genetic predisposition. The total is of 113 over a maximal possibility of 168, that is if each 28 respondents would have given 6 on the Likert scale ($28 \times 6=168$).

The least influential contextual factor for the onset, as with resurgence (Table 2) and recovery (Table 3) is the 'judicial system'.

'Someone else's behavior' is the second least influential contextual factor for the onset for the onset (15/168, Table 1), whereas it is the most influential for the resurgence of a mental or behavioral disorder (107/168, Table 2).

In terms of recovery, as shown in (Table 3), 'interventions' and, 'healthcare system' receive 133/168 and 132/168 respectively.

These are among the least influential for onset (Table 1). In total, the participants gave 4243 for a maximal possible total of 9072 ($28 \text{ participants} \times 6\text{-point scale} \times 18 \text{ factors} \times 3 \text{ dimensions} = 28 \times 6 \times 18 \times 3=9072$). Seven out of the 10 most influential contextual factors are related to recovery and in effect, it is with regards to recovery (1723/4243) that they are globally the most influential, compared to onset (1128/4243) and to resurgence (1392/4243).

Among all contextual factors and dimensions combined, according to the participants in individual interviews who completed the CFQ, the 'social or cultural factors' are the most influential. As per Table 4, the total for that contextual factor is of 325 for a possible maximal total on 504.

Contextual factor-on set	SD	Mean	Total (X/168)
Risk factors	2.2	4	113
Social or cultural environment	2.3	3.3	93
Someone else's behavior	2.4	3.2	90
Fear	2.7	3.2	89
Interpersonal interactions	2.3	3.1	86
Assault or harmful événements	2.4	2.8	78
Housing or the environment	2.4	2.4	67
Impairments, limitations, or restrictions	2.4	2.3	64
Employment or unemployment	2.2	2.3	63
Absence, loss, or death of a close one	2.3	2.2	61
Personal finances	2.4	1.9	54
Social security-welfare	2.4	1.8	49
Water or nutrition	2.3	1.7	48
Education	2.2	1.7	48
Healthcare system	2.2	1.6	45
Interventions	1.8	1.2	33
Someone else's illness	1.8	1.1	32
Judicial system	1.5	0.5	15

Table 1: Influence of the contextual factors on the onset of a mental or behavioral disorder.

Contextual factor-resurgence	SD	Mean	Total (X/168)
Someone else's behavior	2.1	3.8	107
Social or cultural environments	2.1	3.6	101
Risk factors	2.4	3.5	98
Interpersonal interactions	2	3.5	98
Fear	2.5	3.4	96
Employment or unemployment	2.3	3.1	87
Assault or harmful events	2.4	3	84
Healthcare system	2.1	3	83
Absence, loss, or death of a close one	2	2.8	77
Personal finances	2.2	2.7	76
Interventions	2.3	2.7	76
Housing or the environment	2.1	2.6	72
Social security-welfare	2.3	2.3	63
Education	2.3	2.1	60
Water or nutrition	2	2.1	59
Someone else's illness	2.2	2.1	59
Impairments, limitations, or restrictions	2.2	2.1	59
Judicial system	1.9	1.3	37

Table 2: Influence of the contextual factors on the resurgence of a mental or behavioral disorder.

Contextual factor-Recovery	SD	Mean	Total (X/168)
Interventions	1.7	4.8	133
Healthcare system	1.6	4.7	132
Social or cultural environments	1.2	4.7	131
Interpersonal interactions	1.6	4.4	123
Housing or the environment	2	4.1	115
Employment or unemployment	2	3.9	110
Social security-welfare	2.2	3.9	109
Personal finances	2	3.6	100
Water or nutrition	2.2	3.5	97
Education	2	3.5	97
Someone else's behavior	2.1	3.4	94
Risk factors	2.2	3.2	89
Fear	2.6	2.9	81
Absence, loss, death of a close one	2.1	2.8	79
Assault or harmful events	2.4	2.6	73
Impairments, limitations or restrictions	2.2	2.3	64
Someone else's illness	2.4	2.1	59
Judicial system	2	1.3	37

Table 3: Influence of the contextual factors on the recovery process.

Contextual factor	SD	Mean	Total (X/504)
Social or cultural environments	4	11.6	325
Interpersonal interactions	4.4	11	307
Risk factors and predisposition	5.5	10.7	300
Someone else's behavior	5.1	10.3	289
Fear	7	9.5	266
Employment or unemployment	4.6	9.3	260
Healthcare system	4	9.3	260
Housing or the environment	5.1	9.1	254
Interventions	3.9	8.6	242
Assault or harmful events	5.3	8.4	235
Personal finances	4.5	8.2	230
Social security-welfare	5	7.9	221
Absence, loss or death of a close one	4.9	7.8	217
Education	5.3	7.3	205
Water or nutrition	4.7	7.3	204
Impairments, limitations or restrictions	5.4	6.6	185
Someone else's illness	5.5	5.4	150
Judicial system	4.5	3.2	89

Table 4: Influence of Contextual Factors on the onset of a mental or behavioral disorder, on the resurgence of such disorder, and on the recovery process.

These 'social or cultural factors' are followed by 'interpersonal relations' (307/504) and by 'risk factors' (300/504). The least influential contextual factor for all 3 dimensions combined relates to the 'judicial system' (89/504), which is the least influential for each single of these dimensions, as seen above.

In summary, among the three dimensions, it is for the recovery process that the contextual factors were considered to be the most influential, followed by their influence on the resurgence of a mental or behavioral disorder and by the influence on the onset of such a disorder.

Global mental and physical health parity in general practice

The recovery approach has gained traction in mental health policy throughout the world, and much effort is going into the transformation of services and systems to achieve recovery-oriented outcomes [8,9]. Beyond reduction or remission of psychiatric symptoms, recovery-oriented mental health policies and systems seek to support the individuals with mental illness to live and remain active in their community [10]. Generally speaking, two portrayals of recovery stand out amidst the diversity of views: restoration of functioning, and deepening wellness [11]. When recovery is mainly seen as symptom management, the primary focus of personal choice and responsibility in the process of recovery becomes seeking and complying with treatment. Such a "clinical" model does include social functions, but from a professional point of view.

Instead of focusing primarily on symptom relief and management, a second view casts a wider spotlight on restoration of self-esteem and identity, and on attaining meaningful roles in society [12]. While the clinical-recovery model has focused upon the remission of symptoms and restoration of functioning, a rehabilitative view of recovery has been a more subjective and consumer-oriented concept that focuses on the full lives that are lived in the face of, or despite, enduring disability. This second axiom of recovery derives from the Mental Health Consumer/Survivor Movement, and refers to a person's right to self-determination and inclusion in the community life, regardless of disability status and in reference to the rights and duties of citizenship for all.

One of the reasons that explains why persons suffering from a mental disease do not consult for this problem, is that they do not believe that the health system could offer them help and support; that is, they are not looking to treat an illness, but to discuss their "problems" [13]. There is also the perception that this system is insensitive to cultural particularities [14] or having had negative experiences in the past [15]. One of the main dissatisfactions of persons who consult is that they do not feel listened to, and are not considered as persons in their own right during the announcement of a diagnosis of the "F" category of the ICD-10 and the treatment that follows.

Many of them do not wish to go again through such a disempowering experience [16], since the intervention initially proposed focusses too exclusively to a symptom. This symptom, not the person in need, corresponds in advance to a precise description and algorithm treatment, independently, or nearly so, of what the individual lives through and of what he has to say about his living conditions. This is true in such a way that, effectively, the provision of services does not necessarily mean that the needs have been satisfied [17]. Such needs might only be filled for as low as one treated person in six who do seek professional help [18].

If the persons who consult do so firstly for the need of discussing their "problems" and not necessarily their "illnesses", they risk seeing their expectations not satisfied if no question is asked regarding these contextual factors. The fact that attention bears mostly on disease symptoms speaks neither in favor of satisfaction nor of communication, if the reason for people to consult is to speak of their problems. Persons in psychological distress, for example at the Emergency Room, can be frustrated for not being asked what is wrong with their present life that explains their distress, without it being in advance automatically caused by an illness [19]. Hence the importance of asking questions about these contextual factors to be recorded and acknowledged for a more personalized (what the person lives) and global approach.

What could be seen as a limitation of this study is that we were asking if contextual factors influenced the onset of a disorder, the resurgence of that disorder, and/or the recovery process: we were not asking to qualify such influence either as positive or negative. We could have asked for more precision, for example as for "interventions": do they have a more positive or a more negative influence on the recovery process (Table 3).

In the same vein, for the influence of the "health system", we did not seek to differentiate a "physical health system" from a "mental health system" because for most people these are commonly managed in general practice. A research project that would be subsequent to this one could seek more clarity in such matters, but we feel that the idea of applying recovery values and principles not only to mental health but also the physical health and general practice, through the concept of global recovery, is promising in terms of person-centeredness and is worthy of further exploration because mental and physical illnesses often come in combinations and do influence each other [20].

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