Article

Standardised measures of needs, stigma and informal care in schizophrenia using a bottom-up, cross-cultural approach

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ABSTRACT

Background There is a lack of instruments to measure the needs, stigma and informal care of people with schizophrenia that take account of sociocultural variation and patients’ and formal and informal carers’ opinions and experiences.

Aims To develop questionnaires to measure stigma, needs and informal (non-professional) care for people with schizophrenia.

Method We undertook the study in seven countries and in English, Spanish and Portuguese. We first held focus group discussions with patients, formal carers (professionals) and informal carers (family and friends) in Spain, the UK, Argentina, Brazil, Chile and Venezuela to elicit the main dimensions of needs, stigma and informal care. We then held nominal group discussions about these dimensions with patients, family members and professionals in Spain, Portugal and the UK, to develop the instruments.

Results Three hundred and three people participated in 46 focus groups and results were discussed in three nominal groups, each involving eight participants. Three instruments were developed in this iterative process: needs for care (46 items), stigma (38 items) and informal care (20 items).

Conclusions These instruments are based on service users’ and carers’ views and experiences and have cross-cultural validity. They will have application in assessment of outcomes for people with schizophrenia and their families.

Keywords: assessment, informal care, needs, schizophrenia, stigma

Introduction

A number of studies have shown that the outcome and prognoses for people with serious mental illness are better in underdeveloped and developing countries than in industrialised societies.1–4 ‘It is obvious that the outcome of schizophrenia in developing countries is generally more favourable. The reasons for this are far from clear. Research concerning the issues pertaining to better outcome of schizophrenia in developing countries is woefully lacking. This is an area that deserves research attention’.5

Hopper and Wanderling6 examined the ‘provocative finding’ of a differential advantage in the outcome for people with schizophrenia living in ‘developing’ countries. After inconclusively examining a number of potentially confounding variables, they concluded that further research was needed, ‘with particular attention to the need for close documentation of everyday practices in the local moral worlds that “culture” refers to’.

Recently, Jablensky and Sartorius7 reviewed the debate on their original findings and concluded that: ‘the existence of outcome differentials between populations and cultures is not “presumed wisdom” but a real complex issue which should be addressed with standards of precision and rigor that are customary in scientific research and discourse’.

On these grounds, in 2002 the MARISTAN Network (MNW) began a research programme to investigate whether certain sociocultural factors might account for these findings. Our primary objective was instrumental; to develop culturally sensitive, valid and reliable rating scales based on the views and perspectives of users, carers and professionals that could then be used to study whether such factors differ from country to country and/or produce different outcomes in different contexts. We decided to focus our study on three sociocultural dimensions of mental health provision: needs, stigma and informal care.8

Objectives

We set three objectives, to develop:

- a questionnaire to measure the STIGMA of schizophrenia
- a culturally sensitive questionnaire to measure the NEEDS of people with schizophrenia
- a culturally sensitive questionnaire to measure INFORMAL (non-professional) CARE received by people with schizophrenia.

Method

To meet the three objectives we undertook cross-cultural research using qualitative methods followed by consensus generation.

We divided the work into two phases. The aim of the first phase was to elicit the views and opinions of those directly involved. A qualitative approach was
used to determine the content of three assessment tools based on the views of users, informal (family and relatives) and formal carers (professionals). This first phase was undertaken in 2002 in centres in Argentina, Brazil, Chile, Spain, the UK and Venezuela.

The aim of the second phase was to create by consensus a preliminary version of three questionnaires, one for each of the three dimensions of the study. These questionnaires were prepared simultaneously on two continents and in three languages, a fact which reflected the cross-cultural nature of our sample population. This work was undertaken in 2006 in the same countries, with the exception of Venezuela, which was replaced in the second phase by Portugal.

Phase I: focus group discussions

In spring 2002 each centre conducted focus group (FG) sessions with patients with schizophrenia (two groups of men only and two of women only) and with their carers (two sessions with informal carers and two with mental health professionals; Table 1). Each group contained six to eight participants. In total, 46 FGs were performed in the six countries taking part.

Within each group, a researcher facilitated the discussion on the following topics: (1) the needs of people affected by schizophrenia; (2) whether people with schizophrenia need more or different kinds of care, what kind of care they need and who should provide it?; and (3) whether people with schizophrenia suffer stigma or discrimination? If so, in what ways and to what extent?

The facilitator was assisted by an observer. The meetings were audiotaped and lasted an average of 90 minutes. They took place in a neutral environment away from mental health centres. Two centres participated in Europe (Spain, UK) and four in South America (Argentina, Brazil, Chile and Venezuela). The work was carried out in three languages (English, Portuguese and Spanish).

The aim was for all centres to use the same method and share the same database set-up to store the information gathered at each centre. This was done in such a way that each research centre could access the common database online and make its own particular analysis.

Participants: recruitment criteria

PROFILE 1

A purposive sample of people with schizophrenia and other psychotic disorders defined according to the ICD-10 was recruited, and contained a balance of men and women within a wide age range from 18 to 65 years; an illness duration of 3–15 years; psychiatric hospitalisation for no more than 40% of the preceding 3 years and no more than 3 months continuously in the preceding year; and fluency in the national language of each participating centre.

PROFILE 2

Informal carers were people who lived with or were very close to someone with schizophrenia, who regarded themselves as the main providers of informal care and were acknowledged as such by the patients, and who were not employed by mental

<table>
<thead>
<tr>
<th>Country</th>
<th>Users</th>
<th>Caregivers</th>
<th>Total by country</th>
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<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Informal</td>
<td></td>
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<tr>
<td></td>
<td>Men</td>
<td>Formal</td>
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<tr>
<td>Argentina</td>
<td>14</td>
<td>11</td>
<td>52</td>
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<tr>
<td>Brazil</td>
<td>10</td>
<td>16</td>
<td>58</td>
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<tr>
<td>Chile</td>
<td>12</td>
<td>13</td>
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<td>Spain</td>
<td>10</td>
<td>12</td>
<td>48</td>
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<tr>
<td>England</td>
<td>8</td>
<td>15</td>
<td>44</td>
</tr>
<tr>
<td>Venezuela</td>
<td>12</td>
<td>13</td>
<td>51</td>
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<tr>
<td>Total by profile</td>
<td>146</td>
<td>157</td>
<td>303</td>
</tr>
</tbody>
</table>
health or other services. These informal carers were identified by the service users, who, at the same time, gave their consent.

PROFILE 3

Formal carers were mental health professionals with at least 3 years’ experience working with people with schizophrenia. Most played a key role in the treatment of the users who participated in the groups.

Analysis, translation and grouping of texts

The 46 FGs were recorded and the contents of the tapes transcribed. Because each group discussion had been conducted in the language of its participants, English, Portuguese or Spanish, the transcriptions were translated into the other two languages and then back-translated into the three languages to ensure equivalent access and understanding across all centres. The researchers then divided the texts into sentences that were short enough to be considered text units. These units were then classified according to a previously agreed category map (Figure 1). The units were then analysed using the QSR NUD*IST software. The results of this phase were presented in three PhD theses.10–12

Phase II: nominal group discussions

In preparation for the second phase, summaries of the three PhD dissertations were made available in all three languages in the study. These summaries consisted of brief sentences describing the key aspects of each category (Figure 1). All the experts who participated in the NGs (Table 2) received these summaries before the nominal groups (NGs) so they were well informed about the procedures and the outcome of Phase I. They also had access to the full versions of the three theses in Spanish.

In order to prepare the preliminary versions of the three questionnaires, the three summaries (raw material) were each reviewed and discussed by the three NGs. Their main aim was to choose the sentences that were considered most valuable according to the objectives. One NG was performed in each of the three languages.

Participating centres

The NGs took place in the order: University of Granada (Spain), University Nova of Lisbon (Portugal) and University College London (UK).

The whole process was co-ordinated by one of the researchers, a psychiatrist, who was present at the three NG sessions. For the purposes of methodological and semantic coherence, a second researcher participated in NGs 1 and 2 and a third researcher in NGs 2 and 3.

There were eight participants each in Granada, Lisbon and London. In addition, the co-ordinating researcher and the other two researchers mentioned above were only counted once. In each of the NGs, there were at least two participants with sufficient mastery of the three languages and at least one researcher from Latin America was present in each of the NG sessions. Table 2 shows the profile of the participants in the NGs.

NG GRANADA

In this first NG, participants drafted the three initial lists of sentences relating to informal care, needs and stigma. Under the co-ordination of the moderator, the first step was for each expert to write a list of assertive phrases that included all the items in the summary.

![Figure 1 Tree of categories for the analyses of Phase I](image-url)
In the second stage, the sentences were screened and those that obviously overlapped were eliminated, always bearing in mind while phrasing and selecting the exact words, that it would later have to be translated into the other languages. Although asked to show self-restraint, the participants were able to propose new items to be added to the list of statements. The NGs were free to accept or reject any new proposals by voting.

Once the participants had offered their opinions, and the statements had been clarified and classified into groups, the statements were printed out for each participant. Each participant scored each statement on the basis of his/her own criteria regarding the relevance of the statement to the theme (informal care, needs and stigma) on a scale from 1 (minimum relevance) to 9 (maximum relevance). A cut-off point of 5 was agreed and all statements with a median score below this were excluded.

The first drafts of the three instruments were translated into Portuguese and English and sent to the participants at the next NG before the scheduled meetings.

NGS IN PORTUGAL AND UK

The NG participants in Lisbon and London performed a similar task, except that they had the drafts of the three questionnaires produced at the previous NG as a base to work from. Some items were rejected or rephrased to make them comprehensible in the three languages/cultures. Second and third rounds of screening were performed in these NGs and those with scores below 5 were dropped.

Final scoring of the NG participants

As a result of the consecutive work of the NGs, three lists of statements (one each for informal care, needs and stigma) were finalised. In a final consultation, these lists were then submitted to a further assessment of relevance by asking the 24 participants in the three NGs to score the items according to the instructions set out in Figure 3.

A score of 3, as the median, was established as the cut-off point and items that scored less were considered of little or no relevance. Only those statements that were chosen to be part of the instruments would later be included in the pilot validation study.

Results

Phase I

Of the 303 participants, approximately half were users and half were carers. The majority of informal carers were women, mainly users’ mothers or sisters, while formal carers were mainly psychiatrists, nurses and social workers.

The most important aspects of informal care, stigma and needs were identified during Phase 1 (Figure 2). The first NG produced 119 statements, which after the screening procedure for the first
The NG experts also grouped the statements into a new map of categories, which was used to give names to the different headings for each questionnaire (Figure 3).

Figure 3 shows that the NG in Lisbon merged some of the items together and suggested some new ones, so the second draft contained a higher number of statements. These new items were also translated into English. The London NG also rephrased some items and suggested adding various others. Consequently, the third draft contained a total of 152 statements for the three research dimensions. This third draft was translated into Spanish and Portuguese to prepare for the last round of consultation and the final consensus on which items should remain in the instruments.

At the end of this process, we obtained the first versions of the three instruments (on informal care, stigma and needs) simultaneously in the three languages of the study, ready for the assessments of their psychometric characteristics.

Discussion

In order to develop instruments to understand the experiences and needs of people with schizophrenia, a first-stage qualitative approach is required in which thoughts, meanings, stereotypes and prejudices can be elicited freely, reliably and in detail. Gathering data qualitatively provides the validity that underpins the subsequent development of such instruments. We undertook this approach because so many instruments developed in mental health to date have conspicuously lacked a bottom-up approach to the interests of the target groups of people involved. Our painstaking approach across a number of cultures and languages means that the instruments developed arose almost exclusively from the opinions, feelings and motivations of users and others involved in their care. Contrary to usual practice in instrument development, the views and thoughts of experts were relegated to second place in favour of the feelings and opinions of users. The profile of the users and carers interviewed in the FGs ensured that we obtained a representative sample of the population we were studying. One possible limitation was the predominance of psychiatrists in the NGs, however, we strove to ensure that this was offset by the presence of a number of other professionals and the participation of users and relatives.
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The other advantage of our approach was its cross-cultural and cross-language approach in terms of participation of researchers, users and carers. It made our scales more culturally sensitive than other validated tools that are already available. The criteria stressed by Sumathipala: ‘content validity – each item is to assess a content that is relevant to each culture under investigation; the semantic validity – words used in the original and the translation must have a similar meaning; and the technical validity – a similar effect is to be achieved by the measuring technique in different cultures’ guided all our research efforts.\(^\text{14}\)

One of the main challenges of the study was the vast amount of information obtained. Although this rich data set undoubtedly made our results more valid, it also made transcription, translation and analysis, and the choice of themes, more complex and led to delays between data collection, construction of the instruments and the publication of our findings. We encountered a further difficulty when it came to delineating the three topics or domains within the participants’ discourse, because on many occasions these domains are inextricably linked, for example, when a participant talks about the need for a particular type of care that arises because of the experience of a stigma.

Previous studies on needs

A large number of articles have been published in the last 20 years on the importance of studying the needs that, when unmet, limit the recovery of people suffering from schizophrenia and related conditions.\(^\text{15–20}\) In particular, two well-known questionnaires have been developed: the MRC Needs for Care Assessment,\(^\text{24,25}\) and the Camberwell Assessment of Need (CAN).\(^\text{18}\) However, these and other related tools share the same theoretical bases and are limited by the way they were conceived and developed. They were constructed in the 1990s and influenced by the then political framework for identifying needs established by the UK’s Department of Health in 1991: ‘as defined by the particular care agency or authority’ (National Health Service & Community Care Act, 1990); which meant that they were heavily influenced by political and service views. In addition, they both applied a top-down perspective that was based on the views of the professionals and on establishing a consensus between them. Finally, they were responding to a specific public demand within the British context and as such showed their weakness in cross-cultural comparisons.\(^\text{27,28}\)
Previous studies on stigma

The oldest research instrument in this field is the Social Distance Scale, which is one among other tools used to analyse the permitted degree of intimacy. In 1955, Shirley Star developed a method to assess the nature of popular beliefs about mental illness. She presented short vignettes that described mental illnesses to a sample of 3000 Americans. She found that only the vignette describing paranoid schizophrenia was identified by the majority (75%) as a mental illness. In 1996, Lee et al constructed a new scale which, although inspired by the Bogardus Social Distance Scale, criticised the fact that it measured the social distance of the majority group toward the minority and did not take into account the opinions of the minority group on the social distance that they were forced to maintain. In 1997, Link et al used a scale to evaluate three dimensions: (1) devaluation and discrimination, (2) experiences of rejection, and (3) ways of coping with stigmatisation. Later, they created a group of vignettes, based to some extent on those created by Star, to assess the degree of recognition of mental illness by the general population and to measure the social distance people wished to keep from those with mental illnesses. The same team later developed a questionnaire on the humiliation and abandonment felt by users.

Wahl criticised many of the tools and research into stigma on the grounds that they failed to take into account the opinion of the users themselves on the stigma they experienced and the consequent discrimination they suffered. He decided to develop a structured interview, based on the opinions of users and this was applied to a sample of 1300 users from the National Alliance for the Mentally Ill (NAMI).

One member of our group recently developed a scale on stigma based on qualitative data collected by service users from other service users with psychotic illnesses. It is made up of 21 statements which group into three factors, namely disclosure of mental illness to other people, discrimination suffered because of mental illness and potential positive aspects of mental illness. Even more recently, Thornicroft et al published the Discriminating Stigma Scale (DISC) for which candidate items were identified from a review of research and from detailed consultation with research teams at the 28 study sites.

Only two instruments to measure the experience of stigma followed a bottom-up approach to validity like ours, but both were restricted to single cultures and languages.

The work of Angermeyer on stigma merits special consideration. Although he recommended the need to differentiate between anticipated and experienced stigmatisation, he found that people with schizophrenia – our target population – reported concrete stigmatisation experiences more frequently than the depressive patients. A more recent paper on stigma and schizophrenia that anticipated stigma shows hardly any correlation with patients’ specific sociodemographic and clinical characteristics. It would be fair to say that our scale does not disregard any relevant aspect elicited by Angermeyer’s work.

Previous studies on informal care

Our instrument to measure informal care is the first of its kind to assess the intimate knowledge of the care that relatives provide for schizophrenia sufferers. To date, the relations between people with schizophrenia and their families have been studied either as a pathogenic factor for patients (‘Emotional Expression’) and have led to psycho-educative models for training families aimed at improving patient outcomes, or as a so-called ‘burden’ that family members encounter. One example of an instrument to measure the impact of psychiatric disorders on patients’ relatives is the Involvement Evaluation Questionnaire (IEQ). The burden shouldered by a family with a severely mentally disordered relative at home remains an important subject of research. In each of its 22 items, the above-mentioned CAN includes a section that questioned the ‘amount of care’ given by the relatives and friends, but nothing about the care type, quality or satisfaction. It is merely a cost-effectiveness utility question.

To our knowledge, there are still no instruments available for evaluating the therapeutic influences of caregivers on the patient. All over the world, relatives and neighbours offer simple, inexpert care to their patients, unguided by any specific professional training such as family psycho-education. It is very likely, however, that such informal care varies from one culture to another and, thus there is a need for instruments that can measure such care across cultures or traditions.

Conclusions and future work

We have developed three instruments to measure the needs, stigma and informal care of patients with schizophrenia that take account of sociocultural differences between the countries in which they were developed and the opinions and experiences of patients and formal and informal carers. We have just completed assessments of their reliability in study populations in Argentina, Brazil, Chile,
Portugal, Spain and the UK, which will be the subject of a forthcoming publication. The instruments have been designed for use in research or clinical settings to assess the outcomes for people with schizophrenia and their families.

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CONFLICTS OF INTEREST

Non-financial competing interests.

AUTHORS’ CONTRIBUTIONS

FTG participated in the design of the study, co-ordinated the study, attended the nominal groups (NG) in Granada, Lisbon and London and drafted the article. ARG participated in the design of the study and helped with the methodological co-ordination, did the analysis of the FG and NG, carried out the Focus Group in Granada, supervised the transcription, did the input data into the NUDIST© and contributed to drafts of the paper. CA trained the other researchers in the use de NUDIST© software. Carried out the FG in Buenos Aires, supervised the transcription and did the input data into the NUDIST©. LCW carried out the Focus Group in Porto Alegre, supervised the transcription and did the input data into the NUDIST©. DB supervised the study in Brazil and attended the NG in Lisbon and London. JMCA supervised the NG and the study in Portugal. EG supervised the FG and the study in Argentina. MX co-ordinated the NG in Lisbon and attended the NG in Lisbon and London. MGB participated in the initial design of the study. MK participated in the design of the study, supervised the study in UK and contributed to drafts of the paper. CA supervised the transcription and did the input data into the NUDIST©. DB supervised the study in Brazil and attended the NG in Lisbon and London. JMCA supervised the NG and the study in Portugal. EG supervised the FG and the study in Argentina. BV supervised the FG and the study in Chile. MX co-ordinated the NG in Lisbon and attended the NG in Lisbon and London. MGB participated in the initial design of the study. MK participated in the design of the study, supervised the study in UK and contributed to drafts of the paper. CA supervised the transcription and did the input data into the NUDIST©. DB supervised the study in Brazil and attended the NG in Lisbon and London. JMCA supervised the NG and the study in Portugal. EG supervised the FG and the study in Argentina. BV supervised the FG and the study in Chile. MX co-ordinated the NG in Lisbon and attended the NG in Lisbon and London. MGB participated in the initial design of the study. MK participated in the design of the study, supervised the study in UK and contributed to drafts of the paper. SMS participated in the design of the study, supervised the NG in Porto Alegre, supervised the transcription and did the input data into the NUDIST©.

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