



AMHOCN

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Carer Outcome Measurement in Mental Health Services: Scoping the Field

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Executive summary

Background

Consumer outcome measurement has become routine in Australian mental health services, but carer outcome measurement does not yet occur. The current project involved a scoping exercise, designed to explore the context within which carer outcome measurement might be introduced and to identify any candidate instruments. The project focused on carers of adults with mental illness (not children/adolescents or older persons). It examined instruments that consider carer burden, wellbeing and need, not instruments that elicit carers' perspectives of consumers' symptomatology and level of functioning. It addressed four research questions:

- What instruments for measuring outcomes for carers have been developed for use by mental health services, or are relevant to mental health services, both in Australia and internationally?
- How do the available instruments compare in terms of measurement domains, psychometric properties and feasibility for use in clinical practice?
- Of the available instruments which, if any, show best potential for use in Australian mental health services and should be subject to further investigation?
- Is the development of an instrument designed to measure carer outcomes a valuable exercise to undertake at this time?

Method

The project drew on two data sources: (a) a review of the literature on available instruments for measuring carer outcomes and (b) stakeholder consultations with carers from the public and private sector and from non-government organisations. Both were conducted in stages, in an iterative process where one informed the other.

Key findings

The literature review and stakeholder consultations identified 10 instruments with potential relevance to carer outcomes. This list was reduced down to six, and then down to two, with most instruments being rejected by stakeholders on the grounds of inappropriate terminology (e.g., 'medical jargon', incomprehensible language or negative phrasing), technical features (e.g., length, response formats), administration issues and failure to reflect the 'journey' of caring for a person with a mental illness. Stakeholders were of the opinion that the Carers' Quality of Life-7D+ Visual Analogue Scale (CarerQoL-7D+VAS) and Burden Assessment Scale (BAS) might serve the purpose of routine carer outcome measurement with some modification. They perceived value and relevance in terms of at least some of the items and subscales on these two instruments, and recommended that they form the basis of further development work.

Despite reserved support for the CarerQoL-7D+VAS and the BAS, stakeholders were adamant that introducing an instrument to routinely measure outcomes for carers was not practical or feasible at this time, and should only occur in the context of implementing a range of initiatives designed to improve carer outcomes. The carer-specific standard in the revised National Standards for Mental Health Services was highlighted as a context for these efforts. In the absence of any efforts to improve meet the needs of carers, stakeholders felt that the introduction of routine carer outcome measurement would be meaningless.

Recommendations

- Recommendation 1: It is neither practical nor feasible to introduce routine carer outcome measurement into mental health services in the immediate term.
- Recommendation 2: Notwithstanding Recommendation 1, there is benefit for local services to introduce carer outcome measurement and the CarerQoI-7D+VAS and the BAS are candidate measures for as the basis for further development.
- Recommendation 3: Regular collection of carer information is seen as essential, and initial investment should focus on development of data items and monitoring mechanisms to track the implementation of the carer-specific standard in the revised National Mental Health Standards.
- Recommendation 4: A range of interventions designed to improve outcomes for carers should be developed and trialled, with a view to 'rolling out' successful interventions in mental health services across Australia. These interventions should be nationally-consistent, but might be adapted to suit local circumstances.

Conclusions

Carers should be key partners the mental health service delivery system. To date, however, they have not received adequate acknowledgement of their role. The current project suggests that although implementing routine carer outcome measurement in mental health services is premature at present, a range of related activities should be undertaken. Local services may wish to pursue routine outcome measurement in some form. The CarerQoI-7D+VAS and the BAS should be explored as candidate measures for further development in this area. Alongside the implementation of the carer-specific standard in the revised National Standards for Mental Health Services, a range of initiatives to meet the needs of carers should be put in place. Data items and monitoring mechanisms should be developed to assess whether the standard is in fact making a difference, In addition, there would be benefit in scoping the field regarding outcome measurement for carers of children/adolescents and older persons, and examining other aspects of the carer experience, such as their perceptions of services.

Chapter 1: Introduction

Setting the context

Under the National Mental Health Strategy, all States and Territories have implemented systems to monitor outcomes for consumers in contact with inpatient and community mental health services. The suite of instruments used in this endeavour – known as the National Outcomes and Casemix Collection (NOCC) – includes a number of instruments which assess consumer improvement, some clinician-rated and some consumer-rated.

To date, no instrument for measuring carer outcomes has been identified as suitable for routine collection through NOCC, but there is an imperative to do so. There is a growing body literature from Australia and overseas which highlights the impact on carers of providing care and support for a relative or friend with mental illness.¹ There is also mounting evidence that interventions designed to assist carers in their role can have benefits not only for the carers themselves, but also for consumers.^{2,3} In addition, consultations with a range of stakeholders have indicated strong support for the inclusion of a carer instrument as part of a comprehensive set of instruments to evaluate mental health service outcomes.⁴

The National Mental Health Strategy has recognised the need to consider outcomes for carers. The National Mental Health Plan 2003-08 identified improved responsiveness to the needs of carers as a priority and advocated for carers' perspectives to be included in instruments of service quality and effectiveness.⁵ This is reflected in the draft revised National Mental Health Standards which were recently the subject of wide consultation and which have a specific carer standard which explicitly states that mental health services should '... recognise, respect, value and support the importance of carers to the wellbeing, treatment and recovery of people with a mental illness.'⁶

The National Mental Health Information Strategy Committee recognised carer outcomes as one of three outcome domains that needed to be incorporated into systems designed to monitor service delivery in mental health services.⁷ In this vein, carer outcome measurement was identified as a priority in the National Mental Health Information Priorities document: *'Consistent with the National Mental Health Plan 2003-08 emphasis on improved responsiveness to the needs of carers, available instruments of carer well-being and burden will be evaluated, with a view to developing a national standard measurement tool for inclusion in the core outcomes suite.'*⁸

In 2007, the Commonwealth Department of Health and Ageing has progressed this priority with two projects designed to resolve various issues relating to carer outcome measurement. The first was known as the Identifying the Carer Project, and examined current practice, relevant policy and legislation, and preferred processes with respect to identifying carers.⁹ This project was crucial in terms of clarifying who should be involved in the process of carer outcome measurement.

The second project involves an examination of some of the practical issues around consumer outcome measurement, to be conducted in two stages. The first stage – which is the subject of the current report – involves a scoping exercise, designed to explore the context within which carer outcome measurement might be introduced and to identify any candidate instruments. Depending on the findings of the scoping exercise, the second stage might field test any suitable candidate instruments.

The scoping exercise

We were commissioned to conduct the above scoping exercise, and drew on two sources of data to do so: (a) a review of the literature on available instruments to measure carer outcomes and (b) stakeholder consultations with carers from the public and private sector and from non-government organisations. Both are described in more detail in the following chapter.

The scoping exercise was explicitly restricted to a consideration of outcome measures for carers of adults (not children/adolescents or older persons). The purpose of the scoping exercise was to address the following four research questions:

- What instruments for measuring outcomes for carers have been developed for use by mental health services, or are relevant to mental health services, both in Australia and internationally?
- How do the available instruments compare in terms of measurement domains, psychometric properties and feasibility for use in clinical practice?
- Of the available instruments which, if any, show best potential for use in Australian mental health services and should be subject to further investigation?
- Is the development of an instrument designed to measure carer outcomes a valuable exercise to undertake at this time?

The scoping exercise was deliberately limited to an examination of instruments that consider carer burden, wellbeing and need, not instruments that elicit carers' perspectives of consumers' symptomatology and level of functioning or instruments that measure carers' perceptions of services. Carer burden was defined as 'the adverse consequences of caring for a person with a disabling mental health problem, which may be objective (e.g., financial costs) or subjective (e.g., self-perceived psychological distress).'¹⁰ Carer wellbeing was more difficult to define, but was seen as related to a positive state of mind and satisfaction with life in general.¹¹ Carer need was defined as 'a condition that is important to the carer that is not being satisfied in his or her present environment (e.g., information, support).'¹²

The current report

The remainder of this report outlines our approach, describes our findings, and makes suggestions about future directions. Chapter 2 describes our methodology, discussing the literature review, the stakeholder consultations, and the relationship between the two. Chapter 3 presents our findings with respect to each of the above four research questions. Chapter 4 interprets the findings in the light of current developments in mental health service delivery in Australia, and makes recommendations about progressing the carer outcome measurement agenda.

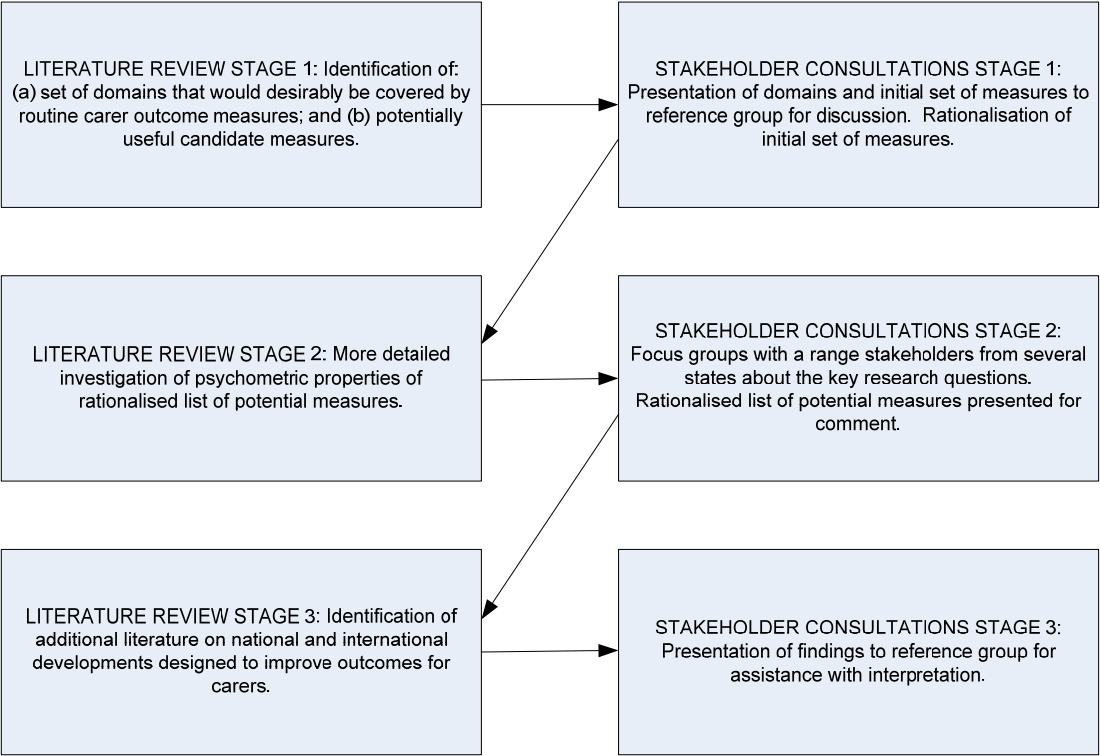
Chapter 2: Method

As mentioned in the previous chapter, the data collection process involved (a) a review of the literature on available instruments for measuring carer outcomes and (b) stakeholder consultations with carers from the public and private sector and from non-government organisations. Both were conducted in stages, in an iterative process where one informed the other.

Stage 1 of the literature review involved the identification of a set of domains that would desirably be covered by routine carer outcome measurement instruments, and the identification of a set of potentially useful candidate instruments. The domains and the initial set of instruments were presented to two meetings of our reference group for discussion, in Stage 1 of the stakeholder consultations. The reference group members were individually selected and included representation from carers, consumers, service providers and policy-makers with experience of the public, private and non-government mental health sectors, all of whom were accustomed to participating in mental health system discussions at a national level. The reference group helped us to refine the domains and rationalise the list of potential instruments, and to focus our line of inquiry. A more detailed investigation of the psychometric properties of the rationalised list of potential instruments was undertaken in Stage 2 of the literature review. The rationalised list also provided a starting point for focus group discussions about outcome measurement in Stage 2 of our stakeholder consultations, which involved meetings with a broader range of stakeholders in several states. In response to issues raised in the Stage 2 stakeholder consultations, Stage 3 of the literature review took place. This involved a search for additional literature on interventions designed to improve outcomes for carers of people with mental illness. Stage 3 of the stakeholder consultations involved presentation of the draft final report to the reference group for assistance with interpretation of the findings.

The iterative relationship between the stages of the literature review and the stages of the stakeholder consultations is illustrated in Figure 1. More detail about each is provided below.

Figure 1: Iterative relationship between stages of the literature review and stages of the stakeholder consultations



Literature review

Stage 1

We conducted a structured search of MEDLINE, PSYCINFO and ISI Web of Science, using the following search terms: ('carer') AND ('mental health' OR 'psychiatry') AND ('outcome' OR 'burden' OR 'wellbeing') AND ('instrument' OR 'instrument'). Potentially relevant journal articles and reports on specific instruments were retrieved by this means, and their reference lists scanned for further pertinent articles and reports. Journal articles were given precedence in this process, on the grounds that the instruments they described had generally been subject to scientific testing and peer review.

A range of inclusion and exclusion criteria were used to develop a shortlist of instruments, bearing in mind that the purpose of the review was to identify instruments that could be used for carers of people with various mental illnesses. Instruments that targeted carers of children/adolescents with mental illness and individuals with physical disabilities were excluded. Instruments that had been initially designed to instrument outcomes for carers of people with specific mental disorders (e.g., schizophrenia, dementia) were only included if they contained a range of items that could be applied across mental illnesses.

Shortlisted instruments were then sourced. Some appeared in full in the relevant journal article, but others were retrieved from a different location (e.g., the developer's website).

A summary of the shortlisted instruments was then developed, which identified the overarching domains covered by each instrument.

Stage 2

Further information on the psychometric properties of the instruments shortlisted by the reference group was sought via a second structured search of MEDLINE, PSYCINFO and ISI Web of Science. This time, the precise names of the instruments were used as search terms. As in Stage 1, journal articles and reports on the instruments were retrieved by this means, and their reference lists scanned for additional material. Again, journal articles were given precedence in this process.

Each instrument was critically appraised, using a checklist that drew on the work of Greenhalgh et al,¹³ Green and Gracely,¹⁴ and McDowell and Newell.¹⁵ The checklist elicited descriptive and evaluative information on each instrument. The descriptive information covered the background and purpose of the given instrument, and provided an overview of its structure, administration and scoring. The evaluative information considered the validity, reliability, sensitivity to change and feasibility/utility of the instrument (see definitions in Table 1).

Table 1: Psychometric properties examined in critical appraisal of candidate instruments

PSYCHOMETRIC PROPERTY	DEFINITION
Validity <ul style="list-style-type: none"> • Content validity • Construct validity • Criterion validity <ul style="list-style-type: none"> • Concurrent validity • Predictive validity 	<p>Refers to the extent to which the instrument measures what it intends to measure</p> <p>Refers to the instrument's comprehensiveness (i.e., how adequately the sampling of items reflects its aims)</p> <p>Involves conceptually defining the construct to be measured by the instrument, and assessing the internal structure of its components and the theoretical relationship of its item and subscale scores</p> <p>Assesses the extent to which the instrument correlates with a 'gold standard' or more established measure of the same theme and can be split into content validity and predictive validity</p> <p>Pits the instrument against a comparable measure or measures at the same point in time</p> <p>Assesses the instruments' ability to predict a future outcome, such as resource use or treatment response</p>
Reliability <ul style="list-style-type: none"> • Test-retest reliability • Inter-rater reliability 	<p>Can be viewed as the extent to which a given instrument gives stable, consistent results, or can be considered as the inverse of the degree of error obtained from any measurement</p> <p>Defined as the degree of agreement when the same instrument is completed by the same individual (or administered to the same individual by the same interviewer) at two different points in time</p> <p>Defined as the degree of agreement when the same instrument is administered to the same individual by different interviewers at the same point in time</p>
Sensitivity to change	Related to both validity and reliability – an instrument that is both valid and reliable, and which demonstrates change over time, can be regarded as being sensitive to change
Feasibility and utility	Related to concepts such as ease of administration, acceptability to stakeholders etc.

Stage 3

Additional literature on interventions designed to improve outcomes for carers of people with mental illness and other relevant developments was also sought. This was additional to the original project brief and it was beyond our scope to do this comprehensively, so selected reports and articles were sought on initiatives that were known to our project team or were recommended by stakeholders attending the focus groups.

A narrative review of this material was undertaken and key interventions and developments were identified.

Stakeholder consultations

Stage 1

A reference group of 11 stakeholders was recruited from our national networks at the commencement of the project to provide guidance with respect to key issues for carers of people with mental illness. As noted above, the composition of the reference group was designed to ensure representation from carers, but also to include the perspectives of consumers, service providers and policy-makers with experience of the public, private and non-government mental health sectors. All were accustomed to participating in mental health system discussions at a national level. This was considered necessary, given the complexity and technical nature of the project. The membership of the reference group can be found at Appendix A.

Early on in the project, two meetings of our reference group were held. Both were attended by two members of our project team who jointly presented information, sought feedback and took notes. The first meeting involved a presentation describing our approach to the project, and sought high-level conceptual input (e.g., on the domains that should be measured in the assessment of carer outcomes). The second involved a presentation of the original instruments identified in Stage 1 of the literature review and sought more specific input on the likelihood that any given instrument would be suitable for use in the field.

Stage 2

Over and above the consultations with the reference group in Stage 1, three focus groups were conducted with carers recruited from a range of public, private and non-government organisations in Brisbane, Melbourne and Adelaide. Between seven and ten carers attended each consultation, with a total of 27 across all consultations.

Again, the focus groups were attended by two members of our project team who took joint responsibility for presenting information, seeking advice and taking notes. Participants were asked to consider whether the development of an outcome instrument should be a priority at this point in time. They were then asked to consider the instruments in the rationalised list and to comment on whether any (or elements of any) would be suitable for the purpose. With respect to the latter, they were provided with a pack containing a hard copy of each instrument and a utility questionnaire relating to each instrument (see Appendix B). Prior to the focus group, they were asked to complete each instrument from their own perspective as a carer and then to fill in the utility questionnaire as it related to that instrument. The utility questionnaire asked whether they thought the given instrument had potential for routine use as a measure of carer outcomes; if so, whether it would require modification (and if so, what sort of changes would be required); and if not, why not. Their reactions to the instruments and their responses to the utility questionnaires were used to prompt discussion in the focus groups.

Stage 3

The final stage of the consultation process involved seeking feedback from the reference group on the draft final report. In particular, reference group members were asked to comment on whether the findings were reported accurately and to assist with the interpretation of these findings. Reference group members' comments were incorporated into the final version of the report.

Chapter 3: Key findings

What instruments for measuring outcomes for carers have been developed for use by mental health services, or are relevant to mental health services, both in Australia and internationally?

Our initial search identified seven potentially relevant instruments covering the broad domains of carer wellbeing, burden and need that met our criteria:

- Carers' Quality of Life-7D + Visual Analogue Scale (CarerQoL-7D+VAS)¹⁶
- Carers' Needs Assessment for Schizophrenia (CNA-S)¹⁷
- Involvement Evaluation Questionnaire (IEQ)¹⁸
- Carers Assessment of Difficulties Index (CADI)¹⁹
- Carers' Assessment of Satisfaction Index (CASI)²⁰
- Burden Assessment Scale (BAS)²¹
- Carers Need Assessment Measure (CaNAM)²²

These seven instruments were examined and discussed by the reference group, and four were excluded on the basis that they were perceived as irrelevant to the target group of carers either because of the domains they covered or the terminology they used. The reference group also commented that, collectively, the instruments did not satisfactorily assess the impact of caring in terms of their own mental health. For this reason, we added three generic measures of mental health and wellbeing to the three candidate measures identified by the reference group. We chose these on the basis that they are already used in the NOCC suite to assess outcomes for consumers and might also be applicable for carers. The final six instruments that were subject to further consultation during the focus groups were:

- Carers' Quality of Life-7D+ Visual Analogue Scale (CarerQoL-7D+VAS)¹⁶
- Involvement Evaluation Questionnaire (IEQ)
- Burden Assessment Scale (BAS)
- Mental Health Index (MHI)²³
- Behaviour and Symptom Identification Scale-32® (BASIS-32®)^{24, 25}
- Kessler-10 Plus (K-10+)²⁶

Table 2 summarises these instruments, providing a brief description of their purpose, their constituent number of items, their mode of administration, and the domains they cover. Copies of each of the instruments can be found at Appendices C-H.

The following two sections consider these six instruments in more detail, based on the findings from the literature review and consultations with carers.

Table 2: Candidate instruments for routine measurement of outcomes for carers of people with mental illness

INSTRUMENT	DESCRIPTION	NO. OF ITEMS	SCORING	ADMINISTRATION
CarerQoI-7D+VAS	The CarerQoI 7D+VAS incorporates a burden component and a valuation component. The burden component assesses seven burden dimensions, and the valuation component uses a visual analogue scale to ascertain level of happiness.	7 plus a visual analogue scale	The burden component requires respondents to indicate whether they have 'no', 'some' or 'a lot' of problems or fulfilment/support regarding the given dimension. For problem-related items, 'no', 'some' and 'a lot' are scored 3, 2, and 1, respectively. For fulfilment/support items, reverse scoring applies, so a high score indicates a high level of burden. The valuation component allows for the calculation of a score from 0 (completely unhappy) to 10 (completely happy).	Self-administered
IEQ	The IEQ is designed to measure levels of burden and distress among family carers of people with a severe mental illness. It assesses how often various events related to caring have occurred during the previous four weeks.	33	Responses to all items are scored on a 5-point Likert scale, 'Never', 'Sometimes', 'Regularly', 'Often', and 'Always', scored 0, 1, 2, 3 and 4 respectively.	Self-administered
BAS	The BAS is was developed to measure both objective and subjective consequences of providing ongoing care to people with severe mental illness, predominantly schizophrenia.	19	Respondents are required to indicate whether they have experienced each of the types of burden 'Not at all', 'A little', 'Some' or 'A lot' in the past four weeks. These are scored 1, 2, 3, and 4 respectively.	Interviewer-administered
MHI	The MHI was developed for use in the RAND Health Insurance Experiment to assess psychological distress and wellbeing of people in the general population.	38	Most items are rated on a scale from 1 to 6 based on frequency or intensity where higher scores reflect more frequent occurrence of favourable mental health symptoms.	Self-administered or interviewer-administered
BASIS-32®	The BASIS-32® was originally developed to assess outcomes among inpatients with mental health problems. Subsequent studies have confirmed its utility as an outcome measure for use across a range of mental health settings. It measures symptoms and behavioural distress in people with a mental illness.	32	Each item is rated from 0 (no difficulty) to 4 (extreme difficulty), resulting in 32 individual scores, five subscale scores and a single total score.	Self-administered or interviewer administered
K-10+	The K-10+ is a version of the K-10, which was developed for use as a measure of non-specific psychological distress. It was originally designed for use in the United States National Health Interview Survey, but was deliberately constructed in a manner that would allow it to have utility in clinical settings as well. The K-10 asks about symptoms of depression and anxiety in the past four weeks. The K-10+ includes an additional four items that quantify the level of disruption and disability resulting from the problems identified in the first 10 items.	14	For each item, the individual indicates the amount of time during the four-week period that he or she experienced the particular problem. There is a five level response scale that ranges from none of the time (1) to all of the time (5). The maximum score is 50, indicating severe distress, and the minimum score is 10, indicating no distress.	Self-administered

How do the available instruments compare in terms of measurement domains, psychometric properties and feasibility for use in clinical practice?

Measurement domains

Table 3 shows that most of the six instruments focus on burden and to a lesser extent wellbeing, rather than on needs. Only the CarerQoI-7D elicits information on needs and the extent to which they are met. This is consistent with the general literature, which suggests that although carer wellbeing and burden have been extensively examined, less attention has been paid to the issue

of carer needs.^{1, 27-30} Stakeholders argued strongly that the needs of carers are paramount, and should be considered in any routine assessment of carer outcomes. They also commented that wellbeing, burden and needs are inextricably linked (e.g., a neglect of needs will increase burden and have a negative impact on wellbeing).

Table 3: Summary of domains measured by candidate instruments

	WELLBEING	BURDEN	NEEDS
CarerQoI-7D+VAS	✓	✓	✓
IEQ	✓	✓	
BAS		✓	
MHI	✓	✓	
BASIS-32®	✓		
K-10+		✓	

Psychometric properties

Our literature review indicated that, in the main, the six candidate instruments had moderate to good psychometric properties. Table 4 summarises the findings of the review, and the full review with respect to each instrument can be found at Appendices I-N:

Table 4: Summary of psychometric properties of candidate instruments

INSTRUMENT	SUMMARY OF PSYCHOMETRIC PROPERTIES
CarerQoI-7D+VAS	The CarerQoI-7D+VAS is a relatively new instrument and has only been subject to a single study of its psychometric properties. This early testing suggests that the instrument has good content and construct validity, and excellent concurrent validity. It also suggests that it has good feasibility and utility. Its predictive validity, test-retest and inter-rater reliability, and sensitivity to change remain untested as yet.
IEQ	Testing of the psychometric properties of the IEQ is limited to only a few studies, but it has been shown to have satisfactory content, construct and concurrent validity and test-retest reliability. There are also indications that it demonstrates sensitivity to change and feasibility and utility.
BAS	Testing of the psychometric properties of the BAS is limited to only a few studies, but it has been shown to have satisfactory content, construct and concurrent validity, and has demonstrated sensitivity to change.
MHI	The MHI has been shown to have adequate to good content, construct, concurrent, predictive validity, test-retest and inter-rater reliability. The MHI has demonstrated sensitivity to change as well as feasibility and utility.
BASIS-32®	The BASIS-32® has been shown to have adequate validity and reliability, and to be sensitive to change during treatment (although the Impulsive and addictive behaviours subscale and the Psychosis subscale perform less well in these areas than do the other three subscales). Arguably, the instrument is also regarded as demonstrating adequate feasibility and utility. Having said this, it should be noted that the developers of the instrument have since prepared a revised version, the BASIS-24®, which only retains three of the original items.
K-10+	The K-10 is extremely widely used, both as a measure of mental health status in general population surveys and as an outcome measure in primary care settings, suggesting that it is well-regarded by the mental health field. The published studies on the psychometric properties of the K-10 are not extensive, but the instrument appears to have adequate to good content, construct and concurrent validity, and test-retest reliability. Its predictive validity and sensitivity to change require further exploration. So too do its feasibility and utility, although its brevity and widespread use in a range of settings augur well in this regard.

Feasibility for use in clinical practice

The general feasibility for use of the instruments was examined wherever possible in the literature review (see above). Stakeholders taking part in our focus groups were asked to consider issues of feasibility more specifically in relation to the roll-out of any given instrument for routine carer outcome measurement in Australia. They raised a number of issues, most of which related to the majority of the instruments, which they felt would render most of them not feasible for use in routine practice, at least in their current form (see Table 5 for a summary of the issues related to

each instrument). They also raised general issues about feasibility, including the lack of readiness of services to implement carer outcome measurement at this point in time.

Table 5: Summary of feasibility issues with respect to candidate instruments, as identified by stakeholders

INSTRUMENT	SUMMARY OF ISSUES RAISED BY STAKEHOLDERS WITH RESPECT TO FEASIBILITY
CarerQoI-7D+VAS	<p>Overall, there was a positive response from each focus group to the CarerQoI-7D+VAS, due to its brevity, simply-worded items, and small number of response options.</p> <p>Issues with the 7D included:</p> <ul style="list-style-type: none"> • Failure to take into account the journey of the carer – e.g., unsuitable for a carer of someone experiencing their first episode of mental illness; • Issues with terminology – e.g., the term ‘relational problems’ has a broad meaning, and in this context does not make much sense; • Preference for response option boxes to appear after the text rather than in the middle; • Lack of a reference time period; • Administration considerations – administration by a clinician or service provider might be necessary in order to ensure understanding of the questions, accurate responses and opportunity for further dialogue; • Uncertainty re. meaning of particular items – additional examples might assist with clarification. <p>Issues with the VAS included:</p> <ul style="list-style-type: none"> • Overly simplistic nature of the scale and perceived tendency for people to mark this kind of scale in the middle; • Lack of explanation regarding what the scale means; • Difficulty with what the term ‘currently’ means in this context – i.e., how long is ‘currently’? • Difficulty with what the term ‘happy’ means in this context – e.g., seems very loose and may be open to misinterpretation, particularly by people from culturally and linguistically diverse backgrounds.
IEQ	<p>Overall, the IEQ was regarded as having some good points, but stakeholders raised a range of issues, including:</p> <ul style="list-style-type: none"> • Length and intrusiveness, particularly for carers of people experiencing first episode of mental illness • Insensitivity (e.g., potentially patronising with respect to the consumer) • Outmoded terminology – e.g., ‘have you guarded your relative/friend from committing dangerous acts?’ regarded as totally inappropriate • Administration considerations – e.g., self-administration likely to result in low rates of completion and inaccurate responses; might be more suitable as an assessment/referral instrument to be administered by a clinician • Concerns over number of response categories – some felt that three response categories would be easier and quicker, although others favoured the existing five because they felt that it might lead to more accurate responses.
BAS	<p>Overall, stakeholders responded positively to the BAS because of its relative brevity and because it could identify anxiety in a respondent. However, stakeholders raised a number of issues about the instrument, including:</p> <ul style="list-style-type: none"> • Negative connotations, too much focus on burden – e.g., some felt that it would be better if it was named the Carer Assessment Scale or similar; • Lack of reference to the carer’s mental health status, wellbeing and needs; • Administration considerations – administration by a clinician or service provider might be necessary in order to ensure understanding of the questions, accurate responses and opportunity for further dialogue; • Lack of relevance to specific carer-consumer relationships; • Lack of meaningfulness of response options, some of which could be merged (e.g., ‘some’ and ‘a little’).
MHI	<p>Overall, this instrument was not popular with stakeholders. Issues included:</p> <ul style="list-style-type: none"> • Length; • Overly medical terminology; • Existing use as a consumer outcome measure, which might intimidate carers and make them feel as though their mental health status was being questioned.
BASIS-32®	<p>Overall, this instrument was not popular with stakeholders. Issues included:</p> <ul style="list-style-type: none"> • Number of response options; Too many response options • Heavy focus on symptoms and no emphasis on wellbeing or needs; • Lack of relevance to carers; • Existing use as a consumer outcome measure, which might intimidate carers and make them feel as though their mental health status was being questioned.
K-10+	<p>Stakeholders felt that this instrument had some merit – e.g., brevity and opportunities for comparison with population-based norms. Overall, however, the instrument was not popular. Issues included:</p> <ul style="list-style-type: none"> • Over-emphasis on burden; under-emphasis on wellness and needs; • Existing use as a consumer outcome measure, which might intimidate carers and make them feel as though their mental health status was being questioned; • Potential only for use in discussion.

Firstly, stakeholders were concerned about inappropriate terminology in most of the instruments. Some objected to the use of ‘medical jargon’ or language that is not immediately comprehensible

to lay people, particularly those with poor literacy skills or those from culturally and linguistically diverse backgrounds. Some also took issue with the fact that the majority of items on the majority of instruments were negatively worded, often agreeing with the essence of the item but rejecting it on the grounds of its negative phrasing. This applied particularly to the burden items on the majority of instruments, because many stakeholders felt that these focused only on the negative impacts of caring for another person, and assumed there were no positive impacts.

Secondly, stakeholders commented on some of the technical features of the instruments. There was a consensus that shorter instruments were preferable to longer ones, because this would encourage carers to complete the instrument and would maximise the likelihood of their providing accurate responses. There were differences between stakeholders with respect to the optimal scoring format for items, with some preferring 3-point scales (on the grounds that they were concise and relatively easy to respond to) and others preferring 5-point scales (because the more refined graduation of responses was seen as likely to increase the accuracy of responses).

Thirdly, stakeholders raised issues about the administration of the instruments. As noted in Table 2, the CarerQoI-7D+VAS, the IEQ and the K-10+ are designed to be self-administered, the BAS is designed to be interviewer-administered, and the MHI and the BASIS-32® can be self-administered or interviewer-administered. Some stakeholders expressed the view that self-administered instruments were preferable because this mode of administration would eliminate any potential for misinterpretation of responses by an interviewer, and would protect carer privacy. Most stakeholders favoured interviewer-administered instruments, however, because they felt that this might alleviate some of the problems with language, identified above, particularly for those who might otherwise struggle to understand the meaning of particular items. More importantly, they indicated that if mental health workers were responsible for ensuring carer outcome measurement occurs on a regular basis, this would necessitate their engaging with carers, would improve recognition of the role of carers, and would create further dialogue about individual carers' concerns. Stakeholders were not confident, however, that busy clinicians would be able to prioritise administration of an outcome measurement instrument. They suggested that carer consultants might be ideally placed to take responsibility for instrument administration, because they believed this would sit well with their role of identifying, assisting, advising and supporting carers at an individual level within the service system. However, they noted that there are currently relatively few carer consultants in mental health services across Australia.

Finally, a number of stakeholders were concerned that the available instruments did not adequately reflect the 'journey' of caring for a person with a mental illness. They felt that the instruments did not capture the experience of providing care, which often begins at the onset of the mental illness in their relative or friend, and continues through the often-episodic course of the illness. This frequently involves significant ongoing interactions with the mental health service system. In terms of the feasibility of carer outcome measurement, this has implications for how questions in a given instrument are framed, and how often (and how) the instrument might be administered. It also has implications for the period covered by the instrument. Four of the six instruments refer to the past four weeks or one month, but the CarerQoI-7D+VAS, the BASIS-32® do not specify a time period for consideration, and this was viewed negatively by many stakeholders.

Of the available instruments which, if any, show best potential for use in Australian mental health services and should be subject to further investigation?

Taking the above considerations into account, stakeholders were of the view that none of the six instruments was seen as ideal, but that the CarerQoI-7D+VAS and BAS might serve the purpose of carer outcome measurement with some modification in services which are prepared to undertake this process. They perceived value and relevance in terms of at least some of the items and subscales on these two instruments, and recommended that they form the basis of further development work

Is the development of an instrument designed to measure carer outcomes a valuable exercise to undertake at this time?

Despite cautious support for the CarerQoI-7D+VAS and BAS, routine carer outcome measurement was not supported at this time. There was a general view that mental health services are not yet ready for the introduction of routine carer outcome measurement.

Stakeholders were firmly of the view that introducing an instrument to routinely measure outcomes for carers would only make sense in the context of implementing a range of initiatives designed to meet carer needs and thus improve outcomes for carers and consumers. They argued that it made sense to introduce routine consumer outcome measurement in mental health services, because these services provide treatment designed to improve consumer outcomes. Routine consumer outcome measurement provides a mechanism for monitoring the effectiveness of these services. In the absence of any efforts to produce positive outcomes for carers, however, stakeholders felt that the introduction of routine carer outcome measurement would be meaningless.

Stakeholders had various ideas about the kinds of initiatives that might be introduced. Some commented that greater acknowledgement of the role of carers should form the basis of any such initiative. They observed that their role in caring for people with mental illness is currently under-acknowledged, and that the significant time and resources they spend in providing care often goes unnoticed. Greater respect for their efforts on the part of mental health services would go some way to improving outcomes for them.

Some made the related point that opportunities to become more involved in the treatment of the consumers for whom they are caring would improve outcomes for them (and, for that matter, for the consumers). Currently, many felt excluded from the treatment process. They described situations in which they were unable to access even the most general information (e.g., information on the symptoms and treatment of a particular mental illness). They also described circumstances where they felt that had had the opportunity to provide input into the treatment plan of an individual consumer, the care of that consumer would have been optimised. In both cases, they felt disenfranchised and frustrated.

Some stakeholders felt that the outcome measurement itself could become part of an assessment and referral system designed to improve outcomes for carers and, in turn, consumers. So, for example, a clinician or carer consultant might work through a selected carer outcome instrument with the carer, and, on the basis of his or her scores on particular wellbeing, burden and needs domains might offer a range of referral options. These might include respite arrangements, support groups, education and information etc, which may or may not be the responsibility of the mental health service.

In making some of the above comments, stakeholders referenced the revised National Mental Health Standards, which include a carer-specific standard (as well as COAG commitment to carers and progressive development of carer legislation in states/territories). Specifically, they considered it necessary to focus future activity on data development and monitoring, noting that such efforts should be an essential component of the new carer standard to ensure efficient and effective implementation. They acknowledged that it would not be possible in the immediate term to evaluate the impact of the standard on long-term outcomes for carers and the consumers they care for. However they felt that it would be possible to monitor a range of related activities including, for example, change in the number of carers identified by services, participation levels, rate of distribution of information kits, implementation of training programs for staff and carers and carer access to services.

Chapter 4: Discussion

Summary of key findings

Our literature review and stakeholder consultations identified 10 instruments with potential relevance to carer outcomes. This list was reduced down to six, and then down to two, with most instruments being rejected by stakeholders on the grounds of inappropriate terminology (e.g., 'medical jargon', incomprehensible language or negative phrasing), technical features (e.g., length, response formats), administration issues and failure to reflect the 'journey' of caring for a person with a mental illness. Stakeholders were of the opinion that it is not practical, feasible or welcome to implement any of the measures in their existing format in the foreseeable future. The CarerQoI-7D+VAS and BAS might serve the purpose of carer outcome measurement with some modification because of their perceived value and relevance in terms of at least some of the items and subscales on these two instruments, and recommended that they form the basis of further development work by individual services committed to working with carers.

Despite reserved support for the CarerQoI-7D+VAS and BAS, stakeholders were adamant that introducing an instrument to routinely measure outcomes for carers should only occur in the context of implementing a range of initiatives designed to improve carer outcomes. In the absence of any efforts to improve meet the needs of carers, stakeholders felt that the introduction of routine carer outcome measurement would be meaningless. However, the inclusion of a carer-specific standard in the revised National Standards for Mental Health Services was perceived as an opportunity to change this situation. In order to evaluate the implementation of this standard it will be necessary to undertake work on data development and monitoring mechanisms with a view to their inclusion in routine data sets.

Recommendations

On the basis of the above findings, we make four recommendations. These recommendations, and detail about how best to implement them, are provided below.

Recommendation 1: It is neither practical nor feasible to introduce routine carer outcome measurement into mental health services in the immediate term.

There is a general view that the time is not yet right for introducing routine carer outcome measurement into mental health services. However, a number of other activities should occur at this point, and the following recommendations relate to these.

Recommendation 2: Notwithstanding Recommendation 1, there is benefit for local services to introduce carer outcome measurement and the CarerQoI-7D+VAS and the BAS are candidate measures for as the basis for further development.

In addition to using the CarerQoI-7D+VAS and BAS as the 'starting point' for the development of the new instrument, consideration should be given to the issues raised by stakeholders in our focus groups. Terminology, technical features, administration issues and reflection of the 'carer journey' are all clearly important. The development of the new instrument should be carer-led, and should involve a team with appropriate psychometric and instrument-development skills.

The instrument should be designed in such a way that, in addition to being used as a routine outcome measure, it can be used for the purpose of individual carer assessment. There are international precedents for this. For example, in the United Kingdom, carers have a right to an assessment of their needs that is enshrined in legislation. The assessment provides information upon which action may be taken (e.g., referral of the carer to various support services).⁹ Field testing of any new instrument should be done with the dual purpose of carer outcome measurement and carer assessment in mind.

Recommendation 3: Regular collection of carer information is seen as essential, and initial investment should focus on development of data items and monitoring mechanisms to track the implementation of the carer-specific standard in the revised National Mental Health Standards.

Data development and monitoring should be an essential component of the new carer-specific standard, in order to guarantee that it is implemented appropriately. Such data development and monitoring should work towards evaluating the impact of the standard on long-term outcomes for carers and consumers, but for now should focus on monitoring a range of activities designed to support carers. Examples cited by stakeholders include change in the number of carers identified by services, participation levels, rate of distribution of information kits, implementation of training programs for staff and carers and carer access to services.

Recommendation 4: A range of interventions designed to improve outcomes for carers should be developed and trialled, with a view to 'rolling out' successful interventions in mental health services across Australia. These interventions should be nationally-consistent, but might be adapted to suit local circumstances.

Several points should be made with respect to Recommendation 4. Firstly, Carers of People with Mental Illness Project,³¹ conducted by the Mental Health Council of Australia and the Carers Association of Australia, made a similar recommendation in 2000. Specifically, it recommended that a 'best practice demonstration project' be funded in each state/territory to provide guidance about how best to promote carer participation and carer responsiveness in service delivery. It suggested that the projects might address a range of areas, including: involvement of carers in care planning; access by carers to consumer information where necessary and appropriate; carer participation in local policy and planning decisions; provision of emotional and social support services for carers; improvement of linkages with community supports for carers; recognition of particular issues for people from culturally and linguistically diverse backgrounds. It recommended that the findings from these projects should then be used to frame criteria to be adopted in the accreditation of mental health services under the National Standards for Mental Health Services. These recommendations were supported in the Identifying the Carer Project,⁹ and have been further reinforced in the draft revision to the National Standards for Mental Health Services.⁶

The second point that should be made with regard to Recommendation 4 is that there are international and national precedents to draw upon with respect to service-level initiatives which might prove effective in improving outcomes for carers. For example, Froggat et al have recently produced a guidebook for working with families as partners in mental health, which suggests a range of approaches to engaging carers and addressing their needs, and provides a number of case studies.³²

The third and final point that should be made in relation to Recommendation 4 is that it relates to service-level initiatives, not broader statewide or national initiatives. Although the latter will also undoubtedly be important in improving outcomes for carers, the focus here is on determining whether local interventions make a difference for carers. These local interventions might, however, be informed by broader initiatives, or articulate with them. They should also be nationally consistent but adapted to local circumstances and in keeping with the service directions of the given organisation. So, for example, a mental health service might trial a program designed to improve carer participation in its policy-making and planning processes, and in doing so might draw on recent work conducted on behalf of the Mental Health Council of Australia designed to identify the most practical model for carer (and consumer) participation at the national level.³³

Conclusion

Carers should be key partners the mental health service delivery system. To date, however, they have not received adequate acknowledgement of their role. The current project suggests that

although implementing routine carer outcome measurement in mental health services is premature at present, a range of related activities should be undertaken. Local services may wish to pursue routine outcome measurement in some form. The CarerQoI-7D+VAS and the BAS should be explored as candidate measures for further development in this area. Alongside the implementation of the carer-specific standard in the revised National Standards for Mental Health Services, a range of initiatives to meet the needs of carers should be put in place. Data items and monitoring mechanisms should be developed to assess whether the standard is in fact making a difference. In addition, there would be benefit in scoping the field regarding outcome measurement for carers of children/adolescents and older persons, and examining other aspects of the carer experience, such as their perceptions of services.

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Appendix A: Reference group membership

Ruth Carson
Helen Connor
Margaret Cook
Tony Fowke
Aaron Groves
Patrick Hardwick
Barbara Hocking
John McGrath
Janne McMahon
Karyn Sinel
Rosemary Warmington

Appendix B: Utility questionnaire

1. Do you think the instrument has potential for routine use as a measure of outcomes for carers of people with a mental illness?

Yes No Not sure

2(a) If you answered **Yes** to Question 1, do you think the instrument could be used as is, or would it require modification?

It could be used as is It would require modification Not sure

2(b) If you answered **No** to Question 1, please indicate the problems you think the instrument has:

3. If you indicated at Question 2(a) that the instrument would require modification, please indicate what sort of changes would be required (e.g., overall changes, changes to specific questions):

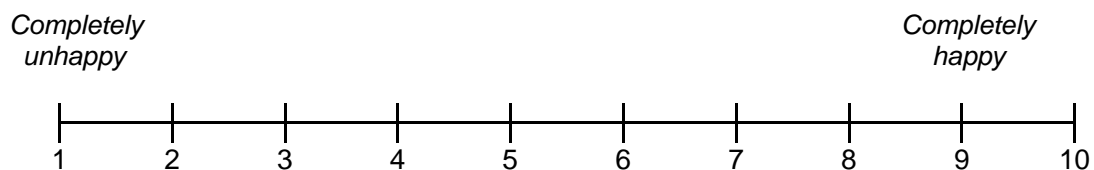
4. Other Comments:

Appendix C: Carers' Quality of Life-7D + Visual Analogue Scale (CarerQoL-7D+VAS)

Please draw an X to indicate which description best fits your current care giving situation

	no	some	a lot of	
a. I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	fulfilment with carrying out my care tasks
b. I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	relational problems with the care received <i>(e.g., he/she is very demanding; he/she behaves differently, we have communication problems).</i>
c. I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	problems with my own mental health <i>(e.g., stress, fear, gloominess, depression, concern about the future)</i>
d. I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	problems combining my care tasks with my daily activities <i>(e.g., household activities, work, study, family and leisure activities)</i>
e. I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	financial problems because of my care tasks
f. I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	support with carrying out my care tasks, when I need it <i>(e.g., from family, friends, neighbours, acquaintances)</i>
g. I have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	problems with my own physical health <i>(e.g., more often sick, tiredness, physical stress)</i>

Please draw an X on the scale below to indicate how happy you feel currently



Appendix D: Involvement Evaluation Questionnaire (IEQ)

Tension sub-scale

How often during the past 4 weeks:	Never	Sometimes	Regularly	Often	Always
1. has your relative/friend disturbed your sleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. has the atmosphere been strained between you both, as a result of your relative/friend's behaviour?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. has your relative/friend caused a quarrel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. have you been annoyed by your relative/friend's behaviour?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. have you heard from others that they have been annoyed by your relative/friend's behaviour?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. have you felt threatened by your relative/friend?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. have you thought of moving out, as a result of your relative/friend's behaviour?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. have you worried about your own future? C8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. have your relative/friend's mental health problems been a burden to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supervision sub-scale

How often during the past 4 weeks:	Never	Sometimes	Regularly	Often	Always
1. have you guarded your relative/friend from committing dangerous acts?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. have you guarded your relative/friend from self-inflicted harm?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. have you ensured that your relative/friend received sufficient sleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. have you guarded your relative/friend from drinking too much alcohol?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. have you guarded your relative/friend from taking illegal drugs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. has your relative/friend disturbed your sleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Worrying sub-scale

How often during the past 4 weeks:

		Never	Sometimes	Regularly	Often	Always
1.	have you worried about your relative/friend's safety?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	have you worried about the kind of help/treatment your relative/friend is receiving?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	have you worried about your relative/friend's general health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	have you worried about how your relative/friend would manage financially if you were no longer able to help?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	have you worried about your relative/friend's future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	have your relative/friend's mental health problems been a burden to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Urging sub-scale

How often during the past 4 weeks:

		Never	Sometimes	Regularly	Often	Always
1.	have you encouraged your relative/friend to take proper care of her/himself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	have you helped your relative/friend take proper care of her/himself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	have you encouraged your relative/friend to eat enough?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	have you encouraged your relative/friend to undertake some kind of activity?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	have you accompanied your relative/friend on some kind of outside activity, because he/she did not dare to go alone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	have you ensured that your relative/friend has taken the required medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	have you carried out tasks normally done by your relative/friend?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	have you encouraged your relative/friend to get up in the morning?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Items not included in a sub-scale

		Never	Sometimes	Regularly	Often	Always
1.	How often during the past 4 weeks have you been able to pursue your own activities and interests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Have you got used to your relative/friend's mental problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	How often have you felt able to cope with your relative/friend's mental health problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Has your relationship with your relative/friend changed since the onset of the mental health problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix E: Burden Assessment Scale (BAS)

Name: _____ Date _____

	Have you, in the last four weeks:	N/A	Not at all	A little	Some	A lot
1.	Had financial problems	0	1	2	3	4
2.	Missed days at work (or school)	0	1	2	3	4
3.	Found it difficult to concentrate on your own activities	0	1	2	3	4
4.	Had to change your personal plans like taking a new job, or going on a holiday	0	1	2	3	4
5.	Cut down on leisure time	0	1	2	3	4
6.	Found the household routine was upset	0	1	2	3	4
7.	Had less time to spend with friends	0	1	2	3	4
8.	Neglected other family members' needs	0	1	2	3	4
9.	Experienced family friction and arguments	0	1	2	3	4
10.	Experienced friction with neighbours	0	1	2	3	4
11.	Become embarrassed because of his/her behaviour	0	1	2	3	4
12.	Felt guilty because you were not doing enough to help	0	1	2	3	4
13.	Felt guilty because you felt responsible for causing his/her problem	0	1	2	3	4
14.	Felt resentful because he/she made too many demands on you	0	1	2	3	4
15.	Felt trapped by your care giving role	0	1	2	3	4
16.	Were upset about how much he/she had changed from their former self	0	1	2	3	4
17.	Worried about how your behaviour with him/her might make the illness worse	0	1	2	3	4
18.	Worried about what the future holds for him/her	0	1	2	3	4
19.	Found the stigma of the illness upsetting	0	1	2	3	4

Appendix F: Mental Health Inventory (MHI)

Instructions:

Please read each question and tick the box by the ONE statement that best describes how things have been FOR YOU during the past month. There are no right or wrong answers.

1. How happy, satisfied, or pleased have you been with your personal life during the past month? **(Tick one)**
 - 1 Extremely happy, could not have been more satisfied or pleased
 - 2 Very happy most of the time
 - 3 Generally, satisfied, pleased
 - 4 Sometimes fairly satisfied, sometimes fairly unhappy
 - 5 Generally dissatisfied, unhappy
 - 6 Very dissatisfied, unhappy most of the time

2. How much of the time have you felt lonely during the past month? **(Tick one)**

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time

3. How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month? **(Tick one)**

1 <input type="checkbox"/> Always	4 <input type="checkbox"/> Sometimes
2 <input type="checkbox"/> Very often	5 <input type="checkbox"/> Almost never
3 <input type="checkbox"/> Fairly often	6 <input type="checkbox"/> Never

4. During the past month, how much of the time have you felt that the future looks hopeful and promising? **(Tick one)**

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time

5. How much of the time, during the past month, has your daily life been full of things that were interesting to you? **(Tick one)**

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time

6. How much of the time, during the past month, did you feel relaxed and free from tension? **(Tick one)**

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time

7. During the past month, how much of the time have you generally enjoyed the things you do? **(Tick one)**

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time

8. During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory? **(Tick one)**
- 1 No, not at all
 2 Maybe a little
 3 Yes, but not enough to be concerned or worried about
 4 Yes, and I have been a little concerned
 5 Yes, and I am quite concerned
 6 Yes, I am very much concerned about it
9. Did you feel depressed during the past month? **(Tick one)**
- 1 Yes, to the point that I did not care about anything for days at a time
 2 Yes, very depressed almost every day
 3 Yes, quite depressed several times
 4 Yes, a little depressed now and then
 5 Yes, never felt depressed at all
10. During the past month, how much of the time have you felt loved and wanted? **(Tick one)**
- 1 All of the time
 2 Most of the time
 3 A good bit of the time
 4 Some of the time
 5 A little of the time
 6 None of the time
11. How much of the time, during the past month, have you been a very nervous person? **(Tick one)**
- 1 All of the time
 2 Most of the time
 3 A good bit of the time
 4 Some of the time
 5 A little of the time
 6 None of the time
12. When you have got up in the morning, this past month, about how often did you expect to have an interesting day? **(Tick one)**
- 1 Always
 2 Very often
 3 Fairly often
 4 Sometimes
 5 Almost never
 6 Never
13. During the past month, how much of the time have you felt tense or "high-strung"? **(Tick one)**
- 1 All of the time
 2 Most of the time
 3 A good bit of the time
 4 Some of the time
 5 A little of the time
 6 None of the time
14. During the past month, have you been in firm control of your behaviour, thoughts, emotions or feelings? **(Tick one)**
- 1 Yes, very definitely
 2 Yes, for the most part
 3 Yes, I guess so
 4 No, not too well
 5 No, and I am somewhat disturbed
 6 No and I am very disturbed
15. During the past month, how often did your hands shake when you tried to do something? **(Tick one)**
- 1 Always
 2 Very often
 3 Fairly often
 4 Sometimes
 5 Almost never
 6 Never

16. During the past month, how often did you feel that you had nothing to look forward to? **(Tick one)**
- | | | | |
|----------------------------|--------------|----------------------------|--------------|
| 1 <input type="checkbox"/> | Always | 4 <input type="checkbox"/> | Sometimes |
| 2 <input type="checkbox"/> | Very often | 5 <input type="checkbox"/> | Almost never |
| 3 <input type="checkbox"/> | Fairly often | 6 <input type="checkbox"/> | Never |
17. How much of the time, during the past month, have you felt calm and peaceful? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
18. How much of the time, during the past month, have you felt emotionally stable? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
19. How much of the time, during the past month, have you felt downhearted and blue? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
20. How often have you felt like crying, during the past month? **(Tick one)**
- | | | | |
|----------------------------|--------------|----------------------------|--------------|
| 1 <input type="checkbox"/> | Always | 4 <input type="checkbox"/> | Sometimes |
| 2 <input type="checkbox"/> | Very often | 5 <input type="checkbox"/> | Almost never |
| 3 <input type="checkbox"/> | Fairly often | 6 <input type="checkbox"/> | Never |
21. During the past month, how often have you felt that others would be better off if you were dead? **(Tick one)**
- | | | | |
|----------------------------|--------------|----------------------------|--------------|
| 1 <input type="checkbox"/> | Always | 4 <input type="checkbox"/> | Sometimes |
| 2 <input type="checkbox"/> | Very often | 5 <input type="checkbox"/> | Almost never |
| 3 <input type="checkbox"/> | Fairly often | 6 <input type="checkbox"/> | Never |
22. How much of the time, during the past month, were you able to relax without difficulty? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
23. How much of the time, during the past month, did you feel that your love relationships, loving and being loved, were full and complete? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |

24. How often, during the past month, did you feel that nothing turned out for you the way you wanted it to? **(Tick one)**
- | | | | |
|----------------------------|--------------|----------------------------|--------------|
| 1 <input type="checkbox"/> | Always | 4 <input type="checkbox"/> | Sometimes |
| 2 <input type="checkbox"/> | Very often | 5 <input type="checkbox"/> | Almost never |
| 3 <input type="checkbox"/> | Fairly often | 6 <input type="checkbox"/> | Never |
25. How much have you been bothered by nervousness, or your “nerves” during the past month? **(Tick one)**
- | | | | |
|----------------------------|--|----------------------------|----------------------------------|
| 1 <input type="checkbox"/> | Extremely so, to the point where I could not take care of things | 4 <input type="checkbox"/> | Bothered some, enough to notice |
| 2 <input type="checkbox"/> | Very much bothered | 5 <input type="checkbox"/> | Bothered just a little by nerves |
| 3 <input type="checkbox"/> | Bothered quite a bit by nerves | 6 <input type="checkbox"/> | Not bothered at all by this |
26. During the past month, how much of the time has living been a wonderful adventure for you? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
27. How often, during the past month, have you felt so down in the dumps that nothing could cheer you up? **(Tick one)**
- | | | | |
|----------------------------|--------------|----------------------------|--------------|
| 1 <input type="checkbox"/> | Always | 4 <input type="checkbox"/> | Sometimes |
| 2 <input type="checkbox"/> | Very often | 5 <input type="checkbox"/> | Almost never |
| 3 <input type="checkbox"/> | Fairly often | 6 <input type="checkbox"/> | Never |
28. During the past month, did you think about taking your own life? **(Tick one)**
- | | |
|----------------------------|------------------------|
| 1 <input type="checkbox"/> | Yes, very often |
| 2 <input type="checkbox"/> | Yes, fairly often |
| 3 <input type="checkbox"/> | Yes, a couple of times |
| 4 <input type="checkbox"/> | Yes, at one time |
| 5 <input type="checkbox"/> | No, never |
29. During the past month, how much of the time have you felt restless, fidgety, or impatient? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
30. During the past month, how much of the time has living been moody or brooded about things? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |

31. How much of the time, during the past month, have you felt cheerful, light hearted?
(Tick one)
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
32. During the past month, how often did you get rattled, upset or flustered? **(Tick one)**
- | | | | |
|----------------------------|--------------|----------------------------|--------------|
| 1 <input type="checkbox"/> | Always | 4 <input type="checkbox"/> | Sometimes |
| 2 <input type="checkbox"/> | Very often | 5 <input type="checkbox"/> | Almost never |
| 3 <input type="checkbox"/> | Fairly often | 6 <input type="checkbox"/> | Never |
33. During the past month, have you been anxious or worried? **(Tick one)**
- | | |
|----------------------------|--|
| 1 <input type="checkbox"/> | Yes, extremely to the point of being sick or almost sick |
| 2 <input type="checkbox"/> | Yes, very much so |
| 3 <input type="checkbox"/> | Yes, quite a bit |
| 4 <input type="checkbox"/> | Yes, a little bit |
| 5 <input type="checkbox"/> | No, not at all |
34. During the past month, how much of the time were you a happy person? **(Tick one)**
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
35. How often during the past month did you find yourself trying to calm down? **(Tick one)**
- | | | | |
|----------------------------|--------------|----------------------------|--------------|
| 1 <input type="checkbox"/> | Always | 4 <input type="checkbox"/> | Sometimes |
| 2 <input type="checkbox"/> | Very often | 5 <input type="checkbox"/> | Almost never |
| 3 <input type="checkbox"/> | Fairly often | 6 <input type="checkbox"/> | Never |
36. During the past month, how much of the time have you been in low or very low spirits?
(Tick one)
- | | | | |
|----------------------------|------------------------|----------------------------|----------------------|
| 1 <input type="checkbox"/> | All of the time | 4 <input type="checkbox"/> | Some of the time |
| 2 <input type="checkbox"/> | Most of the time | 5 <input type="checkbox"/> | A little of the time |
| 3 <input type="checkbox"/> | A good bit of the time | 6 <input type="checkbox"/> | None of the time |
37. How often, during the past month, have you been waking up feeling fresh and rested?
(Tick one)
- | | | | |
|----------------------------|-------------------|----------------------------|------------------------------|
| 1 <input type="checkbox"/> | Always, every day | 4 <input type="checkbox"/> | Some days, but usually not |
| 2 <input type="checkbox"/> | Almost every day | 5 <input type="checkbox"/> | Hardly ever |
| 3 <input type="checkbox"/> | Most days | 6 <input type="checkbox"/> | Never wake up feeling rested |
- 38.. During the past month, have you been under or felt you were under any strain, stress or pressure? **(Tick one)**
- | | |
|----------------------------|---|
| 1 <input type="checkbox"/> | Yes, almost more than I could stand or bear |
| 2 <input type="checkbox"/> | Yes, quite a bit of pressure |
| 3 <input type="checkbox"/> | Yes, some more than usual |
| 4 <input type="checkbox"/> | Yes, some, but about normal |
| 5 <input type="checkbox"/> | Yes, a little bit |
| 6 <input type="checkbox"/> | No, not at all |

Appendix G: Behaviour and Symptom Identification Scale-32® (BASIS-32®)

	No difficulty	A little difficulty	Moderate difficulty	Quite a bit of difficulty	Extreme difficulty
To what extent are you experiencing difficulty in the area of:					
1. Managing day to day life (for example, getting to places on time, handling money, making everyday decisions)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Household responsibilities (for example, shopping, cooking, laundry, keeping room clean, other chores)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Work (for example, completing tasks, performance level, finding/keeping a job)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. School (for example, academic performance, completing assignments, attendance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent are you experiencing difficulty in the area of:					
5. Leisure time or recreational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Adjusting to major life stresses (for example, separation, divorce, moving, new job, new school, a death)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Relationships with family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Getting along with people outside the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Isolation or feelings of loneliness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No difficulty	A little difficulty	Moderate difficulty	Quite a bit of difficulty	Extreme difficulty
--	---------------	---------------------	---------------------	---------------------------	--------------------

To what extent are you experiencing difficulty in the area of:

- | | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 10. Being able to feel close to others | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Being realistic about yourself or others | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Recognising and expressing emotions appropriately | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Developing independence, autonomy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Goals or direction in life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Lack of self-confidence, feeling bad about yourself | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

To what extent are you experiencing difficulty in the area of:

- | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 16. Apathy, lack of interest in things | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Depression, hopelessness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Suicidal feeling or behaviour | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. Physical symptoms (for example, headaches, aches and pains, sleep disturbance, stomach aches, dizziness) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. Fear, anxiety or panic | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

	No difficulty	A little difficulty	Moderate difficulty	Quite a bit of difficulty	Extreme difficulty
--	---------------	---------------------	---------------------	---------------------------	--------------------

To what extent are you experiencing difficulty in the area of:

- | | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 21. Confusion, concentration, memory | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. Disturbing or unreal thoughts of beliefs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. Hearing voices, seeing things | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 24. Manic, bizarre behaviour | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. Mood swings, unstable moods | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 26. Uncontrollable, compulsive behaviour (for example, eating disorder, hand washing, hurting yourself) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please specify:

To what extent are you experiencing difficulty in the area of:

- | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 27. Sexual activity or preoccupation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 28. Drinking alcoholic beverages | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. Taking/misusing illegal drugs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 30. Controlling temper, outbursts of anger, violence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 31. Impulsive, illegal or reckless behaviour | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. Feeling satisfaction with your life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Appendix H: Kessler-10 Plus (K-10+)

Instructions:

The following ten questions ask about how you have been feeling in the **last four weeks**. For each question, mark the square under the option that best describes the amount of time you felt that way.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. In the last four weeks, about how often did you feel tired out for no good reason?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. In the last four weeks, about how often did you feel nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. In the last four weeks, about how often did you feel so nervous that nothing could calm you down?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. In the last four weeks, about how often did you feel so nervous that nothing could calm you down?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. In the last four weeks, about how often did you feel restless or fidgety?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. In the last four weeks, about how often did you feel so restless you could not sit still?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. In the last four weeks, about how often did you feel depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. In the last four weeks, about how often did you feel that everything was an effort?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. In the last four weeks, about how often did you feel so sad that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. In the last four weeks, about how often did you feel worthless?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The next few questions are about how these feelings may have affected you in the **last four weeks**.

You need not answer these questions if you answered 'None of the time' to all of the ten questions about your feelings

11.	In the last four weeks, how many days were you TOTALLY UNABLE to work, study or manage your day to day activities because of these feelings?	_____ (Number of days)
12.	[Aside from those days], in the last four weeks, HOW MANY DAYS were you able to work or study or manage your day to day activities, but had to CUT DOWN on what you did because of these feelings?	_____ (Number of days)
13.	In the last four weeks, how many times have you seen a doctor or any other health professional about these feelings?	_____ (Number of days)
14.	In the last four weeks, how often have physical health problems been the main cause of these feelings?	
	None of the time	<input type="checkbox"/>
	A little of the time	<input type="checkbox"/>
	Some of the time	<input type="checkbox"/>
	Most of the time	<input type="checkbox"/>
	All of the time	<input type="checkbox"/>

Thank you for completing this questionnaire.

Please return it to the staff member who asked you to complete it.

Appendix I: Psychometric properties of the CarerQol-7D+VAS

Background

The CarerQol was developed by Brouwer et al¹⁶ in the Netherlands in 2005, as an exercise in using care-related quality of life measures in economic evaluations. Adapted from a range of care-related burden instruments, with a development approach based on that of the EuroQol instrument, the CarerQol is designed to contain both a description of health status and a valuation element of that health status.

The CarerQol is a relatively new instrument and to date has been tested only once, on a Dutch sample of heterogeneous carers.

Purpose

The purpose of the CarerQol is to measure care-related quality of life in informal carers, meaning those whose profession is not as a carer. It was originally designed to assist in economic evaluations of programs.

Availability

Contact instruments' developers.

Description

The CarerQol-7D+VAS incorporates a burden component (CarerQol-7D) and a valuation component (CarerQol-VAS).

The burden component consists of seven items, each relating to a dimension, or subscale, of carer burden. The burden component requires respondents to indicate whether they have 'no', 'some' or 'a lot' of problems or fulfilment/support regarding the given dimension. For problem-related items, 'no', 'some' and 'a lot' are scored 3, 2, and 1, respectively. For fulfilment/support items, reverse scoring applies, so a high score indicates a high level of burden. The seven items are::

- Fulfilment with carrying out my care tasks
- Relational problems with the care receiver
- Problems with my own mental health
- Problems combining my care tasks with my daily activities
- Financial problems because of my care tasks
- Support with carrying out my care tasks, when I need it
- Problems with my own physical health.

The valuation component uses a visual analogue scale to ascertain level of happiness. The scale ranges from 0 ('completely unhappy') to 10 ('completely happy').

Versions

The original version of the CarerQol-7D+VAS was in Dutch, but it has been translated into English.

Psychometric properties

The psychometric properties of the CarerQol-7D+VAS have only undergone investigation in a single study.¹⁶

Content validity

Brouwer et al's original testing of the CarerQoI-7D+VAS indicated that it had good content validity, although the authors noted that '...it needs to be investigated whether other dimensions need to be incorporated ...A further assessment of the dimensions included in the instrument is therefore warranted and direct carer involvement in the selection of items could provide useful'.¹⁶

Construct validity

Brouwer et al tested the construct validity of the CarerQoI-7D+VAS by comparing the burden component and the valuation component, and found that as scores rose on the burden component, they decreased on the valuation component. They took this as evidence of good internal consistency of the instrument. However, they noted that the instrument only measures how burden impacts on wellbeing via the general valuation scale of the VAS. They commented that, in future iterations, each dimension of burden could have an 'objective valuation' score, in order to avoid the need to control for other differences between carer groups that may affect general wellbeing.¹⁶ This would yield a similar structure to the EuroQoI instrument.

Concurrent validity

Brouwer et al tested the burden component of the CarerQoI-7D+VAS against the Carer Strain Index (CSI) and the Self-Rated Burden Scale (SRB), and tested the valuation component against the Process Utility (PU) instrument. Both the CSI and the SRB are concise instruments that assess carer burden, and the PU is a comparative measure of happiness between a current caregiving role and a hypothetical non-caregiving role. The concurrent validity of both the burden component and the valuation component of the CarerQoI-7D+VAS were found to be excellent.¹⁶

Predictive validity

There are no published data on the predictive validity of the CarerQoI-7D+VAS.

Test-retest reliability

There are no published data on the test-retest reliability of the CarerQoI-7D+VAS.

Inter-rater reliability

The concept of inter-rater reliability is not relevant for the CarerQoI-7D+VAS, since it is designed to be self-administered so there is only one rater.

Sensitivity to change

There are no published data on the test-retest reliability of the CarerQoI-7D+VAS.

Feasibility and utility

The original development work by Brouwer et al suggests that the CarerQoI-7D+VAS demonstrates good feasibility and utility - 98% of participants completed the instrument (with 94% completing the burden component and 99% completing the valuation component).¹⁶

Summary

The CarerQoI 7D+VAS incorporates a burden component and a valuation component. The burden component assesses seven burden dimensions, and the valuation component uses a visual analogue scale to ascertain level of happiness.

The CarerQoI-7D+VAS is a relatively new instrument and has only been subject to a single study of its psychometric properties. This early testing suggests that the instrument has good content and construct validity, and excellent concurrent validity. It also suggests that it has good feasibility and utility. Its predictive validity, test-retest reliability, and sensitivity to change remain untested as yet.

Appendix J: Psychometric properties of the IEQ

Background

The Involvement Evaluation Questionnaire (IEQ) is an instrument that underwent preliminary design and testing between 1987 and 1990 in four Dutch studies to measure the consequences for carers of various consumer situations. The first was a comparative study of day treatment versus inpatient treatment, the second was a study of consumers who had recently attempted suicide, the third was a study of the psychiatric department of a general hospital, and the fourth was a study of consumers undergoing acute care in a community mental health centre.³⁴ The current instrument was finalised in 1992, after testing in two Dutch samples – relatives of consumers with psychotic disorders and relatives of consumers with affective disorders.¹⁸ The IEQ has been translated into several languages (see below).

Purpose

The purpose of the IEQ is to measure levels of burden and distress among family carers of people with a severe mental illness. Studies have investigated the IEQ in the context of both schizophrenia and depression.

Availability

Contact instrument's developers.

Description

The standard IEQ is a self-report 33 item instrument. The first 29 items aggregate into four distinct sub-scales, and the last four items form a 'generic' sub-scale, as observed in the previous four weeks.

The subscales, and the items that comprise them, are as follows:

Tension subscale

How often during the past four weeks:

1. has your relative/friend disturbed your sleep?
2. has the atmosphere been strained between you both, as a result of your relative/friend's behaviour?
3. has your relative/friend caused a quarrel?
4. have you been annoyed by your relative/friend's behaviour?
5. have you heard from others that they have been annoyed by your relative/friend's behaviour?
6. have you felt threatened by your relative/friend?
7. have you thought of moving out, as a result of your relative/friend's behaviour?
8. have you worried about your own future?
9. have your relative/friend's mental health problems been a burden to you?

Supervision subscale

How often during the past four weeks:

1. have you guarded your relative/friend from committing dangerous acts?
2. have you guarded your relative/friend from self-inflicted harm?
3. have you ensured that your relative/friend received sufficient sleep?
4. have you guarded your relative/friend from drinking too much alcohol?
5. have you guarded your relative/friend from taking illegal drugs?
6. has your relative/friend disturbed your sleep?

Worrying subscale

How often during the past four weeks:

1. have you worried about your relative/friend's safety?
2. have you worried about the kind of help/treatment your relative/friend is receiving?
3. have you worried about your relative/friend's general health?
4. have you worried about how your relative/friend would manage financially if you were no longer able to help?
5. have you worried about your relative/friend's future?
6. have your relative/friend's mental health problems been a burden to you?

Urging subscale

How often during the past four weeks:

1. have you encouraged your relative/friend to take proper care of her/himself?
2. have you helped your relative/friend take proper care of her/himself?
3. have you encouraged your relative/friend to eat enough?
4. have you encouraged your relative/friend to undertake some kind of activity?
5. have you accompanied your relative/friend on some kind of outside activity, because he/she did not dare to go alone?
6. have you ensured that your relative/friend has taken the required medicine?
7. have you carried out tasks normally done by your relative/friend?
8. have you encouraged your relative/friend to get up in the morning?

Items not included in a subscale

1. How often during the past 4 weeks have you been able to pursue your own activities and interests?
2. Have you got used to your relative/friend's mental problems?
3. How often have you felt able to cope with your relative/friend's mental health problems?
4. Has your relationship with your relative/friend changed since the onset of the mental health problems?

Responses to all items are rated on a 5-point Likert scale, 'Never', 'Sometimes', 'Regularly', 'Often', and 'Always', scored 0, 1, 2, 3 and 4 respectively.

Versions

As noted above, the original Dutch version of the IEQ was finalised in 1992. The instrument has since been translated into English, Portuguese, Finnish, German, Danish, Spanish and Italian.^{18, 35} A number of these adaptations took place in the context of the European Psychiatric Services: Inputs linked to Outcome Domains and Needs (EPSILON) study, which explicitly involved testing the instrument in a range of languages, in order to broaden its applicability in Europe.

A shortened version of the IEQ, consisting of 27 items, was used in Sydney to investigate the relationship between carer need and burden. For brevity, items were removed from the Tension and Urging subscales.³⁶

An extended version of the IEQ was piloted in Sweden, with results compared to those from the version used in the EPSILON study. The purpose of this pilot was to test if the IEQ was suitable to be used in psychiatric services in Sweden.³⁷

Psychometric properties

The psychometric properties of the IEQ have been examined in a small number of studies.

Content validity

In the testing of the IEQ in 1992 in samples of carers of people with psychosis and carers of people with affective disorders, content validity was found to be satisfactory, with both samples indicating that the IEQ adequately covers all major domains of the consequences of care-giving. Qualitative analysis of an open-ended question in which respondents were asked if any issue had not been covered by the IEQ indicated that there were no missing domains or variables.¹⁸

Further testing of the content validity of the IEQ occurred in the EPSILON Study, when the instrument was translated from Dutch into English. Following a four-step process including back translation and focus group discussions with a range of stakeholders, it was concluded that the IEQ covers the domain of family burden.³⁸

Construct validity

In the Dutch study of 1992, the results from both samples of carers were subjected to factor analysis which revealed a factor structure that aligned with the four subscales, irrespective of whether the analyses were conducted within or across the two samples. The internal consistency – as measured by Cronbach's alpha – was satisfactory in both samples, with a range of 0.74-0.85 for the four subscales to 0.90 for the total score.¹⁸

In the EPSILON study, internal consistency was more complex to measure, as there were multiple sites. However, this study found that Cronbach's alpha values range from 0.68 to 0.86 for the subscales and from 0.87 to 0.91 for the total score. The authors suggest that differences in Cronbach's alpha values are caused as much by difference in sample variance as by differences in true internal consistency. The authors indicated that the internal consistencies of the IEQ scales were, in general, satisfactory.³⁵

Concurrent validity

The IEQ, which can be regarded as a measure of objective burden, was pitted against a Dutch translation of the Maslach Burnout Inventory which assesses subjective burden. The IEQ correlated well with emotional exhaustion and general subjective burden.³⁹ The shortened version of the IEQ was also found to correlate well with the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) in samples of carers of consumers in inpatient and community settings.³⁶

Predictive validity

No published literature exists on the predictive validity of the IEQ.

Test-retest reliability

The relevance of test-retest reliability to the IEQ might be questioned, since it considers consequences for carers, which may change over time. Nonetheless, the EPSILON study found the test-retest reliability of the to be relatively high (at least 0.70).³⁵

Inter-rater reliability

The concept of inter-rater reliability is not relevant for the IEQ, since it is designed to be self-administered so there is only one rater.

Sensitivity to change

There are indications that IEQ may be sensitive to change, but further work in this regard is needed.^{18, 39}

Feasibility and utility

The feasibility and utility of the IEQ also require further testing, but there are positive indications from several studies. Response rates to the IEQ have tended to be high (70%+), and the resultant data tend to be complete with minimal missing values.^{18, 37}

Summary

The IEQ is a 33-item self-report instrument designed to measure levels of burden and distress among family carers of people with a severe mental illness. It assesses how often various events related to caring have occurred during the previous four weeks. Responses to all items are scored on a 5-point Likert scale, 'Never', 'Sometimes', 'Regularly', 'Often', and 'Always', scored 0, 1, 2, 3 and 4 respectively.

In tests of its psychometric properties, the IEQ has been shown to have satisfactory content, construct and concurrent validity and test-retest reliability. There are also indications that it demonstrates sensitivity to change and feasibility and utility.

Appendix K: Psychometric properties of the BAS

Background

The Burden Assessment Scale (BAS) was developed in the United States to measure both objective and subjective consequences of providing ongoing care to people with severe mental illness, predominantly schizophrenia.²¹

Purpose

As noted above, the purpose of the BAS is to measure objective and subjective burden for carers of people with severe mental illness.

Availability

Contact instrument's developers.

Description

The BAS is an interviewer-administered instrument that consists of the following 19 items, the first 10 of which assess objective burden and the latter nine of which assess subjective burden:

Have you, in the last four weeks:

1. Had financial problems?
2. Missed days at work (or school)?
3. Found it difficult to concentrate on your own activities?
4. Had to change your personal plans like taking a new job, or going on a holiday?
5. Cut down on leisure time?
6. Found the household routine was upset?
7. Had less time to spend with friends?
8. Neglected other family members' needs?
9. Experienced family friction and arguments?
10. Experience friction with neighbours?
11. Become embarrassed because of his/her behaviour?
12. Felt guilty because you were not doing enough to help?
13. Felt guilty because you felt responsible for causing his/her problem?
14. Felt resentful because he/she made too many demands on you?
15. Felt trapped by your care giving role?
16. Were upset about how much he/she had changed from their former self?
17. Worried about how your behaviour with him/her might make the illness worse?
18. Worried about what the future holds for him/her?
19. Found the stigma of the illness upsetting?

The items aggregate into six subscales:

- Disrupted activities (Items 3, 4, 5, 6, 7 and 8)
- Personal distress (Items 10, 11, 14 and 15)
- Time perspective (Items 16, 18 and 19)
- Guilt (Items 12, 13 and 17)
- Basic social functioning / Worry (Items 2 and 9).

Respondents are required to indicate whether they have experienced each of the types of burden 'Not at all', 'A little', 'Some' or 'A lot' in the past four weeks. These are scored 1, 2, 3, and 4 respectively.

Versions

The BAS has been translated into several languages, including Spanish⁴⁰ and Swedish.^{41, 42}

Psychometric properties

The psychometric properties of the BAS have been examined in a small number of studies.

Content validity

The content validity of the BAS has been tested in several ways. During its development in the United States, a carer advisory group of six family members of consumers with long-term mental illness reviewed the instrument for clarity and completeness. Following this, the BAS was piloted among two United States samples, one of carers who were nominated by a consumer and the other of carers who sought services for themselves. Both samples ranked items according to the nature of burden in similar ways, with 'worry about the future' receiving the greatest emphasis. These findings were interpreted as evidence of the BAS being a valid measure of burden.²¹

When the BAS was translated into Spanish, it also underwent content validity testing. Specifically, Spanish-speaking focus groups commented on the revised instrument and suggested that several additional items be added. These related to emotional problems and worries about being physically threatened by an aggressive relative.⁴⁰ This suggests that that content validity of the original BAS could be further researched, in order to ascertain its comprehensiveness.

Construct validity

Several studies have examined the construct validity of the BAS. In the original United States trial, both the consumer-nominated sample of carers and the self-nominated sample of carers identified five factors, with Cronbach's alphas of around 0.90. Four of the factors were identical in both samples, but the fifth differed – in the former it was titled 'Worry' and in the latter it was titled 'Basic social functioning'.²¹

Testing of the Swedish version of the BAS identified a three-factor structure (Activity limitation; Feelings of worry and guilt; Social influence), with Cronbach's alpha ranging from 0.73 to 0.88 for these three factors.⁴²

Concurrent validity

The Swedish version of the BAS has also been examined for concurrent validity. Specifically, it was tested against the Quality of Life Index (QLI), the Global Assessment of Function scale (GAF) and the Clinical Global Impression scale (CGI) in two samples – parents of outpatients with schizophrenia and a reference group from the broader community: A correlation was observed between burden and both quality of life and severity of illness.⁴¹

Predictive validity

No published literature exists on the predictive validity of the BAS.

Test-retest reliability

No published literature exists on the test-retest reliability of the BAS.

Inter-rater reliability

No published literature exists on the inter-rater reliability of the BAS.

Sensitivity to change

The original trial of the BAS in the United States found that the BAS has sufficient sensitivity to change to be used as an outcome measure for program evaluation. Specifically, it demonstrated that program participation reduced levels of burden over time.²¹

Feasibility and utility

No published literature exists on the feasibility of the BAS.

Summary

The BAS is a 19-item, interviewer-administered instrument that was developed to measure both objective and subjective consequences of providing ongoing care to people with severe mental illness, predominantly schizophrenia. Respondents are required to indicate whether they have experienced each of the types of burden 'Not at all', 'A little', 'Some' or 'A lot' in the past four weeks. These are scored 1, 2, 3, and 4 respectively.

In tests of its psychometric properties, the BAS has been shown to have satisfactory content, construct and concurrent validity, and has demonstrated sensitivity to change.

Appendix L: Psychometric properties of the MHI

Background

The MHI was developed by Veit and Ware²³ as part of the RAND Health Insurance Experiment in the United States, a study designed to examine the influence of health care financing arrangements on health care utilisation. Adapted from another mental health instrument, the General Wellbeing Schedule (GWB),⁴³ the MHI was designed to assess general psychological distress and wellbeing in a non-patient population.

The MHI has been employed in a wide range of studies. For example, it has been used to assess the mental health of consumers with cancer⁴⁴⁻⁵⁰ and human immunodeficiency virus (HIV),⁵¹⁻⁵³ as well as that of transplant recipients.^{54, 55} It has also been used as a screening tool for depression in older people^{56, 57} and as a general measure of mental illness for primary care consumers.^{58, 59}

Purpose

As noted above, the MHI was designed to measure psychological distress and psychological wellbeing in the general population.

Availability

The MHI can be downloaded free of charge from the RAND Corporation website.⁶⁰

Description

The MHI is a consumer-rated measure comprising 38 items:

- Item 1: How happy, satisfied, or pleased have you been with your personal life during the past month?
- Item 2: How much of the time have you felt lonely during the past month?
- Item 3: How often did you feel nervous or jumpy when faced with excitement or unexpected situations in the past month?
- Item 4: During the past month, how much of the time have you felt that the future looks hopeful and promising?
- Item 5: How much of the time, during the past month, has your daily life been full of things that were interesting to you?
- Item 6: How much of the time, during the past month, did you feel relaxed and free from tension?
- Item 7: During the past month, how much of the time have you generally enjoyed the things you do?
- Item 8: During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory?
- Item 9: Did you feel depressed during the past month?
- Item 10: During the past month, how much of the time have you felt loved and wanted?
- Item 11: How much of the time, during the past month, have you been a very nervous person?
- Item 12: When have you got up in the morning, during the past month, how often did you expect to have an interesting day?
- Item 13: During the past month, how much of the time have you felt tense or 'high-strung'?
- Item 14: During the past month, have you been in firm control of your behaviour, thoughts, emotions or feelings?
- Item 15: During the past month, how often did your hands shake when you tried to do something?

- Item 16: During the past month, how often did you feel that you had nothing to look forward to?
- Item 17: How much of the time, during the past month, have you felt calm and peaceful?
- Item 18: How much of the time, during the past month, have you felt emotionally stable?
- Item 19: How much of the time, during the past month, have you felt downhearted and blue?
- Item 20: How often have you felt like crying, during the past month?
- Item 21: During the past month, how often have you felt that others would be better off if you were dead?
- Item 22: How much of the time, during the past month, were you able to relax without difficulty?
- Item 23: How much of the time, in the past month, did you feel that your love relations, loving and being loved, were full and complete?
- Item 24: How often, during the past month, did you feel that nothing turned out for you the way you wanted it to?
- Item 25: How much have you been bothered by nervousness, or your 'nerves,' during the past month?
- Item 26: During the past month, how much of the time has living been a wonderful adventure for you?
- Item 27: How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?
- Item 28: During the past month, did you think about taking your own life?
- Item 29: During the past month, how much of the time have you felt restless, fidgety, of impatient?
- Item 30: During the past month, how much of the time have you been moody or brooded about things?
- Item 31: How much of the time, during the past month, have you felt cheerful, light-hearted?
- Item 32: During the past month, how often did you get rattled, upset or flustered?
- Item 33: During the past month, have you been anxious or worried?
- Item 34: During the past month, how much of the time were you a happy person?
- Item 35: How often during the past month did you find yourself having difficulty trying to calm down?
- Item 36: During the past month, how much of the time have you been in low or very low spirits?
- Item 37: How often during the past month, have you been waking feeling fresh and rested?
- Item 38: During the past month, have you ever been under or felt you were under any strain, stress or pressure?⁶¹

These items aggregate into six subscales (or lower order factors):

- Anxiety: Items 3, 11, 13, 15, 25, 29, 32, 33, 35
- Depression: Items 9, 19, 30, 36
- Loss of behavioural or emotional control: Items 8, 14, 16, 18, 24, 27, 28
- General positive affect: Items 4-7, 12, 17, 26, 31, 34, 37
- Emotional ties: Items 10, 23
- Life satisfaction: Item 1.⁶²

It should be noted that Veit and Ware²³ originally proposed five subscales, with the single item in the Life satisfaction subscale subsumed into the General positive affect subscale. The six subscale version was proposed by Davies et al, and is being used in the NOCC data collection protocol.⁶²

In turn, the subscales aggregate into two global scales (or higher order factors):

- Psychological distress: Subscales Anxiety, Depression, and Loss of behavioural or emotional control

- Psychological wellbeing: Subscales General positive affect and Emotional ties.⁶²

Each item includes a description of a particular state of mind which is scored on a six-point Likert scale (range 1-6). The exceptions are Items 9 and 28, which are each rated on a 5-point scale (range 1-5). The respondent is required to indicate the frequency or intensity to which they have experienced this state during the past month. Item scores are summed to give six subscale scores, global scale scores and a total score. Prior to summing, certain items need to be reverse scored so that higher scores indicate a higher level of the construct named by the item, scale or index (Davies, 1998).

The MHI can be completed either as a self-report measure or as part of a structured-interview; either way it takes approximately 10-15 minutes to complete.^{61, 63}

Versions

Several alternative versions of the MHI have since been developed, including the briefer MHI-18 and MHI-5⁵⁸ (the latter of which forms the general mental health scale included the MOS-Short Form 20 (SF-20)⁶⁴ and MOS-Short Form 36 (SF-36)⁶⁵). In addition, the MHI has been translated into several other languages, including Hebrew.⁶⁶

The remainder of this chapter focuses on the psychometric properties of the MHI and, to a lesser extent, the MHI-5.

Psychometric properties

The MHI has undergone various examinations concerning its psychometric properties.

Content validity

Several attempts have been made to explore the content validity of the MHI, and certain items have been found to be problematic with particular sub-populations. Gowans et al,⁶⁷ for example, found a multicultural sample had difficulty in understanding the nuances that distinguish some of the items on the Depression subscale (e.g., Item 9 – ‘Did you feel depressed during the past month?’, Item 19 – ‘How much of the time, during the past month, have you felt downhearted and blue?’ and Item 36 – ‘During the past month, how much of the time have you been in low or very low spirits?’), and consequently could not rate them independently. Huebeck and Neill⁶⁸ deleted certain items (e.g., Item 21 – ‘During the past month, how often have you felt that others would be better off if you were dead?’ and Item 28 – ‘During the past month, did you think about taking your own life?’) in a study of adolescents, due to ethical concerns raised by the severity of their language. Likewise, Ell et al⁴⁸ eliminated items deemed inappropriate for newly diagnosed cancer patients.

Construct validity

Numerous studies have examined the internal consistency of the full-length MHI, as measured by Cronbach’s alpha. In these studies, Cronbach’s alpha has ranged from 0.63 to 0.93 for the subscales, 0.90-0.97 for the global scales and 0.93 to 0.97 for the total score.^{23, 45, 66, 69-82} Together, these studies indicate that the MHI has a high internal consistency.

A number of studies have examined the structure of the MHI, considering how well the observed data fit the original model proposed by Veit and Ware.²³ Most have found support for the original structure.^{66, 83, 84} However, some have only found support for the two- factor model (i.e., the global scores)^{68, 73} Others have found a poor fit across all models and/or suggested alternative solutions.^{46, 85, 86}

Concurrent validity

Numerous studies have considered the concurrent validity of the MHI, examining the relationship between its subscales and global scales and comparable constructs on other standardised measures. The following instruments have shown to correlate well with the full-length MHI in the predicted direction: the Brief Pain Inventory (BPI),⁸⁷ the Medical Outcome Study Social Support Survey (MOS-SSS),⁴⁴ the Life Experience Survey (LES),⁴⁴ the Systems of Belief Inventory (SBI),⁴⁴ the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30 (EORTC),⁸⁸ the Positive and Negative Affect Schedule (PANAS),⁴⁶ the Dyadic Adjustment Scale (DAS),⁴⁶ the Purpose in Life Test (PIL),⁸⁹ the Life Regard Index (LRI),⁸⁹ the Sense of Coherence Scale (SOC),⁸⁹ the MOS 36-item Short-Form Health Survey (SF-36)⁶⁹ and the Behaviour and Symptom Identification Scale (BASIS-32®).⁶⁹ However, poor correlations have been found between the MHI and the Life Skills Profile (LFS),⁶⁹ Role Functioning Scale (RFS),⁶⁹ and Health of the Nation outcome scales (HoNOS)⁶⁹ and the Global Assessment Scale (GAS).⁸⁶

Several studies have also considered the concurrent validity of the shorter MHI-5, also assessing its performance against other, more established measures. The MHI-5 has been shown to correlate well with the General Health Questionnaire (GHQ-12),⁸¹ the Rhode Island Stress and Coping Inventory (RISCI),⁹⁰ the General Health Rating Index (GHRI),⁹¹ the Quality of Well Being Scale (QWB)⁹¹ and the Sickness Impact Profile (SIP).⁹¹ The MHI-5 was also found to be highly correlated with all dimensions of the SF-36, in particular Role limitations due to emotional problems (RE), Social Functioning (SF), Vitality (VT) and General Health Perceptions.^{79, 81}

Other studies have assessed the concurrent validity of the full-length MHI to discriminate between subgroups of consumers. Analyses in these studies have found that the MHI can discriminate between those who have experienced stressful life events and those who have not,^{44, 45, 81} those with low level of social support and those with good social networks,⁴⁴ and those with poor physical health and those with no medical problems.^{44, 92, 93} Furthermore, MHI scores have been shown to relate to mental health service use⁸¹ and to discriminate between clinical and non-clinical samples, at least for certain diagnostic groups.^{51, 94, 95}

Predictive validity

Several studies have explored the predictive validity of the MHI. In particular, these studies have focused on the ability of the instrument to predict future service use. Results from the Health Insurance Study indicated that persons with low total scores on the MHI (i.e., high psychological distress and low psychological wellbeing) were more likely to receive mental health care than those with higher scores.^{93, 96}

Test-retest reliability

A number of studies have examined the test-retest reliability of the MHI with retest periods of up to one year.^{23, 68, 69} Generally the reliabilities reported have been adequately high for subscale, global scale and total scores on the MHI. These studies have reported correlations ranging from 0.56 to 0.97, indicating that the MHI is relatively stable over time.

Inter-rater reliability

Only a few studies have examined inter-rater reliability of the MHI.^{56, 85} Overall, these studies have found significant correlations between the self-report and interviewer-administered versions of the MHI. However, there are suggestions that some items (e.g., those to do with suicidal ideation) may have lower inter-rater reliability than the majority.

Sensitivity to change

Stedman et al⁶⁹ investigated the sensitivity to change of the MHI by examining whether consumer's global reports of mental health improvement, stability or deterioration correlated with

changes in MHI scores. They found that those who rated themselves as having improved showed corresponding improvements on the majority of MHI subscales, those who rated themselves as stable showed no change on the MHI, and those who rated themselves as having deteriorated showed a decline on the MHI.

Feasibility and utility

Stedman et al⁹⁷ asked consumers to rate the MHI's utility, using a quantitative scale that defined utility in terms of perceived relevance, effectiveness and usefulness. The MHI scored higher than either the BASIS-32 or the SF-36. Stedman and colleagues have also qualitatively explored the opinions of consumers and other stakeholders regarding the feasibility and utility of the MHI and have found them to report that it is comprehensive, easy to understand, user-friendly, acceptable and appropriate. Having said this, some have criticised the wording of specific items, its assessment period, its response options, its relevance to particular subgroups, and its coverage.^{69, 97}

Summary

The MHI is a self-report instrument developed for use in the RAND Health Insurance Experiment to assess psychological distress and wellbeing of people in the general population. Its full-length version comprises 38 items. Most items are rated on a scale from 1 to 6 based on frequency or intensity where higher scores reflect more frequent occurrence of favourable mental health symptoms.

In tests of its psychometric properties, the MHI has been shown to have adequate to good content, construct, concurrent, predictive validity, test-retest and inter-rater reliability. The MHI has demonstrated sensitivity to change as well as feasibility and utility.

Appendix M: Psychometric properties of the BASIS-32®

Background

The BASIS-32® was developed by Eisen and colleagues at McLean Hospital in the United States as a consumer-oriented measure of symptoms and behavioural distress.^{24, 25} The instrument was originally developed and validated among inpatients, but subsequent studies have supported its use in outpatient and residential settings.⁹⁸⁻¹⁰⁴ As a measure of mental health outcomes, the BASIS-32® has been widely used for research and quality-improvement purposes.¹⁰⁵⁻¹⁰⁹

Purpose

The purpose of the BASIS-32® is to measure changes in self-reported symptom and problem difficulty over the course of treatment for people with a mental illness.¹¹⁰

Availability

The BASIS-32® is a commercial instrument and is not available in the public domain. Copyright is held by the McLean Hospital, and there is an annual fee and site licence.⁶¹

Description

The BASIS-32® is a consumer-rated instrument comprising 32 items:

- Item 1: Managing day-to-day life (e.g., getting places on time, handling money, making everyday decisions)
- Item 2: Household responsibilities (e.g., shopping, cooking, laundry, cleaning, other chores)
- Item 3: Work (e.g., completing tasks, performance level, finding/keeping a job)
- Item 4: School (e.g., academic performance, completing assignments, attendance)
- Item 5: Leisure time or recreational activities
- Item 6: Adjusting to major life stressor
- Item 7: Relationships with family
- Item 8: Getting along with people outside the family
- Item 9: Isolation or feelings of loneliness
- Item 10: Being able to feel close to others
- Item 11: Being realistic about yourself and others
- Item 12: Recognising and expressing emotions appropriately
- Item 13: Developing independence, autonomy
- Item 14: Goals or direction in life
- Item 15: Lack of self confidence, feeling bad about yourself
- Item 16: Apathy, lack of interest in things
- Item 17: Depression, hopelessness
- Item 18: Suicidal feeling or behaviour
- Item 19: Physical symptoms
- Item 20: Fear, anxiety or panic
- Item 21: Confusion, concentration, memory
- Item 22: Disturbing or unreal thoughts or beliefs
- Item 23: Hearing voices, seeing things
- Item 24: Manic, bizarre behaviour
- Item 25: Mood swings, unstable moods
- Item 26: Uncontrollable, compulsive behaviour
- Item 27: Sexual activity or preoccupation
- Item 28: Drinking alcoholic beverages
- Item 29: Taking illegal drugs, misusing drugs
- Item 30: Controlling temper, outbursts of anger, violence

- Item 31: Impulsive, illegal or reckless behaviour
- Item 32: Feeling satisfaction with your life

Collectively, the items constituting the BASIS-32® comprise five subscales:

- Relation to self and others (Items 7, 8, 10, 11, 12, 14, 15);
- Depression and anxiety (Items 6, 9, 17, 18, 19, 20);
- Daily living and role functioning (Items 1, 2, 3, 4, 5, 13, 16, 21, 32);
- Impulsive and addictive behaviour (Items 25, 26, 28, 29, 30, 31); and
- Psychosis (Items 22, 23, 24, 27).¹¹¹

Each item is rated using a five-point scale (0 = no difficulty; 1 = a little difficulty; 2 = moderate difficulty; 3 = quite a bit of difficulty; 4; extreme difficulty) which are used to calculate subscales and total scores by adding the ratings for each item and dividing by the number of non-omitted items. The exception to this rule is the computation of the Daily living and role functioning subscale, which is determined by taking the highest difficulty rating of items 2, 3 and 4 to create a single 'role functioning' rating, and averaging this value in with the remaining six items.¹¹¹

Ratings are based on the difficulty experienced during the preceding period (one week in the original instrument; two weeks in the NOCC collection), ascertained by structured interview (either with a rater present or by telephone) or self-report format (either on-site or through mail-out).¹⁰¹ The structured interview is generally administered if the consumer is not capable of self-report (e.g. due to illiteracy or an excess of symptoms) in which the rating scale choices are presented to the consumer on large index cards. The interviewer reads each item to the consumer who is then required to indicate their response on the cards.¹¹²

In its interviewer-administered form, the BASIS-32® may be used by both professional and non-professional staff due to the absence of training requirements. An instruction manual is available which contains a survey form, a scoring algorithm, a reference list and articles relating to methodology, reliability and validity.¹¹⁰

The BASIS-32® takes on average 5-10 minutes to administer in the self-report format, while the structured interview takes approximately 15-10 minutes to complete.¹¹³

Versions

There are several versions of the BASIS. As noted above, the administration of the original BASIS-32® involves a rating period of one week. A modified version of the original instrument is being used under the NOCC protocol; this Australian version involves a rating period of two weeks.

The original instrument has recently undergone further development resulting in the newly released 24-item version, the BASIS-24® (which involves a one week rating period, in line with the Australian version). Many of the features of the original instrument were discarded in the development process, and, in fact, only three of the original items remain in the new version.^{114, 115}

In addition, the BASIS-32® has been translated into many languages including Spanish, French, Japanese, Chinese, Korean, Cambodian, Vietnamese and Tagalog.¹⁰²

The psychometric properties of the BASIS are considered below. The majority of relevant studies in this area have focused on the original BASIS-32®.

Psychometric properties

Compared with some other instruments, the BASIS-32® has undergone extensive and comprehensive psychometric testing.

Content validity

Several attempts have been made to assess the content validity of the BASIS-32®. Eisen and colleagues,^{104, 116} Cameron et al,¹¹⁷ Graham et al¹¹⁸ and Stedman et al⁶⁹ assessed consumer acceptability of the BASIS-32® by soliciting comments following the administration of the instrument. Eisen et al's^{104, 116} participants reported that the instrument was comprehensive, but participants in the other reports had mixed responses. Concerns identified in the work by Cameron et al,¹¹⁷ Graham et al¹¹⁸ and Stedman et al⁶⁹ related to ambiguous and complex language, an exclusive focus on difficulties and issues with content areas. Recommendations from consumers included the addition of items to cover the outcome domains of greater relevance to them.^{117, 118}

In addition to these general criticisms, respondents in these studies expressed specific concerns over the use of certain items. This led both Cameron et al¹¹⁷ and Graham et al's¹¹⁸ to oppose the use of items with multiple content, including Items 17 (Depression, hopelessness), 19 (Physical symptoms) and 21 (Confusion, concentration, memory), and to regard Items 4 (School), 22 (Disturbing or unreal thoughts or beliefs), 27 (Sexual activity or preoccupation) and 29 (Taking illegal drugs, misusing drugs) as invasive or insensitive. In addition, Cameron et al¹¹⁷ believed Items 11 (Being realistic about yourself and others) and 12 (Recognising and expressing emotions appropriately) contained concepts that were too complicated, and Graham et al¹¹⁸ expressed concern about the appropriateness of the content of Item 7 (Relationships with family) due to possible variation in its interpretation.

Furthermore, the BASIS-32® has been criticized for requiring a reading level too high for individuals with limited literacy skills, and for being difficult to complete for individuals who are acutely psychotic or intoxicated, or have dementia.^{98, 100, 109, 114} Indeed, one of the reasons for the development of the BASIS-24® was to overcome these concerns.¹¹⁴

Construct validity

Numerous studies have examined the internal consistency of the BASIS-32®, as measured by Cronbach's alpha. In these studies, Cronbach's alpha of subscales has ranged from 0.6 to 0.9, indicating that the BASIS-32® has a high level of internal consistency across settings (inpatients and outpatients) and types of administration (structured-interview and self-administration).^{25, 69, 98-101, 104, 108, 116, 119, 120} In these studies, the Impulsive and addictive behaviour subscale and the Psychosis subscale have consistently achieved the lowest Cronbach's alpha (i.e., the poorest internal consistency). Their failure to reach recommended levels was one of the impetuses for the development of the BASIS-24®, according to Eisen et al.¹¹⁴

Studies conducted by Eisen and colleagues,^{104, 116} and by Hoffman et al,⁹⁸ Russo et al,¹⁰⁰ and Chow et al¹¹⁹ examined the subscale structure of the BASIS-32® and how well the observed data fit the five-factor model derived from the original sample of inpatients.²⁵ The original five-factor model was confirmed by an analysis of inpatients.^{98, 100} It was found to fit adequately to samples of community-based consumers,^{104, 116, 119} although items on the Impulsive and addictive behaviour subscale (Item 26 – Uncontrollable, compulsive behaviour; Item 28 - Drinking alcoholic beverages; and Item 29 - Taking illegal drugs, misusing drugs)^{104, 119} and Psychosis subscale (Item 23 - Hearing voices, seeing things; and Item 27 - Sexual activity or preoccupation)¹⁰⁴ had low item-scale correlations. Eisen et al¹¹⁴ suggested that the factor structure may not generalise well to ambulatory care settings, again citing this as one of the reasons for the development of the BASIS-24®.

Several studies have also analysed the intercorrelations between the subscales. These studies have shown that three of the five subscales (Relation to self and others; Depression and anxiety; and Daily living and role functioning) are highly intercorrelated, indicating this instrument may be measuring a single dimension rather than distinct aspects of psychological functioning.^{25, 100, 116}

Concurrent validity

Numerous studies have considered the concurrent validity of the BASIS, with the majority comparing individual item scores, subscale scores and total scores on the BASIS-32® with equivalent scores on other standardised measures. The following instruments have been shown to correlate well with the BASIS-32® in the predicted direction: the Client Assessment of Strengths Interests and Goals – Self Report (CASIG-SR),¹²¹ the Client Assessment of Strengths Interests and Goals (CASIG),¹²² the Outcome Questionnaire (OQ-45),¹⁰⁷ the Short Form Health Status Profile (SF-36),^{69, 104, 116} the Symptom Checklist (SCL-90),^{24, 98} the Child and Adolescent Functional Assessment Scale (CAFAS),⁹⁸ the Hopkins Symptom Checklist (MSCL-43),⁹⁹ the Brief Psychiatric Rating Scale (BPRS),⁹⁹ the Mental Health Inventory (MHI),⁶⁹ the Camberwell Assessment of Need (CAN),¹²³ the Psychiatric Symptom Assessment Scale (PSAS),¹⁰⁰ the Outcome Assessment Program (OAP) Questionnaire,¹²⁴ the Health of the Nation Outcome Scales (HoNOS),⁶⁹ and Lehman's Quality of Life Interview (QOLI).¹⁰⁰ By contrast, performance on the BASIS-32® has been found to be unrelated to performance on the Social and Occupational Functioning Assessment Scale (SOFAS-Revised GAF),¹⁰⁰ the Mini Mental Status Examination (MMSE),¹⁰⁰ the Levels of Recovery from Psychotic Disorders Scale (LORS),¹²⁵ the Global Assessment of Relational Functioning Scale (GARF),¹²⁶ the Life Skills Profile (LSP)⁶⁹ and the Role Functioning Scale (RFS).⁶⁹

A second group of studies has assessed the concurrent validity of the BASIS-32® by examining its ability to discriminate between consumers. The BASIS-32® has been shown to correlate well with objective indicators of functioning, effectively discriminating between consumers who were rehospitalised,^{24, 25, 98} and those who were currently employed or undertaking studies,^{24, 25} and between inpatients and outpatients.¹⁰⁴ It has also been shown to discriminate between consumers from particular diagnostic groups. In general, for example, consumers with depression, psychotic disorders and substance abuse problems have been shown to score highly on the Depression and anxiety, Psychosis and Impulsive and addictive behaviours subscales, respectively.^{24, 25, 98, 100, 104, 107, 127} Likewise, consumers with comorbid mental health and substance abuse problems have been shown to score significantly higher on all five subscales than their counterparts with less complex conditions.^{120, 128, 129} There are some exceptions to this rule, however, with several studies being unable to establish a connection between the BASIS-32® score and diagnosis.^{99, 107}

Predictive validity

Few studies have examined the predictive utility of the BASIS-32®, but those that have found the instrument to be able to predict future service use. These studies have observed that, when assessed at discharge, consumers who subsequently require rehospitalisation score higher than their counterparts who maintain community tenure.^{24, 98, 116}

Test-retest reliability

Only a few studies have examined the test-retest reliability of the BASIS-32®, but their findings are uniformly positive, suggesting that the instrument produces consistent results when rated by the same rater at different points in time.^{24, 25, 69, 99}

Inter-rater reliability

Only a limited number of studies have considered the inter-rater reliability of the BASIS-32®. These have either assessed the self-report version of the instrument against the interview version, or have compared self-report with reports of a close informant. These studies have consistently found good overall inter-rater reliability.^{24, 99}

Sensitivity to change

Several studies have assessed the sensitivity of the BASIS-32® to change by following consumers over time and comparing pre- and post-treatment ratings with independent pre- and post- measures of improvement, deterioration or stability. In general, these studies have found the BASIS-32® to be highly sensitive to change following treatment in both inpatient and outpatient samples.^{24, 25, 69, 98, 100, 104, 116, 123, 130, 131} The Impulsive and addictive behaviours subscale and the Psychosis subscale showed poorer sensitivity to change than the other three subscales.^{100, 123}

Feasibility and utility

Empirical studies and published commentaries suggest that the BASIS-32® demonstrates adequate feasibility and utility. Stedman et al, for example, found that it was rated favourably by consumers in terms of its utility (defined in terms of its perceived relevance, effectiveness and usefulness), although it was not ranked as highly as the MHI. Others have found it to be applicable to a wide range of people receiving mental health treatment, not limited by diagnoses, symptom patterns or treatment setting, user-friendly, adaptable due to its alternative administration modes. It has also been found to place minimal burden on staff due to its brevity, the simplicity of its design and its absence of training requirements.^{99, 103, 107, 110, 116}

Having said this, there have been criticisms of the feasibility and utility of the BASIS-32®. Firstly, the developers themselves have noted that there is 'unnecessary redundancy in the instrument', and cite this as one of the reasons for the development of the shorter BASIS-24®.¹¹⁴ Secondly, Higgins and Purvis¹³² studied the usefulness of the instrument of evaluating program-level outcomes in Californian mental health services. They found that although it had clinical relevance at an individual level, it did not work well when data were aggregated. Consumers consistently and dramatically under-reported their symptoms, and improvements over time were negligible (although statistically significant), rendering it of limited utility at a system level. In addition, the costs and licensing demands meant that other tools were preferable.

Summary

The BASIS-32® is a consumer-rated measure that was originally developed to assess outcomes among inpatients with mental health problems. Subsequent studies have confirmed its utility as an outcome measure for use across a range of mental health settings. The instrument comprises 32 items which collectively measure symptoms and behavioural distress in people with a mental illness. Each item is rated from 0 (no difficulty) to 4 (extreme difficulty), resulting in 32 individual scores, five subscale scores and a single total score.

The BASIS-32® has been shown to have adequate validity and reliability, and to be sensitive to change during treatment (although the Impulsive and addictive behaviours subscale and the Psychosis subscale perform less well in these areas than do the other three subscales). Arguably, the instrument is also regarded as demonstrating adequate feasibility and utility. Having said this, it should be noted that the developers of the instrument have since prepared a revised version, the BASIS-24®, which only retains three of the original items.

Appendix N: Psychometric properties of the K-10+

Background

The Kessler-10 (K-10) was developed by Kessler and colleagues, for use as a measure of non-specific psychological distress to be incorporated into the United States National Health Interview Survey (NHIS).²⁶ Its development began with the selection of an initial pool of 612 items, chosen from existing screening scales. These items were whittled down to 45 by a process that involved refining the domains of interest and discarding redundant and unclear items. Further refinements occurred on the basis of analysis of data from a mail pilot survey and a telephone pilot survey, resulting in the 10-item instrument. The K-10+ includes an additional four items over and above those of the K-10 which relate to the functional impairment associated with identified distress (see below).¹³³

Purpose

As noted above, the K-10 is designed as a screener for non-specific psychological distress.²⁶ The tool was originally designed for use in epidemiological surveys, but was deliberately constructed in a manner that would allow it to have utility in clinical settings as well.⁶³ The 'plus' questions in the K-10+ go beyond the concept of psychological distress captured by the original 10 questions, and assess distress-specific global impairment, distress-specific service use and self-reported physical health contribution to distress.

Availability

The K-10 is readily available and can be downloaded free-of-charge.¹³⁴

Description

The K-10 is a self-report measure of psychological distress, in which the consumer completes questions about symptoms of depression and anxiety in the past four weeks. It is designed to span the range from few or minimal symptoms through to extreme levels of distress, and consequently contains both low-threshold items which many people may endorse and high-threshold items which very few will endorse. For each item, the consumer indicates the amount of time during the four-week period that he or she experienced the particular problem. There is a five level response scale that ranges from none of the time (1) to all of the time (5). The maximum score is 50, indicating severe distress, and the minimum score is 10, indicating no distress.^{63, 133} The specific items are as follows:

- Item 1: In the last four weeks, about how often did you feel tired out for no good reason?
- Item 2: In the last four weeks, about how often did you feel nervous?
- Item 3: In the last four weeks, about how often did you feel so nervous that nothing could calm you down?
- Item 4: In the last four weeks, about how often did you feel hopeless?
- Item 5: In the last four weeks, about how often did you feel restless or fidgety?
- Item 6: In the last four weeks, about how often did you feel so restless you could not sit still?
- Item 7: In the last four weeks, about how often did you feel depressed?
- Item 8: In the last four weeks, about how often did you feel that everything was an effort?
- Item 9: In the last four weeks, about how often did you feel so sad that nothing could cheer you up?
- Item 10: In the last four weeks, about how often did you feel worthless?¹³³

As mentioned above, the K-10+ includes four additional items (Items 11-14) that constitute follow-up questions.^a These items aim to quantify the level of disruption and disability resulting from the problems reported, in terms of the degree of limitation of normal activity, and/or seeking help for the problems. Items 11 and 12 require a response in terms of number of days; Item 13 requires a response in terms of number of consultations; and Item 14 follows the same response format as Items 1-10.

- Item 11: In the last four weeks, how many days were you totally unable to work, study or manage your day to day activities because of these feelings?
- Item 12: [Aside from those days], in the last four weeks, how many days were you able to work or study or manage your day to day activities, but had to cut down on what you did because of these feelings?
- Item 13: In the last four weeks, how many times have you seen a doctor or any other health professional about these feelings?
- Item 14: In the last four weeks, how often have physical health problems been the main cause of these feelings?¹³³

These questions are consistent with the notion that symptoms are necessary but not sufficient for a person to be considered as having a disorder; impairment must also be present.¹³⁵ They are also consistent with the intent of similar questions used in numerous population health surveys to elicit information on the functional impact of distress and service utilisation related to distress (e.g., the National Survey of Mental Health and Wellbeing,¹³⁶ which used similar questions in addition to the core K-10). The specific four questions that constitute the 'plus' part of the K-10+ were first used in Australia in the 1996 New South Wales Health Survey.

Versions

Several versions of the K-10 exist, and two are of particular relevance here. As noted above, the K-10+ includes an additional four questions that capture functional impairment associated with psychological distress. The K-10-L3D differs from the K-10 by rating period, and refers to the last three days, rather than the last four weeks. The NOCC protocol employs the K-10+ with its four week rating period at all collection occasions except discharge from an inpatient setting. At the latter collection occasion, the K-10-L3D (including the additional four questions from the K-10+) is employed, in recognition of the brevity of episodes in inpatient settings.

In addition to the above versions of the K-10, there is a six item instrument (the K-6), which was developed at the same time as the K-10, in the event that space requirements in the NHIS demanded greater brevity than that afforded by the K-10.²⁶ The K-10 has also been translated into many languages, including Arabic, Bosnian, Chinese, Croatian, Farsi, Greek, Hindi, Italian, Korean, Macedonian, Serbian, Spanish, Tagalog, Turkish and Vietnamese.¹³³

The current chapter focuses primarily on the original K-10, since this version of the instrument is the one that receives the greatest attention in the psychometric literature.

Psychometric properties

Various tests of the psychometric properties of the K-10 have been undertaken.

Content validity

Ensuring that the K-10 had strong content validity was a priority during its original development. The process of selecting and refining the potential items on the instrument was assisted by an expert advisory panel of survey researchers, which rated each potential item for clarity and

^a Items 11-14 are not answered if the consumer responded 'None of the time' to all of the questions covered by Items 1-10.

wording. Only those items that were consistently rated as clear were included in the pool of items from which the final 10 were chosen.²⁶

Having said this, little follow-up work has been done since the original instrument was released in terms of seeking assurance from respondents that the K-10 measures what it purports to measure. There has been some published commentary and debate in this regard, although it has focused more on the appropriate clinical cut-off points to use when scoring the instrument, and less on the content of individual items.⁶³

Construct validity

Early work on the K-10 indicated that the instrument has good precision in the 90th-99th percentile of the population distribution (i.e., standard errors of standardized scores in the range 0.20-0.25), as well as good internal consistency (i.e., a Cronbach's alpha of 0.93).²⁶ Later work has provided support for the construct validity of the instrument. For example, an examination of data from the Australian National Survey of Mental Health and Wellbeing (NSMHWB) yielded a Cronbach's alpha of 0.92.²⁶

Concurrent validity

K-10 scores have been shown to be significantly correlated with other instruments that measure symptomatology and/or disability, including the General Health Questionnaire (GHQ),⁶³ the Short Form 12 (SF-12),⁶³ Comprehensive International Diagnostic Interview – Short Form (CIDI-SF),¹³⁷ and the World Health Organization Disability Assessment Schedule (WHO-DAS).¹³⁷

The K-10 has also been shown to discriminate between cases and non-cases of particular DSM-IV/SCID disorders (particularly anxiety disorders and mood disorders, but also other mental disorders) in the general population, and to do so as or more effectively than the GHQ, the CIDI-SF and the WHO-DAS.^{26, 63, 134, 137, 138} For example, when data from the Australian National Survey of Mental Health and Wellbeing¹³⁶ were fitted to a standard Receiver Operating Characteristic (ROC) curve to assess the extent to which K10 distress scores predicted the presence or absence of an anxiety or affective disorder (as assessed by the Comprehensive International Diagnostic Interview (CIDI)), the Area Under the Curve (AUC) was 0.89, which is indicative of very good performance (a perfect measure scoring 1.0).¹³⁴

In addition, a positive relationship has been observed between current K-10 scores and the number of consultations for mental health problems in the previous 12 months,⁶³ and between K-6 scores and levels of work, life and other stressors.¹³⁹⁻¹⁴¹

Predictive validity

No published literature exists on the predictive validity of the K-10.

Test-retest reliability

The test-retest reliability of the K-10 was examined in pilot work undertaken prior to the conduct of computer assisted telephone interviewing (CATI) health surveys in various Australian states. The individual items demonstrated only fair reliability, but the total score and the standardised total score demonstrated excellent reliability.¹⁴²

Inter-rater reliability

The concept of inter-rater reliability is not relevant for the K-10, since it is designed to be self-administered so there is only one rater.

Sensitivity to change

There are no published data on the ability of the K-10 to detect change in psychological distress over time.

Feasibility and utility

There are no published studies that have specifically examined the feasibility of the K-10 as a routine outcome measure. Likewise, there are no published studies that have considered the acceptability and utility of the instrument from the perspective of consumers, carers, clinicians and/or managers, although its brevity augurs well in this regard. Having said this, it must be noted that the K-10 is widely used in a range of settings, suggesting that many relevant stakeholders favour its use. In Australia, it has been incorporated into population surveys that have been conducted nationally^{136, 143} and at a state/territory level¹⁴⁴⁻¹⁴⁷ (although only the New South Wales Health Survey^{148, 149} has incorporated the K10+).

Summary

The K-10+ is a version of the K-10, which was developed for use as a measure of non-specific psychological distress. It was originally designed for use in the United States National Health Interview Survey, but was deliberately constructed in a manner that would allow it to have utility in clinical settings as well.

The K-10 is a 10-item self-report measure which asks the consumer about symptoms of depression and anxiety in the past four weeks. The K-10+ includes an additional four items that quantify the level of disruption and disability resulting from the problems identified in the first 10 items.

The K-10 is extremely widely used, both as a measure of mental health status in general population surveys and as an outcome measure in primary care settings, suggesting that it is well-regarded by the mental health field. The published studies on the psychometric properties of the K-10 are not extensive, but the instrument appears to have adequate to good content, construct and concurrent validity, and test-retest reliability. Its predictive validity and sensitivity to change require further exploration. So too do its feasibility and utility, although its brevity and widespread use in a range of settings augur well in this regard.

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