Carer Appraisal Scale: Second Edition of a Novel Carer-Based Outcome Measure

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Abstract

Carers are known to have valuable information regarding patient functioning. It has been repeatedly cited that failure of communication between mental health services and the carers of patients is related to critical incidents and failures in patient care. Despite this, there are no structured interventions for carers to participate in patient care, let alone assist with measuring patient progress. This study builds upon and expands on a previous pilot study of a similar measure that was developed for a specific old-age population to create one suitable for general adult use. Development of the Carer Appraisal Scale was based on a grounded theory approach, beginning with semi-structured interviews with staff members working in the mental health service of a major tertiary referral center, with intent on refinement by focus groups, carer feedback, and eventual reduction in total number of items via factor analysis in order to create an accessible and brief measure suitable for regular clinical use. It is proposed that this measure provides additional value for services in engaging the carers of patients in a clinically meaningful way that will greatly impact on patient care.

Keywords
caregiving, community engagement, service excellence, survey data, relationship-centered administration

Introduction

Carers are known to have valuable information regarding patient functioning. It has been repeatedly cited that failure of communication between mental health services and the carers of patients is related to critical incidents and failures in patient care. Despite this, there are no structured interventions for carers to participate in patient care, let alone assist with measuring patient progress. This study builds upon and expands on a previous pilot study of a similar measure that was developed for a specific old-age population to create one suitable for general adult use (1).

Background

Clinician-based measures of patient functionality only provide a “snapshot” assessment of the patient at that point in time of the interview (1). Carers are in a better position to view the global health of the patient because of their daily awareness and knowledge of their financial situation, personal relationships, living conditions, and social life (1–3). In addition, care needs for the patients, such as educational, intellectual, and emotional needs, are more apparent to the carer (2). Family carers in particular are in a better position and well aware of physical health problems, inhibited motivation for self-care, and adverse effects treatment for the patient (2).

As opposed to carer involvement in diagnosis, there is little in the literature of the role regarding the carer in assisting in treatment and management of a person with a known clinical history of mental health problems (1). A literature search using various combinations of the terms carer, carer burden, clinician, collateral sources, depression, diagnosis, monitoring, and treatment identified no studies that had...
developed a measure, which compares carers and clinical assessment in patient functioning.

There exist, however, numerous similar scales that suggest how such an intervention could operate when broadened to include patient needs. Camberwell Assessment of Need for the Elderly measures the ratings of staff, patient, and carer on 24 items of needs for the patient and 2 of the carer (4). There are 4 sections to each item: whether a need exists, ratings of help received from family and friends, ratings of help received from statutory services, and whether the right amount of help is given Reynolds et al(4) found that approximately one-fifth of staff were unable to identify whether there were any needs with intimate relationships and money.

The Glasgow Epilepsy Outcome Scale (5) found family carers scored higher than staff carers and clinicians on all subscales, while staff carers scored higher than clinicians on all subscales except one. Family carers provided a more extreme overview of concerns while clinicians underestimate these concerns.

Finally, Allington and Salib (6) found that clinicians’ and carers’ overall assessment of using donepezil treatment for patients with Alzheimer disease was that the carers’ impression agrees with clinicians’ impression. This study used a self-administered questionnaire for carers’ response to treatment on a Likert-type Scale from improvement to deterioration and was compared to clinician-based measures. Items included short-term memory, emotional reaction, communication, and others. These findings suggest that the carers’ opinions are as valid as clinical assessment.

Considering the literature review, the perspectives from carers are crucial when assessing and planning treatment for those with a mental health problems. Some studies showed carers and clinicians in agreement, highlighting the validity of a carer’s perspective, while others showed carers’ and clinicians’ perspectives differing, indicating a need for both perspectives for an overall profile of the patient. Carers’ perspectives have been demonstrated to help guide treatment plans for the individual patient and to guide mental health services at large in generalized care, treatment, and intervention.

**Method**

**Development**

Development of the Carer Appraisal Scale was based on a grounded theory approach, beginning with semi-structured interviews with staff members working in the mental health service of a major tertiary referral center, with intent on refinement by focus groups, carer feedback, and eventual reduction in total number of items via factor analysis in order to create an accessible and brief measure suitable for regular clinical use.

**Interviews**

Psychologists, psychiatrists, family advocates, consumer coordinators, social workers, and doctors were interviewed in person. To ensure the answers were recorded consistently, 2 researchers were present for each interview. Key terms were collated and calculated at the conclusion of interviews to assess the 25 most frequently used terms to create list of items to be used in the questionnaire. Eleven staff members were asked to express their opinions in a semi-structured interview (Online Appendix 1.1).

Due to tied scores in analysis, 27 items were identified: Sleep, Mood, Aggression, Evidence of Symptoms, Hallucinations, Functionality, Medication, Treatment, Psychotic Symptoms, Day to Day Activities, Depression, Suicidal thoughts, Social Isolation, Wellness, Communication, Delusions, Distress, Interactions with family and friends, Side effects of medication, Responding to voices, Self negligent (not eating or drinking), Money/finance, Drug use, Alcohol consumption, Selfcare, Risk to Themselves or Others’ safety.

From these data, items were devised, converting the topics of the items into statements that participants could report on. As an example, the topic “Treatment” was written as “I believe the treatment is going well.” A questionnaire was thus developed. In addition to these 27 items created from interview feedback, 3 supplementary items were included based on recurring terms found in the literature review (4,6). Items were in the form of statements for example “I believe the individual has been sleeping well.” The questionnaire was set out in a 5-point Likert-type scale, where carers were asked to indicate a response, for each of the items, ranging from “strongly disagree” to “strongly agree.” In addition to the scale created, 4 questions were added at the conclusion to the survey to determine the carers’ own perspective of the scale itself.

A specific change was the removal of 1 item that was almost identical to another, and the addition of another item that focused on hope for the consumers in the future. With this change, the final 3 terms were Anxiety, Memory, and Hope, leading to the deployed questionnaire (Online Appendix 1.2).

**Focus Groups**

The draft was analyzed by 2 separate expert focus groups made up of mental health staff members employed by the institution to test content validity, and attain any other additional feedback before distribution of questionnaires began, who were not part of the initial interviews. Two focus groups were conducted to reduce the risk of biases, with 5 and 7 members, respectively. Feedback from the same groups was used to refine the questionnaire prior to deployment to carers. The primary change was altering the language of the items to be clearer and easier to interpret.

**Data Collection**

Questionnaires were administered to carers who were advised that all their responses were confidential and
Results and Discussion
A total of 30 surveys were collated. There was universal support for the scale, with all carers reporting “agree” to “strongly agree” for whether they were happy to fill the scale, if it was helpful for patient care, fulfilling an unmet need or wishing to see it or variation of same in regular use. With regard to factor analysis of the items, questionnaire results were then analyzed via IBM SPSS (Build 1.0.0.1012), for purposes of factor analysis in determining opportunities for reducing the total number of questionnaire items. Survey data underwent principal component analysis, with quartimax data rotation with Kaiser normalization. Rotation was noted to converge in 20 iterations, and 9 components were identified. The variables that had the highest correlation coefficients to these 9 components were Social Activities, Hallucinations, Medication side effects, Danger, Anxiety, Treatment, Alcohol, Aggression, and Hearing voices.

Although the variables of “Hearing Voices” and “Hallucinations” had a high correlation (.414), they nevertheless appeared to exhibit limited variance on analysis, leading them both to be identified as viable components. This is likely due to improved carer understanding of the term “voices” as opposed to “hallucinations.” For this reason “Hallucinations” was eliminated as a viable component.

This leads to an interesting question regarding issues of content validity between clinicians and carers, as clinicians may be more interested in global psychotic phenomenology, and accept persistent hallucinations as unavoidable and usually not warranting intervention; however, carers who do not have psychiatric training and are unable to recognize other psychotic features, but have little difficulty understanding the concept of hearing voices, will be more willing to volunteer this information.

The final scale (Online Appendix 1.3) is therefore based on the above-chosen components, together with a qualitative section for open communication with the patient’s treating team.

Conclusion
This study describes the systematic development of an outcome measure with intent of use in general adult psychiatric settings to assist with service planning and delivery by means of improving communication between carers and clinicians involved in patient care.

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