

Measuring Outcomes for Carers for People with Mental Health Problems

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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Executive Summary

Objectives

We aimed to review available outcome measures and, on the basis of consultation with a diverse range of carers, generate data with which to advise the National Co-ordinating Centre for NHS Service Delivery and Organisation (SDO) programme of:

- instruments that could be used to measure the outcomes of services from carers' perspectives;
 - the further work required to develop these instruments so that they are robust;
 - any outcomes considered important by carers for which measures have not been developed.
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Methods

Consultation exercise

A consultation exercise was conducted with carers, representatives of carer organisations and service providers, to determine which outcomes they considered important. This comprised one-to-one interviews and focus groups with all three groups of stakeholders, and a questionnaire survey of the views of delegates at a carers' conference.

Literature review

We conducted a literature review to identify papers describing instruments measuring outcomes for carers for people with mental health problems and dementia. This comprised electronic searches of Medline (1966–) and PsycINFO (1999–), hand-searching of key journals and obtaining unpublished measures from carer organisations. To be included, papers needed to describe an outcome measure used with carers for people with mental health problems and dementia.

Instrument assessment

To be included in the instrument assessment, measures needed to have been used in studies assessing carer outcomes and either (a) to have been used three times or more, not including by the instruments' authors, or (b) to have been developed in the 10 years prior to the review. Psychometric data on acceptability, appropriateness, reliability, validity, responsiveness, precision and interpretability were extracted and, where appropriate, rated according to pre-determined benchmarks. In addition, the importance to carers for the construct measured and carer involvement in the development of the measure were assessed and rated on

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the basis of the consultation-exercise findings and the data presented by the authors respectively.

Results

Consultation exercise

Forty-four carers, eight carer representatives and four service providers were consulted individually or through focus groups, representing a broad range of views. Carers and representatives of carers from minority groups tended to contribute additional information to the discussion, such as the importance of addressing language issues when designing questionnaires, rather than different views about which outcomes were important. There was little consensus about important outcomes, most participants considering most outcomes important and favouring the assessment of a broad range of outcomes to capture carers' holistic experience. There was greater consensus among participants that carers disliked closed-question questionnaires, especially when sent by post, and preferred semi-structured interviews.

Literature review

We found around 500 published papers, referring to 241 outcome measures used with carers. Forty-nine met inclusion criterion (a), used three times or more, not including by the instruments' authors, and 15 met inclusion criterion (b), developed in the 10 years prior to the review (1994 or later), providing a total of 64 measures eligible for review. Six unpublished measures were provided by carer organisations.

Instrument assessment

Most measures (39) had been developed for use with populations other than carers. The degree and quality of the psychometric testing conducted varied, although there was a trend for measures developed for non-carer populations to be the better validated. Carers had rarely been involved in item generation, even when the measure was developed specifically for them, although their involvement was more common in the recently developed measures.

Conclusions

Several instruments with good psychometric properties were found to measure outcomes that carers considered important. These (a) identified carers whose own health was at risk, (b) assessed aspects of the carers' well-being, namely their physical and mental health, their psychological well-being, their coping and their quality of life or (c) assessed aspects of the caregiving experience, namely the effect of caregiving on the family, the caregiving activities the carer undertakes, how the carer feels about caregiving, the positive aspects of caregiving, the carer's sense of competence and the burden the carer experiences, or the carer's perception of the professional services they have received. In each of these three

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areas there is at least one instrument that could be recommended. Overall the Involvement Evaluation Questionnaire stands out as the most established, comprehensive instrument which measures both the experience of caregiving and carer well-being. All of the instruments require some further work to fully establish their psychometric properties in particular work on appropriateness for, and acceptability to, carers and precision, responsiveness and interpretability.

Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health

Addendum

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