

Focussing on quality of life in treatment

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Summary

There are widespread calls for the implementation of outcomes management in mental health services, which involves routinely assessing individual patient outcomes to analyse the effectiveness of treatment. The emphasis in outcomes management is on aggregating outcome data on the level of groups and services and feeding the results back to commissioners, clinicians and managers to inform their decisions on service development and funding. The most important outcome criterion in mental health service research is quality of life, which is also the 'centrepiece' of outcomes management. In several countries, there are plans to implement the main component of outcomes management, i.e. routine outcome assessment, requiring clinicians to routinely assess patient outcome. However, valid data will only be collected if it is worthwhile for clinicians and patients at the level on which it is collected, i.e. the individual patient level. Concurrent assessment and feedback of outcome data to the clinician and patient so that the information can be used to inform treatment activities might make it worthwhile. A European multi-centre randomized controlled trial is currently underway to test the effect of such an intervention in the treatment of psychotic illness. Keyworkers will systematically elicit patients' views on their quality of life, treatment satisfaction and needs for additional/different care over 1 year. It is hypothesized that the intervention will improve patient outcome by prompting explicit discussion about reasons for progress—and lack of progress—in treatment as a basis for further treatment decisions. If the intervention is effective, it is hypothesized that the effect will be mediated by more appropriate treatment decisions and/or a better therapeutic relationship. Focussing on the patient's perspective in the therapeutic interaction may also facilitate patient involvement in decision-making. Finally, outcomes management is still a technical term, which could benefit from further specification and development in order to exploit its potential for improving treatment processes in mental health care.

Aims of mental health care

The aims of mental health care seem to change over time (Schmiedebach *et al.*, 2000) with different emphases in different periods (e.g. internment, human rights, containing risk). Although there are no universally agreed definitions of what constitutes mental health care (Priebe, 2000), few would disagree that the ideal of all modern healthcare is to enable individuals to maximize their quality of life (Killian & Angermeyer, 1999; Awad & Voruganti, 2000). Consistent with this ideal, the goals of mental healthcare are no longer restricted to reducing rehospitalization and symptoms but now include enhancing an individual's broader role functioning and social integration (Lehman, 1983).

Outcomes management

Enhancing quality of life is central to a new approach in health care called outcomes management, defined as a 'technology of patient experience designed to help patients, payers and providers make rational medical care-related choices based on better insight into the effect of these choices on the patient's life' (Ellwood, 1998, p. 1551). Four techniques

characterize outcomes management: greater use of standards and guidelines; routine assessment of patient functioning at appropriate time intervals; pooling outcome data on a massive scale; and dissemination of these results to relevant decision-makers. The ultimate aim of outcomes management is to improve clinical performance and patient outcomes (Smith *et al.*, 1997).

Outcomes management in the individual therapeutic process

Although widely called for, outcomes management has not been widely implemented. The reasons for this include lack of agreement about what to assess, lack of incentives to assess outcome and organizational resistance to change (Marks, 1998; Harrison & Eaton, 1999). Recently, there have been initiatives to implement outcome measurement in routine settings in various countries. In England, the National Health Service is planning to implement some of the techniques of outcome management. Although the assessment measures have not yet been decided upon, there is the expectation that every patient should have their morbidity, quality of life and treatment satisfaction regularly assessed in all mental health services

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throughout the country. The emphasis in outcomes management is on analysing data on the level of services and groups. Asking clinicians to regularly assess outcome is likely to be perceived as just another piece of time consuming paperwork if the results are only fed back on a service level. Valid data will only be collected if there is some benefit for patients and clinicians on the level at which the data is collected, i.e. the individual patient level. If the clinician and patient can use the information that is routinely collected in a meaningful way in the therapeutic process, routine outcomes assessment—and hence outcomes management—is more likely to happen.

The dominant approach to measurement in outcomes management is pre-post measurement of outcome, which stems from the classic pre-post design in experimental research (Brill *et al.*, 1995). This approach is in line with the emphasis on pooling outcome data on a massive scale so that managers and clinicians can evaluate the quality and effectiveness of a given treatment service or organization (e.g. Smith *et al.*, 1997; Salvador-Carulla, 1999; Slade, *in press*). However, routinely assessing treatment outcome lends itself well to assessing the impact of treatment in individual treatment cases (e.g. Brill *et al.*, 1995; Marks, 1998; Priebe, 1999; Slade, *in press*). Brill *et al.* (1995) call this the concurrent approach to outcomes management, whereby information is gathered at multiple time points for an ongoing evaluation of treatment.

Concurrent outcomes management may have some advantages over pre-post outcomes management. Firstly, the concurrent approach (while allowing a pre-post comparison) can be used to identify the time course of improvement (i.e. when gains occurred during the course of the intervention), which is particularly useful in time-limited interventions (Brill *et al.*, 1995; Marks, 1998; Lambert *et al.*, 2001). Secondly, it may have more ecological validity in evaluating the effectiveness of treatment than pre-post outcome assessment in studies of model services (Brill *et al.*, 1995; Priebe, 1999). In other words, the findings may be more applicable to the 'real world' as opposed to the 'research world' (Harrison & Eaton, 1999; Slade, *in press*) and consequently more generalizable. For example, it has been suggested that case management may be less sustainable in routine settings than under ideal conditions, but ongoing evaluation in routine practice is required to identify how it functions under the pressures of less ideal conditions and how it can be sustained in long-term trajectories of care (Burgess & Pirkis, 1999).

What outcomes should be assessed?

Whether pre-post or concurrent outcomes management is favoured, several obstacles to its implementation have been highlighted (Smith *et al.*, 1997; Marks, 1998; Salvador-Carulla, 1999; Slade *et al.*,

1999). Deciding on the criteria for assessing success is not straightforward. As Perkins (2001) notes, the list of interested parties is potentially long from politicians and pressure groups to patients and carers. Each party may have different views about the goals of treatment and, hence, the relevance and value of different outcomes. What is more, there often exist different perspectives within any of these groups. For example, different professional groups do not necessarily agree about what treatment should be provided and what outcomes are desirable. The outcomes to be assessed will also depend on the disorder being treated. Because of the pervasiveness of serious mental illness, people with complex mental health problems frequently require support in different domains of their life, e.g. managing symptoms, housing, finances, practical skills and relationships. Hence, multiple outcome domains may need to be assessed.

In the context of outcomes management, 'the centrepiece and unifying ingredient of outcomes management is the tracking and measurement of function and well-being or quality of life' (Ellwood, 1988). There is also a consensus in mental health services research that quality of life is the most important outcome criterion (Slade, *in press*). While there is some disagreement about what quality of life is (e.g. Killian & Angermeyer, 1999; Lauer, 1999; Herrman, 2000), there is agreement that it is a complex construct encompassing many domains, at least health, social relations, family relations, work and leisure (van Nieuwenhuizen *et al.*, 1997). There is also debate about the relative importance of subjective and objective indices of quality of life (e.g. Warner, 1999), with some expressing concern about the reliability of subjective assessments of wellbeing and whether they can be treated as objectively as direct assessments of pathology (Ellwood, 1988). Awad & Voruganti (2000) suggest that self-ratings about treatment outcomes by people with schizophrenia have been viewed suspiciously because their cognitive capacity may be compromised. However, cumulative findings indicate that subjective quality of life ratings are reliable and correlate to some extent with clinicians' ratings (Voruganti *et al.*, 1998). Moreover, subjective quality of life indicators in specific life domains are much better predictors of overall wellbeing compared with objective indicators in the same life domains (Lehman, 1983).

Clinician-patient collaboration in treatment

Patient and professional agreement on what constitutes quality of life is important given that enhancing quality of life is the overarching goal of treatment. A number of studies (Shepherd *et al.*, 1995; Mayers, 2000; Angermeyer *et al.*, 2001) have explored definitions of quality of life by patients and mental health professionals. In general, patients' priorities relate to health and social life (work, housing, finance, leisure

activities, joy of life, relationships). Although mental health professionals also prioritize the absence of illness related deficits and medication side-effects along with the availability of suitable professional support, treatment and monitoring (Shepherd *et al.*, 1995; Angermeyer *et al.*, 2001), there is considerable overlap with both patients and professionals emphasizing work, relationships and independence.

The UK Department of Health intends to evaluate treatment 'against the aspirations and experience of its users' (Department of Health, 1997) and the National Service Framework (Department of Health, 1999) states that services should be led by the interests of its users. This is hardly surprising given that a collaborative approach in health service provision leads to better outcomes. A significant body of research in primary care has indicated that a patient-centred approach which facilitates patient participation and actively seeks the patient's perspective in the treatment interaction is associated with increased satisfaction and compliance (Stewart, 1984; Bertakis *et al.*, 1991; Roter *et al.*, 1997), less symptom burden (Little *et al.*, 2001) and fewer misunderstandings with unfavourable consequences (Britten *et al.*, 2000).

These findings are consistent with studies in mental health care identifying the predictive validity of patient's subjective assessments of treatment in relation to outcome. Studies by Priebe & Gruyters (1995a) and Priebe & Bröker (1999) found that schizophrenia patient's satisfaction with their treatment in long-term community care predicted time spent in hospital over a 24 month follow-up period. Among patients with depression, satisfaction with treatment predicted self-rated symptoms at discharge (Priebe & Gruyters, 1995b). Similar findings have been reported with an overlapping construct, i.e. the therapeutic relationship. A positive relationship with one's primary clinician is consistently found to predict a better outcome (cf. McCabe & Priebe, submitted for publication), reflected in indices such as symptomatology, time in hospital and quality of life (Frank & Gunderson, 1990; Ryan *et al.*, 1994; Neale & Rosenheck, 1995; Solomon *et al.*, 1995; Krupnick *et al.*, 1996; Gaston *et al.*, 1998; Svensson & Hansson, 1999; Tattan & Tarrier, 2000).

The MECCA study

Assessing the patient's perspective on their quality of life, treatment satisfaction and needs for care will be at the heart of a concurrent outcomes management intervention to be tested in the MECCA study. This study is a European multi-centre cluster randomized controlled trial (conducted in Granada, Groningen, London, Lund, Mannheim and Zurich). It will involve regularly assessing outcome and feeding the results back to the clinician and patient during their

routine meetings. Quality of life (mental and physical health, accommodation, job situation, leisure activities, friendships, relationship with family/partner, personal safety), treatment satisfaction (practical help, psychological help and medication) and needs for care from the patient's perspective will be systematically assessed every 2 months. This will be done by the keyworker and patient together when they meet. There might be concern that social desirability will influence these ratings, i.e. that the keyworkers' presence will lead to higher ratings than the presence of an independent researcher. However, firstly, researchers are not available in routine settings to assess treatment outcomes. Secondly, Kaiser & Priebe (1999) found only a limited effect of the interviewer-interviewee relationship on subjective quality of life ratings.

A crucial issue for the validity of the intervention will be that the information assessed is understandable and meaningful for both clinicians and patients. According to Ellwood, outcomes management ideally 'consists of a common patient-understood language of health outcomes' (1988, p. 1551). Routine outcome measures should be both valid and feasible: a feasible measure should be brief, simple, relevant, acceptable and valuable to its users (Slade *et al.*, 1999). Each of the questions concerning quality of life, treatment satisfaction and needs for care to be assessed in the MECCA study are brief, simple and relevant to users' concerns (cf. Shepherd *et al.*, 1995; Angermeyer *et al.*, 2001; Lelliot *et al.*, 2001).

The nature of keyworking involves clinicians meeting their patients in a variety of settings, including the patient's home, the mental health team office or the hospital. Regularly assessing outcome across these settings must be practicable. Recent advances in information technology mean that paper and pencil measures can be replaced by computerized assessments using mobile technologies. To this end, a software application is currently being developed so that the assessment can be completed using a mobile hand-held computer. The application will allow the ratings to be entered by the patient and/or keyworker into a database. The results of the assessment will be processed by the application and presented to the keyworker and patient there and then.

The quality of life and satisfaction scores, along with needs for additional care, rated in the current and the previous assessment will be presented in a graphical colour display. The feedback will highlight (a) change over time, (b) dissatisfaction with life domains and aspects of treatment and (c) needs for additional care. This may prompt explicit discussion about the reasons for change and the action to be taken. Information about ratings over time (and how they change according to a person's circumstances) can facilitate a discussion about expectations and progress, or lack of progress, in treatment. The mechanism of action might be fine-tuning or increasing the number of appropriate treatment decisions and/or

improving the therapeutic relationship. It is conceivable that specific interventions could be implemented to improve quality of life ratings (Priebe, 1999). The interventions might be practical to change a person's objective circumstances (e.g. housing) or psychological to change a person's subjective view of their life situation (e.g. cognitive behaviour therapy). The MECCA study will test the hypothesis that such an intervention will—akin to interventions in strategic psychotherapy—stimulate and promote a positive therapeutic dialogue and lead to a more favourable outcome. Hence, improvement in outcome would be mediated through more appropriate therapeutic interventions as decided by the clinician and patient or a better therapeutic relationship in line with a partnership model of care or both.

From outcome to process

The idea of assessing outcome and feeding the results back on an ongoing basis during treatment shifts the focus from treatment outcome to the process of care. It has been noted (Priebe, 2000; Brugha & Lindsay, 2001) that the process of care in psychiatry has been neglected in favour of investigating the structural aspects of care. The latter approach has involved attempts to link the structure of services to individual patient outcome without considering the mediating effects of clinical practice. As all mental healthcare is delivered through the clinician–patient relationship (McGuire *et al.*, 2001), it is not surprising that this is an important factor mediating outcome.

If routine outcomes management does make a difference and improve outcome on an individual patient level, it will be necessary to understand how it is done in practice and what makes it effective. As it stands, 'outcomes management' is a technical term. Although it sounds relatively straightforward, there is limited specification of how it should be done and incorporated into individual care processes. In order to identify how it is implemented and made effective in everyday practice, qualitative studies of clinician–patient interactions will be required. A qualitative technique (i.e. conversation analysis) for analysing interactions between patients and healthcare professionals is receiving increased attention (cf. Drew *et al.*, 2001; Madill *et al.*, 2001). This method analyses what people do rather than what they say they do. As Drew *et al.* (2001) note, conversation analysis has the potential to make explicit how professionals and patients communicate and the interactional consequences of adopting one way of doing things rather than another. Conversation analytic research has shown that how doctors design their talk has certain consequences for what patients go on to say and do and that the doctor (or relevant professional) can create the communicative conditions for more or less patient participation (e.g. Peräkylä, 1998; Heritage & Stivers, 1999). If routine outcomes management

leads to better outcomes, this methodology could begin to specify how outcomes management is done in practice and how the patient and clinician interact more successfully under these conditions.

Conclusions

Outcomes management is widely called for but there are many obstacles to its implementation. Routine outcome assessment will only happen if it is worthwhile for the clinician and the patient at the level at which it is to be conducted, i.e. the individual patient level. A trial to test the routine assessment of quality of life using a hand-held mobile computer which feeds the data back there and then to the clinician and patient is currently underway. It is hoped that the routinely collected data can be made useful for the clinician and patient by informing ongoing treatment activities. If routine outcomes management does lead to better patient outcomes, research on the interactional processes will be required to specify how it can be made effective in clinical practice and to make recommendations about how it can be successfully implemented.

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