Quality improvement

Review: involvement of former or current users of mental health services may improve outcomes in patients with severe mental illness


QUESTION: Does the involvement of former or current users of mental health services in the delivery and evaluation of mental health services improve outcomes in patients with severe mental illness?

Data sources
Studies were identified by searching Medline, EMBASE/Excerpta Medica, CINAHL, PsycINFO, HealthSTAR, the Cochrane Controlled Trials Register, Web of Science, HMIC, and BIDS (all from 1966 to October 2001). Bibliographies of relevant articles were reviewed, and experts and relevant organisations were contacted for unpublished studies.

Study selection
Studies were selected if they were randomised controlled trials (RCTs), controlled clinical trials (CCTs), or descriptive studies in which current or former users of mental health services with serious psychiatric illness (schizophrenia or bipolar disorder) participated in the design and data collection process of mental health service evaluation. Studies were also selected if users trained mental health professionals or if services were integrated by health professionals working together with users in a team.

Data extraction
Data were extracted on the mechanism of involving users, including support available; number of users involved and diagnoses; service or setting of involvement; study design; sample size; and all measures of outcomes for employees who were or had been users and their patients. Patient outcomes included quality of life, hospital admissions, social support, and satisfaction.

Main results
5 RCTs, 5 CCTs, and 2 descriptive studies met the selection criteria. All RCTs compared services involving users with services having non-users in similar roles. 8 studies focused on involving users as service providers, mainly working as case managers in services for patients with severe mental illness. 2 studies each looked at the effectiveness of involving users as trainers or interviewers. The process of service delivery by employees who were or had been users of mental health services differed from that of employees who had not. Users spent more time in supervision (1 RCT) and face to face contact with patients (1 RCT), and they spent less time on telephone or office work (1 RCT). Users had a higher turnover rate and less distinct professional boundaries (1 RCT). Employing users in, or alongside, case management services did not have a detrimental effect on patients’ symptoms (1 RCT), functioning (2 CCTs), or quality of life (2 RCTs). Patients receiving these services had some improved quality of life (2 CCTs). They also had improved social functioning, and fewer reported life problems (2 CCTs). Some patients were less of a burden to their families (2 RCTs). In some studies, patients of employees who were or had been users had longer periods before hospital admission, and fewer patients had to be admitted to hospital (1 RCT and 2 CCTs); some patients had shorter hospital stays (1 CCT), although time in hospital was not significantly different in all studies. Services employing people who were or had been users did not have lower patient satisfaction (2 RCTs). Patients reported lower satisfaction with services when interviewed by other users of the service than by staff interviewers in evaluation research (1 RCT).

Conclusion
Preliminary evidence suggests that involvement of former or current users of mental health services in the delivery and evaluation of mental health services improves some outcomes in patients with severe mental illness, as well as some provider outcomes.

COMMENTARY
This systematic review by Simpson and House examines the effects of involving users in the delivery and evaluation of mental health services. The purpose, scope, and rationale for the review are clearly stipulated as are the criteria for selecting rigorous studies for analysis. The literature search was extensive, combining computer and hand searches, and contact with experts in the field. Of the 298 papers reviewed, only 12 comparative studies were found, 5 of which were RCTs. Meta-analysis was not possible because of heterogeneity of study designs and outcome measures. Few standardised outcome measures were used without modification. Some were adapted versions or selected subscales of existing scales, and others were developed for a particular study. Therefore, outcomes were summarised qualitatively.

The findings of this review, although weak, suggest that involvement of former or current users as providers has positive benefits for the clinical outcomes of patients. It may be that users who serve as providers are more sensitive to the complexity of issues facing those receiving mental health services and less judgmental than professionals. Having experienced mental illness themselves, they may more easily recognise the subtle concerns and difficulties of patients and intervene appropriately. Users who are open about their own history may also offer patients positive role models and opportunities to feel more deeply understood. Authors of the reviewed studies also suggested that user involvement might reduce the rate of hospital admissions because users may have a higher tolerance for behaviour arising from symptoms or may be reluctant to see patients admitted because of their own negative experiences with hospital admission.

Ultimately, the effects of user involvement may show the positive results of limiting medical dominance in mental health and psychiatric care. Both users as providers and their patients may benefit from a model that places them at the centre of services in a way that challenges traditional medical authority and treatment effectiveness. Before definitive conclusions can be drawn, however, further research is needed to explore specifically how users affect the delivery and evaluation of mental health services.

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