Qualitative

People with enduring mental health problems described the importance of communication, continuity of care, and stigma

Kai J, Crosland A. *Perspectives of people with enduring mental ill health from a community-based qualitative study*. *Br J Gen Pract* 2001 Sep;51:730–6.

QUESTION: How do people with enduring mental health problems experience health care?

Design

Community based qualitative study.

Setting

4 general practices serving a disadvantaged locality of 5 wards in {Newcastle upon Tyne}*, UK.

Participants

32 people (56% men, mean duration of mental illness of 21 y) who were identified by their general practitioner as disabled by enduring mental ill health (≥ 2 y impaired social behaviour and inability to keep a job, maintain self care, complete domestic chores, or participate in recreational activities). Exclusion criteria were age < 16 years, dementia or other organic brain disorders, or a learning disability.

Methods

Individual interviews of 45 minutes to 2 hours were audiotaped and transcribed verbatim. Theoretical

saturation occurred after 34 interviews; 2 interviews were excluded because the responders did not acknowledge any experience of mental illness. Data were analysed using grounded theory methods. Emerging findings were tested in 21 group interviews with local health professionals.

Main findings

Good therapeutic relationships were regarded as central in participants' contacts with primary care and mental health services. Several related themes emerged. *Communication in building therapeutic relationships*: in good therapeutic relationships, professionals had effective listening skills and showed empathy and understanding, which allowed participants to express their concerns, negotiate options, and build trust. *Continuity of therapeutic relationships*: participants highlighted the importance of building a continuing relationship with one person over time. Frequent changes in physicians and repeatedly reviewing medical histories were frustrating for participants. *Wrestling with stigma: influence of the healthcare setting*: participants worried about where their healthcare contacts occurred, and the potential that they might be stigmatised by association with other patients. Conversely, another theme highlighted the *value of mutual patient support and specialist settings*: participants who had received prolonged inpatient treatment valued the shared contact with and support of other patients. As they recognised their own illness, they accepted other patients, became less concerned about where they were seen, and focused on developing therapeutic relationships. *Experiences of social exclusion*: participants described a "constant juggling between the competing demands of their mental ill health, trying to minimise the effects of stigma, and coping with poverty, fear and exclusion." Taking control of their lives was hampered by common experiences of victimisation, crime, social isolation, and lack of access to material resources. These constraints increased stress, curtailed opportunities to promote wellbeing, and reduced coping capacity. *Potential contribution of professional care*: most participants considered the value of positive therapeutic relationships within the context of social exclusion and stigma. Health professionals were an important source of support over time that helped them to overcome barriers, identify solutions, and establish control over their lives.

Conclusion

The healthcare experiences of people with enduring mental health problems focused on communication and continuity of care in the therapeutic relationship within the context of the stigma and social exclusion related to mental illness.

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COMMENTARY

The study by Kai and Crosland builds on a growing tradition of combining anthropological techniques and quantitative analyses using interview and demographic data from participants. It expands the literature by including participants from the UK in community rather than psychiatric settings. Readers more familiar with traditional quantitative analyses may cite the means of recruiting participants and the sampling method as raising questions about the generalisability of the findings. For example, the authors excluded people who were acutely ill, might become distressed, or denied having mental illnesses; each of these are issues often relevant to chronically ill individuals. Participants were widely divergent in how long they were impaired, severity of symptoms, need for hospital admission, and the types of health services they were receiving. However, readers must be reminded that grounded theory research is primarily a means of broadening pre-existing perspectives and generating ideas for further research. This study raises critical questions from the point of view of seriously ill patients, and thus provides rich heuristic materials for future qualitative and quantitative research.

Rather than beginning with topics generated by a review of the relevant literature and recording the frequency of their occurrence, the authors used grounded theory techniques to identify common themes in the material. When using such a technique, authors could distort the findings if they imposed their personal beliefs and expectations on the material. It is noteworthy that themes cited by other consumers, such as neglect by the treatment system, spirituality, and comorbid substance abuse,¹ were not exposed here.

Perhaps the authors could have considered the effect of length or severity of illness on individual narratives or analysed their results as a function of non-demographic dimensions using quantitative data, which they provide to describe participants. As a field, we are struggling with how to integrate qualitative and quantitative techniques. This study offers a first step towards such integration. It provides a rich and compelling view of how people with enduring mental health problems view themselves, their providers, and the care we deliver.

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1 "Now that we are listening." Group for Advancement of Psychiatry, Committee on Psychiatry and the Community, 2001. Available from Frances M Roton, PO Box 570218, Dallas, TX, 75357-0218.