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


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 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.” Faking 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.

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.

*Information provided by author.