

# Perspectives of people with enduring mental ill health from a community-based qualitative study

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## SUMMARY

**Background:** The views of people with enduring mental ill health have received limited exploration. Existing work has largely focused on patients in specialist mental health settings, rather than on a wider range of patients in the community.

**Aim:** To explore experiences and perceptions of health care of people with enduring mental ill health.

**Design of study:** A community-based qualitative study using theoretical sampling, in-depth interviews, and grounded methodology.

**Setting:** A total of 34 responders registered with four general practices, serving five wards with a mean Townsend Deprivation Score of 7.75.

**Method:** Subjects were chosen using a theoretical sampling framework and they participated in one-to-one interviews which were audiotaped. Themes were identified and developed by reading transcripts, then they were further refined and classified manually by open coding into key categories using a grounded approach.

**Results:** The primary goal of the responders was to enhance, sustain, and take control of their mental health. The building of positive therapeutic relationships with professionals based upon effective communication, trust, and continuity were important to achieving this aim. However, the settings in which their health care took place could affect responders' attempts to deal with social stigma. Experiences of social isolation, socioeconomic privation, and stigmatisation were often pervasive. These compromised responders' opportunities and their capacity to enhance their mental health, compounding their illness and marginalisation.

**Conclusions:** This study shows the potential of health professionals to empower people with enduring mental ill health, by attending to the quality of communication and continuity of care they provide and to where this takes place. It further underlines a need to address the social stigma and exclusion this group experiences.

**Keywords:** mental health; continuity of care; stigmatisation; professional-patient relations; quality of health care.

## Introduction

THE importance of listening to the views of patients to enhance quality of care has been recognised.<sup>1</sup> However, the perspectives of those with chronic and disabling mental ill health have received limited exploration. Available evidence has focused upon patients in contact with specialist mental health services, notably those who have been inpatients in psychiatric settings.<sup>2-4</sup> While a proportion of people with chronic mental health problems use mental health services, the majority are seen in primary care<sup>5</sup> with high rates of consultation and prevalence in deprived localities, including significant proportions of older people.<sup>6</sup> Existing research has tended to use structured survey rather than qualitative methods and considered satisfaction with services. The needs of patients for greater explanation about services and treatments, and choice of a wider range of therapies, have been identified.<sup>2-4,7</sup>

Currently, the new National Service Framework for Mental Health identifies a need for primary care groups and mental health services to work together towards the appropriate provision of care.<sup>8</sup> There is a need for research beyond specialist contexts with those experiencing a broad range of chronic and disabling mental ill health. In this qualitative study we explored patients' experiences, seeking understanding of their own priorities and of their perceptions of health care in a disadvantaged community setting.

## Method

### Setting

We conducted in-depth interviews with 34 patients registered with four general practices, serving a locality of five wards with a mean Townsend Deprivation Score of 7.75 (range = 6.06-9.35).<sup>9</sup> For example, 68% of the population are without access to a car and 28% of adults of working age are unemployed (range = 21.5-38.6%). The four practices refer to two consultant psychiatrist-led community mental health teams linked to a local hospital inpatient unit. The local research ethics committee granted ethics approval for this study.

### Initial sampling

A theoretical sampling framework was used.<sup>10</sup> Initially, responders were sought who were heterogeneous in age, sex and chronic mental health problem, and registered with one of two general practices. Patients for whom participation might cause distress or who were acutely unwell were excluded by their general practitioners (GPs). Twenty patients were selected from recently developed practice-

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**HOW THIS FITS IN***What do we know?*

Most research on the views of patients with chronic mental illness has been from specialist settings.

*What does this paper add?*

We engaged people with a broad range of enduring mental illness in the community. In seeking control over their illness we found that:

- patients most valued an empathic and continuing therapeutic relationship with professionals;
- fear of social stigma may influence how patients engage with services; and
- the profound impact of patients' social exclusion demands advocacy and social assistance.

held case registers of patients with mental illness.<sup>6</sup> For these registers, GPs had been asked to identify patients they regarded as disabled by enduring mental ill health according to defined criteria (Box 1).<sup>5,6</sup> An introductory letter from the GP was sent to each patient, along with a study information sheet, reply slip, and reply-paid envelope. Eleven patients were willing to be interviewed and stated a preference for being interviewed in their own home or at their general practice. They were contacted by letter or phone (if available) and a convenient time arranged for interview.

*Interviews and data analysis*

Responders were encouraged to discuss and reflect upon their experiences and perceptions of health care in their own words. All interviews were conducted by one of the authors (AC), a social sciences researcher with a nursing background, using broad topic prompts developed by the authors, which were refined during early interviews. The interviews were audiotaped and transcribed verbatim and lasted between 45 minutes and two hours. Information about each responder's level of social disability was collected at the end of each interview using the Medical Research Council (MRC) Social Role Performance Schedule.<sup>11</sup>

Themes were identified and developed by two of the authors (AC and JK) from reading and re-reading interview transcripts. Themes were further refined and classified manually by open coding into key categories using a grounded approach.<sup>10</sup> A further purposive sample reflecting variation in these categories was then sought to elaborate and refine emerging concepts and to seek supporting and non-supporting cases to test the integrity of analysis.

*Developing analysis and purposive sampling*

In early interviews, the nature of previous contact with services appeared to have an important influence upon the views of responders. Therefore, subsequent responders with a range of experiences were sought, including those who had been seen in primary care only, those who had been seen by both primary care and mental health teams in community and outpatient settings, and patients who had experience of inpatient admission to psychiatric hospitals.

The two general practices used for our initial sample had

- Disabled by impaired social behaviour for two years or more as a consequence of mental illness.
- Inability to fulfil any one of four roles: holding down a job; maintaining self care and personal hygiene; performing necessary domestic chores; participating in recreational activities.
- The presence of any one of four types of impairment of social behaviour: withdrawal and inactivity; responses to hallucinations or delusions; bizarre or embarrassing behaviour; violence towards others or self.
- Diagnosis of one of the following: one of the psychoses; a severe and chronic non-psychotic disorder, including depression, anxiety and phobic disorders; obsessional neurosis; severe personality disorder; eating disorder; alcohol or drug misuse; a mental illness which has not been given a specific label.
- Patients were excluded if they had dementia or any other organic brain disorder; a learning disability; or if they were aged under 16 years.

Box 1. Definitions of enduring and disabling mental illness.<sup>5,6</sup>

team members with a special interest in caring for people with mental health problems. Therefore, in later sampling we chose responders registered with two further primary care teams who did not describe a special investment.

Further responders were approached using the methods used before. Interviews, data collection, and concurrent analysis were conducted as before. Saturation was felt to be achieved after a further 23 interviews, giving a total of 34 interviews. This meant that previously collected data had now been repeated by multiple sources and that no new information was emerging. Two interviews were excluded from analysis, as the responders did not acknowledge any experience of mental ill health. Results from the remaining 32 interviews are presented here.

*Enhancing trustworthiness*

Three methods of triangulation were adopted.<sup>12</sup> First, the transcripts were read and discussed by both the authors developing analysis throughout the study. Second, theoretical sampling was used until saturation was achieved. Third, the emerging analysis was tested in 21 group interviews with local health professionals. These involved facilitated case discussions between primary care and mental health teams about the care of their patients with chronic mental ill health. Results from the current study were fed back in these group interviews, using ways in which they could not be attributed to individual patients. By identifying factors that influenced patient care positively or negatively, the analysis of individual patient interviews was indirectly supported.

**Results***Features of responders*

All 32 responders were receiving continuing care from primary care teams. This included 14 who had past contact with local or other mental health services that had ceased more than two years previously, 12 who were currently in contact with local mental health services and who were seeing a mental health professional on a regular basis at the time of interview, and six responders who had never had any contact with specialist services. Three of the sample were

involved in mental health user groups. Of those who had past or current contact with mental health services, 16 had experience of admission to psychiatric hospital. The duration of mental ill health of the responders ranged from five to 40 years (mean = 21 years). All responders were white and English speaking, except one participant who was English speaking but of Pakistani origin. Further characteristics of responders are shown in Table 1.

All of the participants were assessed by the Social Role Performance Schedule (SRPS) as being severely disabled by their mental health problems.<sup>11</sup> All except one of those aged 65 or under were unable to work in paid employment because of their mental ill health. One woman worked six hours per week. Other common features of social disability included: problems in developing and sustaining friendships (all reported some degree of difficulty, with 15 experiencing severe problems) and difficulties in maintaining intimate relationships with a partner (20 reported having no intimate relationship; seven of the remainder reported relationship difficulties resulting from their mental ill health. (Table 2.)

Table 1. Features of responders.

Characteristics	Number of responders
Sex	
Male	18
Female	14
Enduring mental health problem	
Severe chronic anxiety or depression	12
Schizophrenia	6
Bipolar affective disorder	5
Major psychotic depression	3
Alcohol/drug problems	3
Obsessive compulsive disorder	1
No clear diagnosis	2
Living arrangements	
Living alone	16
Living with partner or children	10
Living with parents	4
Hostel	1
Nursing/care home	1
Age bands (years)	
20–29	3
30–39	4
40–49	4
50–59	7
60–69	8
70 and over	6

Table 2. Social disability using the Social Role Performance Schedule.

Level of social disability	Ability to manage housework	Ability to maintain employment	Ability to manage money	Ability to sustain and develop intimate relationships	Ability to sustain and develop relationships	Social presentation (e.g. interaction/activity outside home)	Ability to cope with an emergency <sup>a</sup>
None	10	0	14	5	0	5	7
Low	12	2	9	1	11	14	17
Medium	6	0	6	5	6	10	6
High	3	19	3	1	15	3	2
Activity not applicable	1 <sup>b</sup>	11 <sup>c</sup>	–	20 <sup>d</sup>	–	–	–

<sup>a</sup>For example, how well responders felt they would be able to manage an unexpected crisis, such as being asked to look after children of an ill friend. <sup>b</sup>Living in nursing home. <sup>c</sup>Beyond retirement age. <sup>d</sup>Responder had no partner or spouse.

### Communication in building therapeutic relationships

In their contact with both primary care and mental health services, the development of good therapeutic relationships with professionals was regarded as central. These were characterised as those in which professionals had effective listening skills and showed empathy and understanding. This allowed responders the opportunity to express their concerns, permitting discussion and negotiation of options, and helping to build trust in the relationship. The value and empowering role of explanation, information, and discussion about their illness was emphasised. Responders had experienced and compared a wide range of both good and bad communication with professionals. For example:

*'Years ago they told you nothing ... well I got the impression I was mad — they wouldn't tell you nothing, secret society ... well he [the psychiatrist] is different — he explains things.'* (Responder 28.)

*'She [the GP] just used to sit and talk and explain everything and what was happening, and everything. She was really helpful.'* (Responder 23.)

### Continuity of therapeutic relationship

Responders consistently highlighted the importance of building a continuing relationship with one individual over time. This allowed responders to feel that the professional had developed an understanding of their problems and of possible solutions achievable within the particular context of their own social and medical histories. Experiences of a positive and continuing therapeutic relationship contributed powerfully to the capacity of responders to take control of their mental ill health. This was frustrated when it was not possible to develop a rapport, with changes in doctors in particular requiring responders to repeatedly rehearse their medical histories. This could have an adverse effect on their health by underlining their previous distress and the chronic nature of their problems. For example, one of the responders said:

*'Let's say every time I went I got myself uptight and it got that they were asking me some things that I had already explained. I was just getting settled in with one chap then all of a sudden he'd say: "I'll not be here next time", and straight away I'd be back to square one.'* (Responder 7.)

Indeed, inconsistent messages from professionals could result, creating further barriers to their improvement and their faith in doctors' decision making.

### *Wrestling with stigma: the influence of the health care setting*

Responders worried about where their health care contacts took place. They were concerned about the potential for the stigma of their illness to be increased and for them to suffer stereotyping by association with other patients. Being seen in psychiatric settings, in particular, had left a lasting impression upon some responders. A sense of 'otherness', of not being like other patients, was a recurrent theme, particularly early on in the course of mental ill health. This had a strong effect on perceptions of self, and served to heighten their fears about mental illness. The issue of care setting became bound up with struggling to reject the label of mental illness and to regain control of their life. For example:

*'I remember going up there and there was some people there, I didn't belong there. I thought I was ill but I wasn't like that ... I knew it scared me because I thought, God, I could end up like that — that frightened me a lot.'* (Responder 11, on referral to a psychiatric outpatient clinic.)

*'I went up and it was just no good to me ... I felt I didn't fit in and I didn't like it.'* (Responder 26, on admission to a psychiatric inpatient ward.)

Sometimes these concerns had led responders to reject the care offered at various stages; for example, by cancelling an outpatient appointment, leaving an outpatient clinic before the consultation, or by refusing hospital admission:

*'I just dug my toes in and wouldn't go ... they asked me why and I said I was frightened ... they said: "Why should you be frightened?" ... but it was other patients I was frightened of.'* (Responder 1.)

These reactions appeared to reflect some of the efforts of responders to take control of their situation and to develop strategies for coping. Seeing others whom they perceived to be worse than them was an uncomfortable reminder that things could get worse. Maintaining a distance from visibly 'psychiatric' settings allowed some responders to contain their problems and to help them focus upon improvement. These responders preferred to be seen in a community or general practice setting. These were perceived as offering anonymity and protection from negative feelings and stereotypes of society about mental ill health.

### *Value of mutual patient support and specialist settings*

Other responders who had received psychiatric inpatient treatment over a long period of time highlighted the value of shared contact and support with other patients as a particularly positive aspect of psychiatric care. They accepted other patients as they recognised their own mental ill health. Supportive relationships between patients were commonly described:

*'I found there was people like me in there [in hospital] and just people with problems, and there was some very severe cases and we had some laughs. I think the patients helped me as much as the staff.'* (Responder 10.)

*'It was great when I got in. I used to get on with them [other patients] and used to sit and talk to them. I made friends.'* (Responder 26.)

These responders had become less concerned about where they were seen. Negative attitudes towards psychiatric units and concerns about stigma were overridden by concerns for improvement and support. Developing relationships with mental health professionals then assumed greater importance, as it was perceived that such relationships were likely to be long lasting.

### *Experience of social exclusion*

Living in the community, responders spoke of 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 and mental health was compromised by their experiences of victimisation, crime, social isolation, and lack of access to material resources.

Most had experiences of victimisation where they lived, which they attributed to their apparent differences from others. This led to a climate of fear, with responders not wanting other people to know about their mental health problems. Experiences of both verbal and physical abuse within their local community were commonplace:

*'It's verbal abuse but all at the back of the house so nobody at the front would know.'* (Responder 18.)

*'I got ambushed one night, chucking stones at me, he had a stick, you know.'* (Responder 28.)

The fear of other people finding out about their mental ill health compounded a sense of isolation felt by many responders. Half of them lived alone (Table 1), often following the breakdown of relationships with their family or partner. However, social isolation was not only associated with living alone. Responders living with relatives often found it difficult to discuss their problems with their family or friends. They felt this to be the result of their mental health problems and the attitudes they provoked. For example:

*'They [the responder's family] were not treating me as a normal human being ... my dad classed me as mentally handicapped — that's the way he saw me — not as somebody who had just had a breakdown and able to recover.'* (Responder 26.)

Socialising was further limited by fear of crime. Many were reluctant and afraid to go out, having commonly had experience of crime and burglary. These experiences, combined with fear of further victimisation, made opportunities for socialising hard or impossible to achieve. Difficulty in getting out jeopardised access to health care; for example, in attending health appointments, obtaining prescriptions from

pharmacists, or in undertaking health-promoting recreation. These constraints increased their levels of stress, curtailed opportunities to promote well-being, and reduced their capacity for coping with their illness. For example:

*'It's very stressful really ... the house was burgled once and I've had lots of attempts since ... I've even got bars on now ... I'm stuck in the house now, practically sitting in the corner.'* (Responder 17.)

*'I need to move out of here because I had six burglaries when I was in [psychiatric] hospital and when I came out of hospital they had stripped me of everything I had.'* (Responder 13.)

Almost all the responders felt that their material circumstances had deteriorated as a result of their mental health problems. All but two were reliant upon state welfare benefits for their income, which created financial worries and hardship. Lack of money for transport meant that responders usually had to rely upon local retailers, who were inadequate and expensive.

Ten responders could not afford a telephone, and could not seek help easily even in times of crisis. Typical accounts included:

*'I get paid [welfare benefit] and suddenly I've got nothing left and I haven't got enough food.'* (Responder 8.)

*'The month before Christmas was a really bad time for me. I felt it was really awful to have no-one to turn to, I had nobody to talk to ... I thought, well, just keep taking the tablets, you'll be all right, to myself, but I was really on the bottom and I wasn't on the phone. If I'd had the phone I would have rang the Samaritans, because at one point I did feel suicidal ... I haven't even told my doctor this.'* (Responder 26.)

Participants felt there were few options open to them to enable them to climb out of their poverty. Paid employment was not seen as a realistic option for most of them. Although the majority had tried to work at some time, they had found this difficult to sustain. This lack of opportunity added to their negative experiences of social isolation, creating a reduced sense of self worth.

### *Potential contribution of professional care*

Despite the socially disabling effects of the problems of their everyday lives and of their illness, the majority of responders had a continuing motivation to get better. They located the value of positive therapeutic relationships with professionals within the context of their social exclusion and stigma and their need to protect anonymity about their mental ill health. Health professionals were often key people with whom responders could discuss their problems and mental distress, given these contexts. Some felt that this had formed one important source of support over time, which had helped them overcome barriers. They felt more empowered to identify solutions and establish control over their lives and illness experience. For example:

*'I've coped smashing without them [family] ... the pres-*

*sure's gone down for me because I found I was having to live up to their expectations, you know, and I just couldn't compete with the rest of the family ... I couldn't have done it without the psychiatrist.'* (Responder 27.)

*'I mean he [the GP] was just so good I used to say to him: "I'm sorry if I'm wasting your time", and he would say: "Not at all", he says: "If you feel the need to come and see me, come and see me". I don't know what I would have done without him.'* (Responder 4.)

## **Discussion**

In this study we sought insights from responders willing to articulate their experiences. We involved participants with a wide range of enduring mental health problems across the age spectrum, many of whom were socially isolated. The perspectives of such patients living in a community setting have rarely been heard in previous research. The findings are not, of course, representative of all patients with enduring mental ill health; they must be interpreted with regard to the contexts and characteristics of participants as described.

We acknowledge that our backgrounds as health professionals may have influenced our interpretation of the data. However, our methods have attempted to lay emphasis upon responders' accounts and to enhance the trustworthiness of our findings.

While participants were viewed by their GPs as being disabled by mental illness,<sup>6</sup> their disabilities may inevitably reflect interrelation with their socio-demographic milieu. Beyond perceptions of the GPs who usually saw them frequently,<sup>6</sup> and our use of the MRC Social Role Performance Schedule,<sup>11</sup> we elected not to assess disability or psychiatric disorder using other instruments, given the demands of an already lengthy research interview upon potentially vulnerable people. From a primary care perspective that focuses upon a person in context rather than on a disease, a holistic response to a person's disability is often of more importance than defining to what extent that disability is attributable to a biomedical disorder.

### *Quality of communication and continuity of care*

The findings emphasise that care needs to be built upon good relationships in which there is shared negotiation and communication, with opportunities for patients to discuss and make sense of their illness. This may also be important in concordance about care options.<sup>15</sup> There are clear messages for training and accreditation of health professionals in effective communication skills, and of their importance to patients. The study corroborates research in specialist psychiatric settings and by mental health service user groups,<sup>3,4,7,13,14</sup> but with a broader range of patients with mental ill health in the community. It thus points to substantial resource implications for primary health care where this larger group of patients; for example, those with chronic and severe anxiety and depression, are seen frequently and may require a great deal of consultation time.<sup>6</sup>

Continuity of care for those with mental illness has provoked varied theoretical debate about what it entails and whether it affects patient outcomes.<sup>16</sup> Our responders were

clear about what continuity meant for them. They were equally clear about the negative impact of lack of continuity of professionals upon their care. This should be a key consideration at a time when services are reviewing care delivery.<sup>8</sup> Professionals in primary and mental health care should not underestimate the value of constantly reviewing and reinforcing the continuity of care they provide as defined by patients in this study. It follows that good communication between primary care and mental health teams will be a prerequisite for effective shared care.<sup>13,17</sup>

While messages highlighting communication and continuity echo evidence from other settings, our responders' experiences suggest that they deserve more emphasis. Moreover, when clinical progress with this group of patients can often be frustrating or leave professionals feeling inadequate, it should be remembered that sustaining a continuing therapeutic relationship based upon listening and allowing people to relate their experiences may still yield much of value.

### *Wrestling with stigma*

The contribution of stigma in chronic illness is well recognised, but mental illness appears especially stigmatising.<sup>18,19</sup> For our responders it was socially limiting and disempowering. They had direct experience of victimisation and also concerns about how their mental ill health would be perceived. This influenced their attitudes towards their care setting, particularly in the early stages of service contact. Their responses may reflect a reaction to the biographical disruption and crumbling of self-image that may mark the impact of a diagnosis of chronic illness.<sup>20,21</sup> Central to the label of mental illness is a negation of self that risks invalidating a person's whole identity.<sup>22</sup>

Concerns about low attendance rates for psychiatric outpatient appointments are commonly expressed by professionals, with conflicting views about the influence of stigma.<sup>23,24</sup> In this study, responders who failed to attend psychiatric appointments appeared to see this as a positive choice. They considered it important to take some control over their lives by rejecting negative labels associated with mental illness. This desire to reduce stigma and maintain anonymity should be recognised when orienting services appropriately. Further development of shared care<sup>17</sup> might make a range of acceptable alternatives more readily available and sensitive to patients' preferences, from community settings to traditional hospital-based care. In addition, opportunities for the mutual support that some patients derived from other patients might be facilitated and enhanced when improving models of care.

### *Social exclusion*

Many people with chronic mental ill health face the long-term socioeconomic discrimination<sup>25</sup> and privation, which characterised the lives of participants in this study. As our responders were already disabled by their mental ill health, these factors compounded their social isolation and lessened opportunities to take control over their health. Capacity for personal control, making choices, and social contact are important components of mental wellbeing.<sup>26</sup> Addressing social isolation and social assistance is now a welcome, if

perhaps understated, national service aim.<sup>8</sup> While policy addressing social exclusion may offer hope for the future,<sup>27</sup> health professionals must recognise that they can make a difference by using proactive approaches, including outreach and advocacy.<sup>28</sup>

### Conclusion

This study shows the potential of professionals to empower patients experiencing enduring mental illness by attending to the quality of communication and continuity of care they offer, and to where this takes place. By improving professional training, service delivery and social assistance, we may go some way to ameliorating the experience of mental ill health. However, accounts such as these also demand a collective willingness to address the wider discrimination and inequity which structure people's health and life opportunities.

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