

Primary care

Patients' and health professionals' views on primary care for people with serious mental illness: focus group study

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Abstract

Objective To explore the experience of providing and receiving primary care from the perspectives of primary care health professionals and patients with serious mental illness respectively.

Design Qualitative study consisting of six patient groups, six health professional groups, and six combined focus groups.

Setting Six primary care trusts in the West Midlands.
Participants Forty five patients with serious mental illness, 39 general practitioners (GPs), and eight practice nurses.

Results Most health professionals felt that the care of people with serious mental illness was too specialised for primary care. However, most patients viewed primary care as the cornerstone of their health care and preferred to consult their own GP, who listened and was willing to learn, rather than be referred to a different GP with specific mental health knowledge. Swift access was important to patients, with barriers created by the effects of the illness and the noisy or crowded waiting area. Some patients described how they exaggerated symptoms ("acted up") to negotiate an urgent appointment, a strategy that was also employed by some GPs to facilitate admission to secondary care. Most participants felt that structured reviews of care had value. However, whereas health professionals perceived serious mental illness as a lifelong condition, patients emphasised the importance of optimism in treatment and hope for recovery.

Conclusions Primary care is of central importance to people with serious mental illness. The challenge for health professionals and patients is to create a system in which patients can see a health professional when they want to without needing to exaggerate their symptoms. The importance that patients attach to optimism in treatment, continuity of care, and listening skills compared with specific mental health knowledge should encourage health professionals in primary care to play a greater role in the care of patients with serious mental illness.

Introduction

Patients with serious mental illness such as schizophrenia, bipolar disorder, and recurrent depression consult their general practitioner (GP) more frequently¹ and

are in contact with services for a longer cumulative time than patients without mental health problems, and create a considerable workload.^{2,3} They are also more likely—particularly those with schizophrenia—to have poorer physical health than the general population.⁴

Relatively little research has sought the views of people with serious mental illness on primary care services or encompassed the dual perspectives of recipient and provider.^{5,6} The limited evidence suggests that GPs are willing to take responsibility for physical health care^{7,8} but not for the mental health or overall care of people with serious mental illness.^{5,8} Some GPs also find it difficult to communicate with such patients.⁸ Previous work has highlighted a perceived lack of information for patients about diagnosis and treatment,⁹ overuse of medication and delay in obtaining a diagnosis,¹⁰ and barriers created by stigmatised attitudes.¹¹

Primary care trusts now commission, and in some cases provide, mental health services; there is an increased emphasis on patient access and choice; and the care of patients with serious mental illness is included in the new GP contract, which came into force in April 2004.

We aimed to explore the changing experience of providing and receiving primary care from the dual perspectives of primary care health professionals and patients with serious mental illness respectively.

Participants and methods

We set up 18 focus groups in six primary care trusts in the West Midlands from May 2002 to January 2003. Each group met for about two hours and comprised five to 12 people. Primary care trusts were purposively sampled to reflect differing levels of deprivation and population density. Patients with broadly defined serious mental illness were recruited through existing community based user networks. In each trust the group leader of a non-statutory mental health service user group helped to disseminate information about the study locally and recruit patients. Recruitment was done using a snowballing technique: each leader



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contacted other patients who in turn nominated friends, colleagues, and other contacts. All general practice principals and practice nurses in each primary care trust were invited by letter to attend a focus group.

Procedure and topic guide

The focus groups, held separately for patients and health professionals, were convened in non-clinical settings and were facilitated by HEL (a primary care academic) and either HS (a psychologist) or JQT (a sociologist). All participants were also invited to attend (usually a week later) a subsequent combined focus group of patients and health professionals; about half of the patients and half the health professionals took part. No patient was registered at a health professional's practice. Participants also completed a brief demographic questionnaire (see tables 1 and 2 for data).

We developed the topic guide from a literature review and then piloted it (for details see the full version of this article on bmj.com).

Analysis

Focus groups, data collection, and analysis were concurrent, and focus groups continued until data saturation was achieved. All the sessions were audiotaped and transcribed, and HEL and JQT then developed a thematic coding framework. The final version consisted of 17 themes, 45 main codes, and 39 subcodes.

We analysed the data by organising it into initial and then higher codes that provided insight into identified themes. We sought issues with strong group validation and "sensitive moments" during focus group interactions that indicated difficult but important issues. Analysis also took into account the purposive nature of the sampling, including the different demographic backgrounds and diagnoses of the participants. We examined how conversations between health professionals and patients started and developed. We checked our findings with participants at the start of each combined focus group and sent them a summary of each discussion for comments.

Results

The three major and inter-related themes that emerged were the characteristics of "good enough" primary care, access strategies, and tensions between notions of chronic disease management and recovery.

"Good enough" primary care

Most patients viewed primary care as the cornerstone of their physical and mental health care. Patients and health professionals agreed that the latter had a responsibility to continue prescribing drugs started in secondary care, monitor side effects, and tackle physical health issues. Both groups recognised, however, that it was sometimes difficult to present with or diagnose physical complaints once a mental health disorder has been diagnosed. Some GPs suggested this was related to difficulties in communicating effectively with people with serious mental illness. Most health professionals perceived the mental health care of people with serious mental illness as too specialised for routine primary care and felt they lacked sufficient skills and knowledge (box 1).

Table 1 Demographic details reported by participants. Values are numbers (percentages)

	General practitioners (n=39)	Practice nurses (n=8)	Patients (n=45)
Female	14 (36)	8 (100)	24 (53)
Age range:			
15-19	0	0	1 (2)
20-29	0	0	7 (16)
30-39	9 (23)	2 (25)	18 (40)
40-49	19 (49)	3 (38)	12 (27)
50-59	9 (23)	3 (38)	6 (13)
60-69	2 (5)	0	1 (2)
Ethnicity:			
White	31 (79)	7 (88)	37 (82)
African Caribbean	0	0	2 (4)
Asian	6 (15)	1 (13)	2 (4)
Other	2 (5)	0	4 (9)

The Townsend deprivation scores for the primary care trusts ranged from -3.35 to 6.00 and population densities per hectare from 1.25 to 36.49.

All participants felt that interpersonal and longitudinal continuity was vital for good quality care. However, most health professionals felt continuity was threatened by the national emphasis on achieving access targets and the advent of GPs with a special clinical interest in mental illness.¹² Most patients preferred a continuous doctor-patient relationship and a positive attitude and willingness to learn, rather than the opportunity to consult a different GP with special expertise in mental health.

Anticipating and negotiating access

Health professionals concentrated on the difficulties of accessing secondary care, particularly in an emergency, and the frequency of non-attendance among patients with serious mental illness. They saw few problems in terms of patient access to primary care. However, patients focused almost entirely on strategies for negotiating access and the meaning and implications of not attending appointments in primary care (box 2).

Swift access to primary care was important for patients because of the sudden onset of some mental health crises. Barriers to access included the effects of the illness itself—a lack of confidence and assertiveness, for example, made the appointment system harder to negotiate when they were depressed. Patients with diagnoses of schizophrenia and bipolar disorder described the need to seem "rational" at the

Table 2 Medical background reported by 45 patients participating in study

	No of patients
Diagnosis:	
Schizophrenia	15
Bipolar disorder	4
Recurrent depression	15
Dual diagnosis	3
Anxiety	4
Obsessive compulsive disorder	2
Substance misuse	2
No of patients currently receiving care from GP and mental health services	38
No of patients who have ever had inpatient admissions	35
No of patients who have had inpatient admissions in past 2 years	20
No of patients ever sectioned	10

The average duration of illness was 8.8 (range 1-32) years; the average number of visits to primary care in the past 12 months was 7.2 (range 1-24) visits.

Box 1: Aspects of “good enough” primary care

“I know that I cannot look after people with severe and enduring mental health problems. I do not have the skills or the knowledge. I couldn’t do it well” (GP 1: female, Coventry)

“We were seeing this woman very regularly, and she was known to have some depression, and she presented with bowel symptoms. And when we looked back through her notes, after she died from bowel cancer, we saw we’d offered to arrange scans and investigations but none of us pushed her like we might have done if we hadn’t had that depression thing there” (GP 2: female, Birmingham)

“Continuity is so important” (GP 4: female, Worcester)

“But it’s being ignored in the NHS Plan. It’s standards, standards of care, and it doesn’t matter who you see” (GP 5: male, Worcester)

“You’ve got a familiar face who knows your story and you don’t have to start from the beginning again. She’s seen me deteriorate and come back again. I feel very safe in her hands” (Patient 1: female, Cannock)

“I mean, the GP has to have some understanding of mental health but I don’t expect a GP to you know, know all of the issues to do with my illness. I would though expect him or her to refer me to a specialist person. The important thing is that somebody is looking after you so it’s not just you on your own” (Patient 2: female, Birmingham)

reception desk but if they appeared too “together,” the receptionist might not believe they needed to be seen urgently. Patients perceived a minority of receptionists and GPs as giving priority to physical illness over less visible mental health problems. Noisy or crowded waiting areas were described as difficult to negotiate when patients were anxious or had symptoms of psychosis.

Patients said it was sometimes easier to get an appointment with the help of an “advocate with clout”—such as a vicar or friend who had authority in the eyes of the medical establishment. Access was also

Box 2: Anticipating and negotiating access

“The focus is on risk assessment. But why do you have to be in crisis before you get help? You need to kick up a stink” (Patient 6: male, Worcester)

“It’s traumatic, the efforts needed to get help. No one wins. I feel bad having to do this, to sometimes have to exaggerate the distress I’m in, but I have to, to get the help I need” (Patient 6: male, Worcester)

“If I don’t turn up I wish the GP would simply ask why” (Patient 7: male, Birmingham)

“If someone had come and visited us when I was bad, that would have nipped it in the bud” (Patient 7: male, Birmingham)

“Well, some people don’t come when they’re well and some don’t come when they’re sick, and to be honest it’s a bit of a relief because I can catch up on being late” (GP 4: female, Worcester)

“They are notoriously bad at keeping appointments or turning up you know, so if you say you want to see them on a regular basis they probably won’t keep the appointment and they’ll turn up when you’re not there” (GP 8: female, Birmingham)

described as less stressful for patients who were well known at the surgery. Three patient groups discussed “acting up” (exaggerating symptoms) to help them get an urgent appointment. All patients were distressed by having to do this.

Most GPs described how changing structures such as new teams in secondary mental health care made negotiating access on their patients’ behalf in a crisis stressful and time consuming. One group of health professionals discussed the methods they had used to overcome secondary care barriers and admit patients who were unwell but not yet quite at crisis point, including exaggerating the severity of the symptoms.

Patients said that non-attendance at primary care appointments was often a consequence of a worsening of their illness or an impending crisis. Occasionally it was because of barriers to access in the primary care system. Some patients described arriving at the surgery for an appointment but finding conditions in the waiting room unbearable, leading them to leave the surgery before seeing the health professional. Non-attendance in primary care was described by most GPs as symbolic of patients’ irrational behaviour and chaotic lifestyles.

Management of chronic disease versus recovery

Structured reviews of care—for example, an annual check-up based on a register of patients with serious mental illness—were seen by both patients and health professionals as a positive concept (box 3). Health professionals felt that reviews offered an opportunity to “bench mark” people when well, review and change medication, and identify patients “lost” in the system; they were especially seen as a mechanism for enabling access for “at risk” patients. Patients also felt that structured reviews could facilitate access, might provide an opportunity for mutual education about the illness, and showed care and concern. However, for patients, the focus was more on the underlying attitudes of professionals than on the content of the review.

All but one health professional saw psychosis and recurrent depression as chronic lifelong conditions. Health professionals talked of recovery only in the context of moving on to behaviour therapy as well as medication. In contrast, no patient used the word “chronic” to describe their illness. Most were keen to talk about care that encouraged recovery through particular professional attitudes, including enabling patient choice in treatments, offering talking and alternative therapies as well as medication, and discussing future educational and work opportunities. Recovery could also be encouraged through non-medical means, including support from family, friends, and other patients. A minority of patients highlighted taking responsibility for their own problems and recovery and of having realistic expectations.

Discussion

The findings of this study emphasise the central importance of primary care to patients with serious mental illness. Using combined focus groups (patients and health professionals) helped to highlight many

commonalities and also key tensions between what patients want and what primary care can provide.

Limitations

Although all GPs and practice nurses in the six primary care trusts were invited to participate, only about 8% agreed to. No health professional had a post-graduate qualification in mental health and only the six mental health leads (one in each health professional focus group) had specific mental health interests and responsibilities. Comparisons with UK national statistics suggest that the age range, sex, and ethnicity of the GPs were broadly representative of GPs across England and Wales. Participants represented a wide range of age, ethnicity, and self perceived diagnoses of serious mental illness. Professional-patient hierarchies might have theoretically limited or altered contributions from patients in the combined groups. However, the existence of both supportive and argumentative dynamics between participants, the pattern of how conversations started and developed in the combined groups, and the consistency of individual views expressed in single and combined groups suggest that this was not a significant issue. Practice nurses were the least vocal participants, perhaps reflecting their employee status and their expressed lack of training and expertise with this group of patients.

Box 3: Tensions between notions of chronic disease management and recovery

“When we’re sort of losing it, you can’t tell outwardly that there’s a major problem. If you’ve got a list thing, and you ring up and just have to say ‘Look I’m Mr So and So on your red list’ then you wouldn’t have to go through all the rigmarole” (Patient 9: male, West Bromwich)

“I think you have a better chance of building a partnership if you meet someone when they are well instead of when you are about to section them” (GP 9: female, Worcester)

“I think it’s essential you know what their best state is. You have to be able to benchmark” (GP 11: male, Solihull)

“I mean it is essential that there is some contact and they don’t just get discarded, so we’d be calling them in like we do for coronary heart disease” (GP 12: male, Solihull)

“When I approached my GP, he never gave me any hope that things could change. He said, ‘Well, you’ll be on these tablets for the rest of your life, and it’s like diabetes, just take them for the rest of your life.’ I remember the phrase. And I remember being told I’d never be able to work again, I’d never have an education, never have relationships, never have anything in my life. So, for a period of time I thought well, there’s no hope—it’s not worth living, is it really?” (Patient 9: male, Birmingham)

“... But the thing is, people do recover and they’re never told there are people who do recover, so it’s not a life sentence” (Patient 9: male, Birmingham)

“Some people do go to the doctor and expect a pill and that everything’s going to be OK. But we have to find out for ourselves and realise it isn’t down to a tablet... we have to take some responsibility and not have unrealistic expectations of doctors” (Patient 11: female, Worcester)

What is already known on this topic

Many people with serious mental illness have frequent contact with primary care

Contact is likely to increase with the implementation of recent policy initiatives

Relatively little work has been done in this area, with almost none from the perspective of both patients and health professionals

What this study adds

Most patients with serious mental illness view primary care as the cornerstone of their health care

Although general practitioners feel that lack of knowledge inhibits greater involvement in care, patients value continuity of care, listening skills, and willingness to learn more than specific knowledge about mental health

Most health professionals see serious mental illness as a lifelong chronic disease, whereas patients prefer treatment to have an optimistic approach that recognises the possibility of recovery

Relevance to the existing literature

Many of our findings support those of the few comparable studies,¹³ particularly in relation to access, continuity of care, and the pervasive effects of negative stereotypes of mental illness on health professionals’ attitudes.¹¹ Some of the data (particularly on the balance of continuity; knowledge and attitude; strategies to manage access; and tensions between notions of chronic disease management and recovery) are, however, notably different from previous work.

Implications for policy and practice

Current UK primary care policy says that all patients should be able to see a health professional within 24 hours and a GP within 48 hours and that GPs with a special clinical interest should be introduced across a range of clinical areas. However, patients in this study valued continuity of care, attitudes, and willingness to listen and learn over specific knowledge on mental health.

Patients’ many strategies for gaining access—in particular, exaggerating their symptoms—reflect the concept of “recipient design”¹⁴; studies of calls to emergency services, for example, have found that callers shape the content of their calls to suit the understanding of the recipient and lend credibility to their story.¹⁵ Most patients in this study, however, were uncomfortably aware that exaggeration might feed existing negative stereotypes of malingering, yet felt compelled to use exaggeration as a strategy when access was problematic.

Our findings also emphasise the potential tensions between health professionals’ perceptions of serious mental illness as a chronic disease and patients’ preferences for optimism in treatment that recognised recovery as a possibility. Recognition of a formal recovery

paradigm in mental health is still in its infancy and largely confined to the grey literature, in spite of a growing evidence base that suggests that about half of those with a diagnosis of psychotic illness recover to some extent.¹⁶ Many of the study patients recognised the notion of recovery as important and achievable. The considerable challenge for health professionals and patients is to create a system in which patients with serious mental illness can see a health professional when they want to without needing to exaggerate their symptoms, and can miss an appointment without fearing that their non-attendance will be misinterpreted. The importance attached to optimism in treatment, continuity of care, and listening skills compared with specific mental health knowledge may also encourage health professionals in primary care to play a greater role in the care of patients with serious mental illness.

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Edutainment?

Do your children spend days in front of the computer playing games? Or is this a more accurate description of yourself? Perhaps you think that computer games are the preserve of solitary males who spend mindless hours in front of their console, but many would disagree. You might be surprised to hear that some of the best selling games, such as *Age of Empires*, are historical strategy games. But wherever the truth lies on the educational value of such games, nobody can deny their popularity: users spend many hours interacting with their computer, oblivious to all distractions. This has led some educationalists to wonder if they could harness the fun and interactivity of such games in online learning.

Enthusiasts say that they can and claim that the idea of the solitary player is a myth and that multiplayer games are now the norm.¹ They also say that you can learn not just knowledge but also skills in literacy and numeracy and hand-eye coordination. But there are many naysayers. Learning is not always fun, and we can fall flat on our faces when we try too hard to make it so. Sometimes learning is difficult and takes time and application to achieve learning goals. Also female learners can find it difficult to engage with the seemingly geekish male culture of computer games.²

Can games distract from learning? Sometimes online learning resources can concentrate too much on animation and video and too little on the core learning material. And often learners concentrate more on playing the game or passing the assessment than on actually fulfilling their personal learning needs. Another problem is that good games are expensive to produce, and young learners who are used to state of the art games may be disappointed by dull but worthy educational games.

If you are not put off by all of this you can try the interactive learning modules produced by Trauma.Org.³ In one of the modules you are asked to care for a patient with severe injuries in a casualty department; if you do anything wrong, you're told to apply for a job in a local pizzeria. But if you find this sort of thing forced rather than funny then you can always stick to our tried and tested learning modules on www.bmjlearning.com.

One of our most recent modules for hospital doctors is on the diagnosis of rheumatoid arthritis. It outlines the basics and summarises some of the recent advances, such as the development of a new autoantibody test, anticyclic citrullinated peptide antibody, directed against citrulline-containing peptides. It is highly specific for rheumatoid arthritis (98%), and its sensitivity is similar to that of rheumatoid factors. You can also learn about the role of ultrasound in making the diagnosis: it can detect active inflammatory changes such as synovitis and increased synovial blood flow and is more sensitive than plain radiographs for detecting erosive changes. It is also cheap, non-invasive, and there is no risk of ionising radiation.

And finally, is the module fun? Maybe for rheumatologists.

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