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Primary care

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

Helen E Lester, Jonathan Q Tritter, Helen Sorohan

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

Serious mental illness such as schizophrenia, bipolar disorder, and recurrent depression affects up to 3% of the population in the United Kingdom.¹ Most people in the UK who have such illness live in the community and are registered with a general practitioner (GP). This has implications for primary care as such patients consult more frequently² and are in contact with services for a longer cumulative time than patients without mental health problems, and create a considerable workload.^{3,4} Patients with serious mental illness, particularly schizophrenia, are also more

likely to have poorer physical health than the general population.⁵

Relatively little research has sought the views of people with serious mental illness on primary care services, and almost no research has encompassed the dual perspectives of recipient and provider.^{6,7} The limited evidence base suggests that GPs are willing to take responsibility for physical health care^{8,9} but do not perceive themselves as involved in the mental health or overall care of people with serious mental illness.^{6,9} Some GPs also find it difficult to communicate with such patients.⁹ From the patients' perspectives, previous work has concentrated on the content of the consultation and has highlighted a perceived lack of information and explanation for patients about diagnosis and treatment,¹⁰ overuse of medication and delay in obtaining a diagnosis,¹¹ and barriers created by stigmatised attitudes.¹²

The primary care clinical and policy context for people with serious mental illness is changing: 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 such patients is included in the quality and outcomes framework of 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 the largest or most active 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—that is, each leader contacted other patients who in turn nominated friends, colleagues, and other contacts.¹³ To encourage participation from health professionals with varied interests in mental health issues, 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

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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)		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)

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).

We developed the topic guide from a literature review (including emerging policy documents) and piloted it with six patients and six health professionals in Birmingham. We mapped experiences that patients had had of the NHS by exploring perceptions of ideal care and current issues in receiving or providing care. We sought critical incidents¹⁴ on patients' journeys through the health system from all perspectives. The combined groups additionally explored the roles and responsibilities of patients and health professionals and ideas for improving services.

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. HEL and JQT analysed all the transcripts and field notes and developed a thematic coding framework. The agreed final version consisted of 17 themes, 45 main codes, and 39 subcodes. Evidence that did not seem to fit was sought throughout the analysis, and we modified emerging ideas and themes in response.¹⁵

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 in patient admissions in the last 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.

We analysed the data using NVivo 2.0 (QRS), with data organised into initial and then higher codes that provided insight into identified themes. To help this process, we sought issues with strong group to group validation and "sensitive moments" during focus group interactions that indicated difficult but important issues.¹⁶ Analysis also took into account the purposive nature of the sampling, including the different demographic backgrounds and diagnoses of the participants. We used concordance language software for discourse analysis¹⁷ to examine how conversations between health professionals and patients started and developed. We checked our findings with them at the start of each combined focus group¹⁵ and sent them a summary of each discussion for comments on content and emphasis.

Results

The 18 focus groups involved 45 patients, 39 GPs, and eight practice nurses. 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.

The distribution of men and women was about equal. Patients were aged between 19 and 61 (mean 38) years and health professionals between 31 and 61 (46) years. Mean duration of practice for the health professionals was 21.7 (range 7-36) years for GPs and 23 (14-34) years for practice nurses. The most common diagnoses were schizophrenia and recurrent depression, with a mean duration of illness of 8.8 (range 1-32) years. All patients had seen their GP in the past 12 months, and 38 (84%) were receiving treatment from both their GP and secondary care mental health services (table 2). We chose quotes from the focus groups on the grounds of representativeness.

The three major and inter-related themes that are key to understanding the experience of providing and receiving primary care for people with serious mental illness 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).

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.¹⁸ Patients felt that continuity aided accurate diagnosis, particularly at times of mental health crisis; prevented the retelling of painful stories; enabled trust to develop that in turn facilitated discussions of treatment options; and, above all, allowed patients and health professionals to understand each other as people. Most patients favoured seeing the same GP for their physical and mental health needs, preferring a continuous doctor-patient relationship and a positive

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)

“Well, I think you’re probably right in saying that, to be honest. Because, you can, and I’m including myself in this bracket, can have a tendency to become blinkered, so we fail sometimes to realise that depressed people can also get cancers, can get this and that, and in fact probably are more likely to get certain conditions than others” (GP 3: male, Birmingham)

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

“You save so much time if you don’t have to go over old ground all over again. So everything is smooth for everybody” (Practice nurse: 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)

“But what I want is for him to just tell me ‘Yes, Mrs F, I understand, what depression is, you know, and if you book up maybe next week, and we’ll talk about it’ and you’d feel that would calm down because you’d feel at least somebody was... wanted to listen to your madness. Do you know what I mean?” (Patient 3: female, Birmingham)

“Health professionals, because they are professionals, feel that they should know. But it’s great if they are willing to say ‘I don’t have the answers and I don’t know, and I’m willing to kind of learn from you and find out for you’—but that isn’t always the case” (Patient 4: male, Worcester)

attitude and willingness to learn, rather than the opportunity to consult a different GP with special expertise in mental health. Most patients knew that their GP had little formal training in mental health and did not expect expert advice from primary care professionals. A GP who knew them, listened, and could access help for mental health problems when required was seen by almost all patients as sufficient.

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 appoint-

ment system harder to negotiate when they were depressed. Patients with diagnoses of schizophrenia and bipolar disorder described the need to seem “rational” at the 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 if they asked an “advocate with clout”—such as a vicar or friend who had authority in the eyes of the medical establishment—to make the appointment and accompany them to the surgery. Access was also described as less stressful for patients who were well known at the surgery. Three patient groups discussed “acting up” to help them get an urgent appointment, whereby they felt they had to exaggerate symptoms to get an appointment. All patients were distressed by having to act up but felt that if they did not, they would not get an appointment and their condition would deteriorate further, possibly resulting in an urgent admission.

Most GPs described how changing structures such as new teams in secondary mental health care made negotiating access on their patient’s behalf in a crisis stressful and time consuming. The notion of acting up was mirrored by one group of health

Box 2: Anticipating and negotiating access

“Don’t just tell me OK, that you’ve got to wait because other people are dying. That’s the thing about physical illness. It’s seen as more important . . . I mean they can relate to a broken leg whereas they can’t relate to severe anxiety” (Patient 5: male, Coventry)

“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)

Agreement from others

“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)

“I wish he’d chase it up” (Patient 8: female, Birmingham)

“Because sometimes I can’t even get to the appointment because I’m that bad” (Patient 3: female, 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)

“I would like to think that when I phoned up and spoke to the receptionist I wouldn’t do it unless I felt really desperate. I wouldn’t waste your time or the nurse time or the receptionist time if I said to them ‘this is an emergency’” (Patient 8: female, Solihull)

“You have responsibilities between each other. You make sure ‘look I really am ill this time, I’m not going to abuse the system’” (GP 6: male, Solihull)

“Well that’s right. I wouldn’t do that” (Patient 8: female, Solihull)

“Well you personally wouldn’t do that, but many of them do” (GP 7: male, Solihull)

“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)

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professionals, who discussed the methods they had used to overcome secondary care barriers and admit patients who were unwell but not yet quite at crisis point; these methods included exaggerating the severity of the presenting symptoms to the admitting psychiatrist.

The meaning ascribed to non-attendance at appointments was a key issue for all participants. Patients said that non-attendance 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—for example, difficulties in making an appointment compounded by the prospect of waiting in a noisy reception area when unwell. 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.

Patients' explanations for non-attendance were rarely recognised by the GPs. Non-attendance in primary care was described by most GPs as symbolic of patients' irrational behaviour and chaotic lifestyles, offering a welcome opportunity to "catch up."

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. Registers were particularly seen as a mechanism for enabling access for "at risk" patients—in a similar way to registers for people with brittle asthma or chest pain. 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 discussion of the value of structured care focused 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; many analogies were made to nurse led care of people with chronic physical conditions, such as coronary heart disease and diabetes. Health professionals talked of stabilising and managing patients, and the only example of recovery was 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 instead to talk about the elements of care that encouraged recovery and the need for health professionals to understand the importance of the concept in structured reviews and other consultations. Recovery and indeed hope for recovery could be encouraged by 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 other family, friends, and other patients. A minority of patients were also keen to highlight the importance of taking responsibility for their own problems and recovery and of having realistic expectations of both the health professionals and the medical treatments available.

Discussion

Our findings emphasise the central importance of primary care to patients with serious mental illness. Use of 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 postgraduate qualification in mental health and only the six mental health leads (one in each health professional focus group) had specific mental health interests

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

"You can see somebody is in obvious pain, but like any one of us here, 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)

"Coz what's the point in someone having depression and being put on medication and being left on medication having no effect or possibly detrimental effects? And so I think it would be useful to kind of see the patient at intervals to see if you are feeling better and if the patient says no, then to do something" (Patient 1: female, Cannock)

"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 don't see why serious mental illness should be treated any differently to any other chronic disease" (GP 10: female, Solihull)

"So, you'd quantify mental health as a chronic disease?" (Patient 8: female, Solihull)

"Yes, I do [emphatically]" (GP 10: female, Solihull)

"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)

"Write him off!" (Patient 10: female, Birmingham)

"That's what they done, they'd written me off. 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)

"I asked him whether he [the GP] could give me some kind of realistic view about when I can start to think about things moving along. And, um, what he said was that realistically he thought I should think about taking on a bit of voluntary work, and not to even think about going back to the job that I'd trained at university for, as a social worker. He suggested that I should try and get a job packing boxes for the rest of my career. It really felt I had been let down" (Patient 1: female, Cannock)

"If people do get better it is because they've learnt to accept their limitations and made the best of it . . . It's about our ability to say 'I have a mental health problem.' It's about feeling you have a right to have a mental health problem and not feel guilty . . . if we wait for the rest of society to change we are going to be waiting a while. It needs to start with us. Either that, or we go back to the asylums" (Patient 4: male, Worcester)

"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)

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.¹⁹ Although the patient sampling framework relied on the knowledge of local key informants, participants represented a broad 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.

Relevance to the existing literature

Many of our findings—particularly in relation to access and continuity of care—support those of the few comparable studies.²⁰ Evidence of the pervasive effects of negative stereotypes of mental illness on health professionals' attitudes and behaviours towards people with serious mental illness¹² is also reinforced by this study. 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

We found interesting tensions between patients' views of a good enough GP and recent national policy imperatives. 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. Although patients can be referred to such GPs, a referral reduces interpersonal continuity of care, and the patients in this study valued continuity of care, attitudes, and willingness to listen and learn over specific knowledge on mental health. This suggests tensions with the direction of current policy reforms, and it challenges health professionals' assumptions that mental health expertise is vital to providing care for patients with serious mental illness.

Patients' many strategies for negotiating and facilitating access—in particular, exaggerating their symptoms to get an appointment—reflect the concept in the non-medical literature of "recipient design."²¹ Studies of calls to emergency services, for example, have found that callers shape and modify the content of their calls to suit the background and understanding of the recipient and lend credibility to their story.²² 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. Health professionals' attitudes are understandable given the focus on chronic disease management throughout the new GP contract. Medical training also largely reflects the historical pessimism of "dementia praecox," with expectations of deterioration once a diagnosis of psychosis is made, and the growing medical literature on managing depression as a chronic disorder.²³ Recognition of a formal recovery paradigm in mental health is

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

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.²⁴ For the study patients, however, the experience of serious mental illness was deeply personal, and many 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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