

Trust, choice and power in mental health care: Experiences of patients with psychosis

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Abstract

Background: Trust, choice and power are critical issues in clinical practice, public policies and a post-modern understanding of mental health care. We aimed to investigate the experiences and attitudes of patients with psychosis in relation to trust, choice and power.

Method: We conducted 20 in-depth interviews with patients with psychotic disorders in care of NHS services. The interviews were subjected to thematic analysis.

Discussion: Patients discussed aspects of their care in terms of dimensions that enhance or undermine trust, choice and power. Two interpretive themes emerged from this data. First, patients perceive the need for a shifting balance of power, according to the severity of their illness and their own experience of care, but feel that threats of coercion and neglect disable them. Second, they appreciate the expertise of clinicians, but particularly value 'the personal touch' that goes beyond this expertise, including personal disclosure about their own lives, common acts of kindness and conversation outside clinical matters. Patients view trust as a two-way process with responsibility shared between patient and clinician.

Conclusions: The active involvement of patients with psychosis in their individual care may be strengthened, particularly when they are not acutely ill and have more experience of their illness. While patients value expertise and respect in interactions with clinicians, they also appreciate a 'personal touch', which may go beyond current notions of professionalism.

Keywords

therapeutic relationships, trust, choice, power, psychosis

Background

Mental health care is changing. After de-institutionalization and the establishment of community care, there are new challenges set by the political, societal and cultural context in which we live. Three central issues are trust, choice and power, which feature in both policies (Warner, Mariathan, Lawton-Smith, & Samele, 2006) and post-modern concepts (Muir Gray, 1996). However, the often fierce debate is not always based on evidence of systematic studies of the experiences of patients. The existing research on trust, choice and power suggests that trust is important to patients and can be sustained between clinicians and patients (Mainous, Baker, Love, Gray, & Gill, 2001), increasing patient choice can help engagement with and response to services (Dwight-Johnson, Unutzer, Sherbourne, Tang, & Wells, 2001; Priebe & Gruyters, 1995; Rokke, Tomhave, & Jovic, 1999) but does not necessarily influence outcomes (Coulter & Ellins, 2006), and patient involvement has impacted

more at an organizational level than on individual care (Laugharne & Priebe, 2006). The emergence of shared decision making (Hamman, Cohen, Leucht, Busch, & Kissling, 2005; Hill & Laugharne, 2006) is an example of how trust, choice and power are linked and impact care.

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The aim of this qualitative study was to investigate the experiences and attitudes of patients with psychosis related to these three concepts. In order to expand the research base for developing practice and policy, we asked the following research questions. What are the experiences and attitudes of patients with a psychosis towards building a trusting relationship with clinicians? How much choice have patients experienced in their care, and what is their attitude to patient choice? What were patients' experiences and views on the balance of power in their care?

Methods

The qualitative study used in-depth interviews with patients diagnosed with a psychotic illness under the care of secondary mental health services. The National Centre of Social Research technique of in-depth interviewing was followed as closely as possible (Ritchie & Lewis, 2003). A user-led research group gave advice on the project from an early stage of the study.

The sample was purposive, utilizing as selection criteria gender, ethnicity, diagnosis (the patient's own description of their diagnosis was used) and a history of compulsory detention, as all of these characteristics might influence attitudes and experiences of trust, choice and power. We aimed for saturation, interviewing patients in Cornwall, a rural area with a very small non-white population, and cross-validating the sample by interviewing patients in east London, an urban, multicultural population. Both areas are relatively deprived for the UK. Patients were offered an interview in their own homes or at a local clinic. Informed consent was obtained.

A topic guide addressed the areas of trust, choice and power. This guide was developed by two of the authors, informed by a published literature review (Laugharne & Priebe, 2006). An in-depth interview was used to explore, reveal and generate ideas. When the interviewee touched upon an area but did not expand, probing questions were used to encourage more detailed reflection on that area.

All interviews were conducted face to face by the first author, who disclosed to the patients that he was a psychiatrist. The in-depth interviews took place at the patient's home in Cornwall and at the day hospital in London. Interviewees were usually seen alone, but on one occasion the interviewee asked for her husband to remain in the room. The interviews were taped and transcribed verbatim. The transcriptions were anonymized and have been kept by the authors so that they can be used for independent inspection and scrutiny.

The interviews were analysed qualitatively using components of grounded theory and thematic analysis, aiming for saturation. Interviews were analysed by the first author and independently by three other researchers. The independent analysts (two psychiatrists with at least four years' clinical experience (NG and DC) and one experienced

social scientist (RM)) examined 12 interviews each, and all interviews were analysed by at least two researchers. The analysts familiarized themselves with the data and examined interviews for emerging themes. In this way a numerical index of themes was developed grounded in the interview transcripts themselves. Each interview was coded with this index. Thematic chart grids were established with individual interviews as rows and index themes as columns. Interpretations were then abstracted from these charts. The three analysts reached agreement on the final themes, which were then further refined in iterative discussions in the research team. The framework is available from the authors. Using the final coding framework, 20% of the interviews were coded by two researchers (RL and RM).

The project received approval from the two local ethics committees and was registered for research governance.

Results

In Cornwall a register of patients under an enhanced care programme with mental health services in one area of the county was used. From this register we identified patients with a history of psychosis. We approached them alphabetically by letter inviting them to participate in the study. After nine interviews, we had more male patients over 50 years, therefore we then selectively approached female patients and male patients under 50. Sixteen patients were interviewed in Cornwall, all white in ethnicity (interviews 1–16), eight men and eight women. As 80 people were approached, this represents a 20% response rate. The interviews lasted between 50 and 90 minutes, with most lasting about 60 minutes. One interviewee appeared intimidated by the interview and the interview was stopped and not used in the analysis. In another, the patient's speech was inaudible on tape and also could not be used. The age range of the patients was between 38 and 62 years, the median age being 51. All patients had suffered from a psychotic illness, and the length of illness varied between five and 41 years, the median being 25 years. All patients had been admitted to hospital at some point in their lives, with eight having been admitted involuntarily at least once.

In London, recruitment through the process used in Cornwall was not successful. Therefore patients with a history of a psychotic illness attending a day hospital for acute treatment were approached by day hospital staff to participate in the project. Six patients agreed and were interviewed, two of whom were white British in ethnicity, one African, two black British and one Asian (interviews 17–22). Two women and four men were interviewed, with an age range of 21–40; their length of illness varied between three weeks and 21 years (median four years). The patients in London were younger and had been ill for a shorter time than those in Cornwall.

The total number of interviews was 22, with two (both Cornwall) not being analysed for reasons described above,

Table 1. Themes enhancing or undermining trust, choice and power (number of interviewees in brackets) (*N* = 20)

	Enhance	Undermine
Trust	Reciprocity of trust – depends on the patient as well as the clinician (11) Patient valuing professional expertise (11) Caring/kind attitude of the clinician (10) Continuity of care (10) Reliability/regularity of clinician (10) Clinician delivering promises (8) Clinician listening to the patient (6) Personal disclosure by clinician (4) Clinician positive about the future (3) Honesty (2)	Perceived neglect when unwell (9) History of coercion and perceived threat of coercion (8) Nature of illness itself (7) Relying only on scientific knowledge (2)
Choice	Patient experience/knowledge of illness (5) Time with staff (2) More than medication on offer (2)	Choice not considered by patients (8) Nature of illness itself (8) Lack of information especially in early stages of illness (6) History of coercion and perceived threat of coercion (6) Lack of confidence after illness (4)
Power	Patients feel clinicians use powers of compulsory detention legitimately (14) Patient knowledge and information increases their power (5) Patient sharing responsibility with clinician (3) Clinician sharing responsibility of compulsory detention with other professionals and carers (overcoming confidentiality) (2)	Perceived neglect when unwell (10) Nature of illness itself (7) History of coercion and perceived threat of coercion (5) Other patients abusing power (3) Clinicians straying into areas they should not (3)

and 20 being transcribed and used in the analysis. Of these 20 patients, six described their diagnosis as schizophrenia or schizoaffective disorder, seven bipolar disorder, with seven describing themselves as simply having a psychosis. For the 16 patients from Cornwall, patients had been given a clinical diagnosis on the enhanced care form confirming a psychotic illness. In London, the patients' self-diagnosis was supported by the opinion of day hospital staff. Of the four interviews analysed by two researchers, there was 83% agreement in the coding of the interviews.

The analysis identified patient experiences of specific factors that enhanced or undermined trust, choice and power in their clinical care. While the factors enhancing the three areas were quite different, factors undermining trust, choice and power showed similarities (Table 1).

Factors enhancing trust

Patients thought that trust was an important aspect in their care and spoke of positive and negative experiences of trust with clinicians they had worked with. Personal disclosure by the clinician was described by patients as significantly building trust:

I've got a very good CPN... she knows a lot about my personal circumstances, she knows I've got two daughters and knows I

want to be part of their lives... She's got a nice personal touch to her, she tells me about her family and things. (interview 4, man aged 47)

I had to go to see her [consultant] once because I was upset because I felt pressured to get a job and she said 'It was the same thing for me when I moved to a village but it was the opposite way round, I wanted to work and all the other mothers stayed at home' and she got slated in her village and carried on being a doctor (interview 9, woman aged 38)

In addition to personal disclosure, having a caring attitude and small kindnesses were significantly appreciated as building trust. Time spent not talking about their treatment or care was seen as important in building trust and trips to a café were welcomed:

The CPN, he would know that I was well in the first 15 minutes of his meeting and then we would spend the next 2 hours talking on topics interesting to both of us, we had complete and utter trust. (interview 1, man aged 45)

However, building trust was not viewed as solely the duty of the professional, but a joint responsibility between patient and clinician, suggesting reciprocity of trust. Some comments were critical of other patients who undermined the trusting relationship by their behaviour:

At the end of the day I have the ultimate responsibility for my actions, because if I do something when in extreme psychosis, why am I in that extreme psychosis? It may be because I haven't taken my medication. Whose responsibility is it? Who has responsibility over my medication and whether I take it or not? I do. (interview 9, man aged 38)

The importance of continuity of care emerged as a frequent theme in building trust and patients valued long-term relationships. They became frustrated when trusted clinicians left or were absent for a long time:

Well I mean I've known her [the consultant] for a long time and you could say that we're good friends, you know what I mean, I like her. (interview 3, man aged 55)

It's better knowing somebody when your mind is very, very... if you're familiar with a face it helps. (interview 15, woman aged 48)

Time, I need time to trust people. (interview 20, man aged 26)

The interviewees talked about clinician behaviour and attitudes that helped to build trust. These included their willingness to listen to their patients, being positive about the future, honest in their dialogue, being reliable and delivering on promises:

If someone does what they say they're going to do then you are more likely to trust them... I have to earn people's trust, so they have to earn mine. (interview 9, woman aged 38)

When I've been in hospital she [keyworker] was the only one who visited me... you've got to gain my trust. (interview 20, man aged 26)

Oh yes, regularity, you know, it's simply being there, so that you know when you expect to have an appointment with someone you do see them. (interview 1, man aged 45)

I have respect for her because she's very, she'll prove to you in what she says and done and she listens to your opinions, and being listened to is very important to me. (interview 18, woman aged 40)

Trust is when people have the time to do what you want rather than what they want. (interview 6, man aged 51)

However, patients frequently expressed a trust in staff due to their professional expertise as well as their personal qualities. They viewed clinicians as hard working and qualified to do what they were doing:

If you can't trust the experts, who can I trust? (interview 6, man aged 51)

And the evidence is they try very hard at their job and they study very hard and they're very well qualified. (interview 5, man aged 61)

They are really good at their job and they're very understanding, I think. (interview 19, man aged 26)

Factors undermining trust

The interviewees recognized that the nature of the illness itself could undermine the trusting relationship they had with staff trying to help them. This reinforced the importance of the reciprocity of trust between patient and clinician:

I don't trust myself so how can I trust anyone else? (interview 20, man aged 26)

I don't trust them but I think that's more to do with me than them. They haven't given me any reason not to trust them, I think it's just I do tend to be a bit sort of like that where I think everybody's against me... they haven't done anything to show that. (interview 18, woman aged 40)

The experience of coercive treatment could undermine trust in services in general and consequently in individual clinicians. The experience of coercive treatment often led to a long-term perceived threat of coercion outlasting the period of legal detention:

It's going to be hard to get away from here [day hospital]. (interview 19, man aged 26)

Perceived neglect by services, both in the community and in hospital, strongly undermined trusting relationships:

I don't trust my psychiatrist now because I've had all those manic trips and ended up in the police station while I was supposedly under their care because no one was coming here. The CPN wasn't coming... you rung up and they would just say, 'You'll be alright' and that. I've had so many episodes where I've gone out of control, because they only give you a CPN for 6 months. (interview 7, woman aged 62)

Patients perceived that psychiatrists could be over-reliant on a scientific model of care and this could damage trust:

You can get a bit detached from the realities of life if you consider things from a scientific basis too much. (interview 5, man aged 61)

Their knowledge is restrictive, it's created a sense of reality for them and their society which is only partial truth. (interview 6, man aged 51)

Factors enhancing choice

Patients emphasized that their ability to make choices in their care increases with experience of their illness and the effectiveness of past treatments. This was frequently contrasted with the difficulty in making choices earlier in their illness because of a lack of information about their illness and treatment options:

Consultants have looked at me and they have considered that I've got enough knowledge and experience to be able to have an input into what the medication is. (interview 1, man aged 45)

I've had the problem for nearly 30 years now... I'm able to talk about it more, then it's more taken into account. (interview 9, woman aged 38)

To make choices, the interviewees believed that they need to have information, and to get this they need time with their consultant and other clinicians. They also felt that more options than just medication were required, but sometimes these options have been scarce.

Factors undermining choice

Many patients had simply not considered patient choice as an option in their care:

I've never been a professional, I would hesitate to make a choice until, well, perhaps, if I were to answer that question in a way that said, well, I do think they should be able to make a choice, then I would be making a complete new step in my way of being treated by the system. I would be choosing something for myself. (interview 5, man aged 61)

As with trust, the nature of mental illness was perceived to inhibit the option of choice, as the illness itself can impair judgement:

I think it would be nice in the real world if there was a 50/50 sort of arrangement so the doctor will tell you and you will be involved as well. But I think that's not always possible because it depends on how ill that person is, maybe they might refuse treatment, or they might not know what's going on anyway. (interview 4, man aged 47)

I honestly think if there is any discrepancy about what the patient wants and what the doctors want, I think the doctors should come first on that one, because the doctor is more qualified and also the patient's illness can come into the fact that they are not having a clear picture because they are mentally ill. (interview 10, woman aged 54)

Furthermore, a striking finding from the interviews was that the effects of illness and treatment on patient choice lasted beyond the acute phase. First, patients described a loss of confidence in their own judgement that lasted beyond the illness episode, and as a result they could find being given choice an unwelcome stress:

When you've got a mental health problem and you're given decisions to make, that's the last thing you want, more decisions, choices... it's another thought where it's a burden as well, can be a burden. (interview 15, woman aged 48)

Second, if compulsory care had been applied, the sense of continued coercion outlasted any involuntary detention. As

a result of this perceived implicit coercion, real choice did not seem an option. One patient felt she had to cooperate with treatment as if she became ill her child would be taken into care and she might never get her back:

They have got most of the power over my life. I don't make many decisions because I'm frightened of making the wrong one. I want to bring [my daughter] up into her adulthood... if it means carrying on with this medication until I'm 94 then so be it. (interview 11, woman aged 44)

Factors enhancing power

Some patients were positive about giving power over treatment decisions to clinicians, in acute situations and sometimes over medication:

Well, no, well I'm prescribed my medication, but I accept that anyway. I'm not worried about choice on medication. I know what the doctor prescribes is going to be the right thing. (interview 5, man aged 61)

Forget the patient. Do what's best for him rather than asking their opinion. (interview 6, man aged 51)

Others clearly wanted a significant say in their treatment decisions:

I think I was really in control of that I think [coming off lithium]. I've never been forced to take anything I didn't want to. (interview 16, woman aged 64)

I think unless the patient is totally unable to make a choice on treatment, you should always be given a choice. It's like I choose to take my medication because I don't want to be ill again. (interview 8, man aged 58)

As with choice, patients need knowledge and information to have real power in their care, and they feel more able to exert power after they have had experience of their illness. The interviewees who had been compulsorily detained generally accepted that it had been necessary, but felt this power should have been shared with other professionals and carers. Issues of confidentiality could sometimes get in the way of this wider consultation.

Factors undermining power

As with trust and choice, the nature of the illness, coercion (both explicit and implicit) and concern about neglect in the community undermined the power that patients felt they had in their care. Illness was perceived to cloud judgement and there was a nervousness about giving patients power over decisions when unwell:

But I honestly think if there is any discrepancy about what the patient wants and what the doctors want, I think the doctors

should come first on that one, because the doctor is more qualified and also the patient's illness can come into the fact that they are not having a clear picture because they're mentally ill. (interview 10, woman aged 54)

I think when you're very ill they have to take decisions. (interview 7, woman aged 62)

Involuntary admission was often a distressing experience that led to patients feeling they had little control over their lives, even when retrospectively deemed as necessary:

They had to do what they did but in the way it was done, it was awful. I don't know how they could have done it in any other way, but I wasn't prepared to hand my baby over, they had to get her out of my arms. (interview 11, woman aged 41)

But the sense of coercion seems to outlast any legal detention, as patients feel the threat of further coercion if they do not comply with the requirements of clinicians:

You won't gonna get in a care home unless you agree to take the medication. (interview 1, man aged 45)

I think sometimes the doctors have too much power, especially psychiatrists, they make decisions about where you're going to live. I mean, Dr M basically made a decision on my life. She decided that I was under her care, she decided what medication I was going to have, and she decided where I was going to work. Now, isn't that power? (interview 4, man aged 47)

Patients could feel powerless at the prospect of living in the community with little support, and the threat of neglect by services was apparent in the comments of several interviewees:

I manage my life fairly well, but when I can't manage I've found there's no one to help me manage. (interview 16, woman aged 64)

Now I'm going to the day [hospital], I'll be in there two months, they'll release me and all I'll do, I go back and sit in my room again. (interview 20, man aged 26)

Those interviewed also felt that clinicians could stray into areas of their lives that were not in their area of expertise, such as the patient's spiritual beliefs, which was viewed as an abuse of power. In contrast, some patients criticized other patients for misusing the power they had, and felt that patients who were threatening or intimidating were abusing staff and taking resources away from patients who behaved appropriately.

Interpreting the themes

From these factors enhancing and undermining trust, choice and power, two overarching themes appeared to

emerge – the first encompassing aspects of all three areas, the second mainly focusing on trust.

Patients perceive a need for a shifting balance of power, but feel that threats of coercion and neglect disable them. Patients want a balance of power between themselves and clinicians that moves with time and is dynamic according to circumstances. At the beginning of their illness, a lack of information along with their inexperience means they are reliant on the expertise of clinicians, but with time their own resources increase and they expect more power to shift towards themselves. However, they recognize that at times of crisis, the nature of the illness can necessitate decisions being in the hands of clinicians.

This desired dynamic is threatened by the anxieties of coercion and neglect. They recognize that compulsory detention can be necessary but perceive the threat of coercion continuing beyond the legal framework and reducing their power to make their own choices, undermining their trust in services. The converse experience of help not being present when it is needed further reduces confidence in services and can make them feel helpless in times of illness.

Going beyond expertise – the personal touch. Patients interviewed felt that a trusting relationship with the clinicians they saw was vital in their care. Trust is built on a recognized expertise gained through training and experience, but goes beyond this. It is reciprocal, depending on the attributes and behaviour of patients as well as staff. Patients stressed the value of the personal touch, behaviour in clinicians beyond their professional responsibilities through common humanity – kindness, hopefulness and friendliness. They valued activities with clinicians other than clinical interventions, such as conversations about shared interests. Most interestingly, they especially valued staff who disclosed aspects of their own personal lives.

Contradictory evidence

While the majority of patients talked positively of staff members with whom they had developed a good therapeutic relationship, one patient felt that there would always be a distance between clinicians and patients because of professionals' study and expertise, as clinicians would never know what it is like to be at 'the bottom of the heap':

They're intellectuals who are theorizing well you know, out of touch with reality or normal reality because you know middle class or whatever, they don't know what ordinary people, my sort of level and their [patients'] sort of level, are like. (interview 6, man aged 51)

This was not expressed by other respondents. Another patient believed that patient views should take precedence over scientific evidence, which was contradictory to most expressed views.

Discussion

The patients interviewed engaged easily with the concept of trust but were less forthcoming in their reflections on the concepts of choice and power. This may reflect the power differential between the interviewer, whom they knew to be a psychiatrist, and themselves. However, once they began describing their views and experiences, the issues began to overlap and two overarching themes emerged.

Patients wanted to actively engage with treatment and saw the sharing of power in sharing decisions with their clinicians as a dynamic process. However, there were sources of a sense of helplessness at times. Contributing to this helplessness was a feeling of implicit coercion that outlived any involuntary detention, anger at neglect in the community when asking for help, and a loss of confidence after acute illness. However, those interviewed had a sophisticated view that the balance of power between clinicians and patients should shift according to the degree of illness and the experience of patients over time.

The quality of the clinician–patient relationship was greatly valued by interviewees, who respected clinician training, knowledge and expertise. Continuity of care, reliability in delivering promises and valued listening time were emphasized as building trust. Patients saw relationship building as a joint responsibility, not solely down to the clinician. Patients emphasized the importance of clinicians going beyond professional duties, in the recognition of the value of personal disclosure, small kindnesses and human warmth. This challenges an approach to health services that emphasizes the delivery of treatment packages rather than the caring aspects of the therapeutic relationship.

Strengths and limitations

The limitations of this study include the possibility that those patients willing to be interviewed may have different views to those who refused. Certainly patients with difficulty engaging in treatment may be far less likely to agree to an interview, especially with a researcher who was a psychiatrist. Patients in London were harder to engage in the study. While patients interviewed did not seem inhibited in describing negative experiences of staff and services, the fact that they were willing to engage in the research suggests an inherent ability and willingness to engage in dialogue that may not be typical of the whole patient population. This is a source of bias difficult to overcome in research asking for such direct patient engagement.

The interviewer was a psychiatrist and this may have led to more positive views than would otherwise be expressed. However, any background that the research interviewer has will lead to some biasing of responses, and as a psychiatrist the interviewer had some understanding of the dynamics of patient/clinician relationships. Nevertheless, patients will

bring their own attitudes and experiences to a therapeutic relationship with a psychiatrist-researcher, influenced by the power differential inherent between doctor and patient.

The strengths of the study were a rigorous qualitative method involving three analyses of the interviews and that saturation was reached across two very different settings. There were no major differences between patients from Cornwall and London. Therefore, the preponderance of patients from Cornwall is unlikely to be a source of bias.

Conclusions

Previous research

The findings emerging from in-depth interviews have thrown up some issues that have been important in clinical practice but seldom researched. Personal disclosure by clinicians has always been a live issue in clinical practice and this study supports its value to patients, although in certain circumstances strict boundaries would be wise. There is evidence that continuity of care is important to patients. In a prospective quantitative study, greater continuity of care was associated with better functioning, quality of life and service satisfaction (Adair et al., 2005). There had been a limited number of research papers on patients' perspectives on this issue (Crawford, de Jonge, Freeman, & Weaver, 2004), although recent studies have developed a user perspective and user-generated measure of continuity of care (Burns et al., 2009; Rose et al., 2009). The finding that there is a wide variety of opinions on how much involvement patients want in treatment decisions is consistent with quantitative studies (Adams, Drake, & Wolford, 2007; Hamman et al., 2005; Hill & Laugharne, 2006) and should be addressed in health policies. Encouraging patients who want to actively share in decision making helps them to engage with services (Priebe, Watts, Chase, & Matanov, 2005). Patients' sense of implicit coercion has started to be examined in other research (Kallert et al., 2005), whereas previous studies have observed a lack of empowerment in individual care even if patients are involved in organizational committees (Peck, Gulliver, & Towel, 2002).

Implications for practice

Despite user representation on decision-making bodies, active involvement at the individual patient level can still be improved. The balance of responsibility for decision making in the therapeutic relationship needs to have a dynamic flexibility, taking into account the patient's current condition and considering patient's experience. Training and supervision should strengthen respect and expertise, but also encourage a 'personal touch' going beyond current notions of professionalism.

There is pressure to restrict activity to delivering evidence-based interventions. This study suggests that

spending time with patients beyond the direct delivery of treatment builds trust and the therapeutic alliance. Self-disclosure has traditionally been discouraged as there is a risk of it blurring therapeutic boundaries. These results suggest that this risk is worth taking in at least some situations. The two-way process of building a trusting relationship needs to be specifically acknowledged, in which responsibility is on both the patient and clinician and is not the clinician's alone. Clinicians need to deliver on promises they make, and allow for the loss of confidence patients experience after illness, which may impair their ability to make choices in their care.

Implications for policy

There is a need for improved information delivered in a systematic way if patients are to have genuine choice early in their illness. Patient choice and empowerment are complex areas that need to be considered carefully, and different patients want different approaches to their involvement in care. A universal policy approach is unlikely to be satisfactory. Patient choice in individual care is probably easier to implement for experienced patients. Continuity of care is important to patients, yet recent service configurations can fragment continuity of care, a factor that seems seldom considered in designing service systems. Finally, while coercive care can undermine therapeutic relationships, perceived neglect in the community seems to contribute just as much to the erosion of trust and this should be acknowledged in planning long-term patient care. Consideration should be given on how to address patients' frequent sense of implicit coercion after involuntary detention has ceased.

Future research

Research may have to go beyond naturalistic observations and move to experimental studies that explore how patient experience can be improved through the provision of more information and different clinician behaviour. Qualitative methods may have to be used to understand patients' experiences of central issues in care both in routine conditions and possibly also within the framework of trials.

Declaration of interests

RL, SP, NG and DC are all psychiatrists working in the British National Health Service (NHS).

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Appendix: Other quotations

I mean, it's up to the consultant to decide what medication they give you, but what I'm trying to say is you don't

really get a say in what your medication is. (interview 3, man aged 55)

What's my son going to say when I have to go to the asylum... or he's told his daddy is mad, he's mad because of his genes? So he's suffering before he even starts to suffer. I'm not happy. (interview 2, man aged 42)

It's [trust] very important. I mean if you don't trust the doctor or the nurses, you're always going to have that little bit of paranoid playing in your head. (interview 9, woman aged 38)