An exploratory study of the role of trust in medication management within mental health services

INTRODUCTION

Trust is a fundamental aspect of human relations and becomes relevant in conditions of vulnerability and uncertainty[1]. Vulnerability is unavoidable in healthcare due to underlying anxiety associated with ill health, potential treatment risks, and the reliance of patients on clinicians[2]. Uncertainty exists in terms of treatment efficacy and adverse events[3,4]. Vulnerability and uncertainty are especially apparent in mental health contexts. While trust is vital to the co-operation between service users and clinicians required in chronic disease management[2] trust may be less likely in mental healthcare[5].

Taking medication is associated with vulnerability and uncertainty and therefore trust is likely to play a role in safe medication management[4,6]. However, trust may be difficult to obtain due to perceptions of coercion and because clinicians may believe that service users lack decisional capacity[7-9]. Adherence strongly correlates with trust and open communication about adverse effects facilitates such trust. Clinicians may be reluctant to provide information about adverse effects due to fears that such an explanation could worsen adherence[6,10]. An over-emphasis on compliance and control, and a corresponding lack of open communication, may thus damage trust where patients experience negative outcomes they were not warned about. Incomplete and inaccurate exchange of information may compromise effectiveness and impair medication safety.[7,11,12] For example patients who are not warned about a particular adverse event - due to lack of trust regarding concordance - may not know how to manage it, or whether urgent treatment is needed. Moreover if a clinician does not have an accurate history, because the patient lacks trust in the clinician, it can be difficult to formulate safe treatment decisions.[10,12]

AIM OF THE STUDY

To develop understandings of the role of trust in safe medication management within mental health services.

METHOD

An exploratory qualitative approach following adopted COREQ (consolidated criteria for reporting qualitative studies) guidelines was used with approval by East Kent Research Ethics Committee (09/H1103/36)[13]. Focus groups were used because the group interaction allows participants to compare and contrast their views and experiences, enabling key issues to be developed from multiple participants[14]. With complex issues, such as the use of medication in mental healthcare, it can be difficult to frame the questions and the group format allows participants to develop the questions and identify solutions.

Sample

Focus groups were run across three categories of user of specialist secondary care mental health services – older adult, adults living in the community, and forensic services (one focus group per service) – to develop understandings across varying settings. (In the UK specialist services tend to focus on people with complex mental healthcare requirements, such as, psychosis, whereas most care for uncomplicated care particularly depression and anxiety is provided solely within primary care).[15,16] Groups were segmented to contain participants with certain common characteristics and data was systematically captured to identify commonalities and differences between groups. The number of groups was based upon the necessary number of participants to provide a broad range of perspectives across different mental health contexts.

A mixture of purposive and convenience sampling was used. Sites were based on what was appropriate to obtain a range of different views (purposive sampling) and where groups were relatively easy to form (convenience sampling). Each group contained 6 to 8 participants (see table 1 for sample characteristics, mean age and standard deviation). Potential participants were contacted via mail, a poster and/or an informal approach from the focus group co-facilitator, who also obtained informed consent. The key inclusion criterion was users, or carers (in the case of the older adult service), of secondary mental health services. Participants who lacked capacity to consent would have difficulty with focus groups and were excluded.

Insert Table 1 here.

Procedure

Focus groups lasted 1 to 1.5 hours and were conducted between August 2009 and January 2010. The groups took place on NHS premises and were co-facilitated by a research assistant or service user representative who was familiar with the participants, but had no treatment role. A semi-structured interview schedule (see appendix) was developed to explore service users' views on the nature and influence of trust on medication management.

Data Analysis

The chief investigator carried out a thematic analysis of the transcripts using the method of constant comparison informed by grounded theory. Three coding stages were followed[17]. First, open coding was used to develop categories and sub-categories based on commonly recurring themes. Second, axial coding was used to compare categories and develop concepts and theories. Third, selective coding was used to re-organise the data and consider the themes in relation to trust. A number of techniques were used to ensure validity and reliability, and control for researcher effects and selectivity in data use. Data was independently reviewed by one of the investigators and considered in the light of existing literature. Results which contradicted the key conclusions were actively pursued (deviant case analysis). Finally, member-checking was utilised.

Reflexivity

Qualitative researchers engage very closely with the study participants and must recognise the impact of personal bias and reflexivity, the relationship between the researcher and the participants, on the research outputs[13]. This research, including moderating the focus groups, was carried out by a male pharmacist with over 15 years experience working within mental healthcare. The researcher had no clinical role with any of the participants.

RESULTS

Three main themes, described below, were identified -

Therapeutic Relationship

Quality therapeutic relationships – reflecting clear communication, choice and empathy – were vital in developing trust. Each group emphasised that full communication developed trust:

“They actually told me about most of the side-effects and what was happening. So for me I did really trust the doctors on what they said (Forensic [F]; 6).”

Service users frequently reported incomplete disclosure of information. Generally it was felt that clinicians tended to emphasise the ‘good’ effects of medication, seemingly to encourage adherence and not fully communicate the ‘bad’ effects of medication. This failure to inform damaged trust and inhibited the involvement of service users in medication safety, increasing risk:

“They should tell you more (about side-effects) and I think that when they are talking to you about medication they want you to take they should be prepared to tell you that these are the side-effects that you should look out for, because some of them may be dangerous (Older Adult [OA]; 9).”

One view expressed across the three groups was a lack of choice particularly amidst compulsory treatment:

“They tell us what medicines to take; we do not get a choice (F; 2).”

A lack of choice was disempowering and could increase the risk associated with medication, and due to the reciprocal nature of trust, damaged service users’ trust and adherence – particularly if specific concerns were ignored[18]. Not all service users felt that there was a lack of choice. Articulate, well-informed service users were able to negotiate choice building trust:

“The staff have always listened to me about side-effects and when to change a medication, but that might not be true for everyone else (F; 4).”

However, even in this sub-group choice was constrained and was typically reactive; medication would only be modified after an adverse event. Furthermore, every group believed that service users had a limited voice in relation to medication management, partly because clinicians believed that cognitive impairment prevented service users from identifying adverse events and that due to symptoms of their illness service users may falsely highlight a potential medication error to avoid receiving medication. Service users felt particularly unable to highlight an adverse event or query a prescription if acutely unwell and cognitively impaired, when high doses are used and medication commonly changed. Therefore, service users are most vulnerable to adverse events, and least able to report an adverse event, when one is most likely:

“It’s general policy when you first go in for them to knock you out for more than a 48 hour period, so if they start giving you wrong drugs you’re not going to be in much of a state to argue the toss? (Adult-Community [AC]; 18).”

Experiencing an adverse event could damage trust in the medication, the clinician, and correspondingly adherence, particularly where the service user felt their views were ignored, the adverse event affected their quality of life, or the medication had no noticeable benefit. However, adverse events did not always damage trust. One service user continued to trust the doctors despite medication induced thyroid problems:

"I trust them to give me the right drugs. I have always trusted them (AC; 19)."

Continuity of care was important and service users, particularly in the older adult and adult-community groups, were more likely to trust clinicians who were seen to take time in developing a relationship and demonstrate empathy. There was seemingly a reciprocal relationship between communication and trust, with the potential for improved outcomes within trusting relationships:

"I think it goes back to treating people holistically and as individuals……. You have to build up a rapport with them on both sides in order that you both develop trust with each other. It helps you get better, because you trust somebody you know they are doing it in your best interests (OA; 9)."

Uncertainty and Vulnerability

Service users believed that the use of medication within mental healthcare was characterised by inherent uncertainty and guesswork:

“The most interesting thing is this arbitrary nature which they go about doing these things. Working out what medication you need, how long, how much of it you have to be on (F; 3).”

This uncertainty was a barrier to trust, while also making trust necessary. There was initial uncertainty regarding the presence of disease with clinicians and service users holding different belief systems regarding mental illness[8]. Further uncertainty was associated with efficacy, side-effects and the role of medication in recovery, resulting in service users questioning the competence of clinicians. Several service users suggested clinicians overcame uncertainty by “objectifying” service users, and failing to individualise treatment, which damaged trust:

“They make their mind up as to which drug you are going to go on. And their reasoning well I mean it could be ‘we fancy you on that drug’ and that’s it and I don’t trust them in that way (F; 2).”

Where efficacy was uncertain, service users were reluctant to adhere to treatment – and if the clinician did not listen to the service user’s concerns this damaged trust:

“It is of no consequence……my mood never changes…..Well, I suggested that she take me off drugs – I didn’t think that they were having enough effect. She said no – she dismissed it completely, instantly. (F; 5).”

Medication could have a significant effect. Service users could re-lapse if the dose was reduced, but were also vulnerable to adverse effects, which could damage trust and, due to incomplete disclosure, be unexpected and particularly frightening:

“They put me on some medication I didn’t know what it was, but I thought that I was dying…..I couldn’t move (F; 6).”

Vulnerability was inherent within the illness experience and some service users believed that, to a certain extent, they *had* to trust the doctors. Cognition could be impaired, by mental illness and medication, making it very difficult for service users to express a view[19]. Even when service users did express their viewpoint, they felt that due to the stigma of mental illness clinicians would often not listen:

“And when you question it they just say ‘we think that you are mentally ill’. (F; 2).”

The terminology used, the symptoms of mental illness (in particular paranoia), and observing outcomes in others re-enforced vulnerability – often creating a barrier to developing a trusting relationship.

Service users identified that if they were educated about medication this could protect against vulnerability:

“I think to be educated on some of the things, you can build up much more of an idea of whether what is going on is right (OA; 8).”

However, cognitively impaired and/or isolated service users may not be able to access accurate information. GPs were particularly vital in providing information, but unfortunately appropriate support was not always forthcoming:

“My GP..… he doesn’t get involved. He won’t make any decision (AC; 20).”

Generally, service users, particularly in the forensic group, did not trust statutory safeguards, and did not believe that service users under a section were adequately protected from receiving inappropriate medication:

“I think that if I had refused it would have gone to the second opinion doctor and according to what other people have said then they would have just agreed with the first opinion doctor (F; 4).”

However, in some cases safeguards were considered more robust.

Social Control

Trust relates to beliefs that one’s concerns and interests will be prioritised by the trustee[5]. Yet service users believed that coercion was not for their well-being or in their best interests, but a symptom of an over emphasis on medication and concerns about the risks posed by service users – which are similarly uncertain. Coercion was frightening and traumatic, destroyed trust, and made service users feel vulnerable:

“And force doesn’t promote trust, it promotes fear (AC; 16).”

After coercion the therapeutic relationship was described as becoming more confrontational, with an increased need for future coercive treatment. Service users believed that they had no voice, or rights, under coercive treatment and it was unclear to them whether there were adequate safeguards to prevent medication errors:

“Because some of the times I didn’t need it. They would just think that you did, but sometimes they would get the wrong decision (F; 6).”

The use of coercion was related to fears about adherence and a lack of trust. Non-adherence was not tolerated and service users were often not trusted to adhere to medication, or to be honest about adherence. Clinicians did not always disclose this lack of trust. Service users were however aware of certain signs – such as use of depots – that indicated a lack of trust and damaged the therapeutic relationship. If service users asserted what they believed was their right to refuse medication, coercive methods were used as a threat to enforce compliance in an already vulnerable population:

"I wasn't comfortable with the tablets so I tried it [refusing medication] and I was forced in my view (F; 6)."

DISCUSSION

The Role of Trust

Every group identified the need to trust clinicians in relation to medication management[20]. However, achieving trust was often problematic; service users described the difficulty in developing a therapeutic relationship based on mutual trust[21]. Clinicians were typically seen as only trusting service users who agreed with them, exhibiting less trust if the service user opposed their views, which resulted in a failure to communicate fully. Service users didn't, therefore, trust clinicians to tell them the whole truth about medication, particularly adverse events[5]. Respondents perceived this lack of trust by clinicians as disempowering, because it limited choice in relation to medication and resulted in the use of coercion[22,23]. The use of coercion destroyed any trust that the service user placed in the clinician, because service users believed that coercion was not for their benefit, but an instrument of social control, and that safeguards failed to provide adequate protection.

Inherent uncertainty exists around the use of mental health medication, which makes trust more necessary and yet unlikely[5]. This uncertainty is accompanied by vulnerability, partly because service users are often isolated, cognitively impaired and therefore not able to, or allowed to, make informed choices. Individual vulnerability and uncertainty may be reinforced by treatment contexts – poor communication and unclear lines of responsibility – which further threaten patient safety[19] and inhibit a trusting relationship from developing.

Low levels of trust impacted upon medication management in two main ways. First, the lack of trust could damage adherence, and result in coercion and forcible administration. Adherence strongly correlates with trust; adherence rates may be 3 times higher where there are very high levels of trust.[9,24] Service users were more likely to adhere, when complete information is supplied[25], and to regimens that have been negotiated and reactance theory suggests that using a threat is likely to have a contrary effect and increase non-adherence[26,27]. Therefore, ultimately coercion may worsen adherence by inhibiting a trusting relationship from developing.

Second, it could increase the potential for adverse events. A partnership, involving full and complete communication and informed choice, rooted in mutual trust, is required to safely manage medication. However, within mental healthcare there is a tension between the need for social control and limiting the adverse effects of medication[23]. Service users believed that clinicians generally did not trust their views and opinions, inhibiting information exchange, and a therapeutic partnership from developing. This low level of trust could be considered a latent factor in Reason's model of error causation and increase the risk of medication errors[28].

Practice and Policy Implications

The increased potential for error places additional responsibility on practitioners, who must avoid dismissing medication safety concerns due to stigma. The current policy focus in England and Wales is risk reduction with an emphasis on the use of coercion[5,11]. This study indicates that utilising coercive methods, rather than emphasising a partnership built upon trust, could increase the risk associated with medication in terms of adverse events and the possible consequences of non-adherence. Safe medication management and improved adherence may be most effectively achieved by policies and practices which adopt a partnership, rather than a coercive, approach and focus on trust rather than risk. A good example of a strategy, which adopted a partnership approach, involved the use of advance directives in people with severe mental illness.[18] Adherence at 12 months was higher amongst service users, who were prescribed at least one medication requested in an advance directive (odds ratio = 7.8, 95% confidence interval 1.8 to 34.0).[18] Therefore, orienting services around trust may reduce risk by creating virtuous rather than vicious circles of compliance[5].

Strengths and weaknesses of the study

The views reflect the experiences of service users in a single NHS trust. However, the trust is one of the largest in the country serving a very mixed population and likely to be broadly representative, although this issue should be explored across other populations, including black and minority ethnic populations. Furthermore, the rich data generated from the focus groups conducted in three very different environments resulted in relative data "saturation" and similar issues were identified within a broader study of patient safety[29].

One possible limitation is the group heterogeneity and therefore analysing the results from the groups together may be problematic. However, the data from each group was initially analysed separately and the participants generally expressed similar views in relation to a number of the core themes. There were, however, some important differences in the data generated by the three groups. Participants in the forensic group highlighted a general lack of trust in safeguards, whereas empathy and continuity of care were particularly important to participants in the older adult and adult focus groups.

Future Research

These findings require confirmation and expansion. Trust needs to be studied in various contexts and data sources should be triangulated by interviewing clinicians to understand the clinician’s perspective on trust. Longer-term research objectives should include developing a reliable and validated scale to assess the overall level of trust in relation to medication management within mental health services and interventions to improve trust.

CONCLUSION

To summarise, trust is needed within mental healthcare to ensure safe medication management, but achieving the required level of trust is far from straightforward. The focus groups more commonly referred to vicious circles where low levels of trust, due to (and resulting in) poor communication, made adverse events and/or coercion more likely – further undermining trust. This contrasted to the virtuous circles apparent within trust-based scenarios where service users felt they were given more responsibility and tended to be more honest with clinicians, building further trust and improving adherence. Therefore, the current policy framework should focus on trust rather than risk in order to reduce risks associated with medication. Further research is required to confirm and expand these initial findings.

Acknowledgements

We acknowledge the co-operation of service users from Kent and Medway NHS and Social Care Partnership Trust in this research project.

Funding

None

Conflicts of Interest

IM has undertaken consultancy for pharmaceutical companies that produce medication used within mental health services including Eli Lilly, BMS, Lundbeck, Servier and Astra Zenecca.

PB and MC none.

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Appendix

Focus Group Semi-Structured Interview Guide

- Do you feel able to talk openly to your clinicians and tell them accurate and complete information about your medication?

- Are you told the important potential adverse events?

- When the adverse events of medication are discussed are your views listened to within the consultation?

- Do you think that your clinicians give you a balanced picture about the risks, including adverse events, and benefits of treatment?

- Have you ever received medication against your will? If yes, what impact did this have on your relationship with clinicians?

- Have you ever come across a medication error in mental health?

- How important do you think trust is in ensuring the safe use of medication?

- Do you trust your clinicians to tell you the truth about medication?

■ Does trust, in relation to the use of medicines, exist in mental health?

■ What does it mean for you to trust your doctor about medication?

Table 1 – Characteristics of focus group participants

	Forensic group	Older adult group	Adults living in the community group
Total number of participants	6	8	6
Number of females	0 (all male unit)	4	3
Number of carers	Not applicable	2	Not applicable
Mean age[1] (years)	40.3 (s.d.=17.87)	71.2 (s.d.=4.88)[2] 54 (s.d.=7.07)[3]	41 (s.d.=9.90)
Ethnicity	White British (n=6)	White British (n=8)	White British (n=6)

1 = mean age and standard deviation calculated using SPSS statistical package 17.0.

2 = Mean age of service users in older adult group

3 = Mean age of carers in older adult group

s.d. = Standard deviation