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Barriers to shared decision making in mental health care: qualitative study of the Joint Crisis Plan for psychosis

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Abstract

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Background Despite increasing calls for shared decision making (SDM), the precise mechanisms for its attainment are unclear. Sharing decisions in mental health care may be especially complex. Fluctuations in service user capacity and significant power differences are particular barriers.

Objective and design We trialled a form of facilitated SDM that aimed to generate patients' treatment preferences in advance of a possible relapse. The 'Joint Crisis Plan' (JCP) intervention was trialled in four mental health trusts in England between 2008 and 2011. This qualitative study used grounded theory methods to analyse focus group and interview data to understand how stakeholders perceived the intervention and the barriers to SDM in the form of a JCP.

Results Fifty service users with psychotic disorders and 45 clinicians participated in focus groups or interviews between February 2010 and November 2011. Results suggested four barriers to clinician engagement in the JCP: (i) ambivalence about care planning; (ii) perceptions that they were 'already doing SDM'; (iii) concerns regarding the clinical 'appropriateness of service users' choices'; and (iv) limited 'availability of service users' choices'. Service users reported barriers to SDM in routine practice, most of which were addressed by the JCP process. Barriers identified by clinicians led to their lack of constructive engagement in the process, undermining the service users' experience.

Conclusions Future work requires interventions targeted at the engagement of clinicians addressing their concerns about SDM. Particular strategies include organizational investment in implementation of service users' choices and directly training clinicians in SDM communication processes.

Introduction

Recently, the BMJ carried a call for a 'patient revolution'.¹ The revolution in question was the involvement of patients' in health-care delivery and in decisions made about their treatment. The authors stated:

It's about a fundamental shift in the power structure in healthcare and a renewed focus on the core mission of health systems. We need to accept that expertise in health and illness lies outside as much as inside medical circles and that working alongside patients, their families, local communities, civil society organisations, and experts in other sectors is essential to improving health. Revolution requires joint participation in the design and implementation of new policies, systems, and services, as well as in clinical decision making.

Such a 'revolution' challenges more traditional models of medical decision making, often referred to as 'paternalistic' where the clinician makes a decision they believe is in the best interest of the patient.^{2,3} Challenges to this model include the following: a right for patients to be consulted, involved and informed about their care; the risk of abuse of power; patient experiences that may effect the suitability of a treatment decision; and lesser compliance with decisions in which patients have no investment.^{2,3}

By contrast, shared decision making (SDM) recognizes that both clinicians and service users have expertise, and the most effective decisions will be generated from joint working. Charles *et al.*² defined four necessary characteristics of SDM:

- Both the physician and patient are involved in the treatment decision-making process.
- Both the physician and the patient share information with each other.
- Both the physician and the patient take steps to participate in the decision-making process by expressing treatment preferences.
- A treatment decision is made and both the physician and patient agree on the treatment to implement.

The proposed 'Collaborative Deliberation Model'⁴ further delineates processes involved in

SDM: constructive engagement, recognition of alternative action, supportive dialogue. These processes facilitate the exchange of information and the equality of decision-making process.

While SDM is inherently appealing to patients and service user groups and has been associated with improved outcomes⁵, clinicians often struggle to facilitate the equal exchange of information required. In mental health care, perhaps more so than general medical care, sharing decisions is complex. Issues of patient capacity are at the forefront of many clinicians' reservations. Seale *et al.*⁶ examined psychiatrists' strategies for discussing medication with service users. While there was a rhetorical commitment to egalitarian models of interactions, many took decisions or withheld information that they felt would hinder their preferred option. Service users also have reservations due to power imbalances, not least the legal facility in many countries to treat patients without their consent. How to encourage open and supportive dialogue when there is such mistrust?

Making decisions in crisis situations

While there may be barriers to SDM in routine psychiatric care, crisis situations in which service users have relapsed and may have reduced decision-making capacity⁷, are particularly complex. Making shared decisions about future crisis interventions when the service user is well, may therefore be of benefit to both stakeholders. It may protect clinicians against complaints about treatments to which the service user did not consent and enable service users to maintain control of their treatment.⁸⁻¹⁰

The term 'Advance Statements' can be applied to a range of interventions that allow individuals to make a statement regarding their future care at a time when they are well and have capacity.¹¹ There are different types of Advance Statements, some of which may not involve clinicians (an aspect which may facilitate the free expression of service users' views²); however, clinicians often express concern that service users will make decisions that are at odds with their well-being.^{2,12-15}

Involving clinicians in the generation of Advance Statements may therefore help allay such concerns and improve the likelihood of implementation of the statement's content. Yet, ensuring the recognition of alternative actions, including service users feeling enabled to question or reject clinicians' recommendations, remains problematic.¹⁶ A form of *facilitated* Advance Statement, the Joint Crisis Plan (JCP), was recently trialled in the England. An independent member of the research team – the JCP Facilitator – ensured that clinicians were there to discuss treatment preferences with the service user, although the final content of the plan was the service user's choice. A pilot study conducted in London suggested that the JCP was effective in reducing compulsory treatment under the Mental Health Act and service users felt more in control of their mental health problem.^{9,16–18} However, the definitive trial conducted in four mental health trusts in England – CRIMSON – found no reduction in compulsory treatment¹⁹ raising questions regarding the implementation of the JCPs in wider settings. In this context, the aims of this paper were to understand:

- how the JCP intervention was perceived by CRIMSON participants, both clinicians and service users
- the barriers to SDM identified in the implementation of the JCP

Methodology and methods

This qualitative study was embedded within the CRIMSON trial¹⁹. Participants were randomized to treatment as usual under the Care Programme Approach (CPA)²⁰ or to develop a JCP in addition to receiving treatment as usual. The trial, including the qualitative aspects, received ethical approval by the King's College Hospital Research Ethics Committee (07_H0808_174). In addition, local approvals were received from the mental health trusts, clinical directors and clinical teams.

Each clinical team was visited by the research team to introduce the evidence for the

JCP and to describe what participation in the trial would involve for the team and service users. Caseloads were screened and eligible service user participants approached. If the service user agreed to participate, their named clinician/s would be required to complete some questionnaires, and if allocated to the intervention group, participate in the JCP meetings (described below).

The Joint Crisis Plan intervention

The JCP has been described previously.^{16,18,19} Briefly, the JCP contains the service user's preferences for treatment in the event of a future relapse of their mental health condition. It is jointly made with the service user's psychiatric team who are there to help clarify the service user's wishes. There are two meetings to develop the JCP. At the first meeting, attended by the care coordinator, the service user and JCP facilitator, the service user is given a copy of a list of options to consider putting on their JCP. This list is left with the service user so they can prepare what they would like to say in the final meeting. The final meeting is where the content of the JCP is decided. Attendees are the service user, the clinical team (care coordinator and psychiatrist), and the JCP facilitator and family members. The JCP facilitator ensures that there is discussion between the service user and psychiatric team, but that the content is the service user's choice.

Routine care

In England, mental health care is organized under the Care Programme Approach (CPA).^{20,21} Under the CPA, individuals are assigned a care coordinator (primary contact, usually a nurse or social worker), and a routine clinical care plan that is regularly reviewed. The CPA care plan includes a 'crisis and contingency' section, which should cover the individual's relapse warning signs and plans for treatment. However, in a recent review of the crisis sections of CPA care plans, only 15% of plans were found to have individualized content specific to the service user

about whom it was written.²² Instead, the plans were mostly completed by clinicians and, while meeting organizational requirements, were generic and unlikely to be useful to the service user.

Qualitative study recruitment

Sampling was initially designed to recruit a diverse range of service users and clinicians, and was refined using the principles of theoretical sampling. Clinicians from different professional groups (e.g. psychiatrists, nurses, social workers) were purposively approached if they had participated in at least one JCP meeting. Willing participants provided written and informed consent. Further details of the sample have been reported elsewhere²³.

The topic guide was developed after a literature review,²⁴ piloted in one site and revised throughout data collection. Questions addressed participants' views about the process, content, use and impact of the JCP; for example, 'What was different about the JCP planning meeting? What did you think of the finished plan? How have you used the JCP?' Twelve focus groups (average 90-min duration) involving 35 service users, 22 care coordinators and one psychiatrist were conducted at local libraries. A further 37 semi-structured interviews (average of 1-hour duration) were conducted at home with 15 service users, and at clinical bases with six care coordinators and 16 psychiatrists. Each interview or focus group was audio recorded, transcribed and checked for accuracy. Interviews and focus groups for all stakeholders continued until no new concepts were identified, that is until data saturation was reached.

Data analysis

Grounded Theory Methodology was chosen as the aim was to understand stakeholders' perspectives on the pros and cons of the JCP approach. Coding was undertaken using Constructivist Grounded Theory methods.²⁵ Analysis began with 'line-by-line' coding, generating codes from the data, rather than from a predefined list. Subsequent coding raised

codes to greater level of abstraction or categories, using constant comparison and 'memoing'. An active attempt was made to discover and describe exceptions to emerging categories. NVIVO version 9 was used to help manage data.

To ensure the 'credibility'²⁶ of the analysis, a number of strategies were undertaken. A selection of transcripts from each stakeholder group was independently coded by SF and HL, compared and discussed. There were very few differences, but if present the contested section was re-read, discussed and a consensus was reached. Memos were also discussed with co-authors. Mixed focus groups were held with clinicians and service users, who had previously participated in a focus group or interview, to discuss the emerging analysis. These groups provided an opportunity to clarify emerging concepts and to give respondents an opportunity to re-emphasize points they felt were missed.

There were marked similarities between the points raised by care coordinators and psychiatrists. In this context, we have used the term 'clinicians' to describe views held by both groups, and stipulated the professional group if it was not a common view.

Results

Fifty-one service users participated in the study. Fifty-two were female, with an average age of 39 years and 64% were white, 32% were black and 4% Asian. Of the care coordinator participants ($n = 29$), 58% were women, with an average age of 44 years, and 75% were nurses (ethnicity was not recorded). Sixteen psychiatrists participated: 20% were female with an average of 6.5 years (range 3–11 years) at a consultant level (ethnicity was not recorded).

Clinicians identified four main barriers to the implementation of SDM in the form of the JCP. Each of these barriers appeared to undermine their engagement in the process and subsequent implementation of the plan. In contrast, service users responded well to the opportunity (see

Ref. 23 for a fuller discussion). Service users did identify some barriers to SDM in routine care but believed many of these were addressed by the JCP process. However, the lack of engagement from clinicians decreased some service users' confidence in the JCP intervention as a tool for their empowerment. This section will describe the four main barriers for clinicians and then outline the concerns of service users and impact of clinician-identified barriers on their experience.

Ambivalence regarding care planning

The majority of care coordinators believed that service users did not value or use care plans developed in routine care. Many care coordinators described situations where service users deteriorated very quickly, and were not capable of recognizing and/or complying with the contents of their routine care plans. Care coordinators believed the lack of compliance was the result of service users not caring about routine care plans. A few described service users who had thrown out their routine care plan or had no knowledge of where it was. For example,

One of the reasons I'm so sceptical is that I actually do sit down and do care plans with people, but I go back the next week and say oh can we look at that copy of the care plan again, and they can't find it. And you think... you know... am I really kidding myself that doing it jointly actually does make a difference? (Male, Nurse, Focus Group 1)

This was a point of great frustration for care coordinators as they described how routine care plans were time consuming to complete and their completion was regularly audited by managers.

Rather than meeting the needs of service users, most care coordinators believed that routine care planning was designed to meet the needs of the mental health services. A few care coordinators said that the process of documenting the routine care plan was a measure to protect themselves, rather than seeing any intrinsic benefit in the process or the document for the service user. For example,

Yeah, it covers me in case anything goes wrong. Even though it's got the clients wellbeing at heart, and it's good for the client, but primarily it covers me. (Female, Nurse, Focus Group 3)

One care coordinator described the crisis and contingency component of the CPA plan as 'barking the mantra'. That is, there is a standard care pathway in a crisis and that is what is entered into CPA care plans. For those who did not see additional benefits of the JCP approach in terms of detail, one of the criticisms was that 'service users know what to do.' For example,

Most of them are aware... a lot of them are fairly basic anyway it's just err, contact your care coordinator who may arrange an emergency appointment, and you know to try and see the consultant or the doctor as soon as possible. And then consider home treatment, go to [Accident and Emergency Centre] if it's outside hours. You know it's very standard and the clients just... they know most of it anyway. (Male, Nurse, Focus Group 2)

The JCP intervention was therefore met with scepticism as it was introducing another care plan of questionable value. Firstly, like the experience with the routine care plan, there were examples where they had tried to implement the JCP at the point of relapse, and the service user did not acknowledge the JCP. Secondly, care coordinators believed that the process of the JCP and the actual plan were for service users; some never looked at the completed JCP even though a hard copy was sent to them and a copy was uploaded onto patient records.

Already doing shared decision making

There was a strong commitment to the idea of *joint* care planning amongst clinicians; however, when describing their approach, it was clear that many did not achieve this ideal. Clinicians described identifying a need, making a suggestion, asking for agreement from service users and then recording this. Directing the flow of information in this way could be considered more consultation than SDM. For example,

And if there is anything that I feel needs to go in, I suggest it, I say “what do you think?” And then I say, “the other thing that needs to go in is this” and we go through it. That’s it. I ask them to agree and that’s it. (Female, Social Worker, Focus Group 2)

When I meet the patients, I explain to them what a consultant is. “I am your consultant and am the person who you consult for expert advice. You are in charge.” It is more or less what I tell them. You come to see me and I am your expert. You’re the king in this situation and I am your counsel. I will implore you, at times, to follow my advice like good counsellors would to previous kings and queens. But it is down to you. (Male, Psychiatrist, Interview)

A few psychiatrists acknowledged that encouraging service user engagement in decisions choice is a change from how they were trained and how they have practised previously. For example,

I think this is something pretty new that psychiatrists are coming round to in terms of offering choices and, you know, even when we use, talk about a treatment for that matter, I think we’re coming to a stage now where we offer the treatment and leave it to the service users to make up their minds. (Male, Psychiatrist, interview)

In the above examples, clinicians’ conceptions of SDM often failed to account for the power differential between them and the service user. There were two main areas of difficulty: firstly, their verbal commitment to SDM and advising may be undermined by their interaction style in particular the use of interpersonal pressure such as ‘imploring’; secondly, by identifying needs and suggesting limited options, the clinicians (often unconsciously) may control the discussion and provide little opportunity for disagreement.

Appropriateness of service users’ choices

Another major barrier to SDM as operationalized by the JCP was the prioritization of service users’ choices. Many clinicians described having concerns that service users would make choices that clinicians would not consider to be in the service users’ best interest. For example,

And also, there are things that the service user will want and request and you know it’s not really what they need. You have to find a way, to actually communicate that, get them to understand without actually hurting them or without actually sending a message that you don’t want them to get that, or you don’t want to do it. (Female, Nurse, Focus Group 2)

An opportunity to make an Advance Decision (treatment refusal) was a particular concern for clinicians. Many were concerned that enabling service user choice may, in some circumstances, undermine the service users’ future autonomy. For example,

Whereas it’s often the people who come in with their laminated crisis plan who are the ones you think this is actually being more counter productive in this particular patient’s case because they’re using this explicitly as a way to wield power in this situation. That is fine, because I’m all for patients having power but it’s doing something more than that and it’s allowing them to negotiate both say what diagnosis they want or how they wish services to relate to them. In a way that might from another perspective might seem quite counter productive, both for them and for services. (Male, Psychiatrist, Interview)

In summary, engaging service users in discussions and encouraging service users’ choices was problematic as clinicians were concerned about the potential conflict with clinical beneficence. A few psychiatrists expressed equally strong concerns regarding service user choices, which may be seen to undermine the service user’s autonomy, such as making a choice for increased assistance from services.

Availability of service users’ choices

A further concern was the risk that service users would request treatments or services that clinicians could not provide. A minority of care coordinators questioned whether services are in fact set up to enable service user choice/involvement. For example,

I think to be honest the care plans we had already were more service driven. You know they were a case of, this is a care plan, this is what we

do. Yeah we can ask you what your needs are and what you want to happen, but essentially this is what we do, this is what we can do, and this is what will happen should you ring up. (Male, Nurse, Focus Group 1)

Clinicians were concerned that as the available care, pathways may be quite limited and the JCP process was in fact providing false hope for service users. For example,

You see this is the problem. We're doing the Joint Crisis Plan, but then we're dictating the patient what we can offer. [...] He doesn't really have a choice, if he deteriorates then the only help he will get is through the pathways that is currently being commissioned. If for instance [the SU says] 'if I deteriorate I would like to, err... see the care coordinator straight away', that's not an option. The option is to see the crisis team practitioner, doctor straight away, [...] So in my opinion what were the patients choosing? (Male, Psychiatrist, Interview)

Additionally, clinicians worried that they would not be the clinician dealing with a crisis situation and could therefore not guarantee that the choices made by the service user in their JCP would be honoured.

It's not necessarily you who's there on a Friday night trying to find the bed to do the [...] crisis plan, which then of course, the foundations of the crisis plan are ropery aren't they if you can't actually do what's agreed. Then everybody loses some faith in the point of doing it I suppose. (Male, Psychiatrist, Interview)

The experience of service users

In contrast to the clinicians' views that they were 'already doing SDM' in routine care, many service users described distrusting their clinicians, distrusting themselves and feeling disempowered with regard to making decisions about their care.

There was a perception that clinicians held the expertise and were able to do what they wanted; service users perceived that they had little influence in routine care. For example,

I sort of felt to myself now that you know, well what can I do about it – I can't really change my team. I can't really change their decision, they're

qualified... so it's their decision, I can't really do much about it to be honest. (Male, Service user Focus Group 1)

Most service users described some level of involvement in decisions about their care, but in the majority of cases, they described being informed about choices, rather than involved in decisions. For example, one woman characterized her involvement in decisions as,

We'll see, we're the experts... just keep taking your medication, do what you're told (Female, Service user, Focus Group 2)

A further barrier to SDM was service users distrusting themselves as being capable of engaging in a dialogue with clinicians. For some service users, delusional experiences in the past meant that they regularly doubted their own perspective. Additionally, questioning from clinicians could reinforce this doubt, for example

I have to ask myself whilst [talking to clinicians about treatment decisions] are any of these ideas delusional, are they psychotic? Actually to be honest, once people start talking to you about delusions and psychosis and a lack of insight, you don't half begin to doubt yourself. So yeah, I think I'm probably okay, but I'm having to ... regain my trust I suppose in my own thinking. (Male, Service User, Interview)

The JCP was therefore valued by many service users as they felt that having an external person present during the JCP sessions increased their sense of empowerment and ensured that the clinicians were more reasonable than usual. For example,

Well it was just like, they didn't say "no we can't do that", they said "we'd try and do x..." They were very helpful, they were saying that as the very last resort you will go into hospital... Whereas before my doctor would say to me, well if you sister thinks you're going to go to hospital, we'll put you in (Female, Service user Focus Group 3)

As discussed above, the ideal of SDM and promoting service user choice is something to which many clinicians aspired; however, they described specific barriers as aspects of policy, routine procedures, and concerns about benefi-

cence and responsibility. As the JCP interacted with and exacerbated some of these concerns, many clinicians did not engage with the JCP process – either through not making time for the discussion and not attending meetings or not contributing to discussions. This lack of engagement adversely effected the experience and trust in the JCP for many service users. For example,

I wanted a joint crisis plan cos I thought it might make a difference [...] with regards to how the psychiatrist would approach things if I got sick. Cos I've been sectioned so many times. But I remember, on the day that [the facilitator] came [the psychiatrist] was on the [computer], he was so rude [...] and he was on his [computer] most of the time when [the facilitator] was talking. He had his back turned. (Female, Service User Focus Group 1)

Further, many service users described situations when they unsuccessfully tried to use the plan or limited awareness of the JCP amongst clinicians:

I wasn't at the stage of going in to hospital, but I'd been on a high and they were a little bit worried. And what concerned me was that they didn't have a copy of your crisis plan. (Female, Service User Focus Group 2)

Discussion

The context of ambivalence regarding care planning and questions about the feasibility of service user choice meant that the JCP intervention was met with considerable scepticism by clinicians. Most clinicians believed that the JCP duplicated work and for some, it involved creating another care plan of questionable value. While there was a verbal commitment to the principles of SDM, the majority of clinicians were concerned about the implications of allowing service user's to control the content of their JCP. There were two main concerns, firstly, service users' choices may be in conflict with clinicians' ideas about clinical beneficence; and secondly, the mental health services may not be able to facilitate treatment wishes, either due to limited resources or lack of continuity

between routine staff and those who would be involved in crisis care. Furthermore, many clinicians were not aware that the manner in which they routinely interact with service users (in particular in the way they provided recommendations) may not facilitate the equal exchange of information required for SDM. In this context, service users felt unable to influence treatment decisions, and years of failed attempts to do so left them feeling disempowered, and for some, unable to engage in dialogue with clinicians. These findings are consistent with previous research which has suggested a number of barriers to SDM in mental health care, including providing incomplete information to service users²⁷, nurses lacking sufficient time²⁸, organizational and contextual influences including a lack of structural support for such initiatives^{29,30}, and deficiencies in psychiatrists' communication skills, in particular the need to remain in control.^{31,32} Quirk *et al.*³³ conversation analysis of psychiatric consultations also illustrates how psychiatrists may influence choices in a way that appears to fulfil the SDM ethos but is actually an exertion of control. This is consistent with the findings of our study, and also other analyses from the CRIMSON trial which indicate the prioritization of role enactments associated with clinician accountability²², undermine efforts to interact with service users in a more empowering and person-centred fashion.

Concerns about the clinical utility of care planning and service user choice were a significant barrier to the successful implementation of the JCP intervention. As described elsewhere²³ the mechanism of action of the JCP for service users appears to be the demonstration of respect and promise of consistency in a crisis situation from clinicians; resulting in increased service user empowerment. However, for such positive outcomes to be achieved, clinicians needed to engage constructively in the discussion. The data in the current study suggest that the evidence for the JCP that was presented to teams in initial consultations was not sufficiently persuasive; rather most clinicians had reservations about the process and responded with a lack of

engagement, thus undermining the effect of the intervention, contributing to a lack of impact on the primary outcome.¹⁹

Street *et al.*³⁴ ecological model of communication provides a framework through which to understand these findings. Street's model recognizes that 'in any medical encounter, a number of processes affect the way physicians and patients communicate and perceive one another' (p587). The model requires consideration of both each individual in the interaction and their individual and professional contexts which affect their behaviour. The model suggests that any intervention which focuses on one stakeholder group will be unlikely to succeed as it does not consider the impact of the other stakeholder group. That is, the 'scene must be set' for each stakeholder in the interaction. The JCP protocol 'set the scene' in this way for service users, with the pre-meeting which introduces the JCP and provides them with sufficient time for the service user to consider options and generate a plan for the meeting. Additionally, the JCP facilitator's role was to ensure that service users were supported and empowered to engage in dialogue with clinicians. By contrast, the scene was not set for clinicians. They were informed about the study design at an introductory meeting with researchers, but many received no further preparation for the JCP meeting. Some of the barriers described in this study may have been addressed had clinicians had training or a more detailed introduction to the rationale and the method through which the JCP was obtained. Such dual scene setting is being used in the VOICE trial³⁵ which aims to improve patient-centred communication in cancer care. The trial plans to provide brief initial training in communication to both clinicians and patients to facilitate SDM.

It is clear from this analysis that the delivery of the JCP intervention 'as intended' was partially prevented by contextual barriers such as existing attitudes to the CPA and care planning, ambiguous treatment goals and conflicting role requirements. In this context, the JCP altered routine behaviours in some instances,

but the organizational culture ultimately determined its effect. Organizational change programs, in addition to the implementation of the intervention may therefore be indicated and there is some research evidence for the effect of such a strategy.³⁶

In summary, while the JCP intervention partially succeeded in improving service users' appraisals of the therapeutic relationship and empowering them to engage in decision making with clinicians, the intervention was ultimately undermined by a lack of true engagement of clinicians. The potential benefits of the JCP were not sufficient to assuage clinicians' concerns about accountability, and the lack of clear demonstration and definition of the SDM as part of the JCP meant that clinicians approached the intervention thinking it required little effort or consideration of their behaviour. Future implementation or studies of SDM, like JCPs, must 'set the scene' with clinicians more deliberately by training clinicians in SDM, providing evidence of the 'reasonableness' of service users choices³⁷ and creating an organizational commitment to the implementation of the content of JCPs.

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