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From Admission to Discharge in Mental Health Services: A Qualitative Analysis of Service User Involvement.

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From Admission to Discharge in Mental Health Services: A Qualitative Analysis of Service User Involvement.

Abstract

Background

User involvement and recovery are now widely used terms within the mental health policy, research and practice discourse. However, there is a question mark about the impact these ideas have in everyday practice. Of interest is the degree of involvement in key transitions of care. In particular admission to and discharge from acute inpatient mental health wards.

Objective

To explore the nature of service user involvement in the admission and discharge process into and out of acute inpatient mental health care.

Design

A qualitative study using focus groups.

Setting and Participants

One acute, inpatient mental health ward was the focus of the study. Seven uni-professional focus group interviews were conducted with ward staff, community staff and service users (total number of participants = 52). Conventional, thematic qualitative techniques were used to analyse the data.

Results

The data analysed and presented in this article relates to the loss of the service user voice at the key transition points into and out of acute inpatient care. Due to the lack of resources (inpatient beds and community care follow up) the role service users could play was diminished. In their narratives clinical staff associated the person with the process and used language which dehumanised the individual.

Conclusion

Service users experience numerous care transitions into and out of hospital. As there is the potential for these encounters to have a lasting negative effect, the importance of ensuring service users have a voice in what is happening to them is crucial.

Introduction

User involvement has become a central tenant of the design, provision and evaluation of mental health services. Understanding and recognising the importance of an individual's experience of mental distress from their own perspective, has gained increasing prominence in the past twenty years [1,2]. Closely linked to both the consumer/survivor movement and the concept of recovery, the mantra "no decision about me without me" has become common within the policy discourse [3].

At its core, the user movement is based on ideas relating to self-help, empowerment and advocacy [2] and it provides a challenge to the traditional notions of professional power and expertise [4]. Shepherd et al. [2] argue that these concepts are not new in themselves and have their roots in the American civil rights movements of the 1960s and 1970s. However, Frese and Davis [4] argue that the history of user involvement can be traced back even further to 1845 in the UK when the Alleged Lunatics Friend Society was established and to the period

immediately following the civil war in the USA (when the anti-insane asylum society was set up).

Like the concept of user involvement, Shepherd et al. [2] suggest that "recovery is an idea whose time has come" as it incorporates five current trends in mental health. Namely, social inclusion, more responsive services matched to the needs of people, conceptual changes about the nature of mental health problems, an emphasis on individual rather than collective solutions and self-management [5]. One of the architects of the recovery movement, Anthony (1993: 527) [6] argues that:

> *"recovery is described as a deeply personal, unique process of changing ones attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness."*

Empirical studies such as Corrigan et al., Harding et al. and Perry et al. [7,8,9] provide evidence for some of the underpinning ideas of recovery and challenge the view first articulated by Kraeplin [10] that psychosis has an inevitable downward and deteriorating course. However, the concept is not without its critics [11]. The term may be misunderstood as being synonymous with "cure" and therefore it is perceived to be impossible for people with ongoing mental health problems to achieve recovery [12]. Professionals may also perceive maintenance and recovery to be the same thing [13].

Despite user involvement and recovery being in the ascendency in local and national mental health policy, it has been questioned whether these ideals have led to more collaborative ways of working and shared decision making in the practice setting [14]. It is suggested that service users with mental health problems are more likely to want involvement in decision making in comparison to those with general medical conditions [15]. Peer led initiatives such as Wellness Recovery Action Plans (WRAP) have demonstrated some positive outcomes [16]. However, when initiatives have focused on collaborative planning and decision making between professionals and service users, such as facilitated joint crisis plans, limited evidence of effectiveness has been found [17]. Like many healthcare practice innovations, it could be argued that a gap exists between what is espoused at the policy level or in the research literature (i.e. user involvement across all strata of mental healthcare) and what happens in everyday care situations.

Waring et al.[18] argue that care transitions involve a multitude of health and social care professionals working within and across different organisational boundaries. Taken within this context the movement of service users into and out of acute inpatient mental health wards is particularly complex, given the potential for high emotion and coercive practice [19]. The number of people admitted to a psychiatric hospital on a compulsory basis in England and Wales per head of population increased by over 50% in the decade to 1995 and then rose by 13% from 26, 632 to 30,092 during the decade to 2010-11 [20]. Given that most service users find involuntary treatment a negative experience and describe it as unjustified even 12 months later [21], mechanisms for service user involvement appear to be crucial in this process.

The transition out of inpatient wards (discharge) back to the community is also challenging. Whereas strategies to reduce hospital admissions have received a large amount of research attention, including innovations for more collaborative or user focused approaches (some of which are mentioned above), the same cannot be said in relation to hospital discharge in mental health. The first seven days after discharge from hospital have been identified as a "critical period" of post-discharge care when people with mental health problems are at increased risk of suicide [22]. Although suicide is a devastating consequence it is also relatively rare. In contrast, service users and their carers report a range of more mundane care problems that arise from discharge planning when their views have not been taken into account. Anecdotal reports include descriptions of medication being unavailable for collection and disruptions to social security payments.

In summary, user involvement and the concept of recovery are widely referred to within the policy, research and practice discourses. However, the extent to which this has "trickled down" to make an impact on individual practice and care experiences is unclear. In particular the points of transfer of care from community to inpatient and back to community are areas where the involvement of service users appears crucial and yet under reported. Therefore this study aimed to explore the nature of service user involvement at these key transition points.

Method

Study Design

The data reported in this paper originates from a study that focused on knowledge sharing at the points of transition of care into and out of inpatient mental health services[23]. Using an improvement science methodology [23, 24], it aimed to create a joint narrative with stakeholders (including those with lived experience) of the barriers and facilitators to knowledge sharing. The study also aimed to explore possible innovations which could be implemented to aid this process. This was a single site study which focused on one acute inpatient mental health ward and the teams and practitioners who worked both within that environment and also who supported service users prior to admission and following discharge to the community. Ethical approval for the study was granted and NHS research governance procedures were followed (for details see acknowledgments).

Given the complex interactions between multiple stakeholders and the multi-faceted nature of the phenomenon of study, qualitative focus groups were selected as the method of choice. Focus group interviews allow for the collection of richer data as the individuals involved interact with each other as well as the interviewer to test and develop their ideas, views and opinions [25]. It is suggested however, that the strength of the method is also its largest weakness. The interactive nature of the focus group interview can lead to some individuals becoming dominant and the possibility of hierarchal relationships being relocated from society or the organisation into the group setting [26]. Within mental healthcare, power is a crucial aspect which needs to be considered (for example practitioners can detain service users in hospital against their will). To attempt to redress some of these dynamics the focus groups were organised to be uni-professional (for example mental health nurses), team (for example community team staff) or service user specific.

Recruitment, Sampling and Participants

Due to the single site design, a purposive sampling strategy was used to identify groups and individual stakeholders who had experience of the phenomenon of study. These were: consultant psychiatrists (inpatient and community), junior (inpatient based) medical staff, inpatient mental health nurses (including nurses working in the local 136 suite[1]), health care assistants, community mental health services and service users. In total seven focus groups were conducted and 52 participants were involved in the study.

Participants were recruited by email, phone or personal approach from a member of the research team. Full information was provided both verbally and in writing to those interested in taking part. Informed consent was obtained from all individuals. Participants were made aware that they could withdraw their consent to take part in the study at any time. The nature of a focus group means that it is not possible to assure individuals of confidentiality. However, those who took part were reassured that the raw data would be anonymised as soon as practicable after the focus group had taken place.

Data Collection

[1] The 136 suite is where the police take service users who they have come into contact with for a short period of assessment prior to being admitted to an inpatient ward or discharged back to the community.

Focus groups were conducted in winter 2013/14 in locations and at times convenient for the participants. They lasted for approximately 60 minutes and were audio recorded and transcribed verbatim. Two members of the research team attended each focus group; one acted as the group facilitator whilst the other made detailed field notes to supplement the audio recording.

A semi-structured topic guide (see Figure One) was used to steer the focus group interview and was informed by themes from the literature and the experiences of members of the research team from working in mental health services. A semi-structured approach allowed for a "conversation with purpose" to occur [27] but also had flexibility so that participants could discuss issues which may be particularly relevant to their experiences. Immediately prior to the start of the focus groups, the process was explained to participants. It was reiterated that there were no right or wrong answers and all opinions were valued even if individuals disagreed with each other. After the main group discussion, participants were also given the opportunity to stay behind and speak with the researchers individually if they wished to do so; no one took advantage of this.

Figure One: Subject Areas Considered in the Focus Group Interviews

Areas considered in relation care transitions into hospital:

- What leads to an admission
- Who is involved – including the role of the service user
- How long does it take
- Good practice examples – what is a good admission
- Challenges with the process
- What can go wrong
- What would make the process better
- How, when and by whom is knowledge and information gained, shared and stored

Areas considered in relation to care transitions out of hospital:

- When does the discharge planning process start
- Who is involved – including the role of the service user
- How long does it take – including delays to the discharge process and its effects
- Good practice examples – what is a good discharge
- Challenges with the process
- What can go wrong
- What would make the process better
- How, when and by whom is knowledge and information gained, shared and stored

Analysis

Prior to commencing data analysis the transcripts were checked for accuracy by comparing them to the original recordings. Any additional details from the field notes were also added to the transcripts. Familiarity with the data was ensured by reading the transcripts multiple times. Conventional qualitative methods were used to identify analytical patterns (or themes) across and within the transcripts [28]. Analysing data thematically, although time consuming, provides a concise and coherent account of the story which it tells [29]. After obtaining an understanding of the whole narrative, meaning units were identified within the text [30]. These were then grouped together, without losing the original context in which the statements were made. These grouped units were consolidated into codes and the similarities and differences between them compared. A further consolidation process led to the development of tentative themes which explained the data. Two members of the research team analysed the data individually and then compared the themes which they had identified. A high level of

consistency was found between the two researchers in terms of the themes reported and the relevance of them to the research question. These findings were then discussed with the wider research team for verification purposes. The Nvivo computer programme was used to manage the analysis process.

This article presents and discusses the theme "the lost service user voice". Data in relation to the other themes identified as part of the project are reported elsewhere.

Results

Participants were asked in the focus groups to discuss and reflect on their experiences of knowledge sharing. Of particular interest were the care transition points of going into and out of acute inpatient mental health services. For all the participants (clinicians and service users) these transitions were chaotic, stressful and emotionally charged. Overall, clinical staff expressed a desire to provide the best care possible in these circumstances. Service users recognised the organisational and system constraints which impacted on how care was given and received. However, despite this desire and understanding, the service user voice was lost within the narrative of care.

Explanatory, direct quotations from the focus group transcripts are used to illustrate the analysis presented. To maintain the anonymity of the participants, the quotes are labelled only as being from inpatient, community or service user. Any identifiable details within the excerpts have been removed and replaced with *X.* Comments in square brackets have been added by the authors to aid understanding for the reader and ellipses denote removed sections.

<u>The Lost Service User Voice</u>

The narratives from all the focus groups demonstrate a fraught and competitive environment at the transition points into and out of inpatient care. Inpatient beds are scarce resources and accessing them is extremely challenging. Given this scarcity, service users had a very limited voice in the decision making process related to their admission and discharge from hospital. They recognised that at times they did pose a risk to either themselves or other people and needed to be in hospital against their will. In these situations service users stated that they valued open communication:

> *"But you see sometimes they are right aren't they because we are a danger to ourselves and we're a danger to other people… We could go out in front of traffic and get ourselves killed… but it would be nice sometimes for it just to be dead straight. If someone could say look you're a danger to yourself and you're a danger to others. And maybe we've made an assessment and this is why"* (service user).

However, if service users agreed to admission or identified that a period of respite in hospital would be helpful, facilitating this was difficult. Community staff reported that "informal" admissions (where the service user requests or agrees to go into hospital voluntarily rather than being compelled by law) were virtually impossible unless there was personal contact with the inpatient consultant and you were prepared to do some "wheeling and dealing":

> *"I think it's increasingly difficult to get a bed and especially if you have a patient who is agreeing to come in for an informal bed, it's nigh on impossible to get them an informal bed…We had one person in didn't we informally. I got one person in informally but that depended on a bit of wheeling and dealing with one of the other consultants"* (community team).

As well as being competitive, the environment and culture at these transition points was also conflictual and chaotic. Shared ownership of the "problem" was identified as being non-existent and clinical knowledge was devalued. Community staff reported that they felt their experience of working with an individual was dismissed when inpatient staff reported that they were not psychotic but personality disordered or under the influence of illicit substances:

"So you'd get a patient like who've I've had before whose paranoid schizophrenia, they go into the ward and get re-diagnosed with something completely different, either a personality disorder or psychotic depression… there is no continuity of care. Despite the fact that you've got one consultant quite sure of what is going on and that affects how they decide to work with that person, it changes the kind of care that they are getting. More often than not they get discharged quite quickly because they are not psychotic at all, they have a personality disorder so they have to be discharged" (community team).

This quote raises an interesting point as to whether some service user voices are more valued and valid then others. For example within one of the inpatient transcripts a participant refers to "they're all bloody PD". This was explained by one participant as being a mechanism for being able to emotionally shut off from these individuals:

"It's like PD [Personality Disorder] you know you tick the box…to that so you don't have to care for them. Emotionally you don't have to think about them afterwards you can just forget about them" (community team).

Service users also identified that some people were more likely to get lost within the system. Rather than being based on diagnosis, they suggested that it was those who were quiet and posed no challenge. Service users suggested that to achieve their goals they needed to be persistent and constantly ask for information:

"I think one of the problems X for you and I'll be honest is that you come over as articulate and able to function… and I know you have considerable difficulties but for them you don't cause a huge fuss…You don't kick off big time" (service user).

The culture of care at these transition points was characterised by who had the power and control of the resources required. At admission this was linked to the availability of inpatient beds. At discharge, it was the availability of community staff which was perceived to be the limiting factor. Within this context, service users reported that their expertise in knowing their own mental health and identifying their needs was lost. In relation to his discharge from hospital, one service user described how his perception of health and illness was secondary to the need to free up bed space:

"I was pulled in for what I thought was routine psychiatric appointment with Dr X and I was told 'I want to send you home today'. Out of nowhere… so I didn't take it well. I didn't feel ready to go out… He said he was going to be honest because I deserved it. He had pressure from above to free the beds up and I said to him 'so you don't think I am well enough to go home but it's just you need a few beds' and so I was not very happy" (service user).

It was not just service users who identified this as an issue, staff were aware that increasingly they had to discharge people when they were not ready or did not have the required aftercare to support them in the community:

"We're in a position now that we're having to make some very difficult decisions and discharging people into circumstances that years ago we wouldn't have dreamed of. So we are discharging people without allocated care coordinators with just crisis as a seven day follow up… we've had a couple of incidences where we've had to discharge people to the pavement with no accommodation…And I think as X, I feel very uncomfortable but we're having to do that increasingly more" (inpatient team).

The language participants used to describe the care transitions emphasised that the service user voice was missing. The person and the processes such as referral to other agencies were often perceived to be one and the same. Therefore the narrative was dominated by the word "it". "It" was something to be "picked up and run with", something "which had to be dealt with" or "handed over verbally". Adjectives such as "being bounced from one pathway to the next", "being dumped back in the home situation" or "shipping them out" described the

movement of service users throughout the mental health care system. In this context, service users are perceived as objects to be passed from one service to the next. However, all the participants identified that it was the system that was leading to this situation occurring rather than a deliberate motivation on the part of an individual to exclude or dehumanise service users:

> "*We've probably been quite critical, you've asked us for our opinions really which we have given you our opinions and recognise that they do work hard but they do try very hard with people and sometimes I think it is the systems rather than the people… that let the whole thing down"* (community team).

One participant took this further and stated that the system had removed the compassion from mental health care:

> *"We all come to this job to help people and it is the system that stops us from doing that, heaven help you if you fill out a referral form wrong… the system has removed compassion from care"* (inpatient team).

Service users were also aware of the constraints and pressures staff were working under:

> *"I'm not here to in anyway…defend the system or anything else but actually it is quite hard for them. If you look at the number of staff on and the number of patients actually on the ward and you think of some of those individuals and how much time they take up, I mean there are some very unwell people on that ward"* (service user).

Discussion

This study aimed to explore the nature of service user involvement at the transition points of admission and discharge to an acute inpatient mental health ward. Analysis of the data collected found that despite the current rhetoric of recovery and involvement in policy and practice discourses the service user voice was lost at these key care delivery points. This was evident in the language used to describe what happened during care transitions and also the culture of the teams and organisations involved. Whilst it was recognised that clinicians did not come to mental health care with the intention of working in this way, the current organisational context had removed the compassion from clinicians work.

The narratives described in this study identify that inpatient beds are a precious and restricted resource. Tyrer [31] identifies that there has been a dramatic reduction in the number of beds available from the maximum in 1954 (155,000) to 27,000 in 2008. As the number of beds has reduced this has had a "concentrating effect" whereby the threshold for admission has increased with more service users being subjected to legal restrictions and detained in hospital against their will [32]. This concentrating effect not only impacts on the inpatient environment (potentially making it a more volatile setting) but also on the quality of care in the community [33]. Quirk and Lelliott [32] identify that community services rely on easy access to inpatient beds for respite periods and to manage crisis situations. However, it should be noted that the availability of beds is not the only limited resource highlighted within this study. For the care transition from inpatient ward to community to be facilitated there also needed to be an adequate supply of community staff. These findings indicate, therefore, that the more restricted the resources the increased likelihood that the service user voice will be lost.

At the point of admission to hospital service users identified that they may pose a risk to themselves or others and may need professionals to make decisions on their behalf. However, they were also clear that when they were able to engage with decision making they wanted their voice heard. Initiatives such as WRAP plans [16] and crisis plans [17] were originally conceived to allow service users to express their preferences during a period of mental wellness so that the care plan acts as their voice and expresses their views during a crisis when they are unable to do so. However, given the current context of mental health care provision the implementation of this may be problematic. For example clinicians within this

study noted that should an individual request admission to hospital it was virtually impossible to arrange.

Data from the study also identified that some voices were more likely to be heard than others. Studies such as Lauber et al. [34] demonstrate that service users can experience stigma and discrimination from the negative attitudes of mental health staff. Within the literature particular prominence is given to those with co-morbid substance misuse issues and those diagnosed with Personality Disorder. More negative attitudes are expressed when individuals are perceived to be "not ill" and therefore wasting precious resources or being in some way responsible for their predicament [35]. As well as differential experiences based on diagnosis those service users who were deemed to be quiet were more likely to get lost at care transition points. The service user narrative demonstrates that they were aware of these issues and took active steps to increase the chances that their voices were heard. For example persistently asking staff questions and making demands of them. Just as Quirk et al. [36] found in relation to managing risk, the data from this study demonstrates that service users attempt to take active steps to be heard rather than be passive recipients of staff intervention.

Goffman [37] conceptualised asylums as "total institutions", namely an isolated and enclosed social system with the purpose of controlling the behaviour of individuals who live within it. Although it has been questioned whether the totality of asylums ever existed [38], the "membrane" between inpatient and community care is certainly more "permeable" today [39]. Data from this study suggests that service users experience numerous transitions of care from community to inpatient services (and back again) during their "psychiatric career". For practitioners, care transitions at the permeable membrane involve negotiation, time and the investment of emotional energy. The findings from this study identify that these transitions are "flash points" for conflict between services. As the expectation for shorter admissions gains traction [28] the likelihood is that service users may experience more transitions in their care. Developing interventions and tools which ensure that their voice is heard and are easily implementable in the current context appears to be crucial.

Strengths and Limitations of the Study

This study has illuminated some interesting and pertinent issues relating to service user involvement at the interface of community and inpatient mental health care. However, no research method is perfect and the contribution to knowledge which is made needs to be considered in the context of the methodological strengths and limitations.

Basing the study on a single research site (the inpatient ward) and the clinicians and service users who either work in it or interface with it allowed for an in depth exploration of involvement in the admission and discharge process. However, this approach may also limit the applicability and transferability of the findings to other settings. In particular the way mental health care is organised in respect of separate inpatient and community teams, as in this case, has been widely adopted in England following the *New Ways of Working* report [40] but it is not universal. Similarly, there are variations in the organisation and provision of mental health care internationally. This does not mean that the findings are completely irrelevant; however consideration may need to be given when applying them to other contexts.

As well as this purposive approach, a degree of self-selection of the sample also occurred. For example it was not possible to interview every individual who interfaced with the research site. Those who came forward to take part in the focus groups may have had particularly strong views (positive or negative) and this may have skewed the data. Only those participants who were fluent in the English language could be included in the study. It may be that service users who are non- English speakers had different experiences to those described. A further limitation is the lack of involvement of carers in the study as they may have particular issues and concerns relating to care transitions into and out of inpatient settings.

The interactive nature of focus groups is both a strength and limitation of the method. As identified previously in this article, a group setting allows participants to generate and discuss ideas between themselves. However, it is possible that the responses obtained are not the same as those which would have been generated from a one to one interview. For example individuals may feel inhibited from expressing their views if these are different to the majority. Focus group interviews only provide a snapshot of experiences at a given a time point. It is not clear how consistent these views are and whether they have been influenced (positively or negatively) by recent experiences.

Conclusion

Service user involvement is a central tenant of mental health practice, policy and research. Closely related to the concept of recovery it values expertise by experience on a par with professional knowledge. However, this study has highlighted how at key transition points in care delivery the service user voice can be lost. The current context of care is dominated by restricted resources. Within this climate innovative solutions are needed to make sure that service users are able to influence the delivery of their care at the key points of admission and discharge to hospital.

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