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Please cite this publication as follows:

Sedgwick, R., Duff, A., Lines, S., Akenzua, A. and Jones, F. W. (2019) Family-inclusive practice in a psychiatric intensive care unit. *BJPsych Bulletin*. pp. 1-5. ISSN 2056-4708.

Link to official URL (if available):

<https://doi.org/10.1192/bjb.2019.11>

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Family Inclusive Practice in a Psychiatric Intensive Care Unit

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Abstract

Aims and Method: The National Institute for Health and Care Excellence recommends involving the families of service users admitted to psychiatric hospital care, without specific guidance how to do it. To improve family involvement on a NHS psychiatric intensive care unit, a relatives and carers clinic was set-up. Fifty family members attended and completed questionnaires. Nine went on to take part in interviews; which were analysed using thematic analysis.

Results: Families felt more informed and the increased access to information useful. They felt that the process showed respect for them and their family member and that their contribution was valued. Running throughout the interviews was the contrast with previous experiences, families reported feeling heard and understood and attributed this in part to timing and environment.

Clinical implications: The clinic was viewed positively by families and met the Trust's commitment to including carers, as well as national guidance which suggests it should be part of routine practice.

Introduction

Patients admitted to a Psychiatric Intensive Care Unit (PICU) are nearly always detained under the Mental Health Act¹. It is a recommendation of the Act that carers and family members are involved in the care of those being detained. 'Family intervention' can range from systemic family therapy² to short conversations with nurses³. Common practice in psychiatric inpatient settings is to invite relatives to attend ward rounds during normal working hours. Many tasks are undertaken within the time allocated to ward rounds and it may therefore be difficult to meaningfully engage families within ward round setting. The National Audit of Schizophrenia (NAS)⁴ results indicate that only 9% of trusts surveyed had a majority of carers who reported feeling 'very or somewhat satisfied' with the information and support they were receiving. This highlights a gap in many NHS Trusts in providing family centred approaches to care. Key problems for families seem to be uncertainty around pathways of care and prognosis⁵. In addition, due to work and other commitments, families may be more likely to attend at times when fewer informed clinicians are available⁶. This service evaluation assesses a trial of a consultant led, out-of-hours, family clinic, run in a South London PICU, which was designed to address some of these problems. The service was evaluated using both self-report questionnaires and semi structured interviews to gain insight into whether this innovative way of involving families provided any benefit.

Method

Design and materials

A sequential explanatory mixed methods design⁷ was used, which is a two phase data collection and analysis method. In this study, the first stage was a questionnaire evaluating the service. The questionnaire consisted of 8 items, 5 of which had categorical responses and 3 of which had free text responses (these questions can be seen in Appendix A). This questionnaire was adapted from a previously developed carer group evaluation questionnaire already used in the trust.

The second stage was semi structured interviews. The interview schedule was developed to encourage more nuanced responses than had been possible with the questionnaire.

Examples of these questions are: “What was the experience of the family clinic like for you?” and “Did you feel that anything changed as a result of this session?”. The full interview schedule can be seen in Appendix B.

The host Trust’s Research & Development department approved this project as it was originally part of a quality improvement initiative. All participants were provided with written information about the purpose and nature of the study and signed consent forms prior to participating.

Family Clinic

Two clinics a week were held on two weeknights from 5pm to 7pm. Families could select slots, ranging from 30 minutes to 60 minutes. Most families attended for approximately forty minutes. Where possible, sessions were held outside the PICU, in a quiet room. The families or carers of all new patients were offered a session within the first week of admission. The majority of clinics were facilitated solely by the PICU consultant psychiatrist, but other members of the multidisciplinary team joined the clinic if requested by the family, or there was indication to do so.

Relative and carer involvement in the family clinics was discussed with all patients and where possible patients themselves attended sessions. If patients did not consent to their families attending a family clinic their capacity to make this decision was assessed by the clinical team, along with the needs of other elements of their care, such as the need for the family to be consulted as nearest relative under the Mental Health Act. If patients were not able, or willing, to participate in the family clinic the session was fed back and discussed with them after the session to ensure they remained involved in their care.

Participants and Procedure

Family clinics became routine practice on the ward and therefore families and carers of all newly admitted patients to the PICU were invited to attend a family clinic with the consultant psychiatrist after the initiative was commenced. The first 50 clinic participants completed the anonymised questionnaire. Demographic information on those completing the questionnaire was not collected to maximise engagement and reassure participants that the process would remain anonymous.

For the semi-structured interview participant selection, inclusion criteria were: relatives or carers who had attended at least one family clinic and completed a questionnaire as part of the first phase of the study. The only exclusion criterion was: the service user being an inpatient on the PICU at the time of invitation to the interview. An attempt was made by the research team to contact, by phone, all relatives or carers who met the inclusion criteria and for who up to date contact details were available. Fourteen relatives and/or carers who completed the initial questionnaire consented to the semi-structured interview and 9 of those who consented were available to attend an interview.

Analysis

Quantitative data were analysed using descriptive statistics, so as to provide summaries of the responses, these were mainly in the form of percentages. The descriptive statistics and the free text responses were used to inform the interview schedule. To analyse the interviews, the Braun and Clark⁸ method of thematic analysis was employed as it provides a structured, yet flexible approach to analysing rich data.

The qualitative data were transcribed by the first listed author (AD) and an administrator. Following this, the initial steps of thematic analysis, of familiarising oneself with data, generating initial codes and searching for themes were completed by AD. Themes were developed inductively from the data. In order to ensure consistency and transparency in the theme development regular analysis meetings were held with authors RS and FJ to name, define and review themes. All authors were then asked to review and give feedback on the final theme names and revisions were made accordingly.

Results

Quantitative

Questionnaire responses from the first 50 family members or carers who attended a family clinic were analysed. 100% of families found the opportunity to meet with the consultant psychiatrist 'very useful' as opposed to 'moderately' or 'not useful'. 96% of respondents found the timing of the sessions (5-7pm) convenient and 98% reported that the length (40 minutes) was about right. 84% were happy to meet with just the consultant psychiatrist.

16% would have liked another professional present, of which: 10% would have liked a psychologist, 4% a nurse and 2% an occupational therapist. Most families attended two family clinic sessions, although attendance at the clinic per family or carer ranged from one to seven sessions.

Qualitative

The thematic analysis confirmed the importance that participants placed on the family clinic and expanded on what elements they particularly valued. Three core themes were identified in the thematic analysis of the interview transcripts (Table 1).

Table 1. Themes from thematic analysis of interviews

	Themes
1.	Improved understanding
2.	Valuing the contribution from families
3.	A different experience: a space to share and be heard

Improved understanding

'Improved understanding' was one of the key themes from the interviews. Family members spoke about finding the family clinics useful as they were able to gain an improved understanding of their family member's difficulties, what their diagnosis meant and what the treatments might be. For example:

"He (Dr.) makes it educative for those who do not understand what the treatment is about. He explains it in very simple terms so that everyone can understand and the roles that family members can play in helping the sick." Family 8

"The only thing that changed was that we knew what was going on whereas before we had no idea." Family 4

Family members also commented about the benefits of this improved understanding. Removing some of the uncertainty around diagnosis and treatment made them feel better able to support and understand their family member and provided some relief.

“It’s a huge burden off our shoulders in terms of not knowing, feeling there is so much uncertainty” Family 5

Valuing the contribution from families

“I had the opportunity to make suggestions or just to have ideas and share” Family 3

Family members commented on their contribution being heard and valued. They felt that through the family clinic they received the message that they had an important role to play in the care of their family member, both as a source of social and emotional support but also on a practical level as an advocate or source of information.

“Dr X made it very simple so that it is an illness just like any other illness and that family support is extremely crucial” Family 8

“My husband had had similar episodes prior to this and I don’t think the hospital had been able to retrieve the archived records of past treatment so I think it was helpful that we were able to tell Dr X about these.” Family 2

Five families commented on how important it was that the family have an opportunity to input into the patient’s care because

“In a case like this you need all sides of the story because everyone sees it in a different way” (Family 3).

While it seemed as though having their input prioritised was a novel experience for families, it was one that they considered important and showed respect for their knowledge and feelings.

“So I realised that here they were really caring about the family and were asking us how we feel and were involving us a lot in the treatment. They were telling us that our involvement would have been very important for the patient and for his recovery which I’ve never heard talked about before.” Family 9

“He was considerate and the other guys (Drs) don’t really take into account the information from relatives and carers. They have a ‘we know everything kind of attitude’ which I think just goes against the grain.” Family 1

A different experience: a space to share and be heard

Families commented on the difference of the experience, the environment, interaction with professionals and timing of the sessions. All family members reported finding it easier to ask questions and to have their views heard in the family clinic; which had not been their experience of other forums, such as ward rounds. In ward rounds, they had felt that there were too many people to have space or confidence to express themselves and that their concerns were not given priority:

“Up until then our experience of family meeting time was the ward round and I didn’t find much value in that as there was no actual discussion taking place...there was no possibility of talking or expressing our concerns and even if we expressed our concerns they weren’t met with suggestions for improvement or explanations that sort of thing and it is very important that the family are given that kind of insight.”

Family 5

Participants felt that their time was respected in this clinic. They appreciated the out of hours timing, which was particularly important for those who were employed full time. However, a number commented that they would make time for the family clinic at whatever time it was at because they felt that it was so important. They felt that the clinic was time set aside for their concerns and was not set up simply to meet the agenda of professionals.

“The family meetings were dedicated time whereas ward round isn’t, it’s dedicated to other things, understandably.” Family 2

The clinics were based off the ward which seemed to be something that families valued and the more informal and private environment allowed them to relax during the clinic.

“...being away from that kind of intensity makes a big difference.” Family 5

Discussion

National Institute for Health and Care Excellence guidance states that professionals should work collaboratively with carers, share information and acknowledge the impact for both the patient and their family.⁹ This study sought to evaluate a clinic for psychiatric in-patients' families and carers. The findings were very encouraging, all 50 questionnaire respondents reported finding it 'very useful'. Although 100% approval is unusual, it is in line with other studies that show that family interventions that improve communication have high satisfaction rates¹⁰. Participants felt more informed and found the increased access to information helpful, something which seemed to have been missing from their previous experiences. They also felt that the process showed respect for them and the patient.

The findings of this evaluation fit with a recent document on best practice in mental health¹¹, that highlights the importance of a 'Triangle of care'; namely a therapeutic alliance between service user, carer and professional. This seems particularly important on a PICU where significant restrictions are placed upon patients. Families seemed to feel that there was reciprocity and shared contribution to the development of this alliance; as one family participant put it: *"With the doctor there is a mutual; he asked me questions, I asked him questions, so that is why I preferred it"*. Family 9

The family clinic does represent a significant investment of a limited resource, namely the consultant psychiatrist's time. However, we would argue that this investment is worthwhile, given the highly positive findings of the evaluation and the benefits of family involvement evident from the research literature. For example, other studies suggest that family involvement reduces admissions, helps prevent relapse, and improves adherence with medication¹². Moreover, it is linked to shorter stays in hospital¹³ and reductions in unnatural mortality¹⁴. And, family intervention has been shown to improve quality of life and reduce psychological distress in carers of those with severe mental illness¹⁵: *"...when someone suffers from mental health, I think the whole family suffers"*. Family 3. This service evaluation would suggest that where effort is made to engage meaningfully with families they are keen to participate in the process.

Family involvement benefits patients and carers, and despite the initial outlay, makes economic sense for the NHS as it can prevent service users reaching crisis point. If hospital admission is required, family involvement can facilitate better risk management and safer

discharge. While in this study, there was no objective measure of speed of discharge, families commented on the importance of contributing to a plan for treatment and discharge. They found being informed important and commented on feeling more able to help because of the process. However, the National Audit on Schizophrenia suggests that many carers do not receive the information and support they need⁴. Studies looking at why families are not included in care have found a number of reasons: time constraints¹⁶, staff feeling worried about saying the wrong thing¹⁷, staff not seeing it as part of their role to provide a service for carers¹⁸ and patients not giving or being able to give consent¹⁷. We hope that the family clinic evaluated in this paper provides evidence of how these barriers can be meaningfully addressed and negotiated. Moreover, this evaluation and other literature³ suggest that family interventions need not necessarily be lengthy or complicated to be associated with beneficial effects.

Implications for services

Differences were highlighted between the family clinic and the practice of ward rounds. Families had the impression that the family clinic was a place where their family needs were a priority, contrary to ward rounds which were seen as a place where the needs of professionals were addressed. Arguably the former approach to family involvement is more person-centred, in line with NICE guideline CG136¹⁹. Also, NICE guideline CG178 highlights that involving families and significant others is of particular importance during periods of acute illness.⁹

Where family involvement has been attempted in the past, it has often been in nurse or psychology led services^{16, 10}. We found no previous literature describing examples of psychiatrist led family clinics. However, the results of our evaluation showed that in this acute setting, families especially valued the input of the consultant psychiatrist. This seems likely to be because of the role that consultant psychiatrists often hold in this setting and their level of experience and expertise.

Confidentiality can act as a barrier to professionals sharing information with families²⁰. While the families in this study acknowledged the difficulties around confidentiality, they felt that it was still possible to work with families and appreciated that steps were taken to engage with them within the bounds of confidentiality, in line with current NICE guidance²¹.

Frameworks for information sharing with families exist, and in trusts where clear guidelines regarding this are available to professionals, they are used and found to be helpful²². It has also been suggested that creating information packs for carers about what to expect from mental health services can be helpful¹¹. The host Trust has these, and while carers were not directly asked about whether they had received these packs, no one in the study mentioned being aware of this source of information, suggesting that where they exist they also need to be more widely promoted.

Limitations and ideas for future work

The naturalistic nature of this service evaluation means that there are limitations to how translatable the findings may be in other settings. The data from the questionnaires was positive and it may have been that those who agreed to participate in the qualitative interviews were those who had found the clinic particularly helpful or with whom the psychiatrist had developed a particularly good rapport. It is also possible that the families who did not take up the offer to participate in the qualitative interviews may differ in some way from our study population, affecting how representative the sample was. These considerations were outside the scope of this service evaluation, but would be important factors to consider and analyse in future research trials of services such as this.

Despite these limitations, it is possible to report that the family clinic is practical and implementable in clinical settings and valued by users. Other studies have found that involving families reduces the length of stay in hospital¹³ and while this was outside the scope of this study, it would be useful to evaluate the cost effectiveness of these types of clinics in future research.

Higher levels of family involvement than in ward rounds may be related to the fact that the clinic was run out of hours and the offer, by invitation, of a different kind of meeting. Future research and evaluations could examine how important the timing of the clinic was to family members, versus other aspects of the experience.

Some studies have shown that service users have concerns about their confidentiality being breached and of being disempowered by carer over-involvement¹⁷. Experienced based co-designing first described by Bate and Robert²³ has been shown to be an innovative approach

to service improvement.²⁴ A limitation to this study is that service users were not consulted and therefore it is outside the scope of this paper to comment on their experience. It would be informative and valuable to discover whether this intervention is as acceptable to patients as it is to families and this would be a valuable focus of further evaluation.

Acknowledgements

Lynn Mckenzie, ward clerk, for her assistance in administration of the family clinic.

Declaration of Interests

None of the authors have any financial disclosure or other conflict related to this manuscript.

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