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Please cite this publication as follows:

Taylor, R., Mellotte, H., Griffiths, M., Compton, A. and Koravangattu, V. (2016) Carers matter: promoting the inclusion of families within acute inpatient settings. *Journal of Psychiatric Intensive Care*, 12 (2). pp. 69-77.

Link to official URL (if available):

<https://doi.org/10.20299/jpi.2016.014>

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Carers matter: promoting the inclusion of families within acute inpatient settings

Rumina Taylor¹, Harriet Mellotte², Maria Griffiths³,
Agnes Compton¹, Koravangattu Valsraj¹

¹Bethlem Royal Hospital, South London and Maudsley NHS Foundation Trust, Beckenham, Kent, UK; ²Department of Psychology, Addiction Sciences Building, Institute of Psychiatry, Psychology, and Neuroscience, King's College London, UK; ³Family Intervention and Support Service, Tamworth Road Resource Centre, Croydon, Surrey, UK

Correspondence to: Dr Rumina Taylor, Gresham Unit, Bethlem Royal Hospital, South London and Maudsley NHS Foundation Trust, Beckenham, Kent, BR3 3BX, UK; rumina.taylor@slam.nhs.uk

Journal of Psychiatric Intensive Care

doi:10.20299/jpi.2016.014

Received 23 November 2015. Accepted 27 January 2016

Abstract

Despite their important contributions, many carers report feeling excluded by mental health services. Admission to a psychiatric ward can be a traumatic experience for both clients and their carers. Inpatient teams play a crucial role in engaging families but they report a lack of time, skills and confidence. This pilot study evaluated the feasibility, acceptability and potential benefits of introducing a family service across three acute wards. This comprised staff training, individual carer support and family intervention (FI). The service was found to be acceptable and feasible to implement. Family meetings on the ward increased following staff training, along with reported confidence in working with families. Following FI, significant improvements were found in carer distress, wellbeing, burden and negative illness perceptions and more carers reported having someone to confide in. The total number of ward complaints decreased following introduction of the service. Despite the difficulties implementing family work on the wards, it remains highly indicated. This pilot has shown it is possible to implement an effective and much needed service in an acute setting.

Key words: acute, inpatient, family intervention, psychosis, carers.

Introduction

The Carers Trust (www.carers.org) defines a carer as 'anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support'. Carers are a resource and valued asset with more than 1.5 million in the UK caring for someone with a mental health problem (Worthington et al, 2013). Carers are often the first to become aware of their relative's mental health difficulties, whether it be at onset or subsequent relapse, and enable people to seek help (Carter, 2011), often avoiding admission to hospital as a consequence (Norman et al, 2005). For clients with psychosis, contact with relatives can improve treatment adherence (Garcia et al, 2006) and functioning, reduce hospital stays, and service use (Fleury et al, 2008).

However, the informal caring role is demanding and often prolonged. Carers have little preparation and opportunity for respite (Onwumere et al, 2014). Prior to admissions caregivers are often under pressure and experience feelings of guilt (Mansell & Fadden, 2009). Admission to a psychiatric ward can be traumatic for client and family. Carers experience distressing and persistent stress responses to a relative being admitted, similar to those who have suffered a trauma (Boye & Malt, 2002). Caregivers can find wards intimidating (Askey et al, 2009) and have the same degree of 'burden' (physical, emotional, and social impact of caring) and 'burnout' (emotional exhaustion, depersonalisation, and reduced personal accomplishment) as nursing staff (Angermeyer et al, 2006), highlighting the need to provide them with support and interventions.

Despite their important contributions, many carers report feeling excluded and unacknowledged by mental health services (Crisp et al, 2016). The Schizophrenia Commission (Rethink Mental Illness, 2012) showed that carers save the public £1.24 billion per year but do not receive adequate support or involvement. Inpatient staff have a crucial part to play in engaging families at a distressing time yet report that they do not have the skills, time or the confidence to work with families and that training is unavailable (Stanbridge & Burbach, 2007). Staff report concerns around confidentiality, which can lead to situations where information is not shared and families are isolated (Mansell & Fadden, 2009). Any training provided needs to be tailored to the ward; fitting in with team requirements as well as the needs of clients and families accessing the setting.

A number of national policies such as NHS England's Five Year Forward View (NHS England, 2014), the Triangle of Care (Carers Trust; Worthington et al, 2013), and Care Act (Legislation

Government, 2014) have highlighted the importance of working collaboratively with carers and clients and the National Institute for Health and Care Excellence (NICE, 2014) recommends family intervention (FI) for all those with psychosis. Evidence suggests FI helps to reduce relapse (NICE, 2014) and an inpatient stay offers an opportunity to work closely with families, potentially facilitating earlier discharge with the aim of keeping clients well post-admission, as well as reducing carer distress.

There is limited research on working with families in acute settings perhaps because short admissions challenge traditional views of psychological therapy. One randomised controlled trial (RCT) reported a six-weekly psychoeducational and problem-solving intervention designed to help the family and client cope with hospitalisation and prepare for discharge (Glick et al, 1993). This led to clinically significant improvements in family burden and positive attitude towards the patient at discharge, compared with treatment as usual, with effects maintained at six months. In Western Lapland, Open Dialogue has developed as a psychotherapeutically orientated model of treatment which aims to help those involved in a crisis be together and to engage in dialogue. Open Dialogue offers family and staff network meetings as an alternative to admission, for those experiencing a first episode of psychosis. These aim to bring a narrative to the client's difficulties, increasing trust and support. The model appears to have led to significant decreases in the annual incidence of psychosis disorders (30.3 to 17.1 per 100,000), bed days (49 to 30), and long-stay admissions which fell to zero (Aaltonen et al, 2011).

Schweitzer et al. (2007) developed a comprehensive 18-day systemic training programme as part of the SYMPA project (systems therapeutic methods in acute psychiatry) with the aim of increasing team, client and family conversations to develop a shared understanding of admission, diagnosis and treatment. Training significantly improved communication between staff, clients and carers, maintained by ongoing training. In Somerset a three-day course promoting family inclusive working in inpatient units was found to improve staff confidence in communicating with families (Stanbridge et al, 2009). A simultaneous pilot project invited clients and relatives to meet with the team soon after admission to discuss care. Carers reported feeling heard, included and well-informed (Carter, 2011).

Given the important contributions carers make, their significant distress in the context of admissions, and the known benefits of FI, a family service across three acute wards was introduced. This included staff training, individual carer support and adapted FI. This study aimed to investigate the feasibility, acceptability and potential benefits of introducing this tiered service. It contributes to the limited evidence base evaluating FI within inpatient settings so it was intended that findings could be

shared across other settings and clinical areas. It was anticipated that the service would be feasible to implement and acceptable. We hoped that staff training would be followed by increased interactions between staff and families and decreased ward complaints. We anticipated FI would help reduce client and carer distress and increase wellbeing. However, this was a pilot study with a primary focus on feasibility and acceptability.

Method

Design

This study used an AB (Baseline-Intervention) single group design. A family work service was piloted across two adult acute wards (one male, 25 beds, and one female, 20 beds) and one male eight-bedded psychiatric intensive care unit (PICU) within one borough of an inner city NHS Trust over a two-year period. The service comprised three elements: staff training, a carers' clinic and adapted FI.

Participants

Multi-disciplinary staff attending family 'awareness-raising' training, caregivers attending a carers' clinic, and clients and carers completing FI.

Interventions

Staff Training

MDT members were invited to attend family 'awareness-raising' teaching. Training was co-facilitated by the ward or trainee psychologist and a carer with experience of accessing the ward. It was repeated annually, twice each time to ensure as many staff as possible could attend, and comprised an abridged (60-90 minutes) version of Stanbridge et al's (2009) workshop. Training aimed to develop skills and confidence covering issues such as engaging families, working collaboratively, information-sharing and confidentiality (Table 1).

Table 1 here

Adapted FI

Clients who were admitted to the ward and with a caregiver relationship (defined as parents, partners, other relatives or friends, in contact for at least 10 hours a week) were considered for one of two interventions: either adapted FI or the carers' clinic. Clients and carers were offered FI if the client had a primary diagnosis of psychosis or bipolar affective disorder according to ICD-10 (World Health Organisation, 2010), in line with NICE guidelines. In line with Trust guidance, FI was prioritised for those experiencing persisting symptoms and frequent relapses or presenting with a first episode, for those requesting a psychological intervention, and for families expressing distress or conflict. Clients and caregivers were excluded if they had infrequent contact, if the MDT felt the client was too unwell to engage, if they declined, or if clients withheld consent to contact their caregivers. In these circumstances clients were offered other available psychological approaches on the ward and caregivers were invited to the carers' clinic for individual support.

FI was based on Behavioural Family Therapy (BFT; Falloon et al, 2006), which includes key elements recommended by NICE (2014) such as sharing information about mental health and developing understanding of what helps keep the client well. BFT was chosen over other FI models as training was readily available within the trust. BFT encourages positive communication, shared problem-solving and stress management and this practical skills-based approach was considered well suited to the ward environment and multi-disciplinary staff facilitators. It has a good evidence base in terms of symptom reduction, relapse prevention and reduced carer burden (Berglund et al, 2003; Falloon, 2003).

BFT was provided by two of a number of trained facilitators from the multi-disciplinary team (MDT; clinical psychologist, trainee clinical psychologist, three staff nurses, occupational therapist technician). Families and clients were offered four to six sessions of a formulation led weekly FI rather than the NICE (2014) recommended 10 sessions, to fit in with the average length of stay on the ward. A shorter number of sessions has also been recommended in acute inpatient settings where people are in crisis and time is limited (Mansell & Fadden, 2009). We adapted BFT to suit the acute inpatient context. There was a greater focus on information sharing, medication management, and relapse prevention. Families often worked on either their problem-solving or communication skills, rather than both as the manual suggests, due to time and depending on their goals and needs. The work undertaken was shared with the clients' community teams and referrals for FI post-discharge were made where necessary.

Carers' Clinic

A weekly carers' clinic facilitated by psychology, nursing and medical teams was developed in parallel with FI, based on the work of Carter (2011) and aimed to improve caregivers' experiences of admissions. Carers could attend the clinic regardless of their relative's diagnosis and were offered 30-minute individual slots. Clients usually attended with their families although carers were also offered some time alone with the team. Clinic meetings emphasised the need for the family and team to work together, elicited perspectives of how the client's problems developed, and expectations for the admission. Individual carer support and signposting to services were provided.

Procedure

All potential participants were discussed within the MDT and caregivers were offered either the carers' clinic or FI. Both interventions were advertised on the ward and clients and families were encouraged to self-refer. With client consent, caregivers were then contacted by telephone, given an overview of the service and invited to participate. All appointments took place on the ward.

Measures

Staff Training

Family Contact Questionnaire: When staff attended family awareness training, they were given a questionnaire developed by Stanbridge et al. (2009) which asked them to report: the number of families they had met and discussed issues with over the last month, whether these meetings were planned or unplanned, and how confident they felt in working with families (1=not confident to 5=very confident). This questionnaire was completed immediately prior to training and three months later. The last item rating confidence was also given immediately after the teaching session along with a questionnaire rating satisfaction with the training. A target was agreed to train at least 50% of all MDT staff.

Adapted FI

The following outcome measures were selected as they have good psychometric properties, have been designed to capture the experience of caregiving across the illness phase, overlap with key

areas FI is designed to address, are acceptable to families and service users, and continue to be used to evaluate the effectiveness of FI in severe mental illness (IAPT-SMI; www.iapt.nhs.uk/smi/).

Sociodemographic characteristics: Client and caregiver age, gender, ethnicity, marital status, and occupation were recorded using structured questionnaires and electronic patient notes. Client diagnosis was recorded in addition to details of their relationship to their caregiver.

Wellbeing and distress: Clients and caregivers were asked to complete the Warwick Edinburgh Mental Well-being Scale (WEMWBS; NHS Health Scotland, 2006) and Clinical Outcomes in Routine Evaluation-10 (CORE-10; Connell and Barkham, 2007) before and after FI. The WEMWBS has 14-items assessing general wellbeing, with higher scores indicating better wellbeing. The CORE-10 is a 10-item questionnaire of global distress over the past week, with higher scores indicating more distress. Both measures have good psychometric properties (Tennant et al, 2007; Barkham et al, 2013).

Caregiver confidants, burden, and illness perceptions: The Carer Confidant Questionnaire (CCQ; Onwumere et al, 2014) was used to assess caregiver social support and comprises a single item: 'In general, do you feel that you have someone that you can confide in?' with either 'yes' or 'no' as the response options. The Caregiver Burden Inventory (CBI; Novak & Guest, 1989) is a 24-item questionnaire used to assess the impact of caregiving. A clinical cut-off of 36 suggests significant burnout although scores ≥ 24 indicate a need for respite. It has good internal consistency and test-retest reliability (Borghetti Valer et al, 2015). The Brief Illness Perception Questionnaire (BIPQ; Broadbent et al, 2006) has nine items designed to assess cognitive and emotional representations of illness on a 10-point scale and is psychometrically robust. This measure was adapted to ask caregivers how they perceived their relative's illness, with higher scores indicating more negative illness perceptions.

Satisfaction: The Satisfaction with Family Meetings Questionnaire (IAPT-SMI; www.iapt.nhs.uk/smi/) has seven items and was used for clients and carers to rate: perceived progress during FI; expectations about future progress; satisfaction with FI; feeling understood by the FI

therapists and confidence in the FI therapists. There is an open-ended item for qualitative feedback. All items are rated on a five-point scale.

Carers' Clinic

In order to report on who accessed the clinic and for what reason, the recorded data included: numbers of carers attending, relationship to the client, client's diagnosis, and key issues discussed. The number of client and caregiver complaints was recorded for the three-month period prior to introducing the clinic and then for the subsequent evaluation period (two years). Carers were asked to complete a five-item satisfaction questionnaire after attending the clinic (Carter, 2011). This assessed what carers found helpful and unhelpful about the clinic; how satisfied they were; whether they would recommend the service and an open item for qualitative feedback.

Analysis

Descriptive statistics were used to summarise data from the staff training, carers' clinic, and satisfaction measures (FI and carers' clinic). Paired t-tests were used to compare pre and post scores for the remaining client and caregiver outcome measures following FI. Data were analysed using SPSS version 22 (IBM Corp, 2013).

Results

Staff Training

A total of 102 staff (60%) attended training across the three wards with 48 attending in year one and 54 in year two, exceeding the target of training 50% of staff. Overall, in line with the skills mix on the wards, 88% of those trained were nurses, 3% ward managers, 2% administrators, 5% occupational therapists, and 2% medical doctors.

Prior to training, staff (n=45) reported meeting with a total of 154 families over the previous month giving a mean of 3.4 families per team member. Many interactions were unplanned (54%). At three months post training, those returning the follow-up questionnaire (n=34) reported a total of 117 family meetings over the previous month (mean of 3.4 families per staff member), with 77% being unplanned. Whilst there was no change in the mean number of family meetings for two of the wards, the PICU team increased theirs from 3.5 to 5 family meetings per staff member.

Regarding confidence in working with families, 62% of staff (n=45) rated themselves as 'confident' (rated 4 or 5 on the 5-point scale) prior to training, increasing to 96% immediately after training. The mean rating increased from 3.6 (range=1-5) to 4.4 (range=3-5) but decreased at three months with 71% of staff (n=34) rating themselves as confident (mean rating=3.9; range=3-5). However, at three months no staff member rated themselves as 'unconfident' (rating of 1 or 2).

All staff rated the training as excellent (57%) or good (43%), describing it as 'relevant and useful'. Suggestions for more training of this type over a longer time period were the main comments made in the open-ended feedback item (75%).

Adapted FI

Participants

Over a two year period 22 families engaged in FI. During treatment 16 families (comprising 16 clients and 27 caregivers) completed the intervention (mean=4.2 sessions). Six families were categorised as dropouts having completed fewer than three sessions (mean=1.8 sessions). Reasons included: family reporting no further need (n=1); client discharged or transferred to another ward (n=4); or family going abroad (n=1).

Sociodemographic characteristics:

All clients had a primary diagnosis of psychosis, except two with a diagnosis of bipolar affective disorder. Of the 22 clients offered FI, 77% were male. Client mean age was 37.2 (range=19-76) and caregiver mean age was 48 (range=18-75). The majority of participants (clients=68%; caregivers=58%) were from a black ethnic background, consistent with the population served by the Trust. Most clients were single, unemployed, and living with their caregiver prior to admission. Caregivers were predominantly mothers (Table 1).

Table 2 here

Client Outcomes

Pre and post FI outcome data were obtained for 15 clients (Table 2). One declined to complete the measures. There were no significant differences before and after treatment for the CORE-10 ($t(14) = 0.78, p = 0.48$) or WEMWBS ($t(14) = -1.46, p = 0.17$).

Table 3 here

Caregiver Outcomes

Significant differences were found between scores obtained pre and post FI, for measures of global distress, overall wellbeing, burden and negative illness perceptions (Table 3). Prior to FI, 65% ($n=17$) of caregivers felt that they had someone to confide in, increasing to 96% ($n=24$) following FI.

Table 4 here

Satisfaction with Family Meetings

All participants who completed FI reported that they had made 'progress' during FI with 54% of carers and 41% clients stating that they expected to make 'a lot of progress' moving forward. In addition, 98% felt 'very satisfied' or 'satisfied' with FI and that their therapist understood their problems either 'very well' or 'fairly well'. Finally, 92% said that they had a lot of confidence in their therapist. Talking to someone who cared, being listened to, and being provided with useful information and advice were the main comments made. One caregiver requested that this intervention be offered at the start of a client's admission rather than later and another said that more than six sessions were required.

Carers' Clinic

Over a two year period 119 caregivers attended (Table 4). The majority were mothers (29%), spouses/partners (21%), children (19%) and siblings (19%) of clients. Subsequent to discussions regarding the circumstances of the admission, meetings most commonly focused on providing individual carer support (44%) or sharing information about care plans (43%).

Table 5 here

The total number of client and caregiver complaints per quarter reduced following implementation of the clinic (Table 5).

Table 6 here

All caregivers who returned the satisfaction questionnaire (n=30) reported being 'very satisfied' or 'satisfied' with the clinic and would recommend it. Many valued having a space to meet with the team and receive support (57%). A proportion (27%) found the psychoeducation about diagnosis, current difficulties, and medication helpful and 13% found information about their relative's current care of most benefit. Only 7% reported the service being unhelpful in some way and this was due to the caregiver wanting a longer meeting.

Discussion

Given the important contributions carers make, their significant distress in the context of admissions, and the known benefits of FI, a pilot family service across three acute wards was introduced. This included staff training, individual carer support and adapted FI.

The service was feasible to implement over a two year period and highly acceptable to participants. More than 50% of all MDT staff attended training, describing it as useful and relevant. Indeed they were keen for more of this type of training. Nearly all clients and carers engaging in FI reported being very satisfied or satisfied and that they had made progress during the intervention. Similarly, all caregivers attending the carers' clinic reported being very satisfied or satisfied and all would recommend it. Following implementation of the clinic complaints made to the wards also reduced. It is difficult to know whether this was a direct result of the carers' clinic, given that the data come from all carers on the wards, not just the sub-group who accessed the clinic, but it would be worth investigating further to clarify. Complaints are not only distressing for the individual but also time consuming for staff and therefore costly, indicating potential efficiencies from promoting family inclusive practice.

Staff confidence in working with families increased following training across all wards. For PICU this translated into more family meetings being facilitated by staff members, more than the increase

reported by Stanbridge et al. (2009), whilst others have reported difficulty increasing the number of staff and family meetings following training (Schweitzer et al, 2007) as experienced in this pilot by the other two wards. Staff in the present study expressed a need for further training in this area, in order to develop skills and improve confidence, as did 98% of those in Stanbridge et al's study (2009). However, training plans must consider staff pressures and it may be that longer training, although requested by staff, would be difficult to attend in practice. It is encouraging that training appears able to promote family inclusive practice, however, the sustainability of this collaborative approach needs to be evaluated and it seems likely that further progress will require on-going training and supervision (Schweitzer et al, 2007; Stanbridge et al, 2009).

The carers' clinic appeared most successful in engaging relatives of clients diagnosed with psychosis. Meetings were predominantly used for carer support and collaborative care planning. Carers welcomed being able to discuss the impact of clients' mental health difficulties and in return receive support, as previously reported by Carter (2011).

The majority of clients engaging in FI had a diagnosis of psychosis and were male, which is unsurprising as FI was introduced first on the male ward. Feedback from families suggested that adapted FI, comprising four to six sessions, was acceptable. Six families dropped out of treatment but this was unrelated to the intervention. Prior to FI caregivers were experiencing mild emotional distress, average wellbeing, high levels of burden nearing burnout, and negative illness perceptions. This is consistent with research showing that carers of those with psychosis requiring an inpatient admission often experience high levels of stress and burnout amongst a number of other physical and psychological problems (Kuipers et al, 2010). Over the course of FI caregivers reported having more confidence and showed significant improvements in distress and burden which moved to the non-clinical range, improved wellbeing and more adaptive illness perceptions. Research into the mechanisms involved in reducing caregiver burden is largely unknown. Some suggest that merely offering caregivers an intervention initiates a relationship between carers and services allowing them to feel supported and less burdened (Berglund et al, 2003). Indeed a recent systematic review found that developing alliance, allowing families to share their narratives, and providing support was highly valued by families and sufficient in reducing distress, with fewer requiring more formal skills training (psychoeducation, communication and problem-solving skills) (Gracio et al, 2015). Caregivers in the present study most frequently commented on the support they had been given which allowed them to

feel listened to and understood. They also found benefit from psychoeducation and relapse prevention work.

Client distress and wellbeing improved after FI but not significantly which is perhaps unsurprising given baseline scores were close to non-clinical. This is incongruent with the level of distress that would be expected from clients admitted to a ward. There may have been a positive bias towards offering FI to those in a better mental state or clients could have been minimising symptoms in order to facilitate discharge. Lastly, the client outcome measures used, although psychometrically robust, lack questions regarding relationships with caregivers which may mean they are limited evaluation tools for FI.

There are limitations to this study which mean results should be interpreted with caution. Resources did not allow the inclusion of a control group and the number of participants offered the service who declined or did not attend (usually due to work commitments) was not recorded. The service was acceptable to participants although some fed back wanting a longer time slot at the carers' clinic and more sessions of FI. In order to maximise access to the carers' clinic, sessions were limited to 30 minutes. Similarly for FI four to six sessions were offered to fit with the average length of stay on the ward. This was a manageable amount for clients and caregivers to commit to at a time of crisis and has been recommended in inpatient settings (Mansell & Fadden, 2009). Additionally, formal FI may be neither cost-effective nor appropriate for all families. Some may benefit from support but not necessarily need an intensive intervention (Cohen et al, 2008). Lastly, those engaging in FI were predominately male service users with primarily female caregivers. This may limit the generalisability of our findings.

The next stage of this pilot will include extending data collection to report on any observed impact on relapse, which will require a longer follow up period. A larger study with a control group is also required to rigorously evaluate the effectiveness of promoting family inclusive practice within acute inpatient settings. Nevertheless, this study has shown it is feasible to implement an acceptable and much needed service within the acute pathway in a relatively short time frame.

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