Relatives, friends and AOT staff - working together

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Overview

- Importance of relatives and of working together
- Effectiveness of Family Interventions
- What we can do
- Dilemmas
Importance of relatives – to me, to you, to the people who use AOT services

Our family are always there – staff come and go - this can be a very positive support although they are also important when they feel less supportive or important by their absence

Research has shown that families have a greater impact on relapse than medication (Vaughn and Leff, 1976)

By using a systemic open dialogue approach working with the whole system, relatives, neighbours, friends, employers, 80% of people with first episode psychosis returned to normal social functioning without relapse. Five year follow up. (Seikkula, 2001).
Importance of relatives

• Stressful environments affect recovery - Vaughn and Leff (as long ago as 1976) — people diagnosed with “schizophrenia” returning to low EE homes had much lower relapse rates (13%) than those returning to high EE homes (51%).

• High EE – criticism, hostility, over-involvement

• “EE is an operational thermometer of stress in a particular relative-sibling (or spouse) relationship at a particular time” (Smith and Birchwood, 1990).

• Recognise ‘families as facing problems’ rather than stigmatising them as ‘problem families’.

• Idea that EE may be an adaptive reaction to the stress and loss associated with having a relative with serious mental health challenges
Importance of relatives

• Relapse in high EE families was halved by reducing face to face contact to less than 35 hours per week (Vaughn and Leff, 1976).

• Relatives of AO users say when feeling burdened they value education, information, support, people taking time to understand them, sharing responsibility (Hughes 2007)

• External support, helping people’s understanding, making sense of their experience, problem solving, recognising the positives and reciprocity of relationships, re-attributing challenging behaviours to the psychosis rather than personal character traits can reduce criticism, over-involvement and stress (Stern et al., 1999; Schwartz and Gidron, 2002; Meddings, Gordon and Owen, 2010).

• Recognise that staff also exhibit high EE (inc you and me). Being over-helpful or critical of clients e.g. for being un-motivated, non-compliant, treatment resistant, not following advice (Repper and Perkins, 2003, Meddings, Gordon and Owen, 2010)
TOTAL GROUP
High EE N=71
Low EE N=57

LOW EE
13%

HIGH EE
51%

<35 HOURS
ON MEDS 12%
NOT 15%

>35 HOURS CONTACT
ON MEDS 15%
NOT 42%

Nine month relapse rates taken from Vaughn and Leff, 1976
Importance of working together

• Relatives see AO workers as an extension of the family system – more attuned to the family’s needs than other services (Hughes et al, forthcoming)

Participants described AO services as being responsive to their needs. This helped give them confidence and played a big part in reducing their stress levels. “I don't think there is any time that I have voiced my opinion about something that they haven't done something about. They always do something about it.” (Christine)

Some participants felt that the work the AO team had done with them as a family had brought them closer together and improved family relationships. “. . . the family work has been really helpful, learnt a lot from it but that’s something I don’t think we’d have got if we hadn’t had the outreach worker.” (Irena)
Effectiveness of FI

• Family therapy reduces relapse in long term cases by about 30% - similar levels of efficacy as CBT, employment and clozapine medication (Burbach, 1996, review).

• Family interventions reduce relapse consistently (NICE 2009 review, 32 studies)

• People who use services and their relatives want more access to talking therapies

• Evidence that FI do not cause harm.
NICE recommendations

• NICE guidelines (2009) recommend a minimum of 10 sessions family interventions over 3-12 months for:
  - All families of people with schizophrenia, where there is a risk of relapse or persisting symptoms or
  - All families where the person lives with or is in close contact with family.

• FI can be started in the acute phase

• FI described as discrete psychological intervention where:
  Family sessions have a specific supportive, educational or treatments function and contain at least one of the following:
  - Problem solving / crisis management
  - Intervention with the identified service user
• The Carers Act (Recognition and Services) 1995 (DoH 1996) – carers’ right to an assessment.

• Caring about Carers (DoH 1999) – ‘helping carers is one of the best ways of helping the people they are caring for’.

• Community Care (Delayed Discharges) Act 2003 – carers right to their own assessment and to request a home visit to assess needs before patient is discharged from hospital

• The Carers (Equal opportunities) Act 2004 – aims to enhance the opportunities of carers – assessment to include work, training and leisure needs.
• Healthcare commission audit (1996) – only half of people with psychosis, who were deemed appropriate, had received family interventions

• Many families for whom FI are appropriate are thought to be inappropriate and so the true figure is much lower

• So – what can we do about this?
What can we do?

• Work in family inclusive ways with all the people who use our services

• Offer family interventions where appropriate (using NICE definition as a guide) – all who are in close contact – all who are at risk of relapse or persisting symptoms

• Work with the whole family where possible

• Individualised – tailored approach to each family
What can I do?

1. Involve relatives and friends as a default option in relation to their relative’s care (taking account of client’s own wishes about confidentiality)

2. Involve relatives and friends in the development and review of services and support the development of relatives advisory groups

3. Support the development of relatives and friends groups

4. Reflect as a team to understand what might be going on for families

5. Depending on your skills, offer and engage people in family work
Son
“If she is going to criticise me anyway, what's the point in me trying. She doesn't understand”

Mother
Asks son to hurry up with the washing up so that they can get out to her friends.

Son
Feels stressed, doesn’t do the washing up. Is withdrawn and pre-occupied and grouchy to others.

Mother
“In order to show I’m a good enough mother, I need to get my son to do more household chores and to be more sociable and polite”
Dilemmas in working with families

1. Friend or foe
2. Therapy or support
3. Open communication or breaking confidentiality
4. Caring or over-involved - How involved should we be
5. Are people with severe mental health problems a burden or asset
Friend or foe

• Are relatives, friends and AOT staff friends or foe to one another?

• By seeing this dichotomy we can map ours and others thinking

• Relatives, service users and staff may have different needs and expectations; they may have different goals for the person using the service – sometimes these are conflicting.

• Relatives, service users and staff may have disagreements; relatives might make complaints about the service and staff

• Relatives, service users and staff may have access to different information, from different perspectives, different aspects of the formulation

• The best outcomes are found when we are able to work with our difference and find ways of collaborating to support the recovery of the person with mental health problems

• See also first slides
Therapy or support

What is more important? General support and listening? Education and information sharing? Therapy?

Different types of involvement may be important at different times, with different families, in different contexts.
1. **Information and assessment**  
   for all by all – might be ad hoc  
   General information about the Assertive Outreach Team, crisis or out-of-hours support and other services, about mental health difficulties; and practical support such as care breaks.  
   Relatives are entitled to carers’ assessments to identify their needs.  
   Share more individualised information where the service user consents.

2. **Basic family work**  
   - Psycho-education, basic interventions and support  
   - Relatives and carers groups (Re-think)  
   - Maintenance family work with supervision

3. **Family Therapy**  
   - By two therapists with training and supervision
1. What does the client / family want?
   - May work at different levels with the same family over time
   - Remember that NICE recommends family interventions for all

2. What training, skills, competency do you have?
   e.g. family awareness for level one, some PSI training for level two, family interventions training (approx 16 taught sessions plus supervision e.g. Sussex Partnership and Surrey University course)

3. If you do not have the skills to carry out family work which someone might benefit from – find someone who can – or seek training so that you can

4. Co-working and acting as a reflecting team
   - perhaps a way in to building skills and confidence

5. Importance of supervision
   e.g. supervision group in East Sussex
Open communication or breaking confidentiality

• How is the service user’s right to confidential and person-centred care balanced against a carer’s needs for information and right to support and to be informed of any potential risk?

• What if the person using AOT does not want us to disclose anything about him/her to their relative?
  • In terms of family work
  • When there is a significant risk
Confidentiality - solutions

1. It is important to adhere to the confidentiality of people we are working with.

2. This has sometimes been seen as a reason not to involve relatives and friends – yet it need not be an issue.

3. We must establish limits of confidentiality – and about what issues – often people are happy for us to talk with their relatives.

4. There are times when we have to break confidentiality due to risk and we need to be open about this. Service users and carers can be involved in risk formulation and can contribute to ‘harm minimisation’ planning.

5. Where someone does not want us to disclose information about them we can find ways of working with relatives or friends without breaching confidentiality. Workers can give general information about a mental condition without specific details about a service user and relatives can let staff know their concerns - so relatives and workers can support one another in developing their understanding. (give e.g.)
e.g. Pete asked that someone work with his mother as he was struggling with her criticisms. He did not consent to us sharing any personal information about him with her, including his diagnosis. Nor did he want to attend sessions. We worked with his mother by finding out what she had noticed about her son. She worried about him hearing voices, believing he was a famous footballer and leaving his flat dirty. We helped her to explore what might be going on, including sharing understandings about voices and delusions, which were neither her nor his fault. By considering the wider system, we realised that she was an especially tidy person. We normalised messiness in young men, whilst also checking with the rest of the team that he wasn’t self-neglecting. She talked with friends about their young adult sons who were also untidy despite not being assertive outreach users. She found the sessions supportive. Several months later Pete told one us that his mother had been less critical since family work and he recommended it to a friend.

(Meddings, Gordon and Owen, 2010) p. 170
Caring or over-involvement

- Relatives and people using services need to know that we care – that we genuinely want to help.

- Yet they also want us to be professional and to provide the best evidenced treatments and interventions for their relatives.

- Some people might believe that it is unprofessional to feel an emotional connection with service users and the administrative provision of treatment and adequate support should be enough.

- Other people might believe that showing that they care about a person should be enough to enable that person to overcome their problems.

- Over-involvement (high EE) in staff (as in relatives) can lead to relapse.

- Staff working in AOT have probably got reasons in their own upbringing, attachments and backgrounds which have led them to this sort of work.
Caring or over-involvement - solutions

- Balance of emotional presence and caring with taking care of oneself and maintaining objectivity and low EE

- It is important that teams develop strong shared values and discuss the use of therapeutic techniques.

- It is also important that team members support each other so that workers are not overcome by the emotional aspects of our work and can reflect on their own feelings and involvement.

- Importance of supervision and reflective practice
Burden or asset

- Are people with serious mental health problems a burden or an asset to their families, friends and communities?

- Literature about burden – caring for someone with a serious mental health problem is a challenge - a sizeable literature describes the negative impact or ‘burden’ of caring for someone with serious mental health difficulties (Fadden, 1998). Difficulties include objective and subjective burden – financial difficulties and practical demands; problems with roles and relationships within the family and outside; disruption of household activities and psychological distress
Burden or asset

- Exceptions – Families report that their relatives with serious mental health problems provide companionship, news about family and friends, listen to problems and give advice (Greenberg et al. 1994);

- They contribute to the personal growth of family members: to sense of increased appreciation and closeness; patience and perspective; self-value and purpose; life satisfaction and practical support (Coldwell, Meddings and Camic, 2010)

e.g.s from Coldwell et al.
“*I pick my nephew up from school every Monday*” (individual);
“*My father became very frail …and (son) used to mow his lawn and I suppose I thought after that well if he can mow Grandad’s lawn he can mow our lawn! … that was probably the first time it occurred to me he was capable of actually doing stuff, being useful*” (mother);
“*And so the positive side of that is that I am today who I am.*” (sister)
Burden or asset

• Both / and – relatives and friends with serious mental health challenges are both a burden and an asset – as we probably are to them – and as are all our relationships to some degree

• Families who see positives in their situation use more social support, make sense of their experiences and are more able to cope (Stern et al., 1999)

• Multi-faceted nature of relationships
Useful References


