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Service innovations

Developing a parent/carer support group in an in-patient adolescent setting

It is a stressful experience for parents and/or carers when their child is admitted to an in-patient unit because of severe mental illness.

Parent support groups have the potential to provide a psychosocial network, offering the opportunity for problem sharing and containment of anxiety. Compared with other types of parent groups within community adolescent mental health services, e.g. parent training groups for specific disorders such as conduct disorder (Webster-Stratton, 1996; Scott, 1998) and attention-deficit hyperactivity disorder (Anastopoulos, 1993), little has been published about the process of setting up and running support groups for parents and carers in tertiary settings. The importance of considering the views of carers in clinical management was endorsed in the National Service Frameworks (Department of Health, 2003). The concept of a parent support group at the Regional Adolescent Unit in Birmingham was developed in Spring 2001 by two of the authors, driven by recognition of unmet needs of parents whose children were in-patients, coupled with the specialist registrars' need for training experience in group work.

We therefore aimed to:

- reflect on the process of setting up and running a parent support group in a tertiary setting;
- elucidate and describe themes brought up in the group meetings;
- identify any therapeutic elements, and whether the group was useful.

Method

The limited literature on different models of group work with reference to parents of children admitted to in-patient adolescent units was reviewed. The proposal to re-establish a previous parent support group received support from the in-patient multidisciplinary team and management committee. It was agreed that an open group for parents and carers of children on the two in-patient units would run for 1 hour every 2 weeks, during family visiting time. Ground rules, including confidentiality, were discussed at the beginning. The emphasis was on the specialist registrar/facilitators being empathic and reflective, rather than experts with answers and solutions.

After each meeting the specialist registrar/facilitators would discuss and record the content and process of the meeting, including their own responses, and convey any appropriate information to the nursing staff.

The group continued for 9 months and general themes were fed back to the multi-disciplinary team meetings, promoting reflection and discussion and a monthly supervision with a social worker experienced in group work continued throughout.

After 9 months, one of the authors analysed the content of the group records and collated a number of themes.

Results

Most of the attendees were parents (10), although other relatives did attend. Each group meeting had between three and seven members.

Themes discussed in the group

The recurring themes could be divided into five (overlapping) groups.

Effects on parents themselves

It became apparent that having a child with serious mental health problems can be a traumatic and lonely process for parents. They can experience:

- guilt and blame; feeling themselves to be the cause of their child's problems, together with guilt about their decision to admit their child;
- grief and loss; loss of their previously well child, their previous relationship with their child, the integrity of the family in general and confidence as parents;
- feeling normal life being 'put on hold';
- uncertainty about the nature of the illness and prognosis;
- dread when the phone rings, with the expectation of bad news, especially in relation to deliberate self-harm and absconding;
- adverse effects on parents' own mental health, particularly anxiety and depression; difficulties in continuing working; stress and potential breakdown of the marital relationship;
- difficulty in allowing their own needs to be met;
- alienation because of considerable stigma attached to mental illness in an adolescent with consequent isolation from potential sources of support;
- prejudice, blame and misunderstanding within their own family, friends and health professionals;
- a sense of shame in having a child with these kinds of problems;
- financial difficulties, resulting from loss of earnings and the cost of travelling to the unit.



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Effect on siblings and family

It became clear that siblings could also be deeply affected. They could feel:

- anxiety, guilt, anger and sadness both towards and about their ill sibling;
- confusion about the nature of the illness, and the amount of responsibility the ill sibling could be expected to take for their behaviour;
- anxiety, particularly in relation to deliberate self-harm;
- anger was expressed more frequently by siblings than parents, mainly about behaviour perceived as 'manipulative' and, by implication, controllable;
- resentment that the family was dominated by the ill sibling and that no-one else's needs were being met;
- sadness about loss of previous relationship with their ill sibling;
- stigma of mental illness, leading to alienation within their own peer group.

Relationship with and attitudes towards, unit and professional workers

Parents/carers could feel:

- uncertainty and ambivalence about deciding to admit their child;
- guilt about the admission especially if their child was unwilling and protesting; abandoning their child to an unknown situation when they were very vulnerable;
- relief about their child being somewhere safe and receiving appropriate treatment;
- ambivalence about restricted visiting policy;
- that there were long distances to travel;
- disempowerment as parents and exclusion by staff; decisions could sometimes be made without them;
- it can be daunting meeting all the professionals at once; review meetings;
- gratitude towards staff for help and support at a very difficult time;
- concerns about what would happen when their child was discharged.

Positive coping strategies

The parents used a variety of strategies to cope. These included:

- confiding in supportive and non-judgemental family and friends;
- acknowledging the importance of taking time for their own needs;
- humour, both within and outside the group;
- reassessing their priorities and values.

Effects and usefulness of the group

The parents clearly needed to tell their own individual story, sometimes repeatedly, and to be heard. There was:

- relief about being able to talk openly with others going through similar experiences;
- universality of experience; a powerful sense of no longer feeling so alone;
- mutual support was frequently demonstrated in the group;

- psycho-education and learning about mental health issues in adolescents;
- two-way education between practitioners and parents.

Moreover, it was good for parents to meet the doctors in less formal circumstances in which they were able to be more open. The parents' views could also be fed back to the unit.

Discussion

Usefulness of the group

The cathartic effect of talking about their experiences and feelings appeared to be helpful for the parents; they felt less isolated, and could begin to support each other and not just rely on the 'experts'. The parents felt the doctors were more approachable because of the informal setting. The doctors found it liberating to be less formal and more relaxed; they gained useful knowledge about the parents' experiences and were able to give feedback to the unit.

Difficulties in setting up and running the group

There were several difficulties in setting up the group. Some nursing staff felt that the parents' needs were already being met; there was a lack of support until they knew more about the group and perceived it to be useful. Thus feedback and discussion with the nurses in particular was important.

Timing of the group was an issue. It had to be late enough for parents to attend after work and therefore outside the doctors' normal working hours. Part of the parents' visiting time was used, but some did not attend because of loss of contact time with their child.

Engaging and maintaining sufficient numbers of parents was difficult. This was partly because of timing; also some parents perceived that they were already receiving help and that this might be a group where they had to open up and talk about painful matters.

Supportive factors and limitations

Supervision was especially important when the doctors had difficult periods, such as falling numbers and lack of support from staff. The support of the nursing staff, once established, helped in recruiting members.

There was no systematic evaluation of the group by the parents, although informal feedback was received from the parents who continued to attend.

Implications for future practice

The doctor/facilitators gained useful insight into the parents' experiences and will be more empathic in their



future practice. Some parents need to share their experiences in a safe and relaxed situation. The considerable resources of parents as a group can be underestimated and better utilised. Relevant information should be fed back to the multi-disciplinary team within the bounds of confidentiality. Without the support and trust of the organisation, a group such as this will founder.

The process of setting up and running this group was useful for the specialist registrars' training and learning. For this reason, and for the service itself, it was felt that the group should continue, particularly in the context of the National Service Framework in psychiatry and the importance of engaging with service users.

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Declaration of interest

None.

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