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"Then Mum got taken into hospital": *Young people's experience of parents' admission to psychiatric hospital*

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"It [hospital] was horrible. I didn't like it. Sometimes we didn't even go because I didn't like it. And I did go because I missed her, I had to go, because I missed her and that, but I didn't like it in that place, I hated it" (Dianne, age 15).

This comment, made by a young person when asked what it was like to see her mother in hospital, typifies the dilemma faced by the young people I interviewed about their experience of parents' mental illness. They desperately worry about their parents and try to care for them, but often found their experience overwhelming and hard to cope with, especially when they had little support in difficult times including parents' hospitalisation. Although the effects of parental illness on children have been studied extensively in the past few decades, much of the literature focuses on adverse effects of parental mental illness on children and the association between parental illness and problems in children (e.g. Rutter & Quinton, 1984) and little was known about children's experience until recent years. This paper is based on a qualitative study I conducted on young people's subjective experience of parental mental illness and its impact on family life (Totsuka, 2008). Brief introduction and method sections will be followed by the findings and discussion of implications for practice.

Introduction

In the past several years, there have been more attempts to understand families' experience of parental mental illness from their own perspectives, including children's, which had been particularly under-represented (e.g. Armstrong, 2002; Aldridge & Becker, 2003; Riebschleger, 2004; Stallard *et al.*, 2004). Parental hospitalisation has been identified as a major event that has an impact on families and children. Several studies commented on children's negative experience of hospitals and the need for a more family-friendly environment. My research is one of a few qualitative studies informed by systemic perspectives on the subject. Colmer (2005) interviewed children, parents and professionals and Nolte (in progress) is currently conducting a study on parents' perspectives.

Method

The participants were nine young people of the adolescent and early adulthood age group whose parents experienced at least one hospital admission due to mental illness. They were attending a child and adolescent mental health service in Newham, London. The average age of the participants was 16.6 years, ranging from 13 to 20. Two male participants have a father who has mental illness. Seven female participants have mothers who experienced mental illness. The participants' ethnic background reflected the diversity of the local population. Four participants were of Asian background, three were white (British, European) and two were black (Black Caribbean, African/British). Semi-structured interviews were audio-recorded, transcribed and analysed using 'grounded theory method' (Glaser & Strauss, 1967).

Findings

Young people's accounts of parents' hospital admission

Young people's age at the time of their parents' first hospitalisation ranged from 4 to 14. All but one participant were aware of the name of the parents' illness or diagnosis, which included schizophrenia, psychosis, bi-polar disorder, depression, eating disorder and personality disorder. Seven young people experienced parental hospitalisation more than once. One participant recalled eight recurring episodes. Except for a few who were too young to remember, most participants talked in detail about the circumstances. The meaning of parents' hospitalisation and impact on the young people's lives varied. Some experienced it as a significant event that changed their lives or marked the onset of their parents' illness. For one of the participants, her mother's first admission was a significant event where all her memories started.

> *"It may sound weird but all my memories started from that point. I don't really think anything significant happened in our life before"* (Lisa, age 20).

Her mother's admission was a major event for Lisa, despite the fact that she experienced little change and disruption to her life as her father kept the routines going and she felt protected from seeing her mother while she was unwell. Some participants including Lisa described no precursor to the illness and had a sense of normality when the parents were well. In contrast, for others whose parents were chronically ill, admission signified the culmination or further deterioration of the illness after a long period, during which they were exposed to parents' symptomatic behaviour and sometimes the lack of adequate care due to parents' impaired capacity. Some young people had little sense of normality in family life. Bushra, whose mother has always been ill, had experienced much disruption to her life by the time her mother went to hospital.

> *"I think it started from postnatal (depression) and carried on, and it got worse, because my dad kind of ignored it, and he was never at home. And at that time, there were four of us, all under five in the house, and she was alone most of the day, so it kind of got worse and worse and worse, and then we moved to this house. Mum and Dad used to fight all the time, and dad left, and he never came back, and she was just messed up. We stopped going to school, social workers came to our house to check it out and see what's going on, then mum got taken into hospital"* (Bushra, age 18).

Similarly to Bushra's account, most participants described stressful events that preceded the parents' hospitalisation. Common themes in their accounts included multiple events putting parents under pressure; family relationship difficulties such as conflict between parents or extended family members; parental separation and domestic violence; social problems such as disputes with neighbours; financial or housing problems; change of circumstances such as house move; life cycle changes such as bereavement and arrival of a baby.

Most young people had views about who or what was to 'blame' for their parents' illness. This seems to be part of the process of making sense of their experience and seeking an explanation. Some blamed themselves.

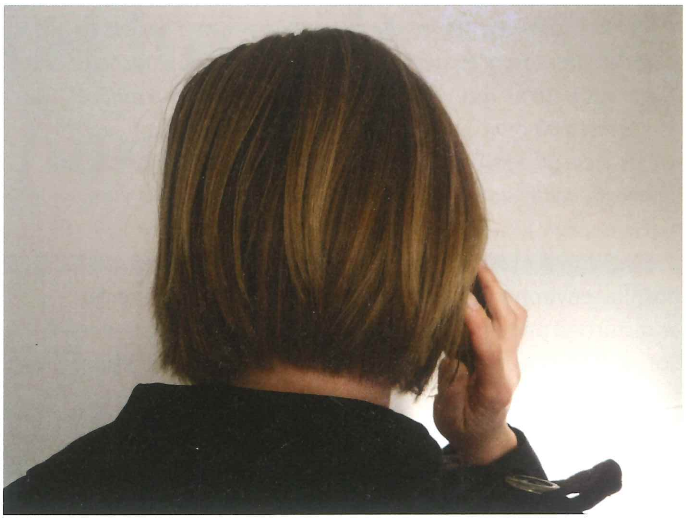
> *"I guess, for the postnatal depression, makes me feel like it was only because of us. Because after I was born, obviously because of me being born. And I know that my birth was painful, my birth was messed up. That kind of makes me feel guilty in general"* (Bushra, age 18).
>
> *"When me and my mum used to argue, big time, she used to say 'Are you gonna drive me mad?' So, and then she did go mad, and it made me think she was right, and the second time round, when we were arguing, she'd say oh, you're gonna put me back in hospital. And she did go to hospital, so I thought maybe I'm too much for her. She can't handle, like, I could be a factor"* (Helen, age 17).

Young people described a range of feelings they experienced at the time of parents' hospitalisation, including relief, sadness, confusion, guilt and worries and often a mixture of them. One young person repeatedly asked for help while her mother was exhibiting "strange" behaviour for months. When her mother was finally hospitalised, she was relieved but felt guilty at the same time for "betraying" her by putting her into hospital.

Responsibility for parents' admission

All the young people who were old enough to remember the parents' admission expressed a view that they had a role in or responsibility for picking up the signs of illness and/or seeking help. The level of responsibility varied depending on circumstances, with the presence of an alternative carer being the most important protective factor. Those who did not have another carer to support them were more likely to take responsibility for caring for their parents and seeking help for them. Dianne was 12 years old when her mother was hospitalised after taking an overdose. She has been in care since.

> *"It happened so fast. When I first went into care, I was in school. And I rang up my mum. She answered the phone, and I was talking to her and said 'Are you all right?' And I knew something dropping in the background and I kind of knew what it was 'cause it was a certain sound of a pill pot. And I went, what was that, she went I've just taken something, and then she didn't tell me anything else, and she hung up on me. And I told someone, and that's when the police and the ambulance went round"* (Dianne, age 15).



Like Dianne, whose account suggests her alertness to potential risk, some young people talked about their worries for their parents' safety and having to be vigilant to keep them safe.

> *"Just not leave her to her own devices but just make sure that she doesn't try and harm herself or anything"* (Naomi, age 16).

Young people's experience of hospital

Five young people who saw their parents at hospital all had negative experiences, which were influenced by their view of hospital's treatment of parents, parents' presentation and the environment. Some young people felt that their parents were not treated well or given the right treatment or even got worse during admission.

> *"It was such a horrible hospital. They really kind of messed her up. They gave her the wrong medication, they really really treated her badly. And I remember that because my dad was so distressed. His life partner is in this hospital and there is nothing he can do. They were not making her better at all but being in there was making her worse"* (Lisa, age 20).

In contrast, Lisa described how her mother received the right help in a mother and baby unit, much to the family's relief.

> *"It was nice there, I know my mum was happy there, and my dad was a lot happier, because he knew they were looking after her properly and also her having the baby with her helped her get better. It was a lot happier place, everyone there was happy and everybody there was helping my mum, doing this for a right reason so when we saw our mum there, we knew about her illness but we were a lot happier that we knew she was in a nicer place"* (Lisa, age 20).

Seeing parents receive help emerged as a crucial theme in what the young people wanted. The lack of help for parents was one of the major issues that caused young people distress and strong feelings such as anger, frustration, worries and a sense that they and their parents were abandoned.

Some young people saw their parents in hospital while they were unwell and found the experience upsetting. In these accounts, parents were often described as not being themselves.

"It wasn't nice. 'Cause she was still, she wasn't herself. I don't know what sort of the word to describe it, but she was sort of like, I know this isn't a nice word, but it's the only one I can think of. She was still a bit mad. She wasn't her. She was like, distant, and her eyes were glazed. And she was just, she wasn't her. And she was walking really slowly, talking about the stuff that wasn't my mum" (Helen, age 17).

Most participants expressed negative views about the hospital environment. Some worried that other "dangerous" or disturbed patients might make their parents' illness worse. Some young people commented on the lack of private space for families.

"They put her in to places with really dangerous people, someone totally rude or violent people" (Lisa, age 20).

"We were not allowed in her bedroom. We were only allowed in where all the families came and visit. There were like lots of people there at the same time" (Helen, age 17).

Lisa thought the presence of other patients in a mother and baby unit was helpful to her mother. She also has good memories of visits to this child-friendly unit, where they played and other patients were welcoming.

"It was a really nice big building, and all the women there had some kind of a problem, and they had their children with them, which was so nice for my mum" (Lisa, age 20).

Discussion

The findings support recommendations from the previous studies that children and families would benefit from a more family friendly environment and privacy in hospital. Although parents' hospitalisation leads to separation and potential disruption to family life, and in turn could result in an adverse impact on children, the accounts of the young people of my sample group indicate that the exposure to parents' disturbing behaviour also has significant emotional impact. This may have implications for children's needs for contact during parental illness. Whether the benefit of ongoing contact outweighs the impact of parents' symptomatic behaviour may depend on many issues such as severity of the parents' illness, illness's impact on the parental capacity in both practical and emotional care, the nature of the symptomatic behaviour, whether it involves children, children's experience of the parents' behaviour and meanings attributed to it, how they are coping and whether they have an alternative carer who can protect them from adverse impact.

The findings cannot be viewed as representative of young people's experience of parental mental illness for a number of reasons, including a small sample size and the method involved which is likely to have resulted in a volunteer bias. The participants and their parents were of the same gender in all cases. It was therefore not possible to explore male participants' experience of mothers' illness and female participants' experience of fathers' illness.

The study provides in-depth understanding of young people's experience from their own perspective, which I believe is helpful for both adult and child mental health professionals. The findings may help clinicians to recognise young people's needs and dilemmas and ask relevant questions to facilitate a conversation about their experience. The study also gives an insight into potential barriers to their voices being heard. Young people are acutely aware of discriminatory views of mental illness in their culture and community. Some young people talked about negative experience of professionals and had a strong sense of mistrust. Young people's loyalty, respect for their parents and protectiveness may make it difficult for them to voice their views. Some participants felt that their parents did not want to talk about the illness or it would be too upsetting for them. In some cases, this made it difficult for the young people to ask questions or seek information they wanted. Being able to talk, if and when they needed to, and being listened to in a context of a safe and supportive relationship emerged as a theme in what young people found helpful and wanted. When such a context was available to them, it helped them to make sense of and cope with their experience.

"I spoke to my mum about it, and asked her exactly how she felt and what happened. She was just explaining what happened in the hospital" (Lisa age 20).

"[Therapy] *helps me to cope. Helps me to bear it. Helps to know someone's just gonna, sort of, understands…it helps me to cope, basically, to bear it, sort of, 'cause it is a lot."* (Bushra, age 18).

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Note

The participants' names have been changed to preserve their anonymity.

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