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Children caring for parents with severe and enduring mental illness

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Children Caring for Parents with Severe and Enduring Mental illness

Findings of a two year study by the Young Carers Research Group (in partnership with Rethink, formerly National Schizophrenia Fellowship) which looks at the experiences and needs of children who care for parents with mental illness, their caring and filial relationships and the nature of professional interventions in these families.

- While parents with severe and enduring mental health problems in receipt of services via the Care Programme Approach (CPA) are generally satisfied with the type of support received from Community Mental Health teams, parenting and *family* support are rarely offered.
- Parents on Enhanced Levels of CPA support receive services from multi disciplinary teams of professionals but this can often be inconsistent or fragmented in nature.
- Parents with severe mental health problems often rely on their children for immediate, flexible and continuous care and assistance.
- Children undertake both domestic and emotional care responsibilities for parents with mental illness. Many will also take on some household management responsibilities.
- Current divisions between adult and children's services mean children are rarely consulted about their needs as children or as carers. However, professionals from both adult and children's services perceive the effects on children of co residency and caring for parents with mental illness to be wholly negative and damaging in respect of childhood experiences and psycho-social development.
- Parents themselves consider their children to be at increased genetic and psychological risk because of the nature and chronicity of parents' illness. However, children/young carers worry less about themselves and more about their parents' well being. Children's concerns and anxieties can sometimes be allayed by caring.
- In some instances caring can help to enhance parent-child relationships and can make children feel *included* when often, outside family environs, they are socially and politically *excluded* from health and social service practice.
- Parents and children/young carers continue to fear and experience discriminatory responses from local and professional communities and agencies that may lead to family separations or child protection procedures. These fears can adversely affect parents' mental health and well being over time.
- As carers, children are rarely included in discussions with professionals from statutory adult mental health and social services nor do they receive, on a regular or formal basis, needs assessments via the Children Act, the Carers (Recognition and Services) Act or the Framework for the Assessment of Children in Need.
- A formal strategy or device for recognising the trigger for the contexts in which young caring can and does occur, and for 'mapping' the experiences and needs of children who care, would be a useful addition to current assessment guidance for young carers and children in need.

Parental mental illness and young caring in context

Research from both medical and social work tells us little about the experiences of children living with a parent who has severe and enduring mental health problems. Evidence from more recent work on young caring tells us less about childhood and caring experiences in the specific context of parental mental illness. Medical investigation and child protection studies suggest that children are at increased risk of a range of adverse consequences when parents have mental illness. These include susceptibility to genetic inheritance, risk of significant emotional and physical harm and serious developmental delay. However, few studies have focused on furthering our understanding about the experiences of children in these contexts from the perspectives of *children and young carers themselves*. Nor has empirical work been concerned with understanding the perspectives of parents in these contexts.

Prevalence of young caring

- Recent NSPCC data suggest young people aged 18-24 have a 4% chance of being a young carer in their childhood.
- YCRG calculations suggest that young people aged 18-24 have a 1.3% chance of caring for a parent with mental illness during their childhood.
- Extrapolating from Office for National Statistics data, at any one time between 6000-17000 young carers may be caring for mentally ill parents.

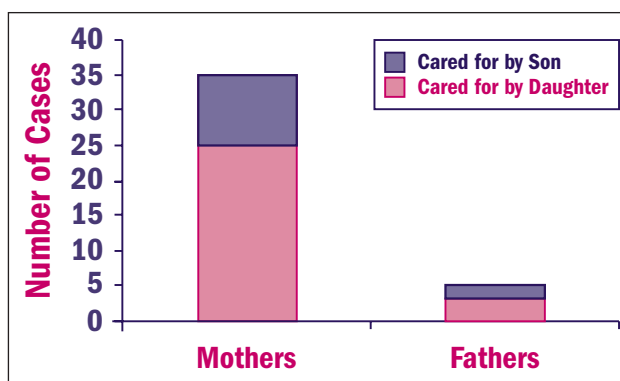
About the study

This study includes the accounts of children (young carers) and parents with mental illness (as well as the professionals involved in the formal care and support of parents) using two phase (semi structured) interview methods, which allowed any changes in parent, child and family circumstances to be monitored and understood over time. Forty children were interviewed about their experiences of co residency and caring for their mentally ill parents; parents themselves (40 respondents) were asked to describe and talk about the nature of their illness, their relationships with their children and their experiences of mental health and other health and social service interventions. Families were asked to identify their key workers, who were then also included in the study. Interviews were conducted at the outset of the project (once the sample had been selected) and ten months later. While the process of sample selection was made more problematic by the nature of the parent respondents' illness – parents could be both wary and changeable about participating in interviews – once interviews had taken place the data obtained revealed a complex picture of parental mental illness and children's experiences of co residency and care. This picture often conflicted with the representation of adult mental illness

(and its effects on children) from medical and social work investigations and particularly from media representations of people with mental illness living in local communities.

Parental mental illness and young caring: breakdown of samples

Gender of Parents and their Young Carers



Families

	Cases
Lone parents	25
Two parent families	15
Parents in paid employment	1
Parents subsisting only on benefits*	30
Parents with only one diagnosed mental illness	11
Extent of comorbidity (more than one mental illness)	18
Comorbidity and other physical health problems	11

* 9 partners were in paid employment

Range of mental illness and combinative mental and physical illness

	Cases
Depression	29
Manic depression	8
Schizophrenia (including paranoid schizophrenia)	7
Borderline personality disorder and personality disorder	7
Others	8

NB: parents could have more than one diagnosed mental illness

Outcomes for parents

When considering parental mental illness, symptomatology and the implications for children of living with and caring for parents thus affected it is necessary to understand the aetiology of mental illness not simply in pathological terms but also in relation to the ecology of

illness. Mental health problems neither occur nor persist independently of the environment, circumstances and life experiences of those affected. In the same way the onset of caring by children arises not only as a consequence of parental illness in isolation. In this respect it is necessary to recognise genetic, expeditious and enduring factors that can influence the onset and chronicity of mental illness among adults and, when they are also parents, the same dynamics that help to inculcate and maintain caring responsibility among children. Genetic factors are undoubtedly significant (children are at increased risk of inheriting mental illness from a first degree relative, for example. By the same token 1 in 4 of the general adult population will experience mental health problems at some time in their lives). We found little evidence of genetic susceptibility among the parent respondents in our study, rather the predominance of expeditious and enduring factors.

Expeditious factors such as life events and trauma, including divorce, bereavement, sexual or physical abuse can trigger mental illness (out of the 35 mothers interviewed for our study, 23 had been sexually or physically abused and said they thought this had been a major factor in the onset of their mental health problems) and, alongside enduring factors, can also contribute to its chronicity. Enduring factors which can help perpetuate symptoms and outcomes of mental illness include:

- **the nature of the mental illness itself and its treatments (incidence of co morbidity, chemical medications and other treatments and their effects).**
- **environmental and demographic influences (quality and location of housing, neighbourhood and community attitudes, including discrimination or prejudice).**
- **economic and financial factors (employment status, poverty and debt issues, access to and adequacy of benefits, social exclusion and isolation).**
- **the nature and effectiveness of formal and informal interventions and support (the range, consistency and continuity of support services, the availability of family interventions, support to children as well as help and assistance from neighbours, friends and relatives).**
- **family concerns (for example, the fear of separation and hospitalisation can have profound impacts on parents and children).**

“I had one occasion ...I'd only been in a job one day and somebody recognised me and told the boss that I was a mental health patient and he got rid of me that day.”
(lone mother with manic depression)

“I don't want my son to end up like I have. I mean, really, I don't think I'm a fit mother for him ...but I love him to bits. I've tried to be a good parent. I've tried everything I can. I've had to bring the three boys up on my own...”
(lone mother, with depression, epilepsy, asthma and thrombosis)

Outcomes for children

It is in these contexts, and particularly where formal support services are exclusive (i.e. patient led), inconsistent and discontinuous, that young caring occurs and persists. Furthermore, children's exclusion from care plans and medical, health and social care interventions helps to perpetuate the adverse consequences for them of co residency and caring for parents with serious mental health problems.

Depending partly on the nature of their parent's mental illness children undertake a range of caring responsibilities for their parents. These include domestic support and some household management (cleaning, cooking, and shopping), which can increase when parents become incapacitated by their illness (for example, when a parent's depression means they become bedridden). Emotional support by children includes a range of tasks that are less easy to quantify or 'measure'. For example, children describe 'sitting with parents' when they are unwell; 'helping when mum can't stop crying'; 'being there when things are bad' etc. In some cases children themselves do not understand the extent of their 'caring' responsibilities. Parents often conceal from their children the fact that if they (the children) weren't available to lend support during difficult times, suicide or self-harming would have been 'the only' option for parents.

Unfavourable outcomes for children of co residency and caring for parents with mental health problems also include children worrying about parents' immediate and long term well being. Children are often afraid of the consequences of asking for help for themselves or of disclosing the nature of their care responsibility to others outside their immediate family. Worrying about parents is a key factor in children's lack of concentration and performance at school. In some cases, helping in the care and support of parents can serve to allay these fears among children and can also help consolidate parent child relationships. Caring can also serve to offset some of the adverse consequences of symptomatic behaviours among parents that can lead to emotional 'absences' particularly during difficult times in their illness.

“I like make (mum) laugh and that, and she'll start laughing, we'll have a laugh and a joke and that. She'll forget all about it, and then I know I've helped. Or when she's struggling, I know I can help her and then, it's just a sense of achievement.”
(Mark, 14)

“She is just so funny, you know, when she's well, she is just the best mum ever. She's not like a normal mum, you can tell her about anything ...she'll understand. And then when she's not well, then we still get on with her, because even though she's nasty to us, I haven't got the heart to be nasty to her back. Because I still love her, and it's not her fault.”
(Julia, 15)

Implications for professionals and for practice

Parents with mental illness, their children/young carers and families as a whole will be supported more effectively when the division between adult and children's services is successfully addressed and reconciled. This involves addressing the current 'patient led' approach, particularly among statutory professionals from mental health services, that leads to adults with mental illness gaining access to a range of inputs from multi disciplinary teams but their children being excluded (through professional lack of awareness, poor practice, limited resources etc.) from statutory support and consultation.

Implications for practice include:

- increased awareness among professionals about the impacts of mental illness on affected parents and their children, and the implications for children of caring in these contexts.
- formal recognition of the triggers for the contexts in which young caring occurs.
- assessments for children as potential children in need and as carers. Assessments should also empower parents with mental illness as parents rather than scrutinise their 'parenting capacity'.
- development of a formal strategy for mapping and monitoring young carers' experiences and needs based on a family approach.
- statutory professionals, particularly from adult mental health teams, need to recognise when their patients are also parents and that sometimes children can be undertaking caring roles and responsibilities that they may or may not want to take on or that may be age inappropriate. This requires a family oriented, inclusive and anti discriminatory approach.
- children as children and as carers need to be included in decision making and consultation with professionals from adult and children's services. Children also need to have their contributions to care recognised and choice should be conferred which allows children to continue or to stop caring.
- children's caring roles and responsibilities can be reduced or even prevented if families receive good quality, reliable and appropriate health and social care support and services.

"A lot of the generic cpns (community psychiatric nurses) in this area have caseloads of upwards of 50-60 people. I've got a caseload of 12. And that's capped. So I can spend far more time looking at all the aspects of the problems people have rather than just mental health problems."

(cpn)

Principal researchers

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Where to find more evidence

Aldridge, J. and Becker, S. (2003) *Children Caring for Parents with Mental Illness: perspectives of young carers, parents and professionals*, Bristol, The Policy Press.
ISBN: 1 86134 400 7 (hard cover)
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Full details of other outputs can be found on the Young Carers Research Group website: www.ycrg.org.uk, in the CCfR brochure or on the website: www.ccfr.org.uk

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