

RESEARCH BRIEFING

**GROWING UP WITH A PARENT WITH
MENTAL ILL HEALTH: MAKING SENSE OF THE
EXPERIENCE THROUGH THE REFLECTION
OF ADULT OFF SPRING.**



GROWING UP WITH A PARENT WITH MENTAL ILL HEALTH: MAKING SENSE OF THE EXPERIENCE THROUGH THE REFLECTION OF ADULT OFF SPRING.

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WHY IS THIS STUDY IMPORTANT?

Significant numbers of children are cared for by a parent with mental ill health across the UK. Although it is generally accepted that this can have a weighty impact on them through childhood both in terms of physical and psychological outcomes, little is known about how the children make sense of it themselves or how this subjective experiences changes and perpetuates through to their adult lives. These children are a hidden population, their numbers are not counted and their specific needs are not highlighted. While professionals in health services, adult social care, and children's services acknowledge the vulnerability of children growing up with a parent with mental ill health, these children fall through the gaps of service provision, unrepresented and silenced.

AIM OF THE STUDY

The aim of this PhD study is to improve policy and social work practice by developing our understanding of the subjective experiences of adults who grew up with a parent with severe and enduring mental ill health and the impact across their life course from childhood to adulthood. Specifically it focuses on how, as adults, they make sense of their childhood, their family narrative and how it impacts on their own adult identity and life.

Key objectives were:

- To describe how individuals understood and felt about their parent's mental ill health, both as adults and also through the retrospective accounts of how they felt as children and adolescents.
- To identify ways in which individuals made sense of and coped with their experiences of parental mental ill health throughout their life course
- To investigate individuals' perceptions of the effect their parent's ill health had upon their development and their current interactions with the social world.

HOW WAS THE STUDY CONDUCTED?

Two clear decisions were made in the design of the study. The first was to interview adults who had grown up with a parent with mental ill health, asking them to reflect on their childhood and thus gaining insight in to the changing nature of experience and understanding across the life course. The second was to not to define mental ill health by a specific diagnosis as it was the individual's experience and not the etymology of the illness that was of interest. This also allowed me to open the study to those whose parents may not have engaged with mental health services.

Twenty individuals were recruited using volunteers after my public speaking and through special interest groups and social media. They ranged in age between 19 and 52, and consisted of five males and fifteen females from five counties in the UK. Within the interviews twelve spoke about their mother, five their father and three both their mother and father as having mental ill health.

They were interviewed using an open biographical method, wherein they were asked to tell the story of their childhood and then left to construct the narrative without prompt or interjection from the interviewer. The interviews lasted on

average 2 hours and 15 minutes.

The data were then analysed using a Thematic Narrative method: transcripts were coded and emerging themes were visually mapped for each participant. Alongside this, a chronological timeline was developed from each narrative identifying framing devices such as turning points, strategies and identity statements. Each timeline was annotated with interpretive notes of both the research and the participant. The social construction and often co-authored nature of the narratives was particularly interesting. Finally, through an iterative process of expanding and collapsing thematic categories, a framework of understanding could be applied across the data set.

KEY FINDINGS

Family dynamic

Family structures and the roles within them are complex and dynamic, they provide the primary frame through which children make sense of themselves and engage with the world around them. The relationship the participants had with each of their parents was significant, This was both in terms of the expectations that they had of them and the potential ability that the 'well' parent could act as a buffer between the child and their other parent's mental ill health. However for the majority of the participants, this appeared to be gendered with participants expressing a higher expectation of nurturing towards their mothers. Their memories of the response of the well parents were that the well mothers largely appeared to 'step up and step in' while the well fathers generally avoided and absented themselves from the dynamic.

The importance of siblings was also raised across the interviews either as an expressed longing of lone children to have had a sibling with whom to share the experience, or as siblings discussing their experiences together. Both the practicalities and perceptions were often very different for siblings. An interesting dynamic emerged, within which older siblings took a primary carer role during childhood, protecting their young siblings from the burden or responsibility of their parent's mental ill health. However as the siblings entered young adulthood, it appeared to be the older siblings that left home first, leaving the younger siblings stepping in to the caring role and feeling unable to leave home themselves, as it would leave their parent alone in an empty nest.

Relationship with ill parent

The relationships participants described with their parent were coloured by the understanding of their parent's mental ill health. For some they felt they were drawn closer, while others felt that the illness drove a wedge between them and their parents, disrupting the parent/child relationship. Many spoke of the boundaries and roles expected within a parent/child relationship becoming blurred. At times this seemed reversed as the participants recalled having to parent their own parent. The level of warmth and connectedness was key to participants, with several recalling feeling rejected and unworthy, which had long term impact on the participants own self-esteem. This emotional disconnect appeared to have a greater influence into adulthood than the physical aspects of care they may have provided. A theme that carried through into the participants' adult narratives, was that of mourning the loss of the relationship with their parent. For some

this took a grieving aspect as they felt the mental ill health represented a figurative death of their parental figure.

Making sense of the illness, managing the risk

Participants recalled becoming aware of their parent's mental ill health in a variety of ways, such as a sudden critical incident or a gradual realisation. Their age and the manner in which they became aware of their parent's mental ill health was significant in terms of how they made sense of it, and their role within it. Another significant factor was the behaviour they saw in their parents which they attributed to the mental illness.

Behaviour which was highly emotional, unpredictable and risky was the most difficult for the participants to manage. However, chronic detached or emotionally flat behaviour had longer term negative connotations for participants. They spoke about the high levels of perceived responsibility and sophisticated strategies that they had to develop to keep both their parents and themselves safe. These strategies served to both minimise the distress and/or potential triggers for the parent and to protect the family from intervention from services, which they feared as being negative and stigmatising.

For a large number of participants the way they managed this burden psychologically was through a process of beliefs and behaviours which have been built into a model of acquiescence. Within this model the primary concern is the parent's mental ill health and the management of the associated behaviours. In response to this the child sees themselves as being responsible for and secondary to the mental ill health; it is about what the parents need not about what the child might need or want. They do not have an expectation that their needs would or should be met, and do not feel justified to express anger about this as it is not the parent's fault but rather a consequence of the mental ill health which is beyond anyone's control or reproach. This lack of regard for self can be exacerbated by the sense of personal blame the child takes for the mental ill health and the parent's subsequent distress. It is also mirrored for the child in the apparent lack of regard or protection that some children received from others, including professionals.

Identity

Many of the participants described their childhood identities as having been constructed in response to their parent's mental ill health rather than through a period of exploration. This was either to disguise the specific circumstances and differences in their family life, that they felt would set them apart from their peers, or in an attempt to present the best version of themselves to manage their parent's illness and the expectations of others. This was described as impression management rather than a true representation of identity, which can be linked to Goffman's presentation of self. Several participants based their identity and self-worth around their protective role towards their parents and the care they provided to them which gave them purpose, place and significance.

Some recognised this as a specific role, such as being a young carer, while many others were not aware of this term until their adulthood. This lack of clarity was attributed both to the term not being widely used during their childhood and because the level of care that they provided was not

adequately recognised.

For many of the participants, speaking about their identity, which was a powerful theme, was around the impact on their childhood memories. This was specifically in terms of memories being distorted or lost altogether. Some participants reflected that this was indicative of the kind of psychological protective processes associated with experiences of trauma.

Impact as an adult

While exploring how their parent's mental ill health had impacted on them in the longer term, many of the participants spoke of adversity, neglect and at times abuse and generally appeared to minimise the effect that it had had upon them. This minimisation could represent a stance taken from the model of acquiescence. However, others took it further and presented it as a redemption narrative stating that they wouldn't change anything, it made them the way they are. They even drew benefit from it, specifically that they were more equipped to help others.

Half of the participants were in committed relationships and while they saw that their childhood experiences had some impact upon them, which ranged in significance and complexity, it had not prevented them from making a meaningful connection with another. Others felt that their experiences either physically or psychologically prevented them from forming adult relationships.

Another tangible impact identified by participants was that of curtailed opportunity and potential during their childhood and into their adult lives, while only one of the participants could be defined as living in a precarious manner (with no paid employment or permanent address). The majority of participants described feeling they had been held back or were compelled to hold themselves back to provide a base from which they could respond to the next episode of parental mental illness.

The sense of holding back also arose from an insecurity in the robustness of their own mental health. While there were not a significant number of participants who reported having mental health problems, a high number described themselves as being excessively worried about their mental health, having to constantly monitor and check themselves and avoid situations they fear might trigger mental illness. For one participant this anxiety and fear of mental illness extended to her children in a way that she recognised was, at times, detrimental to them.

Of course as children grow up, the relationship with their parent endured as did, in many cases, their parent's mental illness. As such, the majority of participants described still providing a substantial level of care to their parents, which was a role and responsibility they could not foresee coming to an end. Several participants responded to this by putting in place firm boundaries, and in many cases managing these boundaries by moving to another geographical area, thus placing a physical distance between them and their parents.

These boundaries became key again for participants who had or were expecting their own children. It was striking that not only did they have to reflect on what kind of parent and family they wanted to be, they also had to set terms and conditions

in order to feel able to manage their ongoing relationship with their parent, and plan how they would orchestrate the relationship between their child and its grandparent. For many, this was about establishing with their parent that they were no longer their primary concern. For one of the participants, this extended as far as ceasing all contact with her father as her children were born. Their focus was on protecting the child from the emotions they themselves had experienced, they couldn't protect themselves but were determined to protect their children. However, for some it forced them again to reflect on how their parents could have been uncaring and harmful in ways that their mental ill health did not fully explain.

Service intervention

It is clear that children growing up with a parent with mental ill health face many of the same challenges that adult carers encounter. Specifically in terms of the disconnect between themselves and services, and being intrinsically involved in the provision of care yet at the same time not included in the decisions made either about the level of care needs or the role of mental health services in meeting those needs. However, with children and young people the likelihood of this disconnect and its impact upon themselves is increased exponentially. They are a largely hidden population all too often overlooked by services. When they do come into contact with services there are significant barriers to communication on both sides. While they provide a substantial amount of care for their parents this is difficult to quantify as are the needs they have themselves as children which are, generally at times neglected.

Nevertheless when asked to reflect on what would have made things better for them as children, the overwhelming sense was not a radical intervention in their family life, it was not a complete removal of their care tasks, although for many it was clear that respite would have been greatly appreciated. The predominant points that participants made were to feel included, to be noticed, acknowledged, respected and considered. This inclusion not only would have made their care tasks more manageable both on a physical and psychological level but would also have ameliorated many of the other issues such as attending school each day without constant worry and forming relationships with peers.

Discussion

A key insight drawn from this study is that regardless of the age of the participant, they remain the child of their parent with mental ill health and as such continue to have the same complex emotional connection. The needs of the child shift and change both in response to the progression of their parent's mental ill health and their own emotional and social development. However, in some cases these needs remain hidden behind a skilfully crafted veneer of resilience, which is built upon a model of acquiescence. This

encompasses the belief that their needs are secondary to others, that they do not matter and cannot make demands of others; that asking for help is risky and finally that they are responsible for holding things together. Findings showed that the ability to step out of the role of child of a parent with mental ill health and reflect upon themselves as autonomous and independent, is key for an individual's personal well-being and fulfilment. This was reflected in an overarching theme within which participants spoke of attempting to create and maintain a distance between their parents and themselves, both physically and psychologically. To do this the participants were not asking for a reimagining of their childhoods or an eradication of their parent's mental ill health. Their experiences had made them the people that they were and, on the whole, they loved and valued their families in their entirety. The findings and analysis suggest they required their vulnerability to be recognised for their needs to be acknowledged and their model of acquiescence to be challenged.

Key Implications for policy and practice

There is a raft of policy which could be utilised to support children growing up with parental mental ill health. However each child's family dynamic is different; their relationship with their parent and the world around them is unique and the manner in which they experience and make sense of their parent's mental ill health is deeply personal. Professionals need to be able to recognise the needs of these children, young people and adults and offer support, driven by research and policy in a flexible and adaptive manner. Support should reflect and adjust to meet the needs of the individual at different stages of their life course, and their level of vulnerability or resilience at that point. Most crucially, any support or provision must be co-constructed with the individual and be meaningful to them, as opposed to being bureaucratically applied or tokenistic.

Key Messages for Practice

- Children growing up with a parent with mental ill health generally do not want sympathy for themselves or judgement levied against their parents. They do not want their family life to be radically different or for professionals to step in and take control.
- What they do want, and need, is to feel visible and valued. They need to have the space to consider their own needs and to have those needs acknowledged by others. For someone to reassure them, 'I know this is difficult, you're doing well, it's not your fault' and an interested adult with whom they can talk about their experiences and feelings.
- They want the care they give to their parent and the love they hold for their family to be respected, for their voice, opinion and concerns to be considered, and finally to be included, truly included not silenced and hidden.

FIND OUT MORE

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EXECUTIVE SUMMARY www.uea.ac.uk/documents

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