

# **Adult Children of Parents with Mental Illness: Losing Oneself**

## **Who am I?**

### **Abstract**

There is a limited body of research that focuses on experiences of families of people with mental illness. While the body of knowledge concerning children of parents with mental illness is increasing, there remains limited discourse surrounding the experiences of adults who have lived with childhood parental mental illness. This paper examined one major theme of a study focusing on parenting narratives of adults who had experienced childhood parental mental illness. The narrative study from a metropolitan area of Australia, reflects adult children's experiences of being overwhelmed with parental mental illness. They felt unsure of their own emotions and felt they had lost a sense of who they were as individual people. Adult children felt confused about their sense of reality, particularly for those whose parent had a diagnosis of schizophrenia or psychosis. Their experiences of loss were closely associated with changing self identity. Further, many of the narratives demonstrated experiences of grief for adult children. Greater understanding of adult children's perceptions of being parented by a person with mental illness, alongside their experiences of loss, has the potential to help health and social care professionals to facilitate greater resilience for families who are living with parental mental illness.

### **Background and Introduction**

There is a general acknowledgement within the literature that children of parents with mental illness are at risk of reduced individual wellbeing and developing their own mental health concerns (Foster et al., 2014). Reupert and Maybery (2007) explicitly noted experiences of reduced "social, psychological and physical health" (p. 362) outcomes for children of parents with mental illness, when compared to children of parents without mental illness. Their study reported children's experiences of attachment problems which were thought to contribute to longer standing relationship issues and maladaptive coping skills, even into adulthood. Specifically Reupert and Maybery (2007) highlighted the attachment bond between parent and child, arguing that a child may seek "sensitive, responsive nurturing" cues from a parent but may actually receive emotional inconsistent responses as a result of parental mental illness (p. 363). The findings by Reupert and Maybery (2007) were more recently corroborated by Pakenham, (2014) when comparing children's experiences of parental mental illness to other familial illnesses such as cancer. The greatest risk to children's wellbeing was clearly associated with parental mental illness compared to any other illness and family member affected

(Pakenham, 2014). This is concerning given data from Australia, highlighted approximately one quarter of children are currently living in families where at least one parent has mental illness (Maybery et al., 2005). Whilst the World Health Organisation (2013) have not presented national or international statistics regarding the number of children currently living with parents with mental illness, they have noted a need to address the mental health needs of children when their parents present to mental health services.

Despite consistent findings about the risks to children who experience parental mental illness and calls for family based practice, there remains limited development in clinical based familial mental health care (Reupert & Maybery, 2014). There have been calls for a multi dimensional approach to support for children of parents with mental illness, ranging from policy changes, societal based considerations (such as: stigma reduction programmes), family based support and parental interventions, alongside work with individual children (Reupert & Maybery, 2007). Whilst there are examples of attempts to develop practices to better support children of parents with mental illness, such as systems to clearly identify children of parents presenting to mental health services (Lauritzen et al., 2014a) and peer support programmes (Foster et al., 2014), progress is limited (Lauritzen et al., 2014b).

In summary, it is anticipated that 23.3% of children are currently living with parental mental illness (Maybery et al., 2009). There is a common risk-based discourse regarding their experiences and needs. Further, whilst there is a knowledge base about the longevity of risks into adulthood, research regarding adult children's stories of self development in light of their childhood experiences of parental mental illness remains scarce. With this in mind, this study sought the parenting narratives of adult children who had experienced childhood parental mental illness. Parenting narratives included being parented in addition to their own subsequent parenting roles.

## **Methodology**

The conceptualisations of narrative inquiry and analysis are not new. Narratives have been considered in both social sciences research (Franzosi, 1998) and psychological work (Quasthoff & Becker, 2005). Humans construct accounts of their experiences with the use of language and narratives (Quasthoff & Becker, 2005). Czarniawska (2004) supported this positioning when highlighting that “narratives are a mode of knowing” (p. 6), as well as a mode of communication. Quasthoff and Becker (2005) contributed to the discourse surrounding narrative inquiry, arguing that the use of narratives allows a narrator to portray their experiences with the use of story characters, including attitudes, behaviours, thoughts and emotions. Yet, narratives to explore one's experiences of illness are limited. Consequently, Kleinman (1998) acknowledged

that there is limited debate and inquiry about illness narration. The authors of this paper argue that this is not unique to the person directly experiencing illness, but also to their family members and carers. In essence, there is a paucity of experiential illness narratives. With this in mind, this paper offers a narrative study, within a social construction frame, for adult children who have experienced childhood parental mental illness.

After approval from an Australian university Human Ethics Committee, media organisations published information about the study using newspaper and radio modes, inviting people to make direct contact with the study researcher. Adult children were invited to participate in the study, to construct their narratives of being parented by a parent with mental illness, alongside their own parenting journeys. Details of the study were provided to potential participants to ensure informed consent for the research study, as agreed with the Human Ethics Committee. Prior to meeting with the researcher, social demographic information and information related to their parents' mental illness was collected from participants. This ensured they fulfilled inclusion criteria and were eligible to participate in the study. The study inclusion criteria consisted of: over the age of 18; have a parent who had been diagnosed with a mental illness; currently a parent, with or without ongoing contact with their own children; English speaking and participants who had not been diagnosed with a mental illness themselves.

All participants met face to face with the first named author on university campuses or private rooms in community centres. During the meeting, participants were asked two main broad questions relating to their experiences of living with a parent with mental illness and their own parenting experiences: What were your experiences of being parented by a parent with mental illness? and What are your own parenting experiences? Thereafter, participants constructed their narratives with minor and limited interjections from the researcher to further expand or to clarify information. As alluded to by Quasthoff and Becker (2005), this allowed participants to be the narrator of their own stories, whilst providing freedom for individuals to establish story characters, events, perceptions and emotions. All of the researcher and participant meetings were audio recorded and professionally transcribed.

There were 13 participants, 10 women and three men, with ages ranging from 30-78 years old (table 1). Analysis was undertaken in a variety of stages, as emphasized by Cassell and Symon (2011) who highlighted the importance of a structured approach to data analysis in order demonstrate study trustworthiness. Initially all de-identified transcripts were reviewed by the research team making note of any obvious themes. Themes from individual participant stories were correlated into major themes and subthemes which were agreed upon by the 4 members of the research team. In addition, all transcripts were reviewed to generate narratives of

childhood, teenager, early adulthood, adulthood and parenting periods. Continual discussions and reflections within the research team ensured trustworthiness of the study, methodology and findings.

## **Findings**

This paper presents one main theme from the findings of the study: a loss of self for adult children who experienced parental mental illness. Other themes, include adult children's experiences of fear and mistrust (XXXXX et al., 2015a) and navigating stigmas and secrecy (XXXXX et al., 2015b) are presented elsewhere. Participants' narratives demonstrated a loss of emotional connectivity with others, a loss of social integration and a perceived loss of opportunity during their childhood. However, loss of knowing oneself was most apparent. All of these factors contributed to the adult children's perception that they had lost awareness of who they were as people; their own sense of reality for some participants and a sense that they didn't really know which emotions they should be feeling. They had lost some degree of their own emotional literacy, in terms of understanding and interpreting their own day to day emotions.

## **Questioning who I am or who I have become**

*Sometimes I don't know what emotion I should be feeling*

Many participants made note of their childhood observations of parental emotions. Some participants reported feeling that as children, they were responsible for their parent's sadness or aggression. Others made alternations in their own childhood behaviours or emotional expressions in an attempt to make the parent better or feel better. Nicole described her experiences of living with her mum who demonstrated mood changes.

*"She would be - she would go from - sometimes she would be very down and very dark, like kind of a black mood. I couldn't shift that. Like, it was - yeah, there wasn't anything I could do about it. Other times she would be quite volatile, like the walking around the house, and the swearing, and banging doors and things like that."*

Nicole made reference to her mother's request to leave Nicole in Australia, so she could travel overseas. Feeling like she herself, had caused her mother's sadness, Nicole reluctantly agreed for her mother to travel. Despite leaving Nicole feeling lonely and sad, Nicole gave greater emphasis to her mother's needs, as opposed to her own.

*"I see myself as being quite parentified in that age. She was very emotionally dependent on me. She wasn't - she didn't have any friends. She didn't have good relationships with other family members. So she sort of relied on her and my relationship as really the only kind of positive one. She was quite lonely and isolated. She would talk about those feelings to me when I was quite young.*

*I think when I was about nine she decided she'd go overseas. I accepted that because I sort of had this sense that Mum had this terrible life and that she needed to go and do something for herself, that she should - that she deserved some kind of life. I suppose, for me, it was sort of a feeling that having me was the cause of that. Yeah, yeah, yeah. So, you know, it was like a bit of a sacrifice, I suppose."*

Many of the events which participants noted, contributed to a sense of mistrust of the parent with illness, by the child. In addition there was clear evidence that the child's positioning of a social 'self', 'me' and 'I' as opposed to a social 'us', 'my family' and 'community' developed. However, the notion of 'self', 'me' and 'I' developed with a disproportionate sense of responsibility for parental emotional well being and parental public behaviours. Furthermore, there has been evidence from the study, that the notion of 'self', 'me' and 'I' were developed with a gross underestimation of the participant's own value and worth to others in their family. All of their needs, including, emotional wellbeing, had less importance as those of other people. Their sense of themselves as people was not paralleled to how they viewed others in their family and wider community. Their sense of self was becoming lost.

The sense of responsibility that adult children had for other's emotional well-being, was not uniquely centred around the parent with mental illness, but was also identified as a major finding for participants with siblings. Three of the participants who had older siblings highlighted the protection they felt from them. They noted that older siblings often knew more about the parental mental illness. Older siblings often attempted to maintain the participant's innocence about the parental mental illness by making no disclosure to them. However, this approach only helped participants in the shorter term. As the parental symptomology increased in frequency or intensity, the children with older siblings noted that they found it exceedingly difficult to understand their parental and familial experiences.

A common theme among participants who were the older sibling, was the overwhelming responsibility they felt to protect their younger siblings. They would actively withhold information from the younger sibling or would try to ensure that they were not physically

present at times when parental symptomology was evident. This resulted in the older sibling's continual hyper vigilance of the parent's presentation. Several of the participants became distressed during the research space, when discussing the responsibilities they felt for their siblings. The adult children felt that they had not been able to protect their younger siblings to what they believed was a suitable level, resulting in additional guilt and sadness.

The participants noted that during their teenager years they became acutely aware of the difference between their family and other families. In addition, they were becoming increasingly intolerant of their daily experiences. The adult children noted that they had to make additional efforts to maintain their own emotional well being. The findings demonstrated a significant period where participants reported feeling they had become, or were becoming emotionally and psychologically overwhelmed as individuals, by their experiences. Living with ongoing isolation within the family; active isolation from others; living with their day to day experiences of parental mental illness symptomology and continually trying to navigate the parental and child relationships was difficult to deal with. They felt they were becoming so overwhelmed that their own sense of self was diminished. The adult children themselves felt they were becoming lost and felt unsure of who they were. Several participants recalled questioning their own identity. Jenny highlighted this

*"It looked as if I was maintaining a double life, if that makes sense. I felt that at school I had to portray this really nice girl and at home I had to portray the adult because my mother relied on me. So I became the cleaner, the cook, everything. My mum just sort of switched off. She just used to go to work and come home. My father was working so I became the parent to my brother. So it was a really, really weird stage in my life. I remember when I was 15 I started questioning myself as to - how do I put it - I used to watch TV and I would try to be the strong person that was on television, if that makes sense. If there was an actor and I liked his qualities, I wanted to be like him."*  
(Jenny)

Several adult children had been drawn to characters on the television as role models for their development, or as Jenny alluded to, to model appropriate coping skills for them to mirror. Given the recognized isolation from adults both within and outside of the family unit and the negative social stigmas associated with parental mental illness, copying the behaviours of children on television or in the media seems to have been at least one available option to help guide participant's social development.

Several participants had developed or assumed differing public and private beings. Adult children perceived the need to maintain a suitable social self which could be presented to others, to be of greater importance than declaring their own emotional needs to others. They noted that they felt they lived differing lives within the home and outside the home in a public environment. Being in a public environment created some normality for them, but they also had to return home with the knowledge that they would be re entering a confusing and lonely world. Several adult children identified that after years of living with a parent with mental illness, particularly with some nature of psychosis, that they themselves found it difficult to ascertain fact and reality from their parents' delusional content and world. A common theme among the participants confirmed that this also happened with their emotional being. They noted that they had differing public and private expressions of emotions. In keeping with the concept of emotional labour, participants felt differently to what they actually expressed. After some time they had become confused about their own emotional being. Maria summarised this

*"Sometimes I don't know what emotion I should be feeling if that makes sense. I tend to internalise quite a lot like I said before, it takes a while to crack me. I guess my first reaction is always anger. I've actually - I think in the last five years I've really changed a lot actually. It's not so much anger anymore, it's more - what would it be? It's probably sadness, I don't know, I can't really think. I mean it's probably more that I don't know what I should be feeling.....I think I was always quick to anger but now I'm not - because I know that - it's not what I am, it's not the feeling I'm feeling but I just used to be angry because I didn't know how to express other feelings."*

Jenny elaborated that she had become adjusted to actively hiding her own emotions during her childhood. She herself, began to create a make believe world of her own emotions. Others began to actively hide their own emotions as Nicole's comment featured:

*"I just kept very quiet and tried not to affect her mood..... when I talked to her about it later, when I was a young adult, and I said, you know, I found that really hard, she (Nicole's mother) said, oh well, that was my way of letting it out. I thought it was better that I let it out than I did something to you. She couldn't sort of see that it did do something to me anyway, yeah."*

In Nicole's narrative, it is evident that she made reference to the greater questioning of childhood experiences of parental mental illness as her age increased. However, she also introduced the notion of perceived enforced emotional silence. Clearly, she articulated that the consequences of emotional expression are more stressful to her than saying nothing at all, so

she made an active decision to limit her own emotional expressions. However, Nicole has acknowledged that there is a personal consequence and impact to perceived enforced emotional silence. Maria also alluded to the notion of emotional expressions being associated with further negative perceived consequences on the adult child.

*"I've never been able to open up and be - not complete like honest with her but I can't - I feel like I can't project my problems onto her so therefore I don't have that - someone to help me through them at that level."*

Interestingly, Margaret started her narrative within the research space, wanting to highlight how her family protected and supported her mother. Margaret sought to positively position the familial support for her mother. Yet, the context of her narratives quickly changed positioning, when articulating her own emotional needs and development. She noted:

*"So for what reason I don't know, but I just decided at an early age that you couldn't look into things too deeply. You just take them on face value and that's how it was."*

Many of the participants recognised their own increased questioning of their situation during their teenager years, in the absence of additional support. This often led to the participants feeling confused about who they were and how they actually felt or their own emotional being. Several participants noted that they spent several years during their teenager years feeling lost, emotionally struggling and trying to find themselves.

## **Discussion**

In the absence of trust for others, whilst attempting to maintain conformity to expected social behaviours and relational expectations, it is postulated that adult children, create an external persona, which they believed would be acceptable within the public domain. This is one explanation to the findings of the study, that adult children create a public versus private emotional and thoughtful being. A significant finding of the study noted an altered development of the self, or process of loss for the adult children. They either had thoughts and feelings which they felt unable to express, to let others know their true self or alternatively, they were unsure of what they themselves felt. This was further reinforced by participants when they felt they had to find themselves, they had to find out who they really were as people during self recovery.

Experiencing loss and becoming lost as a person was a central theme of the findings for adult children. The experience of loss and grief is not unique to bereaved people (Papa, Lancaster & Kahler, 2014), but considered a part of day to day lives. Regardless of its origin, loss is thought



to "evoke intense and often overwhelming sadness, anger, regret and other powerful emotions" (Bonanno, Papa & O'Neill, 2002, p. 193). Loss and the intensity of the subsequent bereavement journey is thought to be associated with self and social identity alongside resilience (Bonanno, Papa & O'Neill, 2002). A study offered by Kosenko and Laboy (2014) considered survival narratives. In their work, participants had "felt parts of themselves had died during the trauma" (p. 503). Similarly, this study with adult children found participants themselves highlighted a perceived loss of themselves while living with childhood parental illness. Participants were very clear that they had developed differing personas for their public and private selves. One explanation could be attributed to the limited opportunities for children and adult children to be involved in self defining activities, as they have been associated with a reduction in the impact of loss (Pape, Lancaster & Kahler, 2014). Adult children in this study had not been involved in past counselling, nor had they been diagnosed or treated for any mental illness. Given this, their experiences of loss may be greater over a longer period of time in light of limited opportunities to positively reconceptualise their own worth. The work of Lazarus and Folkman (1984) reinforces the positioning that it is not simply stimulus or response to stimulus which defines psychological stress, but the relationship between them. Additionally Lazarus and Folkman (1984) argued that an individual's cognitive appraisal of a situation can determine a likely response. In light of the findings from this study, it seems that cognitive appraisal and repositioning of one's situation could possibly change their experiences of loss and grief in positive ways.

Whilst making reference to loss in terms of bereavement, the work of MaCallum and Bryant (2008) offered some interesting insights. They highlighted that people with ongoing experiences of intense bereavement often viewed their own self identity closer to the deceased person. Given the children / adult children and parent relationship, it would seem that children who have experienced childhood parental mental illness would have their self identity closely linked to at least one parent with mental illness. There is evidence from the study findings which is highly suggestive that children and adult children experience a phenomenon of loss with expected changes of self identity.

Loss and grief are thought to be journeys of change with distinctive emotional and cognitive states. Denial, anger, bargaining, depression and acceptance are documented stages (Speiss et al., 2014). Interestingly, parental in-patient admissions in mental health facilities were found to be particularly distressing for children. Often in their parent's absence, they made up stories of parental death (Somers, 2007). As a result of limited understanding of parental mental illness, children may have made up stories of parental death to align with their feelings of loss. Alternatively it may be a similar reaction to the first stage of grief, denial. In an effort to

emotionally process the loss of their parent during an inpatient stay, children process loss as denial, using other stories to explain their distressing parental absence.

All stages of grief as highlighted by Spiess et al. (2014) were identified in participant narratives for this particular study, with differing manifestations and to varying degrees. Denial was not simply linked to the perceived loss of the parent as a consequence of illness, but also evident in denial of one's need and right for emotional expression. Adult children commented that they withheld disclosure of their own emotions in an effort to protect the parent. There was also a role for bargaining attached to their emotional expression, when participants noted that they changed their behaviours in order to influence parental behaviours in some way. Similarly, Spiess et al. (2014) identified anger as a stage of bereavement. Many participants noted their experiences of long standing anger. Some noted anger as the first emotion they feel when faced with daily difficulties, even in adulthood, suggesting that the process of grief may continue for those who have experienced childhood parental mental illness long into adulthood. Depression is another manifestation associated with loss (Spiess et al., 2014). While participants in this study identified feeling low in mood at times and reported childhood periods of depression, none had received a formal diagnosis nor substantial treatment. This may be in keeping with experiences of denial, where adult children deny their own experiences / emotional wellbeing or may point to other resilience and protective factors at play.

## **Conclusion**

This paper highlighted that participants positioned their own emotional health and needs as having reduced importance in relation to their parents. Adult children perceived that they had become overwhelmed as a consequence of the parent being unavailable due to the actual symptoms of mental illness or parental behaviours associated with delusional content. They felt they had lost their own sense of self. They were unsure about how they actually felt with limited emotional literacy. The findings of this study have unequivocally demonstrated that children and adult children who have experienced childhood parental mental illness, experience loss similar to people bereaved.

This study has advanced the knowledge base of children's and adult children's experiences of childhood parental mental illness. Reconceptualising their experiences as a construct of loss and grief will support clinical staff to better cater for the needs of children and families who are experiencing parental mental illness. Consideration of children's experiences within a theoretical framework of loss and grief may positively influence their longer standing experiences and perceptions of loss of self.

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**Table 1:** Participant and Parental Information

KEY – Parental Diagnosis

*S: Schizophrenia*

*P: Psychosis*

*M: Mood Disorder*

*D: Depression*

(as reported to the best knowledge of the participants)

Study name	Gender	Age range	Siblings	Parental diagnosis	Age of participant when parent diagnosed	Parental hospital admission
Edward	M	30-40	No	S	8	Yes
Annette	F	70-80	Yes	S	11	Yes
Nicole	F	30-40	No	P	3	Yes
Kate	F	30-40	Yes	S	Before birth	Yes
Maria	F	30-40	Yes	S	3	Yes
Sarah	F	30-40	Yes	M	5	Yes
Jenny	F	40-50	Yes	S	13	No
Sue	F	50-60	Yes	D	7	No
Peter	M	30-40	Yes	D	14	Yes
Elizabeth	F	40-50	Yes	P	Before birth	Yes
Margaret	F	50-60	Yes	S	Before birth	Yes
Maureen	F	60-70	Yes	D	12	No
David	M	60-70	Yes	S	Before birth	Yes

