

## ORIGINAL ARTICLES

# Loss and change: The challenges of mothering an adult child with schizophrenia

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## ABSTRACT

A qualitative narrative and cross-narrative research method was used to explore how six mothers of adult children with schizophrenia or schizoaffective disorder experienced personal growth and change. Twenty-four largely unstructured interviews were conducted over the course of two years. The following eight common themes emerged across the narratives: Enduring sadness and loss, Distress and struggle, Fluctuations in hope, Feelings of guilt and regret, Concern about their child's future, Impact of their child's mental illness on their other children, Commitment to helping/action, and Personal and relational change. The changes reported by these mothers were set against the backdrop of the nonfinite losses that characterized the realities and uncertainties of their lives since the onset of their child's mental illness. Implications for mental health practice are addressed based on these findings.

**Key Words:** Mothering, Coping and adaptation, Caregivers/caregiving, Coping with mental illness, Schizophrenia

## 1. INTRODUCTION

The challenges and uncertainties of parenting an adult child with schizophrenia or schizoaffective disorder have been richly described in the qualitative research over the past thirty years. Focused primarily on the experiences of mothers, this research literature has drawn attention to the challenging, complex, and at times contradictory nature of caring for a child with schizophrenia.<sup>[1-7]</sup> Mothers have spoken about the "interminable" nature of mothering as they live with uncertainty, isolation, and a lack of understanding.<sup>[6]</sup> They have emphasized the importance of psychosocial and structural support in caring for their child's needs and ensuring their child's safety and well-being.<sup>[3,4,6]</sup>

Similar themes have emerged through interviews with fathers, for example, feelings of devastation and vulnerability,

the stressful nature of care-giving, the difficulty of living with the stigma of mental illness, and considerable frustration with the mental health system.<sup>[8-10]</sup> In a grounded theory study of this parenting experience which included primarily mothers but also some fathers of children with schizophrenia, Milliken<sup>[3]</sup> described parenting over the course of a child's illness as an ongoing process of "redefining parental identity" (p.149).

The stressful nature of this parenting experience is further underscored in the literature on "family burden."<sup>[11-14]</sup> This literature has drawn attention to multiple burdens associated with caring for a family member who has a mental illness including: financial challenges, physical and psychological demands associated with care-giving and advocacy, disruption of household routines, restriction of social activities,

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impaired relationships with others outside of the family, emotional distress associated with difficult and at times bizarre behaviours, as well as secondary distress associated with the reactions of others both within and outside of the family. Several studies<sup>[15-17]</sup> have also drawn attention to an ongoing pattern of grief associated with parenting a child with mental illness. Given the uncertain prognosis and unpredictable course associated with mental illnesses like schizophrenia and schizoaffective disorder, parents also worry about how their child's needs will be met when they are no longer living or are no longer able to provide for, and take care of, their child.<sup>[12]</sup>

With primary emphasis in the literature being on the significant challenges associated with this parenting experience, little attention has been paid to the more positive aspects and outcomes of negotiating this parenting experience. One such outcome, personal growth and learning, emerged as one of six dominant themes in a previous phenomenological study on the experience of fathers of adult children with schizophrenia.<sup>[10]</sup> As is the case for many challenging life events, individuals often find personal strength and learning out of dealing with adversity. In the current study we were interested in learning if and how mothers of adult children with schizophrenia or schizoaffective disorder learn and grow through their parenting experiences, given their primary social role in, and responsibilities for, caretaking their children. We anticipated that the findings could inform recommendations for clinical practice.

## 2. METHOD

Our study was guided by the question: *How do mothers of adult children with schizophrenia or schizoaffective disorder experience personal growth and change as they live with the challenges and uncertainties associated with their child's mental illness?* We used a narrative method and a cross-narrative analysis to answer this question, involving multiple data collection interviews over the period of many months, to capture a more complete understanding of these mothers' experiences as they dealt with the up and down course of their child's illness.

### 2.1 Participants

Participants for our study were recruited via a notice describing the study and inclusion criteria, which was distributed through an email list associated with a local Schizophrenia Society of parents of children who have been diagnosed with a mental illness, as well as through snowball sampling. Each mother needed to: (a) be the genetic parent of an adult child who had been diagnosed with schizophrenia or schizoaffective disorder and actively involved in parenting her child;

(b) feel she had experienced personal growth and change as a consequence of her parenting experience; (c) be willing and able to share and reflect on her parenting experiences in English; and, (d) be willing to commit to two or more audio-taped data collection interviews and one validation interview over the course of several months. Only six participants were included given the limited population base of mothers who were willing to participate in a study that required multiple interviews over a lengthy period of time. By engaging in multiple data collection points over time, we attempted to capture the breadth and depth of this mothering experience as the participants were faced with responding to periods of relative stability as well as acute crises in their children's lives due to their illness.

The six participants ranged in age from mid-fifties to early seventies. Five were Caucasian and one was Asian. All were economically comfortable, had post-secondary educations, and had established professional careers. At the time of the interviews, two were retired. Four of the participants were married and living with their partners, with whom they had parented throughout their child's lifetime. One mother was widowed prior to the onset of her son's illness and another divorced at a time when her son's illness was in an acute stage. Each of the mothers had one or more children, in addition to her adult child who had been diagnosed with either schizophrenia or schizoaffective disorder.

The four sons and two daughters with a diagnosed mental illness ranged in age from 27 to 44. Two were diagnosed with schizophrenia and four with schizoaffective disorder. The length of time since the onset of the illness ranged from seven to nineteen years. At the time of the interviews two of these adult children were living in the same home as their mothers and four were living semi-independently with mental health supervision. Of these adult children, two were working part-time and four were chronically unemployed.

### 2.2 Procedure

After securing institutional ethical approval for our study, we began our recruitment efforts. Brief telephone interviews were conducted with interested participants to answer their questions about the purpose of the study and the nature of their participation, and to ensure they met the inclusion criteria. Individual data collection interviews were scheduled with six mothers. Written consent forms were reviewed and signed by the participants prior to beginning the first interview. The first of the largely unstructured, audio-recorded interviews with each participant focused on learning about her unique family circumstances, what personal growth and change meant to her, and how she felt her experiences of parenting her adult child with schizophrenia or schizoaffective

disorder over time have contributed to growth and change in her life. Subsequent interviews, on average every six months, were conducted with each participant over the period of two years. The participants were encouraged to keep a record of any additional thoughts, feelings, or insights that might arise between interviews, which they often made reference to in the following interview.

The interviews varied in length and ranged from one hour to two and a half hours. The interviews were conducted by the primary researcher, who is the mother of an adult child with schizophrenia. The study participants expressed their appreciation that the primary researcher shared their parenting reality, believing she could understand their experiences in a way that parents of healthy children often could not. Immediately following each interview the primary researcher, recorded her personal reactions to, reflections on, and observations of, the interview in a research journal. These journal entries were included in the process of data interpretation and analysis.

In total, twenty-four interviews were conducted over a period of two years. Conducting multiple interviews over the span of two years allowed us to capture a more complete and balanced understanding of this mothering experience than could be gained through single interview data collection methods. This was particularly important given that this mothering experience can fluctuate greatly over time depending on whether their child is in a relatively stable or more acute stage of the illness. The time between interviews allowed participants to reflect further and gain more clarity on the meaning of growth and changes in their lives, resulting in the participants being able to deepen their understanding and ours, of the nuances of their mothering experiences. Additionally, multiple interviews over time allowed a high level of trust to develop between the interviewer and each participant, facilitating a deeper sharing of personal experiences. Through the use of largely unstructured interviews elements central to the participants' experiences were able to emerge spontaneously. If not spontaneously addressed by the participants, the following open-ended questions facilitated additional exploration and understanding: What does personal growth and change mean to you? In what ways do you feel you have changed personally, in your roles and relationships? What issues, challenges, thoughts or questions have you encountered since the onset of your child's illness? How have you managed these and how have they contributed to your growth and learning? How has your parenting experience influenced your goals/beliefs about life? Are there any new directions or activities in your life that are reflective of the change you have experienced? What, if anything, may have hindered your growth? Have you communicated your

experience to others, and if so, how has this influenced your growth and change? Researcher journal entries following each interview also played an important role in keeping the participant's experience "alive" during the analytic process.

### 2.3 Analysis

The audio-taped interviews for each participant were thematically analyzed including verbatim transcription followed by line by line coding using Atlas ti qualitative software. This process enabled a more in-depth, comprehensive understanding of the explicit and implicit meanings communicated by the participants and resulted in the identification of multiple codes/descriptive meaning units. Taken together these revealed larger themes or patterns that informed the writing of an individual narrative of each mother's experience. Member checks were undertaken to ensure that each mother felt there was "correspondence" (p.67)<sup>[18]</sup> between the interpreted findings and her experiences - that her story, as constructed by the researcher, accurately reflected and resonated with her experiences. These member checks ensured the meaning congruence of the findings. We then identified the themes that were common across the six narratives to gain an in-depth understanding of the common elements in the experience of growth and change for the mothers in this study.

## 3. RESULTS

We begin with an important finding that is directly related to our research question and significantly informs our understanding of how some of the mothers in our study viewed the changes they experienced in their lives. We then provide an in-depth description of the themes that were common across the individual narratives.

Of particular relevance to our understanding of growth and change, we found that as the study progressed, although they initially met the inclusion criteria of believing they had experienced growth and change as a consequence of their mothering experiences, four of the six participants became increasingly uncomfortable with the word "growth" to describe their experiences. These mothers associated the word growth with the implication of a desirable personal gain. It felt incongruous and inappropriate for them to consider having in any way gained personally at the expense of their child's illness. However, the word "change" was fully embraced and fully endorsed by all of the participants and prompted in-depth conversation and description. This finding has important theoretical and clinical implications that will be elaborated upon in the discussion section of this paper.

### 3.1 Common themes

The following eight themes were common to the experience of the mothers in this study: Enduring sadness and loss; Distress and struggle; Fluctuations in hope; Feelings of guilt and regret; Concern about their child's future; Impact of their child's mental illness on their other children; Commitment to helping/action; and Personal and relational change. The themes were experienced in somewhat different ways, and to different degrees, by each participant. Feelings of regret and guilt were expressed by only four of the six mothers. The other themes were evident in all of the individual narratives. Each of the common themes is described below.

#### 3.1.1 *Enduring and pervasive sense of sadness and loss*

Perhaps the most prominent theme/thread in the stories of these participants was an enduring and pervasive sense of sadness and loss related to their mothering experiences. The multiple losses identified by these mothers included losses related to the effects of the illness on their child's life, on their family life, and on their own life. The intensity of their feelings of sadness and loss appeared to fluctuate and parallel the up and down course of their child's illness. During the more stable periods, the sense of loss was more in the background of their experiences. During the more acute periods of their child's illness, the participants experienced a more intense sense of sadness and loss.

The participants shared the sadness and loss they experienced as they watched the debilitating effects of the illness on their child's life, including cognitive losses and impairments, the inability to meet developmental norms, and the loss of healthy functioning. These moms emphasized how painful it was, and continues to be, to witness their child's loss of the ability to enjoy life. They lamented the loss of the kind of relationship they had previously had with their child, before his or her illness, and shared a profound sense of loss in the hopes and dreams they held for their child – which would now likely never be realized due to their mental illness.

The participants also lamented the loss of normal family life – of being able to enjoy holidays and other family occasions. Several mothers talked about the loss of joy and lightheartedness in their families, given the relationship challenges and tensions related to their mentally ill child. Other losses reported in the participants' own lives included loss of control, loss of support, loss of freedom, and loss of their own career aspirations – which for some had to be abandoned due to the ongoing and unpredictable demands of caring for their child.

The nature of these mothers' losses and the losses their child would continue to experience throughout his/her life became more apparent to them over time. As the illness progressed,

their perceptions were that it became less likely that their child would be able to achieve normal developmental milestones such as completing an education, becoming gainfully employed and developing a stable and satisfying career. Similarly, their perceptions were that it became less likely that they would be able to establish a social support system, get married or have a family. These mothers sometimes struggled to find words to describe the ways in which their lives and the lives of their adult child and immediate family members had been impacted by their child's mental illness, given the internal and intangible nature of some of these losses. For example, one mother whose child did not accept her illness and who had family members who would not speak about mental illness struggled to articulate the loss of transparency and authenticity in her life. The loss of certainty in terms of the future was also repeatedly reflected in the stories of the mothers in our study.

#### 3.1.2 *Distress and struggle*

The participants also spoke about the distress and struggle that was part of the experience of living with the ongoing challenges and uncertainties of their child's illness. The early years prior to their child being diagnosed were particularly marked by distress as these mothers struggled to make sense of their child's unusual and sometimes destructive behaviors. During more acute phases of the illness, the participants often found themselves afraid for their child's safety. The participants struggled with the up and down course of the illness and also with the need to change their responses and expectations based on the course of their child's illness and on the extent to which they were included in, and informed of, the treatment decisions made by the members of their child's mental health team.

In addition, some of the mothers experienced distress related their child's inability and/or unwillingness to accept his/her illness. Distress also took the form of anger and frustration for some of the moms in response to a number of injustices including perceived stigma, lack of consultation, or decisions made by mental health professionals that were perceived as harmful to their child. All of the mothers in this study described situations when they struggled with a sense of powerlessness – powerlessness to change the course of their child's illness, powerlessness to have their parenting experiences and knowledge validated by the mental health professionals responsible for overseeing their child's care, and powerlessness to ensure their child's ongoing safety.

#### 3.1.3 *Fluctuations in their levels of hope*

Over time all of the mothers in this study also experienced fluctuations in their levels of hope as they faced and lived with the uncertainties and challenges associated with their

child's mental illness. In the early stages of the illness, hope was highest for these mothers. Like most physical ailments, these moms held out hope that their child would fully recover, return to "normal" and be able to lead a satisfying and productive life. Gradually, the participants came to the realization that their expectation of a return to a "normal life" was a false hope – that their child and his or her life and possibilities would never be the same as they were prior to the onset of the illness. As they watched their child repeatedly cycle through periods of relative calm only to be followed by periods of acute instability – of poor hygiene, paranoia and a high risk of harm to themselves or others, active psychosis – the participants repeatedly found their hopes for recovery or some semblance of a normal life for their child dashed. They felt they had little choice but to put their faith in the mental health system and hope that those who were managing and monitoring their child's medications would help to keep them grounded and safe. Over time these mothers acknowledged their growing recognition that their child's recovery will inevitably be limited given what they perceived to be the irreparable cognitive damage caused by the illness.

### **3.1.4 Feelings of regret and guilt**

Four of the mothers talked about *feelings of regret and guilt* related to various aspects of their mothering experiences. Two of the moms struggled with these feelings when they reflected back on the period before their child was diagnosed. One mother wondered if some of her early parenting responses may have contributed to her child's overall level of distress, and questioned whether this increased stress may have contributed in some way to the degree of difficulty her child experienced after he became ill. Another mother wished she had been more sensitive to her son's hurt and pain during the early stages of his illness, prior to a diagnosis, rather than attributing his behaviour to adolescent rebellion or defiance. Other mothers regretted the months and years it took for their child's mental illness to be accurately diagnosed. They regretted that they were unable to get the help their child needed sooner, and wished they had pushed harder for intervention in terms of the necessary diagnostic assessments and medical support.

### **3.1.5 Ongoing concern about their child's future**

Another pervasive theme in the mothering experiences of the participants was their *ongoing concern about their child's future*. As time went on and the permanence of their child's mental illness became clear, these mothers lived with the growing concern about what will happen to their children when they are no longer able to look out for them. This question was deeply concerning for all of the mothers in this study, particularly the two mothers without partners – a concern that for most was accompanied by a sense of dread.

These moms worried about their child's future housing and health challenges. They expressed concern about burdening their other children with the responsibility for their mentally ill sibling, and reflected on the impossibility of adequately passing on what they had learned over time about caring for their child, to those who would have to assume this responsibility in the future. Having observed the sometimes devastating toll taken by the illness, and having witnessed times of heightened instability and risk, all of the mothers also expressed concern that one day their child might take his or her own life.

### **3.1.6 Concern about the impact of their child's mental illness on their other children**

The mothers in this study also expressed *concern about the impact of their child's mental illness on their other children*. With so much energy and attention being focused on their mentally ill child, these moms were concerned about the costs to their healthy children. They spoke about not having as much time and energy to nurture their other children or to acknowledge and celebrate their successes. They also lamented the loss of normal family life and family holidays – many of which were interrupted or made impossible by a crisis or period of instability in the life of their ill child. Some of these moms worried that there may be more pressure on their well children to be more competent or successful, in part to compensate for what their mentally ill sibling is unable to do or become. Some of the participants also voiced concern about how their child's illness might affect the future for their other children – not wanting them to feel a sense of responsibility for their sibling or to feel burdened to change their life plans or goals due to their sibling's mental illness. On a more positive note, two participants expressed their admiration for their well children's desire and active efforts to make a difference in the mental health system, as a result of having a sibling with a mental illness.

### **3.1.7 Commitment to helping and taking action**

Rather than being defeated by the losses and overwhelmed by their distress, the mothers in this study were *committed to helping and taking action* to ensure their child has the ongoing support and assistance s/he need to live the best life possible, given the circumstances. They recognized that this is a lifelong commitment, and vowed to do whatever is necessary to ensure the safety and well-being of their child. For all of these moms, helping involved learning about the illness and carefully observing their child to better understand his or her changing needs. Several mothers talked about studying their child to the point that they can recognize subtle and important changes – allowing them to take the necessary actions to ensure their child is safe and supported even if this means involuntary hospitalization or medication. Helping

also involved an ongoing search for balance between protecting, and pushing their child to take more responsibility for himself or herself.

Several of these mothers also became active in the mental health community, serving on parent advisory boards and politically advocating for the rights and needs of the mentally ill. The focus of their commitment to action changed over time, from being totally immersed and involved in their child's life and mental health care, to being able to set boundaries and recognize what they can, and cannot do, to support and protect their child. All of the mothers reported that taking action was empowering for them, and helped them to cope with the challenges they have faced, and will continue to face in the future as they respond to their child's changing needs.

### 3.1.8 *Personal and relational changes*

A number of *personal and relational changes* were reported by the participants in this study, as a consequence of living with the challenges and uncertainties associated with their child's mental illness. Through their humbling and profound experiences of responding to their child and his or her illness over time, the participants gained an expanded sense of awareness of, and sensitivity to, the needs and challenges of others. They spoke about becoming more attuned to the struggles of others, being less judgmental, and being more compassionate. The mothers reported having gained increased patience and tolerance, and spoke of increases in their own personal strength and determination through their parenting challenges and experiences, and through witnessing their child deal with his or her ongoing struggles. These mothers also talked about the importance and value of becoming more publically open about mental illness and about their experiences of living with their child's illness – as a way to fight the stigma of mental illness and help create a more accepting and caring social environment for those who struggle with mental illness. Throughout the course of their parenting experiences, these moms found their assumptions about life were challenged. For example they came to realize that life is not fair. Try as they might, they came to accept that they can't take this illness away from their child and are limited in their capacity to protect their child and make his or her life better.

The participants also talked about how their priorities inevitably changed over time, from helping their child overcome the illness, to helping him or her live with the illness. Within their families, these mothers made conscious efforts to become more attentive to, and inclusive of their partners, their other children, and in some cases their grandchildren. Within their own lives, they noted an increased and intentional focus on self-care – maintaining health and balance in

their lives and not letting their child's mental illness consume their lives. Finally, the mothers talked about having gained a greater sense of gratitude and appreciation for their lives, their family members, and their mentally ill child. In the words of one mother: "My son's illness has taught me the meaning of love, patience, and understanding. Despite how he functions, how he reacts, he is loved. I did not know that I loved him this much until after his illness."

## 4. DISCUSSION

Despite the rapidly growing interest in the literature on stress-related and posttraumatic growth,<sup>[19–21]</sup> the findings indicate that this theoretical construct may not be easily understood or embraced by those who are living with a chronic and unpredictable experience like that experienced by the mothers in this study. Four of the six mothers became increasingly uncomfortable with the word "growth" to describe the personal changes they experienced, and with the inference that they might have personally benefitted from their child's illness. As such, mental health professionals who provide support to parents of adult children with a chronic and unpredictable mental illness should exercise caution and sensitivity in applying this conceptual frame to the personal changes parents experience as they live with the significant challenges associated with an adult child's mental illness. Mental health professionals may also gently challenge parental reluctance to accept having personally benefitted from dealing with their child's illness by helping them recognize that this growth was not an intention, but rather a response to what life brings and thus a valued part of the human experience. It may also be a strength that contributes to their ability to cope with the ongoing challenges they face. The conceptual frame of nonfinite loss rather than stress-related growth seems to better represent the experience of the mothers in our study given the ongoing, cumulative nature of the losses they experienced. Nonfinite loss is described in the literature as an enduring loss that retains a physical or psychological presence with an individual with whom one has a significant attachment bond.<sup>[22, 23]</sup> Although similar in some ways to bereavement loss, for the parents of a child with a chronic and unpredictable mental illness, there is no discrete end to their relationship. Their child remains physically present although profoundly changed in multiple ways. As well as the loss of the life they had hoped their child would have in the future (i.e. graduation, marriage, children), these parents must learn to live with loss of who their child once was, and the relationship they once had. Consistent with nonfinite loss, the magnitude of these losses often appear to be unrecognized and unacknowledged by others.<sup>[24–26]</sup> It is important then, that those in support roles understand the complex,

layered, and often isolating nature of this type of nonfinite loss, if they are to assist parents in coping with, and working through, the emotional impact of these losses, provide more adequate support, as well as help mothers make meaning of their experiences.

The findings also extend those reported in previous studies about the distressing nature of this mothering experience,<sup>[2,4-10,12]</sup> by highlighting the specific challenges and support needs of these mothers at each stage of their child's illness (e.g. the confusion and need for information in the early stages of the illness, how to respond to the ongoing and ever changing challenges associated with the up and down course of these illnesses, the need to prepare for the future).

In terms of psychosocial support, the findings indicate that in the early stages of their child's illness mothers need support in dealing with their confusion and distress. They also need assistance in accessing assessment and early diagnosis, as opposed to having their concerns about their child's "strange" and sometimes "bizarre" behaviors dismissed as normal adolescent rebellion. Once a diagnosis is made, accurate information is needed about the causes, nature and unpredictable course of the illness. As they attempt to cope with the primary concern of the moment – be it safety or poor hygiene or housing – mothers need concrete strategies, resources and services.

Over time, an important part of coping and coming to terms with their child's illness involves learning how to identify, accept, and live with what cannot be changed. Mothers need to create some balance in their own lives, to be able to cope with the ongoing challenges and demands they face in supporting their child and responding to the unpredictable course of his or her illness, while also attending to their own needs, and the needs of the other members of their family. Mothers may need assistance in addressing their very real concerns about

their child's future caretaking needs when they are no longer around, and developing concrete financial and guardianship plans.

### Limitations

In interpreting and discussing the implications of the findings, it is necessary to acknowledge that they may be limited by the fact that our sample was small and relatively homogeneous. Notably, the participants were upper middle class women with intact support systems, which likely contributed to their ability to cope with the challenges that they faced. The findings may not reflect the challenges and experiences of mothers with fewer financial and social resources and support. Also, the voluntary and lengthy nature of the study may have encouraged the participation of mothers who were highly motivated to tell their stories and highly committed to the research process and to making a difference in the mental health system. Additionally, the wording of the research question, and in particular the use of the word "growth" as a criterion for inclusion in the study, may have reduced the pool of potential respondents.

## 5. CONCLUSION

Based on the themes of *commitment to action* and *personal and relational change*, it is important to emphasize that the experiences of the mothers in our study underscore the possibility of living well despite the ongoing losses, challenges and uncertainties associated with parenting an adult child with a chronic mental illness. Although at time distressed and discouraged, the mothers in this study valued the personal strengths and coping skills that they gained through dealing with the challenges and uncertainties they faced.

## CONFLICTS OF INTEREST DISCLOSURE

The authors declare no conflicts of interest.

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