

Parental Grief and Serious Mental Illness: A Narrative

Salih Ozgul

Serious mental illness is associated with substantial personal and interpersonal distress and life disruption for the sufferer and for his/her family. A common response to having and caring for a family member with a serious mental illness is feeling loss and grief. This paper presents a representative narrative that attempts to capture the essence of the experience as conveyed by 22 parents of adult children with a serious mental illness. The implication of the narrative is examined.

Over the past sixteen years in my capacity as a therapist, I have had the pleasure and good fortune to work with families and individuals suffering from a serious mental illness. I have personally witnessed and been moved by the emotional turmoil, distress and hurt experienced by individual sufferers and their families. I have also witnessed and been amazed by their courage, strength and resilience.¹

He was a very malnourished baby ... [but] He grew up into a happy bright boy. He did very well at school academically and was very artistic. He loved all sports ... He was popular with other children and teachers ... [at nineteen] ... this was I feel the beginning of the emergence of the symptoms of the mental illness ... his behaviour became strange ... bizarre ... a frightening experience for us as a family ...

Marriage after many unhappy years ended four years after my son became ill ... most carers are mothers ... mostly alone, living in reduced circumstances, getting elderly and worrying about the future for their children when they are gone.

As indicated by these brief excerpts from letters written by the parents of adult children with a serious mental illness, the onset of the child's illness has significant implications for family processes and resources. The onset of the illness means the family system is irrevocably changed.

As a therapist, my strongest sense was that families were grieving, grieving the myriad real and

symbolic losses, as well as the suffering and life disruption commonly associated with such illnesses. The grief was felt deeply, mourning appeared to be prolonged, and adjustment within and across families seemed to vary enormously.

Empirical and clinical literature provides some support for these personal observations. Families containing a member with a serious mental illness have been found to experience significant levels of emotional and psychological distress and disruption to their lives (Bulger, Wandersman & Goldman, 1993; Martens & Addington, 2001; Seltzer, Greenberg, Floyd, Pettee & Hong, 2001; Winefield & Harvey, 1993, 1994). Grief in its different forms is well documented. It appears to be a common reaction to having and caring for a loved one with a serious mental or physical illness or disability (Atkinson, 1994; Bruce & Schultz, 1992; Bruce, Schultz, Smyrnios & Schultz, 1994; Lindgren, Connelly & Gasper, 1999; Miller, Dworkin, Ward & Barone, 1990).

Although my reading provided valuable insights into the various aspects of the grief experience and affirmed that maybe as a therapist I had been listening to my clients, the story nevertheless seemed incomplete to me.

The aim of this article is to share with the wider psychotherapeutic community my attempt to hear, understand and document parental grief experience in response to having and caring for a child with a serious mental illness, through a narrative that I have constructed from many separate accounts. A single narrative cannot hope to spell out everything,



Salih Ozgul, School of Psychology, The Australian National University.

however, through the process of listening to families and telling and retelling the story we may gain a better understanding of these families.¹

Who better to educate and tell the story of parental grief and educate others about it than parents of adult children suffering from a serious mental illness? Twenty-two parents (16 mothers and 6 fathers) of adult children suffering from a serious mental illness volunteered in response to the invitation in flyers provided to local mental health services and support groups to share their stories in a focus group. The identified patients had been all been living with schizophrenia for some years. I facilitated the focus group with the assistance of an intern psychologist (Julia Godresse).

Participants defined group rules they believed would foster a supportive and safe environment including those related to confidentiality, respect and listening. Participants agreed to have the session audiotaped for the purposes of analysing the outcomes of the process. The facilitator then invited participants to describe in their own words their experiences from the onset of the illness to the current adjustment. Participants were also asked to share their views on the support service needs of parents at various stages of adjustment to having a child with a serious illness. Participants demonstrated a willingness to share their experiences, thoughts and feelings. The group process fostered the sharing of their stories without direct intervention from the facilitator other than minimal prompts, reflective listening and empathic responses.

Sessions were audiotaped and transcribed. We identified core themes and then integrated them to form a descriptive narrative of the parents' experience: onset, diagnosis, and adjusting to having and caring for a child with a mental illness.

The Story We Heard

She was a healthy child ... I felt disappointed in myself, like I had failed ... what had I done?

Something was happening but I could not put my finger on it ... I didn't know what I had to do ...

The strongest emotion was feeling helpless ... chaos, spinning out of control, watching it all happen.

Parents sense that there is something wrong, that things are not right. They feel uneasy, apprehensive, or fearful and confused about what exactly is happening. Parents desire to know so they may cope effectively with the changes. They gather information, look for reasons,

and seek answers to gain an understanding of what is happening. Those that feel listened to and supported and receive timely, accurate information feel empowered and move to take action. The majority, however, feel unsupported, isolated, and continue to experience confusion about the nature of the problem. They look for answers within themselves and the child. Anger, frustration, sadness, disappointment and guilt are common, as parents blame either themselves or the child for what they are faced with. Their sense of helplessness is heightened by wanting to help their child, but feeling powerless to do so, feeling like things are happening outside of their control, lacking support and having to 'sit back' and watch things unfold.

Diagnosis of a serious mental illness brings initial relief and hope; relief that the problem is real, that neither the child nor the parent is to blame; and hope that the illness is not as serious as they fear and that it can and will be treated. These feelings are only temporary. Intense sadness and grief follow as the enormity of the loss and the seriousness of the illness unfold. Loss of the child as they knew him/her, loss of the hopes and dreams of the person the child could and should have been, and the impact of changes to the family's life and relationships, all contribute to the grief. With grief comes disbelief, a sense of unreality, not wanting to know and not wanting to believe, along with a yearning that things could go back to how they were before. Common feelings are deep pain, hurt, emptiness, sorrow, fear, guilt and anger and resentment of the unfairness of the illness and of being cheated and robbed.

Relief that it was not just teenage stuff, that no one was to blame and hope that we would get help ...

The second breakdown was even more emotionally distressing ... that's when I fell apart — not the first time ...

It felt like we lost our child, like someone died ... the life he would lead ... the range of things that could have happened.

Sadness came later when we knew how it [the illness] unfolded.

The child's increasing dependency, the burden of caring and the uncertainty about how to help all contribute to their helplessness, hopelessness, anger and frustration. Parents feel further isolated, or shunned by society and at times rejected by their child. Parents appear to resign themselves to their child's serious and possibly lifelong illness and some may come to accept this. However, their grief is not far away, but relieved

each time they are reminded of their losses. Reminded by relapses of the illness, by the disruption in their lives, by the occurrence of special events such as births, marriages and graduations, and the lingering sense that life has stopped for them and their child.

It comes back to haunt you — similar feelings, anxiety, anguish, guilt ...

There are normal periods in between, where a young woman emerges.

It is like my son's life stood still — his friends are going onto university or finding jobs, having wives, families and mortgages ...

You go on feeling the loss over and over again.

Adjustment is associated with being supported, listened to and understood, and with understanding the nature of the illness and its treatment. Parents' wellbeing and adjustment are directly related to the child's mental and emotional state and meaningful engagement in life activities. Support in times of crisis and respite also contributes positively to reducing the burden of care.

Grief too is something we all have to deal with — but eases with time.

Our son has been ill for a long time and we have gone through many emotional periods, because this type of illness lends itself to an ongoing grief and plays havoc with emotions. Until one can fully accept and come to terms with it, it affects the emotion of everyone ... [acceptance] ... that takes a long, long time.

Reflections

As evidenced in the narrative and fragments of personal experiences, grief appears to be a normal adaptive response to having and caring for a child with a serious mental illness. This grief appears to be in response to the many perceived losses, changes in family relationships, disruptions and disabilities caused by the illness.

Grief is commonly thought of as having a beginning and an end point, that is, beginning with a loss event, followed by the grief reaction and then the mourning process where the person adjusts and finally comes to an acceptance of the loss, heralded by the person engaging with their lives more fully in the absence of the loved one. Parental grief appears to be complicated in response to having and caring for a child with a serious mental illness. The parents have no clear lost object and continue to have an ongoing relationship with their living child (Davis et al., 1998;

Solomon et al., 1996). The grief experience appears to be prolonged by the unending series of relapses and remissions, and by the consequent disruption to personal and interpersonal functioning.

Although the chronic nature of the illness presents a source of ongoing grief for parents, the representation of the loss may alter over time. Thus the loss and grief experienced by parents takes on a different meaning, making it difficult for them to assimilate the totality of the loss. This complicates and prolongs the grieving task (Davis & Schultz, 1998, Mohr & Regan-Kubinski, 2001, Tuck et al., 1997).

“Parental grief appears to be complicated in response to having and caring for a child with a serious mental illness.”

The complicated, protracted nature of parental grief, intermittently exacerbated by emotional distress that parallels the life course of the illness, argues against defining parental adjustment and recovery as an absence of grief. But then we have to ask: what does it mean to recover from loss if it is not an absence of grief? Weiss (1993) sets out to answer this important question, and his reflections may prove helpful in this context. Adjustment may be best understood by examining the personal meanings parents attribute to their child's illness, their engagement in meaningful interpersonal relationships and in life broadly, their levels of psychological wellbeing and future orientation.

Being informed about and accepting of the nature of their child's illness and treatment may indicate healthy caregiver adjustment to having and caring for a child with a serious mental illness. The caregiver is firmly in the present, actively and meaningfully involved in interpersonal relationships and life activities. S/he intermittently experiences sadness, anger, frustration and other negative emotions in response to the challenges of the child's illness, but is generally free of disturbing images, thoughts or feelings. S/he sees purpose and meaning and is able to experience pleasure, joy and satisfaction from his/her engagement with the

child. S/he anticipates good things for the future, has plans, and cares about realising them.

These are the conclusions I have come to as a result of hearing parents speak about their experiences. The distress and disruption to family life and the need to support and provide care for families is widely recognised in the clinical literature. Families need to be heard, their experiences validated and normalised. They need to be provided information about the nature of the illness and its treatment, their role in the care of their family member and how to navigate mental health systems and community services. They need to play a meaningful role in their family member's treatment, rehabilitation and recovery. Families need opportunities to share their feelings and experiences in a safe environment that encourages openness in communication, mutual support, validation and affirmation of the family as a unit and each member's role in the family. Siblings in particular may need reassurance of the stability of the family and their role within the family. Families may need to mourn together for those things lost, but more importantly, need to invest themselves in developing new ways of relating to each other and to life that is more satisfying and rewarding.

Processes that facilitate the strengthening of affectional bonds within families, and between family members and others, can strengthen the family and build its resilience to deal with the uncertain nature of the illness. A supportive family environment needs to be fostered where family members engage with each other and the world around them in healthy, meaningful ways, develop realistic expectations of each other and are able to express their needs and have them met. Communication, stress management and problem-solving skills may assist to formulate family solutions to managing and coping with relapse. The care provided to families may take various forms, including family support, psycho-education, counselling, therapy or crisis management. Irrespective of form, care ought to build upon the strengths and resilience of families and that of the diagnosed individual and be sensitively responsive to family needs over the course of the illness.

Conclusion

Parents told their stories but was I able to hear? Did I listen carefully enough? I documented the story, but is it accurate? Does the story really capture the essence of parents' experience? The sample of parents was small in number. They were courageous, but are they

and their stories truly representative? Their stories varied in minor ways, but essentially, they told the same story. The story has been told, but what value does this form of telling have? I have grown as a therapist, in listening to the story. For this I am grateful, but I don't know what you will make of the story and of my reflections, nor what its value will be to you.

One thing is certain: families are hurting. As helping professionals, if we were to conceptualise families' reaction in part as grieving, we might experience the family differently, and be forced to rethink how care is provided to the sufferer and family. The better informed we are about the process of family grieving in response to psychosocial loss and how best to facilitate grief work and strengthen family systems, the greater the opportunity we will have to facilitate meaningful family adjustment. What we need according to Marsh and Johnson (1997) is


... a respectful and empathic attitude toward families, an understanding of their phenomenological reality, an effort to meet their expressed needs, and a goal of family empowerment (236).

Endnote

1. I would like to express my deepest thanks to the brave parents who shared their stories with me. I can't but help feel that I have not done justice to their stories but I hope that I have been able to capture in part the essence of their experience.

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“The geological layers of our lives rest so tightly one on top of the other that we always come up against earlier events in later ones, not as matter that has been fully formed and pushed aside, but absolutely present and alive. I understand this.

Nonetheless, I sometimes find it hard to bear.”

(Bernhard Schlink, *The Reader*, transl. by Carol Brown Janeway, London, Phoenix, 1998: 215–216).

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Editors: Hugh and Maureen Crago

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