

Family Grief and Mental Health: A Systemic, Contextual and Compassionate Analysis

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Although not always named, grief is central to the experience of mental illness — for people diagnosed, their families and their friends. Yet grief is almost absent from the literature and practice of mainstream psychiatry. This curious fact led to the writing of this article by two workers and a carer, with editorial and political advice from a consumer, as a small step in the direction of integrating perspectives of workers, carers and consumers. It examines the nature of grief associated with mental illness, its impact on family members, and why mainstream mental health services do not directly address it, with suggestions for some therapeutic ways to conceptualise and work with it.

‘You are not hit with the pain all at once but gradually always’ (a mother).

Given that talking about death — a very obvious physical loss — is difficult for many of us, we should not be surprised by the silence surrounding the less visible losses associated with mental illness. The stigma of mental illness minimises both acknowledgement of the losses, and the community supports typically provided to people affected by less stigmatised trauma such as accidents or natural disasters. People hospitalised with mental health problems tend not to receive flowers or ‘get well’ cards: carers don’t receive casseroles, and mental health workers don’t receive chocolates and gifts like their general health counterparts (FaST Video series, 1997). The giftshops overflowing with helium balloons, cuddly toys and flowers at the entrance to all major general hospitals are not found in psychiatric inpatient units or hospitals.

Few papers have addressed the specific nature of the grief that accompanies mental illness. Of thousands of references to mental illness generated by a Medline search, only 26 responded to grief and mental illness

and only six mentioned ‘grief’ in the title, (e.g. MacGregor, 1994; Atkinson, 1994; Lafond, 1994; Miller, 1996). Lafond (2000) points out that if unnamed, grief may only be seen in its component parts such as anger, frustration or lethargy, and then dismissed or pathologised. Grief in clients may be misdiagnosed as further symptoms of mental illness, or a condition such as postpsychotic depression. Grief symptoms in family members may be misinterpreted as personality deficits and even as causes of the mental health crisis itself. This is why research exploring the ‘lived experience’ of family members (e.g. Ozgul, 2004) is so important. Similarly, any emotional reactions by workers to the witnessing of loss may be construed as ‘unprofessional’. Workers are often uncertain of their role (Gibbs, 1990) and fearful of the strong emotions that accompany grief. The little that is written (e.g. Miller, 1996) that directly addresses grief and mental health traumas points out that unrecognised grief may hinder progress and recovery. It is our experience, however, that acknowledged grief can be a therapeutic ‘ally’ to movement and change.



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Grief Associated Specifically with Mental Illness

Grief is often unspoken and experienced privately, possibly as self-blame, personal inadequacy or powerlessness. Telling oneself that what one feels is wrong adds to feelings of isolation. Doka (1989) was one of the first to name loss that 'cannot be openly acknowledged, socially validated, or publicly mourned' (xv) and therefore cannot be put into context and given meaning. He used the term 'disenfranchised grief' to describe grief that is real but invisible. Grief associated with mental health crises is often 'put in abeyance' (Perlesz et al., 1988), hence remains unnamed and unresolved. The term 'ambiguous loss' (Boss, 1991) describes losses that suffer an 'absence of public validation, documentation or ritualisation' (59). Rycroft and Perlesz (2001) comment on the difficulty

of mourning in the presence of the one mourned [as] a core constraint to effective resolution of grief in instances of chronic illness, dementia, head injury and serious mental illness (61).

“Naming exactly what has been lost is in itself a difficult but important task.”

Losses associated with mental health trauma reflect the cyclic nature of mental health problems themselves; periodic glimpses of the person as he or she was can make adjustment to the 'new person' or situation extremely difficult. Atkinson (1994) compared 25 families in which parents had a son or daughter diagnosed with mental illness, and 50 parents who had lost a family member through death or acquired major brain injury. On formal measures, parent carers experienced a less acute but more ongoing grief: 'chronic sorrow' (Olishansky, 1962; Burke, Hainsworth, Eakes, & Lindgren, 1992; Eakes, 1995) or 'a lifetime of losses' (Johnson, 2001). It is similar to trying to cope with death without the practical, emotional and spiritual support and acknowledgement provided by a funeral ritual. The following transcript of a family interview conducted with two adult sisters whose brother Tony had died and whose mother had experienced a long-standing diagnosis of schizophrenia, highlights the nature of the difficulty:

The difference between that grief and the grief for Mum is there's no change. You're stuck in this powerless pain. It's part of the same pain, that loss, that painful loss, it's just that it's happened over 20 years; you just go along with it; you react when there's a crisis and you can't blame her, so who do you get cross with? There's no beginning or end or middle part; with our brother who died the process is you can actually see yourself moving through and even though it doesn't hurt any less, it hurts less often. But the sort of grief with Mum is that it's a plateau, it's a plateau of a sort of feeling of loss, a daily loss, and along with all the anguishes that come with living with something like that in your life, you can't get past this grief.

Naming exactly what has been lost is in itself a difficult but important task. The range of intangible but real losses is made alarmingly clear in a father's powerful account.

I grieved because my son suffered and because I had no power to end his suffering. I grieved because he was incredibly limited in his ability to enjoy life in any way that I could understand. I grieved over the loss of companionship I had expected from my son.

I felt pain, knowing that on top of all his other problems, my son had to live with such a sad father. I grieved that he was likely to die an early and perhaps painful death. I grieved because my son seemed to have no place in a world too ignorant and weak to cure him, and perhaps too cold and hostile to care ...

I grieved because my longing to see all of life fit into a meaningful pattern had been frustrated. I grieved because I felt isolated from people and alienated from God.

I grieved because in a time of adversity I proved to be less noble and more vulnerable and needy than I had thought myself to be. I grieved because I could not be a comforter to my wife or to others. I grieved simply because sorrow had entered my life' (Hoyt, 1990: 5, cited in MacGregor, 1994).

As Hoyt's experience makes clear, future dreams may be disrupted and an expected life course lost. People may not articulate their dreams and expectations from life until it is too late. New losses can also emerge at every milestone that is delayed (McAleer, 2003) or not achieved.

Severe Mental Health Crises in Adults

Obviously, the grief experienced by consumers is varied, unique, complex and profound. Out of respect for consumers' 'lived experience' (White, 1988–89) we dare not attempt to summarise the range of their experience here. We encourage consumers and mental

health workers to report and research this area as a matter of urgency. For example, a grief lens may enable us to see 'postpsychotic depression' as an expected part of coming to terms with what has been lost. It is often not until recovery commences that the impact of what has been, and may be, lost begins to register with the person who has suffered an acute mental health crisis. A grief lens may enable this to be seen as a vulnerable time with potential for personal growth, if losses are acknowledged, new possibilities supported and inevitable changes integrated. Nonjudgemental exploration of other traumas, such as posthospital (rather than just 'postpsychotic') shame, guilt and self-hate, might tell us even more than a focus on grief alone. Given that some people experiencing major mental health crises may be vulnerable to suicide at the very time recovery starts gathering momentum, the use of a grief lens may help professionals understand these apparent contradictions and may save lives.

The person experiencing the mental health crisis may see the unexpressed sadness and loss in family members and feel guilty for causing such pain. This can serve to make the individual's own grief more 'unspeakable'. All young people are conscious of their parents' ambitions for their future: when this future is 'taken hostage' by mental illness, the young person is likely to be aware of the loss of this future, not only for themselves, but also for their parents. Such losses may include personal achievements, career and other cultural milestones, independence and children/grandchildren, and so on. The effects of the illness itself, as well as medication, can render invisible the feelings of the person experiencing mental health crises. Sometimes the community seems to forget that people undergoing mental health crises feel love, and the whole gamut of other emotions. Thus, not only the griever, but the griever, can be disenfranchised.

Grieving Children

The losses experienced by children of adults coping with mental health crises should not be forgotten. Miller says the 'principal component of this sense of loss is unutterable feelings of grief for the parent who is there but not there' (1996: 633). Children may grieve for the world that existed before the crisis. The family may have enjoyed happier, more carefree times, a better lifestyle or more intimate communication. There may be more awkwardness in having friends over due to the stigma of mental illness, fewer family outings or family functions. It is only recently that the 'forgotten children' (Cowling, 1999) have attracted

the interest of mental health services and policy-makers, and resources are just beginning to be developed specially for them, such as the video *Hard Words* (Cuff & Pietsch, 1997).

Grieving Partners

Family work in mental health services has focused on parents as carers (e.g. MacGregor, 1994; Atkinson (1994) even though partners represent about 40% of direct carers (PRISM Human Services, Victoria). Mental health crises dramatically change relationship patterns (e.g. from a supposedly equal partnership to a nurse-patient relationship). While changes may be helpful in the short term, it is impossible to know how, when or if, the relationship will return to anything like it was. The changing relationship can be difficult to talk about, as both partners are commonly wary of making things worse. Penn eloquently describes the couple's dilemma:

I am afraid that if I do not speak to you and tell you how I am, I will slowly withdraw and leave you; however, if I do speak to you, I am afraid that you will slowly withdraw and leave me (2001: 39).

Furthermore, it can be difficult to distinguish problems in the relationship that are due to the crisis from those due to other factors. If grief is the normal response to loss, it is likely to be felt when comparing one's relationship to what it used to be, or to the relationships of other couples.

When I was shopping on my own I'd see other couples shopping together and I'd feel so envious of their ordinariness, their lightness, of how carefree they appeared ... I now have a real appreciation of the taken-for-granted living life for the moment — it's good now, it might not be in the future. I enjoy what it is, not what it was, not what it could be, but what it is.

Rolland (1994) writes about the value of externalising the mental health crisis ('illness') and developing rules, for example, keeping the bedroom free of talk about 'the treatment'.

Grieving Siblings

Siblings may have significant responsibility for care but are unlikely to have the same authority, personally or legally, as parents or partners. Siblings can feel like 'the meat in the sandwich' caught between their unwell brother or sister and their parents. Some may experience quite powerful survivor guilt or fear that they may succumb to the same illness. Some can feel an extra pressure to succeed or to avoid being a problem for

their already overburdened parents. Whatever their role, siblings are likely to feel they cannot complain about their lot in life, because others in the family are far worse off. Consequently, the voice of siblings has been slow to be heard. The following was written by a sibling who read an earlier draft of this paper while attending therapy. She had referred herself in order to address what her partner called her anger toward her twin sister, who had experienced mental health difficulties during early family life.

I had never thought in terms of the grief that I must be feeling, or that my parents must be feeling, although as a mother myself I knew that what they felt had to be more intense than what I felt. Nevertheless I now can explain the anger, frustration, loss, dread and sadness that I feel, and maybe now I can turn some of those feelings around, into tolerance, acceptance and generosity of spirit, which surely can only help my sister. I also have never really thought about the grief my sister must have felt, and still feels. Does the medication mask it, now that she doesn't cry like she used to? I thought the crying was part of the illness, and it makes me very sad as I write this that maybe she was grieving for the loss of her old self. It makes me cry to think about it!

Impact on Family Structure

As Rycroft and Perlesz (2001) point out, it is sometimes months or even years before families understand the changes that are likely to occur in the family when one member is diagnosed with a psychiatric condition. Ambiguous losses are particularly difficult to resolve (Boss, 1988). When a family member dies, the family is forced to restructure and redefine itself. When a family member has an episodic condition, the family has to have the flexibility to find ways of maintaining the incapacitated family member's role so that their place in the family is not lost, and yet find temporary ways of fulfilling that role when illness makes this necessary. This leads to a practically and emotionally taxing dilemma for families:

- Being 'too' flexible and accepting may mean that the person experiencing the illness may feel excluded, and deprived of a contributing role in the family;
- Being loyal to the person experiencing the illness, and to their 'wellness', may leave families struggling to know how to survive as a family during acute crises.

Jenny and Loretta are sisters whose mother has a 20-year history of psychosis. They reported that one of the things they grieved about was how their mum's contribution to their own children's

life was restricted because she was not always capable of looking after them. They recounted stories of times when they had risked leaving their children with their mum, only for it to end in near disaster. Jenny took the position that, even though her mum's behaviour may have at times been a little odd, she was the children's grandmother, the children needed and deserved to have time alone with her. Loretta was much more concerned about the safety of her children and felt obliged to prioritise her children's safety over her or her mother's needs.

Each family member, including the person experiencing the mental health crisis, is likely to express grief in different ways and at different rates and these different expressions may lead to further tension and conflict.

Mainstream Mental Health Services and Grief

The preoccupation with categorising and diagnosing mental illness has led to an emphasis on the tangible and objective, and a corresponding de-emphasis of the subjective, emotional, spiritual and symbolic. Because there is no medication for it, a medically dominated system may not actively look for grief, nor recognise it in its more subtle or disguised forms. Grief counselling may not seem a pressing task compared to addressing suicidality and overt symptoms, and therefore its relevance can easily be lost in a busy work environment.

Ironically, psychiatry — the medical specialty that deals with emotions — seems to have little tolerance for strong emotions. Therapeutic models expect that intense emotional expression may be a necessary consequence of treatment, whereas the mental health system tends to be based on concepts of containment. Emotive topics such as grief and loss are often avoided for fear that the painful feelings aroused may induce a psychotic episode. Although this is a legitimate fear, therapeutic techniques allow for safety while facilitating emotional expression. Fear of carers' strong emotions is also pervasive. Professionals often pathologise angry family members, rather than accepting the anger as a normal, expected reaction to their situation. The irony is that anger is often softened when underlying losses are addressed directly and compassionately.

Fear of inducing hopelessness can constrain professionals from exploring the painful changes resulting from a major mental health crisis. However, not addressing grief may *entrench* hopelessness, as family members continue to make unfavourable comparisons between the present and an idealised past. The anger, frustration,

self-blame and sadness resulting from lost hopes and dreams may not be easy to resolve until named as grief, discussed and normalised. Acknowledging and validating losses can assist people to see pockets of hope, even within overwhelming feelings of hopelessness. We can only recognise loss by comparing two points in time (Young, 1994). Family members and clients themselves have ample reference points from early childhood and adolescence with which to compare current shortcomings. Workers usually only have periods of relative disability to compare. This difference in perspective can lead to tension between workers and carers. Workers trying to instil hopefulness and to emphasise progress may become excited over small improvements, serving only to confirm to family members, especially parents, how much of their child's early potential has been lost.

Effective grief work typically requires a safe place in which one person can trust another enough to share feelings of which they may not be proud. Family members may 'censor' or 'outlaw' their own guilt, self-blame, anger, resentment, or shame. Their vulnerability needs to be honoured with space, patience and compassion, all of which can seem impossible in a busy work environment.

Barrett (1987) pointed out that health professions and organisations have procedures that protect the worker from the patient's pain. If mental health workers are compassionate and thus open to understanding the pain and loss experienced by clients and family members, they are at risk of vicarious traumatisation. Their task is to be efficient without losing the human touch in supporting clients and their families. Young & Oliver (1997) found that acknowledging the multiple contradictory pressures on staff helped workers to recognise similar pressures faced by the family members of their clients. Workers need formal as well as informal debriefing, supervision, and a culture that accepts the expression of their personal emotions when supporting family members. If a service system does not recognise or address the impact of grief on both family members and workers, its workforce is at risk of exhibiting chronic sorrow, low energy, pervasive hopelessness, emotional flatness, fatigue and low morale.

The impact of grief on a service system is more closely related to the way it is conceptualised than to the severity of the trauma that induces the grief. For example, oncology units or ICUs at children's hospitals are familiar with tragic events and poor prognoses, but are usually 'up-beat' places in which to work. This may be because of the open acknowledgment of loss and

grief (staff are expected to be tearful and personally moved at times, family members' anger and sadness is anticipated and encouraged). Community support for the conditions that the services treat also contributes to the high staff morale. Imagine the mental health equivalent of the annual Royal Children's Hospital Appeal in Melbourne, which inspires millions of people and raises millions of dollars.

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Therapeutic Responses

When grief is looked upon as a valid and, in its own right, interesting topic of study, it becomes possible to treat it in a way that neither trivialises nor puffs it up, to treat it, in effect, as part of the 'life-space' (Colin Murray Parkes, cited by Lafond, 2000).

Our experience tells us that it is often the simple things that are most helpful when approaching grief. Workers do not need to be experts in specialised 'grief counselling' to help families deal with the grief of mental illness. They may, however, need to rediscover some things they already know about being therapeutic, such as compassion and acknowledgment. It is hoped that the following points may act as encouragement to mental health workers to explore the therapeutic possibilities inherent in using a grief 'lens' in their interactions with clients and families. Remember, 'grief is a most uncomfortable emotion. There is no magic way of preventing, resolving, or curing it' (Wasow, 1995: 112).

Naming the Grief

When Worden (1982) described the tasks associated with grieving, he outlined the first task as: 'Accepting the reality of the loss'. We believe the first task of the worker in mental health is to help make the loss *real* because it often goes unnamed and unacknowledged by families and workers. As Ozgul (2004) found, diagnosis can bring relief to family members; signifying that the problem is *real*.

I found myself sometimes downplaying the significance of grief and loss in relation to mental health. I

have felt anger, confusion and endless immobilising sadness for weeks at a time, sometimes not understanding why I am crying (a sibling).

Workers are in an excellent position to inquire respectfully about the component parts of grief (e.g. anger, confusion) and then gently to name the grief. Even if the professional has had limited experience of grief in her or his own life, good listening skills and empathy will enable the client to feel heard and validated. The old adage, 'Don't just sit there, do something!' might become, as many people before us have suggested, 'Don't just do something, sit there!'

The listener does not have to be the worker — other family members or friends can fill that role. What is important is that the listener has the capacity to 'sit with' expressed feelings of sadness and loss, without feeling compelled to do something about them, or to try to change those feelings. Simple questions are often the best and may not have been asked before by anyone. For example:

- 'How are you feeling/managing/coping?'
- 'Have you found yourselves responding in different ways and then arguing?'
- 'How is your partner/sibling/children coping with this?'
- 'I wonder how things might have been different, if your family not had to cope with mental illness?'
- 'Did you know to expect these feelings?'
- 'How did you expect yourself and your family to cope with this situation?'
- 'What is it that you need right now? What would be the most useful to you personally?'

Once worker and family begin to look at the losses together, the grief can be seen as a normal, healthy response to a major traumatic event. Photographs can be a useful resource, helping workers to get a sense of the family over time, helping everyone understand what has been lost, and validating family members' experience of the difference between past and present. Inquiring about what the person was like prior to the mental health crisis can have a similar effect.

Making Sense of Experience

Acceptance is possibly the wrong word. 'Integration' or finding meaning, may be a better way of describing the process (Lafond, 2000).

It is often validating for individuals to locate their experience within a framework that makes sense to

them. This is why the various 'stage' theories of grief following bereavement are so popular. However, existing frameworks may not fit so well with the ambiguous grief associated with mental illness. Individuals can swing suddenly from one 'stage' to another and back again, or between hope and despair, with little opportunity to reflect and make sense of what they are experiencing. Some information (oral and/or written) about the grief associated with mental illness can be enormously helpful to family members, who often 'censor' their own feelings, at least partly because there is no framework within which to place them. Simply saying that it is normal to experience some grief reactions to all the losses associated with a mental illness, and beginning to name some of the losses for a particular individual or family, will help.

“Helping family members to appreciate that different family members will respond to grief in different ways and at a different pace can help minimise the secondary tensions caused by these differences.”

Normalising and Expressing Grief

Family members don't need to be rescued, only heard. Rescuing can invalidate feelings of grief and lead to shame. Some people are more comfortable with sadness, others with anger, yet others with guilt or blame. Validating the comfortable emotion and creating safe contexts for exploring the less comfortable emotions is important. For example, when one mother began to share her grief about her son's fall from academic, social and sporting brilliance to residential care, her friends and relatives insisted her son was 'still a lovely person'. This mother told her counsellor, 'I felt my truth was taken away'.

Helping family members to appreciate that different family members will respond to grief in different ways and at a different pace can help minimise the secondary tensions caused by these differences. Penn and her team (2001) encourage writing to help thaw the relationship freeze that can occur within families as a result of any long-term illness. Writing in many forms, drawing (symbolic or realistic) and other creative

media can be used to facilitate the expression of grief. Brian Johnston (2001) argues that being able to recognise emotions can be important to recovery. He quotes Carpenter, Bartko and Strauss (1978) who followed up 130 people with a diagnosis of schizophrenia five years later. He found the only symptom which predicted poor outcome was restricted or blunted affect. He also quotes the work of Hodel in Switzerland, who reduced relapse rates by training people with schizophrenia to identify and manage their emotions.

Timing is Important

Lafond describes denial as 'like a shock absorber against bad news' (2000). Consequently any discussion about grief should be 'led' by the client or family member. A gentle initial inquiry can establish people's needs at any particular time, and workers should be careful of becoming 'prescriptive' in relation to any individual's grieving process and timing. Written material outlining the range of common responses to mental illness is useful for this reason. Family members can read it in their own time, and request help when they are ready.

Connecting with Others

Judith Herman (1997) points out that a major task of debriefing after trauma is to help people to reconnect to networks lost to them through what has occurred. The same can be said of grief counselling. People in the general community typically feel uncertain how to respond to people affected by mental illness, thus intentionally or unintentionally isolating the very people who need support. Traumatized people feel isolated psychologically because their concerns are of a different order from those of people free from trauma. For example, a mental health worker involved in a training session, when asked to reflect on her personal experiences of grief, said that soon after her father's death she became extremely angry seeing a stranger casually walk into a newsagent and buy a newspaper as if the world was still normal.

For the reasons above, some people find talking to others who have gone through similar experiences a more realistic starting point for addressing social and psychological isolation. We have occasionally found that some family members are reluctant, possibly too shamed even to do this, but are prepared as a first step, to watch a video (e.g. FaST video series) of others' experiences in the privacy of their own home.

Negotiating Contradictions

Grieving individuals experience two apparently contradictory imperatives: to do the grieving and to get on with life (White, 1988). The community (including mental health professionals) tends to be more comfortable with the latter, and can sometimes push individuals in that direction. Just naming this contradiction, and helping individuals to negotiate the dilemma in their own way, is likely to be far more helpful. Explaining that it is common for grief to co-exist with moments of competence and progress with feelings of loss, loss with relief, love with resentment, can facilitate natural healing. Often we need to encourage moments of 'selfishness'. For example, a mother who is not used to putting her own feelings first may be helped to find a 'safe' place and time for attending to her own needs every so often. Or a couple whose planned retirement trip has had to be delayed may be assisted in organising a small 'respite' holiday on a regular (if infrequent) basis. Parents may be encouraged to give siblings some special recognition or celebration. Family members may also need to give themselves and each other permission to be sad, angry, or scared. The worker may well be able to help them understand and support each other in this.

Grieving Individually or as a Family

It can be powerfully restorative to reach a situation where all family members can share their experience of the mental health trauma but this is not always possible or advisable. Workers may encourage individuals to express their grief and then consider helping family members to share their grief with each other if this seems appropriate. Expressions of grief may start with anyone. For example, one mother revealed, 'I started talking to strangers on public transport, because I knew I would never see them again'. Mental health professionals can help family members to consider whom they would first tell, by asking, 'Who would you feel most comfortable talking to?' Reconnection with others, even entertaining the possibility of doing so, is an important aspect of recovery (Herman, 1997).

Devising Rituals

Acknowledging the absence of community support and appropriate rituals for grieving can be helpful in itself. Asking 'How do you think a person would cope if they lost someone close and there was no funeral and no-one acknowledged their loss?' is one way to help family members see the role of rituals. The most common response to this question is, 'They would

not progress in their grief'. Inviting family members to come up with their own rituals for their situation enhances the chance that the rituals will be meaningful and effective.

Including the Spiritual and Symbolic

A crisis certainly helps a person discover what is most important to them. Encouraging the creative, the spiritual and the symbolic can provide comfort and meaning that more practical help has failed to deliver. D'Souza (2002) asked 79 people attending a mental health service in country New South Wales to complete a simple questionnaire about their spiritual beliefs. He found that 82% thought their mental health worker should be aware of their spiritual beliefs and needs, and 67% reported that spirituality helped them cope with their psychological pain.

We define spirituality in its broadest sense, to include any meaning that an individual uses to connect him/herself to others, to community, to a wider world or universe, or to borrow William James' (1902) words, 'the attempt to be in harmony with an unseen order of things'. In the instrumental and scientifically dominated culture of mental health services, the worker must actively make space to consider spirituality. Professionals who remain neutral towards the spiritual in mental health contexts may be experienced by consumers as rejecting the spiritual (Adams, 1995). A New Zealand study by de Beer in 1998 — reported in D'Souza (2002) — found that only 11% of the mental health clients surveyed felt their spiritual beliefs had been considered in their treatment, despite the majority of these clients believing spirituality to be of importance. Interestingly, the same study found that 94% of psychiatrists reported having no training in addressing spiritual issues.

When deterioration in relationships emphasises what has changed and hence what has been lost, an openness to the philosophical, the spiritual or the noninstrumental may allow people to recognise that some things may transcend the illness. We ask simple and respectful questions such as:

- 'What helps you to cope with the changes and losses you and your family have experienced?'
- 'Could I ask what is important to you in life?'
- 'What are your beliefs about why this has happened to your family?'
- 'What has this crisis taught you about your relationships and about life?'

The Worker's Own Relationship to Grief

Interacting with a consumer, carer or family member experiencing loss and grief potentially connects the worker with his/her own losses. Rather than an indication of 'lack of professionalism', if acknowledged openly it can be an invaluable asset for a worker attempting to understand and empathise with another's pain.

Conclusion

There is no substitute for having the severity of a person's pain respected and acknowledged. Because of the ambiguous and disenfranchised nature of the grief experienced by people with psychiatric diagnoses, simply recognising and naming losses can be a great relief to them and their families. Given the unpredictable and chaotic nature of mental health crises and the busy, instrumental culture of many mental health services, just providing a space to talk about possible losses can be of great therapeutic value. Inquiring about the unique impact of 'mental illness' on the lives of people can be profoundly healing. Tentatively naming the experiences as normal processes of trauma or grief is reassuring and transformative. Simply making it safe for clients to express a range of emotions that typically accompany grief may enhance the possibility that such painful experiences can be navigated and integrated into ongoing family life.


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that positive things can arise from mental health crises, while not understating or invalidating the difficulty and pain typically experienced. After fruitful discussion, we used the phrase 'mental health crisis' or 'trauma', rather than 'mental health problem' or 'mental illness' where possible.

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Boy

Hey!
I'm frightened
Auntie wot you doin' here?
Why y' all staring at me?

You doctors, nurses talkin' 'bout me
To whanau
They know me
Or do they?
Hey! Listen to me

I like to hide under the blankets
Dreaming of being a pop idol
I am y' know
Words come in my head
The music sings in my ears

Auntie — don't tell me you know
How can you?
You keep bossin' me to go to work
My work is music
I compose it in my head

How can you tell me how I feel?
What I should do
My energy is gone
The drugs stop my creative spirit
It flies away in the night

Listen to me now
Listen carefully
Let me be who I am
The pain on your face tells me
You don't know how to love me
Just be there eh!

Let me be who I am
I can sing, play, walk, dance, have fun
Hold me tight in your arms
Believe in me

I can be who I am
Walk beside me not in front with a rope
Listen to the voice of my soul



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Amaryll Perlesz and Ruth McNair, authors of 'Lesbian Parenting: Insiders' Voices', *ANZJFT*, 25, 3: 129–140, have requested that some extra material be added to their paper when the PDF version goes onto the secure section of our site, www.anzjft.com. Any subscribers wanting access to that secure section should contact the Webmaster (webmaster@anzjft.com) for information.