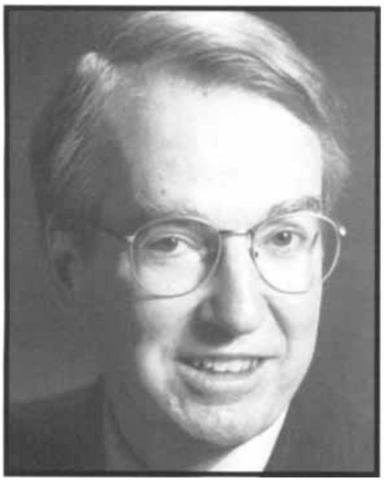
# Chronic sorrow and bereavement care



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**WHEN ASKED TO DESCRIBE** chronic sorrow, both public and professional audiences reveal negative associations: 'endless', 'stuck', 'failure to accept a loss', 'avoidance of real grieving' and even 'complicated bereavement' are common responses. Despite our greater awareness and appreciation of recent bereavement insights such as continuing bonds and episodic grieving over the lifespan, there lingers a strong suspicion that people whose mourning appears to be chronic need assistance from mental health providers. This article, however, presents an alternative perspective that, for some, chronic sorrow should be seen as appropriate, to be expected, even developmentally and empathically sound.

Chronic sorrow has most often been used in association with those who are living with life threatening or ongoing medical or mental health conditions, especially where these are progressive. Parents of chronically-ill children in particular have been susceptible to such labels. In the past, chronic sorrow was seen as a failure to face, adapt to and accept losses, a resistance to moving ahead.

**EDITOR'S NOTE**

*Here Ted Bowman describes the chronic sorrow that can follow major losses, encouraging us to recognise that this is not necessarily a symptom of mental illness. However, it may be, and Prigerson and her colleagues have provided diagnostic criteria for complicated grief (or 'prolonged grief disorder'). In addition to the chronic sorrow described here and other 'symptoms of traumatisation', to fulfil their criteria it is necessary to establish that the 'disorder causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (eg domestic responsibilities)'. In other words, that it interferes with the person's quality of life to such an extent that they are unable to undertake the roles that make life worthwhile*.* CMP

**See the special edition of Omega (2006; **52**: 1-112) for an informed debate on the arguments for and against including complicated grief in the authoritative Diagnostic and Statistical Manual (DSM).*

While there was no clear timeline, chronic sorrow was seen as extending beyond typical periods of acute or incidental mourning and depressive grieving.

Similar associations are common in the bereavement literature. Rando noted that chronic or protracted mourning was included by most writers in their discussions of complicated bereavement. She described it as a continuation of the acute phase of grieving, thus becoming chronic acute grief or chronic sorrow (Rando 1993). Rosenblatt acknowledged that grievers who do not move on are commonly seen as troubled and in need of psychological interventions (Rosenblatt 1996).

Descriptions like these, published in the 90's, are being examined in a current debate about complicated grief. In 2006 the journals *Omega* and *Grief Matters* each devoted a full issue to this topic (see *Bereavement Care* for an overview [Brady 2006]). Ties to this article deserve comment, particularly since in these discussions delayed grief, or a chronic or persistent form of mourning, are often referred to in connection with complicated grief.

Three brief observations:

- A facet of the current debate has to do with promoting the medicalisation of one aspect of grief, something that is raised as a matter for concern in this article (see p24)

**ABSTRACT**

*In this article, the case is made for consideration of chronic sorrow as a non-pathological reality for many grievers. For those who live with an ongoing sorrow, the test of health is their ability to also experience joy and perform the necessary functions of their lives, even while living with chronic sorrow. Personal and national examples are included to enrich the discussion.*

- A key distinction is that chronic sorrow, as defined in this article, refers primarily to what Hogan, Worden and Schmidt call adaptive grieving, in contrast to maladaptive, or a kind of complicated grief that requires clinical intervention (Hogan, Worden *et al*, 2006).
- The current focus of debate is complicated grief following a death. Here, readers are urged to see if a new definition of chronic sorrow, one that grew from involvement with chronic conditions, can also apply to mourning following some deaths.

Much more could be written but suffice it to say that the purpose of this article, like the issues of the journals referred to in this section, is to encourage debate.

## New definitions, another perspective

Susan Roos, in her book *Chronic Sorrow: A Living Loss*, argues eloquently for a more normative perspective for chronic sorrow, suggesting it is about living with irremovable loss (Roos, 2002). Her personal losses include a child who died at age three, miscarriages, and another child with developmental delay, seizures, and autism. Roos contends that, while chronic sorrow has been a long-term and a constant reality for her, it has not necessarily been pathological or negative. Rather, she argues, for those who face the daily demands of living, or caring for someone, with a chronic and debilitating condition, it is their norm. The challenge is to find a balance between grieving and experiences of joy, meaning and fulfilment. Roos urges grief professionals to move beyond more limiting models to see that one can be in chronic sorrow and have a rich, full and happy life at the same time.

> If a way exists to console myself, I think I would have found it by now. I'm too productive to claim to be seriously depressed, and I can feel happy and amused at times, but life just seems wrong (Roos, 2002).

Her model suggests that chronic sorrow includes these characteristics:

- Non-pathological grief response
- Grief largely disenfranchised
- Traumatic onset
- Ongoing, with no foreseeable end
- Constant reminders
- Permanent adaptations or resolution not achievable
- Periodic resurgence of intensity
- Predictable and unpredictable stress points
- Affected person continues to function
- Not a state of permanent despair

I have found these insights and arguments to be challenging, but enriching, in my work with parents of children with special needs, parents bereaved of a child, those who are living with progressive, life-limiting diseases, mental illnesses like schizophrenia, and bereaved people. However, can a model that was developed, at least in part, as a response to chronic medical conditions also have efficacy for bereavement and other losses?

## A national example

Visiting Lithuania in 2006 I found what I came to describe as a form of chronic sorrow. In 1940 the Lithuanian state disappeared from maps, the flag and other symbols were removed and replaced, and national identity was ignored as the Nazis and then the Soviets imposed their rule, language and culture for almost 50 years. In spite of the fall of the USSR and the return of Lithuanian sovereignty and culture in 1988, it appeared to me that chronic sorrow lingered in profound ways, especially in the older generations. Recent writing about long years of political violence and oppression supported my observations.

In studies of political repression, Danutė Gailienė (2005) asserted that decades of research have shown that the traumas of war and political repression have grave, long-term somatic, psychological and psychopathological effects. He describes the Lithuanian citizens of 1940 as having become overnight hostages of an all-destructive system.

One of the major contributing factors to chronic sorrow in the model developed by Roos is that the sorrow is unacknowledged. Parents of children born with anomalies or who live with chronic conditions are presumed to be over their grieving by the time the children are older; hence continual grieving goes unacknowledged and may be pathologised. Similarly after the Nazi and Soviet governments collapsed, there were repeated calls for citizens to forget the past and move on. One survivor described those who returned from prison camps as continuing to live in a kind of pressurised environment where the trauma was unmentionable. 'Unless and until there is public recognition and awareness of trauma, trauma survivors are not recognised either' (Gailienė, 2005).

Gheith reports that gulag survivors in the USSR risked severe punishment if they discussed their experiences, so that a narrative approach for dealing with loss was unavailable (Gheith, 2007). Rosenblatt describes the pain of bereaved parents when communal empathy fails (Rosenblatt, 2000a), and Hardy suggests that repeated experiences of unacknowledged and unmourned loss contribute to dehumanisation.

> It's one thing to lose something that was important to you, but it is far worse when no one in your universe recognizes that you lost it. The failure to acknowledge another's loss is to deny that person's humanity (Hardy, Laszloffy, 2005).

Kleinman and Kleinman look at the still common practice in many countries where eligibility for refugee or safety status, or access to many mental health services, requires people to accept a cultural label of victim. They conclude that those who undergo torture or severe repression first become victims, an image of innocence and passivity. Then they become patients with a disorder (Kleinman, Kleinman, 1996). Roos' model, in contrast, allows for suffering and sorrow alongside health and strength. Here is the way one resister in the Lithuanian struggle described meaning making in the midst of tragedy.

> There are various ways of resistance:
> To survive when you are supposed to die
> To remember when you have to forget
> To think when you must not think
> To notice when you are made to ignore
> To strive to know when you are ordered not to know anything
> (Grinkevičiūtė, 2005)

While national events differ from Roos' description of families, the notion of a dual process of sorrow and joy was useful and applicable to Lithuanian grief professionals. The tendency of many local bereavement workers, and guests like me, was to point toward the almost 20 years of freedom, self-rule, and restoration of Lithuanian identity and to presume that sorrow, especially chronic sorrow, should have passed or been diluted. But, for those who experienced unspeakable personal losses (the gulags, death, prison, including torture, and the loss of trust of neighbours), chronic sorrow was a part of their reality. Acknowledgement was required for a move towards healing.

Questions can be raised, of course, about distinctions between trauma and bereavement, about psychosocial losses like nationality, or language and their similarity and difference from death, and whether or not Roos' model actually applies to a national situation. Nevertheless, there are several implications for bereavement work.

Many immigrants and refugees coming to western countries have experienced oppression and violence, some incidental, others long term. Chronic conditions of any kind can contribute to loss overload and bereaved people may exhibit what appears as an overreaction to a normal death because of the accumulation of losses earlier in their lives. Clearly, for some, the loss of country through tyranny and oppression also leaves scars, in addition to specific and personal experiences of brutality and trauma. My Lithuanian colleagues reported that many of their countrymen were still suspicions about neighbours, the current governments in Lithuania and Russia, and about 'freedom', suspicions that caused many to still be guarded and protective. For me, it seemed like an example of loss of the future story and the ability to dream dreams (cf Parkes, 1986; Janoff-Bullman, 1992; Bowman, 1994, 2000a). Failure of bereavement workers to acknowledge such losses could contribute to, or reinforce, chronic sorrow.

## Bereavement and chronic sorrow

A natural extension of the Roos model would be to perinatal loss, stillbirth and deaths of children in the first year of life. In Rosenblatt's small study of parents, he found that their losses included what the child could have become, sometimes the loss of the parental role, and sometimes the loss of support at times of grieving (Rosenblatt, 1996). In his subsequent study of parental narratives following the death of a child, Rosenblatt found the child continued to be part of the parents' lives and stories long after the death (Rosenblatt, 2000a, 2000b) which some might describe as chronic sorrow.

> Six other sons, and yet
> I know precisely the last pull of pain
> when you came out of me,
> feet first...
> It was the last time we touched
> (Paisley 1999)

Note the time-line and circumstances in this parental description of ongoing grief: six more sons and the sorrow persists and can be palpable.

Grief after a suicide is also often prolonged because grieving the loss gets entangled with how the person died. Failure to uncouple these aspects can lead to chronic sorrow.

> Over 25 years have passed since then, and her death has indeed sunk, as I'd expected, deep inside me. But it is, like any underwater object, crusted over with barnacles of guilt, fuzzy with incomprehension and anger. Suicide is just not death. It is an act that insists; it becomes the unanswered questions, the missed opportunities. It doesn't matter what stories I tell myself: I still believe I should have saved her, could have, and didn't. I missed by moments. Now she is my personal ghost whose hauntings get rarer as the years pass, but who returns nevertheless, to remind me that I will never understand, that I will always be responsible (McCauley, 1998).

In his classic study, Colin Murray Parkes briefly discusses chronic grief. He found that, years after bereavement, many were still preoccupied with memories of the dead person, pining intensely and severely distressed by reminders of them (Parkes, 1996). He suggested that for many, chronic grieving was seen as a duty to the person who died.

It seems that as long as bereaved people are able to function well with daily tasks and can experience beauty in life, the presence of a chronic sorrow could be understood, acknowledged, even supported as an acceptable way of grieving.

## Implications for bereavement workers

1. In spite of all that is known about grief and loss, there is still a tendency to encourage people to move through bereavement to 'life after loss'. Roos and others remind us that many live with constant and chronic sorrow. Closure, acceptance and moving on, it could be argued, should not be part of our vocabulary; the griever's task is better described as learning to live with loss.

2. Grief workers tend to focus on current losses without making full inquiries about past, concurrent and ongoing losses that should be considered part of bereavement care.

3. Those who practice Buddhism, and many other religions, remind us that sorrow is a part of life. If that is true, then chronic sorrow is not some distant or strange emotion but something that may affect any of us (a current example for me is caring for my mother as she moves further into the shadows of Alzheimer's disease).

4. The dual process model of bereavement describes the ability and willingness to grieve as one side of bereavement, and integrating the grief with other things that evoke hope and joy as the other side, suggesting that to be able to do both can be seen as a sign of health. Roos and others seem to support such a model.

5. A major component in Roos' model and the studies of national trauma is the importance of acknowledgement of loss by one's community. Chronic sorrow appears more likely to be exacerbated when the sorrow goes unacknowledged both on a personal and national level.

6. Obviously, there are some whose chronic sorrow does not include the ability also to experience joy. Clinical depression is their reality and they need not only support and acknowledgement but referral to a skilled therapist. The outcome of the debate about complicated grief referred to earlier is important for these people, for their mental health care may depend on it.

## Conclusion

Perhaps Paul Simon had it right years ago when he sang: 'Hello darkness my old friend' and the Minnesota poet Michael Dennis Browne who wrote: 'I don't expect the anxiety to go away, but I want the anxiety to know its place in the scheme of things'(Browne, 2005). Similarly, grieving parent Mary Sheepshanks observed: 'It came as a complete revelation to me in the middle of great misery that the ordinary things that amuse us on a day-to-day basis don't cease to be funny.' (Sheepshanks, 1997).

Singers, poets and parents like these three remind us that sadness is a part of life. Sorrow, as discussed here, can become chronic for all sorts of reasons, but it need not be the dominant narrative of lives. Rather, when balance can be found, long held presumptions about chronic sorrow as pathological can be dispelled. Understanding and acknowledgement can lead to support for grievers, which is the best of bereavement care. ●

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## EVENTS IN 2008

**Consequences of loss: resilience and complications in the grief experience.** 8th International conference on grief and bereavement in contemporary society. 15-18 July. Melbourne, Australia. Key speakers: George Bonanno, Grace Christ, Robert Neymeyer, Colin Murray Parkes, Holly Prigerson, Beverley Raphael, Margaret Stroebe. Email conference@grief.org.au; tel [+] 613 9265 2100.

**Global mourning: death among and beyond ourselves.** 30th ADEC annual conference. 30 April-3 May. Quebec, Canada. Key speakers: Leila Gupta, Stephen Lewis, Kim Phuc. Visit http://adec.org/conf/index.cfm

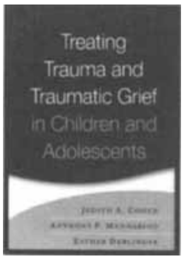
**Events at St Christopher's Hospice.** London. **Candle 10th anniversary conference.** 12 June. Speakers Frances Kraus, David Trickey, Nigel Hartley. **Roots of resilience: what makes a good outcome following disaster.** 14 March. Linda Machin, Stephen Regel, David Trickey. Tel [+44] 20 8768 4656; visit www.stchristophersorg.uk/bookingform

**Song-writing as therapy in palliative and bereavement care.** 7-8 March. Oxford, UK. Bob Heath. Tel [+44] 1865 225886; visit www.sobellhospiceoxford.org;

## BOOK REVIEW

### Treating Trauma and Traumatic grief in Children and Adolescents

**Judith Cohen, Anthony Mannarino, Esther Deblinger**



**New York: Guilford Press, 2006**
**256pp**
**£23.00 hb**
**ISBN 1 58385 308 4**

The authors of this marvellous text have undertaken more randomised control trials than any other group of the effects of trama-focused cognitive behavioural therapy (TF-CBT) for children presenting with post-traumatic stress disorder (PTSD). These children mainly developed PTSD after sexual abuse and so the interventions need a little adjusting to meet the needs of children affected by other traumas. After the bombing of the twin towers in New York, the group did extend their work to meet the needs of children suffering from traumatic grief, although that has yet to be subjected to the same level of evaluation.

The authors developed a series of manuals to guide clinicians in therapy. The approach involves direct work with the child and parallel work with the parents. The therapy focuses on the trauma and the way it has been interpreted by the child so that muddled ideas, inaccurate cognitions and strange memories are tackled directly. Though the approach is very flexible, the authors are aware that by writing it all down, it necessarily appears sequential and rigid, so they are at pains to illustrate how the various elements of treatment interconnect and build on each other.

For readers of *Bereavement Care,* the main interest will be in how the techniques are expanded to deal with traumatic grief in children and adolescents. Like most experienced practitioners, the authors argue that grieving often cannot begin until the traumatic event has been dealt with. Remembering the dead loved one is simply too painful if every time the child tries to remember them, they relive the dreadful circumstances of the death. Thus, practitioners need to be familiar with all the sections on dealing with trauma and apply these before tackling the grief.

Throughout the book, the authors rightly take a broad view of what constitutes both PTSD and traumatic grief. They focus almost entirely on their own manuals, which is fair enough, but somewhat confusingly they use the term TF-CBT as if it was a trade-mark for their approach rather than a generic term for a set of approaches that are developing very quickly worldwide. Thus, they do not say anything about eye movement techniques (EMDR) nor narrative exposure therapy, although they incorporate elements of each in their work. They advise that therapists trained in other approaches should first get training in CBT before trying to apply the package. Such training is available free on-line at www.musc.edu/tfcbt Perhaps this will be a stimulus for UK public sector child and adolescent mental health services to leap into the CBT age. Certainly, there is a great deal of experience and wisdom in the very clear and practical 'lessons' incorporated in this text. ●

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