Sad or mad? Prolonged grief and mental disorder

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In August 2009 Holly Prigerson, with 18 colleagues from across the world of bereavement research, published a paper setting out the possible criteria for a medical diagnosis of prolonged grief disorder (PGD). The article, published in the online, open-access, peer-reviewed journal *PLoS Medicine* (*http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000121*) prompted a huge response, both among professionals and among lay people.

Briefly, Prigerson and colleagues argue that, while grief is 'an unavoidable and normal reaction to … loss', and often manifests in the form of mental distress and even physical ill health, for the majority of people these responses last no more than six months following the death. But a very small number of people continue to experience these symptoms for longer, and their lives can be severely affected. They, the paper argues, should be recognised as suffering from a mental disorder, prolonged grief disorder (PGD), which should be included in the DSM-V and ICD-11 official US and WHO psychiatric diagnostic manuals.

To be included in the DSM, it is first necessary to agree a validated list of symptoms for PGD, and a set of rules, or algorithms, for diagnosing it, based on these symptoms. The paper reports nine symptoms identified by Prigerson *et al* from their study of 291 bereaved people. Someone who continues to experience 'yearning' alongside at least five of these nine symptoms, either daily or 'to a disabling degree', beyond six months after the death, could be diagnosed as having PGD (see Table 1).

Why a formal diagnosis?

Why is a formal diagnosis so important? The authors explain:

> 'Such criteria would be useful because they would allow researchers and clinicians to identify risk factors for PGD and to find ways to prevent PGD. They would also help to ensure that people with PGD get appropriate treatments such as psychotherapy to help them change their way of thinking about their loss and re-engage with the world.'

Table 1: Criteria for PGD proposed for DSM-V and ICD-11 (Prigerson *et al*, 2009)

Category	Definition
A	Event – bereavement (loss of a significant other)
B	Separation distress – the bereaved person experiences yearning (eg. craving, pining, or longing for the deceased; physical or emotional suffering as a result of the desired, but unfulfilled, reunion with the deceased) daily or to a disabling degree
C	Cognitive, emotional, and behavioural symptoms – the bereaved person must have five (or more) of the following symptoms experienced daily or to a disabling degree:
1	Confusion about one's role in life or diminished sense of self (ie. feeling that a part of oneself has died)
2	Difficulty accepting the loss
3	Avoidance of reminders of the reality of the loss
4	Inability to trust others since the loss
5	Bitterness or anger related to the loss
6	Difficulty moving on with life (eg. making new friends, pursuing interests)
7	Numbness (absence of emotion) since the loss
8	Feeling that life is unfulfilling, empty, or meaningless since the loss
9	Feeling stunned, dazed or shocked by the loss
D	Timing – diagnosis should not be made until at least six months have elapsed since the death.
E	Impairment – the disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (eg. domestic responsibilities)
F	Relation to other mental disorders – the disturbance is not better accounted for by major depressive disorder, generalized anxiety disorder, or posttraumatic stress disorder

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A personal view

I was one of the authors involved in writing this paper and Utrecht University, to which I am affiliated, decided to issue a press release about it. Unfortunately, although the release was carefully written to reflect the nuanced findings of the study, several newspapers in The Netherlands published exaggerated summaries of it. For instance, one major newspaper headlined a brief article 'Extended Grief is a Psychological Illness'. The article suggested that people who are grieving for more than six months have a serious mental disorder. This gave rise to various negative and some positive reactions on the internet.

With respect to the positive comments, there were people who felt recognised by the *PLoS* article and things that were written about it in the media. Several people contacted me personally because they wanted to know where they could get professional treatment for this condition. But there were negative reactions as well.

One woman, bereaved by the loss of her son, wrote on her weblog that I was insane because I said that grieving for more than six months is a sign of 'insanity'. It was quite clear that the woman had not read the *PLoS* paper; nor did she ask me to explain the issues with which she disagreed before putting these offensive words on the internet. Several others writing in different forums on the internet were also quite sure that I had never suffered a loss myself; if I had, they said, I wouldn't have said such stupid things.

I was actually quite surprised by these responses to the paper. These people really seemed to think that I, all by myself rather than as one of 19 authors, had made up a theory about when grieving is normal and when it is abnormal. They truly felt they were justified in attacking me personally without first checking what the *PLoS* paper actually says, or how accurately this was reported in the newspapers.

There will always be a handful of people who will react in this way, but I certainly learned the importance of being absolutely clear when saying things about prolonged grief in the media. It is clear that it remains a sensitive topic.

Paul Boelen, assistant professor of clinical and health psychology, Utrecht University, and editor, *Bereavement Care*

A follow-up article, by physician Stephen Workman, in the same issue of *PLoS Medicine*, develops this theme. He argues that advances in modern medicine have made the process of death far less simple and clear-cut. 'Death is often a technologically supported and often prolonged experience.' Likewise, 'the current emphasis on hope and survival and "fighting", even in the final stages of disease, without also facilitating acceptance, may be contributing to the development of pathological grief reactions, including PGD'. Workman reports his own experience of one middle-aged man who stated, as his father lay dying: 'I don't ever want my father to die.'

Workman writes: 'The opportunity for family members of patients who have died to see their family physician or some other qualified individual after six months, in order to identify and treat those suffering from PGD who wish it treated, is very appealing and somewhat comforting, at least to me.'

Looking to the future, he argues that giving PGD diagnostic recognition could improve understanding of end-of-life care, ensure more consistent and effective palliative care, and improve availability and effectiveness of treatment more generally.

Pathologising grief

The paper provoked a huge response across the worldwide web, on professional mental health and medical sites and on consumer advice sites and weblogs.

The responses are highly varied, ranging from actively hostile to warmly welcoming. For example, a news report appeared on *Medpage Today* (*http://www.medpagetoday.com/psychiatry/generalpsychiatry/15427*) shortly after the *PLoS* publication. *MedPage Today* is an accredited daily news service for doctors in the US, who can gain continuing medical education (CME) credits for reading it, which means it has some professional clout. One commentator, ICU-Causality, warmly welcomed the article, with specific reference to a common complaint from psychiatrists that their medical colleagues do not consider them 'real' doctors:

> 'I believe this new Prolonged Grief Disorder's diagnostic criteria will lead to a better understanding among professionals in other medical fields … At long last, psychiatry will gain its deserved respect in the annals of medicine as a field of medicine wherein real health issues occur and our patients can't just "snap out of it"'.

However psychotherapist John Brownson warns against what he calls 'a slippery slope' in seeking to define 'excessive grief' as an illness, 'rather than the natural, human and highly individual response to loss that it is'. His main concern is the six-month time period stipulated as part of the diagnostic profile:

> 'I wonder if the current proposal isn't more about relieving our feelings of helplessness and the possibility of "treating" our patient's grief with medication, somewhere down the road … Our grieving patients do not deserve to be told that their process is an illness, because it's gone on (by our standards) too long.'

Consumer views

On the consumer sites, responses on the *www.perfectmemorials.com* website (a US site selling death memorials) covered a similar range of views. Russell Friedman, of the Grief Recovery Institute Education Foundation in Sherman Oaks, California, argued that research should be looking at what enables the majority of people to manage bereavement without serious psychological distress. Are they

managing their loss better 'because they deal with loss or grief better than the others, or because they have a great deal of connection and activity in their day-to-day lives?'

Pam Brown asked the million-dollar question: 'If the prolonged grief disorder is recognized as a medical condition, what would be the treatment? You state doctors can treat the disorder, but I was just wondering if the treatment methods include drugs?'

Care2.com (*www.care2.com/greenliving/prolonged-grief-nine-symptoms.html*), a consumer website specifically for family carers, hosted a wide-ranging debate on the issue of 'categorization'.

Laurie T wrote: 'Yes, grief can cause stresses that leave a person in a vulnerable state for all kinds of health risks, but it just seems that every emotion is being categorized and analysed to death (no pun intended).'

Theresa Parrish, grief counsellor, felt we should be 'normalising' grief reactions: 'A very, very small percentage of the people I see have pathological reactions to loss, and almost always those few also have pre-existing mental illness. All of the sub-cultures in our society could benefit from normalizing feelings of sadness, anger, emptiness etc as a natural part of grief.'

Chana B, clinical social worker employed in a hospice, observed: 'If someone is unable … to reinvest emotional energy in current relationships (friends, children, grandchildren) after a couple of years, he or she should look into some individual counselling to help them get "unstuck"'.

Bloggers' responses

The personal blogs produced examples both of wise and wacky homespun wisdom.

Dr Deb (*http://drdeborahserani.blogspot.com*) is a US psychologist offering advice and information 'for educational purposes only'.

'Anonymous' felt better for knowing there was now an official diagnosis: 'It has been nine years since my husband's death … I am still grieving over the loss and at least I know I am not crazy and that there are other people in the world that must feel the same if they have a name for it.'

Dawypawny, responding to Ruthyj ('Christian, GreatGrandmother and still learning!' at *http://ruthyjobservations.newsvine.com*), described both the death of her mother, for whom she had cared for seven years, and the sudden deaths of her children:

> 'It takes a person who has experienced this to understand just what a person goes through at the loss of a child … I do agree that talking things out is very therapeutic, but found people who had suffered similar losses to be more aware of the sadness than the therapist I saw … I guess I just hate to see something that is so personal become a disorder.'

Interestingly, only one UK-based blog seems to have picked up the debate. *http://uk.answers.yahoo.com* is a space where people can ask advice (and get it) for whatever problem they are experiencing. The string starts with the Asker (the punctuation and spelling is as it appears on the blog):

> 'Okay, so my dad died when i was nine and my nan last year and ever since then i don't feel remorse sadness or much laughter, i just feel happiness and anger. i looked on the web but all i could find we [*sic*] a temporary disorder but i have had this since last year.'

Asker's chosen 'Best Answer' suggests: 'Sometimes the grieving process can last a long time and everyone is affected differently by this, or it may be that you haven't fully grieved properly yet. Best thing is to see a professional.'

Asker's response typifies the comfort that people appear to derive from receiving an official diagnosis of illness. Perhaps they feel it sanctions their struggle to conform to social expectations of behaviour: 'Thanks very much i went and saw a pshychoanalyst [*sic*] and she said that i had prolonged grief syndrome. I may never be cured but i know what i have now instead of being a boring runt.' ■