2013

Signs of post-traumatic stress disorder in caregivers following an expected death: A qualitative study

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This article was originally published as:
http://doi.org/10.1177/0269216313483663

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Background

Complications of grief are an important area of investigation with potential to improve the well-being of palliative care caregivers. There has been little study of the prevalence or significance of post-traumatic stress disorder for those bereaved after an expected death.

Aim: To identify evidence suggestive of post-traumatic stress disorder symptoms in a population of bereaved caregivers of patients who have died of ovarian cancer.

Design: Caregivers’ recollections of their end-of-life experiences were coded and analysed, using qualitative data obtained from interviews 6 months after the patient’s death.

Setting/participants: Australian Ovarian Cancer Study–Quality of Life Study is a population-based epidemiological study using mixed methods to explore caregivers’ experiences following the expected death of a woman with ovarian cancer. Thirty-two caregivers from the Australian Ovarian Cancer Study–Quality of Life Study participated in semi-structured telephone interviews 6 months post-bereavement.

Results: When describing the patient’s death at their 6-month interview, all interviewees used language consistent with some degree of shock and traumatisation. For the majority, there was also evidence suggesting resilience and resolution. However, a number of interviewees describe intrusive memories associated with physical sights and sounds that they witnessed at the deathbed.

Conclusions: This exploratory study demonstrates the phenomenon of the ‘shocked caregiver’. If trauma symptoms are present in bereaved carers in palliative care, it has implications for palliative care provision. Given that trauma symptoms may be distinct from prolonged grief disorder, this may also have implications for provision of bereavement counselling. Further research into this phenomenon is required.

Keywords

Caregivers, bereavement, post-traumatic stress disorder, palliative
long-term physical and mental health outcomes. However, interrelationships between factors contributing to difficult or complex bereavements are unclear. Also unknown is how best to identify those most vulnerable, and the potential role of palliative and supportive care services in minimising risks.

Investigation of differences between normal and complicated grief has led to consensus definitions for prolonged grief disorder (PGD) — previously called complicated grief. PGD is an abnormal grief response involving intense separation distress and trauma symptoms such as intrusive thoughts and numbness. The relationships between trauma symptoms within PGD and post-traumatic stress disorder (PTSD) have been studied. PGD seems to be clinically distinct from both anxiety/depression and PTSD, though both can be co-morbid with grief. PTSD is an anxiety disorder related to trauma experienced as directly threatening the integrity of self, for example, assault, disaster, accident or life-threatening illness. A PTSD diagnosis may be made for those witnessing trauma, or profoundly affected by the life-threatening illness of another. Diagnostic criteria for PTSD emphasise feelings of helplessness, horror, intrusive and distressing recollections, coping responses involving persistent avoidance of cues linked to the trauma and/or emotional numbness.

PTSD associated with grief is well recognised, mostly after violent or traumatic deaths. In health settings, PTSD has been identified following death in intensive care units, in families witnessing failed cardiopulmonary resuscitation, parents of children with cancer and cancer patients. Population studies of bereaved relatives suggest PTSD occurs in 15%–40% of this group. Bereavement issues previously demonstrated in palliative care caregivers include anxiety/depression, PGD and demoralisation, but prevalence of PTSD in caregivers following expected deaths has not been studied.

Palliative care aims to support patients and families when death from a life-limiting illness is expected. Preparation for death, choices about place of care, managing distressing symptoms and providing personalised, holistic support to patient and family are core activities of palliative care, intended to reduce distress. Nonetheless, despite supporting and preparing families, some caregivers experience PGD. Evidence regarding risk factors is accumulating. They include pessimistic thinking, stressful life events of caregivers, lack of preparedness for death, depression or caregiver burden pre-loss and perceived lack of support after the death. Also significant is the attachment between bereaved person and patient: relationships characterised by more insecure attachment styles, and/or higher levels of communication, expressions of love, affiliation and closeness, carry increased risk for PGD.

Within the palliative care literature, PTSD as a possible complication of grief seems to be largely unrecognised. Nonetheless our clinical experience suggests that trauma symptoms and possibly PTSD may contribute to bereavement morbidity in this population. This exploratory article examines responses to death of a loved one from cancer, focusing on possible trauma/PTSD responses.

Methods

Sample and recruitment

Consecutive caregivers participating in the Australian Ovarian Cancer Study—Quality of Life Study (AOCS QoL Study) who were bereaved during this study were invited to participate in follow-up interviews. AOCS is a prospective population-based study of women aged 18–79 years, newly diagnosed with primary epithelial ovarian cancer in 2002–2006, recruited through major treatment centres and cancer registries. AOCS collected detailed epidemiological, pathology, treatment and clinical outcome data. The AOCS QoL Study included women with invasive cancer alive in May 2005 or recruited subsequently, and their primary caregiver. This study involved all caregivers bereaved between June 2006 and December 2007. Approximately 5 months post-bereavement, caregivers were sent a condolence letter inviting them to participate. Thirty-two of 52 eligible carers (62%) completed written consent. Their key descriptors are listed in Table 1. Ethics approval was obtained from the University of Sydney (12-2005/4/8717) and Queensland Institute of Medical Research Human Research Ethics Committees (P965-H0602-006).

Design and procedure

This study reports qualitative analysis of semi-structured telephone interviews 6 months post bereavement, exploring caregivers’ views about ‘a good death’. Questions were developed for these domains: preparation for death, information/decision-making, emotional/communication issues, last weeks of life, end-of-life care and the death itself. (Example questions include: Was it a difficult death? Would anything have made this experience better/more peaceful?) The interviewer was a trained psychology graduate (N.M.), supervised by clinical investigators. Interviews on average lasted 45 min and were tape-recorded and transcribed verbatim.

Transcripts were coded into parallel strands: one strand described events and experiences happening to the patient, which the interviewee witnessed, and the second described their perceptions of events and emotional response (‘they-statements’ and ‘I-statements’). In reviewing transcripts, language potentially consistent with PTSD was highlighted. Evidence of possible triggers for PTSD was sought among descriptions of the experience of witnessing a loved one’s death, particularly distressing sights, sounds and smells associated with dying.
Results

Coding according to the ‘they-statement’/‘I-statement’ schema made themes of interviewees’ bereavement experiences evident. These extracts are from these ‘I-statements’, exploring the immediacy of deathbed experiences, and highlighting the associated language.

The language of trauma

All interviewees at some point used vocabulary suggesting trauma. Words like ‘shock’, ‘horrible’, ‘traumatic’, ‘awful’, ‘surreal’, ‘couldn’t believe it’, ‘helpless’, ‘horrendous’ and ‘devastating’ occurred in every interview, often repetitively, conveying the intensity of deathbed experiences – emotions these interviewees seemingly re-experienced during the interview. For several, little resolution seemed to have occurred. Interviews addressed their experience of the death (‘what is a good death’), and triggered painful memories; however, the language many used suggested ongoing trauma still disturbing them 6 months down the track – well after expected trauma is thought to subside.

And then she started vomiting up all this brown gunk and it was not very nice to watch, it was pretty horrible … the three nurses were trying to stop this stuff from coming out … they [the children] were there when she died, it must have been uh horrible for them. I just looked around and I saw the look of horror on her son’s face. (EOL1, male partner)

One of my nephews was there and her sister and they said it was just the worst thing they’ve ever seen, like half her insides smelled and felt like they came out and that was um that was horrible for them. I just looked around and I saw the look of horror on her son’s face. (EOL1, male partner)

The language of impact

The power of the experience is suggested by frequent use of words connoting physical impact, and sometimes associated expressions of pain. Most common were ‘it hit me’ or ‘it hit me very hard’. Other phrases, like ‘I fell in a hole’ (after the death), or ‘gutting’, were used. The expression of pain, several times, was simply ‘it hurt me’. Other phrases, denoting the hard work of the final days, were ‘gruelling’ and ‘it was just impossible’, and, recurring repetitively in almost every transcript, the words ‘hard’ and ‘difficult’.

The language of surprise and uncertainty

All interviewees were primary caregivers of a woman with ovarian cancer, an illness often characterised by a long course with multiple recurrences. This trajectory may be misleading or confusing for patients and carers. Nonetheless, death is often predictable, enabling opportunities for preparation; yet, the element of surprise was viscerally evident. Phrases such as ‘I didn’t expect’, ‘just didn’t believe it’, ‘happened very quickly’, ‘difficult to know what was happening’, ‘incredibly quick’, ‘hard to predict’, ‘you can never know’, ‘it wasn’t the way that I pictured’, ‘I was not quite understanding’ and ‘it was a blur’ appear in transcripts like a recurrent motif. Many interviewees recollected conversations with doctors or nurses towards the end, but in recounting these, their memory was often dominated by the sheer unexpectedness of the information, and their difficulty in grasping it.

The language of physical witnessing

Deathbed experiences of these caregivers, their awareness of other vulnerable family members exposed to distressing sights and sounds and their wish to protect them suggest a context in which there is risk of traumatisation. Not all interviewees used the language of witnessing, but those who did frequently added some statement of physical disgust. Thus,

And then she started vomiting up all this brown gunk and it was not very nice to watch, it was pretty horrible … the three nurses were trying to stop this stuff from coming out … they [the children] were there when she died, it must have been uh horrible for them. I just looked around and I saw the look of horror on her son’s face. (EOL1, male partner)

One of my nephews was there and her sister and they said it was just the worst thing they’ve ever seen, like half her insides smelled and felt like they came out and that was um that was something they wished they hadn’t been in there to see because they – I mean death was in the room, it was just hanging, it was just around the corner sort of thing so it was … just it was a gutting thing … I think you can smell death … there’s all those mixtures of emotions so … My son said to me that he couldn’t
go back into the room now. He’d come and said goodbye and he couldn’t look at Nanna again like that. (EOL6, male partner)

The illness was you know absolutely disgusting … if there was any regrets or bitterness it was at the illness. (EOL13, male partner)

One of the most common witnessing phrases was ‘watching her go downhill’ – a phrase conveying both rapidity of change, and the helplessness of the observer.

Intrusive memories
Several interviewees described distressing, intrusive images related to the patient’s death:

My major problems I’m having at the moment are I’m just reliving over those-especially last two days. (EOL17, daughter)

It’s not something you’ll ever forget that’s for sure … They are not good memories you know I find it very, very difficult and very hard to think back at good times you know. For months after she died I was just haunted by that last you know particularly the last week, I found it extremely difficult and the day that she fell over on the floor you know I couldn’t think of anything good – I try – but it was that last week was you know it was pretty awful … the few hours before she died will live with me forever. (EOL13, male partner)

The language of reflection and resolution
Interviewees without exception described deathbed experiences using the vocabulary of trauma. However, at 6 months many appeared to be resolving these experiences to some extent. However, some seemed very overwhelmed and had not yet dealt with it:

Well not really I mean I’m not sure I just sort of – I just sort of feel like perhaps it hasn’t really hit me yet because I’ve had so much to do. But I think perhaps in a way I might not quite realise that she’s gone … So um you know sometimes I – it’s like that and other times I’m sort of angry for the mess that she’s left. (EOL7, female sibling)

Some were able to access positive elements of the experience:

I think it probably brought us closer together and you know we – sort of valued one another’s time together. More appreciate of it. Makes you appreciate what you had. (EOL2, male partner)

The last few weeks were probably a mixture of being very um honest and rewarding … Yeah so very – very, very good experience if you can have a good experience when you’re watching someone die … it was beautiful … I think I was relieved actually … Um oh look she taught us a lot really uh and I’m not sure that we’ve had the time to digest all the lessons yet. (EOL5, daughter)

A few were still rebounding between overwhelming contradictory responses:

Uh and she left behind this bloody carcass. She wasn’t there anymore.

That – I think I would have liked to have known that, that when it happens that’s what happens. I mean you hear – I mean you get surrounded by experts at times and they all talk about the death rattle and all of this sort of rubbish – oh maybe it’s not rubbish I don’t – but um, none of that. It was just um unbelievably um serene and peaceful and pretty awful. (EOL13, male partner)

Outcomes and self-appraisal
An important subtext within these deathbed accounts was of caregivers having done their best, done what was needed and survived. These interviews suggest that positive self-appraisals may assist the transformation of trauma into a more bearable story, thus diminishing its psychological power:

You’re helpless but you do your best – So I feel there is some closure – it takes a long time I’m sure. (EOL3, male partner)

But at the moment I seem to be you know fairly strong … I probably might – I don’t know if I would be able to handle it. But I’m sort of surprised at how I am handling things, and how I have handled my father’s death last year. (EOL7 female sibling)

Maybe it’s age that helps you to cope, age and understanding. I’ve coped better this time than I did with my first wife. (EOL12, male partner)

It’s worked out well I suppose if you can call it that … I’ve seen so many people die in my life and to rush a death or wish somebody dead for me is not right. And if it takes a year to die, it takes a year to die – don’t rush it, don’t speed things up, don’t you know don’t wish it because things have a habit of sorting themselves out in exactly the right sequence anyway … I don’t think there was anything else we could have done. (EOL11, male partner)

However, for several, it seemed the experience rocked their foundations, leaving them disoriented and distressed:

Do you know I can understand some people when they get to suicidal stage where you know you think well shit what’s this all for. What is it all about? There is no purpose or meaning it’s
just a – I don’t know, you get a bit to play in this huge – on the huge stage of life, you do your bit and that’s it, you’re off. (EOL13, male partner)

And I didn’t get peace because I don’t believe that someone goes to a better place, I think they just die and um I mean I don’t know it might be hard for you to hear me say things like that, depending on your beliefs but it’s just um an unnecessary, unfortunate thing that you can’t stop … it’s just such a negative event, there’s not much positive – I don’t think any positives come out of it. So I hope what I’ve said has been helpful to you. I’ve moved on. (EOL8, female sibling)

Discussion

These transcripts convey a striking picture of trauma associated with expected deaths. Highlighting sub-structural emotional content reveals expressions of distress and shock that are repetitively present. While these findings are not diagnostic, and prevalence of PTSD cannot be estimated, nonetheless the language suggests interviewees have experienced a profound trauma. Unlike deaths in ICU, or sudden deaths, possible PTSD has not previously been considered important for expected deaths in palliative care, and as far as we know, no information is currently available regarding prevalence or likely outcomes. The extent of PTSD in this population should be further investigated with longitudinal studies using appropriate assessment tools.

Our initial hypothesis is that expected death has trauma inherent within it, no matter how well families are prepared, or symptoms managed. Trauma may not be proportional to the quality (as currently perceived) of services provided. The experience of waiting and watching while someone dies, without active attempts to prevent death, may perhaps be unendurable for some individuals. While many families and clinicians feel the palliative care approach to death offers a precious, peaceful time for the dying person to spend with loved ones, for others, the same experience may be characterised by shock and distress. Finally confronting death could be, for such individuals, the culmination of an experience of powerlessness. Further study to explore this hypothesis is warranted.

Whether this trajectory is of initial shock followed by growth and resilience after facing an existential phenomenon beyond the individual’s prior experience, whether trauma has similar risk factors and outcomes to other complications of grief, and what preventive and treatment options might be feasible, are questions for future study. Better understanding of these issues could have implications for palliative care provision, regarding what information, preparation and support is helpful for vulnerable individuals. Recognising cognitive effects of trauma on shocked patients and caregivers could lead to different approaches to communication and decision-making, acknowledging people’s limited ability to absorb complex verbal information in this state. In particular, whether home death is appropriate if caregivers are at risk of traumatisation is a question for investigation.

It is likely that these assessments are currently made in routine palliative care practice in ‘subliminal’ ways – so ‘non-coping’ caregivers are monitored or given extra attention. However, reconceptualising the phenomenon of ‘non-coping’ into a framework that identifies trauma, allowing us to study its outcomes, offers a more nuanced framework for supporting shocked caregivers.

Limitations of this study are that interviews were not accompanied by validated PTSD assessment tools. However, the strength of the analysis is how it unmasks trauma language used when interviewees spoke of their experiences. By unlinking this from the trauma trigger – the story of events – caregivers’ trauma is illuminated separately from perceived suffering of the patient. This is a cross-sectional study, providing only preliminary, but highly suggestive, evidence about experiences that may not necessarily represent psychopathology. Purposive studies of PTSD in this population are needed.

Conclusion

Palliative care practice focuses on relief and prevention of suffering, and preparation for death of both patients and loved ones. Skilful care of caregivers requires an understanding of the nature of their experiences, if we are to reduce traumatisation of vulnerable individuals. Identifying the true significance of PTSD in palliative care caregivers is therefore an important future topic of research.

Acknowledgements

We would like to thank the participants who shared their experiences with us in the interviews.

Funding

This study was funded by the University of Sydney Cancer Research Fund. The AOCs QoL Study was funded by the Cancer Councils of New South Wales and Queensland (grant number RG 36/05 New South Wales). Financial support for the parent study (AOCs) was provided by the US Army Medical Research and Materiel Command (grant number DAMD17-01-1-0729), the National Health and Medical Research Council (NHMRC; grant numbers 400413, 400281) and the Cancer Councils of New South Wales and Queensland (grant number RG 36/05 New South Wales). Financial support for the parent study (AOCs) was provided by the US Army Medical Research and Materiel Command (grant number DAMD17-01-1-0729), the National Health and Medical Research Council (NHMRC; grant numbers 400413, 400281) and the Cancer Councils of New South Wales and Queensland (grant number RG 36/05 New South Wales). Additional recruitment was conducted under the Australian Cancer Study (Ovarian Cancer), funded by the NHMRC (199600). Full membership of the Australian Ovarian Cancer Study Group is listed at http://www.aocstudy.org/.

Conflict of interest

The authors declare that there is no conflict of interest.
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