

The sights and sounds of palliative care: Bereaved carers of women with ovarian cancer

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Background – Caregiver distress

- ▶ Family members called on to provide emotional and practical support
- ▶ Feel unprepared for this role
- ▶ Can experience financial distress
- ▶ Existential distress and anxiety related to future uncertainty
- ▶ Poorer physical health due to strain of caregiving can increase caregivers own risk of mortality
 - (Li et al 2003; Pitceathly & Macguire 2003; Christakis & Allison 2006; Beesley et al 2013)

Predictors of high caregiver distress

- ▶ Other life stressors
- ▶ Poorer social support
- ▶ Lower socio-economic status
- ▶ Younger age
- ▶ Lower carer optimism
- ▶ Closer caregiver-patient relationship
- ▶ Distress increases with greater patient physical impairment and need for palliative care

- ▶ (Mellon & Northouse 2001; Schumacher & Dodd 1993; Blanchard et al 1997; Awadalla et al 2007; Moore et al 2011; Carey et al 1991; Christakis & Iwashyama 2003)

Bereavement distress

- ▶ Complications of grief important to examine with the potential to improve the wellbeing of palliative care caregivers. (Workman, 2009)
- ▶ At risk are those whose bereavement is difficult and prolonged, evidence suggests complicated grief have poorer long-term physical and mental health outcomes. (Latham & Prigerson 2004; Prigerson, Bierhals, Kasl et al. 1997)
- ▶ Bereavement issues in the palliative care caregiver population include anxiety/depression, prolonged grief disorder, and demoralisation. (Hudson et al 2011)

Participants

- ▶ Care-givers participating in the Australian Ovarian Cancer Study–Quality of Life Study
- ▶ The Australian Ovarian Cancer Study (AOCS), a population–based epidemiological study, recruited approximately 1500 women with primary epithelial ovarian cancer from across Australia.
- ▶ Approximately five months post–bereavement, caregivers were sent a letter of condolence inviting them to participate in this study.



Quality of life issues in Ovarian Cancer

- ▶ Significant burden on patients and their care-givers
 - High mortality rate
 - Complex, prolonged and multi-modal treatment
 - Characterised by multiple recurrences
 - Many lines of chemotherapy
 - Decreasing duration of benefit over time
 - **Wide variability in survival in women with similar disease characteristics and treatment that is not well explained (Le et al 2003)**

Aims: Quality of Dying and Death

- ▶ Assess the quality of the dying and death experience in carers; and
- ▶ Explore the partners'/carers' concept and experience of 'a good death'

Design

- ▶ The study employed an emergent qualitative design, using procedural direction from grounded theory research. (Corbin & Strauss, 2008; Strauss & Corbin, 1998)
- ▶ Semi-structured telephone interviews ave. 45 mins.
- ▶ Interviews were tape recorded and transcribed verbatim
- ▶ Conducted by experienced psychology graduate who was supervised by clinical investigators

Interview Schedule

- ▶ Questions were developed for the following domains:
 - information and decision making
 - communication issues
 - preparation for death
 - the last weeks of life
 - end of life care
 - the death itself
- ▶ (e.g. Was it a difficult death? What factors do you think are important for a 'good death'? Would anything have made this experience better/more peaceful etc?)

Analysis

- ▶ The transcripts were uploaded into the software program QSR NVivo, Version 8 (2007).
- ▶ Data was analysed based on Grounded Theory and using the constant comparison method
- ▶ Open, axial and selective coding was used to analyze the data. Open coding involved repeated reading of the sections of the interviews and a line-by-line analysis of this data.
- ▶ Axial coding was used to link data and determine the mechanisms that existed.
- ▶ Selective coding was then used to link data together and develop the themes.



Demographics

(n = 32)

Age	Mean 58 (sd 13.4); range 31 – 81 (Patient Mean. 61 years; (range 53-67))	
Marital Status	Married	78%
Relationship	Husband/partner	61%
	Adult Child	25%
	Sibling	14%
Gender	Male	64%
	Female	36%
Location	New South Wales	25%
	Victoria	25%
	Queensland	17%
	South Australia	14%
	West Australia	8%
	Tasmania	6%
	ACT	6%

Demographics (Cont'd)

Occupation

Professional	31%
Trade	20%
Clerical/Personnel	36%
Other	13%

Work Status

Full time	47%
Part-time	8%
Carer	6%
Retired	36%

Education

Year 10 or below	53%
Year 12	47%
Higher Education:	
University	11%
TAFE/Trade	64%
No further study	25%

Themes

- ▶ Key themes related to effective service provision to ensure 'a good death' included;
- ▶ The importance of communication between the patient and the carer and with the family generally;
- ▶ That pain and symptoms were well managed;
- ▶ That suffering was minimised;

Themes

- ▶ That the carer and patient knew what to expect in terms of end-of-life processes and when these may occur;
- ▶ Having an awareness of imminent death to provide an opportunity to communicate and make decisions;
- ▶ That there was a sense of acceptance about the death and that the death was peaceful.

Communication

Aspects of communication included:

- ▶ Acknowledging the differing communication needs of patients and carers;
- ▶ Being given an explanation of what to expect of the dying process; and
- ▶ Open communication about ceasing treatment.

Lack of information

- ▶ *“It was the not knowing what was happening and how long it was going to go on for. We had no idea what sort of time frame we were looking at and of the physical deterioration that would eventuate...no comprehension of that whatsoever” (Male + CG all)*

Communicating about ceasing treatment

- ▶ *“My dad went to get the sodium fluid bags that you put on a drip and uh the chemist didn’t have them. They’d been ordered...And she said oh look we haven’t got any in.*
- ▶ *And I think sometimes I think you know maybe I should have rung around all the hospitals and got hold of them...this all happened before I arrived and the palliative care nurse had said to my parents oh it doesn’t really matter. But I think it could have made [her] more comfortable. And she may not have died for a few more hours or whatever and been in more comfort – instead of being dehydrated because they basically removed the drip” (Female no CG)*

Information about the dying process

- *“Nobody told us (that being so short of breath when lungs filled up) that this was a common problem...It would’ve been nice to know what to look out for...so we could make a decision earlier than having to wait for the last minute, and take her in at 3 or 4 in the morning” (Female CG+ all)*
- *“She just literally stopped breathing and there was an unbelievable change in her body um I think I probably would have liked to have known beforehand what her body was going to be like after she died (Male +CG all)*

Pain

- ▶ Pain when it was not well controlled was seen as a barrier to a 'good' death.
- ▶ *"It was a difficult death in as much as she was in a lot of pain...she was no longer mobile, even getting to the toilet...was almost impossible. She had lost her dignity but I think she was beyond caring at that stage...pain relief was a big issue...she was in a lot of pain and sometimes the pain relief didn't work as quickly as she'd hoped...but the final moments of her death were as peaceful as you could ever wish to be"* (Male +CG)

Being there

- ▶ Commenting about the value of ‘being there ‘at the end of life. This included the sense of ‘being there’ together as a family and also ‘being there’ as a carer to care for the person dying, to talk with them and to be able to touch and hold them and to have nothing left unsaid.

“She had I think five of her grandkids there and both my brother and I, and her daughter-in-law and um so she was pretty good really... and she was not in pain....if I can try and wrap it up succinctly um the death offers an opportunity to say what you don’t say when you think there’s a lot of tomorrows”. (Female)



Background

- ▶ PTSD is an anxiety disorder which may be a consequence of exposure to any trauma experienced as a direct threat to the integrity of self, such as assault, disaster, accident, or life-threatening illness. (WHO, 1993)
- ▶ The diagnosis of PTSD may also 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, and the presence of intrusive and distressing recollections, along with coping responses that involve persistent avoidance of cues associated with the trauma, and/or emotional numbness.(Golden & Dalgleish, 2010)

Background

- ▶ PTSD has been identified following death in intensive care units, (Kross et al 2011; Gries et al 2010, Anderson et al 2008) in family members witnessing failed cardiopulmonary resuscitation, (Comptom et al 2009) in parents of children with cancer (Lindahl Norberg et al 2011) and in cancer patients themselves (Rustad et al 2012).
- ▶ Population studies of bereaved relatives suggest that PTSD may occur in between 15% and 40% of this group. O'Connor, 2010; Elklit & O'Conner 2005, Elkit et al 2010; Kristensen et al 2012)

Studies in palliative care

- ▶ These suite of studies from Denmark suggest potential risk factors:

Personality trait e.g. Negative affectivity

Social support

Locus of control

Predicted 57% variance in PTSD severity (Kristensen et al 2012)

Full time employment

Perceived control

Secure attachment style

Moderated the risk for PTSD (Elklit et al (2010)

Long period of care-taking

High level of somatisation

Disassociation

Associated with increased risk of PTSD

Additional aim

- ▶ To identify evidence suggestive of PTSD symptoms in a population of bereaved caregivers of patients who have died of ovarian cancer.

2nd analysis

- ▶ Transcripts were coded in parallel strands:
 - One strand described events and experiences happening to the patient which the interviewee witnessed
 - The second described their perceptions of events and emotional responses ('they' statements and 'I' statements)

Analysis (Cont'd)

- ▶ 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

Theme: the language of trauma

- ▶ All interviewees used the vocabulary suggestive of some level of trauma
- ▶ “shock”, “horrible,” “traumatic,” “awful,” “surreal,” “couldn’t believe it,” “helpless,” “horrendous,” and “devastating”
- ▶ Conveys the ongoing intensity of the acute experience of the death, emotions which these interviewees seemingly re-experienced during the interview.

Theme: the language of impact

- ▶ Frequent use of words that connote a physical impact
- ▶ “it hit me” or “it hit me very hard”, but other phrases, for instance “I fell in a hole” (after the death), or “gutting”.
- ▶ Other phrases, denoting the hard work of the last days or weeks, were “gruelling” “it was just impossible”
- ▶ Recurring over and over again in almost every transcript but in different combinations, the words “hard” and “difficult”.

Theme: the language of surprise

- ▶ All interviewees were primary caregivers of a woman with ovarian cancer, an illness often characterised by a long trajectory with episodes of recurrent disease and progression.
- ▶ Death is often predictable enabling at least some opportunity for preparation for the loss
- ▶ 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” “it was a blur”

Language of surprise

- ▶ *“Um yeah well um it was a complete shock – she was taken into hospital um with what we thought was a um a bowel problem um and uh we thought it was just a blocked bowel. Uh so I wasn’t overly concerned and then they told us that uh it was the cancer that was causing it and uh it couldn’t be unblocked and so she was going to die....It was a fairly horrible death you know; I didn’t expect it” [Male partner]*

The language of physically witnessing

- ▶ *“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” [Male partner]*

Physically witnessing

- ▶ *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.” [Male partner]*

Intrusive memories

- ▶ *“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 difficultI 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.” [Male partner]*
- ▶ *My major problems I’m having at the moment are I’m just reliving over those – especially last two days [daughter]*

Carers' current grief experience

- ▶ Many carers were experiencing high levels of grief at six months post loss
- ▶ 64 % (n 24) had syndromal levels of Complicated Grief (a score of >25)
- ▶ This included 14 of the 23 male partners



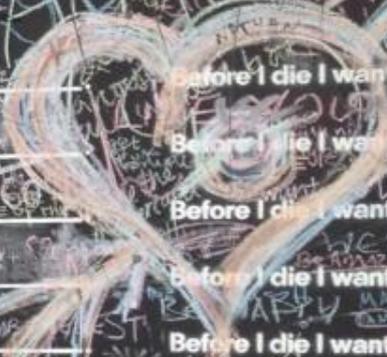
Complicated Grief across time

Time 1 = 6 months	Time 2 = 13 months	Time 3 = 18 months
Sub-syndromal 35%	Sub-syndromal 54%	Sub-syndromal 57%
Syndromal 64%	Syndromal 46%	Syndromal 43%

Before I die...



Before I die I want to



Carer's definition of a good death

- ▶ *“...control in the end. Making the actual decision to you know say no, no more treatment, no more um yeah what is a good death experience um **a lack of sort of trauma...**relative comfort for the person who's going as much as can be achieved. Um support from people around her, or around them”. (Male partner)*

Definition “elusive”

- ▶ Pain and symptom control
 - ▶ Support of family and friends
 - ▶ Supported decision making
 - ▶ Spirituality
 - ▶ Affirmation of the whole person
 - ▶ Death in a nurturing environment
- ▶ Sepulveda, C. et al 2002; Steinheuser, K, Christakis, N et al 2002

Quality of healthcare

- ▶ Overall rating of healthcare provision
- ▶ 1 (worst possible care) to 10 (best possible) –
- ▶ 60% scored 9 or 10 out of 10
- ▶ 95% said they received palliative care;
- ▶ 58% in hospital; 42% at home
- ▶ so it wasn't the perceived care the women got..

Quality of death

- ▶ Overall rating of quality of death
- ▶ (1 = worse possible and 10 = best possible)

- ▶ 11% scored 7;
- ▶ 38% scored 8;
- ▶ 13% scored 9 and
- ▶ 16% scored 10

- ▶ – so 65% said the quality of the death was good (measured at 6 months)

- ▶ Care-givers perception of the quality of death or the quality of care is not the same as their perception of how they experienced the death as a traumatic event or other wise





Outcome and self-appraisal

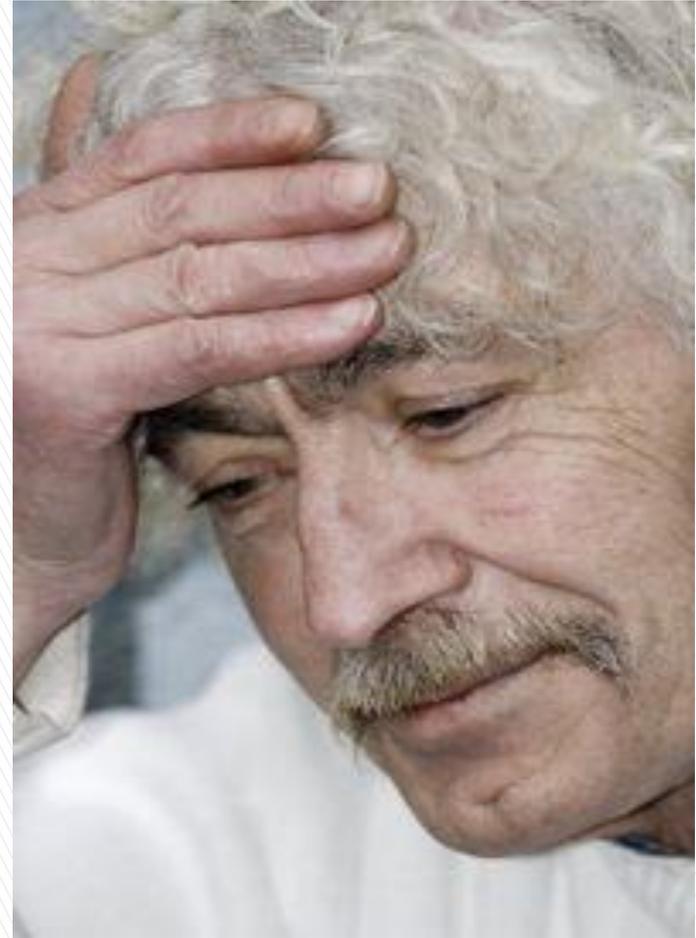
- ▶ *“And I didn’t get peace because I don’t believe that someone goes to a better place, I think they just die and um I mean I don’t know it might be hard for you to hear me say things like that, depending on your beliefs but it’s just um an unnecessary, unfortunate thing that you can’t stop...it’s 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” [Female sibling]*

Resolution

- ▶ *“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” [daughter]*

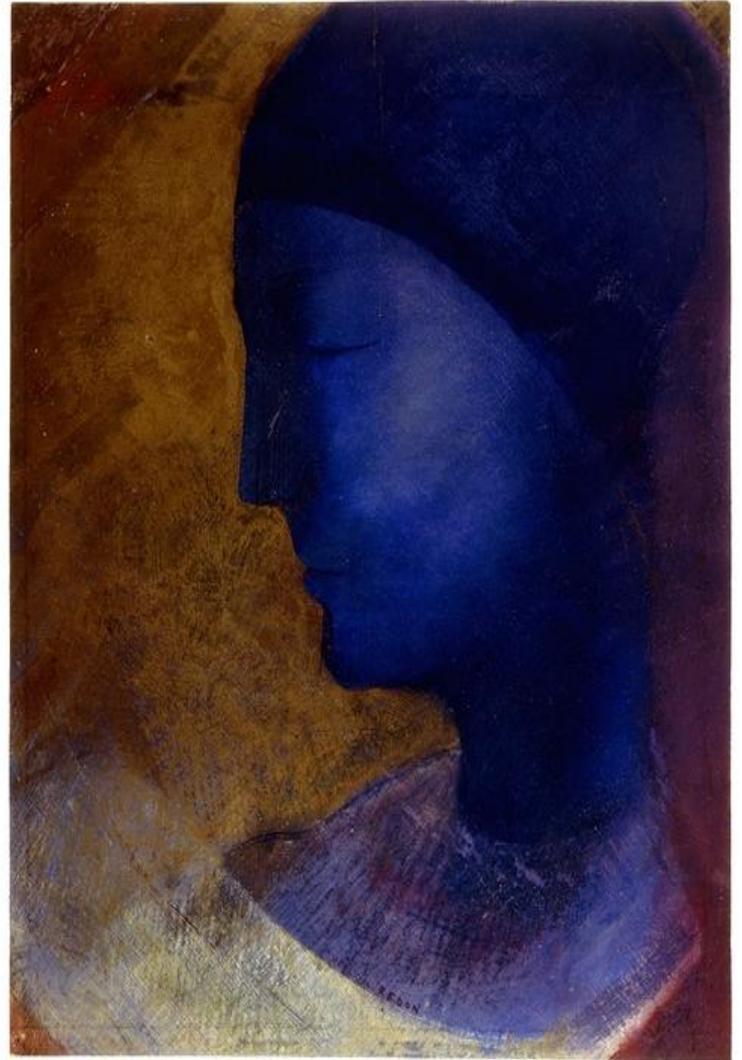
Resolution

- ▶ The desire to re partner, 9 of the 23 male spouses (38%) mentioned the possibility or actuality of re-partnering at the six month interview;
 - *'I would like to have another female in my life....and one of the things I'm confronted with is the moral aspect of the community at large. People have this wondrous idea that now is not the right time. -it's damned easy when you've got people around you, to make up the rules as to how other people should live their life.'*



Conclusion

- ▶ All of the patients were in contact with palliative care services, yet these interview transcripts convey a picture of trauma associated with these seemingly expected deaths.
- ▶ The underlying emotional tone reveals that the expressions of distress and shock identified, **even though some phrases are in common usage**, are repetitively present in this setting.



Conclusion

- ▶ Our initial hypothesis is that expected death has an inherent trauma within it, no matter how well families are prepared, or symptoms managed.
- ▶ Such trauma is not proportional to the quality (as currently perceived) of the services provided.
- ▶ The simple experience of waiting and watching whilst someone dies, without making active attempts to prevent death, may perhaps be unendurable for some individuals.

Existing findings

- ▶ Kristensen et al (2012) found:

Factors such as personality and social support may affect the development of PTSD to higher degree than factors related to the trauma of the death itself.

However preparedness for death and predictability of the loss could reduce the negative consequences of the loss

Previous studies

- ▶ Limitations – age, population
- ▶ Lack of control group
- ▶ Baseline data not available – pre-traumatic vulnerability may have affected the traumatic response, so no causality can be made.
- ▶ Longitudinal data needed to look at prospective role of factors involved in long-term bereavement including characteristics of death.



Future directions

- ▶ Many families and clinicians regard the palliative care approach to death as peaceful, and a precious time for the dying person to spend with their loved ones
- ▶ For others the palliative care phase may be characterised only by feelings of shock and distress.
 - Is this trajectory one of initial shock followed by growth and resilience in the face of an existential phenomenon far beyond the individual's prior experience?
- ▶ If this type of trauma has similar risk factors or outcomes to other complications of grief:
 - What preventive and treatment options might be feasible?

Future directions

- ▶ Longitudinal study to follow-up bereaved carers of an “expected” death and an “unexpected” death
- ▶ Compare “planned and expected” deaths in palliative care and “unexpected” deaths in coronial system
- ▶ Thank you to participants in the interview