“The Journey with the Dying”: How General Practitioners Experience the Death of their Patients

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Background

- Death exposure
- Scarce research, mostly quantitative
- Doctors’ experiences of suffering
  - Displacement, denial, guilt, distress and sadness
- Differences between medical contexts
- Unknown grief responses
Relevance

- Death: health professional’s responsibility
- Communication
  - Impact of own experiences and attitudes on care provided to patients
- Medical education
  - Undergraduate
  - Postgraduate
Methodology

- **Study design**
  - Human ethics committee approval
  - Social constructionist grounded theory (Charmaz)

- **Participants**
  - 11 GPs from Adelaide
  - > 5 years of medical practice

- **Recruiting process**
  - Snow-balling technique
  - Theoretical sampling
  - Saturation
Methodology

• Data collection
  ▫ Semi-structured interviews (April-May 2009)
  ▫ Hand-written notes – Audit trail
  ▫ Interview duration
    • 17 and 58 minutes
    • Average of 30 minutes
Methodology

- **Data Analysis**
  - Simultaneous transcription and analysis
  - Memos
  - Coding
  - Development of a theoretical framework (core category)
  - Members check (8/11)
# Methodology

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Results

"THE JOURNEY WITH THE DYING"

Stages

- Anticipatory grief
  - Private acknowledgement
  - Communicating the diagnosis
  - Continuity of care as a transition
  - The moment of death
  - Family support - Bereavement

Emotional reactions

- Shock, sadness, guilt, acceptance
- Stress
- Confidence, acceptance
- Shock, frustration, anger
- Sadness and relief
- Concern

Coping Mechanisms

- Talking with colleagues
- Finding positives
- Acceptance of death
- Drinking more than usual

Contributing factors

- Professional Identity
- Learning about death and dying
  - From experience
  - From medical school
- Death Beliefs

Appraisal of the situation

- Timeliness
- Finality of the death
- Self-evaluation
- Death awareness
- Self-identification

"The Journey with the Dying"
Discussion

• Model acknowledges life-threatening illnesses
• Encounter with death occurs from awareness
  ▫ Grief
    • Anticipatory grief (+/−)
    • Disenfranchised grief
• Results differ from those reported in other contexts
• Contrast with other care and learning contexts
  ▫ Professional relationship continues - bereavement
  ▫ Experience of the complete “journey”
Key Points

- Awareness
- Doctor’s relationship with death is part of a continuum
- Exposure to the “Journey with the Dying”
- Implications
  - Teaching
  - Grieving
  - Self-care
- Future research
  - Funerals
  - Death certificates
  - Other medical contexts and specialities
Acknowledgments

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THANK YOU

“The Journey with the dying”:
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The journey of death

“I think it is the biggest privilege for doctors to walk with their patients through the death journey, especially if you have been looking after them for a long time...”

(GP 2, female, age 56)
Private acknowledgement

“There is nothing worse than looking at that result and seeing that that person has something incurable and that you are going to need to go and convey that to them. You feel like you are a really bad person, this terrible person that is going to tell them that they have got something incurable. It is a really horrible thing that you have to do.”

(GP 9, female, age 30)
Communication of Diagnosis

“... if you are able to do things that in a way to help a person understand where they are at, you feel that you have communicated things clearly, that you know, the next steps have been clearly set out, those kind of things; and the person appears to be sort of taking these things on. Then that looks that it was a job well done, satisfying if you have done a hard thing and it seems to have gone well”

(GP 5, male, age 45).
Continuity of Care as a transition

“I mean, he was obviously being well cared for (...). They (the staff) were doing what they were very good at. I have no problem with that. (...) I mean I was happy to sit there. When I visited him I was visiting him more as a friend, or at least as a companion than as his doctor. Although I am still a doctor. (...) but it also helps to establish some continuity (...)

(GP 5, male, age 45)
The Moment of Death

“I knew that she was going to die, and I knew it was going to probably happen in the next 24 hours. I had been looking after her probably a couple of weeks at home in that final stage but the actual feeling of when she died was one of actual relief for the family.”

(GP 8, female, age 51)
Looking after the family

“It [the death] just seemed like a natural part of life, so it didn’t particularly concern me. My concern was more for her husband that was left behind and how he was going to manage.”

(GP 1, male, age 55)
Phase 1: Emotional Reactions

“I think there is probably some sense of guilt. You know, “should I have picked it up earlier? Or could I have done something else?” (...) “you think “well, this has happened, I can't change it, yes I it is very sad and it is awful”, but we just have to do the best we can”

(GP 8, female, age 51)
Phase 2: Emotional Reactions

“I think it is an emotional time but so you be in control. (...) When you have to give bad news, you have to be serious, and you know, a little sad, and so, you are really sombre. Like a sombre mood and sometimes you can get a bit of an emotion, and I don’t think patients mind that. I think that’s okay because you are a human too.”

(GP 4, male, age 61).
Phase 3. Emotional Reactions

“If I have a good relationship with the patient I go and see them in the hospital (...) So a few patients have ended up in hospices and I go and see them. The staff is very welcoming of me, and yeah, I am very happy to do it, I mean it is part of the holistic care that I like to give as a doctor. And it is very helpful for me, I say good bye to the patient as well which is also helpful.”

(GP 2, female, age 56)
Coping Mechanisms

• “All the time you actually feel that you’ve become enriched, and that you learn things (...) from every person that you look after you’ve got to learn something from them.”

  (GP 3, male, age 60)

• “I had two whiskies that night, which is more that I normally do. I would normally have a maximum of one, that night not. That really affected me, when I heard her screaming...”

  (GP 6, male, age 60)
Contributing Factors

• Professional Identity
  ▫ Distancing from emotions and attachment.
  ▫ Caring for more than the dying patient.
  ▫ Assuming all sides of medicine
  ▫ Maintaining contact with patients
  ▫ Keeping boundaries
  ▫ Being knowledgeable

• Learning about death and dying
  ▫ Explicit teachings
  ▫ Implicit teachings
  ▫ From experience

• Death Beliefs
  ▫ Personal perspective (non-medical)
Distancing from emotions and attachments

“I feel sad for them and sad for the families, but I don’t engage, because if I engage with every patient that got sick or died, then I would be an emotional wreck and I wouldn’t be able to do my job properly (...) It doesn’t mean I can’t feel sad, it doesn’t mean I can’t acknowledge the sadness.”

(GP 7, male, age 56)
Assuming all sides of medicine

“It is part of being a doctor, and it is easy to be a doctor when everybody gets well. I think the test whether you are really a doctor, who is really able to practice medicine in a quality way, is how you handle what is more difficult.”

(GP 2, female, age 56)
Caring for more than the dying patient

“I guess my role is to help people have the best death they can, and to perhaps also help those around them to help them deal with it as best as they can (…) and be part of that process of them saying their goodbyes and tightening up their lose ends. There was a satisfaction in mind that you had done a difficult job well.”

(GP 5, male, age 45)
Maintaining contact with patients

“If I have a good relationship with the patient, I go and see them in the hospital. I do not charge them or anything but I do visit them in the hospital within my capabilities. (...) It is part of the holistic care that I like to give as a doctor, and I say goodbye to the patient as well, which is also helpful”.

(GP 2, female, age 56)
Implicit teachings

“In the general medical disciplines, once someone looks like there is no hope, basically you just leave (...) the senior doctors just lost interest and moved on. Maybe as an intern you had to deal with the issue of helping someone with symptoms of dying, but the senior consultants and everybody lived on the cases where there was still hope of achieving something for the patient”.

(GP 4, male, age 61)
 Explicit teachings

“Right through we talked about emotions (...) but I don’t feel that it actually prepared you for dealing with it very well”.

(GP 11, female, age 51)
From experience

“I think that as doctors get older and have more personal experiences with death through family and friends (...) then it does increase the understanding of what patients are going through and I think that it does help in some circumstances”.

(GP 7, male, age 56)
Appraisal of the death situation

- Timeliness
- Finality of the death
- Self-evaluation
- Self-identification
- Death awareness

“we (doctor and family) had plenty of time to grieve because we really knew (...) where it is a long process you go through all the grief. So, by the time they die it is not that bad”

(GP 6, male, age 60.)