

Impact and meaning of the last few days of life to relatives

Kathleen Vandenberghe
Counsellor St. Luke's Hospice



Professional carers and their relation to caring relatives

- Intensified care for patients
- How does your contact with relatives interact with your professional role towards patients?

Some introductory thoughts...

- Variable awareness of “a separate / new phase” (sense of chronic illness)
- Uncertainty (or denial) about it being the “last stage” (realisation in hindsight)
- Relatives: a range of roles and relationships.



Meaning and impact of

- Living with a dying person
- Being left by the person who shares their life
(visualisation exercise)

The train pulls slowly away...

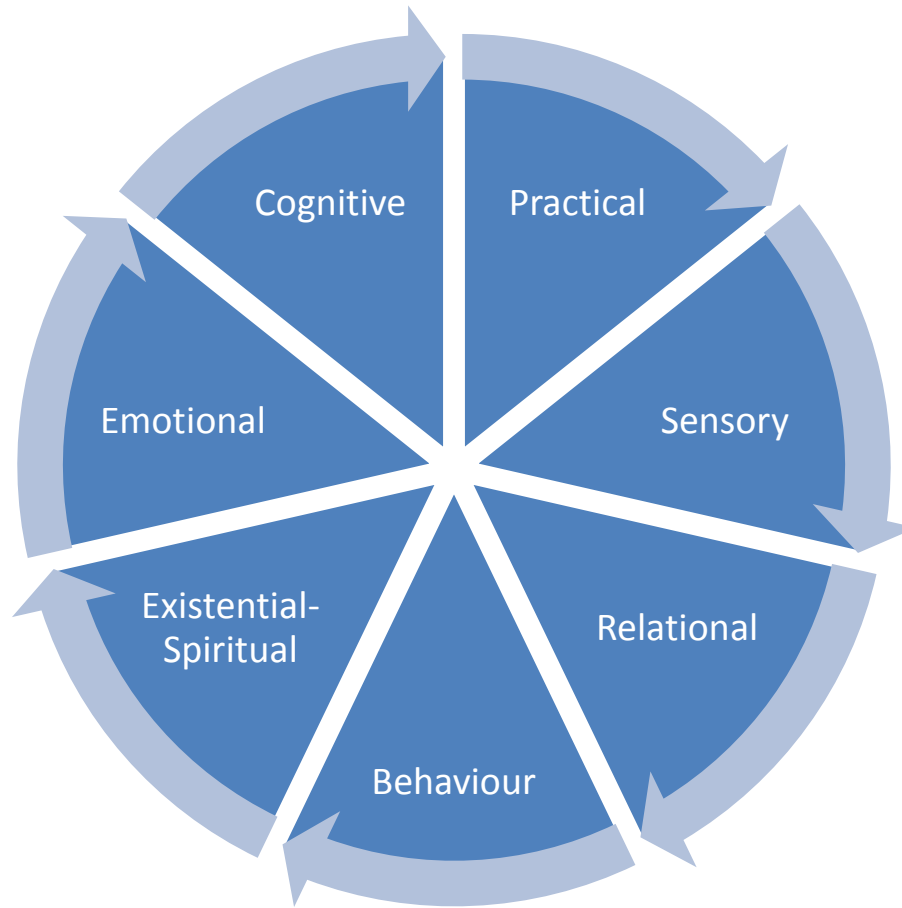


Train du soir, Paul Delvaux, 1957

A definite good bye...

- Turmoil of emotions
- Panic – struggling to know how to be in the right place
- Pre-rational experience
- Absorbed in self – not tuned in to others
- Importance of good bye (wanting it or avoiding it)

An all absorbing experience



Cognitive experience

- Lack of knowledge about dying
- Lack of knowledge about treatment
- Difference between knowing and understanding
- Emotional impact of not understanding (“getting our head around it”)

Emotional experience

- Grieving process
- Mini-scale at every new stage: shock – anger – bargaining – depression – acceptance

Relational experience of patient (1)

- As the patient's responsiveness and their ability to show interest in the carer decreases the patient fades as a full person
 - Empathising with patient's objective needs in this state becomes more difficult
- Life of carer and patient not longer on the same path / fork in the path
 - Conflicting needs trigger guilt feelings
- Not ready for this loss: Ongoing searching – glimpses / eye contact
- Meaning:
 - Carer feels abandoned by patient
 - Patient implicitly puts carer in role of advocate and responsible for their well-being
 - Carer torn between distancing and symbiotic closeness



Relational experience of patient (2)

- Expectation of professional:
 - relate to the patient as a person who deserves best care!
(Suspicious about professionals' ability to engage with non-response patient – cf. Relatives own struggle)
 - Relate to the carer – know their individual needs – be aware they are very sensitive at this time
 - Incorporate carers in care for patient
- Impact: Carers attempt to resolve this torn-ess and negotiate a caring position that suits them (See Twigg & Atkin)

Three ways carers deal with their caring role (Twiggy&Atkin, 1994)

1. **Engulfment:** Subordination to the needs of the patient.
2. **Balancing or boundary-setting:** Carers make space for their own interests.
3. **Symbiosis:** Some gain something from caring which they do not wish to be taken from them.

Behavioural experience

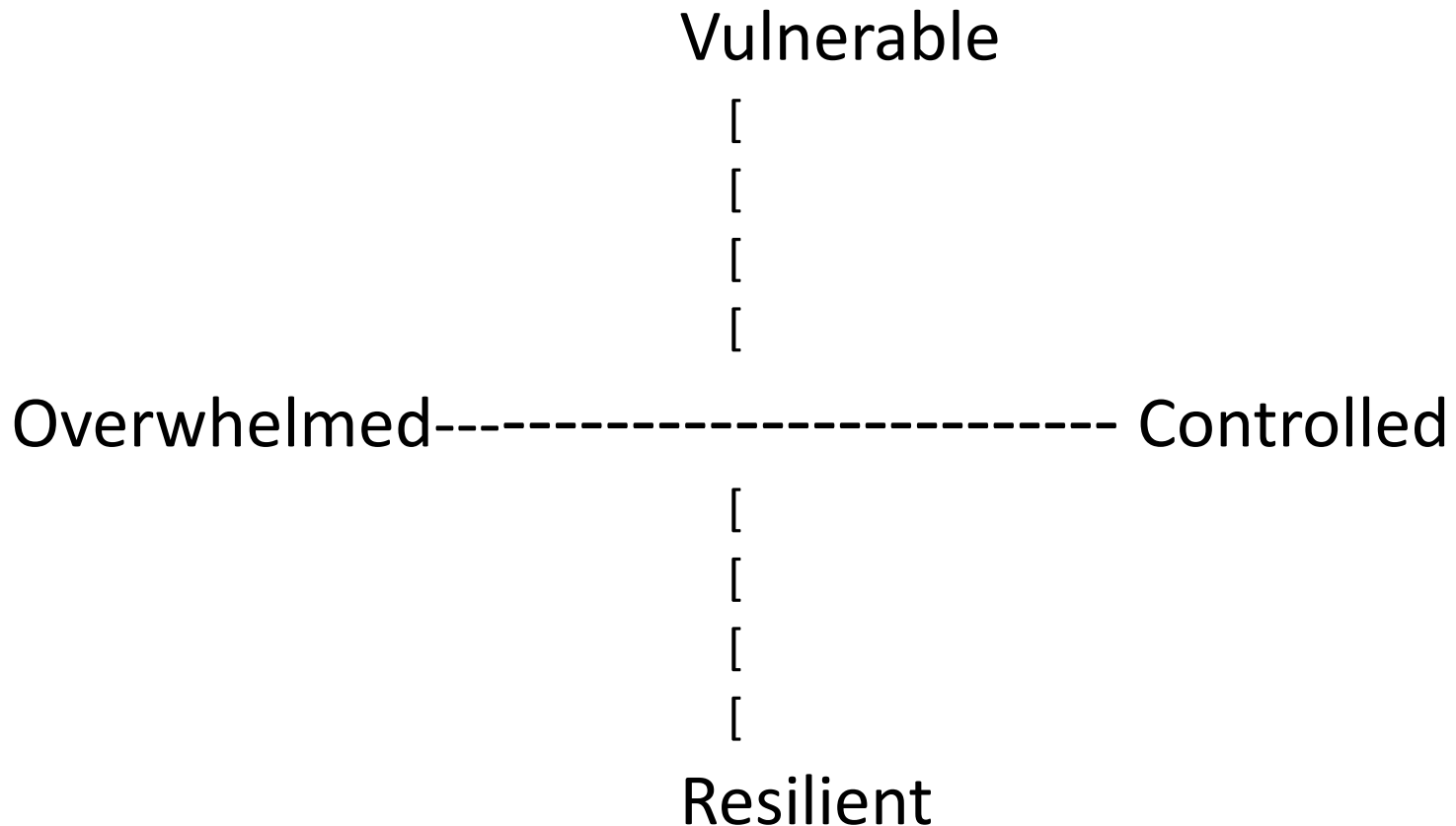
- Feeling helpless
- Attempting to overcome helplessness

Expectation from the professional:

- Knowledgeable
- CARE EFFECTIVELY (NOT HELPLESS) – explain why you do what you do and what your caring intentions are

Range of responses to Loss

by Linda Machin (Help the Hospices)



Sensory experience

- Seeing : e.g. looks as if already dead
- Hearing : e.g. laboured breathing
- Touch: e.g. Very thin
- Smell: e.g. Strong smell of illness, medication, ...
- Taste

Interpretation : uncomfortable for patient?

Expectation from professional: Making more comfortable

Possible Impact on relative:

-uncomfortable... traumatic? - may lead to distancing

-somatic empathy? – may lead to sense they feel what patient feels

Somatic Empathy

- Empathy is not just a cognitive (understanding the other) and emotional (feeling what they feel) mechanism – body processes are intimately involved.
- Empathy is an autonomic nervous system state which tends to simulate that of another person. Body to body.
- Examples: automatically smiling, yawning in response to another = mirroring emotions
- Emotional contagion : being infected by a client's state of mind is often advantageous
- ... Sometimes it is not (being aware / strategies for un-mirroring emotions)

Existential & Spiritual experience

- Experience of space:
 - Patient being in the right place
 - House rearrangements limited by perceived interference with continuity after death
- Experience of time: Life coming to standstill
- Mystery – “aporia” – carers need professionals to acknowledge and share the “unknowable” aspects of the process of dying.

Silence ... In the experience of aporia

An experience of 'aporia' : something that does not allow passage... A non-path.
(Derrida, 2000) The experience that one cannot suffer what the other is suffering (e.g. One cannot die in his or her place). This experience is "not passive". We "are" not silent, but what we hear resides in silence.

Family dynamics

- Partners - (adult) children – young children
 - Different needs and views
- Distress makes people more egocentric: Not effective in responding to each others needs
- Giving each other hope by acting as if it is not imminent
- Focused by “last chance” creates opportunity for healing and making peace (Murphy,1999)

What to do? And what it means

- Join your client where they are and give it your all
 - Hightened alertness to match their intensity
- Acceptance of the real – the real is turmoil and upset
 - Embrace their reality but avoid being caught up in it yourself (risk of ripple effect)