Attachment and the End of Life Experience

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Sarah Hales

> I once asked a man who knew he was dying what he needed above all in those who were caring for him. He said, 'For someone to look as if they are trying to understand me.'
>
> Cicely Saunders (1987)

> …rich connections temper the pain of transiency.
>
> Irvin Yalom (2009)

As at the beginning of life, the end of life requires strong care-seeking and caregiving systems. Unlike in early life, however, when greater independence and autonomy from caregivers are achieved over time, at the end of life individuals face ever increasing need and vulnerability and the inevitability of separation through death. Those with advancing and terminal illness may experience a sense of increasing threat as treatments fail, the disease advances, disability increases and death looms closer. Treatments for many life-threatening conditions such as cancer are improving and life expectancies are lengthening, but when cure does not occur, patients and families are left in a state of chronic threat for longer.

In this chapter, attachment theory will be employed to understand variations in experience and behaviours of dying patients and their loved ones as they negotiate treatment within the health care system. Concepts central to palliative care including the good death, dignity, physician-assisted suicide and grief can all be better understood with the aid of attachment theory. Even more importantly, treatment interventions aimed at supporting an individual's sense of security may be beneficial in reducing distress and facilitating growth in those facing end of life.

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J. Hunter, R. Maunder (eds.), *Improving Patient Treatment with Attachment Theory: A Guide for Primary Care Practitioners and Specialists*,
DOI 10.1007/978-3-319-23300-0_7

7.1 The Patient Experience of the End of Life

Patients with advancing and life-threatening illness are faced with multiple difficulties, including increasing physical disability, pain and physical symptoms, loss of previous identities and roles, dependency and loss of autonomy, challenges to previously held beliefs and world views, and the possibility of death. Indeed, awareness of approaching mortality is the distinct and unique crisis that differentiates patients in palliative care from those in the many other clinical settings described in these chapters. Unlike the temporary challenge of a planned surgery or chemotherapy treatment, for the dying patient, the fact of death may be ever-present, shortening the viewed horizon and creating a sense of persistent anticipatory fear. These death anxieties may include fears of future pain or suffering, dependency and loss of control, lost opportunities, the impact on loved ones, the timing of death or actual death and individual obliteration (Lo et al. 2011).

As with other situations of threat, the approach of the end of life activates attachment, such that proximity to caregivers, both formal and informal, is sought, often in an attempt to improve coping. Those with more secure attachment are better able to seek and receive practical and emotional assistance which help them to adapt to the reality of dying. Therefore, it is not surprising that those with greater attachment security experience less distress at the end of life. In those with advanced disease, greater attachment security is associated with less depressive symptoms, and, in addition, attachment security buffers the impact of physical distress on depressive symptoms. This protective effect is partially mediated through perception of social support (Rodin et al. 2007). Interestingly, older age is associated with less depressive symptoms in those with advanced cancer, and this relationship is partly accounted for by greater attachment security with increasing age (Lo et al. 2010).

Those with insecure attachment may have a more problematic course, having difficulty both accessing and experiencing support from formal and informal caregivers to manage the illness and its associated emotional distress. Those with a preoccupied attachment style may express more distress and fear of death, request more supports and display a lack of confidence in their ability to handle the challenges of dying. Those with a dismissing attachment style may avoid expression of distress and fear of death and may deny or refuse supports when they appear to be needed. Finally, those with a fearful or disorganized style may show both preoccupied and dismissing behaviours, doubting their own ability to manage the dying experience but also lacking confidence in the availability and trustworthiness of care providers. Research on patients with advanced cancer has shown that both preoccupied and dismissing attachment are associated with lower levels of emotional support, which in turn has a negative influence on patient affect, and that preoccupied attachment is directly associated with patient distress (Hunter et al. 2006). For people with advanced cancer, a more preoccupied attachment style has also been found to correlate with referral to psychosocial oncology services (Ellis et al. 2009), which is similar to the link between preoccupied attachment and greater use of health services in other populations.

In addition to helping understand differences in support seeking and distress at the end of life, attachment theory can illuminate several aspects of a patient's experience that are central to palliative care. With the rise of the palliative care and hospice movements, the concept of the 'good death' has received much attention. Experts have described the quality of dying and death as an evaluation of the dying experience as a whole according to one's expectations and values (Stewart et al. 1999). Research exploring this construct has revealed seven broad domains: physical experience, psychological experience, social experience, spiritual or existential experience, the nature of health care at the end of life, death preparation and life closure and the circumstances of death (Hales et al. 2008). However, research in different settings, from North America, Europe, Israel, Australia and Asia, has highlighted that evaluation of dying is subjective and there is no one consistent and universal understanding of a good death (Hales et al. 2008, 2010). For example, some patients express preferences for physical contact or closeness with family and friends at the end of life, while other patients place greater emphasis on maintaining independence and dignity. While numerous factors, including disease stage and culture, influence these preferences, it is likely that attachment style also shapes conceptualizations of the good death. For example, preoccupied patients would prioritize greater contact with close others, while dismissing patients would prioritize self-care and autonomy.

Dignity is another end of life concept much discussed in the palliative care literature and emphasized by some patients as essential to good quality of life at the end of life (Chochinov et al. 2002). Dignity is considered to be multidimensional, and research delineating the dignity construct has identified several attachment-related themes, including independence, autonomy and control, privacy boundaries, social support, care tenor and burden to others (Chochinov et al. 2002). It has been posited that those with a dismissing attachment style might experience loss of dignity more easily and find the loss more distressing (Tan et al. 2005).

Physician-assisted suicide, a frequently discussed and controversial topic (Lewis 2007; Vogel 2011), may also be informed by attachment theory. Research in Oregon, USA, where physician-assisted suicide is legal, found that requests for physician-assisted suicide were more strongly related to wanting control, fear of loss of independence and anticipated distress, than to pain or current distress (Ganzini et al. 2009). As with dignity-related concerns, patients with a more dismissing attachment style may be more likely to experience suicidal ideation in the face of their discomfort with anticipated dependency and loss of autonomy. For those who may be uncomfortable relying on others as a coping strategy, contemplation of suicide may be understandable as a one-person solution to manage anticipated distress.

7.2 The Caregiver Experience of the End of Life

The demands and threats experienced by caregivers while supporting a loved one with a life-threatening illness are different than those experienced by patients, but nonetheless important for clinicians to understand and acknowledge, given the health care system's dependence on informal caregiving and the high morbidity and mortality associated with the caregiving experience (Gladjchen 2004; Grunfeld et al. 2004). Caregivers supporting a loved one with a life-threatening illness are called upon to aid in navigation of the health care system, access information, liaise with medical personnel and provide transportation, economic aid and physical and emotional support for patients. In addition to the stresses of providing care, the threat of their loved one's death may require the caregiver to prepare to lose an important attachment figure of their own. Theories of anticipatory grief highlight that caregivers of those with advanced disease may experience the competing demands of having to attend more closely to the needs of their loved one while at the same time psychologically distancing themselves, as they prepare for a life ahead without the loved one (Evans 1994; Parkes 1996; Johansson and Grimby 2012). In response to these multiple and conflicting stressors, some research indicates caregivers may experience more distress than advanced cancer patients and that insecure attachment styles are a predictor of depressive symptoms in caregivers, even after controlling for objective and subjective caregiving burden (Braun et al. 2007).

The caregiving behavioural system, which complements the attachment system, describes innate behavioural patterns exhibited in response to the needs of dependents in situations of threat. Ideally, caregivers are able to flexibly respond to their loved one and manage their own attachment needs while providing support that is both sensitive and responsive (Bowlby 1982). However, one's caregiving style is influenced by one's attachment style, and, not surprisingly, attachment insecurity can complicate caregiving. Research into adult attachment relationships has highlighted that those with secure attachment are more able to demonstrate the attunement and flexibility required for effective caregiving. Individuals with more dismissing attachment are less likely to provide care or will provide care that is insensitive and controlling, while those with preoccupied attachment tend to care 'compulsively', meaning to provide care driven by their own needs and anxieties rather than care attuned to the needs of the patient (Kunce and Shaver 1994). These caregiving patterns have been demonstrated in research studying advanced cancer patient-caregiver dyads (Braun et al. 2012).

In the case of life-threatening paediatric illness, where the dyad is parent and child, there may be a more intense unavoidable dilemma as parents are stimulated to care for and protect a child they cannot shield from danger, harm and ultimately death (Kearney and Byrne 2011). Research in the paediatric setting has found secure attachment to be associated with better parental coping. Parents with more secure attachment have been found to be more 'resolved' with respect to their child's diagnosis, by which they mean that these parents display an ability to move beyond the crisis of diagnosis, balance mourning with focus on the present and achieve greater acceptance. In contrast, parents who are less securely attached may be described as 'unresolved' with respect to the diagnosis, unable to move past the crisis of diagnosis, remaining overwhelmed, angry or in denial (Marvin and Pianta 1996).

The experience of grief and resolution of grief following the death of a loved one is also likely shaped by attachment. Bowlby theorized that reorganization of one's working models was necessary for successful adaptation to the loss of an attachment figure and rigid models of attachment that preclude change of the internal working model could lead to pathological grief reactions such as chronic mourning or prolonged absence of conscious grieving (Bowlby 1980). Similarly, contemporary grief researchers have argued that attachment shapes grief behaviours (Shear and Shair 2005; Stroebe et al. 2005). It has been hypothesized that the death of a loved one creates a parallel to a child desperately searching for an absent parent. The bereaved person is preoccupied with thoughts of the lost attachment figure and searches his or her mind and external world for representations of the attachment figure, creating the phenomena of misperceptions and believed sightings of the deceased (Shear and Shair 2005). At the same time, the anxiety created by the loss further activates the attachment system creating a 'feed forward escalation of distress' (Shear and Shair 2005).

Attachment theory has informed the dual-process model of bereavement, which describes two categories of stressors that must be dealt with following the loss of an attachment figure. The first of these are 'loss-oriented' stressors which focus on the deceased and include experiencing grief symptoms and attending to bonds with the deceased. The second of these are 'restoration-oriented' stressors which focus on the indirect consequences of bereavement and include attending to life changes and building new identities and roles (Stroebe et al. 2005). In normal grief, bereaved individuals 'oscillate' between the loss-oriented and restoration-oriented stressors, while in complicated grief this pattern is disrupted. The developers of this model suggest that chronic grief tends to be focused on the loss orientation and delayed grief on the restoration orientation, while traumatic grief involves more intense, persistent and highly aroused oscillation between these orientations. They suggest attachment styles may map on to the grief reactions described by the dual-process model. Securely attached individuals may tend to display the normal oscillative pattern, preoccupied individuals may tend to display elevated or chronic grief and the loss-focused pattern, dismissing individuals may tend to display less or delayed grief and the restoration-focused pattern and fearful/disorganized individuals may tend to display traumatic grief and the highly oscillative pattern (Stroebe et al. 2005). Some preliminary research supports the relationship between attachment styles and these grief reactions. In a study of bereaved individuals following loss of a romantic partner, a greater focus on the restoration orientation partially mediated the link between attachment avoidance and less severe grief reactions, although dual-process model variables were not found to mediate attachment anxiety and elevated grief reactions (Delespaux et al. 2013). Bereavement interventions guided by the dual-process model encourage the bereaved to embrace flexibility and shift back and forth between loss-oriented and restoration-oriented tasks (Zech and Arnold 2011).

7.3 The Health Care Provider Experience of the End of Life

Health care providers who care for dying patients are also required to provide attuned and flexible care, while at the same time preparing for the inevitability of patient death. The dilemmas experienced by health care workers may be less intense than for family caregivers but their attachment orientations nonetheless inform their experience and behaviours when caring for dying patients. Unfortunately, medical and health care training has not traditionally focused on these concepts nor emphasized the importance of health care providers distinguishing their own emotions and needs from those of patients and families (de Haes and Koedoot 2003). Treatment decision-making and communication about end of life can be understood as relational acts informed by the attachment orientations of those involved. For health care providers, an emphasis on aggressive life-sustaining treatment for patients with life-threatening disease may be interpreted as a kind of compulsive caregiving, characteristic of preoccupied attachment insecurity. Similarly, avoidance of patients' distress, or of discussions around advanced care planning or death preparation, obfuscation in response to direct questions about prognosis and seeing support for the dying as something better managed by another service may be understood as a more dismissing stance stemming from health care providers' discomfort with emotional dependence.

7.4 Mentalizing Death

The concept of mentalizing refers to the capacity to reflect on feeling states, to distinguish them from literal facts and to accept the possibility of multiple perspectives on events (Fonagy et al. 2002) (see Chap. 9). Given the strong negative emotions generated by thoughts of end of life, death may be a concept particularly difficult to mentalize. For many patients and families, reflections on dying and death are repeatedly silenced due to the terror that emerging feelings will not be tolerable or manageable. But if mentalizing is a process associated with greater attachment security, by which we can regulate affect, use of mentalizing can be seen as an important tool for patients, families and caregivers who face terminal illness.

Much of the literature encouraging open communication around dying within health care stems from a related premise, that practical planning and the process of considering and preparing for death, in the context of a supportive health care relationship, will improve coping at the end of life. A realistic goal of these communications may not be to eradicate fears of death but to tolerate these fears and accept that they can coexist with feelings of hope, joy and contentment. In other words, the process of mentalizing may help patients and families understand and accept the normal fluctuating, shifting and multiple experiences of dying which have been described in the palliative care literature as middle knowledge (Weisman 1972), the living-dying phase (Pattison (1977) or double awareness (Rodin and Zimmermann 2008).

7.5 Attachment-Based Interventions at the End of life

Attachment can help health care providers to understand and respond more effectively to the distress and behaviours of dying patients and families seen in clinics, in palliative care or in intensive care units (Petersen and Koehler 2006; Curtis et al. 2012). This involves first and foremost acknowledging the central role of attachment-driven attitudes and behaviours, and the family as the unit of care, and recognizing the relational aspects of treatment decision-making and advanced care planning discussions. Attachment theory highlights that in the face of the fears associated with the end of life, patients and families benefit from the secure base and safe haven of a health care provider (see Chap. 2) who is attuned and responsive to their unique needs, recognizing these may change with growing threats and new challenges.

Patients with serious illnesses are often advised to think positively and maintain hope, but for those who are afraid and for whom death is not avoidable as they become more symptomatic, these strategies cannot be maintained. Rather than insisting on such an unobtainable state of mind, the individual can be encouraged to reflect on what they are experiencing, their fears, but also their wishes. This use of mentalizing, to reframe the task of dying as one of continued adaptation, allows a health care provider to explore the internal and relational experience of a dying person or their family member, providing support without presuming what constitutes their ‘good’ death. Within the infant-parent dyad, mentalizing is supported when the parent mirrors distress while communicating an incompatible affect (Fonagy et al. 2002). For the patient-health care provider dyad, mentalizing can be supported when health care providers empathize with death-related distress while communicating also resilience and strength. This approach can also be employed in family meetings regarding advanced care planning. Family members can be encouraged to consider multiple perspectives on the dying process, thus facilitating discussion of fears, hopes and possibilities and avoiding the terror and isolation of silence.

Formal therapies for those facing end of life that draw on attachment theory have been developed and studied. Emotionally focused therapy (EFT), based on systemic, experiential and attachment theories, is a couple’s intervention to alleviate marital distress and support reciprocal caregiving. EFT has been adapted to the advanced cancer population and shown to improve marital functioning and patients’ experience of caregiver empathic care (McLean et al. 2008, 2013). Managing Cancer and Living Meaningfully (CALM) (Hales et al. 2015) is a brief, semi-structured psychotherapy for patients with advanced disease that supports affect regulation, attachment security and reflective functioning. Over the course of three to eight sessions, four central themes are explored: symptom and disease management; changes in self and relationships with close others; spirituality and sense of meaning and purpose; and the future, hope and mortality. Preliminary evidence has shown that CALM therapy provides an opportunity for cancer patients to explore their fears, to be seen in human terms by a representative of the health care team and to face the challenges and threats of advancing disease (Nissim et al. 2012). It is associated with a reduction in depressive symptoms and death anxiety and an increase in spiritual wellbeing over time (Lo et al. 2014).

A Clinical Example of the Impact of Attachment Style on End of Life Care

Carla was a 57-year-old woman diagnosed with metastatic ovarian cancer. At her first oncology clinic appointment, she cried throughout, stating repeatedly ‘I don’t know what I’m going to do. I’m a goner.’ She described the experience of receiving her diagnosis as highly traumatic as it took place in a busy emergency room and was communicated by an unfamiliar clinician who ‘dumped’ the news on her without any support. She referenced similar experiences in the past within the health care system which she felt was, overall, impersonal and uncaring. At subsequent oncology appointments, when she was not highly distressed, she would appear cheerful and optimistic stating, ‘I need to focus on the positive and stay hopeful.’ She described episodes between appointments in which she would suddenly feel overwhelmed by a fear of dying and required the presence of family and friends to reassure her. When the team eventually tried to discuss advanced care planning, she was adamant that she wanted to think positively and was ‘hoping for a miracle’. She stated, ‘I absolutely do not want to discuss referral to palliative care’, and this was noted on her chart and dissuaded clinicians from broaching the topic.

Carla is an example of a patient who exhibited behaviours possibly consistent with a preoccupied attachment style. With attachment figures, such as members of the health care team, she often expressed extreme distress, an inability to cope and the need for their proximity and assurances of ongoing support. She described an internal experience of moving back and forth between avoidance of emotional material and being flooded with her death-related fears. Her inability to regulate her distress challenged her ability to engage in the tasks of living with her advanced illness while also preparing for end of life. Considering her attachment style helped her health care team support Carla. They understood the extreme expressions of distress she sometimes displayed in clinic and knew that in response she required staff presence and validation.

One thoughtful trainee who came to know Carla, having seen the warning about discussions of palliative care noted in her chart, was curious enough to inquire ‘what does discussion of ‘palliative care’ mean to you?’ This simple question was an aid to Carla’s mentalizing, as it supposed that there might be multiple meanings and interpretations of a referral to palliative care. Carla was able to say that she thought this would mean the team was ‘giving up’ on her which was a terrifying echo of her past experiences of seemingly uncaring health care providers. Thus, it became clear that treatment decision-making was also influenced by her attachment style.

Carla was eventually referred for psychotherapeutic support from the psychosocial oncology team. A developmental history revealed she had had a father who travelled for work and was often unavailable and a mother who was loving and supportive at times but suffered from depression and anxiety which left her often incapacitated or in hospital and unable to parent Carla. Early experiences of inconsistent caregiving left her worried that attachment figures might not be available to her in times of need. In addition, she lacked the consistent attunement and modelling from attachment figures to develop mentalizing functions, leaving her, in adulthood, often unable to self-regulate her distress. Her therapist established a supportive relationship and was eventually able to interpret Carla's pattern of relational distress as linked to her past experiences of inconsistent caregiving and her fears of being overwhelmed by emotion, which were now impairing her ability to cope with anxieties about her advancing illness. Eventually in therapy, and with her oncology team, she came to tolerate articulating her fears while also acknowledging her hopes. She agreed to a palliative care consultation and began to anticipate and plan for future care needs while also being able to enjoy the health and abilities she still retained.

Conclusion

This chapter has emphasized the distress and threats associated with end of life but also highlighted that this phase can provide opportunities for growth and psychological development. As Yalom (1980) identified in his discourse on existential therapy, death presents a boundary experience that challenges patients and families to face existential threats. He described the sense of mastery individuals may experience facing this greatest fear, via an increased focus on the present and motivation to make change rather than postpone it, the revaluing of small pleasures and the dis-identification with previously long-held problematic identities and beliefs (Yalom 1980). This idea of life-threatening illness as a time of therapeutic opportunity is supported by research demonstrating the potential for psychological growth in the context of cancer and other life-threatening illnesses (Sumalla et al. 2009). Just as at the beginning of life, threats to attachment security at the end of life challenge the attachment system, but if those challenges can be met with flexibility, stronger individuals and relationships may emerge.

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