

Caregiving [and death]

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In its most general meaning caregiving is the providing of what is needed. Caregiving is used both as a noun and as a verb. As a noun, it refers to the organisation of healthcare. As a verb, caregiving refers to both 'taking care of', which means that one's specific needs are met, and to 'taking care for', which means that needs are met with feeling, motivation and engagement. Caregiving is relevant for the issue of dying because it helps people to die in peace and with dignity. Since engagement is believed to be the heart of caregiving, care for the dying is particularly characterised by the care for the emotional impact that imminent death has on the one who dies. Various ideals of care for the emotional impact of death have affected the practises of care for the dying. To explore the ideals of care for the emotional impact of death, a sketch of its ideological development is presented. From there, three main issues in contemporary care for the emotional impact of death are explored.

Ideals of care for the emotional impact of death

Consolation for mortality

In ancient Greece, the ideal of care for the emotional impact of death is particularly reflected in the consolation literature. The main aim of this literature is to achieve inner-world happiness in spite of one's mortality. Consolation is provided through a reflected meditation on the place of death in the cosmic order, the immortality of the soul, and the intangibility of death itself. For example, arguments are presented about the limited meaning of death, about the fact that we all share in our mortal human condition, and about the pointlessness of grieving, for it doesn't help us any further. Care for the emotional impact of death is thus mainly directed at a consolation for human mortality.

The consolation ideal of care for the emotional impact of death is mainly found in Stoicism and (neo) Platonism. Both movements believed that a virtuous directedness of the soul in combination with a renunciation of one's attachment to life console for one's mortality. Although many texts in Greek philosophy provide consolation, Krantor of Solio (ca. 330-268 BC), Cicero (106-43 BC), Seneca (4 BC - 65 AD) and Plutarch (ca. 46-120 AD) are the most important representatives of this genre. At the basis of the consolation literature lies the conviction that feelings should be guided by reason. The ideal of this care for the emotional impact of death was to diminish and control one's grief rather than to suppress one's emotions.

Preparation for afterlife

During the middle ages, the consolation ideal for the emotional impact of death is complemented by the Christian value of suffering. Through the resurrection of Christ, death is no longer the end of everything but becomes the step to a transcendent reality. Suffering is no longer accepted just because of its place in the order of things, but also for its purifying effect on man's sinfulness. Besides heaven and hell as possible places for the afterlife, interest is increasingly paid to purgatory where the soul awaits its final judgment. The church teaches the remission of sins through praying, penance and indulgences. The ideal of care for the emotional impact of death thus becomes directed at the preparation for the afterlife before God's final judgment.

The preparation ideal of care for the emotional impact of death did not conflict with the consolation ideal of the Greeks. Minucius Felix (2nd century), Tertullian († after 220 AC) and Lactantius († ca. 330 AC) elaborated upon stoic thoughts. Boethius (480-524 AC) famously integrated the care as a consolation for mortality with the care as a preparation for the afterlife. Christian consolation texts are written by St. Paul († in 67 AC), St. Cyprianus († in 258 AC), St. Basil (329-379), St. Gregory (332-400), and St. Ambrose (ca. 337-397). A late medieval and popular work on care for the emotional impact of dying is the *Ars moriendi*. This work consoles the dying, warns the terminally ill for

wrong mental attitudes and shows how one should pray and communicate with the dying in order to prepare them for the afterlife.

Humanisation of death

From the renaissance onwards, the preparation ideal for the emotional impact of death becomes criticised. Reformation thinkers, such as Luther (1483-1546), reject the church dogma on the existence of a purgatory and thus the possibility of repentance after death. For them, one's faith in the moment of death becomes crucial. This led to a focus on the death-scene in which the last words of the dying were thought to be indicative for the quality of the transition to the afterlife. Humanists, such as Erasmus (1466-1536), claim that Christ, and not the church, is the mediator between man and God. For them, man has its own responsibility in defining death. The ideal of care for the emotional impact of death thus becomes humanised for it addresses the human capacity to assign meaning to death.

The humanisation of death appears in the texts of various influential authors. For example, Hume (1711-1776) justifies suicide in the case when life becomes unbearable due to sickness, misfortune and old age. Schleiermacher (1768-1834) adds to the orthodox and mechanistic otherworldly consolations the human urge to love each other for we always live in the face of death, and James (1842-1910) opens new perspectives on personal spirituality and immortality. The growing diversity of the meanings of death thus differentiated the ideal of

care for the emotional impact of death various sub-ideals - varying from providing consolation, stimulating penance, bringing about faith, and exciting the experience of the sublime in nature.

Autonomy in dying

From the late modernity onwards, the growth of scientific understanding resulted in more hygiene, higher standards of living and lengthening of the average lifespan. Technological developments, such as artificial respiration, dialysis and penicillin opened the way to increasing control and postponement of death. The ideal of a care for the emotional impact of death became both disregarded and depersonalised. Terminal care often remained unorganised and the imminence of death was generally not communicated to the dying. In reaction to these developments, doubt arose about the appropriateness of endless treatments and new settings for dying - such as hospice and palliative care – came up. Focussing on the individual needs of the dying person, the ideal of care for the emotional impact of death becomes directed at the autonomy in dying.

The primacy of autonomy - together with technological progress, secularization and inner ways of spirituality - forms the context in which present day caregivers take care for the emotional impact of death. Although the concept of autonomy only becomes relevant from the 1960's onwards, its meaning has been developed since the eighteenth century. For example, for Kant (1742-1804) autonomy means to act out of free will in accordance with the objective moral

law; Mill (1806-1873) sees autonomy as the subjective freedom of choice between options; and Sartre (1905-1980) defines autonomy as an identification and engagement with oneself. These differences have significant implications for nowadays ideal of care for the emotional impact of death. Three of these implications are discussed below.

Implications of the primacy of autonomy

Finding the right moment to die

Due to the primacy of autonomy, the suffering inherent to dying is increasingly understood as meaningless suffering. Living in a society where chronic illness is the main cause of death, the elderly are increasingly subjected to physical and psychic limitations. Many of them face a slow but certain loss of autonomy, control and independence. Due to the fragmentation and weakening of religious meanings of death, this loss of autonomy in the dying process is increasingly defined as unbearable, hopeless, and degrading. As a consequence, old people increasingly prepare for a death without suffering.

Increasing is the number of old people who commit suicide. Increasing is also the number of people arrange advance directives in which they settle abstention or termination of treatment in case they should be unable to give informed consent. Termination of treatment in the case of irreversible coma or persistent vegetative state is heavily debated on the basis of ‘what the patient

would have decided'. Although few countries have legalised voluntary euthanasia and physician-assisted suicide, many countries face problems in dealing with these issues. These developments show that individual control of 'when and how one wants to die' has become part of the western context of dying. The ideal of care for the emotional impact of death thus increasingly implies care for what is considered to be the right moment to die.

Finding meaning in dying

The primacy of autonomy changes the relationship between caregiver and the dying person. The dying expresses the need for help of others, decides what personal or spiritual path is to be taken and gives meaning to death. The caregiver is sensitive to the wishes and emotional processes of the dying person and aims for adequate response. As long as this response is connected to the autonomy of the dying adequate care is provided. However, the primacy of autonomy falls short when the dying is overwhelmed by the emotional impact of death. A one-sided care based on autonomy then risks to lose sight on its most important goal: to care for the emotional impact of dying in which one's autonomy is lost.

Care for the emotional impact of death is often a compromise between paternalism and respect for autonomy. Too much initiative may result in misplaced conversations about God and the afterlife or to premature advice. Too much respect for autonomy may result in letting a person die without adequate

care for the emotional impact of death. Although various care ethicists have purported to resolve the dilemma by stressing the mutual relationship between caregiver and the dying person, the problem of autonomy in dying remains paramount. The ideal of care for the emotional impact of death thus increasingly implies care for the annihilation of one's autonomy.

Finding engagement with dying

The primacy of autonomy rejects rather than engages with the phenomenon of dying. The media mostly presents death without connecting to normal experiences of dying; in both public and private it is taboo to speak about death; and the societal focus on youthfulness and ambition disregards the vulnerability and finiteness of life. In healthcare, the focus on treatment leaves little space for the issue of dying; professionals are supposed not to over-identify with the dying; and when dying finally occurs it is mostly in hospitals and nursing homes, that support the dying and their families only to a limited extent. Care for the emotional impact of dying is thus embedded in a disappearing face of dying of western culture.

Generally, engagement largely depends on identifiable mutuality of experiences - people feel closer or more sympathetic to others when they recognise their experiences. Since dying normally lacks such mutuality it is extremely difficult for caregivers to understand what the emotional impact of death is about. In order to know 'when to do what' it is often suggested that

caregivers need to confront themselves with death and dying. Since society increasingly fails to provide the opportunity for such personal confrontations, caregivers lack general experiences with death and dying. Therefore, the ideal of care for the emotional impact of dying increasingly implies care for finding engagement with dying as such.

See also Informed Consent, Death Awareness Movement, Right-to-Die Movement, Ars Moriendi, Caregiver Stress, Terminal Care.

Further readings

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