End of life care for the elderly: a care ethics approach

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Abstract

This article approaches end of life care for elderly people from a care ethics perspective. End of life care should not be confused with assisted life ending approaches and support or euthanasia. End of life care refers to care of people who are dying, immaterial of age or medical condition. Vulnerability is not limited to elderly people (as care-receivers) only but also to caregivers as a vulnerable group in own right.

Care ethics for healthcare is defined as creating a relationship between caregiver and care-receiver (in this case the elderly person), recognising their mutual vulnerability and potential power relationship within the healthcare value chain, and carrying out the responsibility to care for and protect life and its dignity in order to improve quality of life and health and grow personal life orientations. Care ethics is influenced by a changing relationship between caregiver and care receiver, ethical environment, palliative care and social determinants.

Understanding and dealing with end of life care can never be removed from the discussion on quality of life, dignity and human suffering that adds no value to life. The Christian narrative is used to promote and uphold the dignity and prolonging of life. To this may be added, care for the dying. This narrative is built on God as the Creator of life, the duty to care for life and the respect for life no matter the quality thereof.

Keywords:

end of life, assisted life ending support, euthanasia, care ethics, palliative care, elderly people, vulnerability

1. End of life: looking forward instead of backwards

End of life symbolises looking "backward". This is an unavoidable finality. However, the need is more to look "forward" on how to guide and deal with end of life matters. End of life should not be confused with *assisted life ending approaches* and *support* or *euthanasia*. End of life is generally understood as *caring* for people who are dying, immaterial of age or medical condition. The *scope* of end of life care includes matters such as supportive doctor-patient relationships, surrogate decision making, patient's preferences, communication, treatment plan and end of life goals (https://medical-dictionary.thefreedictionary.com/end-of-life).

End of life care gains attention as there is worldwide evidence of a growing elderly society which opens new ethical challenges in healthcare around the value and meaning of life. The opinion is that if one has the right to live, one also has the right to die (see De Wachter, 2013:202).

The end of life care for elderly people is further prominent due to a growing awareness of mental health disorders such as dementia and the COVID-19 virus pandemic which puts vulnerable people such as the elderly at risk.

End of life care efforts become more complicated for elderly people when their existence is not necessarily challenged through illness but rather through *vulnerability*. Vulnerability in end of life care refers to the health and personal risks someone experiences due to disease, treatment and/or context (see World Health Organisation, 2007 and Lategan, 2017). Vulnerability is not limited to elderly people only, but it is accepted that the last phase of their lives and/or the nearing end of life add to a different experience and expectation of life. Naja, Makhlouf, Chebab (2017:4363) define aging as "the lifelong process of growing older at cellular, organ, or whole-body level throughout the life span". They continue by arguing that demographic transition, shift in fertility, reality of mortality and the influence on social life contribute towards aging. Their conclusion is that long-term burden of illness and diminished wellbeing affect patients, their families, health systems, and economies, and it is forecast that these will accelerate. Moreover, this will greatly affect the quality of life of people of age (Naja, *et al.* 2017:4364).

To elaborate on the vulnerability of elderly people: The problem with dementia is that it raises ethical questions around the appropriateness of palliative care, surrogate decision making, dignity of the elderly and whether long-term care facilities are ready to deal with mental disorders. These comments are put into perspective by information from three completed studies on palliative care for people with dementia.

Firstly, the reality of a growing number of older dying people in long-term care facilities across the globe is confirmed in a scoping review of palliative care education by Collingridge Moore, Payne, Van den Block, Ling and Froggatt (2020:1, 2). The review further confirms that improved palliative care has a positive influence on improving care. *Secondly*, there will be a growing need for palliative care for older persons with dementia over the next four decades (up to 2060). Based on the availability of palliative plans for people with dementia, there is a rising need for improving on these plans to meet expectations (Nakanishi & Van der Steen, 2020). *Thirdly*, in their study Bolt, Meijers, Van der Steen, Schols, Zwakhalen and Meijers (2019) investigated the experience of relatives with end-of-life care for people with dementia by comparing the nursing home and home settings. Based on their research, three conclusions were drawn: person-centred care in caring facilities is not the same as at home; in a caring facility relatives must still be involved in the care of persons with dementia; and surrogate decision making remains a challenge both at home and at the care facility.

These observations should be understood in the context of what palliative care and dementia actually are. *Palliative care* is defined by the World Health Organisation (WHO, 2018:5) as “the prevention and relief of suffering of adult and paediatric patients and their families facing the problems associated with life-threatening illness”. *Dementia* is understood by WHO (2012:7) as a chronic or progressive brain disease characterised by the disturbance of multiple higher cortical functions. The WHO’s report on palliative care and dementia deals with the impact that palliative care and dementia have on elderly people. With regard to palliative care, the comment that it “does not intentionally hasten death, but provides whatever treatment is necessary to achieve an adequate level of comfort for the patient in the context of the patient’s values” gives guidance that respect for life and the dignity of the patient are important. The same can be said with reference to dementia. In the WHO’s report the focus is on long-term care for people with dementia. Here too, respect for the person, upholding of dignity and assistance to be independent, where possible, are a confirmation of the value for life that must be respected up to the end of life (WHO, 2012:53).

What is evident from these reports is that the focus on end of life care is not limited to the care receivers, in this case elderly people, only. Care givers have an equal interest in end of life care. Reference can be made to the 2018 European Association of Medical Ethics conference website. At that conference a theme was dedicated to "Rethinking the ethics of aging and the end of life" (www.eacmeweb.com). What was observed, is not only the supportive assistance to end life but the effect that life ending assistance has on the care givers.

The awareness is growing that the *curer* and the *carer* are confronted by the impact that end of life approaches has on them too. Grypdonck, Vanlaere and Timmerman (2018:21) comment on this challenge by saying that sometimes ethical principles cannot be implemented. This reality creates an ethical dilemma in the treatment of patients in general. Furthermore, when the patient and the family have a different view on treatment to that of the care givers, this can become problematic as well. A typical example would be the withholding of treatment such as blood transmission because of religious reasons. Another challenge is where professional ethics demands transparency on a condition whilst family may request that the condition be shared with the patient.

The impact of end of life grows in complexity when the curer or carer becomes the patient him-/herself. Kalanithi, a neurosurgeon, is confronted by the end of life when he learns that he has cancer. A remark, informed by his expert knowledge, captures his *vulnerability* as a patient: "While being trained as a physician and scientist helped me process the data and accept the limits of what that data could reveal about my prognosis, it didn't help me as a patient" (Kalanithi, 2016:31).

There is no doubt that discussions around end of life care remain important and will grow in priority in the wake of national/local endemics and global pandemics of which COVID-19 is a good example. Statistics from the WHO (2020a) at the beginning of June 2020 confirmed that more than 6.5 m people were infected worldwide with the corona virus with 387 155 deaths. In April 2020 it was predicted that for the European region 95% of these deaths will be people older than 60 years. It is further expected that 50% of people dying from the corona virus will be older than 80 years (WHO, 2020b). The morbidity points primarily towards elderly people. The underlying question is that of saving lives in the context of limited healthcare resources. This question is not new as medical health economists have raised the question before: on whom should the available budget be spent? On people that *can* contribute to the economy, or people who *have* contributed to the economy?

The question may be extended to include choices between vulnerable, self-care, private or public patients as well. Whatever the question, the answer will lead to ethical dilemmas.

These comments on end of life care raise another question: *How best can elderly people as a vulnerable group and care givers also as a vulnerable group be guided in the ethical challenges associated with the end of life care?*

This article will consider end of life care for elderly people from a *care ethic*s perspective.

The next section will outline the meaning of care ethics in the broader domain of ethics-based healthcare.

2. An outline of care ethics

The domain of healthcare includes concepts such as medical ethics, bioethics, healthcare ethics, global health ethics and public health ethics: none of these are new concepts, though they may not be equally familiar.

Medical ethics normally refers to the doctor-patient relationship whereas bioethics deals with issues around life and death. Healthcare ethics addresses ethical challenges in the delivery of healthcare. Global health ethics has the objective of addressing cross-national health dilemmas, while public health ethics focuses on shared values to address community health problems.

Medical ethics and bioethics are much debated due to technological developments, cultural orientation and religious confession. The values of the "Georgetown mantra" – respect for individuals and their autonomy, non-maleficence, beneficence and justice (see Ten Have, 2011:27) lead the discussion.

Although the emphasis is on humanity and dignity, there is a need to integrate ethics into all aspects of the healthcare value chain, namely *cure*, *care*, *control* and *community* (Glouberman & Mintzberg, 2001). This means that doctor, patient, caregiver, therapist, manager and community are all affected by ethical dilemmas. Depending on the ethical challenge and subsequent decision, there will be an impact on one or more of these ethical quadrants.

The value that care ethics can add to the broader domain of healthcare lies in making ethics in everyday healthcare more explicit (Vanlaere & Gastmans, 2011:15). Grypdonck *et al.* (2018:9, 10, 11, 24) state that care ethics should not be confused with the ethics of care. *Care ethics is practice orientated* *and deals with ethical challenges in daily care.* Schotsmans (2012:21) adds to this, saying that care ethics is directed at the uniqueness and specificity of the situation and not a common rule or value. Based on the baseline for care ethics, ethical behaviour and decisions are very much influenced by the specific context. Care ethics does not mean translating theory or principles into practice; it is rather a continuous process of learning based on experience. This by no means suggests that there is no framework for care ethics. It suggests instead that the application of care ethics is informed by the situation. A lived experience informed by prior experience and knowledge (presumably a mix of tacit and non-tacit knowledge) inform the understanding an application of care ethics.

The *relationship* between caregiver and care receiver forms the basis of care ethics. Burggraeve and Vanlaere (2017) support the central role of the relationship between caregiver and care-receiver. They go further to say that as care ethics deals with *vulnerable* people, it should also consider how care is influenced by *context* and *power*. They furthermore identify what care ethics is by starting with the situation and the awareness of the other's vulnerability. The vulnerability in the situation evokes involvement by trying to connect with the other, for example through conversation. The situation should assist to identify (often hidden) vulnerability, and at the same time, also the power the caregiver may have. Care ethics is the basis upon which to open a relational space, a way of meeting the other as a person. Their perspectives on care ethics are summarised by the comment that care ethics starts with a caring relationship and not from external principles or rules and by people shaping their responsibility for each other. Care is influenced by context. The question should also be raised regarding the power relationships that may be involved. Both caregiver and care-receiver should be sensitive to people's vulnerability.

Vanlaere and Gastmans (2011:15) also give shape to understanding care ethics by identifying four features of care. These features of care are interwoven and form a synthesis of care: (a) Care is a fundamental way of life and an ethical task. (b) Care combines attitude and activity. (c) Care is reciprocal. (d) Care is meaning-given.

Burggraeve's idea of *growth ethics* can be added to these approaches of care ethics (2016:129-132; 138-139). This may be explained in the context of the *minus bonum* which refers to the "lesser good". Growth ethics refers to what is achievable given what is desirable. This is an "ethics of being underway". Burggraeve frames his view within a Christian liberation ethic by saying that a Christian ethic is never resigned to the facts but always embodies hope

– things can be different. He says: “A Christian ethics, which has to be an authentic expression of Christ in this world, is necessarily and always an ethics of redemption, that is, an ethics of grace, mercy, and liberation from our impotence, guilt, and power of evil” (Burggraeve, 2016:139). Growth ethics presupposes the value that is added to the situation. Schotsmans (2012:137) completes the value growth can add to care ethics by saying that a person does not have ethical *limitations* only but also ethical *possibilities*. Care ethics is to address ethical challenges as they exist with a view to assisting a person to live a life with fearless expectations.

Based on these comments, care ethics in healthcare can be defined as **creating** a *relationship* between caregiver and care-receiver (here the elderly person), **recognising** their mutual vulnerability and potential power relationship within the healthcare value chain and **performing** the *responsibility* to care for and protect life and its dignity in order to **improve** quality of life and health and **grow** personal life orientations.

This orientation towards care ethics will assist in contributing to the end of life care for elderly people.

3. Clarifying concepts related to end of life

As stated in the introduction, end of life care should not be confused with *assisted life ending approaches and practices* and e*uthanasia* as these concepts refer to specific medical interventions. Assisted life ending approaches and practices and euthanasia cannot be removed from this debate although they have a very specific meaning which should be contextualised within the broader end of life debate.

With regard to definition, the following contents may be added to the topics of assisted life ending approaches and practices, and euthanasia:

- Assisted life ending refers to advices and support given to a person to bring the person’s life to an end. Assisted life ending is not administrated by the person providing the assistance to bring life to an end but by the person him/herself who wants to terminate the own life (see Ten Have, Ter Meulen & Van Leeuwen, 2013:305).
- Euthanasia is commonly known as causing the painless death of a person to end or prevent suffering (Burkhardt & Nathaniel, 1998:388). Euthanasia derives from the Greek words “*eu*” and “*thanatos*” referring to a mild or good death. From this general interpretation further classifications such

as "*active euthanasia*", "*passive euthanasia*" and "*slow euthanasia*" followed. Active euthanasia refers to activities that will bring a direct end to life; passive euthanasia is the application of palliative care; and slow euthanasia is where nothing is done because of a lack of support and interventions (see Ten Have *et al.,* 2013:303-304; Cosyns, 2013:116).

These concepts serve as a point of departure from which to identify ethical dilemmas associated with the end of life.

4. Ethical dilemmas associated with the end of life

Ethical dilemmas associated with the end of life cannot be viewed only based on no person having the right to take another person's life. The complexity of matters such as the quality of life, human dignity and health should be considered, and not only illness. In addition, even if the orientation of life is based on a Christian appreciation of life, end of life should also be viewed from various viewpoints.

Ancient Greek philosophers such as Socrates, Plato and Seneca considered the question of whether life should be terminated if it was no longer worthwhile living. They were in favour of ending a life if it was viewed as being no longer of quality. A different opinion was expressed by Hippocrates, who said that life should be prolonged and that no physician has the right to assist anyone to end a life. The word "euthanasia" was first used by Francis Bacon, who distinguished between *euthanasia interior*, that is the preparing of the soul for death and *euthanasia exterior*, which is to shorten life because of severe pain. The euthanasia debate itself started in 1870 with Samuel Williams who proposed that the lives of terminally ill patients should be purposefully ended (https://af.wikipedia.org/wiki/genadedood).

From these views emerged the perspective of the *quality of life* and the idea of when life is no longer regarded as of *sufficient quality* to live. The complexity of this matter deepens when the *autonomy* of a person's right to make decisions concerning his/her life and the *respect* for life – that of oneself and other people – are added to the debate. Patient autonomy is highlighted by the revised Declaration of Geneva (2017). This is highlighted alongside the doctor's obligation to exercise respect, beneficence and medical confidentiality towards patients (Parsa-Parsi, 2017:1972).

Most notable in the ending of life approaches and assistance and euthanasia debates are the *right to make decisions* regarding one's own life and the *universal acknowledged respect and dignity* for life. The challenge arises with surrogate decision making. In making decisions the ethical fact remains that life is not an object that can simply be *given* or *taken* away. I consider taking away life as unethical because it implies the idea that life is meaningless, it is an object and that life can be separated from personhood, the religious heart and the emotional experience of life. From a Christian ethics perspective, taking away life represents the declining of a person's responsibility to care and respect for one's life as well as that of the other. Schotsmans (2010:177-182) emphasises our responsibility to keep on caring for other people. This will include their wellbeing even at the end of life. Our obligation is to do no person harm. Schotsmans follows Levinas by saying that we have the responsibility for other people's lives and that we may not leave any person who is suffering or dying alone. He is very much mindful that such a view is the opposite of the right to self-determination by a patient.

End of life is ethically problematic when life is metaphorically downgraded as if it were a garment that can be thrown away because someone has no further use for it or if the quality of life is of such a nature that it is deemed no longer fit to be part of society. This is especially true when life is viewed from a Biblical perspective. The Biblical protection of life is based on Exodus 20:13 (the sixth commandment). The Hebrew word "*rasah*" used here contains the idea of the unlawful taking of life (Lategan, 2006:143). What should be noted is that there is no qualification of the life stage (for example, old or young), status (for example, unborn or geriatric), or quality (for example, healthy or ill). It is therefore accepted that life must be protected and valued. Based on this perspective it cannot be ethically justified for life to be terminated merely on the basis of quality of life.

The South African Constitution is very clear on the taking away of life. The Constitution recognises 15 basic human rights. It states that "Everyone has inherent dignity and the right to have their dignity respected" and "Everyone has a right to life and nobody, not even the state, has the right to take a life" (https://www.sahrc.org.za/index.php/ downloaded 29 May 2019). The South African law also does not permit assisted ending of life.

From this discussion the fair conclusion can be drawn that all people should be treated with dignity and respect no matter the stage of life. It is for this reason that active euthanasia cannot be ethically supported.

The challenge comes, however, when a person of sound mind makes the decision that he/she would like to request assistance to bring his/her life to an end when, for example, dignity is challenged because of unbearable suffering. Dignity SA (www.dignitysouthafrica.org) aims to change legislation in order to enable mentally sound adults to have access to assisted end of life support. It is believed that this approach will contribute towards the dignity of a person. To view this request as a simple matter of belief or disbelief does not hold water. Schotsmans (2010:181-182) correctly remarks that it is essentially a matter of how human dignity is viewed.

There is a limitation here in that the focus is primarily on *illness* and *suffering* and not on *health* and the *sustainability* of health. Life cannot be defined in terms of its disabilities – it must be understood in the context of its abilities and possibilities. It cannot be denied that there may be a time that life has limited possibilities or meaning. But until such time, the focus must be on the will to live and to maximise the possibilities of life. The emphasis on life can further be informed when the focus is on health. The downside of caring (as opposed to curing) for sick people is the emphasis on illness and suffering, and not on health. Health, as defined by the WHO, is not entirely the opposite of sickness and suffering. In its constitution, the WHO defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946). The WHO (2015:14) echoes the universal human right of geriatric patients to the highest attainable standard of health. For this to happen, favourable socio-economic factors as well as underlying determinants such as nutrition, housing, sanitation and a healthy environment are important to secure a healthy life. Access to health facilities and keeping up with standards of medical ethics are equally important. To this observation must be added that a new way of thinking is to move away from focusing on the cost of elderly care and towards an acknowledgement of the contribution elderly people have made towards society (WHO, 2015:16).

The emphasis on quality of life, health and dignity within the context of end of life care contributes towards the application of care ethics.

5. Back to the ethics drawing board: influences on care ethics

The purpose of this article is to focus on the end of life from a care ethics perspective. Where medical ethics deals with principles and responsibilities in the *doctor-patient relationship in thinking and actions in relation to medical problems*, care ethics commences from a *relationship to address responsibility, vulnerability and power challenges* between the caregiver and care-receiver and all who are engaged in care.

The application of care ethics is influenced by the changing relationship between caregiver and care-receiver, the influence of social determinants in healthcare, the continuous increase in the need for palliative care, and the changing nature of ethics itself.

5.1 The relationship between caregiver and care-receiver

The *relationship* between caregiver and care-receiver is challenged by the changing nature of this relationship. The background to this changing relationship can be found in *participatory medicine*. Participatory medicine represents the idea that the doctor cannot decide alone about a patient. This view can be extended to the entire healthcare value chain (Van Wanseele & Weeghmans, 2013:55-63; Vervotte, 2013:16). This is further confirmed not only by the Declaration of Geneva (2017 – see paragraph 4) but also by how healthcare is managed based on market principles (Ten Have, *et al.* 2013:177-163; Creplet, 2013:100-102). Quality of healthcare is not limited to the way in which healthcare is managed but should also include the quality of relationships. Within a management context, it is about whether things are done right (*fitness for purpose*) and if the right things are done (*fitness of purpose*). This approach is also known as *effective* (are things done right?) and *efficient* (are the right things done?). With regard to the care of the patient, Vanlaere, Burggraeve and Lategan (2019:25-38) refer to time management, which is a major challenge in healthcare and which leads to the bureaucratisation of care. They challenge the perception that slowness in care is laziness. A typical example of this perception is talking to the patient instead of doing something. Another concern is patient centredness. Vanlaere and Burggraeve (2017:45-52) say that care not only has an *object-side*, which complies with evidence-based medicine, but also a *subject-sid*e that refers to the relationship between caregiver and *care-receiver*.

5.2 The role of social determinants

Care at the end of life is also influenced by *social determinants*. The report of the Commission on Social Determinants of Health (2008) points out that factors in the social environment can contribute towards ill health. Ill health is not always the result of physical challenges only. Chan, former Director General of the WHO, commented that social determinants have become as important as dealing with physical challenges in healthcare. Social determinants for health are defined as those social factors that impact on human life. Factors such as low income, little or substandard education, limited employment options, high levels of unemployment and poor living and working conditions are known for their influence on health (Chan, 2017:8). Economic factors, social policies and politics shape these factors and their impact on the health of people.

5.3 Palliative care

In dealing with end of life patients, i.e. *palliative care*, it is not the care itself that is challenging but rather what informs the palliative care. Two examples can be mentioned. *Firstly*, in a study on nursing staff's needs in providing palliative care for persons with dementia, Bolt, Meijers, Van der Steen, Schols and Zwakhalen (2020) report that from a sample size of 416 respondents, the highest-ranking need for support was in dealing with family disagreement in end-of-life decision making. The challenge of shared decision making with regard to palliative care appears to be a valid challenge when dealing with people with dementia in long-term care. This is confirmed in a study by Kockovska, Garcia, Bunn, Goodman, Luskett, Parker, Phillips, Sampson, Jenny, Van der Steen & Agar (2020). The *scoping review* of Collingridge Moore, *et al.* (2020:2, 4, 10-11) identifies organisational strategies to improve the implementation of palliative care interventions. These observations are facilitation, education and training, and internal and external engagement. Based on these observations they argue for the effectiveness of palliative care and then the application thereof to a real-life setting. This will require a changed practice that must be implemented. The baseline will be to have at least the minimum palliative competencies. The summative interpretation is that although palliative care is no new concept within end of life treatment, the caregivers' readiness for palliative care and the reception thereof by the patient (as direct beneficiary) and family (as surrogate decision-makers) will determine the effectiveness in both subject and object side of care.

5.4 Changing ethical context

There is no doubt that (medical) ethics is influenced by a changing world. This will be even more the case as a result of the new normal as influenced by the COVID-19 pandemic. In modern society, ethics is influenced by rationality and technology. Ethics is further challenged by relativism. Pragmatism in accommodating individual needs overshadows the basis of ethics. This is evident in end of life decisions, for example. De Dijn (2003) follows a very sensible classification of ethical dilemmas: he identifies them according to *taboos*, *monsters* and *lottery*. To each of these groupings is given a specific meaning. *Taboos* are informed by cultural divisions such as man-machine, I-other and life-death. It is the one or the other. Ethics is limited to choosing in favour of one of these divisions only. *Monsters* challenge traditional or typical thinking around taboos due especially to bio-medical development. Healthcare workers are challenged by ethical dilemmas that were not known in the past. Suddenly the ethical thinking of the past is no longer appropriate for contemporary challenges. *Lottery* refers to the influence of interest groups on ethical decision-making such as on the autonomy of a patient, the influence of the economy or the market and the abilities of technology and biomedicine. De Dijn's comments outline two major consequences for end of life thinking. Firstly, the autonomy of the patient to decide over his/her own life cannot simply be seen as being against religious belief. Secondly, the context for healthcare, namely a political interest (the state's responsibility to care), economic realities (limited and declining budgets especially in the developing world) and the abilities of technology and science (evidence-based medicine to make an informed cure and care decision) cannot be ignored. De Dijn is not alone in his thinking about ethics in a post-modern society. Schotsmans (2012) confirms that the church may have consensus on many new developments within bio-medicine, but it also has opposing opinions or no opinions at all on new bio-medical developments. The church has never shied away from the quality of end of life care, palliative care or sedation. The church has no consensus thinking over stem cell research, stem cell therapy or euthanasia. De Dijn and Schotsmans are joined by De Wachter (2013:204-205) who also argues that what used to be a borderline issue has now become mainstream, with euthanasia serving as a good example. This ethical challenge is informed by association with Christ's suffering and redemption. The acceptance of one's suffering is understood against this background. However, if there is no link between suffering and the meaning for life, then euthanasia is viewed in a different way.

5.5 Summative comment

The impact of new developments on care ethics and its subsequent application to end of life care cannot be ignored. Medical ethics and the healthcare profession have an important role to play. This is confirmed by De Dijn (2003:122) who comments that healthcare is practised in the interphase between ethics and medical-technical knowledge. He is joined by Schotsmans (2012:17), who comments that ethical responsibility towards life is most useful within medical ethics.

From the above-mentioned influences on ethics in general and care ethics in particular, the following guidelines for end of life care can be presented.

6. “End of life”: A care ethics perspective

In this article care ethics is defined as creating a *relationship* between caregiver and care-receiver (here the elderly person), recognising their mutual vulnerability and potential power relationship within the healthcare value chain and performing the *responsibility* to care for and protect life and its dignity in order to improve quality of life and health and grow personal life orientations.

Based on the arguments presented in this article, the following perspective on the end of life may be offered from a care ethics perspective.

Nullens’ (2006) ethical views are taken as a point of departure. He moves from the perspective that Christian ethics is more than a *summary* and *application* of the ten commandments. Christian ethics is fundamentally about who we are and the search for goodness. To do good, is the driver of Christian ethics. His emphasis is on God who is love and the Biblical perspective that God created man and woman in His image. He makes reference to “missionary ethics”. Here the emphasis is on Christ. For Nullens, ethics is not about the application of commandments or finally formulated answers, but rather about reflection on the situation from a Christian perspective. The Christian perspective informs the medical ethical values of respect, dignity, do no harm and autonomy. These values can be found in a universal ethical declaration such as the Georgetown mantra. From a Biblical-driven medical ethic, the emphasis is on God as Creator and Protector of life, Christ as the Redeemer of life and the Gospel the good news of the eternal life. Life and the treatment thereof should be seen against who God is. Leviticus 19 portrays life against the Holiness of God. The relationship is therefore informed by the religious orientation that life is holy, must be safeguarded, treated at all times with respect and be valued as an integral part of personhood. The relationship is further informed by the central love commandment of do to others. Joubert (1994:125) says of this commandment, that it is not about an *either … or* but rather about *and … and*. Douma (1999:49-50) puts this in perspective by commenting that a Christian orientation will inform a different view on euthanasia, for example, as life is seen to be in the hands of God.

Within this relationship, a patient at the end of life can easily become *voiceless* because of dementia, or regarded as only an object within a *bureaucratised* healthcare system. The authority the doctor, the healthcare practitioner or hospital manager has over the patient should be replaced by *patient centredness* and *autonomy* of the patient (see World Medical Association Declaration of Geneva, 2017). The underlying principle is to do no harm despite the power relationship that may be at hand. All involved in healthcare and cure should be sensitive to everyone's humanity. Ethical decision making can never be removed from the human "experience". Ethics has its origin in motive (why do we behave as we do), habitat (what are the specific circumstances) and the common good (what can be achieved through particular care). De Wachter (2013:282) calls on Levinas' idea of the small goodness that should be experienced by others. The small goodness is a look away from oneself to realise the temporality of existence and to bestow mercy upon another person. Within this approach there is no room for exploitation of authority.

The "missionary ethics" of Nullens (2006) gives context to the responsibility to care for life. The responsibility to care for life cannot mean that life should be upheld at all costs and that every treatment available should be provided if there is no reasonable hope for the patient to live. In the absence of such evidence, palliative care must be provided. This is an example of passive euthanasia which can be ethically justified. Regardless of the mental or physical condition of a patient, active euthanasia cannot be justified as it is unethical for anyone to have the power to decide on this. No Christian ethic can associate itself with such a decision.

In this context end of life assistance cannot be supported. Although the autonomy of the patient's decisions, the quality of life and a respectful death are acknowledged, the Christian viewpoint is still that life is granted by God and that no person has the right to terminate his/her or another person's life (see Douma, 1999:48-50). This observation is not only vested in an interpretation of the sixth commandment but also in the Bible's emphasis on life. Death is never seen as the desired option, even though it is part of life's continuum. Job, for example, highlights the community with a *living* God (Meyer, Nel & Vosloo, 2005). The Sermon on the Mount goes further to reject behaviour where a person's life is degraded – let alone terminated. The basis here is love as motivation (König, 2018:99-100).

In dealing with the end of life, the obvious conclusion is that even at the end of life there can be dignity and expectation. The expectation is not an unrealistic turning around of the end of life but the expectation that, in Christ, life is more than a biological matter. Life (biological) is also a desire to accept the reality of death yet to keep on hoping to live. Burggraeve and Van Halst (2005:154-158) advise that it should not be about organising death and letting people die alone. They advocate for a palliative care that integrates physical, psychological, relationship and spiritual care. The idea behind this integrative palliative care is that no person should be left to die alone. Dying people should experience the presence of another. Burggraeve and Van Halst continue by arguing that such a presence is an expression of neighbourly love. You do it because you want to, and not because you expect to receive something in return (*do ut des*). Another important aspect is added: the dying person should, metaphorically speaking, hand life back to God, either him/herself, or with assistance. This is by acknowledging that God is the Originator of life. Once this is done, life cannot be taken back.

7. Summary

These comments on end of life care as applied to elderly people confirm the following:

- End of life care from a Christian care ethics perspective is based on God as the Creator of life, the duty to care for life and the respect for life no matter the quality thereof.
- End of life care should not be confused with assisted ending of life or euthanasia.
- Elderly people are affected by end of life care as they are vulnerable.
- Elderly people’s vulnerability is confirmed by mental health disorders and the increasing need for palliative care.
- Both care receivers and care givers are vulnerable, although for different reasons, in end of life care.
- End of life care is challenged by ethical dilemmas that go beyond a personal’s moral system.
- Care ethics focuses on implementing ethical care in everyday situations. Relationships, power, vulnerability and growth form the core of care ethics.
- End of life support and active euthanasia are not supported as these actions challenge the protection of life even if the person him/herself has a personalistic view on these interventions.
- Care ethics in end of life treatment can secure the autonomy, respect and dignity of the dying person.

Bibliography

BOLT, S.R., MEIJERS, J.M.M., VAN DER STEEN, J., SCHOLS, J.M.G.A., ZWAKHALEN, S. & MEIJERS, J.M.M. 2019. What do relatives value most in end-of-life care for people with dementia? *International Journal of Palliative Nursing* 25(9):432-442.

BOLT, S.R., MEIJERS, J.M.M., VAN DER STEEN, J., SCHOLS, J.M.G.A. & ZWAKHALEN, S. 2020. Nursing Staff Needs in Providing Palliative Care for Persons with Dementia at Home or in Nursing Homes: A Survey. *Journal of Nursing Scholarship*, 2020: 0:0, 1-10 (open access copy).

BURGGRAEVE, R. 2016. *An ethics of mercy*. Leuven: Peeters.

BURGGRAEVE, R. & VAN HALST, J. 2005. *Al de vragen van ons leven: Een ethiek voor het dagelijkse leven*. Tielt: Lannoo.

BURGGRAEVE, R. & VANLAERE, L. 2017. *The quality of care: a care ethics approach*. Lecture presented at the Faculty of Health Sciences at the University of the Free State on 5 May 2017.

BURKHARDT, M.A. & NATHANIEL, A.K. 1998. *Ethics and issues in contemporary nursing*. Delmar Publications: New York.

CHAN, M. 2017. *Ten years in public health. 2007-2017*. Geneva: World Health Organisation.

COLLINGRIDGE MOORE, D, PAYNE, S, VAN DEN BLOCK, L, LING, J & FROGGATT, K. 2020. Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review. *Palliative Medicine*. 1-3.

CREPLET, J. 2013. *De derde revolutie in de geneeskunde*. Kalmthout: Pharma.be.

DE DIJN, H. 2003. *Taboes, monsters en loterijen. Ethiek in de laat-moderne tijd*. Kapellen: Pelckmans Klement.

DOUMA, J. 1999. *Grondslagen Christelijk ethiek*. Kampen: Uitgverij Kok.

THE COMMISSION ON SOCIAL DETERMINANTS OF HEALTH REPORT. 2008. World Health Organisation.

DE WACHTER, D. 2013. *Borderline times: Het einde van de normaliteit*. Tielt: Lannoo.

DIGNITY SA retrieved from www.dignitysouthafrica.org on 2 May 2020.

END OF LIFE. Retrieved from https://medical-dictionary.thefreedictionary.com/end-of-live 9 August 2018.

EUROPEAN ASSOCIATION OF MEDICAL ETHICS. 2018. Conference website. Retrieved from www.eacmeweb.com on 1 August 2018.

EUTHANASIA. Retrieved from https://af.wikipedia.org/wiki/genadedood on 20 July 2019.

GLOUBERMAN, S. & MINTZBERG, H. 2001. Managing the care of health and the cure of disease. Part 1: Differentiation. *Health Care Management Review*, Winter 56-69.

GRYPDONCK, M., VANLAERE, L. & TIMMERMAN, M. 2018. *Zorgethiek in praktijk*. Tielt: Lannoo Campus.

JOUBERT, S. 1994. *Matteus vandag*. Orion: Halfway House.

KALANITHI, P. 2016. *When breath becomes air*. London: Penguin Random House.

KOCKOVSKA, S., GARCIA, M.V., BUNN, F., GOODMAN, C., LUCKETT, T., PARKER, D., PHILLIPS, J.L., SAMPSON, E.L., JENNY, T., VAN DER STEEN, J. & AGAR, M.R. 2020. Components of palliative care interventions addressing the needs of people with dementia living in long-term care: A systematic review. February 2020. *Palliative Medicine* 34(4):454-492.

KÖNIG, A. 2018. *Die bergrede*. Vereeniging: Christelike Uitgewersmaatskappy.

LATEGAN, L.O.K. 2006. Kommentaar op die verskuiwing in moraal in die hersiene wetsontwerpe oor die vrywillige beëindiging van swangerskap. *Tydskrif vir Christelike Wetenskap*, 42(4):139-149.

LATEGAN, L.O.K. 2017. Growing old: a neglected discussion in healthcare ethics. *Journal for Christian Scholarship*, 53(4):117-138.

MEDICAL DICTIONARY. 2018. End-of-life definition. Retrieved from https://medical-dictionary.thefreedictionary.com/end-of-live on 9 August 2018.

MEYER, O., NELL, I. & VOSLOO, R. 2005. *God se antwoord … is ŉ vraag. Oor God, lyding en die lewe in die lig van die boek Job*. Wellington: Lux Verbi, BM.

NAJA, S., MAKHLOUF, M.M.E.D. & CHEBAB, M.H.H. 2017. An ageing world of the 21st century: a literature review. *International Journal of Community Medicine and Public Health* 4(12):4363-4369.

NAKANISHI, M. & VAN DER STEEN, J.T. 2020. National dementia plans to address escalating global palliative care needs. *Palliative Medicine*. April 2020.

NATIONAL INSTITUTE ON AGING AND THE WORLD HEALTH ORGANIZATION, 2011. *Global health and aging*. World Health Organization. NIH Publication 11-7737.

NULLENS, P. 2006. *Verlange naar het goede*. Zoetermeer: Boekencentrum.

NYS, H. 2013. Medicalisering van levenseinde neemt toe. In Nuyens, Y. and De Ridder, H. (Redakteurs). *Dokter ik heb ook iets te zeggen*. Tielt: Lannoo Campus. 174-186.

PARSA-PARSI, R.W. 2017. The Revised Declaration of Geneva: A Modern-Day Physician's Pledge. *Journal of the American Medical Association*. 318(20):1971-1972.

SCHOTSMANS, P. 2010. *Handboek medische ethiek*. Tielt: Lannoo Campus.

SCHOTSMANS, P. 2012. *In goede handen: geneeskunde en ethiek binnen de kerk van vandaag*. Tielt: Lannoo Campus.

TEN HAVE, H. 2011. *Bioethiek zonder grensen. Mondalisering van gezondheid, ethiek en wetenskap*. Antwerpen: Valkhof Pers.

TEN HAVE, H., TER MEULEN, R.H.J. & VAN LEEUWEN, E. 2013. *Leerboek medische ethiek*. Houten: Bohn Stafleu van Loghum.

VANLAERE, L. & BURGGRAEVE, R. 2017. The quality of healthcare: a care ethics approach. In: Lategan, L.O.K. & Van Zyl, G.J. (Eds). 2017. *Healthcare ethics for healthcare practitioners*. Bloemfontein: SUN MeDIA. 43-52.

VANLAERE, L., BURGGRAEVE, R. & LATEGAN, L.O.K. 2019. *Vulnerable responsibility: small vice for caregivers*. Bloemfontein: SUN MeDIA.

VANLAERE, L. & GASTMANS, C. 2010. *Zorg aan zet. Ethisch omgaan met ouderen*. Leuven: Davidsfonds.

VANLAERE, L. & GASTMANS, C. 2011. To be is to care: a philosophical-ethical analysis of care with a view from nursing. In Leget, C., Gastmans, C. & Verkerk, M. (Eds). *Care, compassion and recognition: an ethical discussion*. Leuven: Peeters. 15-31.

VAN WANSEELE, C. & WEEGHMANS, I. 2013. Patiënten worden partners. In Nuyens, Y. and De Ridder, H. (Redakteurs). *Dokter ik heb ook iets te zeggen*. Tielt: Lannoo Campus. 55-63.

VERVOTTE, I. 2013: We zijn nu anders ziek dan 40 jaar geleden. In: Nuyens, Y. and De Ridder, H. (Redakteurs). *Dokter ik heb ook iets te zeggen*. Tielt: Lannoo Campus.16-29.

WORLD MEDICAL ASSOCIATION DECLARATION OF GENEVA. 2017. Retrieved from https://jamanetwork.com/journals/jama/fullarticle/2658261 on 1 May 2018.

WORLD HEALTH ORGANIZATION (WHO). 1946. *Constitution of the World Health Organization: Principles*. Retrieved from the Internet on 13 July 2017. http:/ www.who.int/about/mission.

WORLD HEALTH ORGANIZATION (WHO). 2007. *A safer future: global public health security in the 21st century*. Geneva: World Health Organisation. Retrieved from the Internet www.who.int on 20 April 2020.

WORLD HEALTH ORGANIZATION (WHO). 2012. *Dementia: a public health priority*. Geneva: World Health Organisation. Retrieved from the Internet www.who.int on 20 April 2020.

WORLD HEALTH ORGANIZATION (WHO). 2015. *World Report on Ageing and Health*. Geneva: WHO Press.

WORLD HEALTH ORGANIZATION (WHO). 2018. *Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers*. Geneva. World Health Organisation. Retrieved from the Internet www.who.int on 20 April 2020.

WORLD HEALTH ORGANIZATION (WHO). 2020a. *Coronavirus disease (COVID-19) Situation Report – 137* on 5 June. Retrieved from the Internet www.who.int on 7 June.

WORLD HEALTH ORGANIZATION (WHO). 2020b. *Statement – Older people are at highest risk from COVID-19, but all must act to prevent community spread*. Retrieved from the Internet www.who.int on 7 June.