Gérontologie et société

Call for papers

"Older people and the end-of-life"

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Questions related to the end-of-life have given rise to numerous articles in scientific reviews and to extended ethical, legal and political debates. The aim of this special issue is to problematize this vast subject in the area of gerontology. We would like to consider this question from two points of view: firstly, by examining the specific issues relevant to the end-of-life of the aged; secondly, by asking how the various conceptions of the end-of-life give rise to specific images of "older people".

The end-of-life, probably more than any other area of life, is inextricably governed by social norms, be they ethical, religious, moral, cultural, medical or scientific. These norms are subject to debate, and we may be left with the impression that the law has the monopoly in the definition of (good) practice *vis-à-vis* end-of-life. This assumption is brought into question by the observation of concrete situations, be they related to the way in which older people conceive of and organize the end of their lives or to medical and social procedures whose aim is to ease, accompany or "hasten" the end-of-life.

Theme 1 – End of life or end-of-life?

It is difficult, conceptually and practically, to distinguish clearly between two stages which, for convenience, we will name here "end of life" and "end-of-life"; two periods of the life-course which are articulated and overlap. The sense of the first, sometimes named "the twilight-years" or the last stage of life, is synonymous with certain definitions of old age. The norms and definitions linked to this expression are fluid, to a certain extent arbitrary, and subject to debate (Castra, 2003; Higgins, 2003). In what sense and in what contexts can we speak of the end of an older person's life? How can on define and delimit this last stage of existence?

When does the "end of life" begin? This question invites us to observe the events intervening in the life-course which constitute an entry into the last part of one's life. It could begin at retirement and/or the end of one's working life. Is it linked to the weakening or rarefication of social contacts; to the onset of disability; widowhood; a change of residence? Maybe one should accord more importance to individual experience and the way older people live and interpret these events? Does this stage of life begin suddenly or is its onset progressive?

To what extent does health and functional autonomy weigh at the end of the life-course and how do these factors combine with social factors? Should the biological conception which describes the slowing down of vital functions be seen as concomitant with psycho-social factors such as withdrawal from social life? In this case, what are the signs, be they biological or physiological (measures of pace, mobility, etc.), psychological (loss of memory or cognitive decline) or social (social participation or isolation), which mark entry into this last stage of existence? How do these representations reflect our times and contemporary legal, scientific and medical norms? Can stages in the diverse end of life trajectories be reversed?

In its second sense, "end-of-life" is incorporated into the rather loosely defined life trajectory described above, in which it figures as the ultimate part of life, preceding death. This stage of life, on the threshold of death, is often conceptualized and administered with reference to legally defined medical concepts and procedures. In France, for example, an important legal dispositive concerning the end-of-life (of which the details may be little known to the general public or even to health-care professionals) explicitly supports the principles and development of palliative care (circulaire du 26 août 1986, loi relative au droit des malades et à la qualité du système de santé du 4 mars 2002, loi Kouchner du 9 juin 1999, loi Leonetti du 22 avril 2005, loi du 16 février 2010, loi Claeys-Leonetti du 2 février 2016).

For the first time in French legislation, the Claeys-Leonetti law, allows doctors to administer *"continuous deep sedation until death*" in order *"to avoid all suffering and being subjected to unreasonable obstinacy"*. This type of sedation, which involves putting patients into deep sleep and prolonging this state until death, can only be proposed to *"patients suffering from a serious and incurable affection"* who are very near to death. The evolution of this legislation is closely linked to historical and cultural constructions (sometimes influenced by cases relayed in the media[1]), which could be analyzed by means of international comparisons (Maglio, 2009), in our case, with particular emphasis on older people.

In these diverse political and cultural contexts, are older people simply patients among others? When making collegial decisions with regard to patients unable to express themselves is age, in all its dimensions (chronological, physiological, psychological, social…), taken into account? Research, such as that of Simone Pennec *et al*. (2014), has shown that in two thirds of deaths palliative treatment had been administered during the last days of life. In what proportions is continuous deep sedation administered to older people? How is their death accompanied? Do we have knowledge of criteria or cases involving older people which represent forms of "unreasonable obstinacy" or euthanasia? If continuous deep sedation is not supposed to hasten death, do specific procedures (regarding dosage or other) exist for older people, taking into account physiological factors or specific geriatric syndromes? What happens when older people have refused medical care and are dying? What do we know about palliative care for older people (proportions by age, reasons for admission and non-admission, duration, types of care, etc.)?

This first theme of this call for papers invites epistemological, ethical, social, legal, medical (geriatric, oncological, etc.), economic, psychological, historical, philosophical (Quentin, 2016) and sociological (Exley, 2004; Walter, 2008) reflections on the end(-)of(-)life. Contributions which question clinical practice on a daily basis and particularly technical and decisional procedures, related to the death of older people will also be welcome.

Theme 2 – Accompanying or accelerating the death of older people

In his reflections on assisted suicide and euthanasia, Anthony Philip Glascock (1997) evokes the "death hastening behavior" of certain traditional societies. This, he says, can be subdivided into three types: killing, abandoning and forsaking. Materialistic explanations have often been advanced to explain, for example, the "murder" of the aged by the Chuckchee of Siberia, their abandon by the Polynésian Lau or the "acts of negligence" perpetrated by the Bolivian Siriono. In these contexts, the aged were seen as endangering the survival of the younger members of the social group. Similar arguments have recently been advanced in the form of a "moral evolutionism": "*in an advanced democratic society one does not end others' lives. One alleviates suffering, one accompanies. If one day one brings death to the more vulnerable among us, even if they have asked us to, this will constitute a rupture of the fraternity which exists in our country*." (Jean Leonetti, 25 September 2018)[2] The Comité Consultatif National d'Éthique (2019) confirms that the Claeys-Leonetti law was

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[1] We have in mind the case of Vincent Humbert (a young man who was left tetraplegic, unable to speak and almost blind after a road accident, whose mother and doctor were put on trial after provoking his death, on his request, the case was largely relayed by the media). Another example is the suicide of Mireille Jospin (the mother of Lionel Jospin, the French Prime Minister 1997-2002) as related by her daughter, Noëlle Châtelet (2004).

[2] https://www.europe1.fr/societe/jean-leonetti-sur-leuthanasie-dans-une-democratie-evoluee-on-ne-donne-pas-la-mort-3764036

not intended as tacit permission for doctors to accompany their patients towards death, but to alleviate their suffering during the dying process.

By contrast, certain countries such as Belgium, Luxembourg, Holland, Canada and the state of Ohio in the USA have decriminalized and/or legalized euthanasia or medical assistance with death (Pelluchon, 2016). Others, such as Switzerland, have decriminalized assisted suicide as long as the act is not motivated by financial gain. How is the legislation specifically related to the end-of-life in these countries historically constructed and what place was given to older people in these contexts? What proportion of older people is concerned by the diverse procedures pertaining to euthanasia, and are they considered on the same terms as other categories of persons?

In July 2014, in Holland, Edith Schippers, Minister of Health, Welfare and Sport and Ard van der Steur, Minister of Security and Justice, mandated a consultative committee to carry out an in depth study on the possibility of legislation enabling euthanasia for a “completed life” (*voltooid leven*)[3]. The report submitted in 2016 concluded that it was not necessary to extend the present Dutch legislation to accommodate requests for “completed life” without medical justification. Although the Ministers disagreed with these conclusions, no new law has as yet been promulgated. Over and above the Dutch situation and the opinions expressed in the context of studies in Holland, in which elderly people spoke of their “completed life” and their desire that it should come to an end (Van Wijngaarden *et al.,* 2015), this debate questions the criteria and type of discourse the proponents of the idea of a “completed life” use to define lives which are finished or devoid of sense. It is important to point out that similar debates on the extension or not of the criteria of access to euthanasia also exist in Belgium and Canada.

Despite the absence of legislation, the fact that this debate has taken place has brought into the open the principle that, rather than being based solely on material considerations or even on the avoidance of suffering or of a bad death, societal accompaniment of death could take into account the demands of older people who esteem that they have arrived at the end of their life. Other debates are based on more economic considerations concerning the end-of-life of the aged, and recent reports (Libault, 2019) regularly cite the cost of the lives of the very old and dependent.

Could requests for euthanasia formulated by older people or by people acting, or claiming to act, on their behalf be related to different aspects of being “tired of life” (Richards, 2016) expressed by certain older people? Or should such behavior be considered as a form of depression, as it sometimes is in psychiatry? Yet again, could it be compared to certain weakly defined syndromes such as the French “syndrome de glissement” (Péru et Pellerin, 2010), often expressed in English as “failure to thrive” (Berkman *et al*., 1989)? In this vein, maybe it is possible to speak of age-linked unhappiness or mental difficulties specific to older people? Is there a particular type of depression linked to age? What are the ontological differences which differentiate between waiting for death, wishing for death, abandoning life, and suicide?

The figures from the Observatoire National de Suicide (ONS 2018), confirm that older people are the category of the population in which the greatest number of suicides can be observed: in 2014 the rate of suicide for men between the ages of 85 and 94 was 83.8/100,000. Older people’s suicides have long been ignored (Charazac-Brunel, 2014), accounting for a small proportion of deaths in this age-group and probably also in view of the short time left to live. Some studies of suicide based on a “psychological autopsy” conclude that between 60 and 90% of older peoples’ suicide can be explained with reference to depression (Rigaud *et al*., 2014). Thus, information for nursing homes and GPs (Doutreligne *et al.,* 2013; Lefebvre des Noëttes, 2014) aims mainly to improve the detection of depression and other psychological ailments. This conception of suicide in the aged is opposed to others, such as philosophical suicide (Lemoine, 2017) or rational suicide (Richards, 2016).

From a legal point of view assisted suicide is tolerated in Switzerland and is included as a separate category in the suicide statistics since the late 1990s: in 2016 12/1000 deaths occurred by suicide and

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[3] https://www.government.nl/documents/letters/2016/10/12/the-government-position-on-completed-life

11.5/1000 by assisted suicide.[4] Research carried out on this subject points to the moral dilemmas encountered by the friends and relatives who accompany the process (Gamondi *et al.*, 2015). In this context we would like to question how assisted suicide is seen by relatives and friends and by doctors who condone this practice and those who do not. Similar questions could also be asked of those who practice euthanasia or other types of medical assistance with dying.

More generally, how do medical staff and families interpret and reply to requests for death formulated by older people; what balance between the right to choose (Carré, 2015) and the failure to take into account physical and moral suffering?

How can we analyze the pro-euthanasia movement and illegal aid with suicide, which would seem to be supported by members of the middle and upper classes, members of the baby-boomer generation?[5]

In connection with this theme, we are soliciting articles which analyze the accompaniment of dying in diverse national contexts, as well as articles on the suicide of older people whatever the context. It would also be interesting to receive articles on "morbid" behavior and other syndromes occurring at the end-of-life.

Theme 3 – The good end of life and the good death

In 2004, *Gérontologie et société* produced a special issue on the "good death". In this issue, Geneviève Laroque quite rightly affirmed that in Western societies dying had become the problem of the aged. This is true in many ways. Statistically first of all, as the modal age of death is above 85. Of nearly 600,000 deaths every year in France 85% concern people over 60 and 50% those over 80 (Pennec *et al.,* 2014). The work of numerous authors (Thomas, 1975; Ariès, 1977; Elias 1985; Clavandier, 2009; Castra, 2015) shows how death and the dying have been kept apart from the living. Death has been institutionalized and medicalized to such an extent that only the death of the aged is deemed socially acceptable. Research on end-of-life trajectories of the oldest old (Pennec *et al.,* 2017) have shown that medical and residential trajectories are closely linked and that during the last months of life transfers to hospital are extremely frequent, including for older people already living in institutions.

Over and above the material dimension, this theme questions the representations and imaginings concerning the thanatic process which influence professional practice in end-of-life situations (Moulin, 2016). The question is also posed as to the way in which professionals, inmates, relatives and friends live with these repeated deaths. What procedures or rituals enable institutions to continue to be places for the living?

In this thematic section on the "good death", we hope to go beyond the traditional opposition between palliative care and "the right to die". Both ideologies are associated at once with the principal of medicalization of death and that of its demedicalisation, both claim that their approach will bring more dignity to the dying (Hintermeyer, 2016; Richard, 2011). These arguments invoke legal and medical justifications. Certain researchers (Cheynet de Beaupré, 2019) argue that that medicine, and to an even greater extent, law are often given too much power and even instrumentalized in the defense of a sort of "right to die" (Fournier, 2016; Ricot, 2017). We would like to further explore these ideas and practices with relation to old age.

Dying of old age has often been considered as an example of a "good death" because it was "natural", is this still the case today? Increased life expectancy raises the question of the quality of life in this time won over death. This increase in life expectancy at birth is largely due to the prolongation of life of the very old, do these extra years enable one to have a "good" end to one's life? What is there to say about lives that drag on (Guillemard, 2015)?

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[4] https://www.obsan.admin.ch/fr/indicateurs/suicide

[5] https://www.lemonde.fr/vous/article/2008/11/22/l-admd-milite-pour-une-nouvelle-liberte_1121894_3238.html

Research has shown that the oldest old when speaking of death (and in particular of their own death) do so in a manner similar to other age groups. Thus, there does not seem to be a specific age-linked attitude: older people hope for a rapid death without suffering, and unconscious (during sleep for example). The frequently express the fear of a difficult, painful, uncontrolled or disabling “passage”, during which they would experience arbitrary conditions and depend on medical help (Amar, 2014). What about these contemporary representations of the good death (Aries, 2005)[6]: how can it be articulated with traditional representations in which the dying person is conscious, prepared, and surrounded by friends and relatives? Feelings can be verbalized reflexively via a self-analytical personal narrative. In modern times, these criteria have found their expression in the credo of palliative care (Barrau, 1993; Higgins, 2003; Moulin, 2016).

In the context of the special issue, this question is asked with relation to older people: how do they die and envisage dying in the modern world. The objective of this third thematic section is to solicit analyses of the death of older people. How are these deaths categorized and dealt with?

In response to criticism, for several years now, retirement homes have been developing programs and actions destined to resolve problems such as that of the “death-disappearance” (CCNE, 2018). Propositions on this subject could involve exploratory research, studies and international comparisons on the way in which the death of older people is coped with socially in care-homes or the social inequalities of older people in the face of death (in terms of access to care, the quality of care and treatments at the end of their lives), with relation to other age-groups.

This theme also questions the choices open to older people at the end(-)of(-)life and questions the way in which they live that part of their lives and prepare their death. This includes, but is not limited to, the question of advance directives. How do older people prepare their own death? What limits, be they temporal, spatial, interpersonal, practical, etc., weigh on their choices? Who do they speak to or consult on this subject, and how is their discourse received? It is probable that people do not talk about death of their wish to die with their doctor, spouse/partner and children. According to Michel Castra (2015), a “good death” is one which is chosen, if the death is well prepared, this may also make it easier for friends, relatives and medical professionals to come to terms with it. In the context of an “individualization of practice”, preparing one’s death may involve the settling of administrative matters linked to death. Preparing one’s funeral, for example, may be a way of avoiding bothering one’s relatives, but also of affirming one’s personality and making sure one’s wishes are carried out after death (Veron, 2010). The preparation of one’s death may also involve implementing it, as in the case of active or passive suicide. What is the role of friends and relatives in accompanying this aspect of life-end? How do they react during the time following death?

To resume, this third theme will accommodate papers which question the way in which older people die and the medical, social and legal (etc.) norms which surround their death. We would be pleased to receive articles which study the places in which older people die, the practice and procedures which accompany those who die and those who remain, be they the medical staff or the families and relatives of those who have passed away. We will also be interested in older people as actors or subjects at the end of their lives and the moment of death.

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[6] This contemporary representation of the good death has in the past been the symbol of a bad or undesirable death (Bonnet-Carbonnel, 2005).

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Submission dates and procedures

Authors should send their completed proposal (8000 words maximum), in English or French, accompanied by a title and an abstract to the review for the 9th December 2019 at the latest.

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