

## REVIEW ARTICLE

# Attitudes towards death and end-of-life care

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**Summary**

End-of-life care represents a unique segment of palliative care. In the end-of-life period, the task of the involved healthcare professionals is to accompany patients during their last days, weeks or months of life to the moment of their death. The way people die has changed profoundly over the past 70 years. Health care is now the main context in which many people encounter death. The focus is on clinical interventions in the end-of-life period with the aim of defeating death, while a broader context and the significance of dying is neglected. Progressive medicalization of dying has inevitably led to changing attitudes towards death and dying in both general population and healthcare professionals. There is a struggle among healthcare professionals and individuals as well to accept the inevitability of death. There has been a growing interest in examining attitudes towards death and dying, in order to achieve a greater acceptance of death with repercussions on adequate planning and implementation of end-of-life care. A thorough understanding and estimation of attitudes to death and dying, both among general population and among health professionals, is required for the development of an effective strategy to promote end-of-life care. Due to the upcoming examination of attitudes to death and dying in Serbia, as well as exploring their influence on attitudes to end-of-life care, this paper presents the current knowledge in this area.

**Key words:** dying, death, end-of-life care

## INTRODUCTION

Comprehensive and available palliative care should be one of the key components of health care. According to the new, consensus-based definition of palliative care from 2020, it represents active, holistic care of individuals across all ages with serious health-related suffering due to severe illness, especially of those who are close to the end of life (1). The goal of palliative care is to alleviate suffering and improve the quality of life of patients, their families, and their caregivers (2). End-of-life care represents a unique segment of palliative care. In the end-of-life period, the task of doctors and other involved health care professionals is to accompany patients during the last days, weeks or months of their life to the moment of their death: during this common journey, their symptoms are treated, the family of the dying patient is supported, they are enabled, if possible, to stay and die in the place they chose, they are helped in their fears and preoccupations. Hence, high-quality palliative care is based on a close physical and emotional contact with dying patients and their relatives (3).

## DEATH AND DYING IN THE 21ST CENTURY

The way people die has changed profoundly over the past 70 years. Death comes later in life and the dying process is often significantly prolonged (4). Death and dying have been displaced from the family and community setting (where they used to take place relying on traditional knowledge and skills) to the health care system. Health care is now the main context in which many people encounter death. Futile and inappropriate treatment can continue into the final hours of life. Due to technological progress and its impact on medicine, especially in terms of mastering the possibilities of long-term life support, defining death has become complex and the technology that accompanies death has become even more sophisticated (5). Death and dying have become unbalanced in high-income countries and increasingly so in middle- and low-income countries - the focus is on clinical interventions in the end-of-life period with the aim of defeating death, while a broader context and the significance of dying is neglected (6). Therefore, especially in the context of acute health-care setting, death and dying are viewed as a clinical problem (the object of treatment/cure, although it is impossible to have a cure since the dying process is irreversible), reduced to a series of biomedical tests and markers with the application of various, often invasive and expensive, medical interventions (intubation, mechanical ventilation, artificial nutrition) that continue until the final hours of life with minimal attention to the patient's suffering (7). Recognition of dying is often made very late, if at all. This progressive medicalization of dying is not accompanied by adequate attention and treatment of

the very diverse symptoms of dying patients with relatively cheap, evidence-based methods within the framework of the palliative care system, i.e., end-of-life care – The World Health Organization estimates that globally only 14% of people in need can access such care (8).

## ATTITUDES TOWARDS DEATH

The progressive medicalization of dying arose on the wave of technological development, as well as the transfer of dying to hospitals and the health care system. “The experiment of making mortality a medical experience” is only a few decades old and has inevitably led to changing attitudes towards death and dying in both general population and healthcare professionals (7). The current prevalent attitude towards dying, especially in high-income countries (dying is not allowed, it is fought against!) is shaped through perceiving medicine as extremely powerful with the desire to defeat death, creating a delusion that we are able to control nature and not that we are part of it. There is a struggle within the health care system (and among individuals as well) to accept the inevitability of death. Dying is less and less present within families and communities. The roles of families and communities have receded as death and dying have become unfamiliar and skills, traditions, knowledge, and confidence in supporting death, dying, and grieving have been lost. Death has become invisible to the family (as it takes place in hospitals), and dependence of both families and patients on the health care system in the process of dying is increasing. The social and cultural contexts of dying essential to providing meaning, connection, and long-term support for those who grieve are at risk of disappearing. Health care cannot replace the sense of coherence, rituals, and traditions nor can it replace long-term mutual support that family and community provide to those who are dying and grieving (6).

## IMPACT ON END-OF-LIFE CARE

Death and dying have become unbalanced and contradictory in high-income countries – health care has a central role in the care of dying with often excessive and futile end-of-life care interventions associated with increased suffering and higher costs. On the other hand, this imbalance is even more striking in middle- and low-income countries, since the rich receive excessive care while the poor receive little attention or relief of suffering, often with no access to opioids (9). Hence, the disadvantaged and powerless suffer most from the imbalance in the care provided to those dying and grieving.

Acknowledging that the changed way of dying over the past 7 decades has also changed the attitude towards death and dying with significant repercussions on the

suffering of dying patients and palliative care at the end of life, the statement of the Lancet Commission on the Value of Death entitled “Bringing death back to life” published in January 2022, set 5 principles of realistic utopia – new visions of what death and dying could be like, i.e. how to rebalance death, dying and grieving (6). The five principles are: 1) the social determinants of death, dying, and grieving are tackled; 2) dying is understood to be a relational and spiritual process rather than simply a physiological event; 3) networks of care lead support for people dying, caring, and grieving; 4) conversations and stories about everyday death, dying, and grief become common; 5) death is recognized as having value. Therefore, death and dying must be recognized as not only normal, but valuable (6).

In recent years there has been a growing interest in examining attitudes towards death and dying, not only because of the attempt to rebalance death and dying and bring about a greater acceptance of death, but also in the context of adequate planning and implementation of end-of-life care (type of interventions, decisions on the type of treatment) which aims to respond to the suffering and problems of the dying. The knowledge of the basics of end-of-life care is often insufficient in countries with underdeveloped palliative care, and very often the contents of end-of-life care are not integrated into curricula.

In the available literature, the studies are oriented mainly towards the examination of attitudes towards death in health professionals and to a lesser extent in general population. One of the most frequently used questionnaires for assessing attitudes towards death is the Death Attitude Profile-Revised DAP-R (10). Death is still a taboo in traditional Serbian culture. Diagnosing an incurable disease (especially in the end-of-life period and when death is approaching) generally leads to hiding the truth from the patient, both by health professionals and family members. A similar cultural pattern is present in China, yet previous Chinese surveys have shown that more than half of the citizens want to be informed when faced with terminal illness, and 92,9% of advanced cancer patients hoped to be informed of their real condition by doctors and family members (11,12). A cross-sectional study conducted in China (published in 2019) examined the influence of death attitudes measured by the Chinese version of the Death Attitude Profile-Revised DAP-R-C and showed that attitudes towards death also influenced attitudes towards the end-of-life care. Namely, fear of death and death avoidance showed a negative correlation with attitudes towards the end-of-life care. That is, those healthcare professionals with a greater fear of death and the dying process, and those who avoided thinking about dying as much as possible, had a less positive attitude towards caring for dying individuals (13). Moreover, the same Chinese study found that although community healthcare providers had positive attitudes towards end-of-life care, they also agreed that most terminally ill

patients did not want to be informed of advanced disease and they were inclined to conceal the truth, reflecting the “denial of death” as a still prevalent mindset and attitude towards death (13). Previously conducted research also showed that the attitudes towards death of healthcare professionals, students and even patients can be changed through education about the dying process and have a positive effect in terms of reducing the fear of death and better care for dying patients (14,15). A study conducted in Jordan on a student population (nursing faculty) also showed a negative impact of fear of death and death avoidance measured by the same instrument on the care of dying patients (16). Similar results, where attitudes to death were also measured by the DAP-R questionnaire, were shown by a Singaporean study, demonstrating a positive effect of a two-day workshop on end-of-life care on changing attitudes towards death and caring for dying patients (17).

There is a clear need for developing end-of-life care in Serbia as one of the important part of palliative care. At the same time, attitudes to end-of-life care, death and dying in Serbia are unknown both among healthcare professionals and general population. The Serbian version of the Death Attitudes Profile Revised (DAP-RSp) Instrument is now available and should enable the assessment of attitudes towards death in healthcare professionals and in general population (18).

The DAP-R questionnaire was developed by Wong et al. with the aim of evaluating and measuring attitudes towards death and it includes 32 questions that form 5 dimensions. Each of the 5 dimensions measures particular types of attitudes towards death as a distinctive multidimensional theoretical construct: Fear of Death (negative thoughts and emotions related to death and the dying process), Death Avoidance (avoidance of thinking and speaking of death in order to diminish unpleasant feelings), Neutral Acceptance (acceptance of death as an integral part of life), Approach Acceptance (implies a belief in a happy afterlife), and Escape Acceptance (understanding death as an alternative to escaping current suffering) (10).

A relevant application of this questionnaire lies in its ability to assess different attitudes towards death and dying and provide a detailed understanding of how people react when faced with the dying process – for example during the care of terminally ill or dying patients, which is the case in the end-of-life care setting. Attitudes towards death characterized by acceptance are fundamentally adaptive and are associated with less anxiety and a greater meaning in life (10,19, 20, 21, 22, 23).

## CONCLUSION

In Serbia palliative care delivery has not yet fully emerged in medical practice. End-of-life care skills are

not sufficiently present among physicians dedicated to the treatment of terminally ill and dying patients. There is now ample evidence that attitudes towards death and dying can shape healthcare professionals' approach to end-of-life care. Non-affirmative attitudes towards death and dying (e.g., fear of death) can be significant obstacles in the development of the meaningful end-of-life care. A more profound understanding and estimation of attitudes to death and dying, both among general population

and healthcare professionals, should be a prerequisite for the development of an effective strategy to promote end-of-life care. Caring for the dying is a gift. Much of the value of death is no longer recognized in the modern world, but rediscovering this value can help care at the end of life and enhance living (6).

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## STAVOVI O SMRTI I ZBRINJAVANJE NA KRAJU ŽIVOTA

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### Sažetak

Zbrinjavanje na kraju života (*end-of-life care*) predstavlja poseban i jedinstven segment palijativnog zbrinjavanja. U periodu završetka života, visoko kvalitetno palijativno zbrinjavanje zasniva se na bliskom fizičkom i emocionalnom kontaktu sa onima koji umiru i njihovim porodicama. Način na koji ljudi umiru se radikalno promenio tokom poslednjih 70 godina. Smrt i umiranje izmešteni su iz okvira porodice i zajednice u zdravstveni sistem u okviru kojeg se primenjuje često uzaludno i neprimerno lečenje čak i u poslednjim satima života. Fokus je na kliničkim intervencijama na kraju života sa ciljem da se pobedi smrt, dok se širi kontekst i značaj umiranja zanemaruju. Ova progresivna medikalizacija umiranja dovela je do promene stavova prema smrti i umiranju kako u opštoj populaciji tako i kod zdravstvenih radnika. Čini se da je aktuelan stav prema umiranju (umiranje se ne dopušta, protiv njega se bori) oblikovan shvatanjem medi-

cine kao izuzetno moćne, sposobne da porazi smrt, stvarajući zabludu da smo u stanju da kontrolišemo prirodu, a ne da smo njen deo. Priča o umiranju u 21. veku postala je neizbalansirana i kontradiktorna. Raste interesovanje za ispitivanje stavova prema smrti i umiranju, kako bi se postiglo veće prihvatanje smrti, povratila izgubljena ravnoteža, a istovremeno omogućilo adekvatno planiranje zbrinjavanja na kraju života. Temeljno razumevanje i procena stavova o smrti i umiranju, kako među opštom populacijom tako i među zdravstvenim radnicima, potreban je preduslov za razvoj i planiranje efikasne strategije za promovisanje zbrinjavanja na kraju života. Zbog predstojećeg ispitivanja stavova o smrti i umiranju u Srbiji kao i istraživanja njihovog uticaja na stavove o zbrinjavanju na kraju života, u ovom radu prikazana su aktuelna saznanja u ovoj oblasti.

**Ključne reči:** smrt, umiranje, zbrinjavanje na kraju života

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