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**Suffering and Healing Relationships in End-of-life Care**

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## **Suffering and Healing Relationships in End-of-life Care**

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### **Abstract**

*The implementation of the Organic Law for the Regulation of Euthanasia (LORE) in Spain in March 2021 has brought a change in the culture and care at the end of life in our country. The decriminalization of euthanasia means that any person who "suffers from a serious and incurable disease or a severe, chronic, or incapacitating condition" can request assistance to die from a healthcare professional, according to the procedure and guarantees provided by LORE (cf. Ministry of Health, 2023).*

*Our research group has extensively studied the wish to hasten death (WTHD) as a clinical phenomenon, which has a prevalence of between 1% and 40% in people with advanced illnesses (cancer, neurodegenerative diseases, etc.) (Monforte-Royo et al. 2011; Rodríguez-Prat et al. 2024). These data show that, in this context, it is not uncommon for a wish to hasten death to emerge. The WTHD has been defined "as a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish [...] must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon" (Balaguer et al. 2016).*

*The wish to hasten death has also been defined as a complex, multifactorial phenomenon that, when expressed, can carry different meanings. On one hand, numerous authors have noted that the WTHD is related to many psychosocial and emotional factors such as depression, hopelessness, loss of control, loss of meaning in life, etc. (Rodríguez-Prat et al. 2024). On the other hand, when the WTHD has been explored from the perspective of patients who have expressed it, it has been shown that its expression cannot be unequivocally interpreted as a request for assistance to die but rather as an expression of a deeper thought, feeling, or experience pointing to a need that cannot be met now. In this sense, the meanings of the WTHD, as described in the literature, refer to what the person implicitly or explicitly expresses when manifesting WTHD: suffering, wanting to protect loved ones from this painful experience, desire to maintain autonomy, or feeling that one wants to live but not in*

this way (Monforte-Royo et al. 2011; Ohnsorge et al. 2019; Rodríguez-Prat et al. 2017).

The complexity and the different meanings and manifestations of this wish highlight that addressing the WTHD of patients at the end of life is a challenge for healthcare professionals. Conversations about death and the desire to die, even in the specialized field of Palliative Care, are often faced as a taboo, and professionals acknowledge lacking the tools or specific training to address these desires (Garner et al. 2011). This reality is related to the perception of the lack of clinicians' confidence to adequately manage the situation (Gerrit et al. 2021).

The suffering of patients, the verbalization of their fears, and the complexity of the advanced illness experience links to the suffering and uncertainty of the healthcare professionals themselves. This tension between the desires and expectations of both parties can generate new suffering for patients, families, and professionals. Regarding professionals, "the effect generated by experiences that violate one's own moral values and beliefs" has been defined as moral distress (Houle et al. 2024). Moral distress is a phenomenon that arises, in part, because healthcare professionals face situations where their moral conscience is affected or, in some way, challenged (Jameton, 1984; Corley, 2002; Fourie, 2017).

Every professional, in performing his/her caregiving role, remains a person with values, moral principles, experiences, beliefs, etc. (Bertran et al. 2021). These values often refer to important concerns for the person, such as freedom, justice, and dignity, or significant goals (happiness, peace, reconciliation, etc.). Different authors suggest that this limitation can be internal, due to a personal failure (such as fear or lack of determination), or external, i.e., due to something situational (hierarchical decision-making or lack of resources) (McCarthy & Deady, 2008).

Although moral distress has also been studied in different clinical contexts, there is little evidence of the impact of the WTHD—in terms of moral distress—on healthcare professionals (Austin et al. 2005; Førde & Aasland, 2008; Sporrang et al. 2006; Wiggleton et al. 2010).

As can be seen, a reductionist management of a critical situation like experiencing a WTHD, without sufficient means and practical recognition of the tension in the internal dimension of both the professional and the patient and their environment, can lead to unspoken and therefore unresolved conflicts among the ethical criteria of the various agents involved: the patient, their family, the professional, the care team, and the guidelines or procedures of the healthcare system.

In this study, we aim to explore which clinical factors can help to promote these meaningful relationships by analyzing the data of a recent training that we developed to help health professionals to better address WTHD in patients with advance illnesses. We also aim to build a philosophical and ethical framework to draw evidence of which attitudes and virtues can foster these meaningful relationships.

**Full Paper awaiting publication**

