

P R E S S R E L E A S E

International study analyses preferences for place of care and place of death of people with advanced diseases to help them be met

A research team, led by the University of Coimbra (UC), is conducting a series of studies with the aim of creating an international classification to record the preferred and real places of care and death of people with advanced diseases. The studies will be carried out in several countries, including Portugal, where, so far, there is no in-depth analysis of patient preferences and their implementation.

In order to fill this gap, the research team is conducting a study, interviewing patients, family members and other relevant people, to understand what the preferences are in Portugal and to what extent they are being met. With this work, the researchers aim to identify the main factors that influence choices, such as factors related to the disease, the environment in which people live or personal motivations. Above all, they want to identify whether or not people's preferences are fulfilled.

"This pioneering research in Portugal will allow a deeper understanding of choices at the end of life, contributing to understanding how individual preferences are fulfilled and how it is possible to improve the monitoring of patients and families", explains the project leader and coordinating researcher of the Faculty of Medicine of the UC (FMUC) and the Center for Innovation in Biomedicine and Biotechnology (CIBB), Bárbara Gomes.

The study is developed within the scope of the research project [*EOLinPLACE – Choice of where we die: a classification reform to discern diversity in individual end of life pathways*](#), led by Bárbara Gomes, funded with 1.8 million euros by the European Research Council. In Portugal, patients followed by palliative care teams (pediatric and adult) of the *Unidade Local de Saúde de Coimbra - Hospitais* and their relatives, who have already begun to be interviewed, are participating in this study. The study is being conducted simultaneously in three other countries: the United States of America, the Netherlands and Uganda.

"This survey will be crucial to fill gaps and improve palliative care strategies in line with the preferences of patients and their families", highlights Bárbara Gomes. The protocol on the development of the study is available in <https://doi.org/10.1177/26323524231222498>.

Recently, the *EOLinPLACE* team reviewed everything that is known so far in the world about preferences for places of end-of-life care and death. They identified 309 studies published in the last 50 years, conducted with more than 110,000 patients (adults and children) and more than 30,000 members of their families, in Europe, North America, Asia, Latin America, Africa and Oceania. The results are now published in *the Journal of Pain and Symptom Management* and are available at <https://doi.org/10.1016/j.jpainsymman.2024.01.014>.

In this study developed by the *EOLinPLACE* team, it was possible to identify "factors associated with a greater or lesser congruence between people's preferences and their actual place of death, and it was possible to realize, for example, that people with non-malignant diseases and low social status had less opportunity to see their preferences fulfilled or respected", highlights Sara Pinto, professor at the Nursing School of Porto, member of the *EOLinPLACE* team and first author of this review. "Accurately identifying these preferences represents a very important opportunity to change their lives in a positive way," she adds.

Home was the most preferred place by patients and also family caregivers. Hospitals and palliative care facilities were preferred places for substantial minorities. While little is known about whether preferences change as the disease progresses, this may happen for some patients and their families.

This review also reveals that people's choices were influenced by three main factors: the disease that affects them; individual motivations (such as dignity, autonomy, or a peaceful death); and environmental factors (such as family support network, comfort, or access to medication). "Patients and their families face several difficulties in end-of-life care at home. The reasons for this are worrying, with patients and families pointing out difficulties in accessing essential medicines, lack of equipment and support at critical moments, in addition to caregiver burden, explains Sara Pinto.

"Knowledge about people's preferences and how they are or are not respected is crucial and requires in-depth analysis so that more and better palliative care strategies can be implemented. Honoring people's preferences, regardless of their health condition and social or economic status, is a critical aspect of ensuring the provision of high-quality end-of-life care to all, reducing the suffering of patients and their families", explains Bárbara Gomes.

The researchers also underline that these studies aim to draw attention to the importance of "people with palliative care needs to think about and express their preferences, getting health professionals to discuss these with families, and, together, find ways to ensure that more people see their preference fulfilled".

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