

4th International Conference on

Palliative Care, Medicine and Hospice Nursing

August 27-28, 2018 | Boston, USA

Last word: Important information about human rights at the end of life

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Statement of the Problem: People in general are surprised as to what happens in a hospital setting and are overwhelmed when trying to understand and make decisions in regards to all that is offered by the physicians that are taking care of them or their loved ones, especially when living naturally is no longer an option. End-of-Life care decision making requires knowledge, not only on what medical sciences can offer, but also on hospital culture, the paradox of resuscitation and prolonging life artificially. The purpose of this study is to discuss the importance of allowing the population to learn ahead of time about what happens in a critical care setting through other people's experience.

Methodology & Theoretical Orientation: An interdisciplinary ethnographic study using explanatory dialogue was utilized during participant observation, through group discussions (family meetings) and individual interviews. A social ecological framework was utilized to focus on the interaction between physicians, participants and the staff to understand the context and timing of when information was received.

Findings: It is difficult for the general population who seek medical care to understand the concept of limited treatment. Healthcare providers and physicians are working towards this challenging task of making patients understand the need to refuse treatment as it may not benefit them, and in some cases, may cause harm.

Conclusion & Significance: Decisions about the end of life are more effective when based in knowledge and discussed ahead of time, without the possibility of imminent loss. Last Word is a book that gives the public the opportunity to know and understand life's cycle before making decisions. It also gives healthcare professionals the chance to reconnect to their human side, and let it flourish above science, skills and technology.

Biography

With over 40 years of experience, as well as working as bedside nurse in critical care, she has also acted in the administrative and educational fields of nursing in Brazil and in the United States. A specialist in palliative care, she founded and headed the End of Life program at INOVA Loudoun Hospital, VA, for nine years. She is an Author, speaker and consultant on topics regarding the end of life. ELNEC (End-of-Life Nursing Education Consortium) trainer and recipient of the ELNEC Excellence Award in 2012 for her commitment to deliver excellent palliative care to critical patients. Recipient of the INOVA Loudoun Hospital Innovation Nurse Award in 2013 for initiating that institution's end-of-life program

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