Loss of Dignity in End-of-Life Care in the Emergency Department: A Phenomenological Study with Health Professionals

Authors: José Granero-Molina, PhD, RN, María del Mar Díaz-Cortés, MSc, RN, José Manuel Hernández-Padilla, PhD, RN, María Paz García-Caro, PhD, RN, and Cayetano Fernández-Sola, PhD, RN, Almería, Spain, Temuco, Chile, London, United Kingdom, and Granada, Spain

Introduction: The objective of this study was to explore and describe the experiences of physicians and nurses with regard to loss of dignity in relation to end-of-life care in the emergency department.

Method: A phenomenological qualitative study was performed. Two focus groups and 12 individual interviews were conducted with a total of 26 participants, who had attended to patients in the emergency department an average of 14.3 years. An inductive analysis was carried out with the use of ATLAS.ti software to seek emerging themes.

Results: Three themes that helped us understand the phenomenon of the loss of dignity in end-of-life care in the emergency department emerged: (1) "Being exposed in a cold world," with the subthemes "improvising dying person care" and "a lack of space to care for the dying person"; (2) "Being self-critical with professional attitudes," with the subthemes "being aware of undignified actions" and "lack of a palliative culture"; and (3) "Family obstinacy and hospital rescue," with the subthemes "making ill-advised choices" and "avoiding burden."

Discussion: The dignity of people who are taken to the emergency department at the end of their life could be undermined by architectural and organizational characteristics, professionals' attitudes, and decisions made by family members.

Key words: Dignity; End-of-life care; Emergency department

Social evolution is changing humans' concept of recovery, life, and death. Although medical technology is able to prolong life,[1] the debate regarding quality of life continues.[2] The use of technology that is focused on preserving life, while seemingly disregarding its quality, may lead to a fear of death being replaced by a fear of dying.[3] Many patients who require palliative care often visit the emergency department for a variety of reasons.[4] Because the emergency department is designed to save lives[5] and focuses on the treatment of life-threatening diseases, caring for a dying patient in the emergency department may lead to problems related to stress, communication,[6] fear,[7] loneliness, lack of privacy, confidentiality, and dignity.[8] In clinical practice in the emergency department, patients, families and professionals may have to deal with palliative sedation,[9] limitations and futility of treatment, do-not-resuscitate orders,[10] and/or advanced directives.[11] All of these issues mean that the process of dying with dignity can be hampered in the emergency department.[12] Understanding the point of view of professionals may help us comprehend patients' reasons for going to the emergency department, better attend to their needs, and improve end-of-life care.[13]

Background

Although dignity is a vague and multifaceted concept that is difficult to measure,[14] it is altering the clinical relationship

José Granero-Molina is Senior Lecturer, Department of Nursing, Physiotherapy, and Medicine, University of Almería, Almería, Spain, and Research Associate, Health Sciences Faculty, Universidad Autónoma de Chile, Temuco, Chile.

María del Mar Díaz-Cortés is Nurse, Torrecárdenas Hospital, Almería, Spain.

José Manuel Hernández-Padilla is Lecturer in Clinical Skills, Adult, Child and Midwifery Department, School of Health and Education, Middlesex University, London, United Kingdom.

María Paz García-Caro is Senior Lecturer, Nursing Department, University of Granada, Granada, Spain.

Cayetano Fernández-Sola is Senior Lecturer, Department of Nursing, Physiotherapy, and Medicine, University of Almería, Almería, Spain, and Research Associate, Health Sciences Faculty, Universidad Autónoma de Chile, Temuco, Chile.

For correspondence, write: José Granero Molina, PhD, RN, Edificio Ciencias de la Salud, Universidad de Almería, 04120, Almería, Spain; E-mail: jgranero@ual.es.

J Emerg Nurs ■.
0099-1767

http://dx.doi.org/10.1016/j.jen.2015.10.020

and legal framework related to the care of dying patients.[15] Preserving a person's dignity implies not treating him/her as a simple medium, but as an end in himself/herself.[16] Every human being has dignity and the right to have his or her dignity maintained.[17] Dignity can reflect the individual's choices, values, ideals, and lifestyle and relates to having control and cognitive ability and feeling comfortable with oneself.[18] Respect, autonomy, empowerment, and communication also have been identified as being the defining attributes of dignity.[19] Furthermore, dignity is an attribute of a good death; dying with dignity is important for patients, their families, and health care providers.[18] Maintaining patient dignity has always been considered synonymous with nursing practice, but if nurses are to provide care that preserves dignity, they need to know the barriers to and facilitators of such care. The meaning of dying with dignity is ambiguous for areas such as the emergency department,[14] where culture change is a lengthy, difficult task that cannot be achieved through laws alone.[20] Because it is designed to save lives and not to provide supportive and palliative care, the emergency department is a difficult and challenging environment in which to die[5,21] and carry out end-of-life care.[22]

Our framework is Chochinov's Dignity Model.[23,24] This model defines 3 central categories that explain the phenomenon of dignity at the end of life: (1) problems related to the illness, (2) the Dignity Conserving Repertoire, and (3) the Social Dignity Inventory. This model has been adapted as a nursing model for dignity in illness[25] and in end-of-life care.[26] Both highlight the importance of the care-related and social-family environment in the loss and/or conservation of dignity. The model emerges from research involving terminally ill patients with cancer who were institutionalized in nursing homes. However, its authors recommended further research in different clinical areas to develop and improve the model.[23,24] The objective of this study was to explore and describe the experiences of physicians and nurses regarding the loss of a person's dignity in end-of-life care in the emergency department.

Methods

DESIGN

This qualitative study was based on Gadamer's hermeneutic phenomenology. According to Gadamer's philosophy, understanding is "being in the world," a process into which the interpreter incorporates his/her opinions, prejudices, and expectations. The hermeneutic circle implies a dialogue with another "you," in a fusion of horizons.[27]

SETTING AND PARTICIPANTS

The study was conducted in 2 hospitals in Almería, Spain: Torrecardenas Hospital (a public general specialized hospital) and La Inmaculada Hospital (a district public hospital). The emergency departments are divided into an observation-seating area, consultation room, and observation-beds area, and between these emergency departments, staff attend to an average of 220,000 emergencies a year. A total of 205 people working in the emergency department—98 nurses, 31 physicians, and 71 physicians in training—met the inclusion criteria: to be a physician or nurse with a minimum of 2 years of experience working in emergency departments and to give consent for participation. Experiencing a personal loss in the year prior to starting the study was an exclusion criterion, because the grieving process can lead to bias.

The participants were recruited through purposive sampling. The study included 26 participants, with a mean age of 38.12 (standard deviation [SD], 5.62) years and a mean of 14.3 (SD, 6.34) years of experience in attending to patients in the emergency department. No professionals refused to participate. When the information being collected was redundant or nothing new was offered, the researchers considered data saturation to have been reached and data collection was stopped.

DATA COLLECTION

Data collection took place between October 2013 and June 2014, through focus groups (FGs) and in-depth interviews. First, 2 FG interviews were conducted, one including 6 physicians (PFG) and another including 8 nurses (NFG), which lasted 45 and 57 minutes, respectively. Second, in-depth, face-to-face interviews were held with 4 emergency physicians and 8 emergency nurses who had not participated in the FGs. The participants were contacted by the lead researcher to arrange an appointment when they were not on call. The individual and FG interviews were conducted in an ED meeting room. Separate dates were arranged to conduct physician and nurse FGs and interviews. Each interview lasted between 60 and 90 minutes. All of the FGs and in-depth interviews were audio taped with participants' consent and started with the initial questions, "What does the term 'dignity' bring to mind for you in the emergency department?" and "What situations lead you to believe that your patients have lost their dignity?"

DATA ANALYSIS

In the analyses of the FGs and individual interviews, a modified form of the stages developed by Valerie Fleming[28] was used:

1. Decide if the research question is relevant in relation to the methodological assumptions.
2. Identify the researchers' pre-understanding of the object of study. The undertaking of this study led the researchers to a self-reflection process on the dignity of dying patients in the emergency department. The research-