

“The roller coaster ride of heart failure”: nursing staff’s perceptions of dignity

“A montanha-russa da insuficiência cardíaca”: a percepção de dignidade pelas equipes de enfermagem

“La montaña rusa de la insuficiencia cardíaca”: la percepción de dignidad por parte de los equipos de enfermería

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Abstract

Objective: The main aims of this study are to a) uncover the nurse’s perceptions of dignity based on their experiences; and b) identify ethical issues experienced by nurses when confronted with individuals with advanced heart failure.

Methods: This study has a qualitative design with an inductive approach using focus group (FG) interviews with registered nurses who meet patients with HF and their family caregivers on a daily basis. A total of 18 Portuguese registered nurses, from two hospitals and two primary health care centers, were distributed across 4 FG. Interviews occurred over a period of about 4 months. Data were analyzed using qualitative content analysis;

Results: The participants emphasized the importance of dignity as ‘being seen as a person’ and ‘respected for the person one is’. The ‘roller coaster ride of heart failure’ is like a pilgrimage that serves to maintain the patient’s dignity within the strictures of the sick person’s role. Addressing the physical, emotional and spiritual needs of patients promotes their dignity, while neglecting their needs threatens their dignity. Three main themes captured the range of ethical problems when nurses care for people with advanced heart failure: 1) Quality of life versus length of time left; 2) Curative versus palliative interventions; 3) Unpredictable and quick death versus expected and prolonged death.

Conclusion: Respecting and protecting dignity is an essential piece of good, ethical, and competent nursing care.

Resumo

Objetivo: Os principais objetivos deste estudo são: a) descobrir quais são as percepções dos profissionais de enfermagem quanto à dignidade baseado em suas experiências; e b) identificar as questões éticas enfrentadas por enfermeiros ao lidar com pacientes com insuficiência cardíaca avançada.

Métodos: Estudo qualitativo com abordagem indutiva por meio de entrevistas em grupo focal (GF) composto por enfermeiros que prestam assistência diária a pacientes com insuficiência cardíaca e seus familiares. O estudo incluiu 18 enfermeiros portugueses provenientes de dois hospitais e dois centros de atenção primária à saúde. Os participantes foram distribuídos em quatro grupos focais. Realizou-se as entrevistas durante período de aproximadamente quatro meses. Os dados foram analisados por meio de análise de conteúdo qualitativa.

Resultados: Ao enfatizar a importância da dignidade, os participantes a definiram como “ser visto como uma pessoa” e “ser respeitado pela pessoa que é”. A “viagem de montanha-russa da insuficiência cardíaca” é como uma jornada que ajuda a manter a dignidade do paciente dentro das restrições impostas pela doença. A

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abordagem das necessidades físicas, emocionais e espirituais dos pacientes propicia dignidade enquanto negligenciá-las os ameaçam. Três temas principais expressaram a variedade dos problemas éticos enfrentados pelos profissionais de enfermagem que cuidam de pacientes com insuficiência cardíaca avançada: 1) qualidade de vida *versus* tempo restante; 2) intervenções curativas *versus* paliativas; 3) morte rápida e imprevisível *versus* morte lenta e esperada.

Conclusão: O respeito e a proteção da dignidade são partes essenciais de uma assistência de enfermagem adequada, ética e competente.

Resumen

Objetivo: Los principales objetivos de este estudio son: a) descubrir cuáles son las percepciones de los profesionales de enfermería respecto a la dignidad con base en sus experiencias, y b) identificar las cuestiones éticas enfrentadas por enfermeros al lidiar con pacientes con insuficiencia cardíaca avanzada.

Métodos: Estudio cualitativo con enfoque inductivo por medio de entrevistas en grupo focal (GF) compuesto por enfermeros que prestan asistencia diaria a pacientes con insuficiencia cardíaca y sus familiares. El estudio incluyó 18 enfermeros portugueses provenientes de dos hospitales y dos centros de atención primaria de salud. Los participantes fueron distribuidos en cuatro grupos focales. Las entrevistas se realizaron durante un período de cuatro meses aproximadamente. Los datos fueron analizados por medio del análisis de contenido cualitativo.

Resultados: Al enfatizar la importancia de la dignidad, los participantes la definieron como “ser visto como una persona” y “ser respetado por la persona que es”. El “viaje de la montaña rusa de la insuficiencia cardíaca” es como una jornada que ayuda a mantener la dignidad del paciente dentro de las restricciones impuestas por la enfermedad. El enfoque de las necesidades físicas, emocionales y espirituales de los pacientes proporciona dignidad, mientras que desatenderlas los amenaza. Tres temas principales demostraron la variedad de los problemas éticos enfrentados por los profesionales de enfermería que cuidan pacientes con insuficiencia cardíaca avanzada: 1) calidad de vida vs. tiempo restante; 2) intervenciones curativas vs. paliativas; 3) muerte rápida e imprevisible vs. muerte lenta y esperada.

Conclusión: El respeto y la protección de la dignidad son partes esenciales de una atención de enfermería adecuada, ética y competente.

Introduction

Heart failure (HF) is a “global pandemic” affecting around “26 million people worldwide” and its prevalence is increasing.⁽¹⁾ Multimorbidity in HF is a emergent concern in older adults who may experience various symptoms of several conditions coupled with progressive vulnerability and frailty.⁽²⁾ HF is a complex disease that places severe strain on patients, families and care systems.⁽³⁾

The predictable demographic changes, particularly the marked aging of the population, imply this syndrome will likely affect a large number of Portuguese. Assuming the maintenance of current clinical practices, “the prevalence of HF in mainland Portugal will increase 30% by 2035 and 33% by 2060, compared to 2011”.⁽⁴⁾

Dignity is key towards ensuring the physical and mental health of this vulnerable patient group.^(5,6) HF patients may perceive their dignity as compromised if they feel neglected by healthcare staff or others, thereby, increasing their vulnerability and other difficulties.⁽⁷⁾ Strengthening patient dignity can enhance patient confidence and satisfaction with care, improve nursing care, decrease length of hospitalization, and ensure positive patient outcomes.^(8,9)

To illuminate the meaning and importance of dignity in the context of old age, Nordenfelt

and Edgar⁽¹⁰⁾ identified four concepts of dignity: a) dignity of merit (depends on social and formal position in life); b) dignity as moral stature (tied to self-respect, character and virtues); c) dignity of identity (tied to the integrity of the subject’s body and mind); and d) human dignity (*Menschenwürde* – pertains to all human beings). They also underlined dignity of identity as the key element of older adult dignity in the context of illness and ageing. This kind of dignity is not constant and can be easily altered (damaged or improved) in the context of care giving. Therefore, dignity of identity was the framework in this study.^(11,12)

Most studies have been carried out from the standpoint of patients and relatives, rather than healthcare professionals. Moreover, few studies⁽¹⁰⁻¹⁶⁾ have investigated the role of dignity in the experience of HF from the perspective of nurses who care for HF sufferers, and none were conducted in Portugal.

The current study forms part of a larger research project that aims to capture the meaning of living with advanced HF from the perspective of patients, nurses, and their family caregivers. Thus, the aims of this study are to a) uncover the nurse’s perceptions of dignity, based on their experiences; and b) identify some ethical issues experienced by nurses when confronted with people with advanced HF. A better under-

standing of what constitutes and affects dignity can contribute to a higher quality of nursing care provided to this specific group of people.

Methods

The study employed an inductive qualitative content analysis method and data were collected using FG interviews. Participants of interest for this study were registered nurses (RNs) working in both primary and secondary health care centers who presumably meet patients with HF and their family caregivers on a daily basis. The inclusion criteria were: a) at least six months experience as a RN; b) able to speak and understand the Portuguese language; and c) be interested to participate in the study. Between October 2015 and February 2016, four FGs were conducted, involving a total of eighteen RNs, using a convenience sample. Table 1 summarizes their sociodemographic data.

Table 1. Participants in FGs interviews divided by health care organization

Health care organization	Hospital	Primary health care centre
Number of FG interviews conducted	2	2
Number of participants (female/male)	7/1	8/2
Age in years, median (range)	38.22 (25-57)	
Years of professional experience, median (range)	15.66 (2-36)	
Years of work experience in present health care unit, median (range)	13.66 (2-28)	

Each FG had four to six participants. The first author conducted the FG interviews at the participants' workplace. The interviews were open-ended with a focus on their experiences of dignity in encounters with older patients having advanced HF. They sought answers to the following three questions: 1) what is the real meaning of dignity?; 2) what are some factors that improve or reduce dignity in the care of people with HF?; 3) what type of ethical issues do nurses experience when caring for these patients? FGs interviews ranged from 1 to 2 hours in length, were digitally recorded, and transcribed verbatim.

The transcribed material was introduced into the QSR NVivo10 software program for management purposes.⁽¹³⁾ Coding was aligned with pre-existing domains of dignity described previously.⁽¹⁴⁾ When necessary, content and codes were either collapsed or fit into pre-existing or different categories until central relationships began to emerge.⁽¹⁵⁾ Each pattern was analyzed for supporting quotation marks from the data.

To increase the trustworthiness, the data collection, analysis and presentation of the results have been a continuous process with discussions in the research group.

Institutional ethics approval was obtained prior to commencement of the study (P29-05/2015). Each participant was informed of nature of the research, was assured of confidentiality and anonymity, and gave informed consent.

Findings

In all FG interviews, there was a high-level of communication between nurses in the process of comparing and contrasting views, and constructing meaning about the interview topic. The results are presented in the three content areas acknowledged by a priori study: meanings of dignity in care; perceptions about factors that enhance and reduce dignity in care; and ethical issues raised by nurses when caring for older people with advanced HF. These content areas comprise underlying themes and categories with interview extracts (Chart 1).

Chart 1. Themes and categories in the qualitative content analysis

Content area 1. Meanings of dignity in care	
Remembering they're a person!	
Protecting people who can't protect themselves	
Content area 2. Perceptions about factors that enhance and reduce dignity in care	
Themes	Categories
Dignity defense	Caring qualities
	Meeting the physical, emotional and spiritual needs of patients
Dignity constrains	Environmental constrains
	Professional constrains
	Individual constrains
Content area 3. Ethical analysis of issues raised by RNs	
Quality of life versus length of time left	
Curative versus palliative interventions	
Unpredictable and quick death versus expected and prolonged death	

Meanings of dignity in care

The main theme that emerged from the data, ‘the roller coaster ride of heart failure’, centered on staff values and beliefs about the need to organize and control human vulnerability. ‘The roller coaster ride of heart failure’ is like a pilgrimage that serves to maintain patient dignity within the strictures of the sick person’s role. It is a means of encouraging social dignity and even patient optimism, which, in effect, should be respected and protected. The theme was supported by the following two categories.

1) Remembering they’re a person!

Nurses conceptualized the older person’s dignity as ‘being seen as a person’ and ‘respected for the person one is’.

“Dignity is the respect for the person, its basic to all individuals” (FG 1).

“Before anything else we have to be respected as a person, and then in our job” (FG 3).

Nurses saw themselves as an important source of help and described their job in terms of giving and receiving, including respect for each individual’s identity. Dignity and self-respect were reinforced when staff felt they had done something good for the person, even involving relatively small actions, and when they felt recognized and proud of their work.

Although staff were aware that each person is exclusive and has different needs, they expressed more or less explicitly that the organization was planned in a way that may jeopardize person-centered care, because older adults were at risk of being cared as a homogeneous group with similar needs.

2) Protecting people who can’t protect themselves

The experience of dignity was associated with patient experiences of self as an integrated and autonomous person, namely a sense of vulnerability to threats or losses to the self. Vulnerability is present throughout our lived experiences as human beings. Nonetheless, a deeper feeling of vulnerability can be seen as an existential attribute of being old and frail.

An individualized care was considered important to promote the older person’s identity during a phase of life characterized by loss and loneliness. Attentiveness to the various needs of older people was highlighted in the interviews.

In the FG interviews, nurses pointed out that “responsibility stretches beyond what human beings do and is something originally ethical, which becomes tangible when one sees the other’s face” (FG 2). Nurses described themselves as advocates of self-care, as responsible for helping and guiding the patient and their family caregiver in finding new ways to live as normally as possible.

Perceptions about factors that enhance and reduce dignity in care

1) Dignity defense

Nurses attending FGs were united in their views of *caring qualities* as factors that promote dignity in care of older adults with advanced HF. Nurses used terms that are synonymous with concept of dignity itself, such as respectability, humanity, empathy, making people feeling appreciated and allowing individual choices. Dignity in care was promoted by being non-judgmental, respecting people’s values, supporting their decision and autonomy, and preserving privacy. *Meeting the physical, emotional and spiritual needs of patients* promotes the dignity of heart patients. Physical safety was highly regarded by participants. Care must be taken to keep them safe and not impose mental or physical injury on them. Emotional security includes ensuring patient privacy patient, considering his/her autonomy. Participants also highlighted respect for religious duties and spiritual tranquility. They mentioned that fulfilling such needs are among the factors affecting patient dignity.

2) Dignity constrains

Environmental constrains centered on promotion of dignity in the hospital ward, rather than in community settings, perhaps reflecting an underlying perception of the hospital as a public

place in contrast to the individual's private space at home, where much of the work of family and community nurses takes place. *Professional constraints* pointed to changes in nursing roles and work that nurses considered uncondusive to promoting dignity in care.

Time limits were seen as generated by understaffing, causing a tension between a quick versus individualized care, as time allocation per patient is reduced.

Low nurse-patient ratios and lack of knowledge were associated with unsatisfactory care. Untrained nurses and younger staff has been associated with a absence of humane treatment that threatens the older people integrity.

Stereotypes included judgments, intolerance and ageism as a particular type of discrimination.

Individual constraints focused on the specific individual attitudes, including lack of respect and communication skills, and certain emotions, promoted by work overload and emotional exhaustion, that hinder dignity in care.

Ethical issues raised by nurses

Deciding whether to stop a life-prolonging treatment was a frequently reported source of conflict. Three overarching themes captured the range of ethical problems when nurses care for older people with advanced HF.

1) Quality of life versus length of time left – “Adequate management of symptoms in the end stages of HF is one of the major concerns of patients and their families. Assertive communication about the impact of treatment on quality of life is of particular importance given that patient preference for either quality of life or length of life can influence patient treatment decision making” FG 2. However, as a HF patient ages and no greater survival benefit can accrue with the addition of new medication and devices, interventions that only treat symptoms will become increasingly important in treatment.

2) Curative versus palliative interventions - In addition to medication, a horde of technical

approaches can aid the HF patient. “Bypass surgery, angioplasty and stent placement can alleviate blockages, but in many cases cannot reverse HF” FG 3.

The current generation of implantable heart assist devices carries a substantial risk of complications, including debilitating strokes and overwhelming infections. Furthermore, invasive technological interventions are often painful. All patients for whom an invasive procedure is indicated must decide how aggressive they wish to be in treating their disease. In most medical practice, “palliative care” means forgoing intensive and invasive interventions that prolong life at the expense of quality of life, but implantable heart assist devices that both improve symptoms and survival for end-stage patients may not fit into this paradigm.

3) Unpredictable and quick death versus expected and prolonged death – “Many of HF patients die not from progressive heart pumping dysfunction, but rather from sudden death secondary to arrhythmias, most of which can be prevented by timely electrical shocks” (FG 4). However, the prevention of sudden cardiac death may not always serve the patient's best interests. In the words of one nurse commenting on life-saving therapies in ischemic heart disease: “we save people from a sudden death only to impose on them a more prolonged death from progressive HF” (FG 1). The same is true concerning Implantable Cardioverter Defibrillators (ICDs). The HF patient contemplating ICD insertion essentially faces a choice of an unpredictable but relatively asymptomatic sudden death or a progressive worsening of symptoms and eventual demise. Furthermore, there is the issue of whether turning off an ICD is ethically permissible, even though a patient has chosen a ‘do not resuscitate’ order. Resuscitative efforts may be inappropriate if subsequently the goals of patient care are unachievable. In some instances, resuscitation may not be the best use of limited medical resources.

Discussion

Nurses in our study regularly connected the practice of preserving dignity with listening to individuals and linking them in decision-making, thereby highlighting a person-centered care. Nevertheless, this study indicates the relevance of participation, as well as how dignity in vulnerability might be protected.

Nurses often believed that dignity was upheld in the relationship with people in their care, through their actions and advocacy on behalf of patients.⁽¹⁶⁾ Our study confirms previous findings of Edlung et al.⁽¹⁷⁾ that highlighted the two different, but connected, views of dignity. One view describing dignity as absolute, constant, and inherent to all human beings, including values such as freedom and responsibility. The other view considering dignity as ethical ideal, which is relative and changeable, with an inner and external side experienced in relation to someone or something. “The changeable inner dignity implies an experienced feeling of dignity with its roots in the source of values that are affected by culture and society”.⁽¹⁷⁾

Undervaluing people may be understood as violating their dignity, for they are not treated as equal human beings. Relational autonomy makes it possible to relate with individuals with advanced HF as equal human beings, despite their frailties. As Eriksson⁽¹⁸⁾ stated, being there for patients and taking responsibility for them is an expression of caring ethics. Nurses’ experiences of ethical problems in care are often described in terms of external responsibility*. However, nurses also exhibit internal responsibility** when they are committed and willing to assist both the patient and relatives in their suffering and decision-making.

Given the irreversible and unpredictable nature of the disease and the high burden of physical symptoms, and psychosocial and spiritual

distress, patients with advanced HF “are encouraged to document their preference for invasive life-sustaining interventions, such as mechanical ventilation and cardioversion, through advance directives or advance care plans”.⁽¹⁹⁾ Findings suggest that to enable patients with advanced HF to make informed treatment choices about their future, patients and healthcare providers should be, respectively, encouraged and educated to be more proactive in discussing clearly the intent of a patient’s current treatment.

Discussion with patient and relatives about forgoing or withdrawing from medical treatment or about Cardiopulmonary Resuscitation (CPR) in end stages HF, as suggested in the current HF guidelines, is one of the most difficult topics for nurses.^(19,20) However, it is essential that nurses initiate the discussion when starting end of life care and continue the discussion during the rest of the patient’s life. Likewise, nurses should discuss these moral difficulties within their team.⁽²⁰⁾ Further research could explore what ethical issues care-providers deal with most frequently and develop recommendations for improved communication on moral issues, which may increase the feeling of professional security and confidence in ethical issues.

Healthcare facilities have the mission to improve professional interactions in order to ameliorate the ethical climate and foster better health outcomes for patients. The organizational environments included in our study —with their low staffing levels, time constraints and work overload — did not promote respect for dignity. In this light, it is important to promote actions by care staff that honor and support patient dignity, resulting in benefits to patients.⁽²¹⁾ During undergraduate education, nursing students should be taught factors and strategies that meet patient expectations of how they would like their dignity to be maintained. This will help develop dignified nursing practices.

The main limitations of this study are related to sampling. Participants were recruited from

* External responsibility “means that one has a moral obligation to do one’s duty in accordance with laws and ethical norms”.⁽¹⁸⁾

** Internal responsibilities “may be perceived as being of a deeply personal nature (virtue) that motivate one to act ethically”.⁽¹⁸⁾

only two primary and two secondary health care centers and reflected the experience within a limited region of Portugal (central region). Another limitation of this study was that the concept of dignity was based exclusively on subjective views of participants and not on the observed practice of staff. It is possible that application of other research approaches would reveal more information about the concept of dignity in this population. Moreover, this study was performed in Portugal, and strategies to preserve and promote patient dignity may differ for individuals from other cultures.⁽²²⁾

Conclusion

This study revealed a more broad understanding of preserving dignity in daily life from the perspective of RNs who care for older people with advanced HF. “This knowledge emphasizes the potential of a dignity-oriented approach to the care of older people” and could help nurses and other health care providers to comprehend the upholding of dignity from a patient’s perspective.

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Collaborations

Sampaio C, Renaud I, Leão PP contributed with the project design, article writing, critical review of intellectual content, data analysis and interpretation and final approval of the version to be published.

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