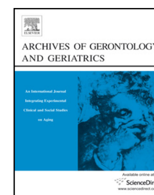
Archives of Gerontology and Geriatrics 70 (2017) 19–27

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger



Dignity and autonomy in the care for patients with dementia: Differences among formal caretakers of varied cultural backgrounds and their meaning

Miriam Ethel Bentwich[a,*], Nomy Dickman[a], Amitai Oberman[a,b]

[a] Faculty of Medicine, Bar-Ilan Unversity, Israel
[b] Department of Geriatric Rehabilitation, Padeh Medical Center, Poriya, Israel

ARTICLE INFO

Article history:
Received 30 October 2015
Received in revised form 30 November 2016
Accepted 5 December 2016
Available online 8 December 2016

Keywords:
Human dignity
Patients with dementia
Formal caretakers
Autonomy
Multicultural perceptions
Quantitative research

ABSTRACT

Background: A key message in the World Health Organization report on dementia (2012) emphasizes this disease as a top priority in public health and the need to improve professional attitudes to patients with dementia, while acknowledging that the workforce in dementia care is becoming increasingly diverse culturally.
Aims: To trace whether there are substantial gaps between formal caretakers from different cultural groups (Israeli born Jews [Sabras], Israeli Arabs [Arabs] and migrants from Russia [Russians]) regarding their stances on the human dignity and autonomy of patients with dementia, as well as understand the meaning of these gaps.
Design & method: quantitative analysis utilizing questionnaires that were filled-out by approximately 200 caretakers from the different cultural groups, working in a nursing home or a hospital.
Results: In nursing homes, substantial differences were found in the attitudes to human dignity and autonomy of patients with dementia between Russian and Arab as well as Sabra caretakers. In the hospital, there was no influence for the ethno-culture variable on dignity or autonomy.
Conclusion: Contrary to past research, in nursing homes, significant differences were found between certain ethno-cultural groups (Arabs and Russians) regarding their stance towards the dignity of patients with dementia. Arab caretakers hold a conception of dignity and autonomy that resonates strongly with person-centered care and outweighs institutional settings as well as may be related to the fostering of virtues.

© 2016 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

Dementia involves the gradual deterioration of cognitive, mental and physical capabilities of an individual, so that as this disease progresses, the individual's ability to comprehend her situation, make intelligible choices and execute them independently decreases. Hence, the individual's capability for autonomy is gradually deteriorating (Burgess, Page, & Hardman, 2003; Leino-Kilpi et al., 2003; Leino-Kilpi, 2000). Additionally, the gold-standard in treating patients with dementia is a "person-centered care" (Edvardsson, Winblad, & Sandman, 2008). This approach for care involves shifting the focus from the task to the person and from the objective and medicalized interests of medicine and nursing professions to the subjective perspective of the person suffering from the disease. Person-centered care, then, also echoes the importance of preserving and respecting the human dignity of persons with dementia. Moreover, behaviors associated with this illness include wandering, agitation, aggression as well as resistance to care (Burgess et al., 2003; Kada, Nygaard, Mukesh, & Geitung, 2009). Therefore, as patients' dependency increases, their care becomes more complex, and further highlights the importance and challenge of preserving and respecting their human dignity and autonomy that is often seen as part of dignity.

When referring to the concept of human dignity, there are numerous philosophical sources offering conceptualization of this term from different philosophical perspectives, and discussing each one of them is naturally beyond the scope of the current article. Nonetheless, we would like to cite two important theoretical perspectives regarding human dignity for two reasons. First, despite their different origin, they may be understood as echoing each other insofar as the depicted types of human dignity

* Corresponding author.
E-mail addresses: Miriam.Bentwich@biu.ac.il (M.E. Bentwich), nomyd@hotmail.com (N. Dickman), AOberman@poria.health.gov.il (A. Oberman).

http://dx.doi.org/10.1016/j.archger.2016.12.003
0167-4943/© 2016 Elsevier Ireland Ltd. All rights reserved.

are concerned. Therefore, by echoing the typology of each other, these two distinct typologies affirm the validity of the different types of dignities they refer to. Second, and as will be further developed in the discussion section, these two theoretical frameworks for understanding human dignity may assist in better understanding the meanings of our study's findings. One source is Lennart Nordenfelt's influential contemporary typology of human dignity which has greatly contributed to contemporary discussions of dignity, particularly in the context of older people's care (Nordenfelt & Edgar, 2005; Nordenfelt, 2003, 2004, 2009; Zisberg, Topaz, & Band-Wintershtein, 2014). The other source is Daniel Sulmasy's intriguing typology about human dignity, based on an historical perspective and an emphasis on the virtue ethics school of thought (Sulmasy, 2008).

Thus, Nordenfelt's account of human dignity has illuminated one possible theoretical explanation for the importance of dignity (and autonomy) in ensuring high quality of older persons care. According to Nordenfelt's typology, one may distinguish between four types of dignity: (a) the dignity of merit; (b) the dignity of moral stature; (c) the dignity of identity; and (d) universal human dignity (in German: Menschenwürde). While the latter type of dignity necessarily pertains to all humans, and cannot be lost since it is a fundamental component of being human, the other types of dignity are subjective and dependent upon external influences. Among these latter three types of dignity, it is the "dignity of identity" that is particularly important in the context of illness and aging according to Nordenfelt. That is, this type of dignity refers to "the dignity that we attach to ourselves as integrated . . . persons . . . with a history . . . and with a future," (Nordenfelt, 2004) and it is specifically significant in the context of aging since this type of dignity *can* be diminished by the acts of others, by external events and particularly by *injury, illness and old age*. Furthermore, according to Nordenfelt, humiliation, in particular, diminishes the dignity of identity, and older persons who are in a situation of dependence when requiring health and social care are particularly vulnerable to loss of dignity (and autonomy embedded in it) through humiliation via acts of social exclusion, as well as physical and psychological abuse or neglect.

Sulmasy's typology of human dignity refers to three types of dignity: (a) attributed dignity; (b) intrinsic dignity; and (c) inflorescent dignity. Intrinsic dignity, which Sulmasy associates with Kant's conception of the term, is parallel to Nordenfelt's universal human dignity, namely the dignity that pertains and belongs to all human beings by virtue of their humanity. Attributed dignity, on the other hand and somewhat resembling Nordenfelt's 'dignity of identity' relates to the "worth or value that human beings *confer upon others* by acts of attribution." Finally, inflorescent dignity, having its roots in the Roman Stoics writings of Cicero and Seneca, refers to the respect granted to people since these people are taken to be flourishing as human beings. That is, they express a degree of excellence or merit that is acknowledged by others as being consistent with and expressive of the intrinsic dignity (Sulmasy, 2008). Therefore, inflorescent dignity can be understood as emphasizing the importance of *virtues* in the materialization of human dignity, a point on which we shall elaborate in the 'Discussion' section. At the same time, this concept of dignity seems to be a combination of two distinct dignity types according to Nordenfelt: "dignity of merit" and "dignity of moral stature."

However, these accounts of human dignity are based on a Western perspective, as Sulmasy emphasizes in his typology. In contrast, with the increased aging of the population in Western-developed countries, the phenomenon of multicultural caretakers working with the older population is increasingly prevalent (Cohen-Mansfield, Garms-Homolová, & Bentwich, 2013; O'Shea & Walsh, 2010). That is, the formal caretakers, who are in charge of caring for the older population in need, do not necessarily share the same Western cultural creed forming the basis for the aforementioned typologies of human dignity. A culture contains sets of values, beliefs, and habits learned during socialization, which shape the worlds of ideas, perception, decisions, and how individuals act. Each caretaker has her own set of cultural values, which is brought into the caring interaction with the patient (Doswell & Erlen, 1998; Rassin, 2008). That is, some activities reflect unique values and traditions that are rooted in caretakers' original culture, Therefore, such values and traditions may influence the caretaker's depiction of human dignity.

Admittedly, some previous studies that focused solely on the conceptualization of autonomy in the context of care for older people (including with respect to persons with dementia) also referred to differences in the comprehension of autonomy among caretakers from different cultures and countries (Davidson et al., 1990; Iecovich & Rabin, 2013; Leino-Kilpi et al., 2003; Mattiasson, Andersson, Mullins, & Moody, 1997; Mullins & Hartley, 2002; Mullins, Moody, Colquitt, Mattiasson, & Andersson, 1998; Scott et al., 2003a). For example, in a pivotal quantitative study conducted in five European countries (Finland, Spain, Greece, Germany and the UK) a number of significant cross-country differences were found, relating to the provision of information, opportunities for decision making and privacy of patients. Another study conducted in the U.S. among nursing staff within nursing homes in Florida found that the race of the staff member (white/non-white) had a pronounced effect on support for various aspects of the patient's autonomy (Mullins & Hartley, 2002; Mullins et al., 1998).

Other studies focused on the perceptions of human dignity by caretakers of older persons in an institutional setting, mainly in Scandinavian countries and the U.K. (Baillie, Ford, Gallagher, & Wainwright, 2009; Dwyer, Andershed, Nordenfelt, & Ternestedt, 2009; Hall & Høy, 2012; Hall, Dodd, & Higginson, 2014; Tranvåg, Petersen, & Nåden, 2013). Most of these studies included reference to the autonomy of older person as part of human dignity, yet these studies were mainly qualitative and less focused on exploring the possible different cultural, racial or national influences on the conceptualization of human dignity. In fact, a pivotal study, conducted in six European countries and focused on the realm of human dignity as it is perceived by professional caretakers of older patients, emphasized their common comprehension of it, rather than exploring possible differences among the caretakers from the different countries or cultures (Tadd, Vanlaere, & Gastmans, 2010; Woolhead et al., 2006)

Some qualitative studies have also focused specifically on the perceptions of human dignity held by formal caretakers with respect to older persons with dementia (Kada et al., 2009; Moyle, Murfield, Griffiths, & Venturato, 2011; Travers, Beattie, Martin-Khan, & Fielding, 2013). However, once again, the main interest of such studies, even when relating to the cultural context of the persons involved, was less about pinpointing the differences in cultural perspectives regarding the human dignity of demented people.

Existing literature regarding the perceptions of formal caretakers about the autonomy and human dignity of their older patients (including those with dementia), then, is lacking in two points. First, insofar as studies that are focused on perceptions of human dignity are concerned, they fail to examine possible differences between caretakers from varied cultural background. Additionally, many of these studies are qualitative rather than quantitative, thereby limited in the ability to produce statistically valid results that may be generalized to the whole relevant population. Second, studies focusing on perceptions of autonomy are detached from the larger context of human dignity, and therefore, even when such studies account for cultural differences,

متن کامل مقاله ← دریافت فوری

ISIArticles
مرجع مقالات تخصصی ایران

- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان دانلود رایگان ۲ صفحه اول هر مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات