



# Making sense of a changed physical body: Why gender matters at end of life



Ana Patrícia Hilário

Center for Research and Studies in Sociology, University Institute of Lisbon, CIES-IUL, Portugal

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## ABSTRACT

The bodily experience of patients near end of life has been presented within sociological literature as largely undifferentiated. The attempt of this paper is to overcome this gap by exploring how gender intersects with the loss of bodily autonomy experienced by hospice patients. The study was conducted in two in-patient hospice units located near Lisbon, the capital of Portugal. A total of ten terminally ill patients were interviewed, along with twenty family members and twenty members of hospice staff. For the men in this study loss of bodily autonomy was a very dramatic experience as it contravened masculine norms. The women's reactions towards their loss of autonomy were less negative compared to those of men and they made a considerable effort to integrate the best as they could their physical condition. This reflected feminine traits. Findings suggested that the loss of bodily autonomy is gendered in the sense that men and women experience it in dissimilar ways.

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## Introduction

While studies within sociology have been very successful in demonstrating gender differences in terms of how men and women experience their ageing (e.g., Canham, 2009; Smith et al., 2007) and chronically ill bodies (e.g., Chapple & Ziebland, 2002; Crouch & McKenzie, 2000), they have not given sufficient attention to the embodied character of gender at end of life. There has been found that men's discourse on how to handle the physical realities of later life tends to reflect masculine norms, namely the need for strength, action and autonomy (Hurd Clarke & Griffin, 2008a). Women, in contrast, tend to demonstrate concern about the ways in which their ill bodies might affect their loved ones (Hurd Clarke & Griffin, 2008a). This has been found to be related to expected feminine qualities that privileged selflessness, nurturing and sensitivity to others. In a similar way, older women's use of self-care has been found to be driven by the desire to reduce the burden placed on loved ones and thus it seemed to be in accord with such feminine ideals. Whereas the achievement of masculine ideals of control and invulnerability has been noted to be at the heart of the

experience of self-care by older men who had multiple chronic conditions (Hurd Clarke & Bennett, 2013b).

As the experience of illness in later life has been found to be profoundly gendered and influenced by masculine and feminine norms the suggestion of a potential 'degenderisation' of patients who are very ill and near the end of life is surprising (Lawton, 2000). A more nuanced conception of the process of bodily deterioration and decay prior impending potential death is needed. While men and women who are dying might encounter similar bodily problems, their reactions towards their loss of bodily autonomy could be highly differentiated due to masculine and feminine norms and further research is needed to explore this matter. The gender dimension might be particularly relevant for the experience of dying and its bodily realities in Portugal as it has been a country profoundly marked by a traditional conception of what it is to be a man or a woman (Andreotti et al., 2001; Lopes, 2006; Moreno, 2006; Wall, Aboim, Cunha, & Vasconcelos, 2001). The questions: 'In what ways does the loss of bodily autonomy affect the sense of self and identity of Portuguese terminally ill patients? Does it differ by gender?' guided the research. The purpose is to explore how the

experience of loss of bodily autonomy at end of life is gendered and influenced by masculine and feminine norms and thereby to offer insights on the embodied character of gender at end of life.

## Background

Theorizing in the field of death and dying has been dominated in the last decades by the sequestration debate – which argues that death has been sequestered from the public domain. This debate has been at the heart of Lawton's (2000) study, where it is said that dying people are sequestered within hospices as a result of the modern Western intolerance of bodily deterioration and decay. The hospice 'served to impose order upon disorder through enclosing and containing the odours emitted from patients' disintegrating bodies within a bounded space' (Lawton, 1998: 134). The body's ultimate vulnerability is revealed and this is what makes the sequestration of dying so necessary (Ellis, 2010). Hospice patients tend to lose their capacity to maintain control over their physical boundaries and, at one and the same time, the ability to act according to their own wishes and intentions – i.e., their bodily autonomy (Lawton, 2000). This has been found by Lawton (2000) to have a debasing impact on hospice patients' sense of self and identity.

Lawton (2000) presented the experience of loss of bodily autonomy as largely undifferentiated. Lawton suggested a potential 'degenderisation' of hospice patients. She argued that along with the process of bodily deterioration and decay patients lose the capacity to do gender. The fact that hospice patients had lost body parts related with sexuality and sexual performance due to cancer treatments had according to Lawton led to a disinvestment in their masculinity and femininity. Lawton's thesis implies that all hospice patients had gone under a surgical procedure or another type of treatment which had led to a loss of their sexual functioning. She argued that 'to lose one's sex is to lose both gender and sexuality simultaneously, for the one implies the other inexorably' (Lawton, 2000: 168).

Lawton appears to draw upon a binary conception of gender in which gender is either lost or maintained and had overstated the centrality of sexuality in the performativity of gender at end of life (Broom & Cavenagh, 2010: 870). While men and women who are very ill and at the end of life might encounter similar problems, their reactions could be highly differentiated due to masculine and feminine norms. The first attempt to counter the paucity of research on masculinities and dying was made by Broom and Cavenagh (2010). These authors argued that there is an incompatibility between the 'slow death' and male identity. They found that the ability to maintain the masculine status within the dying process is central for men's willingness to perform the 'good fight' against death.

The model of 'dying well' advocated by the proponents of the modern hospice and palliative care movement (Clark & Seymour, 1999) is challenged by the Western hegemonic masculine script (Broom & Cavenagh, 2010) which constructs men as independent, tough and physically competent individuals (Bennett, 2007; Canham, 2009; Smith et al., 2007). This model draws upon a singular idea of what constitutes a 'good death' – 'a pain free death; a death at home; death as personal growth; death according to personal experience; an aware

death; and open acknowledgment of the imminence of death;' (Clark, 2002: 907) – and thereby does not take into account how patient's biographies may shape and constrain experiences of 'dying well' (Broom & Cavenagh, 2010; Gott et al., 2008).

When experiencing prolonged death and growing physical deterioration men might be more concerned in being in control of their bodies and minds, while for women the need to reduce the burden their condition place on others might be a central concern (Arber, Vandrevalla, Daly, & Hampson, 2008; Hurd Clarke, Korotchenko, & Bundon, 2012) due to markers of femininity that privileged selflessness, caregiving for others and family orientation (Cameron & Bernardes, 1998; Prentice & Carranza, 2002). These feminine traits have been found to be at the heart of the reasons why women are more likely to care for their elderly/dying relatives than men (Twigg, 2000; Widding Isaksen, 2002). Nevertheless, women might find to be more difficult to care for the men in their lives as intimate caregiving appears to threaten their sense of masculinity and to challenge traditional notions of gender relations wherein man occupies a dominant position (Calasanti, 2006; Calasanti & King, 2007).

## Methods

Fieldwork was carried out in two in-patient hospice units for cancer and non-cancer patients located near Lisbon, the capital of Portugal. Interviews were conducted with 10 (5 women and 5 men) terminally ill patients. All the patients who accepted to be interviewed suffered from cancer. Those who were mentally confused, unable to express themselves or were too unwell to permit data collection did not take part in the study. The patients have been in the in-patient hospice for more than 48 h and their condition was stable albeit some suffered from major pain. The patients were aged between 45 and 80 years-old. Seven patients were currently married, one was divorced, one was widowed and one single (never married). All patients – except two – had children. Interviews were conducted with 20 family members aged between 41 and 78 years-old. Wives were found to be the most significant person to the patient, followed by daughters and husbands. The accounts of hospice staff members provided a basis for triangulation and therefore 20 members were interviewed. Most were women and aged between 23 and 64 years-old.

The aims, harms and benefits of the study were explained to participants and written consent for interviews was obtained. Participation was voluntary and participants were informed that they could withdraw at any time without consequences. The rights of anonymity, confidentiality and privacy of participants were respected. Interviews with patients were conducted at their bedside, while interviews with family members and hospice staff were conducted in a private area of the unit, for between 40 and 90 min. No joint interviews were made. Interviews with patients were on average shorter than interviews with family members and hospice staff. This was because of patients' debilitating and deteriorating condition. The interviews were semi-structured and included questions such as: How did you react to the loss of bodily continence? What do you feel about using diapers? How did you react to the loss of ability to walk? What do you feel about the need of others help? Albeit a topic guide was followed, the

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