



Masculinity, moralities and being cared for: An exploration of experiences of living and dying in a hospice

Alex Broom^{a,*}, John Cavenagh^b

^a University of Sydney, Faculty of Health Sciences, Sydney, Australia

^b Newcastle Mater Misericordiae Hospital, Australia

ARTICLE INFO

Article history:

Available online 4 June 2010

Keywords:

Australia
Masculinity
Hospice
Moral practice
Palliative care
Identity
Death
Dying

ABSTRACT

Hospices are playing an increasingly important role in end of life care in Australia and internationally and the in-patient hospice experience has not been well documented by social scientists. This paper explores some important facets of the contemporary hospice experience through an examination of the perspectives of 11 male and 9 female Australian in-patients in the last few weeks of their lives. Through a series of qualitative in-depth interviews, we explore their conceptions of death and dying and their experiences of being cared for. The results illustrate a range of important themes including: tensions around what constitutes 'the good death'; dying and caring as moral practice; and, the centrality of gender identity and relations in shaping experiences of dying *and* caring. We argue for a sociological approach to death and dying that better elucidates the interplay of identity, morality and relationality at the end of life.

© 2010 Elsevier Ltd. All rights reserved.

Introduction

The hospice¹ is an increasingly important site for end of life care in Australia and internationally (Clark, 2007), yet the in-patient experience has received relatively little attention from sociologists. Practical, ethical and emotional difficulties have often limited sociological research on the hospice experience, with difficulties faced in gaining access to hospice sites, recruiting participants, interviewing and even justifying the effort of participation (Kendall et al., 2007). As a result, despite several key sociological studies over the last few decades (e.g. Glaser & Strauss, 1968; Kellehear, 1990; Lawton, 2000), there has been a paucity of research on patient experiences of end of life care, and particularly in-patient hospice care. As such, there is a real need for developing a better sociological understanding of this critical and expanding area of care, particularly given the fact that hospice care has evolved significantly in structure and ideology in recent years (James & Field, 1992). Furthermore, how the in-patient hospice experience varies within different sub-groups of the population (e.g. according to gender, ethnicity and class) has received little attention from

sociologists. Given the under-researched character of hospice care and its complex institutional, professional and cultural evolution, we developed the current study to explore some important facets of the contemporary hospice experience, grounded in the stories and experiences of patients themselves.

Background

The sociology of death and dying has become a prominent area of study over the last few decades, providing valuable insight into the role of socio-cultural processes in shaping end-of-life care (e.g. Clark & Seymour, 1999; Glaser & Strauss, 1965, 1968; Howarth, 2007a; Kellehear, 1990, 2008; McNamara, 2004; Prior, 1989; Riley, 1983; Seale, 1998b). Within this literature there has been regular debate over the politics and ideological purposes of ideas about 'the good death' (Gott, Small, Barnes, Payne, & Seamark, 2008; Hart, Sainsbury, & Short, 1998; see also Seale, 1998a). On the one hand, the notion of 'the good death' has been deployed within the hospice movement to signify death with dignity, peace and comfort (Kubler-Ross, 1969). On the other hand, 'the good death' has been critiqued as a form of social control (McNamara, Waddell, & Colvin, 1994, 1995) and as potentially marginalising divergent forms and experiences of dying (Hart et al., 1998). These concerns are enhanced within a context of a growing recognition that the capacity to 'die well', within any given normative framework, may be differential between groups of individuals (Howarth, 2007b). Yet, contemporary palliative and hospice care is still largely

* Corresponding author. Tel.: +61 413060436.

E-mail address: a.broom@usyd.edu.au (A. Broom).

¹ In Australia, hospice is used to refer to end of life care in an *in-patient unit* and this is how we use the term in this paper. In the United States hospice refers to a program where patients are cared for at home and in the UK it can include in-patient and out-patient *and* broader multifaceted care.

underpinned by particular models of 'dying well'. The 'revivalist' good death, for example, described by Clark (2002), reflects an agenda within palliative care that a 'good death' should feature such things as: 'being pain free', 'acceptance', 'closure', 'awareness' and 'individuality' among other things (see also Seale, 1998a). While such components are not *prima facie* problematic, their normative and prescriptive potential is worth considering. Indeed, models of 'dying well' have tended to be driven by academic and clinical perspectives, with little research evidence available on what patients themselves believe to be 'a good death' (see for an exception Gott et al., 2008; also Kendall et al., 2007). The limited research available suggests patients' views of 'a good death' may conflict with the values upon which palliative care is predicated (Gott et al., 2008). In their recent study Gott et al. (2008) found that older people's views of a good death often conflict with the revivalist model, with their participants not desiring open awareness of death, acknowledgement of the imminence of dying, or supporting the concepts of autonomy and individuality (Gott et al., 2008). We were interested in exploring hospice patients' views of different forms of death and dying (good, bad or otherwise) and how these reflections would be shaped by their own biographies. In other areas of health and illness, patient experiences have been shown to be greatly influenced by gender, ethnicity and class (Hallam, Hockey, & Howarth, 1999; Howarth, 2007b), yet little work has been done on hospice patients' perspectives. This paucity of research is particularly the case for the study of masculinities and dying.

Howarth (2007b) argues that there has been a privileging of middle-class 'verbalised' versus working-class 'stoical' forms of dying and caring in the academic literature. Similarly, the influence of masculine identities within the dying process has not been given significant attention. Lawton (2000) touched on the interplay of hospice care and gender identity, suggesting a potential 'degenderisation' of hospice patients through loss of capacity to 'do gender' (particularly through sexuality). Such an analysis, from our perspective, tends toward a binary conception of gender (gender identity as either maintained or lost) and, furthermore, may overstate the centrality of sexuality in the performativity of gender at end of life (see Lawton, 2000, pg. 168). We argue for a wider view of the interplay of masculinity and dying that extends to the potential loss of cultural and inter-personal roles (Broom & Tovey, 2009; Smith, Braunack-Mayer, Wittert, & Warin, 2007). This is situated within an understanding that there has been a tendency within the social sciences to interpret end of life experiences as largely undifferentiated in their bodily and emotional impact (Howarth, 2007b). We argue that a more nuanced conception of death and dying is necessary, and exploring the role of contemporary masculinities is an important starting point (Emslie et al., 2009; Parsons, 1997). This necessarily includes, we argue here, reflection on the experience of being cared for.

The politics of caring has been well documented in the sociological literature (e.g. Field, Dand, Ahmedzai, & Biswas, 1993; James, 1989; Thomas, Morris, & Harman, 2002), and feminist researchers have emphasised the negative consequences of informal caring for women (e.g. Thomas, 1993). Research on caring has traditionally examined the hidden and feminine character of this work (Emslie et al., 2009; Exley & Letherby, 2001), whereas the experiences of men and those people who men care for have been given relatively little attention (see Emslie et al., 2009; Kirsj, Hervonen, & Jylha, 2004; Parsons, 1997; see also Crocker, 2002; Karp & Tanarugsachock, 2000; Ribeiro, Paúl, & Nogueira, 2007). In the context of hospice and palliative care, research has indicated that carers might underplay their own needs while trying to represent the voice of the person needing care (Grande, Todd, & Barclays, 1997). Moreover, and taking a more theoretical bent,

caring for the dying has been examined as moral practice, as a site of inter-subjectivity involving the reconstitution of the 'competent social agent' (Chattoo & Ahmad, 2008). Moral practice, in this context, denotes ideas about how people should treat others and be treated by them, including, as Sayer posits (2005), matters of justice and fairness, and relations of recognition, care and friendship. Yet, little is known about how notions of responsibility, gift and reciprocity operate within the hospice from the dying person's perspective. There has been sporadic research in selected out-patient settings which has illustrated the gendered character of the carer/cared for dynamic, including forms of intense emotional labor, and the desire to maintain gender roles/dynamics (e.g. Emslie et al., 2009; Exley & Letherby, 2001). What it is like to be cared for at the end stages of disease and while living in a hospice is largely unknown.

Methods

The project was developed by the authors to explore men and women's experiences of in-patient hospice care. Research with palliative care patients requires rigorous procedures to ensure ethical process is achieved. As part of getting ethics approval (from University of Newcastle Ethics Committee and Hunter Health Ethics), we developed a formal protocol for identifying potential interviewees based on willingness and capacity to participate. The sample frame comprised of patients currently enrolled in the in-patient palliative care program at the hospice for at least 10 days and who had become stable after admission. Local clinicians were briefed on the study and were asked to identify potential participants. They were asked to consider for inclusion *only* those patients who were cognitively able (i.e. achieved a score of > 23 on the Mini Mental State Examination (Tombaugh & McIntyre, 1992)), without significant pain, and who had been assessed as being capable of giving consent. If patients expressed interest in participation after being told about the study, a member of the clinical staff would provide an information sheet which explained the project in more detail. After approximately 24 h a clinical staff member would then return to the patient to answer any additional questions and ascertain whether they wish to discuss participation with AB.

The interviews took place between August and December 2008. In total 28 patients expressed an interest in participating in the study. Three opted to withdraw once the interview had begun and 5 others who offered to participate initially were not cognitively able to participate once AB had arrived to do the interview. Neither group have been included in the sample presented here. A total of 20 patients receiving in-patient hospice care participated in the study. Eighteen had been admitted for pain and symptom management and end-of-life care, and 2 for respite care. Eleven of the participants were male and 9 were female. This was not intentional but merely reflects the relatively even mix of men and women in the hospice. We note that the participants self-selected after reading about the study and that the data should be read in light of this. It seems likely that those with 'something to say' (i.e. keen to reflect on their hospice experience, whether positive or negative) would be more likely to offer to participate. Further work is necessary to explore a wider range of hospice experiences and the current study should be viewed as a platform for future investigation.

All the respondents were interviewed in their own rooms in the hospice unit, for between 20 min and 1 h, depending on onset of (additional) pain/tiredness. The interviews were digitally recorded and subsequently fully transcribed. The interviews were relatively unstructured, exploring their experiences of living and dying in the hospice and their experiences of being cared for. An interview schedule guided the discussions and it included questions such as:

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