



Resisting decay: On disposal, valuation, and care in a dementia nursing home in Denmark



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ABSTRACT

This paper approaches institutionalized dementia care as a site of societal disposal, valuation, and care for human life. Drawing upon six weeks of ethnographic fieldwork and ten qualitative interviews carried out in a Danish dementia nursing home in 2014, we analyze how nursing home staff, through everyday care, uphold the value of life for residents in severe mental and physical decline. We argue that life's worth is established when residents gain qualities of personhood and agency through substitution processes carried out by staff. Yet the persistent absence of conventional personhood and autonomous agency in residents (i.e. capacities for memory, consciousness, language, and mobility) evokes experiences of ambiguity in staff and relatives of residents. We close the article with a discussion of this ambiguity and the significance of the nursing home as care institution in the welfare state. Dementia care, we propose, is not only about preserving the lives of people with dementia. At stake in the daily care practices around severely disabled residents in the nursing home is the very continuance of the main principles of the welfare society.

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1. Introduction

In the edited volume “Gray Areas: Ethnographic Encounters with Nursing Home Culture,” Philip Stafford writes about the fear often associated with the nursing home as an institution: “The institution is feared. Those who work within have low status in our society. Those who live within endure a social death, cut off in many ways from the outside world” (Stafford, 2003:17). A similar statement from a European context is made by Paul Higgs and Chris Gilleard in their book “Rethinking Old Age:” they coin their concept of “the fourth age,” defined as “a location stripped of the social and cultural capital of later life which allows for the articulation of choice, autonomy, self-expression and pleasure” (Higgs and Gilleard, 2015:14). The authors argue that much of the fear of this fourth age in modern society relates to the dread of being institutionalized: “of ‘ending up’ as a ‘non-person’ in a nursing home” (Higgs and Gilleard, 2015:20). Conducting ethnographic fieldwork

in a dementia nursing home in Copenhagen, we have found this fear of the nursing home pertinent to the Danish setting, articulated not only in the public media outside the nursing home (Kristeligt Dagblad, 2012; Berlingske, 2006), but also by our informants, either working in the nursing home, or having their family members living as residents in the nursing home due to late-stage dementia.

People with dementia will, as the disease progresses, enter “the fourth age” (Higgs and Gilleard, 2015) and some will also eventually need institutionalized care to survive. In Denmark, two-thirds of people living in nursing homes have dementia, a proportion that is expected to rise in the coming years (Ældresagen, 2016). In a chapter in the “Grey Areas” book referred to above, J. Neil Henderson writes about Alzheimer units, and refers to Otto von Mering’s observation that nursing home placement of elderly people in need of care is American society’s form of a ‘double burial’: “When a person is extracted from home because of dependencies that interrupt his or her ability, or his or her family’s ability, to cope with the exigencies of life, the nursing home placement process becomes step one in a double burial ritual. (...) At this point, the sometimes lengthy step two of the double burial ritual begins. Rather than lie supine on the burial scaffold, as in some cultures, the patient languishes in long-term care patienthood until

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biological functions cease, at which time the second, and final, burial occurs" (Henderson, 2003:154–155).

Dementia care is thus a relocation of the person with dementia who can no longer conduct domestic life, propelling a reconfiguring of personhood and the value of life as it is resettled geographically as well as socially. People who age into a dementia disorder are further vulnerable to questions of personhood as these diseases are associated with liminal states between life and death (Kaufman and Morgan, 2005). In being depicted as a trajectory of progressive decline that gradually leaves the sufferer socially dead until biological death eventually occurs, dementia reflects the associations of death already poignant in the nursing home setting. Yet at the same time, the very distribution of nursing homes all over Denmark expresses political commitment of the caring state that compromised lives are valuable and hold intrinsic worth that must be protected.

Studying how the value of life is practiced and experienced in the field of dementia, we find sociologist Kevin Hetherington's (2004) work on disposal offers analytical power as it simultaneously addresses questions of relocation and valuation. In this paper we thus conceive of nursing homes as conduits for societal disposal of people with dementia, and evaluate ethnographically how staff and relatives practice and experience the value of life of the person with dementia in the Danish welfare state. We do so *not* to argue that "the now-institutionalized person's psychosocial self is slain at the nursing home door" (Henderson, 2003:154–155) as part of a double burial. Rather, we approach dementia care as disposal from the perspective of the "care multiple" (Law, 2010) that nursing homes are intended to fulfill: in the welfare state, dementia care should uphold simultaneously the quality of life for the individual dementia sufferer, his/her family, and the social order of a caring state. We shall demonstrate that what intuitively seems as an incompatible combination (namely disposal of and care for people with dementia) reveals new insights into the creation of value taking place in the nursing home so profoundly associated with death and decay.

The questions we ask are: How do staff maintain the personhood and life of residents 'disposed of' into the dementia nursing home? What kind of moral navigation do staff and relatives of residents engage in when seeking to create lives worth living for people with dementia? We shall argue that caregivers uphold biological bodies, restore agency and biographies, and create open futures and societal belonging for the people with dementia. Yet despite caregivers' extensive practices of preservation, they are faced with moral ambiguities when decay, and the powerlessness it carries, become present.

First, we present the empirical background of our study. Second, we present the theoretical and analytical frameworks of disposal, valuation and personhood and how they apply to institutionalized dementia care. We then analyze the care practices and experiences involved in creating lives worth living in the nursing home, and investigate the moral unease accompanying attempts to preserve life at the margins. Closing the paper, we discuss how advancements in biomedicine and the prospect of aging societies only give urgency to practices and meanings of disposal and care for people with dementia. When caregivers maintain severely disabled and profoundly passive residents as active, participating citizens, they not only preserve the individual lives in their care; caregivers also sustain and reproduce principles and values of reciprocity and democracy fundamentally constitutive of Danish welfare society.

1.1. Empirical background

Denmark has a history of strong welfare state involvement including institutionalized care for the elderly. In the early stages of

dementia the sufferer will typically stay at home and be cared for by a spouse and/or members of the extended family. Further along the disease progression, family care can be supplemented by in-home care, and the person with dementia will typically be encouraged to take part in various activities at a day-care center or go on short 'respite stays' [aflastningsplads/ophold] in a nursing home to reduce the strain on the primary caregiver(s). When caring becomes too strenuous a burden for the relatives, the person with dementia will typically be signed up for a room in a nursing home in which care is provided day and night. Nursing homes are run and organized by the Danish municipalities and thus financed by the collectivity of tax-payers, meaning that only a small amount of the cost is left to individual payment.

Care for disabled people is thus not a financial issue for the individual citizen in the Danish welfare state, as it secures assisted living for those in need. On the other hand, this welfare apparatus means that nursing home care has been—and still mostly is—equal for all. Private nursing homes have only in recent years slowly begun to emerge, meaning that for most people it is not possible to choose freely between care solutions. Sparked by Danish media reports of poor nursing home care and cases of neglect, caring for the elderly with dignity is frequently debated publicly and also regularly discussed politically. In spring 2016, the government proposed a "dignity billion" to improve conditions for elderly people living in nursing homes, and in May 2016, 470 million Danish Kroner were allocated to the development of a National Dementia Action Plan aimed at improving life for people with dementia (Ministry of Health, 2016). These political initiatives illustrate how, within a welfare state context, 'proper' elder and dementia care continues to constitute an unsettled predicament.

2. Disposal, valuation, and personhood

This paper builds on an interest in the ways in which the disposal of persons and bodies constitutes a significant activity through which ordering of society takes place (Hertz, 1960 [1907]; Douglas, 1984; Fortes, 1987). In Mary Douglas' (1984) classic anthropology of purity and danger, the removal of certain things—symbolically conceived of as dirt and pollution—constitutes an elimination of "matter out of place" that stabilizes social categories. Drawing upon this vocabulary in his designation of the nursing home as a grey area between the medical and domestic domain, Stafford describes the institution as an "area of ambiguity, liminality, sacredness, contagion, pollution, taboo, contested meaning" (Stafford, 2003:11).

As pointed out by Henderson, moving people with dementia into nursing home care keeps the still able-brained and able-bodied members of the family and of society from 'defilement' of their independent, healthy lives (Henderson, 2003). While we rely on similar theoretical legacies of relocation, disposal, and valuation of bodies, our aim is not to simply argue that nursing home care constitutes a double burial. Rather, we approach the relocation of bodies and persons into welfare state spaces as part of the creation of value. When the person with dementia is repositioned from one context (home) to another (the nursing home), institutionalized care is put in place to prevent the person with dementia from dissolution. How is the value of life managed when an already existing person with a name, history, and biography is no longer held in trust by family members, but by state employed caregivers in the nursing home?

In his article on secondhandedness, Hetherington (2004) argues for a new stance towards disposal: rather than conceiving of our ways of getting rid of different things—not only those objects we designate as rubbish and dirt—as a finalizing endpoint activity, actions of disposal can be recognized as continuous practices,

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