Journal of Aging Studies 42 (2017) 1–8

Contents lists available at ScienceDirect

Journal of Aging Studies

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

"They are different now" – Biographical continuity and disruption in nursing home settings

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ARTICLE INFO

Keywords:
Ageism
Biographical approach
Disability studies
Long-term care

Introduction

Research on nursing home care has identified routines and institutionalization as problems (Reed & Payton, 1997; Ziemba, Perry, Takahashi, & Algase, 2009) and person centeredness as part of the solution. Broad goals express that older people in nursing homes should be able to live "as normal and unconstrained a life as possible" (Kane & Kane, 2005:121) and "receive support to maintain interests and habits" (2009/10:SOU18). While similar goals have been prominent within disability policies, a notable difference concerns comparisons that are used to establish what is a normal life. Eldercare policies emphasize person centeredness and biographical continuity within the context of care. Disability policies emphasize the right to be able to live like "others", a comparison that invokes contexts and categories that are external to disability and care (Jönson & Taghizadeh Larsson, 2009; Erlandsson, 2014).

In this article we will investigate the translation of policies on personalized nursing home care into practice and use a "disability lens" (Jönson & Harnett, 2016) to highlight weaknesses inherent in the goal of biographical continuity. Research on biographical continuity in eldercare has so far paid insufficient attention to what it means to "maintain interest and habits" for nursing home residents with multiple impairments and diseases. What aspects from before should be taken into account? Are some conditions regarded as just causes for abandoning these goals? By introducing a disability lens we point towards the possibility of using new kinds of comparisons and goals regarding living conditions for people in nursing home settings.

The aim of this article is twofold, 1) to examine how goals to personalize nursing home care through biographical continuity are discussed by persons directly involved as residents, their relatives, staff and managers of nursing homes and 2) to use a "disability lens" to introduce alternatives to biographical continuity as means to counter institutionalization. Through the use of an "Equal Rights Framework" that is inspired by disability models of Scandinavia, we will demonstrate that the focus on personhood that has been used to fight institutional models may in fact play into an ageist dynamics.

Biographical continuity in nursing home settings

Research on nursing home care is vast and ranges from studies on residents' wellbeing and quality of life (Garland, Oyabu, & Gipson, 1989; Kane, 2003; Zimmerman et al., 2005), to studies on care work and the conditions of care workers (Fjær & Vabø, 2013; Juthberg, Eriksson, Norberg, & Sundin, 2010; Pekkarinen, Sinervo, Perälä, & Elovainio, 2004). Several studies have described life in the nursing home in terms of inflexible routines (Persson & Wästerfors, 2009), loss of identity (Ryvicker, 2009), lowering of self-esteem and reduced sense of personhood (Scourfield, 2007). Consequently a large body of research has aimed at replacing task centered and depersonalizing care arrangements with approaches that focus on the personhood and biographical continuity (McCormack & McCance, 2006). Theoretically, goals to maintain residents' identity and habits are expressed in continuity theory (Atchley, 1999) and are central in approaches such as the person-centered care paradigm (Kitwood, 1997; McCormack & McCance, 2006), culture change (Corazzini et al., 2015), relationship-centered care (Nolan, Davies, Brown, Keady, & Nolan, 2004) and in life history approaches (Villar & Serrat, 2017; Edvardsson, Fetherstonhaugh, & Nay, 2010; McKeown, Clarke, & Repper, 2006; Surr, 2006).

The strength of a personalizing approach is obvious; the fact that people are different and have unique life histories and unique habits and interests becomes a fundament of care. This traditional way of

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http://dx.doi.org/10.1016/j.jaging.2017.05.003
Received 23 January 2017; Received in revised form 7 April 2017; Accepted 16 May 2017
Available online 25 May 2017
0890-4065/ © 2017 Published by Elsevier Inc.

countering institutionalization has been successful, but the application of a "disability lens" reveals an inherent weakness. Traditional approaches that focus on personalization tend to frame rights in relation to personhood *within* the context of care. Goals, such as to enable residents to live according to their identity and be like "themselves", refer to personal characteristics that are difficult to transform into rights. The obvious risk is that increased frailty and adjustment to the context of care are regarded as "natural" changes caused by the aging process and reasons for not maintaining established habits and interests (Jönson & Harnett, 2016). A "disability lens" makes evident a tendency to use internal, rather than external, comparisons in eldercare. It is thus possible to reveal a dichotomy of institutionalization versus personalization and investigate other types of comparisons – external to the context of care – that may improve the welfare of older persons with extensive support needs.

Swedish nursing home care

In this article we use the internationally established concept of *nursing homes* to emphasize that the type of residential care discussed represents the highest level of care available outside the medical hospital ward. Residential care facilities in Sweden are formally labelled *special housing for older people*, and care services are covered by Sweden's Social Services Act. Aging-in-place, i.e. a preference to provide home-based care, has been the leading principle of Swedish eldercare since the 1950s, and for reasons of cost, the general threshold for moving into a care facility has been raised during the last few decades. As a result, those moving into residential care now have massive care needs and the majority have dementia (National Board of Health and Welfare, 2014). The responsibility for nursing homes was moved from the health care sector to municipal social services in 1992, and thus *from a medical model to a social care model*. The Social Services Act was based on the idea that older people in need of care should "as far as possible be able to be like others and have a situation similar to others" (Prop. 1979/80:1, p.212). To achieve this goal, municipalities were urged to focus on providing home care and making care facilities homelike (Lundgren, 2000; Szebehely & Trydegård, 2012). Facilities are no longer referred to as institutions and there have been efforts to introduce amenities that are typical of regular apartments. With very few exceptions, nursing home residents have private rooms with an en-suite bathroom and a kitchenette. In policy documents, residents are referred to as tenants and their private rooms are formally regarded as rental apartments, even if they are located in a corridor of a former traditional institution. The type of individualized small-scale (avoiding ward-like arrangements) care that is described in efforts to introduce a "culture change" (McCormack et al., 2008) constitutes mainstream nursing homes in Sweden. The relatively good living conditions in Swedish nursing homes (in terms of physical environment, privacy and social activities) provide a specific context for ambitions about maintaining interests and habits. For instance, in a Swedish nursing home the facility will in itself serve to maintain certain habits of residents: They furnish their apartments with private furniture, they are allowed to smoke inside their apartments, they have a private bathroom and they can (often) bring their pets.

Method

The data for the study was collected within the research project "Improving everyday conditions by reconceptualizing eldercare through the lens of disability policies". One aim of the project was to investigate tensions inherent in efforts to provide personalized care in collective settings like residential care facilities. The present article was based on 20 interviews at four nursing homes located in two medium-sized (100,000 inhabitants) Swedish municipalities. Twelve interviews were conducted in the form of focus groups or pairs, and eight were conducted individually (all four managers and four of the residents). In total we interviewed 46 persons: 19 residents, six family members, four managers and 17 staff members. A detailed description of sampling and methodology is described in Harnett & Jönson (2014). The project was approved by the regional ethics review board in Lund (Dnr 2013/349).

Theoretical approach and analytical framework

In the article we will use a constructionist approach and regard phenomena like biography, needs, age, illness and impairments as sociological topics to be studied, rather than given facts or causes for a particular arrangement (Bodily, 1994).

In order to question ideas that are often taken for granted in eldercare and analyze the way normality and rights are constructed through comparisons, we used a framework that is inspired by disability policies (Jönson & Harnett, 2016). The framework, called the "the Equal Rights Framework", is based on the Scandinavian normalization principle and its claim that (younger) persons with impairments should be provided with living conditions that are as similar as possible as those of other members of society.

The framework that we have developed consists of three types of

Type of references	**Internally oriented – care and impairment**	**Externally oriented – society in general**
Context-centered	The contexts of care or impairment	Other contexts invoked as comparison
Category-centered	Other care users or categories relating to care or impairment	Other categories invoked as comparison
Personhood-centered	The unique person in relation to care or impairment	Other aspects of the unique person invoked as comparison

Fig. 1. An equal rights framework for persons in need of support and care.

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