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Journal of Aging Studies

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



Official conceptualizations of person-centered care: Which person counts?



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ARTICLE INFO

Article history:
Received 30 November 2012
Received in revised form 7 March 2013
Accepted 26 March 2013

Keywords: Person-centered care Residential care Minimum standards Discourse analysis Choice Autonomy

ABSTRACT

Numerous studies have indicated that a "psycho-social" person-centered care approach, involving the delivery of a compassionate, respectful model of care, leads to a high quality of life, particularly for older people living in residential care. This has prompted policy-makers to endorse this approach. Yet, some commentators have argued that the model of personcentered care in official government policies equates to a "consumer-based" rather than a psycho-social approach, as it focuses solely on offering service-users more choice and on promoting independence. However, as such arguments are made in the absence of any empirical analysis, it is unclear both whether such a distinction exists in practice, and, if so, how this alternative model developed. This study explores the development of minimum standards for residential care settings for older people in Ireland in order to address this gap in our understanding of person-centered care. Findings confirm that a consumer-driven model of person-centered care underpins the Irish Standards; residential care is portrayed as a hotel-like service and residents as discerning consumers, which may be unsuitable for older people in residential care with limited capacity to make key choices. Analysis indicates that this model can be seen both as an extension of consumer-driven policies endorsed by many neo-liberal governments, and also of policy-makers' fears of losing their autonomy when they reach the "Fourth Age". This study is particularly illuminating, given the similarities between the Irish care system with England, Scotland, Wales, Northern Ireland and Australia.

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Introduction

Over the last ten or fifteen years, it has become widely accepted by academics, policy-makers and practitioners that "psycho-social" person-centered care, which aims to nurture the intrinsic "personhood" of each care recipient, is the best model for improving older people's quality of life, particularly for those living in residential care (Chou, Boldy, & Lee, 2002; Fossey et al., 2006; Kane, Lum, Cutler, Degenholtz, & Yu, 2007; McCormack & McCance, 2010). These findings have prompted policy-makers to endorse this approach. Yet, some commentators have argued that the model of person-centered care in official government policies equates to a "consumer-based" rather than a psycho-social approach, as they typically focus

solely on promoting independence and offering service-users more choice in selecting a service that best suits their needs. However, such arguments are made in the absence of any empirical analysis, and so it is unclear both whether such a distinction exists in practice, and, if so, how this alternative model developed.

This article seeks to analyze how person-centered care is conceptualized in official care policies for older people, and to develop our understanding of how this model developed. It reports on a case study conducted on the development of a key policy document for the Irish residential care sector, the National Quality Standards for Residential Care Settings for Older People in Ireland (Health Information and Quality Authority [HIQA], 2009), in which both a discourse analysis of the document was conducted as well as interviews with those who contributed to its development. The article first delineates the psycho-social and consumer-based models of

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person-centered care as described in the current literature. The conceptual framework for the study is then set out, in which it is proposed that the development of a consumer-driven model of person-centered care may be a consequence of two related phenomena — firstly, the rise of the "citizen-consumer" in neo-liberal countries, and secondly, the denial of the Fourth Age. The Irish context is then described, followed by a detailed overview of the methods and findings. The article concludes with a discussion of the implications of the findings for the organization of residential care for older people.

Person-centered care

In the 1970s, a movement developed to fight for the rights of people with disabilities to be recognized. Supporters of this movement argued that society needed to better accommodate people with disabilities, rather than vice versa (Oliver, 1990). The Disability Movement prompted care practitioners to develop a new, more holistic model of care which aimed to meet individuals' subjectively-defined needs (Epp, 2003). Out of such work grew the psycho-social person-centered model of care, first developed within the field of dementia in 1988 by Tom Kitwood in his attempt to describe a model of care that aimed to maintain the intrinsic "personhood" of each individual care recipient (Kitwood, 1997). Kitwood (1997) referred to personhood as "a standing or status that is bestowed upon one human being by others in the context of relationships and social being. It implies recognition, respect and trust" [p. 8]. A person-centered approach requires empathetic care to meet care recipients' six psychological needs: love; attachment; comfort; identity; occupation; and inclusion (Kitwood, 1997). The model is made up of four elements, each of which have equal weight: valuing people with dementia and those who care for them; treating people as individuals; looking at the world from the perspective of the person with dementia; and a positive social environment in which the person living with dementia can experience relative wellbeing.

While Kitwood's conceptualization of a person-centered model of care was written specifically for people with dementia, his work has been further developed for all older people, particularly those living in residential care who don't necessarily have dementia, but who have significant caring needs. McCormack (2003), who has been instrumental in developing an operational model of person-centered care, emphasized the need for carers to be able to particularize the care-recipient's unique sense of personhood through an understanding of the care recipient's "authentic values", namely, the decisions they make that expresses all that they believe important about themselves and the world, as well as the adoption of "imperfect duties" (including being compassionate, concerned, benevolent and respectful) (McCormack, 2003). Thus, person-centered care requires engagement between the carer and the care recipient, forming a "care partnership", whereby the carer seeks to develop a meaningful relationship with the care-recipient and offer personal support and practical expertise, while enabling them to follow the path of their own choosing (McCormack, 2003).

It is no surprise that governments have endorsed personcentered care, given the wide body of empirical evidence indicates that it is of benefit to older people, particularly those living in residential care, promoting feelings of well-being and giving a greater sense of autonomy and independence (Chou et al., 2002; Eales, Keating, & Damsma, 2001; Guse & Masesar, 1999; Kane et al., 2007). According to Nolan, Davis, Brown, Keady, and Nolan (2004), the first key reference to personcentered care for older people in policy documents in the UK was in the National Service Framework for Older People (NSF) (Department of Health UK, 2001). However, in this key document, person-centered care was defined as care that 'respects others as individuals and is organized around their needs (Nolan et al., 2004, pg. 46), leading Nolan to argue that it was autonomy based on individualism and independence and could thus be seen as the application of consumerism to healthcare. Referring to both NSF and other related policy documents, Brooker (2007, p. 21) described this approach as "a far cry from the stance that was described by Kitwood with its emphasis on authentic communication and changing care cultures". Other critics have argued that the approach is repeated in subsequent documents and is ill-suited to the needs of those living in residential care settings, many of whom have dementia or other cognitive impairments, or physical disabilities which can prevent them from exercising choice (McCormack, 2001; Wilkinson, Meyer, & Cotter, 2009). However, as outlined below, research on this alternative "consumer-driven" model is limited; to date there has been no systematic analysis of such policy documents in order to demonstrate that this model actually exists. Furthermore, little attempt has been made to explain how it developed. However, governance scholars have widely documented the rise of the "citizen-consumer" in public policies more generally, thus offering a potential explanation for its manifestation in person-centered care policies. The rise of the citizen-consumer forms part of the conceptual framework for this paper, as outlined below.

Conceptual framework

The rise of the citizen–consumer

As outlined above, the Disability Movement had a profound effect on the organization and delivery of care services, particularly for younger people with disabilities. Lobbying and campaigning led to a profound shift in perceptions about people with disabilities; no longer were they seen as dependent and interchangeable "patients", but individuals with the right to have a say about the services they used (Oliver, 1990). Choice and autonomy became keywords in the Disability Movement, as a way of recognizing the rights and personhood of each individual. However, over the same period, "choice" was becoming a defining characteristic of another movement — the rise of consumerism. According to Gilleard and Higgs (2005), the post-World War Two era was characterized by affluence and the rise of a youth culture, and so the teenage years in the 1950s and '60s became a training ground for a lifetime devoted to consumption. By the 1980s, the focus on consumerism throughout the Western World was ingrained; people defined their individual identity through the choices that they made as consumers (Gilleard & Higgs, 2005). Central to this process was the privileging of individual agency, or autonomy, and a focus on liberation and self-expression. Scholars have argued that the two different perspectives of "choice" have gradually become combined and distorted

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