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Changing the culture of long-term care through *narrative* care: Individual, interpersonal, and institutional dimensions☆

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ABSTRACT

Interest in the practice of narrative care with older adults is continuing to grow (Kenyon & Randall, 2015). Significant attention has been paid thus far to various formal interventions or programs that enhance the narrative development of individuals in later life by helping them to express and explore their unique life story. Comparatively little, however, has been paid to the many informal opportunities for practicing narrative care in long term settings that occur amidst everyday interpersonal interactions - e.g., staff-resident interactions in nursing homes. Even less attention has been paid to the importance of cultivating an overarching institutional narrative that provides a supportive context for the practice of narrative care in general. This paper will contribute to discussions of "person-centered care" by arguing the need to change the culture of long-term care so that narrative care is practiced on all three levels at once: individual, interpersonal, and institutional.

Introduction

The last few decades have witnessed a progressive change in the culture of long-term care for older adults that seeks to go beyond the traditional biomedical model that treats them as "patients" and defines them in terms of the illnesses they suffer. Among the core principles of this new philosophy of care, the need to provide "person-centered care" is most widely cited. That is, those who receive care in the context of long-term institutions are ultimately unique human beings whose biographical continuity must be preserved and whose preferences and points of view on daily life situations must not only be taken into account, but to the maximum extent possible be respected and followed (Edvardsson, Fetherstonhaugh, & Nay, 2010).

Such a principle underlines the importance of the concept of personhood and its preservation. At the same time it highlights the question of what "a person" really is. Among the approaches that try to define personhood and its different dimensions (Caddell & Clare, 2010), a *narrative* approach has particularly promising implications as far as practice is concerned. According to this approach, people make sense of their experiences, and indeed their *identity*, through the creation and sharing of stories. As such, it can be used as a framework to make sense of a series of interventions and practices that are focused precisely on the uniqueness of how people "story" their lives. To refer to that set of interventions and practices, Bohlmeijer, Kenyon, and Randall (2011) have proposed the term "narrative care" (see also Kenyon & Randall, 2015).

Our aim in this article is to highlight the importance of the narrative approach in optimizing the professional care that is provided to older adults in long-term settings, and to argue that – on an individual, interpersonal, and institutional level - it opens up valuable avenues for preserving their personhood. To this end, we will first discuss briefly how the narrative approach can improve our understanding of the challenges older adults experience in such settings and, second, examine different strategies for the use of narratives on all three levels to improve the quality of care they receive.

Challenges to narrative identity in later life: the impact of institutionalization

Across various disciplines within the social sciences, there has been a growing interest in narrative as a key element in a range of phenomena in our lives as human beings (Czarniawska, 2004). A cornerstone of this perspective is that we need to make sense of ourselves and our world, and that we achieve this through constructing, telling, and sharing stories that provide continuity, coherence, and purpose to personal experience (McAdams, 1993).

This interest in narrative has also had an impact on our understanding of the experience of aging and later life (de Medeiros, 2014; Kenyon, Bohlmeijer, & Randall, 2011; Villar & Serrat, 2015), particularly on the situation of older adults living in long term institutions. Indeed, experiences such as moving to a nursing home or dealing with severe dependency can represent major challenges to people's capacity to go on

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elaborating and participating in stories that provide them with a positive and open sense of meaning in life. Put simply, they represent *narrative* challenges (Randall, forthcoming). By this we mean that the maintenance of narrative identity can become extremely problematic - particularly for those with dementia, whose capacities and strategies for storing and retrieving, organizing and sharing autobiographical elements are compromised, especially in advanced stages of the disease. What is more, the act of entering a long-term institution is, itself, often experienced as an irreversible and indeed terminal stage of life, leading to the premature belief that one's life story has basically ended and that no new chapters can possibly be added to it. This belief, which psychologist Mark Freeman (2011) calls "narrative foreclosure," involves a serious threat to the maintenance of narrative identity among older people in long-term care. Related to narrative foreclosure is "narrative loss" (Baldwin & Estey, 2015), which is the progressive erosion of our sense of identity due to losing familiar routines, circumstances, or audiences that reflect back to us our story of who we are. In a word, we become *de*-storied. In extreme cases of narrative loss, to which unfortunately institutionalization so often contributes, our story can shrink so much within us that we risk succumbing to "narrative atrophy" (Randall, forthcoming).

In a radical way, the very definition of oneself as a *person* can depend on social acknowledgement. As authors such as Tom Kitwood (1997) have proposed, a person is "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust" (p. 7). In this regard, typical interactions in institutional contexts not only influence the narrative identity of the people living there, but can be a determining factor in the extent to which these people are even considered as "persons" in the full sense of the word. In some institutions, depersonalizing practices such as addressing people in a childish or standardized way; ignoring their needs in favor of professionals or caregivers' ones; labelling them (most times in terms of clinical diagnoses) and thus stigmatizing them; and depriving them of control over their own lives – in effect, de-storying them - are all too frequent (Sabat, 1994). The result is the appearance of ill-feelings that are expressed as passivity, confusion, agitation, or aggression, which in the case of people with dementia get interpreted, in turn, as symptoms of the disease.

In a similar vein, Baldwin (2008) proposes the term "narrative dispossession" to refer to those situations in which persons who receive institutional care (above all, those with dementia) are denied the opportunity of narratively expressing themselves. In effect, their stories are "kidnapped" by the prejudices of the professionals, which traditionally are influenced by the view of aging itself (and certainly of dementia) as a process of irreversible decline and loss of capacity (Clark, 2015).

In the case of aging in general, the dominant meta-narrative at work in Western culture is a "narrative of decline" (Gullette, 2004). According to it, aging involves a process of deterioration that irrevocably affects all dimensions of the person. Assuming such a narrative leads us to consider older adults from the perspective of deterioration and decay, to interpret their behavior in terms of loss, and to see aging itself as a kind of pathology that requires medical treatment (Kaufman, Shim, & Russ, 2004) – in short, as "a problem to be solved" (Cole, 1992, p. 241). Overall, subscribing to such a view leads to, and even justifies, the association of later life (particularly, institutionalized later life) with a reduction in power and prestige and a corresponding cutting-back of opportunities that older adults are afforded.

Strategies for narrative care: individual, interpersonal, and institutional

Different strategies have been proposed for overcoming the sorts of challenges just outlined and enabling the achievement of a viable and plausible personal narrative for older adults living in long term care settings, a narrative focused on their remaining capacities rather than those they have lost. Such strategies, which promote what we are calling narrative care, can take a variety of forms, depending on which dimension of older adults' lives – the individual, interpersonal, or institutional -we have in mind.

Narratives in individual care

Perhaps the most widely known, used, and evaluated strategies for narrative care are programs whose central objective is precisely to restore, share, and value the autobiographical memories of older individuals by means of some mode or other of "reminiscence work" (Webster & Haight, 2002), "life story work" (Kunz & Soltys, 2007), or simply "storywork" (Randall, 2010). This includes a broad range of interventions: from solo activities to group work, from life story interviews to memoir-writing to scrapbooking to family trees, and from simple reminiscence to life review to life review *therapy* (Bohlmeijer & Westerhof, 2011).

Simple reminiscence is suitable both for healthy older adults who want to share their autobiographical memories with others and for those experiencing some degree of cognitive impairment or dementia. The goal of simple reminiscence is to increase social contacts, positive emotions, and overall life satisfaction (Bohlmeijer & Westerhof, 2011). This kind of reminiscing can be promoted in institutional settings through group interventions using triggers to recall positive events or experiences (Westerhof, Bohlmeijer, & Webster, 2010). Additionally, this mode of reminiscence requires only basic skills on the part of professionals, whose functions are to facilitate the emergence of memories and to encourage other participants to enrich them and share similar memories in turn (Westerhof et al., 2010).

In contrast with simple reminiscence, life review is addressed mainly to older people who are experiencing difficulties in finding meaning in life or in coping with the sorts of setbacks and transitions that can come with later life (Bohlmeijer & Westerhof, 2011). Life review is normally more structured than simple reminiscence and includes the recall and integration of both negative and positive life memories; moreover, it involves an evaluative component as well (Bohlmeijer & Westerhof, 2011). The goal of this kind of reminiscing is to improve aspects of mental health such as self-acceptance, self-efficacy or agency, and the capacity to experience meaning and purpose in life, elements that are closely related to personal identity (Westerhof et al., 2010). It requires well trained professionals, since they are in charge of giving structure to the sessions, establishing links between older people's stories and their present situation, and helping them to reorganize their memories in more positive, meaningful ways (Bohlmeijer & Westerhof, 2011).

Finally, life review therapy is aimed at helping older people who are experiencing severe mental health problems, such as depression or anxiety (Bohlmeijer & Westerhof, 2011). In this case, the goal is to promote personal changes and to alleviate symptoms associated with the illness. The focus is on reducing pessimism and stimulating the positive functions of reminiscence (Bohlmeijer & Westerhof, 2011). Since it is addressed to persons with severe mental illness, this type of reminiscence evokes life stories that are often saturated with problems and reflect the person's dissatisfaction with his or her present or past. Therefore, the practice of it requires professionals with extensive training and experience in psychotherapy (Westerhof et al., 2010).

Pivotal life events and difficult life crises or transitions are associated with increased reminiscence activity (Korte, Bohlmeijer, Westerhof, & Pot, 2011), since they require the person to put adaptive skills into play. In the words of Dan McAdams (2008), they "demand more storytelling work" (p. 253). Moving to a long-term institution is one such crisis due to the feeling the older person commonly has of having lost certain important spatial, temporal, and relational landmarks that previously sustained their sense of identity – what we referred to earlier as "narrative loss." In these cases, reminiscence-based interventions may help the residents to reinstate a sense of community and to restore their identity in more positive terms (Steunenberg & Bohlmeijer, 2011). Additionally, as mentioned above, these same kinds of reminiscence