



A conversational, small-story approach to narrative care for people with dementia living in care institutions: Strategies and challenges

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ABSTRACT

The aim of the paper was to define what narrative care is and identify and discuss everyday conversational narrative care strategies regarding people living with dementia in long-term care institutional settings. To do so, we differentiate between two approaches to narrative care: a big-story approach (reflecting on life stories) and a small-story approach (enacting stories in everyday conversations). The paper is focused on the second approach, which appears to be particularly fit to be used with people living with dementia. We identify three main strategies to implement this approach in everyday care: (1) prompting and sustaining narratives; (2) valuing non-verbal and embodied cues; and (3) constructing narrative environments. Finally, we discuss some training, institutional and cultural barriers and challenges for providing conversational, small story-based narrative care for people living with dementia in long-term care institutions.

Natalia, a 20-year-old nursing assistant working in a Spanish long-term care institution for older people, told us, “Today has been a bad day at work. My supervisor told me off because I was talking with a resident. She told me that I shouldn’t chat when there were so many tasks to do and that, anyway, that resident has dementia, so I was wasting my time with her.” This anecdote illustrates a critical point about the importance (or the lack of importance) that talking with people living with dementia is afforded in many long-term institutions. The goal of this article is to argue why talking, and specifically telling and sharing stories, with people living with dementia is a key ingredient of humane, quality care.

The awareness of narratives as something crucial in care contexts comes hand in hand with the emergence of person-centered models of care. These models share the approach that care should focus not only on the diagnosed illness but also on the person as a whole (Kitwood, 1998). Therefore, care receivers are viewed as unique human beings whose biographical continuity must be preserved and whose points of view on and experiences of daily life should be respected and followed (Edvardsson, Varrailhon, & Edvardsson, 2014). These biographical and subjective points of view are, to a certain extent, constructed narratively as people make sense of their experiences and indeed of themselves by composing and sharing stories (Bruner, 1991). Some scholars have even argued that being a person implies having a personal story and being

able to participate in narrative interchanges (Caddell & Clare, 2010).

Institutional long-term care settings for older people do not appear to be aligned with constructing and sharing unique, personal stories (Doyle & Rubinstein, 2013; Williams & Warren, 2009). Preserving personhood becomes especially critical for people living with dementia, whose capacities for retrieving, organizing and sharing stories are often compromised by the disease, particularly in its last stages (Dempsey et al., 2014). Some authors have proposed the concept of *narrative care* as a way to organize care in such a way that it supports older people in maintaining personhood (e.g. Baldwin, 2015; Vrerink, Jacobs, Mulder, & ten Kate, 2022). For example, Baldwin (2015) stated that narrative care was such a novel concept at that time that it was too early to provide a formal definition encompassing all its facets. However, as new studies and proposals using the concept of narrative care have appeared (e.g. Berendonk et al., 2020; Berendonk, Blix, Randall, Baldwin, & Caine, 2017; Blix, Berendonk, Clandinin, & Caine, 2021; Hydén & Forsblad, 2020; Villar & Serrat, 2017; Vrerink et al., 2022), it is now time to address this task. This is the main objective of this article, focusing on people living with dementia in long-term care institutions.

Consequently, we first define what narrative care is, differentiating a big-story approach (reflecting on life stories) from a small-story approach (enacting stories in everyday conversations). Secondly, we focus on the second approach, which appears to be particularly fit to use

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with people living with dementia. We identify three main strategies to implement this approach in everyday care (prompting and sustaining narratives, valuing non-verbal and embodied cues and constructing narrative environments). Finally, we discuss some challenges for providing conversational, small story-based narrative care for people living with dementia in long-term care institutions.

What is narrative care?

When definitions of narrative care are analyzed and compared, we can see a common core that refers to a practice, a way of providing care that takes the storytelling nature of personhood into account and put it at the very center of care practices. However, the nature of this practices can be understood in at least two different ways.

For some authors, narrative care refers to practices oriented towards achieving or sustaining personal life narratives that underpin personal identity. Thus, Kenyon and Randall (2015) define narrative care as “interventions which, in their implementation, focus on the person and his or her unique life narrative” (p. 143). They consider narrative care as the applied aspect of the theoretical field called narrative gerontology. Similarly, Villar and Serrat (2017) understand narrative care as a “series of interventions and practices that are focused precisely on the uniqueness of how people ‘story’ their lives (...) strategies enabling the achievement of a viable and plausible personal narrative” (p. 44–45).

Other authors take the focus away from the individual life story as the object of narrative care and emphasize instead the process of narration (i.e., the activities carried out to try to make sense of everyday activities) as the central issue of narrative care practices. Thus, for Berendonk et al. (2017), narrative care “entails acknowledging and respecting the unique experiences and stories of each person's life” (p. e12156). More explicitly, this author states in a more recent article that “narrative care is a matter of creating opportunities for narrative expressions, a matter of actively engaging in storytelling activities and a matter of active acknowledgement that experiences are always unfolding in the living” (Berendonk et al., 2020, p. e12278).

This tension between a product-oriented (the life story as the object of narrative care) and a process-oriented (the storytelling as the object of narrative care) approach reflects the distinction between big and small stories first developed by Bamberg (2006). It also reflects the biomedical emphasis on interventions over in-the-moment subjective experiences or quality of life.

A big-story approach to narrative care

A ‘big story’ approach privileges structured narratives, stories that locate different life events at specific space and temporal coordinates and provides a framework to the person (the narrator), offering unity and purpose to their lives (McAdams, 2021). This approach assumes that a life story is made up of temporally interlinked biographical memories that are stored in the person's mind, a representation that is consciously accessible and represents the person's self, their identity (Westerhof, Alea, & Bluck, 2020).

In the case of people living with dementia, such autobiographical memories may fade away, or access to them may be blocked by the disease, risking the maintenance of personal identity (Caddell & Clare, 2010). Therefore, it is not surprising that most interventions labelled as narrative care have followed a big story approach, trying to sustain and ‘refresh’ the life stories of people living with dementia, with the aim of preserving their identity as long as possible (Dempsey et al., 2014). For instance, reminiscence programs (Westerhof, Bohlmeijer, & Webster, 2010) and life story books (Elfrink, Zuidema, Kunz, & Westerhof, 2018) have been used in institutional contexts for older people, including people living with dementia.

Reminiscence programs include a broad family of interventions, conducted individually or in groups by a professional. The focus is on eliciting and sharing autobiographical memories, typically using

memory triggers, such as music, pictures, newspapers, objects from the past, or other types of props (Westerhof et al., 2010). As well as helping to preserve identity in people living with dementia, reminiscence programs can have a positive impact on quality of life, cognitive functions, social contacts and emotions (Cotelli, Manenti, & Zanetti, 2012; Macleod, Storey, Rushe, & McLaughlin, 2021; O'Shea et al., 2014; Park, Lee, Yang, Song, & Hong, 2019).

Life story work is another more recent, narrative intervention based on a big story approach that has been used with people living with dementia in long-term institutions (e.g., McKeown, Clarke, Ingleton, Ryan, & Repper, 2010). Life story work entails gathering and recording autobiographical information from the person (and sometimes with the help of their relatives), including meaningful life events and personal preferences and priorities. This often results in the construction of life story books (Elfrink et al., 2018), which can subsequently be used to enhance person-centered and de-standardized care. They, therefore, contribute to enabling the voice of the person with dementia and maintaining their personhood (Berendonk & Caine, 2019; Doran, Noonan, & Doody, 2019; McKeown et al., 2010), especially in the eyes of others. There is little research into the effectiveness of life story work, but some studies show its potential for enhancing quality of life, cognitive functioning, communication and mood (Elfrink et al., 2018).

A small-story approach to narrative care

In contrast to interventions based on autobiographical narratives, the small-story approach emphasizes the value of the modest, mundane narratives appearing in conversational settings (Bamberg, 2006). These narratives are not the solid product of a personal reflection on one's own life but rather fluid conversational creations linked to the context in which they appear to the participants' dynamic “here-and-now” interactions. In fact, these small stories do not need to refer to momentous, defining and well-formed autobiographical episodes, as they mostly refer to everyday and apparently banal experiences by which the person expresses their perspective: for example, whether I prefer to wear bright colors instead of darker ones, whether I felt any pain in my session with the physiotherapist today, or whether my roommate snores a lot and does not let me sleep. Thus, these ubiquitous small stories are the narrative fabric interweaving an engaged social life. In institutional contexts, interactions around everyday care situations (e.g. bathing, eating, or moving) could be ideal situations for enacting these small stories focused on ordinary experiences. Therefore, these exchanges and conversations around ordinary experiences that can take place when both the care provider and care receiver are involved in care tasks, far from being seen as a time consuming resource (or even as a waste of time, in the case of people living with dementia), can actually be an essential ingredient of humane, quality care. That is because small stories are also, like big stories, a way to preserve and maintain personhood, understood as “a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements” (Kitwood, 1997, p.7).

This socially constructed way to validate personhood is also related to an interactional view of sustaining selfhood. At this point, it is important to take into account that selfhood may be expressed in at least three different ways (Sabat, 2002): (1) A sense of self as a self-conscious, structured and narratively coherent and consistent version of the self that we construct intentionally; (2) a sense of self as an agent capable of acting in the world which does not require self-consciousness but is embodied in our habits and everyday activities; and (3) selfhood understood as the different presentations of ourselves that we enact in social interactions (e.g. different roles we adopt) and requires the cooperation of others for recognizing and validating how we present ourselves. A big-story approach to narrative care points mainly to the first version of selfhood, that is, to preserve one's self-conscious life story. However, a small-story approach is related to maintaining the other two expressions of selfhood: (1) it emphasizes embodied verbal,

but also non-verbal, everyday narratives by which people are active agents trying to influence their world and at the same time, (2) it reveals the co-construction of everyday interactions by which people recognize, validate and define each other's personhood.

In the case of people living with dementia in long-term institutions, emphasizing a small-story approach will make it possible to sustain these two expressions of selfhood, aiming to bypass both the communicative difficulties caused by the disease and the lack of attention and narrative dispossession pervasive in institutional contexts. Dementia may cause a progressive difficulty for the construction of a coherent life story, which limits the application of a 'big story' approach or makes it dependent on biographical information provided by relatives (rather than the person with dementia) if what we seek is reliability and consistent correspondence to facts (Berendonk & Caine, 2019; Witham & Haigh, 2018). In contrast, the situated, embodied and co-constructed nature of small stories, whose reference is frequently the here-and-now needs and interests (regardless, the theme of the small story refers to a past memory, to the present situation, or reflects a future wish) could be particularly applicable (and accessible) for people living with dementia.

Narrative care, and specifically if we consider its focus on embodied conversational, co-constructed small stories appearing in everyday interaction, also promotes and sustains narrative agency, that is, the ability to express oneself in a form that could be recognizable as a narrative (Baldwin, 2008), understanding narrative in its more basic and broad form as an account of connected events or experiences (De Fina, 2017). The enactment of narrative agency depends fundamentally (as we will argue in the following sections) on having the opportunity to express oneself narratively and is key for preserving a sense of personal identity and control over one's own life, as well as for continuing to participate actively in the community (Baldwin & Greason, 2016).

Are small stories present in institutional care?

One might expect long-term care institutions for older persons where residents are surrounded by other residents and by staff most of the day to be a good place for interchanging small stories. On the contrary, evidence suggests that in these institutions, narrative opportunities are severely restricted and loneliness and lack of communication are routine phenomena (Nyqvist, Cattán, Andersson, Forsman, & Gustafson, 2013; Pitkala, 2016). The dominant task- and efficiency-oriented approach to running long-term care institutions exacerbates the lack of meaningful social contact. Pressed by tight time schedules, staff working in care homes may find it difficult to establish any communication beyond their assigned tasks, preferring to interact among themselves (Doyle & Rubinstein, 2013), especially when such interactions are not valued as part of the so-called care work, as Natalia reported in the first paragraph of this article.

Under this premise, the contact between staff and people living in care homes prioritizes instrumental care-related activities over social interactions. Communication often becomes merely instructional, consisting of short standardized imperative sentences and evaluative comments that facilitate completing the task at hand (Allan & Killick, 2014; Westerhof, van Vuuren, Brummans, & Custers, 2013; Williams, Ilten, & Bower, 2016). In some cases, the emotional link between staff and residents is relegated to the completion of the instrumental task or is just used to make care tasks more efficient or quicker (Carpiac-Claver & Levy-Storms, 2007; Levy-Storms, Claver, Gutierrez, & Curry, 2011; Savundranayagam, 2014); however, person-centered interactions could benefit from more focus on psychological needs rather than task completion (Custers, Kuin, Westerhof, & Riksen-Walraven, 2011; Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven, 2012). Often, the voice and stories of people living with dementia are 'kidnapped' by the perspective of the professionals, who interpret their behavior through the lens of dementia and as a symptom of the disease, leading to 'narrative dispossession' (Baldwin, 2008). Others have argued that current structures of institutional care may contribute to 'narrative

foreclosure' in everyday interactions, that is, a feeling that one is living in an irreversible and terminal stage of life, leading to the premature belief that one's life story has ended and that no new chapters can possibly be added to it (Bohlmeijer, Westerhof, Randall, Tromp, & Kenyon, 2011).

In this context, knowing how to promote and carry out everyday conversations in long-term care institutions, especially involving people living with dementia, becomes crucial. The following section describes some strategies for applying a conversational, everyday, small-story approach to caring for people living with dementia in long-term care institutions.

Promoting narrative care in everyday interactions

As argued in the last section, small stories, told in everyday conversations and including those appearing in ordinary care tasks, could be a way to promote personhood and narrative agency, which is particularly key in the case of interactions involving people living with dementia. In this section, we define three strategies for facilitating the emergence and maintenance of these small stories in an institutional care context: (1) prompting and sustaining narratives when they appear; (2) recognizing and valuing non-verbal cues and embodied narratives; and (3) promoting narrative environments.

As we describe these strategies, we will mainly focus on the staff's role in preserving narrative agency. The reason for this is that the contact and interactions with staff (and particularly, with direct care workers) are, by far, the most frequent contacts for people living with dementia in care homes (Williams & Warren, 2009). However, we should not forget that narrative agency is also at stake in other types of interactions, for instance, conversations with relatives (e.g. partners, children, grandchildren) or with other people living in the same institution, including other people living with dementia (e.g. Mok & Müller, 2014).

Prompting and sustaining narratives

A fundamental aspect for promoting narrative care in institutional settings is changing the communicative and conversational practices that are normal in this kind of organization. These practices are, in many cases, asymmetric. That is, professionals tend to take on the active and controlling role in interactions with residents, who become more passive recipients of communication and whose attempts to initiate an interaction are easily ignored by staff (Bennett, Ward, & Scarinci, 2016; Savundranayagam, 2014) given the task-oriented ethos of institutional settings.

Therefore, one of the keys for sustaining narrative agency in people living with dementia is to reverse this situation by stimulating and prompting their participation in everyday interactions. Some strategies have been proposed for doing this (see, for instance, Ryan, Byrne, Spykerman, & Orange, 2005; Savundranayagam & Moore-Nielsen, 2015). A first strategy is *recognizing personhood*, which implies conceptualizing the person with dementia as a person by addressing them by name, greeting them, looking for visual contact with them, or including biographical information in the interaction. Another strategy is *negotiating*, which implies asking about the needs, preferences and wishes of people living with dementia. As well as giving them a sense of control over their lives, this information is an excellent point of departure for informal conversations. Finally, *validation strategies* imply understanding the point of view and subjective experiences of people with dementia. It supposes that staff should take into account and empathize with the needs the person with dementia could be expressing when they talk to them.

There is some evidence that applying these communicational strategies drives and sustains the narrative agency of people with dementia. For instance, they increase the participation and cooperation of people living with dementia in informal conversations, the quantity of personal

information they contribute to conversations and the number of times they ask for both clarifications and further information from their conversational counterparts (Savundranayagam, Sibaliya, & Scotchmer, 2016).

Besides strategies for prompting the appearance of narratives in everyday interaction with people living with dementia, there are other kinds of practices oriented towards sustaining and enriching their participation in the small stories once they appear. In contrast with big stories (e.g. the life story), small stories are not conceived as a product constructed individually and based on past memories but rather as the result of a shared process of construction. In this respect, storytelling is a collaborative accomplishment among participants. Since people living with dementia may have cognitive and communicational difficulties for collaborating in the process, their counterparts (typically, staff members in the case of people living in institutional care contexts) are essential in facilitating and supporting this participation.

This supportive process, which some authors call 'scaffolding' (Hydén, 2017; Hydén & Forsblad, 2020), implies that the cognitively intact participant (e.g. a staff member) sustains the threatened narrative agency by taking an active role in interactions, assuming control of the conversation and completing and correcting those aspects (missing words, redundancies, lack of consistency, etc.) that hinder the construction of a comprehensible narrative. Thanks to this active intervention, people living with dementia can keep on participating and enacting their narrative agency.

Scaffolding involves the use of repairing and facilitating strategies (remembering the theme of the conversation, clarifying what the person with dementia means, filling the gaps left by the person with dementia, linking and organizing fragmentary elements of the narrative, etc.) that provide the necessary support for the co-construction of stories. Scaffolding prevents and solves those moments in which the person with dementia needs support to go on, while at the same time reinforcing the capabilities of people living with dementia and encouraging them to continue participating (Ryan et al., 2005; Savundranayagam & Moore-Nielsen, 2015).

Valuing non-verbal cues and embodied narratives

As people living with dementia may have progressive difficulties remembering and telling their stories in oral form, the capacity of recognizing and taking advantage of the non-verbal, embodied forms of narratives progressively increases.

In the case of dementia, recognizing the crucial importance of embodied forms of narrative involves at least two interrelated aspects, firstly, it means to be aware that the body is an instrument for communicating and 'performing' narratives. Taking advantage of the body and its resources (sounds, gestures, movements, facial expressions), we can, even in advanced stages of dementia, continue exercising our agency, aiming to have an impact and some control over the surrounding world (Kontos, 2004). Secondly, it involves that the body is also a 'repository' of entrenched forms of personhood, aspects that make the person unique and that are present regardless of the degree of dementia: certain physical appearances, habits rooted in our body through gestures, mannerisms, ways of moving facial expressions, etc. Therefore, the body conforms a unique way to be in the world, a pre-reflective and pre-conscious base of personhood (Kontos, 2015; Kontos & Martin, 2013).

Emphasizing the embodied aspect of the person implies that the cognitive dimension is not the main (and certainly not the only) dimension of personhood, whose damage (e.g. in dementia threaten those affected with 'loss of self' (Caddell & Clare, 2010)). The presence of an embodied selfhood makes it possible to highlight non-cognitive facets that are preserved as the illness advances. These embodied views of dementia facilitate approaching the behavior of people living with dementia not from the lens of the disease as pathological symptoms but as attempts to interact with the world, enact agency and express needs

(Dupuis, Wiersma, & Loisel, 2012).

From a narrative point of view, the permanence of an embodied selfhood enables the person with dementia to keep on enacting their narrative agency, that is, continue expressing themselves in ways that can be interpreted as narratives in local interactive situations. These narratives do not necessarily speak about the disease but rather about needs in the here and now. There are many strategies for facilitating the maintenance of narrative agency using embodied resources. For instance, Hydén (2013) assumes that narratives appearing in everyday conversations are not just a collaborative process but also a multimodal process. In other words, they have a cognitive and verbal dimension but are also bodily performed through the eyes, gestures, movements, prosody and non-verbal sounds. These elements, which people living with dementia preserve until the latest stages of the disease, help them to go on telling stories and maintain, thanks to them, their bond with the world and with the people around them.

Other authors (e.g. Twigg & Buse, 2013) emphasize the role that appearance and personal care may have for sustaining a narrative that is consistent with the past of the person with dementia. In this case, caring for clothing and physical appearance should not (or not only) be motivated by the need of meeting certain standards of cleanliness, hygiene and good looks. It is a process in which the person with dementia, with the support of staff or relatives, can reaffirm their identity and value and it provides many opportunities for engaging in narratives, expressed in a verbal or non-verbal way (Buse & Twigg, 2018).

Finally, artistic expression is also a way to maintain the narrative capabilities of people living with dementia. Their remaining bodily resources can be used to continue telling stories following alternative paths that are less dependent on verbal and cognitive skills. Music, for instance, can be used to reveal and communicate emotions, even in advanced cases of dementia (Kontos & Grigorovich, 2018), and its benefits for people living with dementia are well-known (e.g. Särkämö, 2018). Dance and movement (e.g. Melhuish, Beuzeboc, & Guzmán, 2017), visual arts (Windle et al., 2018), theatre (Boersma, van Weert, Lissenberg-Witte, van Meijel, & Dröes, 2019) or other creative storytelling programs (e.g. work on TimeSlips, Basting, 2006) have also shown a positive impact on the quality of life of people living with dementia and their relationship with carers. They are, therefore, a potential resource for helping people living with dementia to express narratives, although they have been approached very little from this perspective.

Constructing narrative environments

Beyond the strategies focused on the interactions between people living with dementia and the staff and how to open everyday care situations (bathing, eating, moving, etc.) to storytelling, narrative care also involves designing organizational arrangements for composing stories and reinforcing residents' narrative agency or what can be called the design of narrative environments.

One of the elements of these narrative environments is providing opportunities for people living with dementia in care institutions to have meaningful interactions beyond their contact with staff in care activities. These interactions foster the enactment and reinforcement of narrative agency and are the result of what Theurer et al. (2015) call 'a conceptual shift from resident care to resident engagement' (p. 204). This shift involves at least three social actors: peers (that is, other residents living in the same care institution), relatives and the community.

In the case of peers, it is necessary to provide physical and relational spaces and times to create and develop friendships and social relationships among residents, including people living with dementia. Creating a positive atmosphere and designing meaningful activities that facilitate these relationships is key to creating relationships in which stories can flourish (Roberts & Bowers, 2015). Stories are even more likely to appear if the relatives are encouraged to participate in institutional life. Due to their bond and previous knowledge of the person with dementia,

the interaction between family members and people living with dementia can facilitate the narrative flow and promote individualized care (Backhaus et al., 2020).

Finally, narrative care is also promoted by the openness of the institution to the community in which it is embedded, for instance, supporting people living with dementia in using public social spaces (squares, parks, streets, etc.), participating in social events outside the institution, or even fostering intergenerational relationships with children or other age-groups within or outside the care home. This participation not only provides opportunities for telling stories from the past but also new experiences to be told as stories and shared.

Apart from providing opportunities for social interactions, creating narrative environments also implies changes concerning the organization of work in care institutions. For instance, personal information about residents can be recorded and updated in narrative terms. Instead of decontextualizing lists of preferences, habits of life ‘facts’, this information could include brief experiences and everyday anecdotes written as narratives. This format, if made accessible to all staff (and particularly, to direct care workers), could be an excellent source of opportunities for interaction. In this regard, technology could facilitate documentation and easy access to information (e.g. Thoft, Møller, & Møller, 2021).

Interdisciplinary meetings are also a context where narratives can be implemented. They are an excellent place for different professionals to compose and share with their co-workers their stories about residents and care experiences so that a common narrative, integrating different points of view, could be obtained. Rather than reflecting hierarchies and power dynamics among different professions and disciplines, these meetings should include – if not center – direct care workers, who are the ones who share and interact most with residents and are likely to be the staff members who know the residents best and other stakeholders, like relatives and the residents themselves, even in the case of people living with dementia.

Specifically, the participation of people living with dementia in interdisciplinary meetings makes it possible to inquire about and take into account their voice and narrative in decisions that involve them, including their care plans. This provides an excellent opportunity for exerting and promoting the narrative agency of people living with dementia, as well as helping staff to become aware of the complexity and uniqueness of each person and the human, respectful and personalized approach they require (Villar, Celdrán, Vila-Miravent, & Serrat, 2018).

The challenge to carry out narrative care

Now that some strategies and practices concerning a conversational, everyday approach to narrative care have been reviewed, we might wonder what barriers there are to putting them into practice or increasing their use. Identifying these barriers could help to deactivate them and focus our efforts. These barriers can be found in three inter-related levels: individual, institutional and sociocultural.

From an individual point of view, some staff members are too focused on task completion and are unaware of the importance of everyday conversations with people living with dementia and how these conversations can be enacted and sustained. Training in narrative competencies, particularly among direct care workers, is essential. These narrative competencies include the capacity for listening. Staff should be attentive to the verbal or non-verbal signals that can trigger narrative agency in people living with dementia. This also includes what Berendonk et al. (2020) and Vrerink et al. (2022) call ‘narrative curiosity’.

In our view, narrative curiosity involves at least two related aspects. Firstly, having a genuine interest in the person with dementia and knowing their life story, preferences and values, not as an objective but as a way to better understand their perspective and subjective construction of here-and-now experiences. Secondly, narrative curiosity implies being open to building a personal relationship with people living

with dementia, a relationship established in symmetric terms and going beyond the completion of care tasks. That is, staff members should be prepared to be open and emotionally involved with the people they care for, which will not only favor seizing opportunities for narrative care but also be a source of meaning and satisfaction for staff (Paudel, Resnick, & Galik, 2020). Such emotional involvement needs training but also support from work mates and, obviously, needs to be part of the organizational philosophy.

Unfortunately, these skills and attitudes are missing in most professional curricula and the organization of work tasks in most care institutions neglects (and even in some cases discourages) personal interaction, which leads us to consider the second level of barriers: the institutional ones. Such institutional barriers have an impact on the individual level and, as we will see, are, at the very least, facilitator factors reinforcing the individual barriers just discussed.

Although a conversational approach to narrative care does not need large economic investments, it does require enough time and tranquility among committed staff to build a relationship, co-create narratives and be able to reflect on them. That is, it requires adequate staffing and avoiding as much as possible work overloads and pressure to complete a lot of care tasks in a short time. These situations, which particularly affect lower-paid, direct care workers, are commonplace in nursing homes and lead to burnout, absenteeism and turnover (Broetje, Jenny, & Bauer, 2020). Changing this situation implies a commitment from the institution to a cultural shift that emphasizes the residents’ psychosocial needs and not just their body and physical needs, a cultural shift that also needs the involvement of the administration and government agencies at different levels, providing policies and funding accordingly.

In other words, narrative care involves leaving a task and efficiency-oriented philosophy of care, a model that is still very frequent among long-term care institutions and opting for a person-centered model of care (Edvardsson et al., 2014; Hedman, Sandman, & Edvardsson, 2021). It requires the commitment of staff members and particularly direct care workers, with a more fluid, flexible, personalized and de-standardized approach to care (Cohen-Mansfield & Bester, 2006). Staff should be consistently assigned to specific residents to facilitate building relationships (e.g. Roberts, Nolet, & Bowers, 2015) and empowered to take the initiative to talk and chat with residents, promoting their narrative agency using the strategies discussed above. Thus, narrative care (and specifically, a conversational, small-story approach to narrative care) is, in our view, a necessary component of any attempt to implement a person-centered approach to care in institutional contexts (Villar & Serrat, 2017).

The institutional commitment to person-centered models and practices of care, in turn, depends on the presence of certain cultural representations of dementia (what we can call ‘metanarratives of dementia’, e.g. Baldwin, 2008), which would be a third kind of barrier. That is, the kind of care we provide to people living with dementia and the care we consider they deserve when living in long-term institutions depends on how we define people living with dementia and their needs and rights. Thus, traditionally, dementia has been conceived as an exclusively biomedical phenomenon, as a process of irreversible deterioration that turns people who suffer from the disease into a kind of “empty shell” or even a “living dead” (Behuniak, 2011; Birt, Poland, Cispke, & Charlesworth, 2017). This view reduces the person to a diagnostic label, leading to expectations of low competence, consolidating a power imbalance between care receivers and caregivers (Roberts & Bowers, 2015) and severely decreasing opportunities for people living with dementia to express themselves and have their voices heard. That is, their narrative agency is greatly reduced.

Narrative care needs a different approach to people living with dementia, an approach that recognizes the fluid and complex nature of dementia (McParland, Kelly, & Innes, 2017), the remaining capacities people living with dementia always have and their dignity as people and rights as citizens, qualities that persist regardless of the severity of the disease. Initiatives promoting dementia-inclusive societies in which

everyone has a basic understanding of what dementia is and how to approach people living with dementia in a respectful way are essential to realizing this goal (WHO, 2021).

Conclusion

The aim of the paper was to define what narrative care is and identify and discuss everyday conversational narrative care strategies regarding people living with dementia in institutional contexts. We have also discussed some of the challenges we face for putting these strategies into practice.

In our view, narrative care, and particularly narrative care based on everyday conversations, is not a technique and even less a kind of “therapy” we can choose to implement in institutional care contexts. Offering narrative care does not imply formal objectives and it cannot be restricted to specific spaces and times. On the contrary, it is more a style of providing quality care and, in general, of relating to residents and, particularly, to people living with dementia. A style that should be present in all interactions and be embedded within all care tasks, since the objective is not to have programmed times for putting the spotlight on stories but rather to maintain a storied relationship with people living with dementia, which is inherent to any social interaction.

Narrative care implies connecting affectively with people with dementia, letting their voice be heard and, most importantly, also taking their viewpoint seriously and using it to personalize care and improve the quality of life of people living with dementia. This would contribute both to sustaining personhood and promoting citizenship rights of people living with dementia in care institutions. Therefore, narrative care is a necessary ingredient of any approach that aims to be person-centered.

Finally, we also need to recognize that the discussion carried out in the present article has its limitations. Firstly, we have only considered narrative care in long-term institutional care of people living with dementia; however, it can also be applied in other care institutions (e.g. hospices, hospitals, mental health units) or even in other non-institutional contexts of care (e.g. professional home care, or people living at home and receiving care from relatives). Although most considerations included in this paper could also be relevant in these contexts, any situation would also have its own specific strategies and challenges. Secondly, we have not provided any empirical results of the impact of narrative styles of care on people living with dementia, staff, or organizational aspects. That kind of research, which is virtually nonexistent as yet, is much needed and would probably involve using qualitative methodologies, including conversational or observational analysis.

Evidence of positive impacts on quality of life and other dimensions of the actors involved could be a further argument for promoting narrative care. Moreover, its implementation is also an ethical imperative: it is essential to humanize relationships with people living with dementia in institutional settings and provide quality of care. This quality, beyond its health and physical components, needs to include, both for people living with dementia and their relatives, key aspects such as support to personhood and relationships with staff (Milte et al., 2016). In this respect, we agree with Kenyon and Randall (2015) that narrative care is core care, a fundamental element in attending to another person's needs and is as important as providing food, shelter and medication.

Data availability

No data was used for the research described in the article.

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