

A Narrative Care approach for persons living with dementia in institutional care settings.

Short title: Narrative Care for persons living with dementia

AAM (authors' accepted manuscript) version

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Abstract

Aims and objectives: We will provide insights in the theoretical background and key concepts of a Narrative Care approach, such as narrative cultures, narrative curiosity, narrative co-composition, and narrative reflective practice.

Background: Care understood as narrative practice underscores the importance of experiences and how these shape identities. Important to the quality of care in institutional care settings is the ability of care providers to cope with complexities and uncertainties in older adults' stories, which can be realized by attending to ways that foster and co-compose evolving and forward-looking narratives. Recognizing these ongoing co-compositions means that persons living in institutional care settings and care providers live, tell, retell, and relive their experiences. A change in the current institutional culture is necessary to implement care as narrative practice. To support such a change, approaches are needed that foster a focus on experiences and relationships and make relational ethics central to care.

Methods: The proposed Narrative Care approach is the result of an iterative development process involving a literature review, interviews with, and observations of, care providers, dialogues with an advisory committee, and consultation with experts.

Main contributions: The proposed Narrative Care approach aims to help care providers a) to recognize the importance of curiosity in a person's verbal and embodied narratives – especially for those living with dementia; b) to take note of individual experiences in all of their complexity and uncertainty; c) to respect these narratives; d) to open up spaces to co-compose new narratives; and e) to allow care providers to engage in narrative reflective practices that shape who they are and are becoming.

Conclusion: The introduced approach responds to the need of implementing strategies to think and work narratively in institutional care settings.

Keywords

Narrative Care; Persons living with dementia; Relationship building; Institutional care; Embodied narratives; Relational ethics; Narrative Reflective Practice

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Summary Statement of Implications for Practice

What does this research add to existing knowledge in gerontology?

- Narrative Care is an approach to care practice that forefronts experience; experiences of people living and working in institutional care settings, such as long term care.
- Narrative Care is an approach, which highlights persons are narrative beings, and the centrality of relational ethics to care.

What are the implications of this new knowledge for nursing care with older people?

- Recognising and acknowledging the complexity of Narrative Care, it is important to establish narrative cultures in institutional care settings, such as long term care.
- Care providers are critical in the implementation of Narrative Care and need to have the opportunity to engage in narrative reflective practice.

How could the findings be used to influence policy or practice or research or education?

- The significance of concepts such as embodied narratives, narrative co-composition and narrative reflective practice must be integrated in the education of all care providers.
- Narrative Care is complex and long-term intervention studies are needed to demonstrate the impact on culture and providing care, such as resident outcomes.

FINAL VERSION

Introduction

Care providers in a nursing home had experienced showering situations with one of the residents [Mrs. Smith] as challenging. Mrs. Smith resisted showering but was unable to tell the care providers why. Eventually, through a conversation with her family members they learned she had always preferred cold showers. Family members articulated an embodied narrative the care providers had failed to see (The experience was outlined in a study published in Berendonk, Kaspar, et al., 2017).

Drawing on experiences, such as Mrs. Smith's, and the call for a "narrative turn in health care" (Bohlmeijer, Kenyon, et al., 2011, p. 371), we propose a Narrative Care approach for persons living with dementia in institutional care settings¹. Central to this approach is the link between social inclusion and care practices that consider both care providers² and persons living with dementia and their care partners. This proposed approach emphasizes the notion that humans are narrative beings with multiple ways to story lives, including the ways people embody narratives. The purpose is to promote the development of narrative literacy (Baldwin, 2010) among care providers, that is "the ability to recognize and work with narratives in all their diversity, strangeness, and splendor" (p. 251), and to engage in narrative reflective practice (Clandinin et al., 2010). Through the proposed approach, care providers are encouraged to support the narrativity of persons living with dementia, acknowledge and foster embodied narratives, and co-compose forward looking stories. By learning and implementing narrative skills, care providers might be able to engage in interactions differently, respect diverse narratives, support identity development, and create Narrative Care environments. Throughout the article, we draw on examples from our lives, practices, and research.

Narrative Care involves the creation of new experiences that emerge out of previous experiences, alongside, and with, another human beings. Its starting point is within people's past and present experiences. By virtue of its respect for residents', care providers', and care partners' experiential lived narratives, Narrative Care has the potential to reshape task-oriented, technical notions of care. We understand Narrative Care as an holistic approach, working from an understanding of care as a narrative practice (Berendonk, Blix, et al., 2017; Blix et al., 2018). Narrative Care is an opening to the numerous possibilities for co-composing stories inherent in everyday care situations such as bathing, eating, and the provision of medication. Narrative Care is a way to keep the futures of older adults open

¹ We use the term institutional care settings referring to the following settings across the continuing care continuum: long-term care, assisted living, supported living, personal care homes, nursing homes, residential long-term care facilities, etc. Within all settings professional care providers provide 24/7 services within a defined space.

² We use the term (paid) care providers to distinguish care provided by unregulated care providers (i.e. care aides, personal care workers, or nursing attendants) and regulated care providers (i.e. licensed practical nurses and regulated nurses) from care provided by care partners such as family members and friends.

(Baldwin, 2015). As new avenues of narratives open up, residents' and care providers' stories continue to grow. Co-composed narratives are shaped within a relational space, making visible the layered relationships between care providers and residents.

Developing the Narrative Care approach

The proposed Narrative Care approach is the result of an iterative development process involving a literature review, interviews with, and observations of, care providers, dialogues with an advisory committee, and consultation with experts. The team of authors comprises researchers, a practicing family physician, nurses, and educators.

Literature review and qualitative study³. The first author carried out a review of the literature on Narrative Gerontology, Narrative Care, life story work, reminiscence work and similar approaches. After summarizing existing approaches, she conducted a qualitative study in a Canadian nursing home that was considered a best practice institutional care setting for providing Narrative Care. Within the nursing home, she engaged in observations and conducted formal interviews and informal conversations with care providers. Four interviews with two registered nurses and two social workers were recorded. She also engaged in observations in a special care unit for persons living with dementia where she also had conversations with a registered nurse, a licensed practical nurse and two unregulated care providers. All audio-taped conversations were transcribed. Field notes and transcripts were analyzed using Mayring's (2010) content analysis.

Advisory committee input. Results of the literature review and the qualitative study were discussed with the advisory committee comprised of all co-authors as well as stakeholders from the Alzheimer Society of NAME REMOVED and persons living with dementia and family caregivers. The committee agreed on philosophical assumptions of Narrative Care and identified relevant elements of this approach.

Expert panel discussion. The final development step was a discussion of the proposed Narrative Care approach with experts. Key elements of this approach were updated according to the recommendations of the expert panel. The eight experts came from four different institutional settings in one Canadian province. Their backgrounds were social work, recreational therapy, and nursing management. Two gerontologists participated in the panel.

³ Ethics approval for the project (particularly for interviews and observations) was granted by the Health Research Ethics Board at the University of NAME REMOVED (NUMBER REMOVED). Operational approval was obtained from the nursing home in Atlantic Canada where the first author conducted field work.

Disrupting Stories: Contexts of Institutional Care Settings and Dementia

Just yesterday, I [AUTHOR] rode my bike past the institutional care setting, where I volunteered more than 30 years ago. I remember the long afternoon walks where we took some residents for walks in small groups. The routes mostly led past farm yards and open fields, cats and dogs following us as we disrupted their quiet afternoons. I still remember some residents so clearly. I too remember some of the nuns, who provided care to many of the residents. At the end of each afternoon the residents' evening meals arrived and I stayed to provide assistance with the meals. The food almost always looked bland, without much texture or smell. On the days that I was there I settled into one of the rooms shared by two residents. I was largely unaware of the formal diagnosis of the residents, but I recall thinking that they must suffer from dementia. As a teenager, I recall the strong sense of suffering that accompanied dementia, as I struggled to imagine what it would be like to live with an illness that impacted my ability to remember. Often the two residents were silent, a silence with which I was at ease. As I assisted with their meals, a nun entered and the atmosphere changed notably. She turned to the food and, looking at me, stated, "Now who is going to be the queen tonight?" I was puzzled and wondered what she meant by this. She then took the spoon from me and assisted the residents at such speed with their meals that it took my breath away. Within seconds their plates were empty and their bodies left gasping for air. She left the room, stating "You both are queens!" The incidents left me bereft and over the next few months I started to slowly pull away from the institutional setting, plagued by an uneasiness and fear that I would once more witness such care. I did not know how to disrupt these experiences at the time. It was many years later that I slowly found ways to disrupt this as I began thinking about, and with, Narrative Care.

Institutional care settings are often meagre narrative environments (Randall & McKim, 2008), marked by a lack of continuity and staff shortages (Vaismoradi et al., 2015). Care providers are under pressure and care practices are often task oriented (Chaudhury, 2008; Ward et al., 2008). Unregulated care providers focus on tasks like bathing and feeding, while regulated care providers are responsible for medications, wound care, and documentation (Daly & Szebehely, 2012; Scales, 2014). Some care providers in institutional care settings have compared their tasks to assembly line efforts (Daly & Szebehely, 2012, p. 143). They have voiced the need for more time to build relationships in order to provide quality care (e.g., Banerjee et al., 2015; Daly & Szebehely, 2012; Ward et al., 2008) and report a lack of time for social interactions including talking with people (Knopp-Sihota et al., 2015; Mallidou et al., 2013).

A consequence of a lack of time for relationships is a risk that care providers may not have opportunities to fulfill their role as significant others and cannot support persons living with dementia in telling and retelling stories of their lives, in words, music, art making or other forms of expression. AUTHOR felt the significant impact of this in an institutional setting she volunteered in more than 30 years ago. Given the narrow conceptualization of the abilities of those living with dementia, care providers may not be able to imagine themselves as co-composers of residents' stories. In cases where people are not able to tell their stories or are not heard, they risk being 'de-storied' (Bohlmeijer, Kenyon, et al., 2011, p. 368). Identities are

constituted by means of narratives in and through time (Smith & Sparkes, 2008), in each new encounter (Taylor & Littleton, 2006); that is, identities are constructed through embodied interaction. Consequently, 'de-storying' may threaten identities and could lead to experiences of dehumanization (Baldwin, 2009). In other cases, like Mrs. Smith's, it may lead to confrontations or an inability to adopt care practices that reflect the experiences of residents. Physically moving into, and subsequently living in, institutional care settings may disrupt the stories people live and tell. This disruption can happen when people are placed in another complex storied place. Institutional care settings are themselves part of, and embedded within, larger social and cultural narratives. The challenges embedded in moves from one storied context to another is even more profound for persons living with dementia, as they often are no longer able to remember and/or articulate significant events and experiences, or to express themselves in spoken or written language (Baldwin, 2005, 2006), and may have additional challenges in their autobiographical memories (Naylor & Clare, 2008). In addition to these challenges, institutional care settings do not stimulate the co-composition and telling of new stories, and care providers are not given opportunities to attend to, and engage with, residents' stories. This has ramifications for persons living with dementia as they are deprived of opportunities to tell stories (Berendonk & Caine, 2016; Doyle, 2012) and to make themselves visible within these new storied contexts. Furthermore, ways in which persons with dementia are constructed by others, especially when they are in the moderate and advanced stages of their illness trajectories, create further challenges. If persons with dementia are no longer seen as individuals composing lives and as humans living storied lives, there are fewer opportunities to tell their stories because there are fewer people who deem their experiences as important to listen to. This is further influenced by perceptions that persons living with dementia do not tell stories at all, as the expected ingredients of a story (i.e. beginning, arc/structure/storyline, or complicating action/critical event) may be missing (Hyvärinen et al., 2010); their stories are discounted because they do not follow the 'normal' or expected story structures.

Experiences of Social Exclusion in Institutional Care Settings

It is paramount to focus on institutional settings because people in these settings are among the most vulnerable populations, and social isolation is highly prevalent in persons living with dementia (Bruce, 2004; Spenceley et al., 2015). These settings are entered primarily to access care, and institutionalization is the norm as persons living with dementia get older and become more care dependent (World Alzheimer Report, 2013). Barriers to social inclusion for persons living with dementia in institutional care settings and their care partners are multifaceted and persistent (Cantley & Bowes, 2004; Government of Canada, 2014).

Over recent years, researchers have inquired into experiences of connectedness and relationships of persons living with dementia in institutional care settings, noting the crucial importance of opportunities to talk about their experiences in order to maintain and sustain self and identity (Surr, 2006). Persons living with dementia feel lonely and isolated (Cahill & Diaz-Ponce, 2011; Clare et al., 2008; Moyle et al., 2011) and have expressed their longing for social contact and stressed the importance of positive relationships with significant others, including care providers (Cahill & Diaz-Ponce, 2011; Moyle et al., 2011; Surr, 2006).

Throughout the course of dementia, persons are often no longer able to maintain contact in the same manner as before, and, in the advanced stages of dementia, need help to foster relationships. Here, care providers play a critical role (Cahill & Diaz-Ponce, 2011; Clare et al., 2008).

Simultaneously, unregulated care providers also feel marginalized and excluded – they too are isolated, underrepresented, their work is not well acknowledged (Caspar et al., 2016; Janes et al., 2008), and little is invested in their training (Afzal et al., 2018; Bowers et al., 2003; Cantley & Bowes, 2004). Where unregulated care providers rarely have access to residents' care plans (Caspar et al., 2016), they have to improvise the care they provide.

A turn towards Narratives

Several years after I [AUTHOR] left the institutional care setting as a volunteer, I took up employment as a care aide. I remember wondering about what care meant; I remembered the gasps for air from people who did not choose to become queens. Those were the days when I left exhausted from daily routines and a fast pace, reminiscent of the race to become queen. It was difficult to consistently disrupt this. Over time, I found small ways to attend in different ways – the time spent with a resident during scheduled bath time, quiet night shifts that allowed me to sit and read to residents who were unable to sleep, or Sunday mornings spent accompanying residents to church – these were the moments in which I could ask, 'Who are you?' It was during these times that I turned towards experiences; experiences expressed through narratives.

As Nussbaum stated, life is a “complex narrative of human effort in a world full of obstacles” (Aviv, 2016). This connection between human lives and narrative is critical to our proposed approach in the context of persons living with dementia in institutional care settings. Telling stories to, and with, others shapes our identities and ongoing identity making (Bruner, 2004; McAdams, 2001, 2006). At the same time as we story our lives, that is, live and tell stories of our lives, we are also characters in others' stories. Others, too, story us. Lives, understood in this way, are told and lived in relation with others and are marked by co-composition. Lives are also lived and told in relation with larger social, cultural, linguistic, institutional, and familial narratives, and – as Nussbaum pointed out – are marked by complexity. In the

processes of moving into an institutional care setting and subsequent institutionalization, this sense of identity development and co-composition may get lost. This loss comes with the risk of narrative foreclosure (Bohlmeijer, Westerhof, et al., 2011) and social isolation, and minimises or, at worst, dismisses who people are.

Small moments alongside residents allowed me [AUTHOR] to begin to build relationships that moved beyond the ordinary expression of care. It allowed moments where questions could be asked, where time spent together remained unstructured, yet focused on what mattered. Even so, experiences like Mrs. Smith's continued. Moments where I, as a care provider, did not recognize the embodied narratives that continued to unfold in the care I provided.

While persons living with dementia may have difficulties remembering and telling their stories, life is more than the recall of, and expression of, stories in oral forms. Embodiment is an important resource for persons living with dementia. It is critical for care providers to know that a fundamental source of selfhood is the body (Kontos, 2005) and that narratives are embodied (Randall & McKim, 2008). Baldwin (2010) has highlighted the meaning of embodied narratives for a comprehensive understanding of the narrativity of persons living with dementia, suggesting it is "a narrative of embodiedness, incorporating the individual experience (emotional and psychological) within a network of narratives (social) which ultimately provides meaning (spiritual) for those involved" (p. 247). Brockmeier (2014) confirms that narratives are critical to our understanding of human identity, regardless of the ability to call forth words or speech. Scholars explored the meaning of clothing and dress (Twigg, 2010; Twigg & Buse, 2013), and appearance (Ward et al., 2014), and pointed out the importance for persons living with dementia to express their individuality and identity using nonverbal means, that is, through and with their bodies.

There is, as Theurer and colleagues (2015) argued, a need for a social revolution in institutional care settings. Currently, activities focus on distraction or entertainment rather than on meaningful relational engagement for persons living with dementia. There is a need to involve persons living with dementia in creating meaningful activities that foster relationships between persons and improve social inclusion in institutional care settings, i.e., the involvement of persons living with dementia in creating Narrative Care environments. Our conceptualization of Narrative Care offers *both*: Attending to, acknowledging and fostering, the spoken and embodied narratives of the past *and* the co-composition of new experiences in the present.

As I [AUTHOR] remember the event that marked the beginning of pulling away from the institutional care settings, I see now how little I knew about each resident. When working as a care aide, this sense did not change, except now I was, at times, privy to the medical diagnosis of some residents. There were no visible practices at play that asked residents who they were as people. I was never asked who I was in relation to the people with whom I worked. I wonder what stories I would have told. Would I have told them about my stories alongside my grandmothers? Or mentioned

my grandmother's death when I was 9 years old, a death that continues to remind me about the precariousness of life?

The proposed Narrative Care approach

Every person is shaped by different experiences, contexts, times, and places. Therefore, there is not *one* Narrative Care approach – there can be as many Narrative Care approaches as people working and living in institutional care settings. Our proposed approach, including four key concepts, build on the ideas of other scholars who have not necessarily explicitly referred to Narrative Care. Implementation has to be understood as a continuum; Narrative Care is always work in progress.

Key concepts

Narrative Care aims to change the culture and structures in institutional care settings, to trigger the narrative curiosity of those involved in care, and to change care practices. The following concepts are key:

- 1) Narrative cultures
- 2) Narrative curiosity
- 3) Narrative co-composition
- 4) Narrative reflective practice

Narrative cultures

Persons living in institutional care settings must be respected as persons; their frailty, diseases, or diagnosis should not be the only lens through which they are seen. First we call for others to see them as people – people like Mrs. Smith. Through emphasising relationships, a different culture begins to be shaped. Institutional care settings are not merely places to die; they are places to live, to develop new relationships, and to co-compose new stories. Relationships are co-composed in every encounter (Westerhof et al., 2014). In narrative cultures, care providers involve residents and their friends and families in conversations. Such conversations assist care providers to understand residents' wishes, preferences, embodied habits, likes and dislikes. In these interactions other ways to provide care are also explored – Mrs. Smith's care providers now provide cold showers.

Narrative Care must be integrated in training care providers in long-term care settings. The provision of time and space for care providers to engage in reflective practices is crucial.

Narrative Care is not only a mindset but is closely associated with structural environments. It is necessary to create physical, social and relational spaces that invite relationships among residents, between residents and care providers, and among residents, families, and care providers. Moreover, Narrative Care involves an openness to community, for example

through opening institutional care settings to those in kindergartens and schools and, thereby, fostering intergenerational relationships. Such meetings are not only opportunities to share stories of the past but also encounters in which new adventures can be co-created in the present.

Narrative Care implies an interplay between residents, care providers, care partners, and management teams in the institutional care settings. It is critical to amend the process of care planning by giving all care providers, especially unregulated, access to existing documents, e.g., the social history, developing new ways to document and update information about residents' life stories, and integrating care providers into care planning. While documentation is essential, it should not be restricted to traditional care plans. Care plans must be living documents centered on residents' diverse and unique experiences. Written information must be accessible to all care providers who are directly involved with residents.

Spaces for ongoing exchange of stories and reflections on embodied narratives between care providers must be created. Systematic ways of exchanging insights with residents' significant others such as family members and friends must be established. Unregulated care providers should be included in family conferences and formal meetings. Organizational modifications in institutional care settings may be necessary to facilitate collaboration between regulated and unregulated care providers and to foster the participation of residents and care partners in defining quality of care. Support from all levels of management in settings, defined responsibilities, modified inter-professional collaboration and communication, and systematically enhanced communication with all care partners is necessary.

[Narrative curiosity](#)

Narrative Care implies being curious with an openness to negotiate and re-negotiate relationships and actions, and openness to co-composing relationships (Westerhof et al., 2014). Narrative Care is not separate from other care tasks. Rather, Narrative Care should be integrated in everyday life in long-term care settings. Care providers need to be able to listen 'openly and respectfully' (Baldwin, 2015, p. 184), observe and communicate; they should be interested in relationship building and co-composing stories as well as in reflecting on their stories. Furthermore, care providers have to be aware of the importance of narrated and embodied stories. Creativity, imagination, and playfulness (Lugones, 1987) are critical elements that make relationships central in care.

We anticipate care providers will engage with people to understand the meanings of individual's experience. While care providers often have comprehensive knowledge about residents, Narrative Care means that it is not enough to know details of each person's life,

details such as their preferences, habits, or rituals. It is also important to inquire into, and be curious about, each person's experiences, which underlie such preferences, as behaviors and actions always carry meaning. By learning to ask 'Why?' we might better understand the complexities of the experiences underlying preferences, habits, and rituals. In Narrative Care we wonder: Why is this experience meaningful to a person? What part does it play in the told, re-told, lived, and re-lived stories of the person? And what part do care providers play in the experiences?

Narrative co-composition

Care providers often become significant others for people, especially if people do not have relatives and friends with whom they are in touch on a regular basis. Therefore, care providers should be aware they sometimes become *the* crucial 'response community' and co-authors for people's stories (Hallberg, 2001). This acknowledges that experiences are always in the making, that the here and now, even for persons with dementia, is not a fixed story, but one that continues to evolve. Co-composition allows for new stories and experiences to unfold. For this to happen, care providers need to have knowledge and be attentive to 'narrative agency' (Baldwin, 2008, p. 225). 'Narrative agency', the ability to tell one's story through words or body, requires care providers to pay close attention to stories persons living with dementia cannot tell for themselves. Care providers need to recognize that they are in relation and that who they are impacts the stories lived and told. Hence, it is important to acknowledge that we live in a narrative web –within "narrative landscape[s]" (Estey-Burt & Baldwin, 2014, p. 61).

Narrative reflective practice

Care providers need to engage in narrative reflective practice in order to inquire into their personal and professional identities. Narrative Reflective Practice (NRP) is a process of self-facing in which care providers engage in narrative inquiry into the stories they are living and telling in relation with residents. Through engaging in NRP, the relational aspects of identities are emphasised. The process of NRP works within a three dimensional inquiry space of temporality, sociality and place. Care providers reflect on their unique practices "in the midst" of their lives, their institutions' lives and their residents' lives. Within their stories of experience, they inquire by attending temporally (not only to what was happening in the moment but what happened before and subsequently, to the moment), by attending inwardly to their emotions and moral judgements, and outward to events and activities, while always being attentive to the places where events are happening. They reflect on who they are within their stories of practice in a reflective and reflexive process of writing their stories, sharing them with co-workers who in turn reflect on what they hear, and by retelling their

stories which leads to changed practices. Within small response groups, each care provider has opportunities to inquire into their experiences over time (Clandinin et al., 2010).

How could Narrative Care potentially change care?

Narrative Care necessitates a cultural change in institutional care settings, which emphasises relationship-building and acknowledges diversity of experiences. Such a cultural change creates a context of inclusiveness and honours a reciprocal approach:

The focus on narrative in eldercare has a reciprocal perspective; it doesn't stop with the care receiver. In helping their clients to story their world, caregivers are also investing and extracting personal biographical energy, which in turn reflects on and influences their way of giving care. (Ubels, 2011, p. 321)

Narrative Care contributes to the notion of 'holding somebody in narratives' (Lindemann Nelson, 2010). Holding, in this sense, means understanding, and sustaining, a person's sense of identity, a person's stories to live by. However, it is "not only other people who hold us in our identities. Familiar places and things, beloved objects, pets, cherished rituals, one's own bed or favorite shirt, can and do help us to maintain our sense of self" (Lindemann, 2010, p. 163). In providing Narrative Care, care providers, family members and significant others contribute to holding persons living with dementia in stories, even as they co-compose new stories and are supported in narrative identity development. Holding a person in this way is only possible when we continually inquire into their experiences, as well as our own, and allow relationships to continually evolve. In the inquiry process we make visible that experience is a valuable source of knowledge.

Long ago I [AUTHOR] left the institutional care setting I volunteered in, and most nuns have now retired, yet, my mother, now in her 80s, still volunteers there. As I listen to her stories, I hear how different her experience is. Many people she interacts with are friends, former colleagues, or parents of children she knew as a Kindergarten teacher. She knows, or has been part of, their experiences in different ways. She, too, is part of their unfolding lives, at times in ways she never anticipated. My mother makes visible all of the relationships she holds in the institutional care setting, relationships that stretch over years. I wonder how different my experiences would have been, had I been able to make connections with people in the ways my mother so easily can. I wonder if I would have been able to speak up during the competition to become queens – if the relationships with residents would have called me to act upon my relational responsibilities, to recognise them as people in the making.

Novelty of the introduced Narrative Care approach

This Narrative Care approach is distinct from other narrative approaches, such as life story work (Bruce & Schweitzer, 2014) and reminiscence work (Thorgrimsdottir & Bjornsdottir, 2016). These approaches focus on the individual, while Narrative Care is an inclusive approach with a system perspective focusing on residents, care providers, care partners and the cultures in the long-term care setting, rather than the individuals' stories.. Furthermore, Narrative Care explicitly highlights the importance of embodied narratives. The approach does not focus only on sharing and telling verbal narratives, it also emphasizes paying attention to embodied narratives that can help to hold persons living with dementia in their narratives. Finally, the approach provides a counter narrative to understandings that persons living with dementia no longer have stories to tell.

Concluding thoughts

Narrative Care involves the creation of new experiences that emerge out of previous experiences, alongside, and with, another person. Its starting point is within people's past and present experiences. Narrative Care has the potential to reshape task-oriented, technical notions of care. As new avenues of narratives open up, residents' and care providers' stories continue to grow. Co-composed narratives are shaped within a relational space, making visible the layered relationships between care providers and residents.

Implementing an approach that necessitates a cultural shift in institutional care settings is crucial. The culture will be marked by a) relationships among all persons living, working in, and visiting these settings; b) an inclusive approach of care planning and decision making that focuses on experiences; and a culture that c) recognizes, values, and incorporates "multiple voices and experiences of everyone involved in the care context" (Dupuis et al., 2016, p. 87).

Despite a shift in labelling institutional care settings to reflect a focus on people living in these settings, the settings still carry elements of 'total institutions' (Goffman, 1961), and do not have well-established ties to care partners. This augments the challenges of social inclusion. Despite recognising the importance of social inclusion and its fundamental link to notions of a 'good life' and of 'doing good', the implementation of approaches focused on fostering social inclusion are for the most part absent in institutional care settings. Change in the current culture of institutional care settings is required as part of implementing care as a narrative practice. To support such a change systematically, approaches need to foster a focus on individual experiences and relationships and make relational ethics central. We have outlined one possible approach for the creation of care practices and settings, which are more

socially inclusive for both care providers and persons living with dementia. We call this approach Narrative Care.

AAM version

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