

Chapter 15

Fostering Resilience in Dementia Through Narratives: Contributions of Multimedia Technologies

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This chapter brings together recent innovative uses of multimedia tools to explore narratives of people with a diagnosis of dementia. The foundations for this work are located in an understanding of the concepts of resilience and well-being and the role of narrative-based reminiscence in fostering resilience, especially as applied to people with dementia. The work collected here focuses on supporting people with a diagnosis, their families, and their communities. We begin with a discussion of the conceptual foundations underpinning this research.

Resilience and Well-Being

The concept of resilience has a long history in the study of human development, emerging initially from research on child development and arriving more recently in the gerontological literature. Although resilience has been described as a personal attribute, it has been more recently interpreted as a dynamic process (Ryff and Singer 2008). While there are various definitions of this process in the literature on aging, central features include the presence of life challenges or adversity, and the maintenance or regaining of physical health and psychological well-being. It has been argued that the concept of resilience may be preferable to the notion of successful aging as a way of emphasizing positive aspects of health (Harris 2008), specifically because it can accommodate adversity as central to the process. This argument rings true in the case of people with dementia, especially given that conceptualizations of dementia and successful aging within current public discourses are not entirely compatible; resilience, on the other hand, encourages a focus on well-being that reminds us of the possibility of positive outcomes despite dementia (Harris 2008). This assertion also encourages a closer examination of the concept of well-being, including well-being in the context of dementia across all levels of severity.

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We take as our starting-point for this examination the work of Ryff and Singer (2008), who base their definitions on theoretical concepts of well-being articulated in Aristotle's descriptions of eudaimonic (versus hedonic) happiness, in the work of philosophers such as John Stuart Mill and Bertrand Russell, and also in the work of twentieth century humanistic psychologists such as Frankl, Rogers, and Maslow. Drawing on these foundations, Ryff and Singer propose six dimensions of well-being including: (1) self-acceptance, involving awareness and acceptance of one's personal strengths and weaknesses, (2) positive relations with others, acknowledged as a central feature of a positive, well-lived life, (3) personal growth, involving the continued development of personal potential, (4) a sense of purpose in life, including the search for meaning in adversity, (5) environmental mastery, involving the ability to find or create an environment that fits one's personal needs, including the ability to control and manipulate that environment, and (6) and autonomy, arguably the most western of all dimensions, which emphasizes qualities such as self-determination and independence (Ryff and Singer 2008, pp. 20–23).

In recent years, there has been increasing evidence to support claims that many people with dementia continue to live meaningful lives with a sense of purpose, maintaining a sense of autonomy and environmental mastery, as well as positive relations with others, and demonstrating ongoing personal growth. Autobiographical accounts of living with dementia (e.g. Henderson and Andrews 1998), as well as the findings of predominantly qualitative research studies and the emergence of self-advocacy groups (see Harris 2008) all indicate such resilience. Much of this evidence, however, focuses on individuals in earlier stages of dementia. Interpretation of what constitutes well-being becomes more complex with increasing severity of dementia.

Kitwood (1997) wrote extensively about well-being in people with dementia claiming that the inevitable losses associated with dementia cause these individuals become increasingly dependent on others to support their well-being, primarily through recognition and support of their unique personhood, which incorporates their life history, values, and personal preferences. His now-famous definition of personhood as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood 1997, p. 8) is primarily a relational one, and as such it is very consistent with Ryff and Singer's dimension of positive relations with others as a source of well-being. Indeed, Ryff and Singer (1998) suggest that while the relative importance of each dimension may be different across cultures, this relational dimension of well-being may be the most universal. However, Kitwood's insistence on the importance of others in supporting the well-being of persons with dementia goes beyond envisioning positive relations with others as a single dimension of well-being; instead, he suggests that it is through the informed intervention of others, creating a supportive social environment, that the person with dementia can realize and demonstrate other dimensions of well-being, even into more severe stages of dementia. Although Kitwood's work has been criticized for lacking sufficient evidence for such claims (Baldwin and Capstick 2007), supportive evidence can be found in the work of others, which illustrates, for example, the capacity of people with more severe dementia to seek meaning in their circumstances or to exploit opportunities for creative work (Sabat 2001).

Although Kitwood's work explores a relationally based concept of well-being in persons with dementia, it fails to adequately address the issue of well-being in others within their social networks; indeed, the concept of relational care arose in part out of such criticisms (Baldwin and Capstick 2007; Hellström et al. 2005). Yet, if resilience and well-being for persons with dementia are increasingly located in their social networks of family, formal carers, and community, the resilience and well-being of others within those networks are also of central concern, a point that is addressed in a growing body of literature on this topic (Gaugler et al. 2007; Ortiz et al. 1999).

Fostering Resilience Through Narrative

We are narrative beings, with our very selves constituted through the stories told by and about us. It is not surprising, then, that narrative has been identified as a therapeutic tool to support resilience in those coming to terms with adversity (Caldwell 2005; Neimeyer and Levitt 2001). But how can this tool be adapted for those with dementia, especially when increasing cognitive losses can fragment the performance of meaningful narratives? The value of drawing on the unique life histories of people with dementia to enhance care practice has been generally acknowledged; most often this has involved seeking biographical information from those familiar with the person with dementia. More recently, however, there is growing attention to ways in which carers can support the person with dementia as teller of his or her own narrative, finding ways to understand that narrative, however, fragmented (e.g. Hydén and Örluv 2009; Sabat 2001). Reminiscence activities are another form of narrative therapy for individuals with dementia, with some evidence to support their use. Woods (1994), for instance, demonstrated that reminiscence activities offer people who have dementia the opportunities for more successful social interaction, providing not only positive experiences for persons with dementia, but also helping carers for persons with dementia in institutional settings appreciate the unique experiences and life histories of those persons (see also Hagens et al. 2003). Reminiscence activities do not always lead, however, to successful interactions (Woods and McKiernan 1995), creating the risk of frustration for both persons with dementia and their conversation partners.

In this chapter, we describe three innovative approaches to engaging narrative as a therapeutic device; these draw on the foregoing literature, but also broaden the scope of exploration to include the role of family, friend, and community relationships in fostering resilience. Each of these three approaches draws on multimedia technologies, capitalizing not only on their potential to create new ways of engaging in narrative constructions, but also, as Caldwell (2005) suggests, their ability to generate legacies for families and communities.

In addition, all three approaches acknowledge the importance of social relationships as a source of well-being by seeking ways to foster that well-being both in persons with dementia and those caring for them. Finally, each of the three approaches draws in some way on narratives that are grounded by a sense of place and community, emphasizing narratives as joint constructions that maintain and strengthen relationships.

Narrative Approaches

Fostering Resilience Within Families by Enhancing Personhood

Resilience requires an inner strength that can come from relationships that are affirming. This is especially true for families who struggle to maintain relationships in the face of chronic illnesses, such as dementia, that affect cognitive and communicative abilities. As discussed earlier, a key approach to fostering resilience for persons with dementia involves supporting and enhancing their personhood. However, because personhood is a relational concept that necessitates consideration not only of persons with dementia but also those who care for them, it is important to examine *shared* activities that involve both family caregivers and individuals with dementia. Current research findings on shared activities suggest that although both parties may work together on activities, family caregivers tend to deal with their emotions alone, which consequently may hinder their own coping or adaptation (Hellström et al. 2005). Therefore, it is critical to examine the ways in which collaborative activities promote the sharing of experiences and emotions for both parties.

One example of a collaborative activity that enhanced personhood is StoryCorps' *Memory Loss Initiative*, which was a national interviewing project in the United States that gathered oral histories of individuals with early stage memory loss by encouraging participants to focus on emotion-based memories. The goal of the Memory Loss Initiative was to support and encourage people with illnesses such as Alzheimer's disease, vascular dementia, and mild cognitive impairment (MCI) to share their stories with family and friends. Conversations were recorded in a booth that was outfitted with equipment for producing a broadcast-quality CD, which was given to participants and also archived at the Library of Congress with participants' permission. Each booth was operated by a StoryCorps facilitator who received training on how to communicate with individuals with cognitive-communicative impairments. The training focused on memory and communication impairments, as well as language-based strategies that elicit communication, such as asking questions that were emotion- or experience-focused instead of questions that focused on specific dates (Kensinger et al. 2004; Small and Perry 2005). In cases where storytellers with memory loss did not have a family member who could conduct the interview, facilitators completed the interview.

A recent study investigated the impact of StoryCorps' Memory Loss Initiative on storytellers with memory loss and their family members (Savundranayagam et al. [in press](#)). StoryCorps interviews related to the Memory Loss Initiative took place at several sites in three cities (Milwaukee, Chicago, and New York). Follow-up telephone interviews were conducted with 42 persons with memory loss, along with 27 family members who participated in the StoryCorps interviews. The interviews were analyzed using the process of constant comparative analysis to identify themes that emerged from the conversations.

Findings revealed that the StoryCorps experience was a meaningful activity that offered opportunities for feeling comfort and acceptance, for enjoying precious moments with one another, for reflection and engagement in meaningful conversations, for re-affirming both the selfhood of individuals with memory loss and their

relationships with family members, for leaving a legacy for future generations within families, and for being part of national history. Given that the purpose of the StoryCorps interview was to share stories and life histories, family members tended to choose personhood-affirming topics that addressed personal preferences, family and intimate relationships, and educational and occupational history. These topics were more likely to elicit conversations than questions that tested the individual with memory loss because the focus was on emotions surrounding the topics listed above (Kensinger et al. 2004). Moreover, the StoryCorps facilitators and family members created a positive social environment by perceiving the experience as an opportunity to showcase the stories of individuals with memory loss. This was especially apparent in the comments about legacies; if individuals with memory loss did not experience a positive social environment, they would not have commented on the importance of the present moment or on the value of their legacies. Both the choice to interview and the act of interviewing acknowledged the worth of the person.

The study findings also illustrated that enhancing personhood, which has most often been viewed in terms of the *individual* with memory loss, is in fact about strengthening reciprocity in relationships. Relationships can easily be taken for granted, but even more so when disease process and disease management threaten to take precedence. By re-affirming and validating the person with memory loss, family members were able to value their existing relationship. Unlike collaborative activities where the focus is solely on the person with memory loss, an emotion-based oral storytelling experience, such as StoryCorps, offers a meaningful way to collectively reflect on past memories and begin a personhood-affirming dialogue. This dialogue allows family members to share their emotions about caregiving directly with the individual suffering from memory loss, instead of processing them alone, which is a prevalent caregiver practice (Hellström et al. 2005). This dialogue also allows persons with memory loss a chance to share emotions based on family stories.

The StoryCorps approach, which focuses on emotion-based conversations, creates new possibilities for family caregivers to foster resilience using personhood-enhancing conversations. It teaches family members that communication is not about answering questions correctly. It is about experiencing shared activities that celebrate relationships. In doing so, the relationship identity of both the storyteller with memory loss and his or her family member is maintained. StoryCorps' Memory Loss Initiative was a powerful experience that acknowledged the personhood of both storytellers with memory loss and their family members (Savundranayagam et al. [in press](#)); as both parties began to appreciate the present moment in addition to past histories, they were actively involved in creating legacies that will impact their existing and future relationships.

Fostering Resilience Within Care Settings: Visual Life Stories

Visual Life Stories (VLS) is a photo-based biographical tool designed for a study exploring how familiarizing long-term care (LTC) staff with residents' life stories can support personhood and contribute to person-centered dementia care. Kelson's concept

of VLS is based on a definition of life story as a “personal narrative that thematically links events” occurring in a person’s lifetime (de Medeiros 2005, p. 6). In her qualitative pilot study conducted in Canada, Kelson (2006) created VLS of two LTC residents with dementia. Each was in the form of a 13-minute DVD presentation about the person’s life that had been produced, based on the resident’s personal photographs, through guided conversations with the resident and his or her family. This photo-based biographical tool was designed to support person-centered care by providing formal caregivers and nursing home volunteers with information about the residents’ life histories.

Kelson conducted her study in two phases. The first phase involved conversational interviews with each resident with dementia and his or her family members. These discussions were based on the viewing of their family photographs. As other studies have found, the use of visual prompts in this study supported residents’ ability to recall and share their life stories. In reflecting on their photographs, resident participants frequently added to the familial accounts of the experiences depicted in the photos, which included childhood photos, wedding and holiday shots, family celebrations, and photos of friends. In the second phase, draft VLS presentations were developed and brought back to participants for clarification and approval. Resident responses to viewing of their VLS revealed how the presentation allowed them the opportunity to re-connect with the emotions embedded in the photographs and to re-visit aspects of their past selves. For example, Claire commented: “*You’ve taken me, taken me in my thoughts, deeply,*” “*Happy memories, happy memories,*” and “*I was lost when he went, but for the time we were married, we were very happy.*” The other resident participant, Jack, also reflected on his life, “*You forget what a good life you’ve had,*” and recollected identity: “*I like to tinker with machinery.*”

Participating family members expressed enjoying the opportunity to view photos with their relative, to reminisce, and to re-live family history and shared memories. Family members’ participation was integral to VLS production and might be seen as a positive vehicle to support family involvement in care by drawing on the expertise that can come from their intimate knowledge of their relative. Interestingly, family members also noted how the VLS might have helped smooth their relative’s transition into care, which had been difficult for both participants.

Following completion of the VLS, four focus groups involving 26 staff members in the two long-term care facilities were conducted. Participants viewed and discussed the feasibility and therapeutic value of the VLS. Content analysis of the textual data generated in these sessions led to the identification of the following five themes.

Knowing the Resident. The majority of staff expressed the importance of knowing the resident in order to provide person-centered care. Staff noted how they learned new information about the resident through the VLS, information that represented key aspects of the resident’s identity, such as a favorite pastime, family structures, personal preferences, and other information that impacted the resident in the present.

Comments shared during the focus groups revealed staff insights regarding the potential of the VLS to affirm the personhood of residents with dementia. For example, one manager commented on the continuity of the resident’s personhood: “*It [VLS] shows who they were and is a reminder of truly who they still are.*”

A nurse noted how *VLS* led to a shift in focus from the resident in the present to the resident over time:

If you walked upstairs right now and you see Claire walking by you'll think of her more as the person she used to be instead of the person she is right in front of you and less of the dementia and more of her history.

Staff comments revealed their enthusiasm for the potential of the *VLS* to support them in their specific roles within the care team. They discussed the possibility of it helping to create a more positive social environment by supporting more effective, meaningful communication in care, citing examples of both informal and formal resident/staff interactions (e.g. meeting a resident in the hall or bathing a resident). Moreover, responses indicated an appreciation for the qualitative difference between visual presentations of residents' life stories versus facilities' current use of text-based documents (i.e. two-page summaries) left in resident charts. As one staff member said, "*Pictures tell a lot that's true.*"

They want everybody to know everything on the first day. Staff shared how family members often expected them to know a great deal about their relative's life history, beginning at the time of admission. This expectation created a level of stress for both staff and family carers, and it led the majority of staff to conclude that families would support the addition of the *VLS* to care delivery.

Effects of Macro-Level Policies. Across all four focus groups, management staff referred to changes in healthcare policy that have negatively impacted their ability to gather comprehensive, accurate biographical information on residents prior to admission. Other changes regarding eligibility for care have resulted in residents being admitted at a lower functional level with more significant cognitive challenges. These policy outcomes serve to highlight the potential role of the *VLS* to assist residents who are increasingly unable to present biographical information to formal caregivers without assistance. According to one manager, "*...we used to be able to get quite reliable information from the resident themselves, now virtually, you can't really...*"

Effects of Micro-Level Demands. Staff offered important insights into organizational level challenges that created barriers to their ability to deliver person-centered care. Staff shared their perceptions of increasing workloads, high resident to staff ratios, rising care levels, and significant time constraints, captured in one aide's comment that "*We're always racing against the clock.*" In the long-term care facilities studied, care aides did not attend care plan meetings where residents' social lives were discussed, nor did they generally have access to the resident charts. This meant that front line staff had little alternative but to receive their information about residents' lives from the residents themselves. Given that the resident population is increasingly challenged in their ability to communicate, this approach seems problematic. Care staff felt that a brief accessible tool like the *VLS* would effectively reduce some of these organizational barriers.

In conclusion, this pilot study suggests that the development and sharing of *VLS* support resilience in LTC settings, in large part by allowing staff to see beyond the labels of "resident" and "dementia," interacting instead with the *person* in light

of his or her unique life story. Clearly, staff members want to better understand the people they provide care for and *VLS* represents a possible means to this end. Given the receptiveness of staff to the presentation of residents' histories in a *VLS* format, the potential of this tool to support personhood and well-being amongst LTC residents appears to be promising.

Fostering Resilience Through Shared Histories

Social reminiscence (Cohen and Taylor 1998) refers to the activity of recollecting and sharing personal memories in a one-to-one or group setting. In dementia care, reminiscence is popular as a relatively simple group activity that takes advantage of the typically well-preserved long-term memories of older people with dementia as their memory for recent events is progressively undermined. Old photographs, artifacts, and music are commonly used to prompt recollections among group members and provide an enjoyable way for them to pass the time.

Reminiscence also has the potential to facilitate and support communication and the development of relationships between people with dementia and those who care for them. This may be particularly true when conversational topics are drawn from shared histories, relevant in some way to all participants. The extent to which group reminiscence activities as compared with individual sessions fulfill this potential for building relationships remains, however, an empirical question; it is unusual for reminiscence to take place as a one-to-one activity in most dementia care facilities. This may be due in part to staffing levels and limited time available for staff to find stimuli to support conversation on an individual basis, but it could also be due to challenges in maintaining ongoing one-to-one conversation with persons with dementia.

The Computer Interactive Reminiscence and Conversation Aid (CIRCA) project in Dundee, Scotland, set out to provide an easy-to-use computer system that can draw on the shared history of participants to support one-to-one interactions between caregivers and people with a diagnosis of dementia (Alm et al. 2004). CIRCA contains a database of approximately 600 media files, including digitized photos, music, and film clips. It incorporates touch-screen technology, making it easy to use both for persons with dementia and their caregivers; either one of the conversation partners, who sit together in front of the computer screen, can select an item that may prompt a recollection or comment. These responses then form the basis of conversation between people with dementia and caregivers as they share their stories and experiences.

CIRCA requires no previous computing experience; there is no mouse or keyboard, and no training is required to start using the program. Upon starting CIRCA, the users are offered three themes to choose from, such as, for example, Entertainment, Recreation, and People and Events. Users make a selection by touching one of the three themes appearing on the screen. Within this theme, users are then offered a further choice between photographs, videos, or music. A key feature of the program is that each time it is opened, media are randomly accessed from the database files

so that only a subset of files are available (for example, only three of seven possible themes will be available in any one session). This feature ensures greater equality between the interactants; neither participant can predetermine what media will be accessed.

A second feature of the CIRCA program is that the files draw on generic rather than personal media from a time period associated with long-term memories, thus highlighting the shared history of a community. The CIRCA program developed in Dundee was designed primarily for Dundee seniors, either locally (as in, for example, photographs of a typical Dundee street scene from the 1950s) or more globally (as in short film clips from mainstream movies such as *Casablanca*, or popular songs from the 1940s such as *Siegfried Line*). In fact, the program captured the shared history of Dundee so well that the local Science Centre has included it as a kiosk exhibit intended to promote intergenerational activities for a target audience of primary school students who frequently attend with their grandparents.

In a series of studies, the CIRCA system has proved easy to use and provides an enjoyable shared activity that can promote well-being both for people with dementia and their caregivers. Analysis of the interactions during CIRCA sessions (as compared with interactions during traditional reminiscence sessions) showed that for people with dementia, even relatively severe dementia, CIRCA provides the opportunity to make choices and engage as an equal partner in a one-to-one conversation with a caregiver. Such opportunities are consistent with dimensions of well-being including autonomy, environmental mastery, and positive relations.

Evaluation of CIRCA identified three major outcomes for care staff: (1) staff saw the people with dementia in a new light; (2) staff re-evaluated their perceptions and expectations of their interactions with people with dementia; and (3) using the computer to run one-to-one sessions improved staff feelings of competence as caregivers (Astell et al. 2009). CIRCA also provided opportunities for enhanced well-being, for both staff members and people with dementia, through improved positive relations.

These findings support the use of social reminiscence as an engaging one-to-one activity for people with dementia and caregivers. Both caregivers and people with dementia enjoy participating in CIRCA sessions and the evidence suggests that this engagement facilitates communication and strengthens relationships. Additionally, the findings from the CIRCA project highlight the utility of generic (as opposed to personal) materials as prompts for reminiscence in dementia care, as the CIRCA contents successfully elicited recollection and sharing of personal memories by people with dementia and caregivers.

Discussion

In this chapter, we considered the question of how narrative can be leveraged as a tool to support resilience for people affected by dementia, their families, and communities. Through StoryCorps, persons with dementia and their family members were supported to engage together in meaningful conversations through which they

co-constructed stories from the past, but in so doing they were also sustaining and strengthening their relationships in the present and contributing to the collective stories of the nation. *Visual Life Stories* also provided an opportunity for persons with dementia and their families to work together toward the construction of a personal history narrative, but with the intent of sharing it within a residential community. By providing a basis for understanding the person with dementia, this tool potentially enables better person-centered care, thus supporting well-being and quality of life for everyone involved – residents, family members, and care staff alike. CIRCA is also designed for use primarily within a care environment, but draws more on the narratives of a community than on individual life stories to support meaningful conversation between persons with dementia and their caregivers.

While each of these tools brings something unique to an overall project, there are important similarities to consider as well. The most obvious of these is the fact that each one is made possible in part because of the opportunities afforded by digital media. The technology itself should not be overlooked for its role in supporting resilience through narrative. There is a very real sense in which history is brought to life through the recorded voice, through photographs, film, and music. So much of our life's narrative is beyond language (Baldwin 2009), and with these technologies we are better equipped to harness the power of personal stories. With these technologies at our disposal, we not only have better ways to elicit and convey narratives, allowing us to overcome some of the barriers posed by illness such as dementia, but we also have better ways to share these narratives with others, over time and across place.

Of course, just because we can, does it mean that we should? Dawn Brooker was very astute in her observation that “filing cabinets in care facilities around the world are full of information about people's lives, but still care staff will not know even the rudimentary facts” (Brooker 2004, p. 220). If these sorts of tools are to be just one more depository of information that is stored away, never to be used in any meaningful way, then why make the effort? By way of answering this question, we want to argue that these kinds of tools are different in more than merely technical ways. They are not just different ways of getting at and sharing the information, but rather they rely on technology that is supporting a different way of engaging around these narratives, and it is this question of how we might engage around the narrative that makes a difference.

First, these technologies are not offering narrative as a simple strategy to be taken up by family members and care providers to help support the person with dementia, but rather are offering a way of creating an *interactional environment* (O'Connor et al. 2007) that itself supports the well-being of everyone involved. The findings of Kelson's study regarding how care staff responded to *VLS* suggest that the focus groups were in and of themselves an important part of the tool. The benefit was not just in the information conveyed through the *VLS*, but was also in the opportunity to talk about it together as a community of practice who share the goal of providing better person-centered care. Similarly, CIRCA is a tool whose primary purpose is to create an environment for supporting meaningful interactions between people with dementia and their care partners.

Second, the matter of history is obviously an important thread in all of this work. In some way, each of these projects takes on the task of drawing out stories from the past. But in each case, it is not just the individual narratives that are important, but also the shared histories that have shaped who we are and how we are in the world. Engaging around shared histories is made possible in part because of the opportunities afforded by the different media. The significance of the technology itself should not be overlooked. These digital tools seem to have some way of extending the reach of these stories – they are no longer “merely” personal, some kind of possession of the individual, but rather are something to which we all belong in some way. StoryCorps is perhaps the best example of this, with its goal of not only creating stories for families to share, but also bringing together these stories of a nation into a collective whole. In different ways, all three projects described in this chapter demonstrate how history can be brought into a communal space where people can engage with each other, sharing common histories and bridging the cultural and generational divides that separate us.

Next Steps

When it comes to technology, questions about next steps are often of the technical sort, e.g. “How do we make it better?” But as health and social scientists, our priority should be to ask: “What counts as better?” Certainly if we are to consider this question from an individual perspective, Ryff and Singer’s framework of resilience may provide some important direction. Although these kinds of multimedia-based tools have not been subjected to extensive research, there is evidence in these preliminary studies to suggest that they may support particular aspects of resilience both for people with dementia and those who care for them, sustaining positive relations with others, sense of life purpose, and environmental mastery. Further research to explore this application of multimedia tools in greater depth would contribute to a more nuanced understanding of the relationship between narrative and resilience in the context of dementia.

While it is important to consider the benefits of such tools for the individuals involved, this early work suggests that we also need to ask questions to help us understand the context in which these kinds of technologies emerge and used in everyday practice, and about the impact they might have on the broader community. For example, how does the socio-political milieu of residential care (or indeed the broader healthcare system) affect the potential of these kinds of technologies? Kelson’s findings suggest that the need for something like *VLS* emerges with the shifting socio-political climate of residential care that has made it more difficult to get to know residents. Is it possible that as healthcare environments become increasingly depersonalized and fast-paced there will be increased pressure to produce technologies that support social engagement? This broader contextual view highlights the importance of moving beyond the individual level ask how narrative,

especially given the opportunities afforded by new technologies, can be leveraged to support something we might rightfully call *community* resilience. These three projects have each, in different ways, directed us to consider the idea that communities can be strengthened to better accommodate the challenges of aging and dementia. Further research will be needed to explore how emerging technologies can build on ideas of narrative to help create these possibilities.

References

- Alm, N., Astell, A., Ellis, M., Dye, R., Gowans, G., & Campbell, J. (2004) A cognitive prosthesis and communication support for people with dementia. *Neuropsychological Rehabilitation*, *14*(1–2), 117–134.
- Astell, A. J., Alm, N., Gowans, G., Ellis, M., Dye, R., & Vaughan, P. (2009) Involving older people with dementia and their carers in designing computer-based support systems: Some methodological considerations. *Universal Access in the Information Society*, *8*(1), 49–59.
- Baldwin, C. (2009) Narrative and decision-making. In D. O’Connor & B. Purves (Eds.), *Decision-making, personhood, and dementia: exploring the interface* (pp. 25–36). London: Jessica Kingsley.
- Baldwin, C. & Capstick, A. (Eds.). (2007) *Tom Kitwood on dementia: a reader and critical commentary*. Maidenhead, UK, New York: Open University Press.
- Brooker, D. (2004) What is person-centred care in dementia? *Reviews in Clinical Gerontology*, *13*, 215–222.
- Caldwell, R.L. (2005) At the confluence of memory and meaning - life review with older adults and families: Using narrative therapy and the expressive arts to re-member and re-author stories of resilience. *The Family Journal*, *13*(2), 172–175.
- Cohen, G., & Taylor, S. (1998) Reminiscence and aging. *Ageing and Society*, *18*, 601–610.
- de Medeiros, K. (2005) The complementary self: Multiple perspectives on the aging person. *Journal of Aging Studies*, *19*, 1–13.
- Gaugler, J.E., Kane, R.L., & Newcomer, R. (2007) Resilience and transitions from dementia caregiving. *Journal of Gerontology: Psychological Sciences*, *62B*(1), 38–44.
- Hagens, C., Beaman, A., & Ryan, E.B. (2003) Reminiscing, poetry writing, and remembering boxes: Personhood-centered communication with cognitively impaired older adults. *Activities, Adaptation, & Aging*, *27*(3/4), 97–112.
- Harris, P.B. (2008) Another wrinkle in the debate about successful aging: The undervalued concept of resilience and the lived experience of dementia. *International Journal of Aging and Human Development*, *67*(1), 43–61.
- Hellström, I., Nolan, M., & Lundh, U. (2005) ‘We do things together.’ A case study of ‘couplehood’ in dementia. *Dementia*, *4*(1), 7–22.
- Henderson, C.S., & Andrews, N. (1998) *Partial view*. Dallas, TX: South Methodist University Press.
- Hydén, L.-C., & Örluv, L. (2009) Narrative and identity in Alzheimer’s disease: A case study. *Journal of Aging Studies*, *23*, 205–214.
- Kelson, E. (2006) *Supporting personhood within dementia care: The therapeutic potential of personal photographs*. Unpublished master’s thesis, Simon Fraser University, Vancouver, British Columbia, Canada.
- Kensinger, E.A., Anderson, A., Growdon, J.H., & Corkin, S. (2004) Effects of Alzheimer disease on memory for verbal information. *Neuropsychologia*, *42*, 792–800.
- Kitwood, T. (1997) *Dementia reconsidered*. Buckingham, UK: Open University Press.
- Neimeyer, R. A., & Levitt, H. (2001) Coping and coherence: A narrative perspective on resilience. In C. R. Snyder (Ed.), *Coping with stress: Effective people and processes* (pp. 47–67) Oxford: Oxford University Press.

- O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., Drance, E., Donnelly, M., Chaudhury, H., & Beattie, B. L. (2007) Personhood in dementia care: Developing a research agenda for broadening the vision. *Dementia*, 6, 121–142.
- Ortiz, A., Simmons, J., & Hinton, W.L. (1999) Locations of remorse and homelands of resilience: Notes on grief and sense of loss of place of Latino and Irish-American caregivers of demented elders. *Culture, Medicine, and Psychiatry*, 23, 477–500.
- Ryff, C.D., & Singer, B. (1998) The contours of positive human health. *Psychological Inquiry*, 9(1), 1–28.
- Ryff, C.D., & Singer, B. (2008) Know thyself and become what you are: A eudaimonic approach to psychological well-being. *Journal of Happiness Studies*, 9, 13–39.
- Sabat, S. (2001) *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford, UK, Malden, MA: Blackwell.
- Savundranayagam, M.Y., Dilley, L.J., & Basting, A. (in press) StoryCorps Memory Loss Initiative: Enhancing personhood for storytellers with memory loss. *Dementia: The International Journal of Social Research and Practice*.
- Small, J.A., & Perry, J. (2005) Do you remember? How caregivers question their spouses who have Alzheimer's disease and the impact on communication. *Journal of Speech, Language, and Hearing Research*, 48(1), 125–136.
- Woods, B. (1994) Management of memory impairment in older people with dementia. *International Review of Psychiatry*, 6(2/3), 153–161.
- Woods, R. T., & McKiernan, F. (1995) Evaluating the impact of reminiscence on older people with dementia. In B.K. Haight & J. Webster (Eds.), *Art and science of reminiscing: Theory, research, methods, and applications* (pp. 233–242). Washington DC: Taylor and Francis.