

Narrative, Objects, and the Construction of the Self: How We Might Remember When We Have Forgotten

Lynne C. Howarth, University of Toronto, Canada

Abstract

Dementia and Alzheimer's disease know no boundaries. While this much is known, there is little beyond the medicalization of onset to provide insights into individuals instantly marginalized by a diagnosis with no future. The role of objects and storytelling in supporting the well-being and engagement of those dealing with Alzheimer's disease and related dementias (ARD) has recently become an accepted strategy in non-medical interventions for the disease. Many care facilities, day programs, and associations providing support for ARD offer reminiscence and story sharing as regular activities. Building on research undertaken to explore how objects can be used as memory cues to evoke a memory of a person, place, event, or artefact in an individual's personal narrative, this paper makes a case for mobilizing object memoir to empower the voices of the cognitively disabled. It argues for respecting the individual storyteller, not for the person he or she once was or may become in the future, but as someone with a unique identity and an inherent value as she or he is in the present. Object memoir as a readily invoked activity not only adds to the self-worth and social efficacy of an individual with ARD, but also fosters meaningful connection with family, friends, and other caregivers who may be experiencing the loss of their own stories as memories of a shared past fade or disappear.

Keywords: Alzheimer's disease; common reminiscence; disability life writing; object memoir; storytelling

Publication Type: research article

Introduction

Imagine being an invited guest at the opening of a state-of-the-art residence in a large city dedicated to the care of individuals with dementia. The design is homelike, with no more than six individual rooms leading off from a kitchen and dining area, with two such "pods" on each of two floors. Each floor features a large common living room with comfortable sofas and chairs, a large-screen television, and an assortment of magazines, books, puzzles, and games on low shelving units which also hold a variety of houseplants. A common garden area, planted with colorful annuals and several kinds of vegetables, with outdoor furniture, a barbeque, and well-stocked bird feeders, is readily accessible from the first-floor living room. People at the event wander in and out at will. The ribbon-cutting includes local politicians, health-care workers, residence staff, residents and their families and friends, and members of the media. You strike up a conversation with a well-dressed and impeccably groomed woman, perhaps somewhere in her early 70's. You share the usual pleasantries of weather, family, some recent travel, and also discuss the look-and-feel of the residence and its importance in offering personalized care to those in cognitive decline. She mentions a lifelong career in public service,

then excuses herself to take the elevator to the eighth floor. The residence has only two floors, and, in an instant, everything you have assumed about this woman based on your conversation, her personal stories, her dress, and her demeanor changes. She is not a visitor like you; she is a resident.

The introduction opens with a story that may or may not be true. It is detailed, vivid, visual, and includes a surprise ending. It is a premise for an exploration of the construction and communication of self through narrative (oral and written), and the actualization and expression of self through the objects one accumulates throughout the life course. It illustrates how the stories we tell about ourselves, and, as appropriate, our possessions, initiate sociality and the building of relationships. The opening story also sets the stage for considering what happens to a sense of self, and to the communication and expression of that identity when a major disruption, such as the onset of Alzheimer's disease and related dementias (ADRD), intervenes to change the course and, importantly, the recall or memory of one's life and construction of self. What role might personal stories and objects play when their association with an individual's past may have been forgotten, in part, or in full?

This article explores the different types of personal narrative, both oral and written, and how we construct identity and communicate a sense of self through our stories. Memory and storytelling, and their importance to fostering happiness and positive mental health and wellbeing will be examined relative to the process of reminiscence. We will consider the emergence of disability life writing, and narratives specific to memory function, and to ADRD in particular. From storytelling we will move on to examining the role of objects (possessions, personal artefacts, treasured mementos) in actualizing and expressing self and identity across the life course, and how objects are being used to foster positive mental health in therapeutic and institutional care of those with ADRD. We will conclude by revisiting both storytelling and objects and their respective roles in constructing and communicating self-identity, offering additional insights gained through a study of individuals with mild or early-stage ADRD employing common reminiscence. Final thoughts will address the question raised earlier, that is, what role might personal stories and objects play when their association with an individual's past may have been forgotten, in part, or in full? The response may also shed light on how we might interpret the "surprise ending" of the opening story quite differently.

Our Stories, Ourselves: Personal Narratives and the Construction of Self

In his introduction to an exploration of personal narrative, Ingraham (2017) notes that

People tell stories. And not just novelists or screenwriters: We all tell them. At the dinner table, on the phone, in the classroom, at the gym. In everyday talk—and in writing—we tell stories that relate the quotidian events of our day, funny happenstances, major and minor scenes from our past. In short, all the ordinary and extraordinary moments of our lives are eligible for expression through the vernacular sharing of personal narratives. (pp. 55-56).

Constructing stories, according to Baumeister and Newman (1994) represents one phase in an individual's process of making sense of his or her experiences, of coming to an understanding of an event (p. 677). These personal narratives represent exercises in self-interpretation and are motivated by four needs for meaning, needs which also guide the interpretive structuring of the story. As Baumeister and Newman (1994) explain, in addition to impressing, entertaining, or

teaching others, stories:

...satisfy a need for purposiveness by depicting the attainment of significant goals or fulfilment states. Others satisfy a need for justification by portraying one's actions as consistent with values, norms, and expectations and by explaining intentions in a comprehensible, acceptable fashion. Other stories help satisfy a need for efficacy by encoding useful information about how to control the environment. Lastly, many stories support the narrator's claims to self-worth by portraying him or her as a competent and attractive person. (p. 688)

Jerome Bruner (2004) adds yet another dimension to the constructivist view of self-narrative as stories that do not occur in the "real world", but are constructed in an individual's mind. He concludes his examination of life as narrative, believing that, "the ways of telling and the ways of conceptualizing that go with them become so habitual that they finally become recipes for structuring experience itself, for laying down routes into memory, for not only guiding the life narrative up to the present but directing it into the future. I have argued that a life as led is inseparable from a life as told" (Bruner, 2004, p. 708). This argument would suggest that our life course is, essentially, as the stories we tell about it, and not necessarily a "true account" of life as it was, as it is, and as it will be. Our stories are ourselves. Or, as Bruner (2004) asserts, "In the end, we *become* the autobiographical narratives by which we 'tell about' our lives" (p. 694).

Our individual stories may assume different forms and content depending on context, timing, situation, stage of life, the particular state of our life, the nature and size of our audience and our relationship to it, etc. While Ingraham (2017) refers to the vernacular sharing of moments of our lives, G. Thomas Couser (2011) expands on oral storytelling to include written or recorded narrations of everyday life. These he defines as "memoir" - a particular genre of life writing that he considers, "especially expressive of cultural values" (p. 233). He adds that, while we all "do" life writing in the form of a job application, a resumé, a personal school essay, or a tell-all personal introduction, or have it "done" for us in an annual evaluation, a medical or scholastic record, an honorary citation, or obituary, few of us will actually have an opportunity or the inclination to write a lengthy life story, *per se*. Memoir allows us to go beyond the format of the institutional record, to colour outside the box of a formalized life story, to tell our stories about our daily lives as we live them, anecdotally. As such, personal memoir, "offers the possibility of taking control of our own stories" (Couser, 2011, p. 234).

Memory and Storytelling: The Process of Reminiscence

The role of memory in the telling of autobiographical stories is given particular prominence in discussions of reminiscence - the phenomenon of remembering our lives. In their review of reminiscence and mental health, Westerhof, Bohlmeijer, and Webster (2010, p. 699) stress that reminiscence is a "naturally occurring phenomenon" throughout the lifespan (i.e., not confined or distinctive to "the aged" or those approaching vulnerability and death), that memories can be "willfully recollected" and forgotten ones recalled, and that remembering is "veridical" (i.e., truthful, veracious) relative to ones existing schema about the self, as well as the social situation at hand when memories are shared. While the Westerhof et al. (2010) article focuses on different forms and uses of reminiscence (i.e., Table 1, p. 701), what is germane to this paper is evidence of the positive relationship between reminiscence functions and feelings of happiness, and indications favoring reminiscence as an intervention for mental health outcomes.

Westerhof et al. (2010, pp. 711-712) note the widespread use of simple reminiscence, life review, and life-review therapies in interventions among a diverse range of individuals and groups across the life course, and reminiscence programs in primary schools, higher education, museums, churches, assisted-living communities, nursing homes, and dementia care, among many others. As they observe, further, “The included activities have also been diverse, from autobiographic writing, storytelling, instructing younger generations about past events, oral histories interviews, scrapbooks, artistic expressions, family genealogy, to blogging and other internet applications” (Westerhof et al., 2010, p. 712). Simple reminiscence is used for older adults who experience the sharing of autobiographic memories as meaningful, and as a social activity that enhances positive feelings. Life reviews offers a more structured activity through individual interviews and guided autobiography groups. Individuals across the life course looking for meaning in their lives or struggling with transitions or adversity, focus on both positive and negative experiences to remind and guide them as to successful strategies for coping in the past. Life-review therapies require specialists who can assist older persons with mental health issues of depression or anxiety to focus on memories that stimulate a positive self-identity (Westerhof et al., 2010, pp. 712-713). Regardless of the type of reminiscence selected, all emphasize a person-centered approach to autobiographical memory recall and focus on the efficacy and effectiveness of interventions on mental health across the lifespan.

Personal Narrative and Disability: The Agency of Storytelling Outside the Box

Through personal narratives, whether oral or written, we construct self-identity, representing to ourselves and others who we believe ourselves to be relative to our experiences and our relationships as we understand, interpret, and/or remember them. How, why, and when we recount our narratives will also depend on what is motivating us to share. Our own perceptions of self will not always or necessarily align with others which is especially true when stories of physical or mental illness and disability are concerned. Davis (2006) reminds us that, “Life writing (life narrative, autoethnography, autobiography) emerged alongside the disability rights movement as a counter narrative to medicalized discourses that position the disabled body outside the boundaries of normalcy” (p. 3). Couser (2006) adds that “It provides people with disabilities the power to occupy the subject position in the face of decades of misrepresentation” (p. 401)

For individuals with ADRD, personal narratives offer the unique perspective of cognitive decline from the inside out. While there are many biographical accounts penned by caregivers (e.g., Bayley, 1999; Keaton, 2011), and several high-profile fictionalized depictions of ADRD (e.g., Genova 2009; Thomas 2014), autobiographies have assumed a prominence of their own during the 21st century. First-person narratives (e.g., DeBaggio, 2002; Bryden, 2005; Taylor, 2007; Mitchell, 2018) document the changes that the author experiences, and his or her evolving physical, emotional, and spiritual responses to progressive decline - accounts that are true and unsentimental representations of an individual in flux. Such textual renderings of change, are likewise reflected in the stories of individuals told through online media, such as blogs (e.g., Swaffer, 2019), videos (e.g., Bute, 2012), social media posts, and association-supported sites (e.g., Alzheimer Society of Ontario, 2019). These various examples of memoir offer evidence of Couser’s (2006) assertion that narratives about our daily lives as we live them offer the possibility of going beyond the institutional record, of stepping beyond the medicalized version of individuals with cognitive decline and gaining control of our stories and our identities. As Bute (2012) notes in her online video, “Now and forever I am still me.”

Kontos (2015) references storytelling as one example of creative expression programs being implemented in long-term care facilities as an “emotion-oriented” approach to improving the quality of life of individuals with dementia (p. 176). In contrast to medicalized discourses and care practices that may view expressive behaviors as problematic or disruptive, respecting the person with ADRD as an “embodied being” recognizes his or her agency for self-expression in meaningful and creative ways, whether verbal (storytelling) or non-verbal (performance). This “new ethics of care” with its attention to human agency, represents a significant innovation and positive step towards understanding ADRD, “not as an independent neurological process, but rather as an experience through which nature, history, culture, power, and discourse all speak simultaneously” (Kontos, 2015, p. 178).

While autobiographies are true representations of their authors, reflecting both their personal perceptions and genuine responses to their changing life situation, they are perhaps more usually interpreted by others as guideposts, or as early warning signs of what is to come. They are as instructive as they are revealing. I would argue, however, that they do little to bridge the solitudes separating caregivers from those in their care, aside from building awareness and understanding - themselves valuable, but insufficient as the gap widens with disease progression. In a paper discussing experiences of loss as expressed in two autobiographies penned by Alzheimer’s disease caregivers, England and Ganzer (1992) observe that,

As we shift through their insights, peak moments, daily burdens, and expressions of feeling, we come to understand that beneath the story, with its descriptions of daily activity lies another level of meaning. Autobiography, then, is a way of keeping the image of the family member alive and present. (p. 16).

They chart the interdependence of a series of losses, beginning with a loss of function relating to memory, domestic and self-care activities (shopping, cooking, managing household finances, driving, dressing, personal hygiene, and grooming), and social and other engagements. As the family member becomes more dependent, the caregiver begins to lose his or her independence in direct proportion, also giving up time for ongoing, important productive activities.

England and Ganzer (1992) identify further in the two caregiver autobiographies, a series of more devastating losses for family members and caregivers, alike (p. 18). Subsumed under the rubric of “loss of meaning”, are losses of dignity and “moral certitude”, including the experience of role reversal. Lost, too, across time is the privacy and solitude for both the dependent and the caregiver. Perhaps the most difficult loss of all, they note is “... the loss of ritual mourning, the caregiver’s social right to grieve at a time when the loss or death of the person is most keenly felt” (p. 9). They ask, with great poignancy, about when that mourning should begin - as memory fails, as a sense of time and place unravels, when speech is uncertain, at the actual moment of death? Because death is unpredictable, even protracted, the past history of, and future direction for, the dependent person - in essence, his or her life story - is lost to the caregiver. As England and Ganzer (1992) conclude regarding the two works that were the focus of their study, “In writing their own stories, [the caregivers] write the biographies of their loved ones so that they are now present in their absence” (p. 20)

Our Objects, Ourselves: Personal Possessions and the Actualization of Self

Within the disciplines of sociology, psychology, anthropology, and narrative studies, cherished personal objects – and the stories individuals tell about them – are seen as “representations”

or extensions of the self. Objects and their associated narratives are a means of self-expression and assist in the maintenance of a cohesive identity. Objects also provide a “socializing” function whereby individuals “differentiate” or “integrate” themselves with others (Csikszentmihalyi & Rochberg-Halton, 1981). The role of objects and storytelling in supporting the well-being and engagement of those dealing with progressive loss in cognitive functions brought about by ADRD has become an accepted strategy in non-medical interventions for the disease. Many care facilities, day programs, and associations providing support for ADRD offer reminiscence and story sharing as regular activities, as described earlier in the paper. The following sections will address the place and relevance of personal objects across the life course, generally, and the use of mementos and self-memory boxes for continuity of identity of individuals with ADRD in care facilities, specifically. The paper will then describe how storytelling and objects are brought together in the activity of common reminiscence, offering examples of outcomes and potential benefits from a study of individuals diagnosed with mild or early ADRD.

While the literature of material culture is vast and rich, it is limited here to considerations of the nature and role of personal objects to individual identity and memory function. It is premised on David J. Ekerdt’s (2015) statement, that “The sum of one’s possessions can be conceived to be something as dynamic as the life course itself, as a convoy of material support. Hardly fixed and static, the convoy provisions changing bodies, role involvements, social relationships, developmental thrusts, and the consciousness of time” (p. 318). The concept of a “convoy” of materiality being acquired, managed, archived, discarded, bequeathed, or otherwise disposed of across a lifespan aligns with a construction of self-identity described earlier through the creation of stories, memoir, reminiscence, and autobiography subsumed under the broad reach of personal narrative. Making the link between stories and objects is a seamless one where each both constructs and reflects the self and memory over a lifetime.

Further to this, as Ekerdt (2015) explains:

Possessions have communicative value for telling stories about oneself. They are a way to evaluate in oneself and others how well life is going, and where it might go next. Just as possessions can signal conformity to age expressions and scripts, they can also be deployed for rebellion and resistance to age. Thus, an ongoing career of consumption actualizes and expresses the life course. (pp. 313-314).

What happens when the life course takes unexpected turns, requires changes in possession management, or necessitates disposition of personal objects? How does one separate from a lifetime of objects, and, particularly, from cherished ones? Where mementos fulfill a role of mediation, supporting one’s sense of self, of relative place or space in the world, of sociality, what does their dispossession portend for stability, let alone, continuity of identity? While such separation may occur because of a change in roles, or migration, or physical disability, or age-related vulnerability, what occurs when cognitive decline, particularly that of memory loss, challenges continuity of identity, in essence, taking the person away from the object, rather than removing the object from the individual? While a person diagnosed with ADRD may relinquish a household of possessions in moving to a care facility, having to choose a familiar “cherished few” items for daily living, what value will those have in preserving a sense of self as memory function continues to decline?

Dementia is a set of progressive, degenerative conditions that impair brain cell function, impeding cognitive abilities for the demands of daily living. Across time changes will occur in

activities relating to decision-making, wayfinding, communicating, and remembering, the latter perhaps the condition best known in public awareness. Alzheimer's disease is the most common type of dementia, which, along with related dementias (collectively referred to as ADRD) is fatal and has no known treatment or cure at this time. Gradually, and irreversibly, the disease affects how a person thinks, feels, and acts. While some individuals may become less expressive and withdrawn, it is still possible to reach people with Alzheimer's disease even in the very late stages. It is important to remember that a person may still feel joy, anger, fear, love, and sadness, even as such responses and/or the degree of those emotions may appear out of character to those who have known the individual well.

Contemporary dementia care facilities are increasingly adopting within their design a customized display case, known as a "memory box" (or self-memory box) for collocating personal objects that physically express aspects of an individual's life that he or she may no longer be able to communicate. A photograph, a map, a hockey puck, a figurine, or a stuffed animal might "stand in" for a person, place, event, activity, or other cherished entity (e.g., a pet) that held an important place in the individual's life. As G. B. Gulwadi (2013) explains, "Memory boxes have three purposes: to establish one's identity; to serve as a spatial orientation cue to assist residents in finding their way back to their room; and to act as a tool for reminiscence" (p. 106). The use of self-memory boxes in care facilities for ADRD has been shown to improve how others, such as family and care-givers, understand and relate to the individual (Hagens, Beeman, & Ryan, 2003), essentially offering a personal context and connection, or a starting point for conversation. This, in turn, can impact the level of care and foster opportunities for on-going social engagement (Kitwood, 1997). However, though the objects housed in the "memory box" may be personal, they are not necessarily selected by the individual him or herself, but may, instead, have been chosen by family or other care-givers.

The Intersection of Stories and Objects

"Common reminiscence" (Grasel, Wiltfang, & Kornhuber, 2003; Westerhof et al., 2010) is also aimed at promoting social engagement and the expression of self through the use of objects. It does so, more directly, through structured group activities aimed at evoking conversation, memories, and stories through the utilization of props. Assisted care facilities provide such programming - often around a common theme - as do commercial firms, such as BiFolkal (<http://www.bifolkal.org/>) and Memory Lane™ (<http://memory-lane.tv/>), with products (e.g. videos, audio CDs, memory books, photographs and slides, tactile objects) and programs to support remembering and reminiscing. Based on her study of individuals with mid-stage Alzheimer's disease, Basting (2003a, 2003b, 2009; Fritsch et. al., 2009; George et. al, 2011) has developed TimeSlips™ - a group storytelling activity that creates a narrative around a generic photograph, and focuses on the validation of each individual's contribution. Subsequent research on the use of theatrical improvisation to create community engagement within a secure long-term care facility is documented in *The Penelope Project: An Arts-Based Odyssey to Change Elder Care* (Basting, Towey, & Rose, 2016).

Whether an individual or group activity, and regardless of whether objects are selected personally or by others, the practice of common reminiscence underscores the continuous validation of self-identity, and the expression of "self" to others through objects as a means of building connection, fostering greater understanding, and being a part of a social group. Structured storytelling activities with objects or props provide participants with a common and "neutral" space for engaging in conversation and rich interaction with others. The objects, in

essence, give “voice” to individuals who are often marginalized or isolated in their daily lives.

Exploring Pathways to Memory - Insights from Research Using Common Reminiscence

That stories and objects can contribute to happiness, sociality, and a sense of well-being of persons experiencing progressive cognitive decline was observed through a study, “Exploring Pathways to Memory,” undertaken by the author and student research assistants in Toronto, Canada, and funded from 2009 through 2013 by the Social Sciences and Humanities Research Council of Canada. While details regarding methodology and data analysis have been reported previously in the literature (Hendry & Howarth, 2013; Howarth, 2014), this current discussion highlights outcomes from a set of activities of common reminiscence conducted with eight individuals who had been diagnosed with early-stage or mild ADRD. It is important to note that early-stage differs from early-onset ADRD, the former indicating progression of the disease (mild/early stage; moderate/middle stage; severe/late stage), and the latter connoting younger onset. Those with mild ADRD may function independently, still able to work, drive, and engage in social activities, while experiencing some difficulties with memory and concentration. Study participants with mild ADRD recruited for the Exploring Pathways to Memory study were able to give informed consent and did not necessarily require caregivers to assist with sessions, aside from helping with reminders, or asking questions of the researchers on behalf of the participant. Those who volunteered to take part were recruited from a local Alzheimer’s association, from one residence offering assisted-care, and from two independent-living apartment complexes for seniors where support workers were available on a contract basis.

While the final number of participants was small (n=8), each participant engaged in a minimum of three sessions, with further follow-up as required. Recruiting offered some challenges, perhaps because those who are initially diagnosed with ADRD must use their time and energy to address the disease; participating in a research program might be low on their list of priorities or seem far removed from the immediacy of their new life situation. Nonetheless, those who joined and continued with the three to five sessions per participant were committed, engaged in the process, and generous with their time. The common reminiscence sessions were conducted over a two-year period, with each audio-recorded and augmented by extensive field notes summarizing participant-researcher interactions and any actions involving the physical tokens.

The Exploring Pathways to Memory study was designed to examine the role of representation – in the form of tokens serving as memory cues – in sense-making, and memory recall for individuals with mild Alzheimer’s disease. Representations here were seen to act as surrogates for some person, place, event, or object identified in a participant’s personal narrative as expressed during the first informal interview session. For example, in response to an invitation to describe an activity that the individual had particularly enjoyed, a participant might tell a story of playing hockey with friends in the parking lot of a nearby school supply manufacturer. At two subsequent sessions with the participant, a representation - or “token” - that might evoke an association with that hockey memory (e.g., a hockey puck, or a photograph of the parking lot, or a Hilroy scribbler, or a food item described in the story) - along with tokens evocative of other people, places, events, or objects described during the first session - would be offered to the participant for comment. The researcher provided the token. Through the act of interpreting or “making sense” of the representation or surrogate, a participant might make an association that led to some recall of his/her initial story/narrative. In some cases, recall was vivid, a near match to the initial recollection; in others, more detail was added to the initial story, and, on

occasion, the participant simply spoke to an entirely different narrative. Likewise, the "memory cue" or representative token might elicit no recall at all.

Thus, while the study made no attempt to be a tool for empirical assessment of memory recall, its intention was, instead, to examine how tokens might influence the nature of sense-making and recall, through such features as story context, sequence, content, and the richness of detail. Analysis of data suggested that there were no discernible patterns in the responses to memory cues. The nature of story context, sequence, content, and richness of detail were not predictable, varying by participant, and with no one approach consistent with any single individual. To assess any direct link between a surrogate token, and the original memory it was chosen to represent, was a non-starter. It may be that a certain song may evoke a particular memory, but the story that surrounds either the song or the situation may vary across recounting, and will most certainly differ as to context, sequence, content, and richness of detail. With even subtle changes in memory function, the song may be given a new meaning, or become disassociated with the original meaning. A connection may be altered, or disappear.

Having come to that determination, the research team (the author and student research assistants) decided to invite participants to bring a meaningful object, a memento, to the third, or a fourth session, depending on availability. It seemed reasonable that, whereas a memory cue provided by the researchers might not be sufficiently evocative to recall a story, a representation provided by the individual with the memory might support a better or more immediate connection. This study, too, provided little evidence to support any claim that context, sequence, and content, and richness of detail for retelling a story around a memory would be more predictable or reliable were the token or cue to be provided by the participant. While confounding the researchers in terms of study design and progress towards addressing the role of objects in facilitating memory recall, participants were genuinely and fully engaged in the activities and expressed some pleasure in return for the next scheduled session. Some indicated disappointment when a session or their continued participation in the study ended, having enjoyed their time with handling objects and being invited to share stories about them. Participants who had sometimes seemed reticent or reserved at the first session, or who had even apologized that we had never had the opportunity to relate to them prior to their diagnosis, were relaxed, talkative, humorous, sometimes self-effacing but unapologetic, self-assured, and quick to make eye contact. While there were sometimes discernible difficulties with memory or with concentration, ease with the process and individual social skills became more apparent at each subsequent meeting.

As noted previously, common reminiscence encourages structured activities around storytelling, promoting social engagement, and the expression of self through the use of props. Throughout the Exploring Pathways to Memory study, there was no way of knowing if, or how much a participant's story was "true", authentic, "real". We had assumed that each memory represented an actual person, place, event, or tangible artefact in the individual's life and that the recall of that memory would be likewise "verifiable" and consistent with the original. In that sense, we were not respecting the inherent value of the story and the storyteller, per se. Why was it of consequence if the memory or its accompanying rendering was accurate or actual in fact? It appeared that we were falling into the trap of assuming that an account of a past is of value only if it is real - the freezing of self in time gone by.

As researchers, we were ascribing an identity to each participant based on how or how well he or she recounted a past that might or might not have been or happened "in fact", rather than

validating the individual *in situ*. Just as wearable camcorders will capture and replay a single day such that one can remember and relive everything that happened that day as many times as one chooses, so, too, was the Exploring Pathways to Memory design seeking confirmation of a participant whose identity is valid solely as it has existed in the past, and continues to return there repeatedly. That is a self-identity designed for the researchers and not for the individual with ADRD who continues to evolve. Perhaps this concern is best summarized by Cooley (2011) who observed:

To this litany of some of the most marginalized members of society's now, many of whom are figured as having tenuous or non-existent relations to the future, we might add cognitively disabled adults Your life story now ceases to have a credible narrator - at least in the eyes of those secure in their cognitive "normalcy." (p. 318).

In video recordings showing TimeSlips™ in action, one initially sees individuals, many of whom are in wheelchairs, disengaged and unresponsive. As the photograph to be discussed appears, and participant contributions to a story about that image begin to fill the flip chart, bodies straighten, and humorous banter and laughter increase in volume. It is a transformation to engagement and social inclusion, for most if not all involved. A son comments about his father that he is coming to value the person his father is becoming, and no longer looking for the man he was. It is a poignant comment and an astute one. Common reminiscence modelled along the lines of a TimeSlips™ program encourages the validation of a self that is continuously evolving - both those with and without ADRD. It was a moment of clarity for the Exploring Pathways to Memory team intent on recall of a memory assumed to be fixed and unassailable in fact, rather than a story expressive of a self in flux.

Interpreting Outcomes from Exploring Pathways to Memory Object/Storytelling Sessions

While it was not possible to determine or measure with any certainty if or to what degree objects used in common reminiscence sessions assisted in memory recall, what we were able to determine was the importance to participant self-image and identity to be invited to share stories with others, and to be engaged in meaningful social interaction free of judgment. It was apparent that researcher interest was fully trained on each individual, and that there was active listening and genuine appreciation for what the storyteller had to say. Simply to be asked and respected for one's contribution provided validation and acknowledgement of each participant's importance and place.

One of the study participants, for example, asked to be permitted to speak to a group of potential recruits who were, themselves, attending a weekly meeting for those recently diagnosed with ADRD. As the study team described the sessions, inviting future participation, "Mike" spoke to what his engagement in Exploring Pathways to Memory had meant to him. He noted that he had been nervous about attending but was encouraged to do so by his wife. He mentioned that he had had a successful career as a pilot, but that his ADRD diagnosis had brought that to an end. He spoke of losing confidence, of an increasing sense of worthlessness, and even of a sense of "disappearing", of becoming more invisible. Being asked to talk about himself and about what was important to him was a positive experience. He commented on how he felt valued, and how much his own life stories seemed to matter, not only to him but to others. He looked forward to the object/storytelling sessions and encouraged others to become involved. Not only was "Mike" a compelling ambassador for the project, but also a source of insight to the team as to the

inherent value of close listening to an individual who was feeling increasingly marginalized in his own space. It was driven home to us, as researchers, that, in a life that becomes more uncertain as time passes, such affirmation of personal worth is reassuring, bolstering self-esteem. While we had no tools for measuring such outcomes from the Exploring Pathways to Memory study, we did witness changes in demeanor and self-confidence of participants as sessions progressed, and certainly have further evidence of the transformative potential of common reminiscence through the example of TimeSlips™.

Object Memoir as Strategy: Common Reminiscence, Cognitive Decline, and the Evolving Self

Recognizing the potential and benefits of self-efficacy, sociality, and affirmation of individual worth that accompany activities around common reminiscence, the idea of “object memoir” has been considered as a means of empowering those experiencing progressive cognitive decline, and overall loss of ability. Object memoir forges a connection between objects and stories, within a narrative context of disability life writing (Couser, 2006, 2011) that moves the marginalized beyond discourses of medicalization. Object memoir suggests a strategy for telling (life) stories, and for empowering those whose cognitive disabilities have relegated them to a category of “no future”.

It is in this space of progressive loss that we see an opportunity for object memoir. Engaging in common reminiscence around an object, whether familiar to either the individual with ADRD or the attending member of the family, a friend or caregiver, offers a neutral “space” for storytelling to occur. The object is the focus of attention, the tangible artefact which is central to whatever is shared about it. If I am telling the story about it, then the story is mine, and mine alone - not to be corrected, interrupted, or judged. In traditional talking circles, whoever holds the talking stick is invited to talk, and only that storyteller is allowed to speak until the stick is passed along to the next person. This creates a safe, respectful space, where everyone is free to engage without censure. It is within the space of an object memoir that we can tell the stories of our lives, regardless of their veracity or provenance. This is a present state that may bear little or no resemblance to a past, or show evidence of any connection to a future. To illustrate the potential of object memoir to create meaningful connections when memory or a loss of function in recalling the familiar, including a family member or friend, is no longer essential to being together, I offer the following story.

Shortly after presenting findings from the Exploring Pathways to Memory study and their implications at a conference, I was approached by a young man who was visibly upset. He told me about how much he had loved his grandfather, and about how they spent hours together simply talking. When his grandfather was diagnosed with Alzheimer’s disease, and as his memory and ability to speak began to fail, their times together became more silent, and increasingly uncomfortable for the grandson. He said he did not know what to talk about, and, as his grandfather could no longer recognize him as his grandson, he stopped going to visit. He noted that, without being able to share stories of their past together, it seemed futile to continue trying to communicate. He expressed deep regret, saying that, had he known that they could have talked about some of the mementos in his grandfather’s room or even unfamiliar objects that were much in evidence around the residence more broadly, he could have continued simply “being” and sharing time with someone very special to him. This was a conversation reminiscent of the son’s comment in the TimeSlips™ video, mentioned earlier.

Whereas TimeSlips™ uses photographs selected at random by staff leading a storytelling program with individuals with mid-stage Alzheimer's disease, object memoir allows for individuals to self-select mementos, or for objects to be contributed to a session by anyone attending. This, of course, could be as simple as a one-on-one visit, or a regular program at a community center, a library, a residence, or an association meeting. Stories need not be recorded, but they must be permitted a close listening, must not be challenged, and must be accorded the value they deserve as important to the storyteller. The teller must be treated with respect and dignity, and as the sole authority as to its veracity. The power of an object memoir is to give voice, an identity, a presence, and a meaning to someone in the present. By focusing on the present moment, unencumbered by regrets about a past that is less remembered, or worrying about a future that may allude any previous expectations, we are free to experience the person as he or she is, and not as she or he was or could be. We can begin to make new, meaningful connections, and to build bridges of conversation and genuine sharing in place of walls of silence.

Conclusion

The research design for the Exploring Pathways to Memory project was exploratory and relied on multiple approaches for understanding how one “gets to” or “gets back to” memory. As with any pathway, there are false starts, dead-ends, and trajectories that go in circles. But one can also find a way, or many ways, to understand a research question or questions, and be surprised at unexpected insights across the journey. It is likely most truthful to admit that we never found one, several, or perhaps any pathways to memory, per se. But we did find an approach which, while not on any particular course towards memory recall, did offer the stuff of memory in terms of stories about the self, about identity, about place and value within a life, and about the social engagement of meaningful time in conversation, together. That is when we cease to be a nobody and become a somebody, whomever that body may be in the present.

Acknowledgements

The author acknowledges the Social Sciences and Humanities Research Council of Canada for funding the Exploring Pathways to Memory project under its Standard Research Grants program, 2008-2012. She is likewise grateful to those who participated in the study.

References

- Alzheimer Society of Ontario. (2019). Stories of hope. Retrieved from <https://alzheimer.ca/en/on/Get-involved/Share-your-story/Stories-of-hope>
- Basting, A. D. (2003a). Exploring the creative potential of people with Alzheimer's disease and related dementia: Dare to imagine. In J. L. Ronch & J. A. Goldfield (Eds.), *Mental wellness in aging: Strengths-based approaches* (pp. 353-367). Baltimore, MD: Health Professions Press.
- Basting, A. D. (2003b). Looking back from loss: Views of the self in Alzheimer's disease. *Journal of Aging Studies*, 17(1), 87-99. [https://doi.org/10.1016/S0890-4065\(02\)00092-0](https://doi.org/10.1016/S0890-4065(02)00092-0)

- Basting, A. D. (2009). *Forget memory: Creating better lives for people with Dementia*. Baltimore, MD: Johns Hopkins University Press.
- Basting, A.D., Towey, M., & Rose, E. (Eds.). (2016). *The Penelope Project: An arts-based odyssey to change elder care*. Iowa City, IA: University of Iowa Press.
- Baumeister, R.E., & Newman, L.S. (1994). How stories make sense of personal experiences: motives that shape autobiographical narratives. *Personality and Social Psychology Bulletin*, 20(6), 676-690. <https://doi.org/10.1177/0146167294206006>
- Bayley, J. (1999). *Elegy for Iris*. New York, NY: St. Martin's Press.
- Bruner, J. (2004). Life as narrative. *Social Research*, 71(3), 690-710.
- Bryden, C. (2005). *Dancing with Dementia: My story of living positively with Dementia*. London, England: Jessica Kingsley.
- Bute, J. (2012). What dementia is to me [video]. Retrieved from <https://vimeo.com/40513833>
- Cooley, R. (2011). Disabling spectacles: Representations of Trig Palin and cognitive disability. *Journal of Literary & Cultural Disability Studies*, 5(3), 303-320. <https://doi.org/10.3828/jlcds.2011.24>
- Couser, G. T. (2006). Disability, life narrative, and representation. In L.J. Davis (Ed.), *The disability studies reader* (pp. 399-401). New York, NY: Routledge.
- Couser, G. T. (2011). Introduction: Disability and life writing. *Journal of Literary & Cultural Disability Studies*, 5(3), 229-241, 349. <https://doi.org/10.3828/jlcds.2011.20>
- Csikszentmihalyi, M. & Rochberg-Halton, E. (1981). *The meaning of things: Domestic symbols and the self*. Cambridge, England: Cambridge University Press.
- Davis, L. J. (2006). Constructing normalcy: The Bell Curve, the novel, and the invention of the disabled body. In L.J. Davis (Ed.), *The disability studies reader* (pp. 3-16). New York, NY: Routledge.
- DeBaggio, T. (2002). *Losing my mind: An intimate look at life with Alzheimer's*. New York, NY: Free Press.
- Ekerdt, D.J. (2015). Possessions as a material convoy. In J. Twigg & W. Martin (Eds.), *Routledge handbook of cultural gerontology*. Retrieved from <https://www.routledgehandbooks.com/doi/10.4324/9780203097090.ch40>
- England, S.E., & Ganzer, C. (1992). The many faces of loss: autobiography of the Alzheimer's experience. *Illness, Crisis, and Loss*, 2(2), 13-21. <https://doi.org/10.2190/IL2.2.c>
- Fritsch, T., Kwak, J., Grant, S., Lang, J., Montgomery, R., & Basting, A. D. (2009). Impact of TimeSlips™, a creative expression intervention program, on nursing home residents with dementia and their caregivers. *The Gerontologist*, 49(1), 117-127. <https://doi.org/10.1093/geront/gnp008>

- Genova, L. (2009). *Still Alice*. New York, NY: Gallery Books.
- George, D.R., Stuckey, H.L., Dillon, C.F. & Whitehead, M.M. (2011). Impact of participation in TimeSlips™, a creative group-based storytelling program, on medical student attitudes toward persons with dementia: A qualitative study. *The Gerontologist*, 51(5), 699-703. <https://doi.org/10.1093/geront/gnr035>
- Grasel, E., Wiltfang, J., & Kornhuber, J. (2003). Non-drug therapies for dementia: An overview of the current situation with regard to proof of effectiveness. *Dementia and Geriatric Cognitive Disorders*, 15(3), 115-125. <https://doi.org/10.1159/000068477>
- Gulwadi, G.B. (2013). Establishing continuity of self-memory boxes in dementia facilities for older adults: Their use and usefulness. *Journal of Housing for the Elderly*, 27(1-2), 105-119. <https://doi.org/10.1080/02763893.2012.754817>
- Hagens, C., Beaman, A. & Ryan, E. B. (2003). Reminiscing, poetry, writing, and remembering boxes. *Activities, Adaptation & Aging*, 27(3-4), 97-112. https://doi.org/10.1300/J016v27n03_07
- Hendry, E., & Howarth, L.C. (2013). Memory, truth, and storytelling: Evoking narrative from individuals with mild Alzheimer's disease. In Kristin Hodges, Eric Meyers & Heather O'Brien (Eds.), *Tales from the edge: Narrative voices in information research and practice*. Proceedings of the 41st Annual Conference of the Canadian Association for Information Science, Victoria, B.C.
- Howarth, L.C. (2014). Drawing clocks without time: Alzheimer's, marginalization, and the liberatory potential of object memoir. In Matthew Griffis, Heidi Julien, & Lisa Given (Eds.), *Connecting across borders: Globalization and information science*. Proceedings of the 42nd Annual Conference of the Canadian Association for Information Science, St. Catharines, ON. Retrieved from <https://journals.library.ualberta.ca/ojs.cais-acsi.ca/index.php/cais-ascii/article/view/886/799>
- Ingraham, C. (2017). The scope and autonomy of personal narrative. *Written Communication*, 34(1), 54-74. <https://doi.org/10.1177/0741088316683147>
- Keaton, D. (2011). *Then again*. New York, NY: Random House.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Philadelphia, PA: Open University Press.
- Kontos, P. (2015). Dementia and embodiment. In J. Twigg & W. Martin (Eds.), *Routledge handbook of cultural gerontology*. Retrieved from <https://www.routledgehandbooks.com/citation?doi=10.4324/9780203097090.ch22>
- Mitchell, W. (2018). *Somebody I used to know*. London, UK: Bloomsbury.
- Swaffer, K. (2019). Creating life with words. Retrieved from <https://kateswaffer.com/daily-blog/>
- Taylor, R. (2007). *Alzheimer's from the inside out*. Baltimore, MD: Health Professions Press.

Thomas, M. (2014). *We are not ourselves: A novel*. New York, NY: Simon & Schuster.

Westerhof, G.J., Bohlmeijer, E., & Webster, J.D. (2010). Reminiscence and mental health: A review of recent progress in theory, research and interventions. *Ageing & Society*, 30(4), 697-721. <https://doi.org/10.1017/S0144686X09990328>

Lynne C. Howarth (lynne.howarth@utoronto.ca) is a current Professor and former Dean at the Faculty of Information (iSchool), University of Toronto, Canada. Between 2011 and 2013 Howarth completed a two-year affiliation as Distinguished Researcher in Information Organization at the University of Wisconsin-Milwaukee iSchool. She was honoured with the Distinguished Scholar *Lectio Magistralis* in Biblioteconomia, Florence University, Italy, in 2011, and presented with the ALISE/Connie Van Fleet Award for Research Excellence in Public Library Services to Adults in 2016. She conducts research, publishes, and teaches in the areas of knowledge organization, representation, and curation of the cultural record, and the design of information programs and services to persons with disabilities, with a particular focus on cognitive impairment. Across the 2008-2019 period, she has completed three successive studies relating to objects, memory, and storytelling, each funded by the Social Science and Research Council of Canada (SSHRC).