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"IN MY OWN WORDS"
Writing Down Life Stories to Promote Conversation in Dementia

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Writing is a form of memory.
(Alan Dienstag)

INTRODUCTION

Communication is central to sustaining personhood for individuals with dementia, as demonstrated by the conversation analyses presented earlier in this volume. Our applied dementia focus concerns the collaborative elicitation of life story fragments in conversation and the use of written recordings of these stories as triggers for future conversation in longterm care settings. In this chapter, we briefly overview one-on-one work with conversational remembering boxes and life story binders. Then, we present two case studies for a program of group storytelling and life story binders implemented on two hospital units: a complex care unit where patients may stay for months or years and a unit for patients with dementia awaiting, often for months, placement in longterm care. The objective is to record the individuals' own words to optimize their chances of retrieving stories from their lives for sharing, elaboration, and personal connections with staff, peers, and family.¹

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As seen in all the chapters of this book, eliciting language from persons with dementia can be challenging. Here, we have highlighted successes to raise expectations of what is possible (Thompson, 2011). Many portions of conversational or group sessions were very difficult, with residents passive and responding minimally. Often it took multiple sessions before individuals accessed more language and extended cognition, usually because of a topic of interest or greater comfort over time or just a good day.

We begin with an overview of the literature concerning the impoverished communication environment of longterm care and the use of reminiscence and storytelling to enrich opportunities for individuals with dementia to interact meaningfully.

**COMMUNICATION ENVIRONMENT FOR INDIVIDUALS WITH DEMENTIA
IN LONGTERM CARE**

Overcoming Communication Predicaments of People with Dementia in Institutional Care

Research over the past 30 years has established many aspects of the Communication Predicament of Aging (Ryan et al., 1986) whereby conversational partners often make it difficult for older adults to communicate effectively because of stereotype-driven communication (Harwood, 2007). This negative feedback cycle contributes to excess disability, especially for elders with cognitive, sensory, or physical impairments and for those in institutional environments (Ryan, 2010). For example, the use of elder speak (characterized by high pitch, exaggerated intonation, simplified vocabulary and grammar, nicknames, and repetitions) has been associated with decreases in self care and resistance to care in longterm institutions (Williams, 2011). Figure

7.1 displays the Communication Predicament of Aging Model, including the opportunity for elders to be supported in using selective assertiveness to resist patronizing, dismissive, and overly nurturing behaviors (Ryan, 2010).

Over this same period, researchers have introduced models for counteracting the overly controlling, overly nurturing, or efficiency-oriented approaches typical in nursing homes. Lubinski (2011) emphasizes the importance of creating a positive communication environment to optimize communication. To reduce excess disability and limit behavioral problems associated with boredom and loneliness, Montessori methods focus on modifying the task and preparing a supportive task environment to optimize the chance for performance success and gradual improvements (Orsulic-Jeras & Camp, 2000).

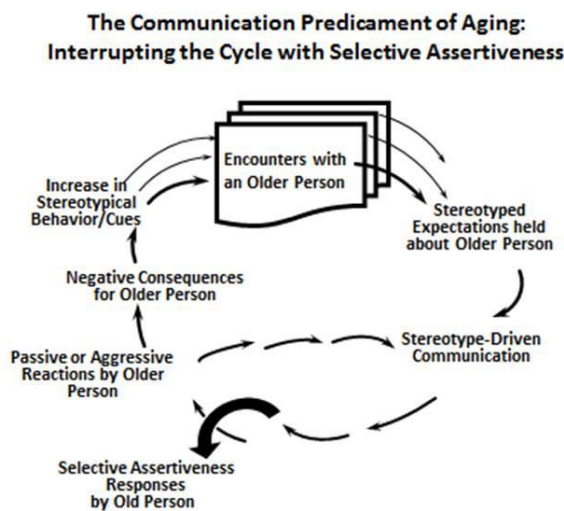


Figure 7.1 The Communication Predicament of Aging-. Interrupting the Cycle with Selective Assertiveness (Reprinted with permission from Ryan, 2010, p. 78.)

The Communication Enhancement Model with its health promotion emphasis can be applied for work in dementia to improve conversation through individualized assessment of remaining abilities and sensory impairments, high expectations, mutual support, and optimized settings (Orange, Ryan, Meredith, & MacLean, 1995). As the individual is empowered, interactions become more reciprocal and fulfilling for them as well as staff (Davis, 2005; Hagens, Beaman, & Ryan, 2003; Ryan, 2010).

In line with all these models, Kitwood (1997) demonstrated the role of personhood-oriented approaches in reducing excess disability among longterm care residents with dementia. With the support of others, individuals with dementia can maintain communication, connection, and well-being. Family and caregiving staff serve the person by holding on to the memories and using them to support conversation (see Backhaus, 2011; Basting, 2009; Davis, 2005; McFadden & McFadden, 2011).

Such relationship-sustaining approaches foster resilience among persons with dementia. That is, sharing life story memories can enhance the capacity for well-being despite declining abilities (Purves, Savundranayagam, Kelson, Astell, & Phinney, 2011). Given the time and

listening attention, individuals with moderate dementia can access longterm memories. As the person connects with their life story, language fluency improves and related memories come forth. Orientation to current person, place, and time can even emerge as the interaction continues.

Reminiscence for Personal Conversation

Reminiscence (also called personal storytelling and life story work) has gained prominence for promoting conversations with individuals with dementia since longterm memories are retained longest (Killick & Allan, 2001; Thompson, 2011). Support for personal narratives to add meaning to lives within dementia is increasing. Those with dementia can tell stories that retain the conventional storytelling structure, and they find this social activity engaging and enjoyable (Fels & Astell, 2011). Moreover, people with dementia exhibit higher discourse quality within a reminiscence group than in a formal assessment (Moss, Polignano, White, Minichiello, & Sunderland, 2002). For a small sample of people with dementia, reminiscence sessions led to higher verbal fluency in post-test than regular everyday conversational approaches (Okumura, Tanimukai, & Asada, 2008). Nonverbal interchanges among peers also improved over the five group sessions.

Through a meta-analysis of reminiscence studies, Bohlmeijer, Roemer, Cuijpers, and Smit (2007) have shown a significant influence on life satisfaction and emotional well-being, somewhat stronger for community dwellers than longterm care residents. Bohlmeijer et al. (2007) imply that benefits in dementia are constrained by the reluctance to engage in therapeutic life review reminiscence as opposed to an overprotective focus on positive reminiscence alone.

Moos and Bjorn (2006) did a systemic review of evaluations of interventions using storytelling specifically with individuals with dementia. Benefits identified include communication, social integration, and positive affect (see also Moss et al., 2002). Storytelling in dementia stimulates creative expression, which is associated with increased well-being for older adults of all levels of functioning (Sierpina & Cole, 2004). However, Moos and Bjorn (2006) do argue that the focus on intervention studies for dementia may be premature and that more qualitative research on how to support creative expression in dementia is needed. Writing Down the Words to Promote Conversation In writing story fragments, we want to take the benefits of a personhood oriented conversation or a reminiscence group beyond the moment, as a trigger for future satisfying conversations.

The StoryCorps Dementia project offered the public in many locations across the United States the chance to record a conversation between a person living with dementia and a family member (Basting, 2009; Purves et al., 2011). Each family member was prepared with prompts emphasizing emotion-based or experience-based questions, rather than facts and specific details. The audio recording of the co-constructed story afforded a positive experience in the present, future moments with the storyteller, and a family legacy. TimeSlips programs for dementia group storytelling (Basting, 2009) highlight the value of collaborative story creating (without stressing recall) that stimulates growth, humor, and emotional connection—creating a script and performing at a high standard for audiences. In both of these approaches, a record of the story takes the benefits beyond the initial storytelling.

Our main goal in the chapter is to explore the impact of writing down life story fragments of individuals with dementia. A few individuals in early stage dementia began in the 1990s to publish narratives of their dementia experiences (see Ryan, Bannister, & Anas, 2009), and then to create the Dementia Advocacy and Support Network International (DASNI) for mutual support primarily through writing on the Internet. A successful first goal of these original authors/leaders was establishment of support groups within Alzheimer's Societies for themselves— those with

dementia, not just for caregivers. Access to the writings of dementia peers has confirmed to many newly diagnosed individuals that living with dementia is a possibility; it's not just a terminal illness. By putting individual faces on the illness, these stories of living with dementia decrease societal stereotypes and may reduce the communication predicaments endured by peers. The writings vividly demonstrate that dementia is experienced in highly varied ways and that remaining abilities, purpose, and a supportive environment can help individuals maintain satisfying lives well beyond what experts anticipated (Ryan et al., 2009). For readers with dementia as well as authors, published dementia stories can renew a positive sense of identity, including feelings of accomplishment and belonging (Ryan et al., 2009).

Dienstag (2003) reports on Lifelines Writing Group, created for community-dwelling people with early stage dementia. Members of the writing group, recruited from a larger support group, were already acquainted with each other. For three years, even while abilities declined, participants wrote briefly with topic prompts and read their work to each other. Story selections and participant quotations highlight how similar the creative process and outcomes were to writing groups everywhere. Working with non-dementia groups in longterm care, Schuster (1998) observed that sharing their written stories enabled residents to explore past and current identities.

But what about those people with more advanced dementia, those in institutional care? How can writing assist them? One should first probe alternate ways for the individual to read and write (Ryan, Spykerman, & Anas, 2005). Although handwriting typically deteriorates, use of a marker pen and wide-lined paper or even a computer with enlarged font can support writing in some residents—especially highly educated people and those admitted to longterm care for medical reasons with an earlier stage of dementia. Oral reading is a long-retained skill—probably with enlarged print in a simple font. Reading one's own dictated words is a skill lasting even longer (Hagens et al., 2003; Moore & Davis, 2002).

Various dementia programs have incorporated written memory aids in longterm care to manage everyday life and to support memory for important current information (Bourgeois, 1993; Elliot, 2011; Orsulic-Jeras & Camp, 2000). The use of prosthetic memory aids builds upon the longer-retained skill of oral reading. Moreover, personalized life story memory books with visual images accompanied by short sentences have nurtured conversations with family caregivers and nursing home staff increasing factual statements; decreasing ambiguous, incorrect, and unintelligible utterances; and enhancing topic maintenance (Egan, Berube, Racine, & Leonard, 2010; Hoerster, Hickey, & Bourgeois, 2001; Maclagan & Grant, 2011).

Most often in longterm care, individuals with dementia need to have their stories written down for them—or audio or video recorded. Their stories can be shared in future conversations based on the written record, audio or visual recordings, or transcripts (see Davis, 2005; see also Davis & Maclagan, chapter 4, this volume). A communication partner can make use of recorded stories to support retelling and elaboration within future conversations, in particular by prompting with the exact words and phrases previously used by the person with dementia (Hagens et al., 2003; Moore & Davis, 2002).

John Killick began visiting nursing homes in the 1990s to write down the words of residents—to honor persons with dementia by attending to their words so specifically (Killick & Allan, 2001; Killick, 2003). He has urged us to preserve the communicative moment in writing so as to respect personhood, as well as to individualize care (Killick, 2003). Killick (2003) arranged the words from individual interviews into poems for the speakers to share with staff and families. Sharing their writings, the person can be repeatedly seen in an environment typically inducing invisibility.

After years studying communication predicaments in nursing homes (Ryan, 2010), the first author used storytelling and then storywriting to shift focus to enhancing communication with older adults with dementia (Ryan & Schindel Martin, 2011). We began with a reminiscence group for five people with dementia (Hagens et al., 2003). From the beginning, we sought ways to write down life story fragments for sharing beyond the group. Collaborative poems were created from the reminiscence sessions—taking advantage of the unique role of metaphor, ambiguity, and discontinuities in poetry, as opposed to prose—to use the language of dementia and to combine memories across individuals. Participants' words were written large in front of the group and re-read for elaboration during pauses. In between sessions, the facilitator arranged the words into a poem, which was then reviewed by the group. Group poems were posted in the residents' rooms to encourage reading aloud with staff and visitors. To stimulate future conversations, individual interviews were used to write down elaborations on recollections originating in the group and also to create an individual poem based on the participant's own words. Objects, photographs, and favorite audio/visual tapes were collected with the help of family into a Conversational Remembering Box together with the written stories and poems. Anecdotal evidence indicated positive response to subsequent uses of the boxes for conversations with facilitators, staff, and family. Residents could often identify their own words without remembering storytelling groups or the memory box. Continuing work in longterm care underlined the value of dementia group poems for reminiscence by other peers and for reading aloud the poems with one's own words later on during palliative care (Hagens, Cosentino & Ryan, 2006).

Although life story work, especially writing down life stories for future conversations, offers a great deal of promise, only exploratory research has been conducted. As Moos and Bjorn (2006) and Thompson (2011) both argue, additional qualitative research is needed to enrich our sense of the process of writing stories down and using them later on as well as to identify the range of possible communication and psychological benefits and the conditions most conducive for those benefits. To provide this type of qualitative data, we have conducted a number of case studies. In the two sections that follow, we explore one-on-one and then group activities for prompting, producing, recording, and sharing reminiscence or life stories.

ONE-ON-ONE WORK: CONVERSATIONAL REMEMBERING BOXES AND LIFE STORY BINDERS

In this section we highlight six case studies selected from recent student projects to paint a broad picture of the process and impact of written conversational memory aids. The undergraduate students of gerontology or health studies were in their early 20s, native-like speakers of English, and most had experience volunteering or working in longterm care. Each student spent at least six sessions observing in the longterm care center before their project; each student was supervised off-site by the first author as well as on-site by a field supervisor. Across multiple longterm-care settings, each student interviewer held multiple conversations with a person with dementia, in longterm care assisted living homes or long-stay hospital units. Initial conversations focused on eliciting new stories, while the later sessions made increasing use of the written conversational aids. Staff evaluations of conversations with the memory aid are cited where available, but staff participation was difficult to recruit for unfunded student projects.

Conversational Remembering Boxes

For these four case studies, the interviewer gathered items for a Conversational Remembering Box (referred to in conversation as a memory box) during the conversation sessions, sometimes

with help beforehand from family (Hagens et al., 2003). As stories were elicited, new ideas for the memory box arose. A photograph was taken of physical items that did not fit into the box. For favorite places and items no longer available, computer images approved by the participant were printed. Stories prompted by the items were written down at the time by the student as they were told. The student then typed the story and printed it out in appropriate font and size. The participant and student read the story together, and any changes suggested by the participant were made. The story was then placed in the memory box, along with a journal and pen for other conversational partners to record elaborations and new stories to enrich the memory box. Note that the stories were often only one or two sentences, sometimes a paragraph or two.

Individual Participant 1: Claire Jones

Claire Jones is a recently widowed 78-year-old female with moderate-stage dementia. Throughout the seven conversations, Claire required little prompting. However, she was prone to repeating and going off on tangents.

The process of finding items for the memory box and gathering stories were two threads braided together. Claire's family (both deceased and living members), her role as a twin, and leisure activities with her husband were important to her. Claire actively brainstormed with the interviewer about how to represent her music and gardening in her memory box. The interviewer strived to ensure that the stories were recorded in Claire's exact words. Claire supported the idea of the memory box: "I forget a lot and I think the Memory Box would help."

The staff member using Claire's remembering box to converse with her reported the conversation to have been "very educational, in ten minutes I learned a lot about Claire, her children, twin sister, husband and what she enjoyed in her life." The memory aid was especially beneficial because she had only recently begun working at the facility. She recommended placing signs outside or in the resident's room inviting staff or visitors to make use of the residents memory box.

Individual Participant 2: Gary Dufresne

Gary Dufresne, 82 years old and exhibiting mild dementia, participated in eight sessions. At first in the conversations Gary was apathetic, making only passive responses. The turning point for him was becoming engaged in gathering items that he believed would best represent him for the memory box, especially reflecting his passion for the farming life. Gary was especially proud of a detailed family history book that dated back to his grandfather and could tell stories as he went through the pictures. A photograph of the book's cover was included in the memory box in order to encourage others to make use of this resource. A staff member engaged Gary in a conversation with the memory box, whose contents he was happy to show her. Through her short conversation with him, she was able to tell that this memory box was an important way for him to keep his name alive. She believed it was beneficial to have the box in his room not only for staff and visitors but also so "he can look through the box when he is feeling blue and see everything he has done."

Individual Participant 3: Julia McDow

Julia McDow, in her 80s, has moderate dementia accompanied by visual and hearing problems. Even so, she was able to relate to her personal photos in the memory box, and sometimes she could read her stories from the box. In addition to photographs, the memory box included a journal of stories that Julia had written two decades earlier for her grandson, a crocheted blanket, and a needlepoint seat cover. She began to relate to the interviewer and the project in the fourth (of seven) session when together they read excerpts from her old journal.

She began to show reciprocity by asking about the interviewer and to converse with her (e.g., "I'm happy to see you again"). Repetitive questioning disappeared in later sessions.

Story

I have a lot of grandchildren. My granddaughter Anna and grand son Frank live in Alberta. I don't think I have ever been there. I have been up north to Yellowknife and the United States. I don't see my great grandchildren that often but I do see my grandchildren from time to time. I got to watch my grandkids sometimes. That was fun. I don't see them too much now. Cooper is an actor in New York. Cooper, Patrick and Lisa are Mandy's children.

Conversation about family photos after reading the story aloud:

Julia: I like this part about my grandchildren. It makes me miss them.

Interviewer: Does looking at their pictures make you feel better?

Julia: Sometimes. I look at those pictures sometimes. (Referring to conversational box)

Interviewer: That's nice to hear. When your grandchildren visit, you should show them. They would love it.

Julia: Yeah, (laughing)

Individual Participant 4: Larry Morrison

Larry Morrison, in his 80s, had been diagnosed with dementia and Parkinson's disease. He did not move much, used little eye contact, and had few comprehensible words throughout the nine sessions. He was almost exclusively interested in watching television, especially sports. For him, the memory aid became his story! His wife was keen and helped him select items for his Conversational Remembering Box—golf, bicycle and carpentry gear, and, interestingly, his old wallet containing IDs.

Since he was so attentive to the television and experienced so much motor difficulty with speech, Larry was seen as a good candidate for a computerized Conversational Remembering Box (see Purves et al., 2011, for discussion of computerized memory aids and the use of generic memory cues). A PowerPoint slide presentation (available in his memory box in both CD-Rom and DVD formats) was created with photos and generic images of his sports interests, including audio and video clips. The interviewer was only able to elicit two- to three-word phrases, but Larry consistently engaged very directly nonverbally with the slide show and showed his comprehension and appreciation. Here's a brief exchange that served as a graduation' conversation. After spending time looking at a collage of pictures during the final session, the interviewer asked Mr. Morrison which picture was his favorite.

Larry: Up at the top

Interviewer: This one?

Larry: No, above that picture (pointing to the only picture above)

Life Story Binders

In other student projects, we focused more on the written stories by placing them in life story binders. The students wrote down the story fragments as they occurred in conversation, entered each one in the computer, and printed it out for the participant, who suggested elaborations and changes as they wished. Sometimes this process was repeated a few times for elaborations.

Then the revised printed story was placed in their binder. Most of the time these stories would be at least a paragraph long—not as brief as the ones in the Conversational Remembering Box. These stories served to spark conversations in interchanges for eliciting and editing them together and in subsequent use of the story binder.

Individual Participant 5: Max Alden

Max Alden, in his mid 70s—our sole participant with Korsakoff's dementia—had been in medical isolation for several months. Although he agreed to participate, he began the sessions verbally and nonverbally expressing reluctance. Content to be on his own, he repeated "don't need anybody." By the third session, he was speaking more readily, especially about his family and how he had always taken care of his children. In the latter sessions, he expressed his sense of humor and enthusiasm to talk. For instance, in the fourth visit, he greeted the investigators with "I'm in a very good mood today. Ask me anything you want!" and later "Do you guys know about it? I must tell you then!" His change in attitude may well have been due to the fact that student interviewers became more comfortable in the intimidating medical setting and more skilled in talking with him about his experiences rather than facts. His stories were rich in detail, but he told the same ones over and over.

For example, pointing to a youth pictured in a graduation gown, he said, "He's not my biological son. Took care of him since he was a baby. He was the son of a family friend down the street. They had some problems, so I took him in. He graduated, became RCMP. Now studying to become an officer. His name is S. He listens to me. You know why? Because he respects me. No matter how rough things were, I always looked after my kids. So when he brought his girlfriend here, I noticed she was a smoker and I told him to dump her, and he did. Then he brought B. As soon as I saw, I said he hit the jackpot. I said, 'Marry her' and he did."

This story was part of an ongoing process of life review, searching for meaning and connection. He found himself with severe health issues and strained relationships with his children. He was trying to reframe his life by talking about a positive relationship. He saw himself as an expert with wisdom to share—telling stories and talking about the written stories promoted his sense of connection to himself and others.

Individual Participant 6: John Yorks

John Yorks, age 93 and exhibiting disorientation to time, place, and person, participated in nine sessions. Although he was socially isolated, not connecting with others in the home, he showed enjoyment and active engagement from the start. He stands out because of his pride in the physical binder.

His first response was, "How much do you want for it?" He thought the binder was very good and it deserved to be paid for. As soon as he was aware that the binder was full of his own stories, he responded with, "Wow we did an excellent job, very good. I think the kids will be quite proud of this." He emphasized that "it is nice to read about yourself. It reminds me of my accomplishments and important memories."

Three staff members used the story binder with John. One reported, "I saw him visibly go back in years in his mind and relax and enjoy the conversation, and that way I could get a better picture of the person he used to be." Another staff member indicated, "These stories allowed me to assist the resident in having a one-on-one conversation about his life experiences and the times that meant so much to him."

GROUP STORYTELLING AND LIFE STORY BINDERS

Next, we describe a group-based clinical intervention that extends our work with life story writings to support future conversation. Individual life story memory aids were created from group storytelling sessions, which themselves fostered conversation and relationship-building. This clinical life story intervention was initiated and implemented by Debra Crispin, spiritual care specialist (the second author), and Michelle Daigneault, recreation therapist (third author), on two longer-stay units of the teaching hospital where they work. The first author was involved as a consultant once writing down stories was identified as the basic approach.

The project was inspired by the necessity to find a way to get to know our patients. From our clinical experience leading reminiscence groups with cognitively impaired older adults, we sensed the potential to make better use of life story fragments elicited within the group process. Writing down these life stories could create a conversational resource to support person-centered care and the spiritual needs of the patients.

No audio recordings were made. Groups were facilitated by one or both of the leaders, who also wrote down the stories with occasional help from student volunteers. These life story fragments (our focus), after being entered into the computer and printed, were shared with the participant, who helped edit and integrate them into stories—often over multiple sessions with individuals. Especially rich fragments of conversation during the group were also written down at the time for research purposes.

The group storytelling process was based on the best of group reminiscence and life story work. Much of the literature in this area is guided by Kitwood's (1997) thesis that personhood is affirmed through connection and relationship. For instance, a study in Britain showed that older people in aged care prefer activities that include reinforcing a sense of identity and a sense of belonging (Fels & Astell, 2011). Group storytelling has been found to increase the sense of self and enhance participation for individuals in the later stages of dementia (Moos & Bjorn, 2006).

Moss et al. (2002) conducted one of the first studies examining the effects of reminiscence group activities on discourse interactions of people with Alzheimer's disease. They found that less structured environments yielded qualitatively better discourse patterns, particularly related to selecting and maintaining a topic, requesting additional information about a topic, changing a topic during conversation, and turn-taking. The same study found that some participants began with sharing, developed in mutually beneficial exchanges, resulting in a higher level of trust. The added stimulation of the group experience works to help people access memories. The group experience also promotes or improves a sense of meaning and purpose (Hagens et al., 2003; Moss et al, 2002).

Life story work yielding a resource for conversation can assist other care staff with a better understanding of their patients and insight into their values (Moss et al, 2002). For example, Hagens et al. (2003) noted that short personal stories in the memory box were used to calm sleepless or restless patients, especially helpful to unacquainted staff.

In summary, the purpose of the group storytelling and story binder program is to facilitate conversation with and between patients with dementia, get to know patients through the stories they tell in order to enhance patient-centered care, partner with families to gather stories about those who are not able to access memories independently, and use the written story as a tool to facilitate conversation between a patient and other patients, family members, and staff.

We will present our experience with two storytelling groups—the first in a complex care hospital unit with mostly cognitive and communication impaired patients, with only some participants diagnosed with dementia, and the second in a recently organized dementia unit within the same hospital. Working with the new unit allowed the opportunity to 'begin again' with a

focus specifically on dementia. Group storytelling and life story binders were deemed to be especially important for these longterm patients lost in the acute hospital system—enduring stressful testing and numerous room/unit transfers without much opportunity to find a sense of belonging or even personhood.

Group Storytelling in a Complex Care Hospital Unit

The setting for this story program is a complex care unit within a large teaching hospital. Many of the medically complex patients have stayed for more than one year in this unit, which has been shifting from a long stay unit to a 90-day slow rehabilitation focus. Initially, many patients had a diagnosis of dementia. The number is declining as the nature of the unit changes. The unit serves a highly diverse population in terms of physical, cognitive, communicative, social, and emotional impairments.

Group Storytelling Process

For 2 ½ years, the two facilitators have held 60-minute reminiscence-style storytelling sessions weekly with 5-15 participants. Group members range widely in cognitive and communicative abilities. The overall process will be described first, followed by elaboration through the experience of one participant with moderate but progressing dementia.

For each group session, a reminiscence theme is announced. Topics from the distant past yield the best recall: childhood best friend, the house where I grew up, my job, my first car, what I do for fun (favorite pastime), proudest moment, and greatest accomplishment. Advanced preparation includes posting topics ahead of time for patients and their families. It turned out to be especially useful to partner with families (contacted in person as opposed to mail/telephone) to obtain details for likely stories. Facilitators sometimes work one-on-one beforehand to retrieve memories and create a written story to be shared in the program. Often, it is enough to chat while guiding individuals to the session to help them remember a relevant story. Sometimes they read or tell their own story. Other times staff reads or tells it for them.

A social atmosphere is created for group sessions by sitting in a circle and beginning with introductions. Sensory prompts—photos, objects, food, smells, sounds—help to highlight the theme of the day. A flip chart can record words (one per line) as participants brainstorm words related to the topic. More spontaneously, articles from the daily newspaper, often with photos of local people and places, can create an environment for discussion. Concrete questions elicit more talk, but the facilitator works to broaden or deepen the discussion to access other experiences or feelings.

Some prompts work especially well, such as "Tell us about music— what music do you like?" One person responded by singing a complex song that he had sung for his mother in his teens. Misunderstood questions need a follow-up to clarify, such as, "Tell us where you came from" (looking for country of origin)—misunderstood: "from my room," "from home," "from Hamilton"—switch to "Where were you born?"

As the goal is to involve everyone, it is important for participants to take turns for conversation and questions. "Clapping" to show appreciation is a good way to finish each person's contribution/story. This activity builds individual confidence and group social identity. Importantly, clapping as a signal to stop also reinforces turn-taking. For some with physical limitations, "clapping" is a symbolic movement of foot or finger acknowledging appreciation of the story. However, reinforcing turn-taking by clapping may also inhibit spontaneous conversation. Facilitators need to watch and listen for responses from other group participants before clapping

is initiated. A small group session may lend itself to more back and forth conversation, so clapping might be out of place.

Group management problems do, of course, arise. Participants who interrupt can be reoriented to topic and activity or reminded of turn-taking. It helps to position a facilitator or helper directly beside individuals who may require extra support due to cognition, hearing, vision, or anxiety.

Apart from the specifics of starters and continuers, the approach and "presence" of the facilitators play a significant role in the success of the encounter. Open posture and gestures, engaged eye contact, and appropriate touch to help direct and maintain attention create a safe space for conversation and sharing. Facilitators need to be prepared for emotional reaction to topics, questions, or someone else's story. Often, given time, members of the group support a tearful or anxious member. After seeing and hearing a co-patient crying and talking about missing his wife, a patient whose speech was rarely oriented to the situation looked com- passionately at his co-patient and said, "Your lunch is waiting," pointing to staff delivering lunch nearby. Members are even quicker to support happy or proud comments with congratulations or cheers. The level of caring and encouragement among group members has been impressive. The sense of community and connection that is created within the group even rolls out to interactions between members of the group outside the group setting. One patient encouraged another during physiotherapy with personal knowledge gained from the story group.

Indicators of group-ness observed in these sessions include nonverbal signals such as sympathetic facial expressions, gestures, or even hand signals, hugs, and hand holding. One participant gave the facilitator a hug and said, "You can come again," meaning she enjoyed the experience and would like to do it again. She has severe word-finding difficulty and is not able to join in conversation easily.

Throughout the group sessions, a key goal is to write down life story fragments for the individuals. Stories (brief episodes of a few sentences or more complex stories of a few paragraphs) are transcribed and printed for the participants. The stories are placed into binders for each patient, which are kept in their room to be read by families, staff, and volunteers. New stories are posted on the wall in the patient's room. These are used as prompts to help the participant access elaborations or new memories— which are then recorded. The goal is for staff and family to use these stories as conversation starters.

We continue to look for ways to facilitate staff involvement. Time for in-service training is a continuing problem. New stories are now posted in each patient's room before being put in the binder to ease staff access. We have created a Best Practice poster for display on the unit for staff, patients, and others. Perhaps most important for encouraging staff, we now refer in the unit to the story fragments as conversation starters instead of 'stories.'

A section has been created on the individual patient rounds sheet where information is shared that may promote greater person-centered care. This might be from the story project, or knowledge staff have gained through conversation during personal care or from family. With the support of the unit manager, each week we post a new story/conversation starter about a patient in the nursing station.

An especially positive response occurred after the facilitators read a conversation starter at nursing rounds about a patient who can't speak much but can write. Many people don't take time to wait for her to write, so they were amazed when we told her detailed story. It had practical clues for how to be with her. Some reactions from the nursing staff are, "I can't believe that you got that story from that patient," and "Now we will know what to do with her to make her happy like sing her a song or play music for her."

Complex Care Group Participant: Ray Harrison

Resident on the unit for more than 10 years, Ray Harrison is in his late 70s with moderate dementia. Over the 2V2 years, we noticed significant progression of the disease. He more frequently did not know where he was or identify any staff. We elaborate on the impact of the storytelling activity by describing Ray's experiences.

Ray attended storytelling group weekly approximately 40 times (30 with stories). Initially, he was a passive participant. He enjoyed sitting in the group, attended all sessions, and was well known to group regulars. He initially did not contribute due to difficulty accessing memories and social anxiety. Pre-group preparation with Ray proved the key to enabling him to participate more actively. The facilitator worked with Ray individually just prior to group time to help put his story together based on the topic, and then read Ray's story aloud for him in the group. Ray was able to elaborate on the story and answer questions from other participants.

As staff accumulated knowledge of Ray's life and experiences through recorded stories, they could help elicit more conversation during the group, occasionally eliminating the need for advanced preparation. Ray would tell detailed stories of his experiences once he was reminded of his accomplishments, as illustrated in this discussion of Thanksgiving in the group.

Asked about his memories of Thanksgiving, he said, "No, nothing to add." The facilitator then reminded him and the group of his years volunteering as a cook at the Mission. Asked if he participated in preparing a special meal for the people, he spoke easily. The story unfolded of the day put on for the people who came to the mission. He spoke of the food they would prepare, the choir, the real feeling of home and community he tried to create. He spoke compassionately about families and individuals.

Telling this story to the group reconnected him to his contributions. It reconnected him to his faith and his genuine caring personality. The group clapped, affirming social identity and acceptance. The group congratulated Ray for his years of volunteering in the community. Feeling validated and affirmed, Ray smiled.

Ray's life story binder served as a tool for staff from time to time. When Ray was anxious and confused, the Recreation Therapist brought his book to him. The book helped settle Ray, reminding him of how he shared many stories with the group, contributing to the 'community' on the unit. He would reflect on his stories, memories of events and family, his contributions and work, his qualities and strengths. Ray relives the events as the stories are read back to him, and this helps to reconnect Ray to his community and to himself. Sometimes when Ray would be just sitting, staff and patients would engage him in conversation based on the stories shared. When Ray only had a few stories collected, he showed the book to staff with the comment, "My whole life is in this book."

The story binder served as a transition tool when Ray was recently transferred to a longterm care facility. The binder serves as a concrete reminder to Ray of his time at the hospital. Group facilitators suggested to staff at the new facility ways they could use the binder and followed up with a visit after two months. Although supportive comments were received initially from a nurse about the binder, on follow up, she admitted she did not work closely with the patient and did not know any details from the binder. We have learned to speak with direct care providers. We also learned it would have been helpful to have some stories in the book about the people he knew at the hospital, where he had spent 10 years.

Group Storytelling in a Transition Dementia Hospital Unit

With two years' experience on the first unit, the storytelling program was introduced on a recently created Alternate Level of Care (ALC) unit within the same hospital. This is for patients who no

longer have acute medical issues. Most have dementia and are awaiting longterm care. They might spend months on this unit. Some with difficult-to-manage problems such as exit-seeking, aggression, and sexually inappropriate behavior will wait even longer. Ages range from 50s to 90s.

Storytelling groups are held twice a week: one morning group and another more deliberately social afternoon affair ("Coffee, Tea and Me"). Groups have from 4-12 participants, often the same in both groups. Approximately 40 percent of the participants speak English as a second language. Whoever is up and interested is welcome, depending on the level of staff support available. Individual stories are transcribed and the printed pages hung in the patient's room. Staff are informed of ways these could be used as 'conversation starters' After the first few months, based on our experience in complex care, conversation starters' for specific patients were shared at weekly clinical rounds.

Group sessions proceed in a manner similar to those for the first unit. The two weekly sessions highlight the relative strengths of small and larger groups. Small groups allow easier accommodation for hearing, vision, and attention as well as more opportunity for individual engagement. An all-inclusive group conversation is more feasible. Yet, larger groups with those of mixed cognitive/communicative ability can make it possible for those with very limited ability to experience the benefits of socialization, to participate in the group nonverbally, and sometimes to contribute, with support, after hearing the stories of others. Early on in the sessions, a series of autumn/Thanksgiving topics were presented, with leaves, chestnuts, wild flowers, and pumpkin pie as prompts. Newspaper articles were useful, especially one about the 175th anniversary of the local Farmers' Market, which included old photos of farmers bringing their goods to market and townspeople making purchases. Related to this theme, we present a small group conversation and the case of one participant to illustrate how the program has elicited conversation and connections.

Dementia Group Conversation Excerpt

Participants in a small group of six responded to a photo prompt showing a woman surrounded by shelves of preserves. Dave, unable to initiate memories, had named her "Woolie." He has a great sense of humor, and everyone laughed at the name. He could not explain why he chose it but appreciated the laughter.

Facilitator: Dave, what do you think this woman's name is?

Dave: Woolie.

F: Woolie?

Dave: Yes, Woolie.

F: Why did you choose that? Does that mean something to you?

Dave: No. (He laughs and everyone else joins in.)

F: OK, This woman's name is Woolie. What else can we tell about her?

Lucy: She is a farmer's wife and she does the preserving every year.

Charlie: There is a lot of food. She must live on a big farm in the country.

Anna: It could be in Saskatchewan.

F: What else can we tell about her from the picture?

Robert: She looks happy and is enjoying what she has done. She must have a lot of people to feed or perhaps she sells things at the market.

Alice: I can remember my mother sitting on the back porch peeling baby onions all day with a piece of bread in her mouth.

Anna: Why did she have bread in her mouth?

Alice: She said it kept her eyes from watering.

Anna: I didn't know how to peel anything. When we moved to our house in Davidson, I had a wood and coal stove. The women had to teach me how to use it. They were very patient and very kind.

Alice: I don't know how to preserve anything. My mother did it all. You learn it from your mother or you don't do it.

Elizabeth: I enjoy the fall weather. People cook nice things.

This group conversation is a combination of jointly creating a story about the picture and telling stories from individuals' own lives. While our focus is usually on life stories, responding creatively to this prompt yielded engagement among the patients. As Basting (2009) has demonstrated through her TimeSlips program, inviting a group to create a story takes the pressure off remembering while at the same time building upon participants' own stories. Each comment follows appropriately from previous ones. The final comment—a great summary of the experience of fall—showed that Elizabeth, otherwise a passive participant, had been engaged throughout. Anna's setting of the story in Saskatchewan reinforces the idea that even without specific recall, what they do creatively may tell their story anyway. Dave's use of humor supports his lifelong self-identity and gives him an important role in the group even after memory and initiation skills are gone.

Dementia Group Participant: Charlie Strand

Charlie Strand, 82 years of age, has moderate dementia. He awaited transfer to geriatric psychiatry due to aggression and sexually inappropriate behavior. He was teary about not being with his wife. He attended group sessions regularly but rarely initiated. During this series of four consecutive story groups, he progressed from contributing very little to not being able to stop. The written versions of the stories told across sessions are presented here. In the first session, Charlie only interacted with the story facilitator and offered lists of food and family at the dinner. In the second session, he recounted concrete details of the typical walk in the woods after Thanksgiving dinner.

Thanksgiving When I Was a Child: For Thanksgiving when I was a child we would have the whole family around the table: brothers Phil, George, Reg, and my sister May and my Mom and Dad. We would have a chicken or turkey, pumpkin pie, squash, turnip, tomatoes, parsnips, carrots, cranberries, stuffing and gravy.

The Woods at Thanksgiving: Sometimes at Thanksgiving we would take a walk back in the bush. We would look at the beautiful leaves on both sides of the path. We saw blackberry canes and sometimes we saw mushrooms. We picked them and ate them.

In the third session, in response to photographs of horses and wagons at a farmer's market, Charlie continued his story throughout the entire story time, even though we thanked him and clapped at the end of his time. He thought each question that was asked was asked of him. He stopped when the facilitator changed places at the table so she was not directly across from him.

Our Animals: We had 8 or 9 pigs. In the fall we would sell them out. I would hitch up the horses to the wagon and we would take them to the market. We had 7, 8, or 9 ducks. We used to

have 8, 9 or 10 chickens and a rooster "cock a doodle doo"! (Big smile on his face.) We had a special rooster that got a prize at the fair.

The next day Charlie was singing a barnyard animal song at lunch time.

In the fourth story session with the picture of a woman surrounded by preserves, he gave many details of caring for the apple trees and making cider. Although he was not oriented to others in the group, they were interested and told their own stories about apple cider.

Making Cider: The windfall apples were good for cider. We used to get a gallon or gallon and a half of juice from them. First of all you have to squeeze the juice out. The cider mill was over in Lynden. We put it in a milk can. Then you heat it up and put it in jars and can it. We used to have apple crates that we stored the apples in. We put them in a clean, cool place.

Conversation between Charlie, His Family, and a Group Facilitator

The facilitator read Charlie's stories to him and his niece and sister-in-law. After the others had asked him about many things he did not remember, Charlie related this story about playing baseball:

Charlie: Sometimes we would ride our bikes into Lynden and play baseball. All the bases were fixed up good. We had two good bats and a real good ball.

F: Did you have a glove?

Charlie: No, not many had gloves.

Niece: I bet you were a good hitter!

Charlie: I hit the ball pretty good.

Niece: I bet you hit home runs!

Charlie: No, but I was a good hitter. (C explained that once someone was out they went out to play in the field and everyone moved forward. It was a rotation type of game.) After the game we would take off home from Lynden. When Charlie was transferred on a Friday, the team gathered his stories and sent the binder along with him.

Very grateful to have the binder, the nurse on the new unit reported on Monday, "*We read it from cover to cover and used it every day over the weekend. It was very helpful in time of transition, in getting to know his family and work history. I think Charlie is finding it easier to trust us because we know about him. It is helpful to have a source of concrete and familiar stories to help distract and bring pleasant memories.*"

Charlie recognized the words and stories as his own when they read it to him. The binder is kept by his bedside, and more information is added as they go. It is encouraging to have staff recognize the value of the stories to support communication and as a tool to avoid triggers of reactive behavior. After 2 ½ years of working with this program, we continue to look for ways to engage direct-care staff in incorporating the stories into care, both in our own setting and in receiving facilities.

Lessons Learned from the Dementia Group

Some practical lessons include the following: to provide one-to-one preparation when necessary to make group participation possible; position facilitators, any helpers, and participants strategically; and limit noise and other distractions. At least two staff are needed, one to write as the other supports conversation. If one is required to leave for any reason, the other must try to

maintain the group focus. Even so, such interruptions can instantly destroy the sense of group. Our groups have survived many uncontrollable institutional interruptions (e.g., overhead announcements, beeping IV poles, call bells, and clinical staff addressing a particular patient for medications or tests), but it would be advisable to seek out quiet spots for groups to meet. Further education of staff may help minimize interruptions. Having the group at the same time at the same place with the same facilitators is helpful to some. Looking on their activity calendar to orient themselves can help them prepare ahead of time.

Given appropriate support, everyone wants to communicate and belong: to be in relationships and connect. This program is popular—often the only activity chosen by the more reluctant or disoriented individuals. Patients not only get to tell their story, they create meaning, reclaim social and personal identity, and see beyond the presenting impairment of their fellow patient to the person (Ryan et al., 2009). One patient commented about another whose career story had just been read aloud: *"I thought he was just a man in a chair. Now I know he won international awards for his work."*

When conversation lags or patients are unable to access memories, it may help to direct them back to photographs or props. Writing the topic and prompts on a white board or flip chart may make it more accessible to some. Use of prior knowledge of patients may spark a memory. Sometimes patients will encourage others to share or remind them of a story they heard them tell previously. This is one advantage of having people of varying levels of cognitive ability in the same group. Debriefing helps in recognizing what has happened in the group and how the process may be improved. People with dementia are so varied and access to remaining abilities so unpredictable that the facilitators learned to prepare well and then be open to what might happen this time.

Facilitators are continually surprised by what happens in the group each week; surprised at the stories told and how previously hidden abilities can suddenly show up in conversation. This may relate to assumptions made about each patient. The group presents an opportunity to challenge ourselves, to open our minds and raise our expectations. Expectations can limit outcomes—even limit the choice of who participates in subsequent sessions. It was not clear a particular woman wanted to participate: her chair was faced away and staff were warned by others not to try to move her chair. She held her head down and closed her eyes during the session. The facilitator left her until last, not sure she would participate. It turned out she was hard of hearing. When the facilitator spoke loudly directly to her, she raised her head and gave very short responses. It felt like pulling teeth—no sign of involvement until after the session. When the facilitator touched her hand lightly and thanked her for being there, the participant clutched her hand and said, "I like you."

We are also surprised at the level of caring and community that develops amongst patients in the moment and, in some cases, over time. We are able to capture story fragments, but we are not able to capture the richness of the group process. We are particularly moved by the positive impact the group has on non-verbal patients. Often, members of the group who are able to verbalize are extremely supportive of those who cannot. It is obvious from facial expressions and gestures that they enjoy the experience of listening and benefit from being part of the group.

Sometimes difficulties in the group are due to one participant who enjoys the group but disrupts repeatedly. One very disruptive patient was eventually able to wait and take his turn after being redirected by facilitators several times. Then, a co-patient used the same strategy and language when interrupted during his turn. "We are taking turns telling stories. It is my turn right now. You can have a turn when I am finished." The other patient settled, listened, and waited. The co-patient let him know when he was finished and encouraged him to tell his story. Noticing this from outside the room, nursing staff were amazed. Once in a large group of 12 around a long

table, the group was having difficulty hearing because two group members at the far end of the table were having their own conversation. Facilitators tried to get these two to stop talking while another was telling her story. It turned out that they were processing what was happening by explaining it to each other.

Even if someone is unable to access memories, they may still be able to have a meaningful conversation. One woman with advanced dementia who spoke unintelligibly almost non-stop attended a story group. This was a particularly good day for her. It was early in the morning. It was a small group, and the room was quiet. She was able to say her name when we did introductions. When it was her turn to share, she was able to say, "I don't remember." She went on to have a meaningful conversation about not remembering. At the end she said with a smile on her face, "Sometimes, it all just goes" (she shrugged her shoulders and threw her arms up over her head). Another woman was very hesitant to be part of the group because she could not remember. With support, she was able to tell a story about herself. She then said, "Usually I don't join in conversations. I feel so embarrassed because I can't remember. I don't feel that way here." Others shared their feelings about not being able to remember.

DISCUSSION

Through individual and group case studies, we have illustrated the conversational process of eliciting life stories as well as the impact of written life stories on subsequent conversations for residents with dementia living in institutional care. In one-to-one or group conversations, paying attention to the specific words of individuals with dementia increases their conversation and their sense of connection. We have also shown how the written stories elicit continuing and elaborated conversations as well as comments of appreciation and surprise at their remaining ability. Instances of humor, mutuality, and relationship feed the conversational partner (Davis, 2005).

Through one-on-one and group collaborative storytelling we have continued to learn the importance of writing down the words of forgetful individuals whose words are often ignored. Writing down life story fragments for longterm care residents offers staff, volunteers, and family members a specific approach to overcoming communication predicaments associated with dementia and institutional living. As called for by Moos and Bjorn (2006), our qualitative research adds substance to the ground-breaking work by Killick (2003; Killick & Allan, 2001) and our own earlier efforts to use writings to support conversations (Hagens et al., 2003, 2006). In terms of models, this person-centered approach creates a prepared, enhanced communication environment enabling persons with dementia to assert their identities and connect with others on their terms (Elliot, 2011; Lubinski, 2011; Ryan, 2010).

Implications for longterm care staff and others working with individuals with dementia are many. Written life stories can be a prompt for future conversations, for chats during daily care, and for calming restless, confused, or aggressive residents. We learned to use the term conversation starters to entice busy staff to make use of these prompts. Information about residents' past experiences can enable staff to deliver better personalized care (Moos & Bjorn, 2006). Beyond that, using the specific words of a resident for storytelling can be a more direct way to connect to the story and the resident's sense of personhood.

In the group setting we learned how one person's story sparked conversation and connections. We also learned that priming individuals prior to the group storytelling sessions was valuable, and absolutely necessary for some. Priming could be done with reading from the life story binder or chatting about the topic on the way to the group. Groups whose participants have varying levels of ability to converse are helpful. The more able create the social experience for the less able and may act as models or provide prompts for others. As exemplified in Hagens et

al. (2006), a more able resident can be recruited for three-way conversations intended to assist a less able resident to recall life story fragments or to write' collaborative poetry.

Written stories of persons with dementia can be used in other ways in longterm care. For example, published quotations about dementia experiences can elicit fruitful conversation in group or individual conversations—letting the authors provide the words and allowing participants to recognize those words that resonate (Ryan et al., 2009). The Hagens et al. (2006) poetry anthology is another especially good resource as it offers words from peers in a form particularly accessible in dementia—short lines, metaphor, multiple interpretations—and a form that assists conversational partners to veer away from their typical insistence on logic and reality.

One of the biggest challenges is staff education and gaining staff support. Staff feel they have no time to read stories, share the ones they hear during care, or attend information sessions. The facilitators are hard pressed to find the time to run the groups, write down the stories, type and print them, and read them with the patient before the next group. More support from management is necessary to include this work in elder-friendly and person-centered care initiatives. In Northern Ireland, the Northern Health & Social Care Trust (NHSCT) collaborated with the Reminiscence Network of Northern Ireland to establish life story work in all its residential and day care facilities serving people with dementia. In their report, the authors note the challenges of conflicting priorities, inconsistent senior management support, staff resistance or inertia, and competing demands on resources. Despite official policies, achieving an enduring change in values, ethos, and longterm care remains a huge challenge (Gibson & Carson, 2010).

Our descriptive case studies of one-on-one conversations and group storytelling point toward several directions for future research on the impact of life story writings. Before a major intervention study, it would be useful to explore the use of group storytelling in conjunction with individual conversations and the value of beginning with Conversational Remembering Boxes and aiming toward life story binders. It would seem that group storytelling and individual conversations might well support each other in terms of motivation and abilities to access memories. Memory boxes with brief conversation starters might work best for care staff, while life story binders might work best for pastoral care staff, family, and volunteers. Actually, the latter could be involved in preparing further conversation starters and locating items/images for the conversation memory box. Finally, as suggested by Bohlmeijer et al. (2007), life review in dementia might work by building up the written life story through appropriate prompts addressing both positive and negative emotions. Through all these qualitative studies, a priority should be upon developing appropriate measures for residents with dementia—for feelings of self-esteem, well-being, remembering with help, and belonging (see Purves et al, 2011).

What about personal and generic prompts to elicit life storytelling? Astell and colleagues (Astell, Ellis, Aim, Dye, & Gowans, 2010; Purves et al., 2011) have raised intriguing questions for dementia. Astell et al. (2010) present a small study in which the focus on memory with family photographs elicited lower quality speech than generic images without the press to recall specific details. Generic photos and images do elicit life storytelling as we know from Montessori materials. Astell's work creates an important distinction between personalized and individualized. Thus, generic photos and images do elicit life storytelling when choice is involved (Astell et al., 2010; Bourgeois, 1993; Elliot, 2011; Maclagan & Grant, 2011; Purves et al., 2011). Van den Brandt-van Heck (2011) uses the same generic images with a generic story or opinion/feeling questions in Theme books and a summary of the individual's own storytelling in Life Story books—thereby offering a personalized option, as needed. Thus, it seems that generic stimuli chosen for shared history can be effective in group storytelling or computer games when there are many options. Moreover, use of generic photos from participants' shared community history can be particularly effective in putting the person with dementia on a more equal footing with a

healthy conversational partner and emphasizing community membership over illness (Basting, 2009; McFadden & McFadden, 2011; Purves et al., 2011).

Intervention studies can address two different aspects of the use of written life stories to foster conversations. First, short-term interventions could be evaluated in terms of improvements in specific discourse and nonverbal features of the interactions as well as psychological benefits to the individual of ongoing sessions (Maclagan & Grant, 2011; Moos & Bjorn, 2006). Second, longer term interventions, including caregiver training and emotional support for caregivers, could be evaluated. Evaluations could address group participation, care staff use of the life story memory aids, improvements in person-centered care, and psychological well-being of the residents (Davis & Smith, 2011; Egan et al., 2010; Maclagan & Grant, 2011; Thompson, 2011). For individuals with moderate dementia, life story writings are elicited through deep listening, creativity, and openness to the moment. The writings themselves, in Conversational Remembering Boxes, life story binders, or another form, then can promote deep connections in future encounters to enrich life in a longterm care setting (see Ryan & Schindel Martin, 2011).

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