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The Role of Narrative in the Life Participation Approach to Aphasia

Barbara B. Shadden, PhD; Fran Hagstrom, PhD

This article explores the relationship and integration of a narrative and the life participation approach to aphasia (LPAA). Literature from the social sciences situates narrative as a fundamental life concern of humans. Health, illness, and particularly stroke narratives are explored as processes that are inextricably intertwined with the life participation of persons with aphasia and their significant others. The role of self-narratives (storying of self) in recovery and in regaining a sense of coherence in the life story is discussed as part of assessment and treatment that can further the life participation of those affected by aphasia, a guiding principle of LPAA. A brief case study is interwoven with the text to explore the theoretical linkages between narrative and the LPAA, and to demonstrate the role of social others for the storying of self during group therapy. **Key words:** *aphasia*, *group therapy*, *life story*, *LPAA*, *narrative*

AS DELINEATED by other articles in this issue, the life participation approach to aphasia (LPAA) emerged in response to patients' and providers' demands for alterations in the ways that individuals with aphasia received treatments (LPAA Project Group, 2000, 2001). LPAA is derived from an essentially social model for understanding aphasia and the needs of persons with aphasia, as well as their significant others (Simmons-Mackie, 2000a; Simmons-Mackie & Damico, 2007). As such, it targets social reintegration of the person with aphasia. More than changes in specific assessment and treatment procedures, LPAA reflects a change in philosophy. One point emphasized in this model is the fact that decreased impairment and/or increased functional skills do not automatically enhance participation and well-being at the societal level.

An examination of the intervention targets identified in LPAA highlights this social focus. Targets include both personal (internal) and environmental (external) factors, but all targets situate the person with aphasia within social contexts (LPAA Project Group, 2000, 2001). In effect, a factor becomes an LPAA target primarily because it influences the social functioning of those affected by aphasia. The LPAA scope of practice depends on two coexisting variables: communication support regardless of language or physical status, and facilitation of reengagement in life for all living with aphasia. Thus, assessment and intervention must focus on participation, not just of the individual with aphasia, but also of those in the individual's extended social network. The term *aphasia network* is used in this article to maintain the concept of the individual with aphasia plus the extended social network.

The LPAA differs from other intervention approaches because of its unique focus on the life concerns of persons living with aphasia. Goals must be grounded in real-life activities, and reengagement in this real-life domain is underscored by the LPAA mandate to identify and strengthen those activities in daily life that reflect the individual's priorities for participation. LPAA outcomes are identified collaboratively with

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From the University of Arkansas, Fayetteville.

Corresponding author: Fran Hagstrom, PhD, Program in Communication Disorders, University of Arkansas, 410 Arkansas Avenue, Fayetteville, AR 72701 (e-mail: fhagstr@uark.edu).

the client, and success should be measured by analysis of engagement in life activities (and satisfaction with this engagement), social connections, and quality of life or emotional well-being. Early published statements about LPAA (LPAA Project Group, 2000, 2001) underscored the "dual function of communication—transmitting and receiving messages, and maintaining social links" (p. 236). As a result, LPAA has had an impact on service delivery to those with aphasia and their significant others.

One aspect of the LPAA that deserves further focus is the role of illness narratives and, more broadly and positively, life stories or personal narratives. These support life participation by targeting the social validation of the teller and by reflecting the degree of success or failure of that individual in regaining participation (Harter, Japp, & Beck, 2005a). Narrative identity is part of the fabric of one's daily functioning. In fact, social engagement and participation are carried out primarily through narrative processes. Varying forms of narrative constitute the tools available for communicating wants, needs, perspectives, and priorities. More fundamentally, individuals use narrative to share those life stories that help them establish an identity that is recognized and validated by communication partners (Shadden & Agan, 2004; Shadden, 2005). One's life story has a timeline, and the shared storying of self is an ongoing process that is subject to external influence (Holstein & Gubrium, 2000).

Much of the discussion about narrative identity can be found within the psychological, communication, and sociological literature, all of which have implications for the LPAA. The purpose of this article is to integrate these concepts by exploring how the LPAA model addresses the profound alteration of life stories brought about by aphasia, as well as the need to expand perceptions of the nature of life participation. The manner in which life participation is linked to illness or health narratives will be described. Aphasia will be characterized as imposing critical limitations in the use of narrative as a tool, resulting in impairments in internal communication as well as in socially shared communication. Thus, for the life participation approach to be truly effective in the social reintegration of persons with aphasia, there must be awareness of the role of self-narratives (storying of self) in recovery and in regaining a sense of coherence in one's life story. As noted earlier, LPAA is often described as focusing on life concerns. Narrative is indeed one of the most fundamental life concerns of humans, not in the restricted sense of telling a story with good organization, but more broadly, in terms of framing and supporting an interpretation of one's life (Holstein & Gubrium, 2000).

To explore the theoretical linkages between narrative and the LPAA further, a brief case study of 42-year-old Dennis will be interwoven with the text.

Dennis attended a stroke support group for the first time approximately three years after he suffered a stroke resulting from a ruptured aneurysm. He displayed flat affect, and spoke in a soft, tentative manner. He evidenced only a mild fluent aphasia at this time, but he referred consistently to frustrations with word-finding and communication in general. Considerable additional cognitive impairment was reported. As is the custom in this group, Dennis and his accompanying friend Fred received almost exclusive focus in their first session. The group facilitator took notes on basic information and specific comments.

Although contact with Dennis and his significant other has been limited to three support group sessions, the narratives produced by both Dennis and Fred have been discussed throughout this article. This particular case study was selected because Dennis' shared life story, derived from comments made during the support group, illustrates a number of important themes in understanding the role of narrative in life participation. Although it would have been possible to select someone with more severe aphasic impairment to illustrate key premises, Dennis' story is easier for readers to follow because of his apparent articulateness. However, there were times when he simply gave up trying to communicate because of word-finding problems. The themes emphasized the following sections:

- The *personal myth* we all hold in the lifelong process of negotiating, maintaining, and modifying our sense of self or *identity;*
- the role of the *illness/health narrative* in moving forward with life postaphasia;
- the concepts of *narrative wreckage* and *biographical disruption* as applied to the health crisis associated with the onset of aphasia;
- the *biographical accommodation* that is associated with framing the illness/health narrative in a coherent framework that makes sense or *meaning* of the life changes;
- the fundamental human desire for a sense of *agency, power,* or *control* in one's life;
- the need for *social others* and groups to recognize and validate the emerging life story and the societal response as perceived by the affected individual; and finally
- a "morphing" of *my* unique story to *our* narrative, as evidence of regaining a sense of life participation.

No attempt has been made in this article to provide a manual for narrative assessment and treatment in the LPAA context. Instead, theoretical premises about the centrality of narrative processes are introduced to encourage clinicians to move into a vital, engaged role as facilitators in the narrative framing, constructing, and modulating sense of self that is needed if people are to participate fully in life. It will be argued that, given the fact that communication is essentially a social enterprise, a critical objective throughout the clinician-aphasia network collaboration is to problem-solve and scaffold generative environments for acting in and on the world. Thus, for LPAA, a vital aspect of clinical action for persons with aphasia is using narrative communication as the means for integrating aphasia network perspectives to frame who they are and how they will "be" within the ongoing flow of everyday life after stroke.

NARRATIVE IN DAILY LIVES

Simply defined, *narrative* is story telling. The small and seemingly inconsequential, as well as the large and dramatic, pieces of life are woven together by each human being for self-understanding and for presentation to others (McAdams, Josselson, & Lieblich, 2006b). Narrative is fundamentally at the heart of being human, in that the ever-changing stories of people's lives encapsulate each person's, family's, and culture's essential humanness (McAdams, 1993). Narrative differs from verbal interactions such as listing, recounting, joking, praising, or summarizing, in that stories involve agents who act with purpose within scenes or frames of meaning (Burke, 1945; Goffman, 1959, 1967). Narrative is an enculturated organizational structure for meaning making, in which people, places, objects, and actions are joined by infused values and beliefs (Sarbin, 1986, 2000; Shotter, 2003).

The act of story telling is often pictured as an interchange between a teller and one or more listeners. However, the argument has been made convincingly that all narratives contain the "voices" of others (Beck, 2005; Wertsch, 1991), situating their beliefs, feelings, and values. Beck (2005) called this the morphing of "my story" into "our narrative" (p. 63), a concept to be discussed later in the context of aphasia. In essence, one's personal narrative does not exist in isolation, but instead intersects with, incorporates, and responds to the words, ideas, actions, interpretations, and timelines of others. As a result, narrative is uniquely a human development (Donald, 1991) that is always occupied by more than one person's perspective on life. This makes narrative a powerful tool for understanding meaning and taking/conveying perspectives that are inherently situated in everyday life (Sarbin, 1986). As McAdams, Josselson, and Lieblich (2006b) suggested, we are all storytellers, and we are also the stories we tell, a concept derived from James' (1963) earlier work defining "I" as self-as-story teller and "me" as self-as-tale-told.

Stroke survivor Dennis had been a high-powered business consultant who traveled extensively within the state. He was accustomed to others reporting to him, and spoke of thriving on his status within the organization. Fred indicated that Dennis was "on the fast track." Both Dennis and Fred frequently used reference to Dennis' previous status as a mechanism for introducing him to the group and for explaining why the impact of his stroke was so profound.

During the first support group meeting they attended, it was clear that Dennis was struggling to formulate (or reformulate) a coherent life story that would allow him to reconcile his past with his present and to frame some sense of a future. At stake was a sense that there was no self. For example, he noted: "They keep telling me to let go of Dennis, the old Dennis—he's dead and gone—but I miss Dennis." He also indicated, "I died 3 years ago—that's what the doctors said should have happened, and I do believe I should have died. Well, I did die . . . I went away."

With respect to a sense of identity or self, Dennis also indicated, "I don't look at myself as a man anymore. I'm erased." Equally poignant was his statement, "I look in the mirror . . . well, I can't . . . I just started to be able to . . . I don't know who that person is." He also expressed a kind of duality of self, "It's like there are two of me. From here down (gestures to neck down), it's wanting to go, go, go, but from here up . . . nothing."

Health narratives

Narrative provides a mechanism for healthy adjustment to threatening life events, facilitating the search for meaning, the needed sense of regaining mastery, and the redefining of self that must exist for a viable personal story to be created to make sense of a threatening illness event (Monks, 2000). Because of the centrality of narrative in these processes, many disciplines in recent years have focused attention on illness narratives. Frank (1995) suggests that illness itself is a call for stories. "Illness threatens not only the individual's physical integrity but all the individual's identity and sense of self in the world" (p. 55). Thus, illness narratives are required to help individuals repair the damage to sense of self in present and future, to make meaning out of the "narrative wreck" imposed by a medical crisis (Frank 1995, p. 55), and to restore the patient's voice (Sakalys, 2003). Illness narrative provides a kind of "witness [for] the experience of reconstructing ones' own map" of the past, present, and future (Frank, 1995, p. 17).

As an understanding of illness stories has grown, the term *health narrative* has gained some prominence, and the terms are often used interchangeably. In the health narrative, health is the focal issue and narrative provides an important way for the individual, the family, and even social others who do not know the individual to negotiate illness. As Harter, Japp, and Beck (2005b) stated, "health narratives emerge as complex performances in the midst of enveloping life and social narratives that can enable or constrain, stigmatize or empower, confuse or enlighten individuals as they attempt to restore continuity when faced with the disruption of illness, suffering, or trauma" (p. 29). Beck (2005) made the point that health narratives are embodied narratives, in that the physical body of an individual is the setting of the story, and that the course of retold, upgraded, and changing stories will be played out on the stage of a "body" in need of healing. The conscious use of the term *health* situates these stories within the larger context of one's ongoing life story. Health narratives also help each person recognize that the discussion of any particular illness must extend beyond the individual's story to the larger group(s) with which the person identifies, and more broadly, the social institutions, agencies, and professional groups that have an impact on the lives of person's living out a particular illness narrative. A focus on health also underscores the fact that, at least in the Western world, health is held as a core value, and as such, cannot be ignored in understanding recovery from or living with any illness.

Early and ongoing work of theorists such as Frank (1995, 2002, 2005), Brody (2003), Kleinman (1988), Charon (2001), and Dasgupta and Charon (2004) have steered healthcare professionals in the direction of actively eliciting and responding to the narrative framing of the illness experience. The sharing of illness or health narratives is now viewed as critical to the well-being and quality of life of those touched by the illness experience. Illness narratives are particularly critical in traditional healthcare systems in which the medical narrative of patient incompetence and powerlessness tends to trump all other narratives (Duchan, Maxwell, & Kovarsky, 1999; Frank, 1995; Mackay, 2003). In medicine, the narrative of "getting better" is presented in terms of a *restitution* narrative, reflecting health as a core value in society (Japp, Harter, & Beck, 2005). For the ill patient, however, the illness narrative is more of a *quest* story, and the telling and retelling of the initial medical crisis often takes the form of a chaos story for which meaning can be created only through the sharing of the experience (Frank, 2005).

Dennis and Fred shared Dennis' somewhat dramatic stroke story in detail, including his being found 16 hours poststroke in a motel room hours from home, the immediate crisis of survival transitioning to months of rehabilitation, dwindling support of family, and almost total abandonment by other friends. Fred provided many visual details of the surroundings in which Dennis was found, including descriptions of his belongings in the motel room and descriptions of his behavior before and immediately after surgery to repair the aneurysm. Much of this story took the form of a chaos narrative, in which a stream of random and seemingly unreasonable events led to a catastrophic life change.

Fred's perspective on the illness narrative dominated the pair's sharing of the experiences of the initial months poststroke, particularly during the first support group session. In subsequent sessions, he continued to assist in co-construction of the story, but Dennis began to take the lead in initiating comments, responses, and questions. In breakout groups, Fred confirmed the centrality of his role in helping Dennis reframe his life post-stroke. At one point he noted, "This is the first time I've heard him tell someone else what it's like for him. I didn't even know that he could without my help." The social nature of the co-constructed narrative process is evident in this comment. Dennis' illness narrative was retold at the beginning of each subsequent support group meeting, with particular emphasis upon the extent of the neurological damage suffered and the uniqueness of his situation.

Although classification of narrative type is an interpretive process, both authors of this article agreed that Dennis and Fred's comments clearly distinguished the restitution narrative, as presented by those within the medical system, from the quest narrative that defined Dennis' current life. With respect to the medical restitution narrative, there were frequent references to what the doctors reportedly said about original prognosis and unexpected improvement. Almost always, there was a tone of dismissal, a suggestion that the doctors had no understanding of the impact of the stroke. For example, Fred stated: "What they told me ... it couldn't have been farther from the truth. They were supposed to be the experts. I doubt it!" In contrast, Dennis' quest narrative is evident in his repeated descriptions of ongoing physical problems, including severe headaches and a tendency to shut down physically when over stimulated. Much of the time, he characterized his current life as dominated by the illness narrative of pain and bodily dysfunction, and his questions to the group reflected an underlying quest for health and/or freedom from physical misery. He also sought relief from his ongoing struggles with communication, asking: "Will I ever be able to say what I want when I want to? How can I do anything if I can't talk right?"

Given the rather dramatic quality of his illness narrative, Dennis' response to a new member at the third session was interesting. The new couple (Bob and Janine) described Janine's ruptured aneurysm and subsequent medical struggles for survival, then recovery. Once again, a dramatic medical survival story was being shared. Given Dennis' sense of being medically unique and thus isolated, a sense of relief and sharing would have been anticipated. However, both Dennis and Fred began matching the stroke narrative provided by the new couple. At times, it seemed that there was almost a competition to "one up" the new story. While these behaviors are open to different interpretations, both authors of this article agree that this pattern appeared indicative of the centrality of the actual stroke narrative in the lives of Dennis and Fred, and the fact that Dennis, at least, seemed to be mired down in the illness narrative as his definition of self and life in the present tense.

Stroke narratives

Although illness or health narratives share common elements across many health conditions, Dennis' story suggests that there are also elements unique to the stroke experience. There is now a core group of publications that address stroke narratives—the telling of one's account of experiencing a stroke and its consequences (Rappaport, 1993, 2004; Rittman et al., 2004). In these publications, the topic of illness narrative intersects discussions of recovery, community, and reconstruction of self in the specific context of stroke. Ironically, many of the stroke narrative studies use subjects whose communication is essentially intact. However, there is much to be learned about narrative and life participation from review of research in this area.

For example, McKevitt (2000) noted that illness narratives are important to stroke survivors because they help the survivors make sense of their suffering, allowing them to order life events, and share that ordering with social others who can validate the story. Mold, McKevitt, and Wolfe (2003) noted that the outcome of stroke is a profound biographical disruption in the life story. Typically, that disruption is associated with loss of a sense of control of body, self, and life progression. The powerlessness of the stroke survivor is a recurring refrain in stroke narratives (MacKay, 2003). Faircloth, Boylstein, Ritman, and Gubrium (2005) and Faircloth et al. (2004) underscore this concept of biographical disruption and note that what is needed is biographical accommodation that allows those touched by stroke to construct revised but meaningful lifelines poststroke. Part of that reconstruction involves reframing identities to encompass a new life story that includes the illness event yet has health as a core value. Within speech-language pathology, Armstrong and Ulatowska (2007), among others, have studied stroke narratives. While focusing on the use of evaluative language, their work also highlights the importance of telling the story in shaping the perceptions of the person with aphasia and his or her significant other.

For Dennis, all discussion of life post-stroke was framed in terms of the narrative wreckage and biographical disruption created by the stroke. He often referred to a sense of humiliation related to being unable to accomplish very basic daily activities. Typically, these failures were contrasted with his previous successes in his professional life.

Given the importance of timelines in personal narrative, Dennis' clear sense of temporal disruption was particularly interesting. He indicated that he had assumed that the stroke was the end in numerous ways, including the perception that he would die soon. While comforted to discover that there were people in the room who had survived as long as 17 years, this knowledge appeared to fill him with a kind of terror. He perceived those years as more of the painful non-existence he was currently experiencing.

Dennis referred repeatedly to age in comments such as: "If I were older, it might be okay. I just can't face a long future with all of this" (gesturing to body and head). This part of his illness narrative appeared to be distinctively linked to stroke. From his perspective, stroke was a disease of old age. Both Dennis and Fred referred repeatedly to his previous professional status in power, and the void left in his life by the stroke that took away that power. In fact, Dennis stated quite explicitly, "I was somebody. People worked for me. Now I'm nothing." In effect, he appeared to be locked in to his stroke narrative, unable to move past his perception of health (the way it was) as the only desirable life target (core value).

Connecting LPAA and narrative identity

Within the past 15 years, increased attention has been focused on narrative identity as fundamental to one's daily functioning. Most research has been grounded in the perception that much of what passes for everyday conversation among people is storytelling in one form or another and that narrative is indeed a root metaphor for human experience (Sarbin, 2001). As such, narrative is at the heart of life participation and has implications for the LPAA.

Personal narrative is fundamentally grounded in language and communication

(McAdams, 1993). With the impairments in language associated with aphasia, the active construction and reconstruction work of narrative is jeopardized (Shadden, 2005; Shadden & Koski, 2007). Furthermore, it has been established that life stories need to be resilient and flexible if they are to facilitate moving on in life after an unexpected biographical disruption (McAdams, 1993). Sadly, one hallmark of aphasia is the reduction of flexibility in using this tool we call communication.

In LPAA, the dual communicative roles of *transmission* and *interaction* are seen as central to the life participation process. This is intriguing in light of McAdam's (1993) assertion that the two central themes in life stories are *agency* and *communion*. Broadly conceptualized, transmission can be viewed as linked to agency, in the sense of the power, mastery, and/or achievement that can be accomplished if we use our communication to transmit and receive critical information. Similarly, McAdams' (1993) term communion refers to relationships and intimacy, concepts parallel to the role of interaction in the LPAA. When considering the life participation goals of any individual with aphasia, it may be that these goals can be grouped loosely into these two domains of agency and communion, with interventions matched appropriately to the targeted goals.

From the perspective of agency, in Dennis' illness narrative and extended life story, one recurring refrain was a profound sense of powerlessness, of loss of control and agency. This was clear during discussions of his impulsive behavior and the fact that all control over his money had been legally given to his friend Fred. "Everything has been taken away from me . . . everything." As he discussed the emptiness of his days, he expressed a need to "do something," to be productive again, but suggestions from the group were rebuffed for a variety of reasons most of which centered around his sense that the suggested activities were somehow too insignificant in the context of the person he used to be, someone who was at the peak of his career.

Narrative processes are critical to the concept of recovery in the LPAA and are tools for regaining active participation in one's life. Illness narratives and life stories target the social validation of the teller and reflect the degree of success or failure of that individual in regaining participation. For persons with aphasia and their significant others, there has been a profound alteration of both their life stories and the ability to communicate or modify these narratives in different social contexts. At its core, the premise of life participation as a primary intervention goal must encompass the role of communication in renegotiating a sense of self or identity (Shadden, 2005). Life participation must address more than engagement in desired activities. It must target an individual's ability to participate in core social interactions that allow narrative exploration of one's life story and associated sense of self or identity. In effect, it must actively support the biographical accommodation needed to maintain a sense of a meaningful lifeline.

As Armstrong and Ulatowska (2006, 2007) suggested, people engage others in interaction when they share stories. Narrators want recognition—as a validation of the story, as acknowledgment of the self they are presenting—and they look to others for specific responses that will provide that needed recognition. Narrative processes, specifically the communication and reframing of an illness narrative, are central to the initial therapeutic encounter, as discussed later in this article. According to the research by Haidet, Kroll, and Sharf (2006), patients' perspectives on their own illness—its place in their overall life story and the possibility for change—influence strongly the partnership between healthcare provider and patient, as well as the degree to which the patient takes initiative in the treatment process.

Isolation was a powerful refrain for Dennis. He clearly believed that others in his previous circle of friends had rejected him, a perception supported in Fred's commentary. In discussing his isolation, Dennis noted that young men don't want to deal with him and that older people, who might understand his experiences better, wouldn't want to be friends with someone younger like himself. Although not stated clearly, it appeared that Dennis himself was not particularly inclined to self-identify with older adults.

Finally, one particularly intriguing parallel between the principles of LPAA and the current views of health narratives is the emphasis in both upon larger social units than the individual and his or her significant others. LPAA acknowledges both internal and external influences in the pursuit of fulfilling life participation (Elman, 2000; LPAA Project Group, 2000). At the internal level, a focus on meaningful real-life outcomes requires attention to the evolving personal narrative of those affected by aphasia. On the external level, social forces (e.g., disability rights organizations), political changes (e.g., funding cutbacks, limitations on treatment sessions), and groups in which an individual participates (e.g., church, organizational boards, book clubs) all are characterized by their unique communal narratives (Rappaport, 1993, 2004). The person with aphasia may find it difficult to conform to the communal narrative with impaired language tools, and the community or organization may not be flexible in accommodating the individual. In other words, narrative processes are central to life participation at a societal level as well as at the individual level of psychological well-being.

The social context of the support group appeared to provide important affirmation to both Fred and Dennis. It is interesting to note that Fred initially sat somewhat outside the group circle, indicating that he was simply there to provide support for his friend. By the third session, however, he had joined the circle and appeared eager to participate in the narrative. He also began talking more readily about his own life post-aphasia.

In the first support group meeting, Dennis received input and encouragement from other stroke survivors and their significant others. As a result, he became more animated and interactive. He finally said, "That's what I have missed the last 3 years—having a family, someplace where I belong." He also acknowledged that he was handling the stress of the situation well because, "I'm comfortable with these people. They understand. They look at me and don't see a freak." The importance of community and social acceptance was underscored by the statement, "Finding out there are others like me—I can't believe it—it's like a dream come true." And at the end of the session, in a powerful shift, he indicated, "I'm not the same person. Okay, so I have to accept that I can't be the same but ... *we* sure want it." A sense of *our* narrative grounded in community was emerging out of *my* unique story.

NARRATIVE, LPAA, AND CLINICAL PROCESSES

LPAA, narrative, and the role of the clinician

There is always debate about the appropriateness of clinicians relating personally to individual clients. As Hinckley (2005) noted, clinicians have attempted traditionally to maintain personal distance. However, fundamental tenets of the LPAA, as well as recent explorations of narrative medicine, challenge the assumption that disengagement is the appropriate and/or necessary stance. In medicine, emphasis has been placed on the development of what has been termed "narrative competence" (Charon, 2001) and what has also been described as "narrative understanding" on the part of caregivers who listen actively (Beck, 2005). *Narrative competence* is defined as the "ability to acknowledge, absorb, interpret and act on the stories and plights of others" (Charon, 2001, p. 188). In many instances, the speech-language pathologist (SLP) may be in the unique position to hear and understand the illness narrative of the person with aphasia, even when compared with significant others. If SLPs are to follow the tenets of the LPAA, the narrative that occurs in the clinical interaction provides a critical opportunity for facilitating the creation and modification of the health narrative and broader life story that must be renegotiated in the context of aphasia. Indeed, the SLP may be the first who can provide the needed recognition for the aphasia network to move forward with viable senses of self and/or identity. The groundedness of LPAA in social contexts provides the possibility for narrative validation, which is fundamentally social.

Hurwitz (2000) explicitly linked clinical engagement with narrative processes, indicating that "an ocean of words" is available to clinicians. He suggested that people are continually engaged in narrative events, yet may not take advantage of the opportunities provided by such events in order to enhance life participation. He also suggested that the clinician has an obligation to help the client reframe the life story that has been disrupted. With persons with aphasia, the language tool is impaired, so the communicative processes necessary for sharing one's health narrative are disrupted. It can be argued that SLPs have both a professional and personal obligation to reduce the limiting effects of the aphasia in order to support the sharing of personal narratives. It should also be noted that, under ideal circumstances, individuals would choose to share their life story with listeners who are best suited by relationship, skills, and interest (McAdams, 1993). Persons living with aphasia have fewer options, and thus SLPs' responsibility is further highlighted.

Narrative, LPAA, and assessment

LPAA provides guidelines for assessment, emphasizing the determination of relevant life participation needs of clients given their competencies as mediated by shared social roles and situational support. This focus for LPAA assessment is most closely aligned with the Societal Level described in the World Health Organization "Components of Health" (Threats, 2004). Assessment at the societal level is concerned with the nature and extent of a person's involvement in life situations as determined by what an individual actually does within his or her relevant social context (e.g., practice law, attend Rotary Club).

Simmons-Mackie (2000b, 2004) suggested that this level of the ICIDH code captures the "personal experience" of aphasia. It is the personal experience of aphasia that is conveyed via narratives by members of the aphasia network. The stories of past and possible futures are told, edited, and retold within families, healthcare planning units, and agencies. Each telling is an ongoing and changing communication about the situated life of the person with aphasia who is struggling to renegotiate not only *how* routines are approached anew but also *who* he or she is to himself or herself and to others

Pasupathi (2006) also highlighted the importance of the language and interactions in the daily "fabric of our lives." These conversations about everyday self are vitally linked to identity, and they are also at the core of life participation. It is in these conversations that people express views of themselves from the past, and may provide hints of future selves they would like to see developed. Anyone who has worked with persons with aphasia and their families knows how the loss of these everyday, routine verbal interactions can be extraordinarily disturbing. McAdams, Josselson, and Lieblich (2005, 2006a) have explored ways of understanding the role of life stories of persons faced with diverse challenges by discussing the exploration of an individual's personal myth and the importance of sharing it. As Gregg (2006) points out, most narrative research explores forks in the timeline, points of disruption or impairment, as these events require alterations in personal myths from the perspective of the individual and significant others.

From an assessment perspective, it might be useful to modify elements of McAdams et al.'s (2006b) Life Story interview structure for probing health narratives in aphasia. One advantage of this interview approach is that it allows clinicians to develop a better sense of the personal myths that govern a client's perception of self. Such interviews also might shed light on the meaning attributed to aphasia and the degree and nature of the sense-making processes the client is going through (Pals, 2006). This approach, however, relies heavily on direct answers to interview questions. Thus, any attempt to use such an approach with individuals with aphasia presents needs for communication to be supported to minimize the role of language in the sharing.

A combination of analytical tools can be used in conjunction with the Life Story interview structure (McAdams et al., 2006b) to further allow clinicians to establish baseline perspective and collaborate to identify specific goals for reengagement in life. Hagstrom (2004), when analyzing interviews, used a functional individual system framework to determine person/family focus on the physical characteristics of illness, the role of social others in maximizing functionality, and the range of cultural tools used to achieve everyday actions. Shadden (2006) has used the Linquistic Inquiry and Word Count (LIWC; Pennebaker, Booth, & Frances, 2001) analyses for similar purposes. Both approaches are grounded in narrative and focus on communication of perspective, values, and beliefs about life and what it takes to "live" (i.e., reengage) after stroke.

A growing number of assessment instruments are available to probe quality of life for persons with aphasia and their significant others. Quality-of-life measures provide an opportunity to assess current status and treatment outcomes from a holistic perspective, although most do not actually attempt to capture the health narrative and/or life story. For several years, Kagan and colleagues have been developing the A-FROM, the Aphasia Framework for Outcome Measurement (Kagan, 2005; Kagan et al., 2006; Kagan & Simmons-Mackie, 2007). The A-FROM is designed to provide a framework for assessment that encompasses LPAA concerns, the ICF model, and elements of the Disability Creation Process model (Threats, 2004; Noreau, Fougeyrollas, & Vincent, 2002). The A-FROM focuses on documenting (in an aphasia friendly format) outcomes related to living with aphasia. Consistent with LPAA, the framework was built upon broad stakeholder input. Among other elements, A-FROM probes allow the person with aphasia and those in his or her social network to express the impact of aphasia on identity and to share aspects of each participant's life story, including a sense of timelines encompassing past, present, and future.

Narrative, LPAA, and treatment

Advocates of the LPAA have had an extensive impact on the nature of current treatments for aphasia, as can be seen by even a brief review of current research in journals such as *Aphasiology* or examination at the programs of national conferences such as the ASHA Convention and Clinical Aphasiology Conference. Group treatment approaches are becoming increasingly common (Elman, 2006; Elman & Bernstein-Ellis, 1999; Glista & Pollens, 2007). There is also growing interest in narrative processes beyond the measurement of discourse behavior as perceptions of the role of clinicians have expanded (Hinckley, 2007). Similarly, the impact of aphasia on identity or self is receiving greater focus.

Of particular clinical interest is the challenge of finding different behaviors to document in order to better understand those changes that reflect narrative elements consistent with LPAA, as discussed in this article. Current treatment approaches do emphasize conversational parameters such as initiation and responsiveness, domains that capture more functional and participatory behaviors. However, it may be necessary to find ways to explore qualitative aspects of communication content. For example, Armstrong and Ulatowska's (2006, 2007) research with evaluative language in aphasia opens up possibilities for capturing the use of language for functions more directly reflective of narrative self, such as judgment, opinion, etc. The LIWC software (Pennebaker, Booth, & Francis, 2001) provides analysis of a broad spectrum of linguistic content domains, including references to self and other that may allow for quantitative tracking of qualitative aspects of communication content, particularly content related to a sense of self. Documentation of broad categories of topics (personal, past history, future, social others, etc.) can illuminate changing concerns as related to one's life story.

Group interventions hold great promise in meeting the goals of the LPAA. Group participation, if successful, illuminates the changing concerns referred to above and yields a sense of embracement (Burls & Caan, 2004), of being absorbed by the community narrative, and transitioning from the "me" to the "us." It is the essentially social context of groups that permits narrative sharing and identity renegotiation (Shadden & Agan, 2004). From the perspective of the LPAA and narrative, critical elements of group process include (a) the social environment for constructing self and coming to terms with life timelines; (b) a commitment to the participants' ability to narrate their life stories (including health narratives), with an essentially clean slate in the presentation of self; (c) communicative support; and (d) a commitment by social others in the group to keep the story going and to recognize the person with aphasia and those in the aphasia network. Additional changes in the analyses of group work can be expected as cross-fertilization of ideas about narrative, identity, and life participation increases across multiple disciplines.

One area of interest for LPAA proponents is the manner in which the life story, and thus life participation, influences one's response to the onset of aphasia. Although it is no surprise that individuals at different ages have different needs, the Life Stories work of McAdams and colleagues (2006a) clarified the importance of age-related stages in the construction of life stories. Group interventions can target the sharing of life stories and provide a framework for linking past, present, and future in the lives of persons with aphasia post-stroke, regardless of age. One of the hallmarks of a mature identity is the sense of self-functioning as productive and contributing member of society. Indeed, the need for self-definition remains a preoccupation through most of our adult years, the period McAdams (1993) describes as the mythic stage in our narrative construction of self. Young and middle-aged adults are actively engaged in working on the life story, fine-tuning it to support a sense of an empowered and engaged self moving forward. It is only in our later years that we begin to look back.

In Dennis's story, much of his sense of hopelessness appears to result from his sense that the stroke disrupted his life story when his professional trajectory was one of greater and greater success and empowerment. As noted in earlier comments, he is keenly aware that most others in the room are older. His sense of disconnect between where he should be in his life story and where he actually finds himself is captured in his statement: "I became unconscious feeling like a 22 year old and woke up feeling like an 82 year old, and I still feel that way."

Dennis' experiences in the stroke support group demonstrate the ways in which different intervention settings and approaches, particularly groups, may provide the type of context necessary to the LPAA.

Both Dennis and Fred noted that therapy, and specifically speech-language therapy, was extremely frustrating to Dennis. After a number of question probes, Dennis was finally able to explain that "They didn't understand me. No one listened. They didn't want to. They tried to make me do things that don't matter." It takes little imagination to interpret this as an indictment of the health care system's lack of recognition of and response to Dennis' sense of loss of self and his desperate need to voice his story.

Over three support group meetings, group members have tried to help Dennis find ways to move forward. Efforts were made to assist him in creating an inventory of what he still had and could use. Ironically, as Fred pointed out in a breakout group, Dennis' days were indeed quite full, but he saw no value to the activities that engaged his time and attention. From the perspective of narrative and life participation, it appeared that he had considerable difficulty allowing others to reframe his life story and identity, to move into the present and anticipate a future. He had written his life story and illness narrative in terms of a successful past, a devastating illness, a present without hope and without future, and a self that is abhorrent in many ways. Without changing this narrative, Dennis will not be able to participate more fully in his life.

It is possible that the support group will be able to provide him with a sense of community membership that will allow him to begin reframing his life story. Indeed, there is evidence that this process has already begun. However, his life participation will be incomplete and impaired unless he creates a narrative with a present and a future. It is clear that he will need a safe forum for sharing his evolving life story, one where he will be recognized and validated.

At present, the support group is providing Dennis with an opportunity to create an autobiographical record of his stroke narrative through sharing of memories and group validation of his experiences. One of the key elements in the support groups' community narrative is the belief that life goes on post stroke/aphasia, that persons with aphasia and their significant others continue to evolve and edit their life stories, and that changes in the nature of life participation are expected and do not diminish the individual. For Dennis, one can hope that sharing his narrative and listening to the narratives of others will alter his perspective on his life story. In the support group, he has found acceptance and empathy, but it is the community narrative of moving forward that will be most powerful.

CONCLUSIONS

Every life story postaphasia is unique, and life participation needs are highly variable. The central premise of this article has been that the ongoing reframing of life stories, in the pursuit of a sense of continuity in narrative identity, is at the heart of life participation. In particular, the illness and/or health narrative plays a critical role. The LPAA highlights the social context that must be addressed in serving persons with aphasia. Furthermore, the LPAA model places communication at the heart of both success and failure in moving on with life, at reintegrating a modified self into previously central environments and interactions.

An expanded understanding of the role of narrative processes in furthering the LPAA should help SLPs better serve persons with aphasia and their significant others. Healthcare professionals have unique opportunities to facilitate these narratives. SLPs, in particular, spend countless hours listening to and interpreting the fragments of the life stories of clients, and they must use those experiences to accomplish more than simply improving word-finding skills or enhancing auditory comprehension. This article highlights the fact that professional interactions with persons with aphasia and those in their social network are active narrative processes. SLPs become part of the social context in which those in the aphasia network explore their health narratives and their ongoing storying of self.

Hopefully, the experiences and story of Dennis and Fred underscore the impact of stroke and aphasia on perceptions of self and identity. Both men provided illness and personal narratives, highlighting the critical role of telling one's story in the process of moving forward with life participation postaphasia. Dennis, as he entered the group, was relatively fluent linguistically and able to articulate feelings and experiences that facilitated understanding of his personal narrative. That same ability may not be available to others entering a group; yet the need to tell their story and renegotiate their perceptions of self and identity remain essential for moving forward with life.

Theorists writing about narrative processes acknowledge the centrality of language and communication to successful framing of self and identity (Schegloff, 1982; Shadden & Koski, 2007). There is also consensus about the social mediation of identity and life participation. Finally, researchers and clinicians agreed that, in the context of a profound illness experience such as stroke and aphasia, success in maintaining and modifying one's life narrative is dependent on a fair degree of flexibility and resilience in story-telling. Ironically, for persons with aphasia, it is these elements that have been impaired as a result of brain damage. Thus, at a time when communication, flexibility, and social interaction are most needed, the person with aphasia is robbed of the necessary resources. Aphasia may be the enemy of the framing, maintaining, and modifying of one's personal narrative or storying of self. If one espouses the theoretical tenets of the LPAA, SLPs should accept responsibility for facilitating the ongoing narration of self, including the health/illness narrative that is part of the larger life story.

The premise in this article is that humans are essentially storytellers, and it is the sharing of stories that helps people maintain and modulate their identity throughout a lifetime (McAdams, 1993). If we accept this premise, then aphasia strikes at the heart of this essential process. For clients with aphasia, rather than being able to present the world with an "I" that is equivalent to self-as-storyteller, they are mired down with a "me" that exists primarily as the self-as-told by others (James, 1963). To be consistent with the LPAA, clinicians must focus directly on supporting and furthering narrative processes that promote reengagement in full, productive lives. This requires creating environments and opportunities that allow persons with aphasia to transform their unique individual stories (about "me") into narratives that speak clearly of a larger social story of "us" (Moss, Parr, Byng, & Petheram, 2004).

Ways must be found for persons with aphasia and their significant others to move past the narrative wreckage and biographical disruption of the onset of aphasia to create biographical accommodations that

- make sense or meaning (coherence) out of life events,
- allow for ongoing construction and reconstruction of one's sense of identity to be reconstructed over time,
- support the critical need for a sense of personal agency or control, and
- situate individuals within meaningful social contexts in which they are valued and validated by others.

Fortunately, there is growing emphasis today upon aphasia interventions that can accomplish these narrative challenges (Byng, Cairns, & Duchan, 2002; Byng, Pound, & Parr, 2000; Rappaport, 2004). These may include the renewed emphasis on group treatment, continuing support for approaches using volunteers and partners to enhance life participation, as well as increasing use of discourse-, script-, or conversation-based interventions. Narrative processes are inextricably intertwined with the life participation of persons with aphasia and their significant others. A better understanding of the nature of personal and health narratives can further the life participation of those affected by aphasia. Such an understanding will also enhance clinicians' ability to focus on social action as characterized more broadly by other disciplines in the social sciences (Simmons-Mackie & Damico, 2007). The challenge is to find ways to support the storying of self that is critical to life participation.

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