"Hopeless, Sorry, Hopeless"
Co-constructing Narratives of Care With People Who Have Aphasia Post-stroke

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Despite widespread support for user involvement in health care, people with aphasia (PWA) report feeling ignored and disempowered in care contexts. They also rarely have the opportunity to give feedback on their experiences of care post-stroke. However, it is important for health care professionals to hear this feedback, both to understand the broader illness narrative and potentially to inform improved practice. Health care professionals who work with PWA should be trained and supported to co-construct narratives of feedback on care. In this article, I consider the knowledge, skills, and attitudes underpinning co-construction in this context and use examples from interviews with 2 PWA to illustrate narrative competence, the richness of their stories, and what lessons might be learned. The development of responsive, person-centered health care systems would be assisted by valuing such narratives and giving a voice to a group of people so familiar with health care services but also so rarely heard. **Key words:** *aphasia*, *co-construction*, *narratives of care*, *patient feedback*, *rehabilitation*, *stroke care*, *supported conversation*

THERE is a growing and influential literature in speech–language pathology on the value of attending to the narratives of people with aphasia (PWA) post-stroke (Barrow, 2008; Hinckley, 2008; Mitchell, Skirton, & Monrouxe, 2011; Parr, Byng, Gilpin, & Ireland, 1997; Shadden & Hagstrom, 2007; Shadden, Hagstrom, & Koski, 2008). This is based on the recognition that, even in the context of language disability, storytelling is fundamental to making sense of one's changed circumstances, coming to terms with post-stroke experiences, and reconstructing the new self and identity (Brumfitt, 1993).

People with aphasia are no different from others who have experienced biographical disruption through illness (Becker, 1997; Bury, 1982; Toombs, 1993). Aphasia is often embedded in other disabling consequences of stroke (Anderson, 1992; Becker & Kaufman, 1995; Kaufman, 1988) and is part of a broader picture of change (Hilari, 2011). The desire by PWA to tell their stories is demonstrated by the number of published personal accounts of their experiences (Green & Waks, 2008; Hinckley, 2006; Moss, 1972; Parr, Duchan, & Pound, 2003; Raskin, 1998; Wulf, 1973). Sometimes these are expressed differently, such as through poetry (Edelman & Greenwood, 1992; Pound, Parr, Lindsay, & Woolf, 2000), or accessed through families (Brown, Worrall, Davidson, & Howe, 2011; Hale, 2002; Michallet, Le Dorze, & Tétreault, 2001; Pound, Parr, & Duchan, 2001; Servaes, Draper, Conroy, & Bowring, 1999).

The argument in this article is that such narratives may be useful, not only to the narrator in working through biographical

disruption and facilitating adjustment but also as a valuable source of information to service providers. The focus is how PWA, particularly those with moderate and severe impairments, may be enabled to give feedback through their narratives to health care professionals on the quality of the services they receive as they transition through acute, subacute, community rehabilitation phases, and beyond. This is an important consideration in a context where all users of health services, whether communication impaired or not, are increasingly expected to be partners in health care, to take on more responsibility, and share decision making (Easton & Atkin, 2011; Edwards & Elwyn, 2009). Certainly, within speech–language pathology, the views of PWA regarding their care are increasingly being noted (Hersh, 2004, 2009; Kagan & Duchan, 2004; Worrall et al., 2011). Researchers and clinicians in the field are using this feedback to develop creative ways of working (Hersh, Worrall, Howe, Sherratt, & Davidson, 2012; Kagan et al., 2008; Kagan & LeBlanc, 2002; Pound, 2011; Pound, Duchan, Penman, Hewitt, & Parr, 2007; Simmons-Mackie et al., 2007) and helping people live successfully with aphasia (Brown, Worrall, Davidson, & Howe, 2012).

However, beyond speech–language pathology, relatively little attention is given to how health care professionals communicate with PWA (Burns, Baylor, Morris, McNally, & Yorkston, 2012). This is the case even within research on health care professional–patient communication. There are, however, some notable exceptions, from the nursing field, which involve detailed explorations of how understanding and connection can be developed between nurses and PWA (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Sundin, Jansson, & Norberg, 2002). Even though the experiences of PWA in hospital and rehabilitation are deeply influenced by their variable communication encounters with doctors, nurses, and other health care professionals (Parr et al., 1997), such stories tend to remain untold or aired to a limited audience. Just as there are few opportunities for patients in general to give feedback

on care, arguably, PWA are even less likely to raise their concerns successfully during quick consultations, write letters, make telephone calls, or complete patient surveys. People with aphasia often are excluded from broader research studies in stroke because researchers may assume that the aphasic language deficits will make participation too difficult (Dalemans, Wade, van den Heuvel, & de Witte, 2009; Townend, Brady, & McLaughlan, 2007). This means the needs of PWA are not always recognized, their views on services are rarely heard, they remain in a disempowered position with reduced options for influence, and they are at increased risk of dissatisfaction or adverse events (Burns et al., 2012; Hemsley, Wernick, & Worrall, 2013). This situation is unsatisfactory. Kagan and Simmons-Mackie (2013) have recently suggested that speech–language pathologists should be doing more to counteract these trends by spreading the word about the needs and concerns of PWA with their professional colleagues in related health care professions.

This begs several questions. First, do PWA, particularly those with more severe impairments or those without family, have enough opportunity to share their views about their care with their medical, nursing, and allied health care professionals? Second, how might these professionals be assisted in understanding these views? Third, considering the realities of busy and constrained clinical environments, how might such exchanges result in positive change?

To start addressing these questions, I suggest two broad arguments. The first is that health care professionals who work with PWA should have the knowledge, skills, and attitudes to co-construct narratives. The second is that health care professionals can recognize that narratives may be valuable sources of feedback on services the person has received, as well as biographical accounts.

Ellis (2008) defined co-constructed narratives as follows:

Co-constructed narratives are stories jointly constructed by relational partners about epiphanies in

their lives. This approach offers a way for participants to actively construct a version of a relational event that provides insight, understanding, and an in-depth and complex reflection on what occurred. (p. 85)

In this context, my focus in arguing for increased knowledge and skills on the part of professionals is not on a therapeutically oriented, mediated analysis of what the story reveals about a relational event, or even necessarily only about epiphanies—although certain experiences may be just that. Rather, I am interested in how, through the right knowledge, skills, and attitudes, the health care professional becomes a communication (*relational*) partner who can collaborate with a PWA to help reveal and express a narrative that then makes sense to both. The health care professional is not simply reporting the story but also scaffolding and "actively constructing" it with the PWA because the language deficits would otherwise render the story inaccessible. This relates closely to my second argument about narratives being sources of feedback. The process of co-constructing narratives should not only involve helping to retell but also encourage a level of insight and reflection on how the PWA may have experienced an aspect of care or rehabilitation. This reflection, in turn, might encourage health care professionals to initiate positive change.

In the body of this article, I develop these two arguments. I have summarized the key points involved in co-constructing narratives in Figure 1 with suggestions about how these points might be implemented in practice. Then, I illustrate the application of narrative analysis with interviews with two women with moderate to severe expressive aphasia.

KNOWLEDGE, SKILLS, AND ATTITUDES UNDERPINNING CO-CONSTRUCTION OF NARRATIVES

Knowledge: Awareness of narratives

As McKevitt (2000) has pointed out, although the term "narrative" has been used in different ways, it is essentially a story. Charon (2006) defined a story as needing "a teller, a listener, a time course, a plot and a point" (p. 3). Narrative skills allow an understanding of a story told by another person. Charon (2006) argued that only when that understanding allows the listener real insight into what the teller is experiencing can "care proceed with humility, trustworthiness, and respect" (p. 4). Thompson (2009) put it clearly: "...all care providers could become better caregivers by learning to take a narrative stance" (p. 189).

Frank (2014) wrote about narrative ethics as weaving closely into narrative medicine. He drew attention to the focus on the patient, on dialogue, and the need to see another's perspective as at least plausible and worthy of respect. He also pointed out that health care professionals, along with others, are cast as characters in patients' stories: "The pedagogical objective is to enable people to participate more fully in the dialogues in which they co-construct each other's life stories. Those dialogues are practices of care" (p. S19).

Frank (1995) also made the point that illness narratives are not just stories *about* illness and a changed body but also need to be seen as told *through* the body. This is clearly relevant for PWA who tell their stories through a body that no longer has easy access to the language required for them. An added barrier is that the doctors, nurses, and other health care professionals working with people with more severe aphasia may believe their stories are inaccessible, or "failed" narratives as McKevitt (2000, p. 80) put it, even if there is the desire to tell them. This assumption means that opportunities to share narratives that incorporate feedback or service evaluation (whether positive or negative) are further reduced and unlikely to be heard by the professionals they most concern.

Narratives of experience in the health care system are an integral part of the illness narrative itself and such experiences need to be shared. For PWA, systems to support that process of sharing need to be carefully and sensitively constructed. According to Charon (2006):
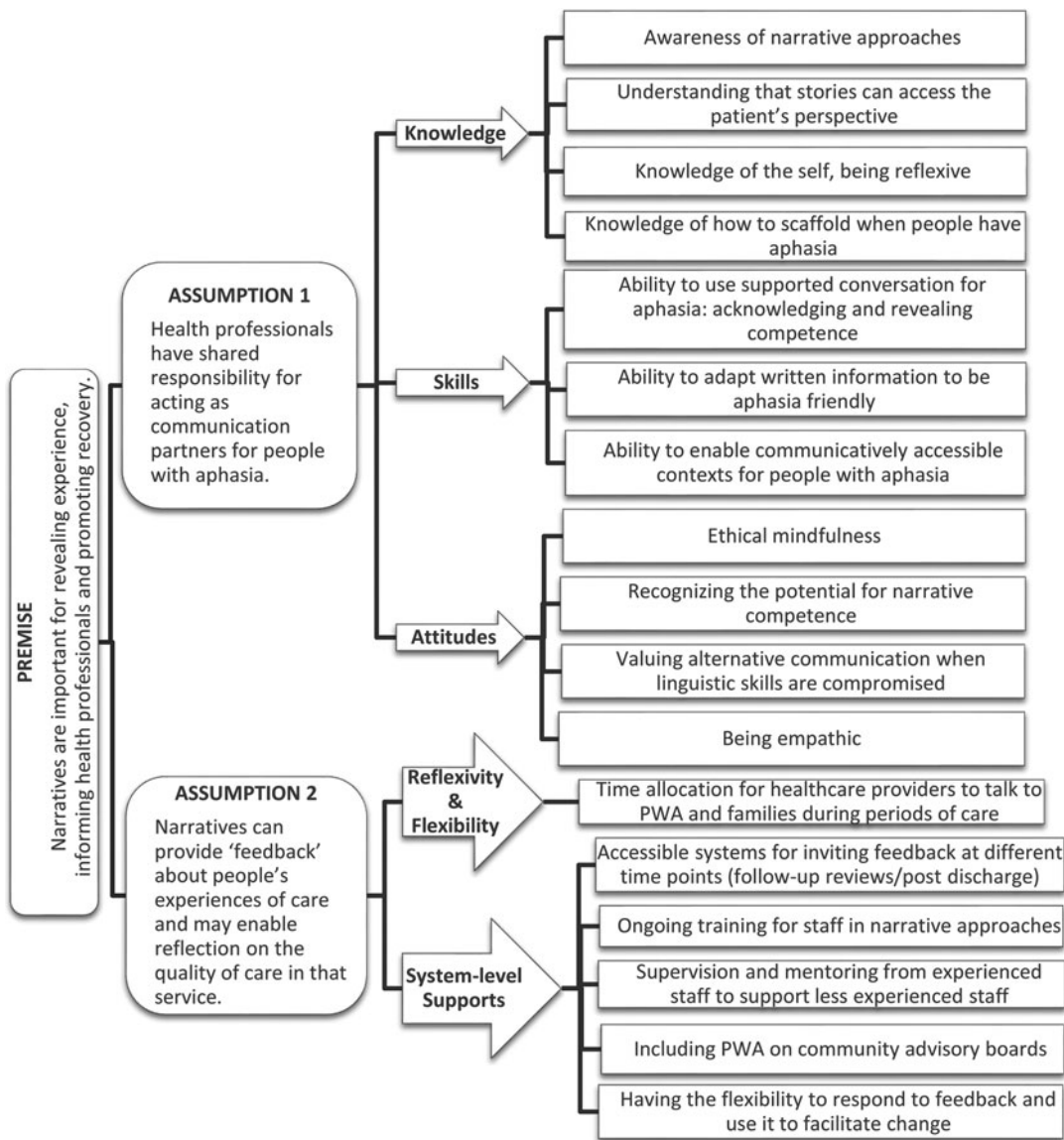
Figure 1. Co-constructing narratives of care with PWA. PWA = people with aphasia.

Listening for stories is what we in health care must learn to do. To listen for stories, we have to know first of all that there are stories being told. We have to notice metaphors, images, allusions to other stories, genre, mood—the kinds of things that literary critics recognize in novels or poems . . . . What I am trying to convey is the kind of listening that will not only register facts and information but will, between the lines of listening, recognize what the teller is revealing about the self. (p. 66)

For people with severe aphasia, more is needed even than listening between the lines. The listener also needs to join with the person to create the narrative because it can only be achieved collaboratively. A health care professional in a caring role may become a communication partner co-constructing, scaffolding, and contextualizing an ongoing, changing story (Clandinin & Connelly, 2000), thereby allowing the person to make sense of what

has happened to him or her and what might yet happen. Not only this process of scaffolding relies on knowledge on the part of the practitioner but it also *creates* knowledge. The knowledge gained through this process may include insights into how the person is experiencing being in the health care system and what he or she wants from it.

There are accounts of the scaffolding between severely expressively impaired speakers and their communication partners—often spouses. For example, Goodwin (2004) described in detail how Chil, a 78-year-old man, 13 years post-stroke, with severe aphasia, was able to use prosody, sometimes over nonsense syllables or repeated strings of single words, to convey an opinion or emotion, to use gesture or mime, and to make use of things in his environment to draw attention to the intended meaning. But importantly, Goodwin noted how Chil linked his message to his communication partner:

Although he can barely speak, Chil positions himself as a forceful, consequential storyteller. The resources needed to do this do not reside within his skin, mind, or self alone. Instead, he requires the collaboration of others, as he mobilizes their power to speak in order to say what he wants said. (p. 165)

Similarly, Oelschlager and Damico (2003) showed how a man with severe aphasia and his wife collaborated to reveal competence in him and that they worked together to interact successfully. The man with aphasia did the kinds of things that ordinary speakers do when searching for words such as verbal strategies (cutoffs, erms, pauses, revisions, restarts, and the use of negative tokens such as "no"), nonverbal signs such as diversion of gaze from listener, and linguistic strategies such as *wh*-questions or metalinguistic comments ("how should I say that?"). However, in his case, these were far more intrusive and took longer than one would expect. His wife, his conversation partner, offered "guess sequences," which were not only helpful but also identified him as a competent speaker. She also used "alternative guess sequences," which were longer but kept the conversation

flowing. Her strategies in assisting the word search demonstrated collaboration, respect, and her expectation of her husband as narratively competent.

Skills: Supporting conversations with PWA

At a very practical level, health care professionals need the tools as well as the knowledge and awareness to support conversations with PWA. Supported Conversation for Adults with Aphasia (Kagan, 1995, 1998) is well established in the aphasia literature. Kagan's work in training doctors and other health care professionals through the Aphasia Institute is described at http://www.aphasia.ca/health-care-professionals. Kagan's (1995) premise is that aphasia may mask competence normally revealed through conversation. By acknowledging competence (e.g., implicitly through humor, tone of voice, natural gesture, or explicitly) and then revealing that competence through a range of supports, PWA may be in a position to share their stories. Examples of supports include writing key words, drawing, pointing to resource material such as pictures, photographs, or personalized biographical portfolios, ensuring the person can respond, providing yes/no options, extra time, different modality options for responses, and verifying responses. Communication partner training (for a recent summary, see Hinckley, Douglas, Goff, & Nakano, 2013) is also well developed and greatly increases the opportunities for participation across a range of contexts. In addition, people with moderate and severe aphasia can be supported to participate in consultations, evaluations, and research through adaptations to qualitative interviewing (Luck and Rose, 2007) and via "aphasia-friendly" adaptations to written information (Rose, Worrall, Hickson, & Hoffmann, 2011).

Attitudes: Appreciating narrative competence

As well as being aware of narrative co-construction, and having ways to support conversational exchanges, health care

professionals need to have a positive attitude to the value of stories and the ways in which PWA demonstrate their narrative competence. Guillemin and Gillam (2006), writing from a narrative ethics perspective, suggest that "actively attending and engaging with a story can be ethically enlightening and equally meaningful for the listener or listeners and the storyteller" (p. 26). These authors recommend that health care professionals adopt an attitude of "ethical mindfulness," which is an awareness of everyday ethically important moments, of noting when things don't *feel* quite right and having the confidence to express those concerns, of being reflexive and being able to challenge accepted practice. If health care professionals engage with stories from a position of ethical mindfulness, they can appreciate patients' psychosocial, emotional, and existential concerns in a more responsive and active way (Frank, 1995; Greenhalgh & Hurwitz, 1998; Kleinman, 1988). This kind of attitude and disposition is a precursor to the sensitive co-construction needed for someone with aphasia (Hydén, 2011).

Researchers have explored the narratives and narrative competence of PWA. For example, Ulatowska et al. (2013) define narrative competence as "the ability to produce stories that are worth telling and are pleasing to listen to" (p. 37), characterized by coherence and clarity (demonstrated through temporal–causal sequences, appropriate referencing, and evaluative language for expressing feelings and opinions). For their study, Ulatowska et al. (2013) analyzed personal narratives from 16 people with mild to moderate aphasia. Despite some expected difficulties with reference and decreased amount of language because of word-finding difficulties, the authors concluded that most of the participants demonstrated narrative competence. With more focus on evaluative language specifically, Armstrong and Ulatowska (2007) also argued people with mild to moderate aphasia could convey attitudes and feelings even if their syntax and semantics were impaired. They suggested that evaluative devices, such as repetition, direct speech (re-

porting the speech of others or one's own speech directly), use of metaphor, and use of emotive words or phrases, could function to compensate for lexical and syntactic problems and increase the "tellability" of a narrative. Although little has been done to explore the narrative competence of people with more severe aphasia, Armstrong, Mortensen, Ciccone, and Godecke (2012) found these people "could contribute significant amounts of opinion-giving" (p. 22), retaining aspects of evaluative language, especially devices to express intensity of opinions, even when linguistic content was sparse. Not surprisingly, the participants with severe aphasia in the study by Armstrong et al. (2012) relied heavily on their communication partners to scaffold their narratives and provide them with opportunities to be active in the interaction.

Despite a degree of overlap between knowledge, skills, and attitudes, these three aspects are useful in clarifying the ingredients for satisfying and productive exchanges between health care professionals and PWA. Narratives need to be viewed as important sources of information, valuable both in the telling and in the listening. In the context of aphasia, narratives have value when a communication partner can scaffold and co-construct a story with the help of supported conversation techniques and a positive attitude toward the PWA as narratively competent.

VALUING FEEDBACK FROM PWA TO EFFECT CHANGE

Considering the many points of contact that PWA post-stroke make with the health system, it is not surprising that comments and opinions about therapy and health care services are closely woven into wider illness narratives. Such comments are often about individual encounters even when fleeting, but they also include concerns about broader systemic issues such as lack of time with health professionals, administrative issues around appointments and accessing information (Burns et al., 2012). Parr et al. (1997) noted that one of the most

common complaints, from their interviews with 50 people with aphasia in the United Kingdom, was being "talked over" (p. 16). On the contrary, feeling respected, feeling acknowledged, and being treated with sensitivity were valued and noted. Worrall et al. (2011), in their interviews with 50 PWA in Australia, found participants wanted, among other things, information, access to services, dignity, and respect.

We should not be surprised by complaints made by PWA about information and communication barriers to health care, but we should be concerned by attitudinal barriers. Burns et al. (2012) note that many medical schools now offer students training in effective communication skills, but this training rarely extends to managing exchanges in the context of communication disorder. This is problematic considering the number of people with communication impairments within health care environments (O'Halloran, Worrall, & Hickson, 2009). There are often few avenues to hear feedback from PWA once they have moved through a particular phase in care or rehabilitation. However, raising awareness of the competence of PWA as narrators, the skills of supported conversation, and the value of narrative as a vehicle for feedback may have broad benefits to a range of health care professionals, not just speech–language pathologists. The very act of reflecting on feedback and of working to co-construct narratives of care is *performative* in the sense that the process itself assists in the removal of the attitudinal barriers central to many of the concerns that PWA may be trying to express.

ILLUSTRATION OF NARRATIVE ANALYSIS AND CO-CONSTRUCTION: TWO CASE STUDIES

Participants

The two people described here to illustrate narrative co-construction were interviewed as part of a large, National Health and Medical Research Council-funded Australian study exploring person-centered aphasia rehabilitation (Howe et al., 2012; Sherratt et al., 2011; Worrall et al., 2011). Ethics approval was granted both by the University of Queensland and all participating health care institutions. Between 2006 and 2008, in three cities across three states in Australia, 50 PWA post-stroke (with diagnoses confirmed by their speech–language pathologists), 48 family members, and 34 speech–language pathologists participated in in-depth semi-structured interviews. All interviews with the PWA were video recorded, transcribed verbatim, and analyzed using qualitative thematic analysis. The PWA were invited to tell their stroke story and talk about their goals at different times in their recovery. The two people whose stories are retold in this article were selected for illustrative purposes because they demonstrated expressive difficulties and provided narratives of feedback about their care.

Interview techniques

The interviews were supported as described by previous researchers (Kagan, 1998; Luck & Rose, 2007), with files of pictures, photographs, rating scales, pens, and paper on the table. During the interviews, I used open and closed questions—with the latter particularly to narrow down and verify responses, guesses, requests for clarification, and rephrasing responses to check for further verification.

Analysis

Following Armstrong and Ulatowska (2007), analysis of these two cases was not just around the content of the text but it also highlighted the use of evaluative devices: repetition for emphasis, direct speech, metaphor, and emotive words. These devices reveal rich information in a conversational context that is collaborative.

I also used Labov's (1972) framework, which Riessman (2002) sees as "an essential first step" to interpretation (p. 251) for these two cases. In this framework, narratives have an internal structure consisting of six common elements, although not all necessarily

have to be present to make a well-formed story: an abstract to alert to what is coming (A), an orientation (O), a complicating action (CA), an evaluation (E), a resolution (R), and a coda to round it off and bring it back to the present (C). Labov (1972) suggested that personal narratives have both a referential function (describing what happened in the story) and an evaluative function (describing the meaning of it as experienced by the speaker). The framework has been applied here as a way of guiding the reader to the preserved elements of internal structure, referential and evaluative meanings, despite the limited linguistic skills of the two women reported in this article. At the same time, it also demonstrates that the excerpts do not always tell a well-formed story, that some elements are missing or conveyed in unusual ways, but that the work of the interviewer as conversation partner can help to reveal and interpret the key points. As McKevitt (2000) has noted: "Consideration of how communication problems shape the production of narrative is instructive, since the role of the interviewer in that process becomes all the more transparent . . . " (p. 94). Much of what happens in the interview involves clarifying (cl) or clarification plus scaffolding where the interviewer suggests extra information (cl + s), and so this process has been included as an illustration of co-construction.

The following extracts demonstrate two ways to make sense of the stories. In Phoebe's excerpt, the co-constructed narrative is drawn from a single section of interview. Here, the story is contained despite being enriched by the overall context of the interview. Eleanor's story, on the contrary, occurs over several separate sections of the interview so that co-construction involves piecing sections of story together to build up to the "time course, the plot, and the point" mentioned previously. Neither of these narratives are "rich" in the traditional sense (McKevitt, 2000), but they become so through collaboration with the interviewer. I report my impressions and interpretations of the interaction in these case examples in the first person.

CASE 1: PHOEBE

Phoebe was 61 years old at the time of interview and lived in residential care. She had an adult son, and her husband visited her daily. Her stroke, 8 years earlier, had left her with a chronic Broca's aphasia (Aphasia Quotient [AQ] = 72.3; Kertesz, 1982) and hemiplegia. Following years of diabetes, her right leg had been amputated and she was in a wheelchair. Our interview, which appears in Table 1, took place in her comfortable, but institutional, room. I asked Phoebe about her memories of being in hospital, how she coped in the early days without any expressive language, and whether she understood at the time what had happened to her. My focus was on her communication issues—She had said "talk" very definitely when I had asked her what was important to her during the early period post-stroke. Then, as shown in line 1 in Table 1, she directed the flow of the conversation to tell me a story, clearly of importance to her.

What struck me about this story, reviewing the video recording of it later, was that at the time, I was very slow in picking up what was going on. I missed the word /endʒət/ and only realized later that it was probably "inject." Had I listened, I would not have gone off on a tangent about physiotherapy or nursing staff simply moving the hemiplegic arm. I initially missed Phoebe's main narrative because of *my* (speech–language pathology) focus on communication strategies and the provision of assistance with communication (such as a chart of useful pictures including words such as "pain," which she could have pointed to at a time when she had no verbal output at all). When I started to move the conversation back to the issue of communication in line 24, Phoebe immediately brought me back to her concerns in line 25—"blood coming out," laying her arm across the book of pictures that I had open. This is illustrated in the screenshot in Figure 2. Phoebe's most vivid memory of that time was the trauma of having blood taken and of the pain in response to the nurses' repeated and unsuccessful efforts to find a suitable vein. Phoebe became animated

Table 1. Phoebe's narrative of having blood taken

Speaker	Transcript	Code
1. Phoebe	In [name of hospital], the nurses come in	O
	and /endʒət/ {?inject} arm and oh, scream, scream.	CA
2. Interviewer	What, they were trying to move it [the arm]?	cl
3. Phoebe	Yes, yes.	
4. Interviewer	It was painful?	cl
5. Phoebe	Yes, yes.	
6. Interviewer	Ah.	cl
7. Phoebe	Scream, scream.	CA
8. Interviewer	Gosh. Were the physios trying to move you or the nurses were trying to move you?	cl + s
9. Phoebe	Yes.	
10. Interviewer	Ahh. So here, you remember it being painful?	cl + s
11. Phoebe	Yes.	
12. Interviewer	A painful time. But you couldn't tell them?	cl
13. Phoebe	No.	
14. Interviewer	I see. So the most important thing for you there was talking. Because you wanted to tell them how you were feeling?	cl
15. Phoebe	(nods)	
16. Interviewer	Would it have been helpful . . . let's see (opening up communication book of pictures) if you had had something like (looking through) . . .	
17. Phoebe	I think my arm's dead.	E
18. Interviewer	Yeah.	
19. Phoebe	Dead. (lifting hemi arm and dropping it down)	E
20. Interviewer	Well now it doesn't hurt when you move it, does it?	cl
21. Phoebe	Yeah.	
22. Interviewer	But you can't move it very much? And so they were testing you were they? Checking you? And it was very painful then?	cl
23. Phoebe	(nods)	
24. Interviewer	OK. (turning to book again) But if you had had a picture and it said *pain* on it, then you would have been able to say *pain* (indicating that she could have pointed to the picture). Would that have helped you? Would it have helped you to have something like this?	cl + s
25. Phoebe	I think now, the (laying good arm on table) the arm, and blood coming out.	O CA
26. Interviewer	You mean blood tests?	cl + s
27. Phoebe	Yes.	
28. Interviewer	You mean they were trying to take blood?	cl
29. Phoebe	Yes, yes.	
30. Interviewer	Is that what they were trying to do on this side?	cl
31. Phoebe	Awful, awful.	E
32. Interviewer	To take blood.	cl
33. Phoebe	(again laying arm across table) Blood coming out . . . awful.	E
	You had to put the needle, needle, needle (showing me multiple puncture points by touching repeatedly on my arm).	CA
		(*continues*)

Table 1. Phoebe's narrative of having blood taken (*Continued*)

Speaker	Transcript	Code
34. Interviewer	Ah, they couldn't find your vein?	cl + s
35. Phoebe	Veins!	O
36. Interviewer	Ah, so that was what was happening?	cl
37. Phoebe	Yes.	
38. Interviewer	So they kept trying to do that … blood tests?	cl + s
39. Phoebe	I know.	
40. Interviewer	Yeah. So your memories of that are not good?	cl + s
41. Phoebe	Not good.	E

Note. Following Labov (1972), six common elements in coding the narrative: abstract (A), orientation (O), complicating action (CA), evaluation (E), resolution (R), and coda (C). Extra codes to show co-construction: clarifying (cl), and clarification plus scaffolding where the interviewer suggests extra information (cl + s).

as she told me her story: twice she placed her left, mobile arm on to the table in the position usually adopted when blood is taken. She used emotive words such as "scream," "awful," and "needle" in repeated strings, described her arm as "dead" with "blood coming out." In line 33, she took my arm and poked it repeatedly as she said "needle" to show me exactly how it had been for her.

In terms of Labov's structure for the story, I had no abstract (A) but Phoebe was able to orient (O) me to the place and people ("the nurses come in"). In the transcript, I have categorized the injection, the "scream" reaction, the repeated attempts ("needle, needle, needle"), and the "blood coming out" as the complicating action (CA) of the story. Her word "awful" is her evaluation (E). As a co-

Figure 2. Phoebe recounting "blood coming out" (de-identified) to the author.

constructor of this story, I would add that Phoebe clearly initiated the telling of the incident of having blood taken and that this story must have had considerable significance for her. Perhaps, the pain of repeated attempts to find a vein was worsened by the enormous vulnerability of being without language. Maybe the nurses did little to explain what they were doing at the time or that they did but not in a way that Phoebe could understand. Maybe she felt that they did not respond appropriately to her obvious discomfort. Maybe watching blood pouring out of her arm was terrifying. On the surface, this could have been a routine procedure that one would not have thought worth telling all those years later and it was possibly a private story that her family might not have known, have thought to report, or even remember. Nevertheless, by remembering, initiating, and telling this story 8 years on, and particularly in the animated way that she did, Phoebe demonstrated its power in influencing how she felt about that period and the care she received. Her use of repetition, of prosody, of gesture, nonverbal communication, emphasized dramatic words, and of physically expressed emotion supplemented the relatively few words available to her. Her metaphor of the "dead" arm captured her sense of physical loss. For me, having flexibility within our interview, time, and the opportunity to replay and reflect on both what

Phoebe said and how she said it permitted a window to those experiences. Perhaps, a lesson from this narrative of feedback could be that something considered routine by a health care professional may be experienced as so traumatic to a patient (particularly one unable to ask questions or grasp any degree of control) that she chooses to tell that story 8 years on to a relative stranger who is prepared to listen.

CASE 2: ELEANOR

Eleanor was 34 years old when she had her stroke, related to a long-standing blood-clotting disorder. She had been living alone in her own apartment and had been working as a nurse within the nursing home sector but was unable to return to work after her stroke. Her AQ was 66.5. I spoke to her 4 years after the

stroke at her home—a neat, organized place that reflected her pride and self-assuredness. Eleanor's account included key issues arising in the month she spent in hospital and then 3 months in rehabilitation. The narrative shown in Table 2 refers to a consultation with her neurologist that she and her mother attended.

Prior to this excerpt, Eleanor had oriented me to the place and people involved in her narrative, but the line "No, test? No. Mum, fine. Me!" was said very expressively and really captured the essence of the complicating action (CA). Through her agrammatic turn, Eleanor conveyed a whole exchange: "What is the result of that test? Yes, you can explain that to my mother. But what about me? It's my stroke and I am a professional so tell me." When she said "Me!" she pointed to herself, eyebrows raised. I interpreted her evaluation of this narrative (E) as

Table 2. Eleanor's consultation with her neurologist

Speaker	Transcript	Code
1. Interviewer	Did you get enough, enough information from him?	cl
2. Eleanor	No.	
3. Interviewer	OK. It's hard when you have lots of questions and you can't ask the questions . . .	cl + s
4. Eleanor	Mmm (nodding in agreement).	
5. Interviewer	Is that what happened? You wanted to ask and then you couldn't ask the questions?	cl
6. Eleanor	No, test? No. Mum, fine. Me! (pointing to herself)	CA
7. Interviewer	OK. So he [the doctor] did all the talking to her [your mother]. Didn't actually talk to you?	cl + s
8. Eleanor	No. No.	
9. Interviewer	OK. So he didn't address you. He addressed your family for questions. OK.	cl + s
10. Eleanor	Sorry, yeah.	
11. Interviewer	OK, so all the information was through the family.	cl
12. Eleanor	Mmm, yes.	
13. Interviewer	Yes, OK. Erm, again, looking back on it, do you think that was because he didn't know that you could understand what was going on, or he was too busy to give you the time?	cl
14. Eleanor	I don't know. I don't know. X-rays, family. Me, nothing. Nothing.	E

Note. Following Labov (1972), common elements in coding the narrative: complicating action (CA) and evaluation (E). Extra codes to show co-construction: clarifying (cl), and clarification plus scaffolding where the interviewer suggests extra information (cl + s).

disappointment and irritation at how information was shared with her mother but not with her directly: "X-rays, family. Me, nothing. Nothing."

As well as feeling sidelined by her doctor, Eleanor was unhappy with the nursing care, particularly in the rehabilitation center. At that point, she had a dense, right-sided hemiplegia and, although she understood that the staff members were encouraging her to be as independent as possible with activities of daily living such as showering and dressing, she was left neither able to care for herself nor cared for. She felt dirty. The following excerpts in Table 3 illustrate this.

Although the line "Horrible . . . teeth, no!" doesn't look much like the complicating action, it contains it: "I really wanted the feeling of having a clean mouth and tried to clean my teeth myself but couldn't manage it. The nurses didn't want to help me because they felt it was part of my rehabilitation to try to do it myself . . . ."

Similarly, her comment "dish, big" was so well complemented by her mime of trying to cut up her food one-handed that it became the complicating action of that section of narrative. The consequence of feeling dirty, unkempt, and undignified was that Eleanor withdrew from social interaction. Initially, I did not connect the narrative about her physical care and her feelings of isolation in the rehabilitation unit. But Table 4 shows they were connected and deeply interwoven with her sense of self as a nurse and a proud, young, independent woman. Perhaps, she felt let down by her professional colleagues and she hinted in the interview that she perceived her nurses may have distanced themselves from her because she was also a nurse. For her to be seen, disabled, dependent, and in what she considered a horrible place, was not acceptable. She waited to reconnect with friends once she was home.

Later in the interview, Eleanor also revealed that the decision to stay for 3 months in the rehabilitation unit was made by her understandably anxious mother because of her concerns that she would end up needing nursing home care—a thought that appalled Eleanor, not only because of her age but also because she considered herself as the staff member, not the resident. Going home was her highest goal and clearly motivated her to accept the services on offer.

Eleanor's interview continued around her physiotherapy, and speech–language pathology appointments dominating her time once she was home. She had received a lot of therapy over the previous few years but was currently in a gap between services. The theme of "waiting" arose repeatedly through the interview—she used the word multiple times. Eleanor gestured using the phone to demonstrate her attempts to follow up on anticipated appointments: "waiting, waiting . . . waiting, waiting . . . . Hopeless, sorry, hopeless." She said she needed more therapy, still being in her 30s: "Young, speech therapy, young." She held hopes to return to work, to be the person she felt she really was: "Registered nurse, me." Eleanor's story of managing stroke and aphasia was deeply connected to her experiences of being on the other side of the health care system. Her previously articulate, professional self was now in a struggle to regain whatever it could, frustrated by the waiting and by being spoken over. She used repetition for emphasis, emotive words such as "horrible" and "hopeless," gestures, and mime. Her apologies were perhaps a sign of the embarrassment that others in her profession were unable to provide her with the care that she would have expected. Or, perhaps her use of "sorry" was because she felt slightly guilty about complaining about anything in a health service that she had worked for and wanted to work for again.

Eleanor's narrative was broken into snippets, so I needed to piece them together to see the fuller story. Within each excerpt, I offered clarifications (cl) with closed questions, to enable yes/no responses, and suggested scaffolding options (cl + s) for her to respond to, or to check that I had correctly understood a nonverbal response. Her feedback related to the desire to feel dignified and in control. She was not prepared to be seen by

Table 3. Eleanor's account of feeling uncared for

Speaker	Transcript	Code
1. Eleanor	Horrible . . . teeth, no! (grimace, look of distaste).	CA
2. Interviewer	Oh, yes, I see. Cleaning your teeth.	cl + s
3. Eleanor	Urgh, germs, urghgh.	E
4. Interviewer	OK, alright.	
5. Eleanor	Mmm. Mmm, bad. (shaking her head)	E

Speaker	Transcript	Code
1. Interviewer	So how much, by then (pointing to sheet with name of rehabilitation center on it), could you do for yourself and how much did you need them to help you?	cl
2. Eleanor	Eating?	
3. Interviewer	Everything. Eating, activities of daily living . . . you couldn't do it there?	cl + s
4. Eleanor	Nothing. Sorry.	
5. Interviewer	I see. So you felt very dependent on the nurses having to help you with everything?	cl
6. Eleanor	Er . . . dish, big (indicating a round plate in front of her and miming a hemiplegic arm and trying to cut food one handed).	CA
7. Interviewer	Cutting up?	cl + s
8. Eleanor	Oh, yes, bugger. "Err?" "No! No!"	CA
9. Interviewer	They wouldn't cut it up for you?	cl + s
10. Eleanor	No, no.	
11. Interviewer	Oh, I see.	cl + s
12. Eleanor	Sorry. Yes.	

Note. Following Labov (1972), common elements in coding the narrative: complicating action (CA) and evaluation (E). Extra codes to show co-construction: clarifying (cl), and clarification plus scaffolding where the interviewer suggests extra information (cl + s).

any of her friends and colleagues if her teeth were not clean or if she had spilt food down her gown. Among other things, this feedback raises the issue in rehabilitation about how far staff should push someone to tackle activities of daily living by themselves and how much help to offer. Although Eleanor knew she had to learn to eat and wash herself again with one working hand and arm, her evaluation was that the experience was "horrible" and that the place was "horrible." Perhaps, transitioning Eleanor more gently, and including her in the decisions about the rehabilitation plan, could have prepared her to feel comfortable enough to allow those visitors, who wanted to support her further, in through the door.

DISCUSSION

In this article, I have used excerpts that provide narratives of feedback about health care events from Phoebe and Eleanor to show how, even in the context of impaired language, lessons can be drawn about how care might be given and received. In order for this to happen, conversation partners need to assume an active role in supporting, co-constructing, and valuing these narratives. I have suggested that knowledge and awareness of narrative,

Table 4. Eleanor connecting her care with her social isolation

Speaker	Transcript	Code
1. Interviewer	OK. So your main problem in the [name of rehabilitation hospital] was that you felt lonely?	cl + s
2. Eleanor	Mmm, yep. Lonely, yep.	E
3. Interviewer	It shows how important it is to get visitors when you're somewhere like that.	cl + s
4. Eleanor	Oh . . . me, no. Sorry.	E
5. Interviewer	It wasn't the visiting?	cl
6. Eleanor	No. Friends, no.	CA
7. Interviewer	You didn't want them to come in?	cl
8. Eleanor	No.	
9. Interviewer	Oh, that's interesting.	
10. Eleanor	Thank you.	
11. Interviewer	So you refused then to have visitors?	cl + s
12. Eleanor	Yep. (laughs)	
13. Interviewer	Why did you do that?	cl
14. Eleanor	Er . . . nurse.	
15. Interviewer	Of course. Is it the idea that nurses are not allowed to get sick? Is that right?	cl
16. Eleanor	(laughs, thumbs up sign)	
17. Interviewer	If you hadn't been a nurse, if you were not a medical person anyway, would it have been different?	cl
18. Eleanor	No.	
19. Interviewer	So it was you, actually. You still wouldn't have wanted people to come in?	cl
20. Eleanor	No. [name of rehabilitation hospital], horrible, oh no. Oh, no.	E
21. Interviewer	You didn't want people to come in there?	cl
22. Eleanor	[name of rehabilitation hospital].	
23. Interviewer	They didn't want you to have visitors?	cl
24. Eleanor	Mmmm?	
25. Interviewer	Did they discourage . . . ?	cl
26. Eleanor	No, no, no.	
27. Interviewer	But you didn't want to see people there?	cl
28. Eleanor	Mmm, yeah. Horrible. Sorry. Horrible.	E
29. Interviewer	What was it about it that was horrible?	cl
30. Eleanor	Nurses. Horrible. Sorry, horrible.	E

Note. Following Labov (1972), common elements in coding the narrative: complicating action (CA) and evaluation (E). Extra codes to show co-construction: clarifying (cl), and clarification plus scaffolding where the interviewer suggests extra information (cl + s).

practical skills, and positive attitudes toward PWA as narratively competent are required by the full range of health care professionals who come into contact with PWA.

In addition to the training in general communication skills that health care professionals are required to master, it may be possible to extend this to include people with communication impairments such as aphasia by offering training in supported conversation strategies and the ability to recognize retained pragmatic abilities, evaluative devices, nonverbal language, and residual lexical abilities. Moreover, when those health care professionals are able to value even disjointed narratives, and have a sense of ethical mindfulness, they

are in a good position to benefit from them. Such narratives may contain pointers to existing communication and information barriers in services. Perhaps, more fundamentally, I suggest the process of narrative co-construction can help reduce attitudinal barriers so frequently described by PWA. It is also possible that, with better communication skills, the nursing staff and the neurologist who featured in Phoebe's and Eleanor's stories might have managed those encounters slightly differently in the first place, thereby improving their patients' experiences of care.

Patients may give feedback at the time of receiving services or sometime later, and their comments may be formally elicited or spontaneous. Arguably, the experiences of PWA in the health system could remain hidden unless PWA are offered supported channels for feedback such as the conversational interviews of the type shown with Phoebe and Eleanor. Standard methods such as patient satisfaction surveys can be adapted to be "aphasia friendly," but in conversational narratives, PWA have the opportunity to raise issues that may not be anticipated and that are important to them. Moreover, the process of narrative co-construction is itself relationship building. It sends a message that the person is worth listening to and that the health care professional is interested in learning and reflecting on the lessons in the story. Making the effort to employ conversational supports and narrative co-construction affirms the competence of, and respect due to, PWA.

The arguments in this article are not new, but they are meant to focus attention on ongoing problems. They draw on existing work from aphasiology, narrative medicine, and narrative ethics. The challenge is now to put the ideas from these fields into practice more widely. More awareness is required within the health and rehabilitation systems to implement the necessary changes to address the concerns of people such as Eleanor and Phoebe. Training in supported conversation, for example, through the Aphasia Institute (Kagan, 1995), is ongoing and well received.

For example, applications of this training are now available in relation to social work (Rowland & McDonald, 2009) and nursing (Jensen et al., 2015). However, the findings from the study carried out by Parr et al. (1997) are now nearly 20 years old and yet the concerns of PWA in more recent studies remain frustratingly similar (Hersh, 2009; Worrall et al., 2011). There are opportunities for further research in this area, not only in evaluating training programs for health care staff but also in relation to the application of narrative approaches to health care (Charon, 2006) and their relevance even for people with communication disorder (Hinckley, 2008). Narrative approaches have perhaps been assumed to rest on intact language skills, but this perspective fails to include the potential for co-constructed interaction. In order for real change to be made, research needs to include all stakeholders, including PWA, and to explore how feedback on care might enable positive and meaningful improvement (Kagan, Simmons-Mackie, Brenneman Gibson, Conklin, & Elman, 2010).

CONCLUSION

More needs to be done to address how PWA can receive care that is communicatively accessible, responsive, person-centered, and respectful. We need to recognize that the knowledge, skills, and attitudes that underpin co-constructed narratives are important for all health care professionals who work with PWA, and we also need greater awareness of the impact of language and communication disabilities on those being cared for in the health care system. Narratives are a powerful way of raising issues and giving feedback even when they need to be produced collaboratively. Attending to the narratives of PWA highlights that there are a variety of ways of telling a story just as there are of receiving that story and responding to it. It also shows that even the most unlikely of stories may contain something fundamentally important and worth acting on.

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